

**The Pain is Far from Over: Exploring the Experiences of Parents and Adolescents  
Following Discharge After Inpatient Surgery**

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A thesis submitted to the Department of Graduate and Postdoctoral Studies in partial  
fulfillment of the requirements for the degree of Master's of Science in Nursing

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## Thesis Abstract

**Background:** Pain management is a major issue in post-operative care. Little is known about the pain management experiences of parents and adolescents following discharge from inpatient surgery. Studies examining pain outcomes following day surgery suggest that children often experience severe pain and parents are challenged in providing pain care.

**Objective:** To explore the pain management experiences of parents and adolescents following discharge from hospital after inpatient surgery.

**Results:** Thematic analysis found that parents and adolescents were challenged in providing pain care. School return was more difficult than anticipated yet parents and adolescents were unsure how to navigate pain at school. Discharge education focused on analgesic management, leaving participants to discover non-pharmacological strategies on their own.

**Conclusions:** Recovery from post-operative pain following inpatient surgery is challenging; nurses and healthcare professionals need to better prepare parents and adolescents to meet pain care needs following discharge.

**Keywords:** *pediatric, pain, adolescent, parent, inpatient, post-operative, pain management, discharge*

### Acknowledgements

First and foremost, I would like to thank Dr. Paula Forgeron for her support throughout the process of writing this thesis. Paula was there from the initial conceptualizing stages of the research, through pushing me into a methodology that she knew would pique my interest, to guiding and supporting me through the process of performing my first qualitative analysis. Without her support this journey would have been much more challenging and much less interesting.

I would like to thank Jess Romeo and Brenda Martelli, without whom this research would have been impossible. Despite intensely demanding roles at the hospital, both Jess and Brenda managed to find time out of their days to both aid in the screening and recruiting of participants as well as to aid in the conceptualization of the sample. From approaching patients and families in hospital and clinic, to mailing out retrospective recruitment letters, to taking the time to collaborate with my busy work schedule to meet patients together, the role that they played in the production of this research cannot be understated.

I would also like to thank my committee, Dr. Gail Macartney and Dr. Julie Chartrand for taking the time to not only support me through reading my work and providing exceptional feedback but also to aid in the data analysis process itself, providing outstanding insights and broadening our understanding of the experiences of the participants. I would also like to thank Denise Harrison, my external examiner, as well as the whole of my defense panel for coming together and working so hard to meet tight time deadlines that I am sure were not easy.

I would also like to thank my family for the support throughout the whole process of doing my Masters, in particular my Father for the expedient and much needed copy editing.

And finally, my gratitude is extended to the parents and adolescents who took the time to participate in the study and share their experiences with me and the research team, especially during a painful and difficult period in their lives. The information that was shared is invaluable, as with it hopefully we can effect major changes in the future of post-operative pain management at home.

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## **Chapter 1**

### **Introduction**

### **Introduction**

One of the most important issues in post-operative patient care is pain management (International Association for the Study of Pain, 2017); with adequate control of pain improving quality of life, reducing complications, and facilitating recovery (International Association for the Study of Pain, 2010; Rabbitts, Palermo, Zhou, & Mangione-Smith, 2015). Inadequate management of pain in pediatric populations has been found to increase morbidity and mortality (Anand et al., 1999; Carr & Goudas, 1999; Peelen, Kalkman, & Meissner, 2013; Stoll, Hansen, Bell, Walsh, & Carlo, 2015), and is a risk factor for the development of chronic pain (Crombie, Davies, & Macrae, 1998; Reddi, 2016). Inpatient surgical patients are starting to experience shorter lengths of stay following surgery (Clarke & Rosen, 2001; DeSena, Nelson, & Cooper, 2015). As trends in overall hospital length of stay decreases (Macy et al., 2009; Tess, Glenister, Rodrigues, & Wagner, 1993), much of the recovery process, including pain management, occurs in the community setting. Early discharge for children and adolescents postoperatively means parents must take on the caregiver role in pain management for their child (Vincent, Chiappetta, Beach, Kiolbasa, & Latta, 2012). Moreover, in the population of adolescent patients, this may result in patients taking on the responsibility of pain management themselves.

There exists very little research focused on exploring parents' and adolescents' pain management experiences after discharge from inpatient surgery (e.g. spinal fusion, pectus excavatum repair), however one study of 167 parent/child pairs examined the relationship between pre-operative pain catastrophizing (negative experience of actual or potential pain) and post-operative pain following posterior spinal fusion for both parents

and adolescents (Birnie, Chorney, El-Hawary, & PORSCHE Study Group, 2017). While the authors found a positive correlation between adolescent pain and pain catastrophizing, they did not find a similar relationship between parent pain catastrophizing and adolescent pain. The most striking finding of the study was that at 6 week follow up, the adolescents reported ongoing mean pain scores of 2.5 out of 10 (SD 2.1) regardless of pain catastrophizing (Birnie, Chorney, El-Hawary, & PORSCHE Study Group, 2017), indicating that patients experienced post-operative pain for a significant duration of time following inpatient surgery. Another study by Rabbitts et al. (2017) explored the postoperative pain experiences of 15 parent/adolescent dyads following spinal fusion, pectus repair, and hip osteotomy using family interviews. The study found that both parents and adolescents were unprepared for surgery and the resultant pain adolescents experienced, culminating in many challenges in the recovery at home. The dyads in the study stated concerns regarding safety and injury post-surgery, and described the increased reliance of adolescents on parents as a significant stress. The study however interviewed parents and adolescents together, potentially resulting in the participants needing to censor responses from each other, and thus research specifically examining the individual experiences of parents and adolescents is necessitated.

While these studies help us understand some aspects of the experience of parents caring for adolescents following inpatient surgery, the body of literature is small and thus in order to gain more insight into the post-operative experiences of parents and children, we must look to research on outpatient surgeries (e.g. tonsillectomy, inguinal hernia repair, myringotomy tube insertion). This field of research suggests that post-operative pain management is a significant issue in the home setting. For example, Wilson et al.

(2016) examined the severity and duration of pain in 251 patients age birth to 18 years undergoing head and neck surgery (e.g. adenoidectomy, myringoplasty, tongue tie), finding that on average post-operative pain lasted for 9 days. Similarly, Stanko, Bergesio, Davies, Hegarty, and Von Ungern-Sternberg (2013) followed 100 children post tonsillectomy to determine the incidence and intensity of pain on post-operative day (POD) 3 and 7 by telephoning parents to assess their child's pain intensity using a Visual Analog Scale (VAS). The authors found that tonsillectomy was associated with significant pain at home into POD 7. Furthermore, an integrative review of 51 articles on the pain management practices for children and adolescents undergoing tonsillectomy concluded that post-operative pain peaked on POD 2 and 3, but moderate to severe pain lasted up to 14 days (Howard et al., 2013). Clearly, post-operative pain at home remains a problem for children and adolescents who undergo outpatient surgery, which suggests that children and adolescents who have inpatient surgery may also be at risk for significant pain at home following discharge, particularly as inpatient stays are shortening.

Unfortunately, studies report that children and adolescents who undergo minor surgeries as outpatients ("ambulatory" or "day surgery") report severe pain following discharge. This may be related to suboptimal pain management by their parents, as it has been reported that following day surgery, children and adolescents often do not receive medication after discharge (Fortier, MacLaren, Martin, Perret-Karimi, & Kain, 2009). Parents have cited a range of concerns that contribute to suboptimal pain care for their child's day surgery pain including fear of drug tolerance, medication side effects, and addiction to analgesics (Fortier et al., 2009). Parents also have been found to believe that

analgesics should be used as a last resort (Hamers & Huijer Abu-Saad, 2002). This finding is troubling, as proper pain management is needed for positive post-operative outcomes. Based on the literature, parents and children require assistance in managing pain at home following day surgery, suggesting that pain management may also be an issue for those following inpatient surgery. However, we know little about the pain management practices of parents and adolescents following their child's discharge from inpatient surgery.

The focus of much of the research in the field has been on children under 12 years of age or pediatric populations as a group from 0-18 years of age, with little research specifically exploring the experiences of adolescents. A study by Gillies, Smith, and Parry-Jones (1999) on 251 adolescents undergoing both inpatient and outpatient surgery found that adolescents in both groups experienced moderate to severe pain on POD 1 (mean pain intensity 5.5 out of 10 for tonsillectomy patients) and 3 (mean pain intensity of 2.77 out of 10 for all patients), often with only one dose of opioid analgesics given even by health professionals. Parents in the study cited fears related to addiction and side effects. This study did not report on how adolescents engaged in their own pain care following surgery. However, a study by Sng et al. (2012) found that while admitted post-operatively, pediatric inpatients between the ages of 6 and 12 years engaged in self-directed actions to relieve pain (e.g. distraction, imagery) and alerted parents of the need for medication, indicating that they could and do play an active role in their own pain management. Understanding more about how adolescents are involved in their post-operative pain care would provide insight to inform interventions.

Clearly, outpatient post-operative pain in the community is a major concern, as children and adolescents experience significant pain at home and their parents are challenged in meeting their pain care needs. Similar risks may be present in the population of adolescents undergoing inpatient surgery. Further research is needed to understand the role that adolescents play in managing their own postoperative pain following inpatient surgery. Given that undertreated pain at home could lead to an increased risk of post-surgical chronic pain (Crombie, Davies, & Macrae, 1998; Reddi, 2016), research to understand the post-operative pain experiences of parents and adolescents at home following inpatient surgery is proposed.

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**Chapter 2**  
**Literature Review**

### **Literature Review**

There is a scarcity of research on parental pain management at home following major surgery, as well as on adolescent's post-operative pain management at home. Three studies were found that explored these two topics. The first was a Canadian study conducted by Ferland et al. (2017) which examined factors that predicted post-operative pain intensity in 43 adolescents (12-18 years of age) undergoing spinal fusion for idiopathic scoliosis, both while in hospital and at home 6 weeks post-operatively. Factors measured before and after surgery were distress (self-reported psychological measure of state-trait anxiety and saliva cortisol levels), self-reported pain intensity on a 0-10 numeric scale (preoperatively, 48 hours post-operatively, and at 6 week follow up), and a standardized measure of scoliosis severity. The authors found that cortisol was not associated with anxiety or pain intensity post-operatively. The only significant predictor of post-operative pain intensity in the study was pre-operative pain intensity. The study reported that 48% of adolescents continued to have pain (mean score of 2 out of 6, SD 0.8) at their 6 week follow up. Though this study examines adolescents undergoing inpatient surgery and some aspects of their post-operative pain at home, the study did not provide insight into the experiences of postoperative pain on adolescents themselves or their involvement in their own postoperative pain management. The study also does not include the parents and therefore it is unclear how their pain management practices may have impacted pain at 6 weeks. Nevertheless, this study does suggest that post-operative pain remains an issue for adolescents following spinal fusions for at least 6 weeks, indicating a need to understand more about adolescents and parents post-operative pain management experiences at home after planned inpatient surgery.

In a recent descriptive qualitative study, Rabbitts et al. (2017) explored the experiences of 15 parents and their children (age 10-18 years) following discharge for spinal fusion, pectus repair, and hip osteotomy as well as 17 perioperative healthcare providers (surgeons, nurse practitioners, child life specialists, physiotherapists, inpatient nurses) using interviews to understand child and family experience surrounding inpatient surgery and to identify barriers/facilitators to the providing of adequate pain care from stakeholders. Parents and patients were interviewed together. Key findings from the family interviews indicated that children and families felt unprepared for both surgery and the degree of post-operative pain, and that recovery at home was challenging, as children were unsure about safety and feared injury. Parents reported feeling stressed due to the increased reliance of their children for pain intervention as well as the increased need to assist them with activities of daily living. The study interviewed children and parents together, which while allowing for an understanding of the phenomenon from the perspective of the family as a unit, does not allow for an in-depth of understanding of the role of the individual within the unit, as participants may have had to censor responses in order to respect others in the interview (Rabbitts et al., 2017). A more nuanced understanding of adolescents and their parents as individuals could be gained from separate interviews.

Vincent, Chiappetta, Beach, Kiolbasa, & Latta (2012) examined the effect of a parental pain management teaching protocol on the pain care of 138 children between the ages of 7 and 12 years who were hospitalized post-operatively for 23 hours or greater following spinal fusion, pectus repair, appendectomy, or osteotomy. The pain management teaching protocol focused on the effects of unrelieved pain, pain

assessment, and the use of pharmacologic and non-pharmacologic pain control. The control group received normal care, which was non-standardized, and dependent upon the health care provider. The authors collected data through phone calls on POD 1, 2, and 3, as well as a pain log for the three days post-discharge to capture pain intensity, amount of analgesics delivered, use of unplanned services, satisfaction with pain level, and parent and child expectations of pain. The researchers found that children reported moderate pain, which did not significantly decrease in the intervention group. There were also no significant changes in medication administration within the intervention group and despite reporting high levels of pain, parents and children both reported satisfaction with levels of pain. The authors concluded that simply providing written and oral discharge information was not adequate to change parental medication administration at home following surgery. Further research is needed to more fully understand parental experience and beliefs surrounding pain management and analgesic education as information alone may be inadequate to alter parent behaviour. Moreover, the intervention in this study focused on parent education, therefore it is not known if educating adolescents as well as parents would improve outcomes.

Given the limited research on the topic of parent and adolescent post-operative pain management at home following major surgery, a wider review of the literature was warranted. Research focusing on management of pediatric outpatient surgical pain, parental/adolescent management of inpatient surgical pain, and management of outpatient pediatric cancer pain was reviewed. The following literature review provides insight into the context of acute pain management by adolescents and parents both post-operatively or in the home setting.

**Management of Pediatric Pain Following Outpatient Surgery**

There exists a substantial body of research examining parental pain management practices following outpatient or “day” surgery. Although outpatient surgery is less complex than surgeries that require adolescents to stay for 24 hours or longer, the literature on outpatient postoperative pain provides insight into the experiences of parents in providing pain care in the home setting. Tonsillectomy is one of the most frequently studied pediatric surgeries used to examine parents’ post-operative pain management practices at home. Two such studies found that children experienced moderate pain, and found no statistically significant differences in improving parental analgesic delivery between intervention and control groups (Huth & Broome, 2007; Paquette et al., 2014). For example, Paquette et al. (2014) examined whether nurse follow up calls improved post-operative outcomes including pain outcomes and analgesic administration for children at home post-tonsillectomy. The study included 45 children between the ages of 4 and 12 years. The nurse phone calls were on POD 1, 3, 5, and 10. During these calls nurses provided support, answered parent’s questions, promoted pharmacologic, physical and psychological interventions and assessed the patient’s wellbeing. The results suggest that nurse follow up phone calls had no effect on the pain intensity, but did reduce the need for access to other health services not related to pain (Paquette et al., 2014). Children in this study continued to have significant pain, with median pain scores on POD 1 of 5.0 out of 10, receding to 2.0 out of 10 by POD 5. No relationship between the number of analgesics delivered and pain intensity was discovered, suggesting that either the phone interventions did not provide adequate support for parents or that the prescribed analgesics (acetaminophen and codeine) were not adequate to meet the post-

operative pain needs of patients in the immediate postoperative period at home. A further intervention study aimed to improve parent post-operative pain management for their child's post tonsillectomy and adenoidectomy also found no improvement in the intervention group; Huth and Broome (2007) conducted a prospective unblinded randomized control trial of 79 patients between the ages of 7 and 12 years (86% white, 55% female) to assess the effect of an instructional pain management audiotape intervention (given to parents on discharge) on post-operative home outcomes (e.g. pain intensity, fluid intake, emesis, and opioid intake) post-tonsillectomy and adenoidectomy. These authors found no statistically significant difference between the intervention group and the control group in terms of pain intensity. Children in both groups experienced a moderate degree of pain, as assessed using the Oucher pain intensity score tool (Beyer, 1984). It is unclear why there were no improvements in parents' pain management capacity in either of these two intervention studies. However, it is possible that the interventions did not target the concerns or challenges parents face as they are premised solely on parent education. It may also be that other factors impact parents' pain management strategies that are not overcome by educational interventions alone, suggesting that an in-depth understanding of their post-operative pain management experiences is warranted.

There also exists a body of research examining pain management in surgical outpatients beyond the population of adenoidectomy/tonsillectomy. Walther-Larsen et al. (2016) conducted a prospective observational study of 149 children over 1 year of age who underwent day surgery (including orchidopexy, phimosis, hernia repair, and other minor surgeries) to determine how parents managed their children's pain. Outcomes of

the study found that pain assessment and medication administration (acetaminophen and ibuprofen) as per a defined protocol were adhered to by parents more on POD 1 which resulted in lower pain scores on POD 1 compared to POD 2. It is unclear why parents deviated from the pain management protocol on POD 2, but the authors proposed that one of the challenges for parents in managing pain at home is linked to their confidence in assessing pain in their child to guide analgesic administration.

In trying to improve pain assessment both in hospital and at home, Franck, Allen, and Oulton (2007) conducted an intervention study with a control group to examine the use of a novel pain assessment scale to determine the effectiveness of this strategy for improving pain assessment and analgesic administration. These authors assessed the benefits of using a temporary tattoo pain scale (TTPS) on the forearm of 111 children, ages 6 to 12 years, who underwent both inpatient surgery (requiring 3 days of hospitalization) and minor outpatient surgery. The TTPS was not a previously validated tool. The premise was that the temporary tattoo would be a visible trigger for nurses and parents to assess the child's pain and provide analgesic based on the assessed level of pain intensity. The children in the intervention group experienced an increase in the number of pain assessments performed by nurses while the children were in hospital and by parents when the children were outpatients but only for POD 1. Despite an increase in pain assessments, the intervention was not linked to improvements in the administration of medication or a reduction in pain intensity, suggesting that pain assessment is not the sole factor in helping parents provide analgesics at home to manage their child's post-operative pain. The use of a parent specific pain assessment tool was examined by Kankkunen et al. (2009) to determine if a parent-aimed tool improved child's pain

assessment and management. The authors conducted a randomized control trial involving 50 parents of children aged 1 to 2 years undergoing day surgery to further evaluate the effectiveness of the Parental Post-Operative Pain Measure (Chambers, Reid, McGrath, & Finley, 1996). There were no statistically significant differences between the intervention group and the control group in terms of pain intensity. However, parents in the intervention group felt less satisfied with their child's pain relief, suggesting that an appropriate tool may at least aid in the assessment of pain if not in its treatment.

Several studies examined the effects of parental ethnic background and their post-operative pain management beliefs for their children. Batista et al. (2012) used the Parental Pain Expression Perceptions questionnaire (Zisk, Grey, Medoff-Cooper, & Kain, 2007) with 215 parents whose children were 1 month to 17 years of age to examine the relationship between ethnicity and parental perceptions of post-operative pediatric pain. The authors found that Spanish speaking Hispanic parents held more misconceptions regarding pediatric pain expression than English speaking Hispanic or White parents. Despite this finding, the authors ultimately concluded that parents of all ethnic backgrounds hold misconceptions about pediatric pain treatment, meaning that misconceptions about pediatric pain treatment are not ethnically dependent. A qualitative study by Olshanky et al. (2015) explored parent pain management concerns of Hispanic parents whose children had undergone outpatient surgery. Sixty-five parents were interviewed on their child's POD 2 and POD 7 and voiced concerns regarding the safe administration of medications and identified many barriers to the delivery of quality analgesic care, citing generational, familial, and social factors such as intergenerational differences in the valuing of the treatment of children's pain. The parents in Olshanky et

al.'s study also identified factors related to economic disadvantage, such as lower rates of analgesic use due to financial cost and their lack of transportation negatively impacting their ability to access medications. We do not know if similar factors (e.g. analgesic misconceptions, economic factors) impact parent and adolescent pain management practices at home following inpatient admission for surgery or how they may further complicate the management of pain at home.

Across these studies post-operative pain management at home continues to be a challenge for parents following minor outpatient surgery. Studies suggest that parents are hesitant to provide analgesics at home and that the assessment of pain intensity alone is not adequate to guide their administration of analgesics. This suggests parental educational interventions may not meet all the needs of parents, as they do not appear to improve pain management at home. It is likely that these issues, and others, are relevant to the management of more complex post-operative pain at home for adolescents undergoing planned inpatient surgery and their parents. Given that most of the literature about parents' management of their child's post-operative pain focuses on younger children who are more apt to accept their parents' decisions around their pain management, there may be other factors which need to be considered in managing post-operative pain at home amongst adolescents who undergo major surgery. Therefore, exploring the post-operative pain management experiences of both adolescents and their parents following major surgery is required to understand if additional factors impact an adolescent's pain management in the home setting.

**Parental Management of Inpatient Pediatric Surgical Pain in Hospital**

There exists a growing body of research pertaining to parental/patient management of pediatric inpatient surgical pain in the hospital setting. Many of the studies in this area include children and adolescents who have undergone major surgery and thus provide insight into some of the challenges parents and patients encounter when managing post-operative pain due to major (inpatient) surgery as opposed to minor (outpatient) surgery.

In terms of parental pain management in hospital, research indicates that parents may be inadequately prepared for discharge due to a lack of involvement in the care of their children while they are in hospital. For example, in a qualitative study Hoon Lim, Mackey, Li Wee Liam, and He (2011) explored the experiences of 14 parents whose children had undergone inpatient surgery (no specific surgeries were listed but children were hospitalized for greater than 24 hours) to better understand how they managed their child's post-operative pain while in hospital. The findings suggest that parents were instructed to use non-pharmacologic interventions and could only request analgesics from healthcare providers while in hospital. This suggests that the role of these parents in their child's pain management was limited, and other than providing non-pharmacological interventions they were not true decision makers in the administration of analgesics. This may result in parents not gaining the necessary competency to manage their child's post-operative pain following discharge home.

A lack of integration into the inpatient care team leaves parents ill-informed, often being aware of the severity of the pain of their child but perhaps believing that this is normal if their requests for analgesia are not addressed and thus may help to explain why

parents still report being satisfied with the level of care received from hospital staff despite their child's high levels of pain intensity. For example, Twycross and Finley (2013) interviewed 10 parents whose 8 children required 48 hours of hospitalization after undergoing inpatient surgery (no surgeries were specified), and found that although parents reported their child experienced severe pain post-operatively, they felt that nurses had done all they could to control their child's pain. An additional study by Chng et al. (2015) examined 60 parents of children from 6 to 14 years who had undergone inpatient surgery in a Singaporean hospital using the Pain Management Knowledge and Attitudes questionnaire (which the authors developed for and sought to validate through this research). They discovered that parents held only moderate degrees of knowledge regarding pediatric pain care. The parents in the study were generally satisfied with the level of post-operative pain management their child received, however it is not known if they were satisfied with adequate levels of pain care (pain intensity ratings were not reported) or if they were satisfied because they were unsure what adequate pain care should include. Nevertheless, there are studies that indicate that parents expect differing approaches to and more information for their child's pain care from nurses. For example, in a questionnaire-based survey of 206 parents of children between the ages of 6 and 12 years undergoing inpatient surgery, Lee, Vehviläinen-Julkunen, Pölkki, and Pietilä (2010) found that parents believed nurses should use more non-pharmacologic interventions, that information provided was inadequate, and that appropriate and understandable information should be provided. If parents experience challenges in receiving adequate pain care for their children while in hospital under the care of hospital

staff, it may be unreasonable to expect they will be prepared to care for their child at home.

### **Child and Adolescent Management of Inpatient Pediatric Surgical Pain in Hospital**

There are minimal studies exploring the knowledge, behaviours, and experiences of children and adolescents engaged in their own postoperative pain care while in hospital. One of the studies in this area used interviews with 15 children between the ages of 6 and 12 years to explore their post-operative pain experiences (Sng et al., 2012). Main themes spoke of self-directed actions to relieve pain (e.g. distraction, imagery), children's perceptions of actions nurses and parents undertake to relieve pain (e.g. assessment, analgesic administration), and suggestions for nurses and parents to relieve pain (e.g. distraction, being present). Children in the study experienced mild to severe pain post-operatively (ranging from 2 to 10 out of 10), which was managed using a variety of cognitive and behavioural methods of non-pharmacologic analgesia, such as distraction and imagery. The suggestions of the children and adolescents for parents to help in their pain management were to aid in the use distraction, as well as maintaining parental presence while in hospital. The participants identified the use of analgesics as a method for pain management, which was made easier by the use of a patient controlled analgesic pumps, or by alerting parents to deliver medication. This study suggests that children have the capability to use and identify effective pain management strategies, and thus further research into the personal pain management experiences of both children and adolescents is warranted.

Despite feeling as though they have been adequately prepared for discharge, the lack of integration into the medical care of their child may leave parents unaware of their

child's discharge needs. For example, Schuh et al. (2016) conducted a cross sectional study capturing data using a discharge questionnaire with 181 parents whose children age 7 to 17 years were admitted to a cardiac surgery ward and found that 96% of the parents believed they were well prepared to take their child home on discharge day despite many parents misunderstanding major aspects of their child's treatment in hospital (e.g. 8% of parents were unaware that cardiac catheterization was not considered a type of surgery by clinicians). The researchers found that more attention needed to be given to educate parents in pain management strategies while in hospital in order to better prepare them for discharge. The lack of integration into the pain management team, inadequate information provided on discharge, and reported satisfaction with the care of children in moderate to severe pain may culminate in inadequate pain control by parents in the community setting, and thus further research is required.

### **Outpatient Management of Pediatric Cancer Pain**

Parents whose children have cancer often manage their child's cancer-related pain at home, and thus research examining pain management in this population is relevant to the proposed research, particularly given that at times pain treatment strategies are similar to those used for acute post-operative pain management. A study by Pritchard et al. (2010) used open-ended interviews to explore the symptoms of most concern to 48 parents of children with cancer. The parents in this study cited that pain was one of the four most important symptoms to manage, highlighting the critical importance of pain management for parents when caring for their child at home. Even within the population of pediatric outpatient cancer patients, assessment of symptoms including pain is an area which parents experience challenges. In a recent cross-sectional study involving 100

parents of children with different types of cancer, Williams, Piamjariyakul, Shanberg, and Williams (2015) evaluated the use of the Therapy-Related Symptom Checklist for Children (TRSC-C) (Williams et al., 2012) to help parents assess cancer related symptoms including pain. The study results demonstrated that the TRSC-C was a useful tool, as it aided parents in monitoring symptoms including pain, and aided in determining when to intervene. A similar tool may aid parents and adolescents who have undergone planned inpatient surgery monitor post-operative symptoms at home.

Parental factors may also be linked to their child's pain outcomes, particularly in the home setting where health professional support is not available. A study involving 137 parents whose children were treated for cancer was conducted to evaluate how parental anxiety was related to their children's pain and quality of life (Link & Fortier, 2015). Measures of parental anxiety were related to increased levels of child pain intensity, suggesting that parental factors (such as encouraging pain behaviour and maladaptive coping) may lead to suboptimal pain management at home. Two other cross-sectional studies also suggest that parental factors contribute to inferior pain outcomes in children with cancer. Parents of children with cancer in the home setting were examined by Fortier et al. (2012), who surveyed parental perceptions of their child's pain expression and attitudes towards analgesics to determine if these factors had an impact on their pain management. One hundred and eighty-seven parents completed measures that captured their attitudes towards analgesics, child behaviours parents perceived as being pain related, parent anxiety, and parent reports of their child's emotional activity, social ability, and temperament. Results indicated that parents did not understand how children express pain, feared the side effects of analgesia, were concerned about addiction, and

held many misconceptions regarding analgesic use in children. In a follow-up study to examine barriers to parents' analgesic administration, Fortier et al. (2014) conducted a cross-sectional daily diary study involving 45 parent/child cancer dyads. The children in these dyads were between the ages of 4 and 17 years. The researchers concluded that analgesic administration at home was low despite children and adolescents experiencing pain, parents who reported misconceptions regarding analgesics were less likely to provide adequate pain care, and cancer pain in the home setting is not adequately managed. If parents of children with cancer hold misconceptions regarding appropriate pain management, it is likely that parents of children and adolescents undergoing surgery do as well.

In determining other factors that may impact cancer pain management at home, Hechler et al. (2009) used semi-structured interviews to explore if boys and girls with cancer differ in their recollection of pain and pain experiences and if parents and patients differed in their recollections of pain. The study involved 112 cancer patients between the ages of 12 and 18 years and their parents, finding that girls recalled higher levels of pain intensity. Furthermore, parents and adolescents differed significantly in their perceptions of pain at the seventh day of the diary study despite being similar at the beginning. Girls reported higher pain scores than their parents and boys reported lower pain scores than their parents. Given that post-operative pain may last beyond 6 weeks it is likely that adolescent's experiences of pain and their parent's perceptions of pain may differ, which would lead to a disconnect in pain management between the parent and the child.

**Relevance**

As demonstrated through the literature review, post-operative pain management following discharge from inpatient surgery is underexplored. Major issues highlighted across the literature review included the sub-optimal management of children's post-operative pain at home following outpatient surgery and cancer pain management in the home setting, frequent concerns and misconceptions by parents regarding the use of analgesics in the treatment of their child's pain, and a lack of effective educational intervention procedures for parents. The literature review speaks to the scarcity of research exploring the experiences of both parents and adolescents in pain management following inpatient surgery. The findings in this literature review largely suggest a need for a more comprehensive understanding of the parent and adolescent pain management dynamic in order guide the design of effective intervention strategies. The goal of this thesis research is to shed light on the challenges (e.g., beliefs, attitudes, concerns, knowledge gaps) faced by parents and adolescents as they attempt to manage post-operative pain in the home setting following an adolescent's inpatient major surgery.

**Purpose of Thesis**

The purpose of the research is to explore the pain management experiences of adolescents and their parents in the community setting post-discharge from inpatient surgery. In depth understanding of the experiences of adolescents and parents in managing post-operative pain at home following inpatient surgery may provide insights to inform interventions to support parents and adolescents in effective pain management at home.

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### **Chapter 3**

#### **Methodology and Methods**

## **Methodology and Methods**

### **Methodology**

Interpretative Phenomenological Analysis (IPA) is a qualitative research methodology focused on meanings and beliefs of participants, which is a valuable approach when the topic of interest is the lived experiences of the participants (Crist & Tanner, 2003). IPA as described by Smith and Osborn (2003) was used as the methodology for this research. IPA acknowledges both the role of the researcher and participant within the construction of knowledge and the socially constructed origin of truths, and thus falls within the constructivist paradigm (Guba & Lincoln, 1994). As an interpretative phenomenological approach, IPA has roots in the philosophy of Martin Heidegger (1927), who espoused that ontology itself is hermeneutical, as one can only experience the world through interpretation, and thus accordingly acknowledges the active role of the researcher within the research process. This implies that the researcher can only access the perceptions of the participants through the lens of their own conceptions (Smith & Osborn, 2003), which allows the researcher to both accommodate for and address their own role within the analysis, providing knowledge from both the viewpoints of the participants (emic) and of the researcher (etic). Given that there is a scarcity of research on the complexity of managing post-operative pain at home in adolescents following major surgery, IPA provides an approach to include the experiences of both adolescents and parents (as perceptions of the experience may differ) while acknowledging the role of the researcher in the co-construction of knowledge and in the interpretation of the findings. Thus, an understanding from the perspective of both

members of the relationship (parent, adolescent) is necessary to provide meaningful insights to this multifaceted experience.

### **Research Question**

What are the lived experiences of parents and adolescents managing post-operative pain at home following major inpatient surgery?

### **Sample and Setting**

A purposeful sampling method was used to invite adolescents undergoing inpatient surgical procedures and their parents at the Children's Hospital of Eastern Ontario who recovered in part at home in the community setting under parental care. Purposeful sampling methods involve selecting participants according to the aims of the research, which allow the researcher to more easily study information rich cases in-depth (Palinkas et al., 2015).

Inclusion criteria for adolescent participants were those who:

- 1) were between 12 and 18 years of age;
- 2) had surgery for spinal fusion, periacetabular osteotomy, pectus excavatum repair, mammoplasty, ileostomy, colostomy, colectomy, exploratory laparotomy, femoral varus derotational osteotomy, or femur fracture;
- 3) were hospitalized for  $\geq 24$  hours post-operatively, who had surgery no longer than 6 months prior;
- 4) were English speaking.

Inclusion criteria for parent participants were those:

- 1) whose child/adolescent were between 12 and 18 years of age;

- 2) whose child/adolescent had surgery for spinal fusion, periacetabular osteotomy, pectus excavatum repair, mammoplasty, ileostomy, colostomy, colectomy, exploratory laparotomy, femoral varus derotational osteotomy, or femur fractures;
- 3) whose child/adolescent was hospitalized for  $\geq 24$  hours post-operatively;
- 4) who were English speaking.

Exclusion criteria for adolescent participants were those:

- 1) with developmental delay (e.g. global developmental delay);
- 2) with major psychiatric diagnosis (e.g. bipolar disorder, depression, generalized anxiety disorder, borderline personality disorder);
- 3) who experienced significant surgical or medical complications (e.g. sepsis, dehiscence, or pulmonary embolus),
- 4) with chronic pain diagnosis prior to surgery,
- 5) who were hospitalized for greater than 14 days

Exclusion criteria for parent participants were those whose child/adolescent:

- 1) had developmental delay (e.g. global developmental delay);
- 2) had major psychiatric diagnosis (e.g. bipolar disorder, depression, generalized anxiety disorder, borderline personality disorder);
- 3) experienced significant surgical or medical complications (e.g. sepsis, dehiscence, or pulmonary embolus),
- 4) had a chronic pain diagnosis prior to surgery,
- 5) was hospitalized for greater than 14 days

Two teams were used to recruit patients for the study; The Children's Hospital of Eastern Ontario (CHEO) Orthopedics team was responsible for recruiting all orthopedic surgery

patients, including those undergoing spinal fusion, femoral varus derotational osteotomy, femur fracture repair, and periacetabular osteotomy. The Acute Pain Service (APS) is a consult service and when consulted, are responsible for the pain management of patients undergoing inpatient surgery (generally seeing most inpatient surgical patients on post-operative day 1) and was responsible for recruiting patients undergoing surgery for pectus excavatum repair, mammoplasty, ileostomy, colostomy, colectomy, and exploratory laparotomy. The Nurse Practitioners (NPs) for each service were the initial point of access to participants.

**Sample size.** Sample size for phenomenological studies capturing data using individual interview methods and analyzing data using IPA ranges from 5-18 individuals (Smith & Osborn, 2003). Sample sizes are not predetermined in qualitative studies as factors such study design, the scope of the study, nature of the topic, and depth of the data influence overall sample size (Morse, 2002). Therefore, 6 participants for each study were targeted. Data analysis was ongoing throughout data collection and was used to determine the depth and breadth of the data as well as the final number of participants. Overall, 7 participants for each study were recruited between September 2018 and March 2019.

### **Recruitment and Consent Procedures**

The researcher used both prospective and retrospective recruitment strategies. For prospective recruitment, during post-operative consultations with the patients, the NPs for Orthopedics and APS would ask eligible potential participants if they were interested in learning about the study from a member of the research team. If the answer was yes, the researcher met with potential participants to inform them about the nature of the study, went over consent materials (Appendix A), offered an opportunity for participants to ask

any questions, and obtained consent. At this point the researcher collected contact and demographic information to contact the participants for interview following discharge and post-operative follow-up. The participants were followed by one of the NPs during their inpatient admission, and the NPs informed the researcher of their date of discharge and follow-up appointment. When post-operative recruitment was not possible during the inpatient admission, patients were recruited during their post-operative follow-up appointment with the Orthopedics NP where, before meeting the researcher, the NP would introduce the study and ask the potential participants if they were interested in participating. If the answer was yes, the researcher met with the participants to inform them about the nature of the study, went over consent materials, offered an opportunity for participants to ask any questions, and obtained consent. At this point the researcher collected contact information to contact the participants for interview. The researcher did not contact anyone who consented to participate until after discharge and post-operative follow-up, at which point consent was reconfirmed via telephone and audio recorded.

Retrospective recruitment was accomplished by the Orthopedics NP mailing out letters (see Appendix B) briefly explaining the study to all patients who had had spinal fusion, periacetabular osteotomy, or pectus excavatum repair in the past 6 months. The APS NP was unable to engage in retrospective recruitment due to the time constraints of their position. The retrospective recruitment letter included the contact information for the researcher and potential participants were free to contact the researcher if they were interested in participating. At this point, respondents were screened for meeting inclusion/exclusion criteria, and consent forms were e-mailed to interested potential participants. Potential participants were contacted by phone after mailing the consent

form and had the opportunity to ask any questions they may have had about the study. It was then determined if they were interested in participating, which if they were, a date and mode for the interview were established. On the day of the interview, consent was then confirmed verbally using the verbal consent script (Appendix A) and audio recorded prior to the interview, ensuring that the participant understood the study and informed consent was given. Overall, 12 letters were mailed out, with 2 respondents, both of whom met inclusion criteria and participated.

### **Data Collection and Analysis**

**Data collection.** The principal investigator offered the option of performing interviews with adolescent and parent participants in person, by telephone, or by Skype. Though in-person interviews may have many benefits, telephone/Skype interviews were incorporated to allow for more diversity in participants, as some participants were located a prohibitive geographical distance from CHEO. Telephone interviews are a valuable qualitative research tool as they allow for flexibility in terms of geographic location of participants, limit costs, enhance safety, and allow for greater accessibility through scheduling flexibility (Drabble, Trocki, Salcedo, Walker, & Korcha, 2016). Telephone interviews also proved to be very flexible for participants with busy schedules. Skype was also offered as an option for interviews. Skype is an application used for communicating over the internet using voice, video, and text (Skype, n.d.). As per a systematic review conducted by Sullivan (2012), Skype allows interviewers and interviewees to interact in a manner more similar to face-to-face interviews, as important aspects of interpersonal interactions such as non-verbal communication are conveyed. Moreover, Sullivan (2012) suggests that with younger generations, online representations

of self are more authentic. Despite the variety of interview options offered, all participants opted for telephone interviews.

Interviews did not take place prior to the 2-week post-operative follow-up with their surgeon, instead taking place after discharge no sooner than post-discharge day 14, and no later than 6 months following surgery. Waiting until after the adolescent's first follow-up appointment with their surgical team ensured that the pain management course was not altered by serious post-operative complications. When post-operative follow-up was delayed, interviews were rescheduled to take place after the rescheduled appointment. As shown through a study by Wilson et al. (2016), post-operative pain in ambulatory patients is generally highest on post-operative day 7 to 9, as patients are still healing but attempting to resume activities of daily living. Therefore, conducting interviews after the two week period allowed time for their pain to most likely reach peak pain intensity levels, generally begin to subside, and ensure that the adolescent and parents had time to experience management of post-operative pain at home after a major surgery. Additionally, as post-operative pain should begin to recede after a two week post-operative period, the adolescents were more likely to be in a more comfortable state to be able to participate in an interview.

This study was not a dyad study. The research question was not to compare or contrast the experiences in managing post-operative pain between parents and adolescents but rather to understand the experience of both parents and adolescents who manage adolescent post-operative pain in the home setting. Thus, adolescents who were interested could participate even if their parents were not interested and vice versa. However, in the case of both members of a family (adolescent and parent) volunteering to

participate, adolescents and their parent(s) were interviewed separately to provide an opportunity for adolescents to voice their experience without feeling constrained by their parent's presence and vice versa. Interviews were arranged at a time that was convenient for participants including on different days for parents and adolescents. The participants were given assurances of confidentiality (see further discussion in Confidentiality and Data Management). The researcher conducted telephone interviews alone in a private room with a closed door. The interviewer asked the same of participants. Though dyads were not specifically targeted, all participants recruited were dyads, though this was not relevant in analysis as responses for each participant within the dyad were not compared, contrasted, or viewed in the context of the responses of their parent/child.

Individual interviews commenced with questions moving from the general to specific and from less to more personal to help build rapport and trust during the interview (Smith & Osborn, 2003). Interviews were guided by a semi-structured topic guide (see Appendix C) with probes to allow the interviewer and interviewee more opportunity to explore areas of concern and interest (Smith & Osborn, 2003). These guides (adolescent version; parent version) were piloted with a healthy adolescent and parent to ensure the adolescents and parents easily understood the wording of the questions and the flow of the interview. Interview times ranged from 30-60 minutes. Participants were assured if they were unable to continue the interview for any reason a follow-up interview could be scheduled, with the exception of if a participant sought to withdraw from the study, which did not occur. Interviews were audio recorded and transcribed for data analysis by a professional transcriptionist. The researcher did not

answer any questions about the patient's care and would suggest the patients refer to their attending care provider for questions concerning their health care.

**Data analysis.** Data was analyzed using thematic analysis as described by Smith and Osborn's methodology Interpretative Phenomenological Analysis (2003). The analysis involved the engagement of the researcher in an ongoing and interpretative relationship with the data. The principal investigator worked in an ongoing capacity with the thesis supervisor (Dr. Forgeron) who has expertise in IPA to review the process, content, and initial impressions, and discuss any potential data collection concerns (e.g. wording of a probe question). Analysis occurred as transcripts were received. This approach to analysis assists in determining when recruitment should close, as it allows for the evaluation of the depth of data obtained in an ongoing capacity. Data collection was completed upon data saturation.

The aim of IPA data analysis is to learn about the meanings, beliefs, and experiences of participants for a given phenomenon (Smith and Osborn, 2003). To begin the analysis of each transcript, the researcher began by immersing himself in the data, performing a close reading of the transcripts. The researcher also performed a reading of each transcript while listening to the audiotapes to ensure accuracy of transcription and to examine verbal nuances. Thematic analysis as proposed by Smith and Osborn consists of four steps. The first step involves an initial close reading where the researcher notes significant or interesting responses for future use in thematic analysis. In the second step, the notable responses are coded using identifying terms (codes). Codes were reviewed with the supervisor to seek guidance and discuss relevance of codes with the responses. Codes identified in the initial two interviews were used to assist with the coding of each

subsequent case with idiographic (specific to the interview) findings being noted during the initial read of subsequent interviews. When new codes or emergent themes were noted, previous interviews were re-read to ensure that these new codes or emergent themes were noted if present. After each participant's interview was coded the next phase of analysis was to group the codes for each interview into higher-level headings that Smith and Osborn (2003) call "emergent themes". IPA is committed to an idiographic understanding of each participant's experience (Smith & Osborn, 2003), which is aided by the process of developing emergent themes for each participant.

Through an iterative and reflective process, each emergent theme was then compiled and moved into a single document to help identify experiences across the participants where applicable. Exemplar quotes from the interviews were grouped under the emergent themes to assist in refining clusters of emergent themes (or categories) into themes with sub-themes. Using the arrangement of themes and subthemes, the researcher met with his thesis supervisor regularly and also met with the extended research team to formulate a list of main themes, compiling a final master document with specific reference to each participant and their quotes. Working with the research team provided an opportunity for the inclusion of additional researchers in the analysis process, which is advocated by Conroy (2003) as it enlarges the hermeneutic spiral by providing the benefits of brainstorming and discussions with other researchers. The meetings with the thesis supervisor and the research team were also used to ensure that the findings were grounded in the transcripts and that no one voice dominated the analysis.

The final step in the analysis involved translating the information from the table into a narrative format including the direct referencing to the accounts (exemplar quotes)

of the participants to support interpretations (Smith & Osborn, 2003). This narrative form was conducted with the help of other researchers (in this case the supervisor and committee members) to ensure the thematic analysis was grounded within the data.

### **Confidentiality and Data Management**

**Confidentiality.** Participants were informed of the efforts made to respect confidentiality. They were informed that their clinicians (e.g. nurses, surgeons) would not be informed if they took part in the study or did not take part in the study. Identifying information was not shared with those other than the principal investigator and his thesis supervisor. The other members of the research team only had access to aggregated data during the final analysis phase, which did not include any identifying features.

Participants were informed that all names and identifying information (e.g. clinician's names, adolescent/parent names) were removed at the time of transcription. Each participant was assigned a participant identification number and this number was used on all data forms (e.g. demographics, transcriptions) to help with confidentiality. Only the principal investigator had access to the list of participant names and ID numbers. Aliases were used in the analysis to further provide confidentiality and these aliases are and will be used in the dissemination of the findings (e.g. publications, research/teaching presentations). ID numbers and verbal consent forms were stored separately to avoid the possibility of connecting the two. The professional transcription service was required to sign the attached confidentiality form (Appendix D).

**Conservation of data.** Participants were informed that results are stored securely in password protected encrypted files with all personal identifying information removed on the CHEO server, and will remain stored there for 7 years after completion of the

study as per CHEO ethics requirements, after which time, the researcher will permanently destroy the files in accordance with CHEO guidelines. The confidentiality agreement with the transcriptionist states that they are to permanently delete all files from their computer once they have been transferred to the principal investigator.

**Voluntary participation.** Participants were informed that they did not have to take part in the study, that their decision to take part would have no effect on their health services, that both adolescents and their parent(s) did not have to consent to participation in order for the other to be included in the study, and that any participants could withdraw at any time. Participants were informed that withdrawal would result in the destruction of their data unless consent was given for its use. Participants were informed that they could refuse to answer any question at during the interview without fear of negative consequence. Withdrawal could occur at any time prior to data analysis.

**Benefits and risks.** All possible efforts were made to minimize the risk of participation in the study. Participants were informed of the risk of discomfort inherent in the disclosure of personal experience during the interview process. In order to address this risk, the option to have a de-briefing session after the completion of the interview with the thesis supervisor was offered as an opportunity for the participants to voice any personal concerns with their experience with pain or research participation. The thesis supervisor is an Associate Professor of Nursing at the University of Ottawa and a former Clinical Nurse Specialist in the area of pediatric pain and worked with this population directly in the clinical milieu for over 10 years and has another 19 years of direct patient care experience.

Although the principal investigator is a pediatric nurse, the participants were reminded at the beginning of the interviews that the principal investigator's role is that of the researcher and not clinician. Therefore, if the participants had questions about their personal healthcare management, including the pain management that they had received, they were directed to their pediatric healthcare team and/or their family physician.

There was also a risk in terms of the vulnerability of the participants in parent/child dyads (or triads if both parents participate) and the disclosure of personal information. In the case that both parent(s) and child participated, no information from each interview was shared with the other parties in the family unit. Participants were asked to conduct the phone interviews by themselves in a room with a closed door (which the researcher did as well); however, it is acknowledged there was no way to ensure that the participants complied with this request. Participants were informed that the principal investigator and his supervisor would keep all information confidential unless required or permitted by law (for example, risk of harm or risk of harming someone else).

**Rigour.** Goodness was used as a framework for rigour in this study. In order to enhance the goodness of this qualitative study as per Tobin and Begley (2004), six elements were taken into consideration in the analysis and discussion of this research: the foundation (the philosophic grounding of the research), the approach (the methodologic soundness of the study), the collection of the data (explicit reference to the means of collecting data and making decisions regarding it), the representation of voice (reflection of the both the voices of the researcher and of the participants, the art of making meaning (the presentation of insight through the interpretation of the data), and the implication for professional practice (the recommendations implied from the analysis). For example, a

constructivist epistemology underpinned the interpretative nature of the phenomenological data analysis, each step in the recruitment and data collection steps has been made explicit, and the researchers have made sure that no participant's voice is dominant within the representation of the data.

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## **Chapter 4**

### **Adolescent Patients' Management of Post-Operative Pain After Discharge, A Qualitative Study**

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This chapter is an unpublished manuscript formatted for submission to

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### **Abstract**

Adolescents are typically admitted for a short period of time after inpatient surgery, leaving much of their recovery to occur at home. Pain, and thus pain management, is a major component of recovery at home. Research amongst pediatric outpatient surgical patients has found that pain experienced in the community setting following discharge is often severe and is related to knowledge deficits resulting in inadequate pain management. However, there is a little research on community pain management following inpatient surgery. Interpretative Phenomenological Analysis was used to explore the pain experiences of seven adolescents who underwent inpatient surgery. Semi-structured interviews were conducted two to six weeks post-discharge. Three themes were identified that described their experiences including managing severe pain at home with minimal preparation, changes in the parent-child relationship, and difficulties returning to school and regular activities. Involving adolescents directly in discharge education, particularly with the use of novel interventions and coaching, may improve outcomes.

### **Introduction**

Pain management is a major issue in post-operative patient care (International Association for the Study of Pain, 2017); adequate treatment of pain improves quality of life, reduces complications, and facilitates recovery (International Association for the Study of Pain, 2010; Rabbitts, Palermo, Zhou, & Mangione-Smith, 2015). Inadequate pain management in children and adolescents can increase morbidity and mortality (Peelen, Kalkman, & Meissner, 2013; Stoll, Hansen, Bell, Walsh, & Carlo, 2015), and is a risk factor for the development of chronic pain (Reddi, 2016). Acute pain is a common side effect of surgery, which is typically treated in hospital post-operatively. As hospitals strive to decrease inpatient length of stay (Macy et al., 2009), post-operative inpatients experience shorter lengths of stay following surgery (Clarke & Rosen, 2001; DeSena, Nelson, & Cooper, 2015), leaving much of the recovery process to take place at home in the community setting. Earlier discharge of children and adolescents post-operatively results in parents taking on the role of pain management for their children when they previously would have been in hospital (Vincent, Chiappetta, Beach, Kiolbasa, & Latta, 2012). Moreover, for adolescents who have had surgery, this may mean that they take on aspects of the pain management role themselves (Sng et al., 2012).

There is a paucity of research exploring patient's experience of post-operative pain management following inpatient surgeries (e.g. spinal fusion, colectomy), though one recent study of 167 parent/child dyads explored the correlation between parents' and adolescents' pre-operative pain catastrophizing (negative experience of actual or potential pain) and post-operative pain following posterior spinal fusion. The researchers found a positive correlation between adolescents' pain catastrophizing and their post-operative

pain, meaning that those with higher pain catastrophizing had higher pain scores (Birnie, Chorney, El-Hawary, & PORSCHE Study Group, 2017). Moreover, they also found that participants reported a mean pain score of 2.51 (SD 2.11) out of 10 at 6-week follow-up (Birnie, Chorney, El-Hawary, & PORSCHE Study Group, 2017), suggesting that adolescents may experience post-operative pain for a significant duration of time following inpatient surgeries.

Adolescents' ability to manage pain at home following inpatient surgery may also be negatively impacted by pre-discharge preparation. In a recent descriptive qualitative study, Rabbitts et al. (2017) explored the experiences of 15 parents and their children (age 10-18 years) following discharge for spinal fusion, pectus repair, and hip osteotomy as well as the experience of 17 perioperative healthcare providers (nurses, nurse practitioners, physiotherapists, surgeons) using interviews to understand child and family experience surrounding major surgery and to identify barriers/facilitators to providing adequate pain care in the home setting. Key findings from the family interviews indicated that children and families felt unprepared for both surgery and the degree of post-operative pain, and that recovery at home was challenging as families were unsure about safety and feared injury. Parents experienced stress from their child's increased reliance on them for care. Children and parents were interviewed together which while allowing for an understanding of the phenomenon from the perspective of the family as a unit (Rabbitts et al., 2017), does not allow for an in-depth of understanding of the role of the individual within the unit, as participants may have to censor responses to respect others in the interview. A better understanding of adolescents and their parents as individuals could be gained from separate interviews.

It is unclear how in-hospital teaching and modelling prepares parents and adolescents for discharge, however a systematic review by Twycross et al. (2015) found that nurses did not administer opioids as often as they could to adolescents in hospital post-operatively. It is possible that if adolescents do not receive adequate analgesia in hospital by clinicians, they may perceive that they also should not self-administer analgesia (e.g. opioids) even when they are experiencing pain. Understanding the pain care challenges adolescents encounter in managing their post-operative pain at home would help develop informed strategies to support them to help ensure that they are ready to participate in their post-operative pain care.

Research on the experiences of adolescents undergoing outpatient surgery (e.g. tonsillectomy, inguinal hernia repair, myringotomy tube insertion), suggests that post-operative pain management is a significant issue in the home setting. Pain following head and neck surgery (e.g. adenoidectomy, myringoplasty, ankyloglossia) identified that adolescents continued to experience pain an average of 9 days post-operatively (Wilson et al., 2016) and post-tonsillectomy, children and adolescents continued to experience moderate to severe pain at home into post-operative day (POD) seven (Stanko, Bergesio, Davies, Hegarty, & Von Ungern-Sternberg, 2013) and as long as into day 14. (Howard et al., 2013).

The pain reported by children and adolescents post-operatively may be related to suboptimal pain management by parents, as it has been reported that children and adolescents often do not receive any analgesics after discharge from outpatient surgery (Fortier, MacLaren, Martin, Perret-Karimi, & Kain, 2009). Parents have cited a range of concerns including fear of drug tolerance, medication side effects, and addiction to

opiates (Fortier, Wahi, Bruce, Maurer, & Stevenson, 2014). Parents have also been found to believe that analgesics should be used as a last resort (Hamers & Huijter Abu-Saad, 2002). A study that captures the experience of adolescents managing their post-operative pain at home following an inpatient stay would help illuminate the interplay between parental beliefs towards use of analgesia with those of the adolescent.

The focus of much of the research in the outpatient surgery pediatric population has been examining issues related to children 12 years of age and under or adolescents as part of a group from 0-18 years of age. Little information exists specifically exploring the experiences of adolescents. A study by Gillies, Smith, and Parry-Jones (1999) on 251 adolescents undergoing both inpatient and outpatient surgery found that adolescents in both groups experienced moderate to severe pain on POD one and three, often with only a single dose of opioid analgesics administered by clinicians. Clinicians reported fears related to addiction and side effects as reasons for providing minimal opioid analgesic. It was unclear how adolescents engaged in the role of managing their own pain following surgery. However, a study by Sng et al. (2012) found that children between the ages of 6 and 12 years admitted to being post-operatively engaged in self-directed actions to relieve pain (e.g. distraction, imagery). The study further discovered that they also alerted their parents to the need for medication, indicating that children can play an active role in their own pain management. It is likely that adolescents could be more involved in their pain care with proper preparation.

Clearly, post-operative pain at home remains a problem for children and adolescents who undergo outpatient surgery, suggesting that adolescents who have inpatient surgery may also be at risk for significant pain at home following discharge.

Adolescents may also play an important role in their own pain management. Undertreated pain at home could lead to significant adverse effects for recovery and increased risk of post-surgical chronic pain (Reddi, 2016). Therefore, this study sought to understand the post-operative pain experiences of adolescents at home following inpatient surgery.

### **Methods**

Interpretative Phenomenological Analysis (IPA), as described by Smith and Osborn (2003), was used to guide this study. IPA is a qualitative research methodology focused on meanings and beliefs of participants, which is a valuable approach when the topic of interest is the lived experiences of the participants (Crist & Tanner, 2003). Therefore, IPA methodology allowed for an exploration of the pain management experiences of adolescents. IPA aligns with a constructivist paradigm as it focuses on the idiographic understanding of the participants (a unique personal phenomenon), highlighting the multiple realities of an experience, and is grounded in the belief that knowledge is socially constructed (Guba & Lincoln, 1994).

### **Participants**

A purposeful sampling method was used to prospectively and retrospectively recruit adolescents undergoing inpatient surgical procedures at a tertiary care pediatric hospital in central Canada and who recovered in part at home in the community setting. Inclusion criteria were adolescents who: 1) were between the ages of 12 and 18 years; 2) had surgery for spinal fusion, periacetabular osteotomy, pectus excavatum repair, mammoplasty, ileostomy, colostomy, colectomy, exploratory laparotomy, femoral varus derotational osteotomy, or femur fracture open reductions; 3) were hospitalized for  $\geq 24$  hours post-operatively; 4) had surgery no longer than 6 months prior to the study, and 5)

spoke English. Exclusion criteria were adolescents: 1) with developmental delay; 2) with major psychiatric diagnosis; 3) who experienced significant surgical or medical complications (e.g. deep vein thrombosis, infection); 4) with chronic pain diagnosis prior to surgery; or 5) who were hospitalized for greater than 14 days. Exclusion criteria were used to limit the potential complications affecting the adolescents' pain experience.

Adolescents were prospectively and retrospectively recruited through the Orthopedics and Acute Pain Service Nurse Practitioners (NPs). For prospective recruitment, the NPs introduced the study to eligible participants who were in-hospital during the post-operative admission or at the two-week follow-up appointment and obtained their authorization to be contacted by the research team. For retrospective recruitment, letters introducing the study were sent from the NPs to eligible participants with the contact information of the research team, whom they could contact if they were interested in more information or to express an interest in possibly participating.

### **Procedures**

#### **Ethics**

The Research Ethics Boards (REB) at the tertiary care pediatric hospital where the study was held and the REB of its affiliated university approved this study. Informed consent was obtained from all participants prior to data collection, and demographic data was collected at this time. All data was de-identified (e.g. names and identifying data removed during transcription), and a unique study number and pseudonym was given to each participant's data. All data were password-protected and stored on the secure hospital server and will be kept for seven years in accordance with REB requirements.

#### **Data Collection**

Interviews were conducted no later than 6 months after discharge and no sooner than following the patient's two-week follow-up appointment to allow for adequate experience with managing their post-operative pain while home but yet time for their pain to subside to the degree where it could permit engagement in the interview. Research suggests that post-operative pain in outpatient surgical patients is generally highest on POD 7 to 9 (Wilson et al., 2016), and thus interviews were not conducted any sooner than after patients' two week follow up appointment in clinic. This allowed for the adolescents' post-operative pain to peak and begin to recede, as well as to ensure that the pain management course was not altered by serious post-operative complications.

Interviews were offered by telephone, in-person, or by Skype depending on participant preference and to ensure that those living farther from the hospital had the opportunity to participate without the burden of commuting. Interview questions moved from the general to specific and from less to more personal to help build rapport and trust during the interview (Smith & Osborn, 2003). Questions ranged from "Can you tell me a little bit about yourself?" to "What was the hardest thing about dealing with your pain after surgery?" Probes were used to elicit more information and allow the interviewer and interviewee more opportunity to explore areas of concern and interest (Smith & Osborn, 2003). The interview guide was piloted with a healthy adolescent to ensure that the questions were easy to understand and that the flow of the interview allowed the adolescent to share their experience. Interview times ranged between 30-60 minutes. A professional transcriptionist transcribed the interviews.

**Analysis**

The thematic analysis was guided by Smith and Osborn's (2003) approach to IPA. The first step began with a close read of the transcripts, which was completed while listening to the audio recording, ensuring accuracy of transcription. This step occurred as transcripts were received. Step two included a second read of the transcripts during which the researcher noted interesting and significant responses by writing words or phrases to denote meaning (coding). In collaboration with the second author, these codes were reviewed to develop a list of codes to use with the subsequent interviews. As more transcripts were analyzed, additional codes were added to the list if required. When a new code was noted, previously coded interviews were reviewed to determine if these newer codes were present in the previously coded interviews. Next, the codes for each transcript were grouped into higher-level themes for each participant, paying attention to an idiographic understanding of each participant's experience at the individual level before being analyzed in terms across participants. Through an iterative and reflective process involving collaboration with the research team and second author, the emergent themes for all transcripts were then compiled into larger, major themes to help identify experiences across the participants, including exemplar quotes from the data for each theme.

**Rigour**

Rigor for this study was guided by Tobin and Begley's (2004), six elements of goodness: foundation (the philosophic grounding of the research), approach (the methodological soundness of the study), collection of the data (explicit reference to the means of collecting data and making decisions regarding it), representation of voice

(reflection of the both the voices of the researcher and of the participants), the art of making meaning (the presentation of insights through the interpretation of the data), and the implications for professional practice. For example, interpretative phenomenological analysis is grounded in a constructivist philosophy and thus provided methodological soundness to the study. Data collection included individual interviews, which allows for the idiographic focus of IPA. Representation of voice and meaning making were attended to by having the research team review the analysis, question the data, and provide feedback on the inclusion of all participants' voices.

### Results

Overall, seven adolescents were recruited. Five underwent spinal fusion, one underwent pectus excavatum repair, and one had a bilateral femur fracture repair. Participants ranged in age from 13 to 17 years, with four female and three male participants. The length of admission ranged from four to thirteen days. From prospective recruitment efforts six adolescents were approached and five participated, and from retrospective recruitment efforts 12 letters were mailed out to eligible participants, resulting in two adolescents responding, with both participating. All interviews occurred over telephone. Interviews were conducted between September 2018 and March 2019 and ranged from 30 to 60 minutes. See Table 1 for demographic information.

Insert Table 1 here

Overall, three main themes were identified: *We Weren't Prepared for This: Being at Home with Pain*; *I Know Myself Best: Changes in Roles and Relationships*; and *I Just Miss My Friends: Returning to Normal Life*. Division into themes is meant to enhance clarity for the reader and is an artificial abstraction of the holistic, idiographic

experiences of the participants. As a result, strict delineations between the themes do not exist and there are many intersections.

### **We Weren't Prepared for This: Being at Home with Pain**

Most participants reported severe pain following discharge with some reporting pain scores of up to 10 out of 10 using numeric 0-10 pain scales. Catherine mirrored the experiences of many others in stating "I have to say like it was pretty intense, like it's the worst pain I've found." The severity of pain suggested that most of the adolescents were not receiving adequate pain management once they were home. Gabrielle, like many of the participants, described a significant decrease in physical function due to pain severity, stating "There's muscle pain actually on both sides of my spine, it was completely terrible, like I would have to stay in one position for two minutes and I just couldn't move because it was just so bad." It was not only the intensity of the pain that adolescents found difficult but also the duration of the pain. The majority of participants (six of seven) reported ongoing pain at the time of the interview which for some, like Isabelle, was almost 6 months post-operatively, as she described:

The pain has been quite frustrating and longer than I had thought it would be and is also, I wouldn't say worse than I thought, but I didn't think it would be this bad for this long... Like I still thought that I'd be in pain at this point but I didn't think it would be this bad this long that I would still had to be taking Aleve [naproxen] in the hallway and gabapentin at my lunch break before third period.

However, pain is an individual experience with varying degrees of intensity and duration. One participant, Brenda, reported that her post-operative pain following her spinal fusion

only lasted one week and was well controlled without opiates following discharge, stating “At first it was a lot but after like it didn’t hurt much.”

Despite most participants’ reporting severe pain at home, adolescents almost universally voiced a preference for being home compared to in hospital, as expressed by Brenda who stated, “I prefer being at home than in a hospital and yeah like, it [home] was real comfortable.” However, being at home was at a cost in terms of the effectiveness of the analgesics administered, as described here by Catherine and shared by others, “When I got home from the hospital like they had just switched me from the IV meds to oral medication, I found that really hard because when they were going through the IV they would work a lot better.”

Participants demonstrated limited knowledge and experience in pain management. Only two adolescents had experience managing post-operative pain, with Nathan describing the pain following his appendectomy as non-existent, stating “They removed the appendix and the pain was gone.” Isabelle described the pain following her prior scoliosis surgeries as much more easily controlled compared to the pain she experienced during this post-operative recovery:

With other surgeries I experienced pain, I wouldn’t say it was that bad, I could handle it with Advil [ibuprofen], Tylenol [acetaminophen] and a little bit of morphine, but I wouldn’t be on the morphine any longer than probably four days and I’d be just on Tylenol and Advil.

In terms of managing pain at home following surgery, adolescents largely focused on the role of pharmacologic interventions, only discussing non-pharmacologic interventions in a limited capacity and only when prompted. Some adolescents noted

despite using a range of pharmacologic as well as physical and psychological interventions, they were not always able to control their pain and at times analgesics barely helped. Kyle described this helplessness:

At home I felt like a lot of the time there was nothing we could do, there was nothing that helped for my pain in the foot, no medication I had helped with it, like I don't know, it took the edge off but it didn't really, it still hurt like crazy.

The adolescents reported being unprepared for potential adverse outcomes which left them on their own in times of crisis. Kyle described the need to perform an Internet search for pain interventions during a pain crisis:

I had another pain in my calf but this one was a lot worse, where my muscles tensed up and we didn't know what to do, like we weren't prepared for this, so then we just kind of searched up what could help.

The adolescents' concerns surrounding pain management in the post-operative period largely centered on the use of opiate analgesics. Adolescents stated concerns about dependency, some noting the wish to discontinue the opiates as soon as possible, voicing concerns about disliking the taste, feeling sedated and "out of it", nauseated, and vomiting. Participants noted that they would try to not take the opiate analgesics if possible, with Kyle describing trying to discontinue opiates as soon as possible, stating "I tried to get myself off like some big medications like the hydromorphone and tramadol pretty fast but now I would just take like two Tylenols before I go to bed". Concerns regarding addiction could have stemmed from a range of sources including media and social climate, with Isabelle stating:

It frightens me I think, just because you know, you see in the movies all about it, I know the doctors and the nurses were really good about giving you the smallest dose that will still be effective but still.

Isabelle noted feeling as though she experienced some withdrawal symptoms when discontinuing opiate analgesics:

I knew morphine was the hard one just because I was on it for so long and I knew to certain extent it was quite addictive and I think it's not myself that got addicted to it, but I feel like my body did to a certain extent because I feel like if I missed a dose I'd get a bit of a headache.

Despite concerns about opioids, many participants stated that opiate analgesics were the only effective medications in terms of relieving their pain. From their accounts, the adolescents spoke of a wide range of challenges, which included inaccurate information such as Isabelle's misunderstanding of physical dependence versus addiction or being unsure where to find information to help with their pain. These challenges caused a tension of how best to manage pain at home

### **I Know Myself Best: Changes in Roles and Relationships**

In the transition from hospital to home, adolescents needed to adapt to new roles and responsibilities. The adolescents described increased dependency on parents compared to pre-surgery, which was pronounced in the initial post-discharge period and described in the context of being unexpected and causing significant distress.

Not surprisingly, adolescents spoke of a varying degree of responsibility throughout the recovery process. Some adolescents reported that parents were entirely responsible for their care and pain management, others spoke of a shared decision-

making process while others spoke of their autonomy. Isabelle described the importance of her autonomy, stating “My parents are great about letting me advocate for what I need, like I know myself best and they knew that I knew what I needed”, whereas Eric described his dependence on his parents:

It was mostly my parents, because my parents were like, you don’t pick up anything, we got you, don’t worry about getting the water, don’t worry we’ll get you the food. Just stay here you know. Then I was mainly staying in bed for like the first week.

Parents were responsible for administering analgesics, but in the cases of more shared decision making, adolescents were responsible for alerting parents of the need for breakthrough analgesics and having an open discussion about when analgesics should be discontinued. Catherine described this process:

I started to say ‘Oh I don’t think I need it [morphine] like I feel fine’ so, like together we would sort of figure out ‘Ok we can stop taking Tylenol and instead we’ll just give you like Advil and we’ll do less morphine and more Advil’ so it was like, we worked together but like I wasn’t afraid to tell them that.

The adolescents spoke of the limited effectiveness of parents as caregivers at times, sometimes feeling as though there was nothing that they could do, with Catherine describing:

There wasn’t really much they could do, like they helped me like, they would give me anything that I needed like pillows to put behind my back but, yeah they were very supportive and they were always there for me to help me but they couldn’t really take the pain away other than with the meds.

Some of the adolescents expressed a desire to be more independent in their pain management. While discussing the importance of autonomy and self-reliance, the adolescents described feeling like they could have been responsible for their own medications, as Kyle described:

Yeah, it was like they just, they did a good job of it, but I felt like I could have easily took it [medication] whenever and been responsible, to know how many hours to take after my next pill and stuff like that.

In terms of adapting to new roles and responsibilities, the adolescents almost universally stated that they felt prepared for discharge, though they described discharge teaching as being focused on their parents instead of including both their parents and them. The adolescents also stated that the discharge teaching largely focused on pharmacologic pain management, as explained here by Catherine “I think that they [nurses and doctors] did everything that they could, they gave us all the different medicines, I mean I didn’t really know much about it because they were mostly telling my parents.” The adolescents did not speak of learning any specific pain management skills directly from staff, but learned indirectly from watching nurses during the post-operative period, as Kyle described “In the hospital we did that before physio, like I would take hydromorphone an hour before physio so that’s what we started to do at my house.”

### **I Just Miss My Friends: Returning to Normal Life**

In the initial post-discharge period, adolescents spoke of difficulty performing activities of daily living, such as eating, drinking, and changing clothing. As time went on, the adolescents voiced significant difficulty returning to their regular life, including

school, sports, jobs, extracurricular activities, as well as time with family and friends. Many aspects of adolescent identity are embedded in their engagement in educational, recreational, social activities, and for some, employment (Graetz, Fasciano, Rodriguez-Galindo, Block, & Mack, 2019); and as post-operative pain was a significant barrier to their engagement with these activities, this was a cause of significant distress to all participants. Gabrielle described the distress caused by this isolation:

Well it does take a strain on how you feel emotionally because like as a teenager you want to get outside and you want to go do things, you want to see your friends, it's kind of hard when you're stuck at home and like you can't do much.

The area that was most discussed by the participants was the effect that post-operative pain had on their capacity to return to school. School is the main site of adolescent social and leisure life as well as academic life. The negative effect on school performance (e.g. attendance, grades) was substantial, with most adolescents stating that they were unable to attend school due to their pain and recovery time. Nathan described that he was forced to be removed from school and become homeschooled following non-steroidal anti-inflammatory related gastritis:

Because of the Advil I took [for my pain] my stomach got really hurt, so it's been 3 months I've been vomiting every day, well I had to stop taking pretty much everything... I went to the ER like 5 times for that, and I also had to quit school for this year for the rest of this year.

The adolescents noted that their grades suffered as a result of their decreased attendance and capacity for work, stating that the teachers expected the same out of them as they did from other students despite their recovery from inpatient surgery. Other

adolescents spoke of the associated stresses of once being a high achieving student but being unable to perform at their prior capacity. Catherine described this stress, stating “I’m like a student who like is always wanting to get like a hundred percent in each class so for me like being out of school and like being behind and things is like a little stressful to me.”

Contributing to the adverse educational outcomes (especially through school absence) of the participants were school regulations that interfered with pain management. Isabelle spoke of her inability to adequately control her pain at school as the school would only allow her to bring certain medications:

It’s a bit harder to control just because I can’t take that many medications and I can only bring certain ones to school just because I am in high school and they won’t let you bring like certain medications with me, which is understandable.

The inability to adequately control her pain with analgesics ultimately resulted in her needing to resort to leaving school early on many days when pain became unbearable, even five months post-operatively. Participants did not speak of planning for the return to school with any member of the healthcare team. However, it was not solely school that was challenging as work also became a concern. Isabelle was frequently unable to perform her job, which she stated was a major concern, voicing “By the time I’m done school, it’s really, really hard at that point to do my job and that’s also a really important part of my life.”

Adolescents also spoke of difficulty in resuming social activities with friends and the associated emotional stress with others stating that the inability to spend time with family and friends was one of the worst parts of the recovery process. Nathan stated that

his removal from school resulted in a significant reduction in his ability to spend time with friends, stating “I also had to quit school for this year for the rest of this year... I just miss my friends”. This is concerning as participants spoke to the value of time spent with family and friends as a means of post-operative pain management, stating that laughter and distraction were some of the most important means of controlling their pain, with Isabelle describing:

Laughter is the best medicine and that’s so true. One of my sisters is absolutely amazing, she could tell when I am in pain and she would come over and she would sit with me and talk and make me laugh until I am able to be at a pain level when I can do my class work.

### **Discussion**

When recovering from inpatient surgery at home in the community setting themes of *We Weren’t Prepared for This: Being at Home with Pain, I Know Myself Best: Changes in Roles and Relationships*, and *I Just Miss My Friends: Returning to Normal Life* help to describe the experiences of the adolescents.

The results of this study align with those of previous research examining the post-operative experiences of adolescent and children for a range of surgeries, which indicate that pediatric patients experience severe pain at home following inpatient and outpatient surgery (Birnie et al., 2017; Gillies et al., 1999; Stanko et al., 2013). This severity of pain indicates significant difficulty in the managing of post-operative pain in the community setting. Of particular concern is the duration of pain reported by the participants, with six out of seven patients reporting pain ongoing at the time of interview; three of the seven of these participants meeting diagnostic criteria for post-surgical chronic pain, which is

defined as surgical related pain lasting over three months post-operatively (Steyaert & Lavand'homme, 2018; Williams, Howard, & Liossi, 2017). Within their struggle to manage their post-operative pain, some of the participants expressed concern about the use of opiate analgesics, with participants in both our study as well as those in the study by Fortier et al. (2009) noting concerns regarding addiction, tolerance, and side effects. Our findings also support the findings by Rabbitts et al. (2017) suggesting that adolescent post-operative inpatients were unprepared for discharge, the severity of their pain and the management of pain in the community setting, while demonstrating a lack of understanding of the use of physical and psychological pain management techniques.

Of particular note in this study was the difficulty participants experienced returning to school. Research has shown that adolescents who experience chronic pain have exhibited diminished school attendance due to pain, potentially leading to significant academic impairment (Dick & Riddell, 2010); adolescents who experience chronic pain have also been found to experience impaired working memory making to return to school difficult without adequate support (Mifflin, Chorney, & Dick, 2016). To improve school related outcomes for adolescents with chronic pain, researchers have suggested that teachers may benefit from an understanding the biopsychosocial nature of pain, as well as becoming involved in the development of strategies to accommodate ongoing pain management in the classroom (Logan, Catanese, Coakley, & Scharff, 2007). Despite the participants in our research experiencing acute pain rather than chronic pain, they too were challenged by their ability to attend school and to maintain their academic standards. Research examining interventions designed to ameliorate school re-integration following surgery are needed including, for example, a pre-surgery

school reintegration plan with teachers as well as an educational intervention workshop for educators on the effects of postoperative pain on academic capacity.

The adolescents in this study spoke of their desire to maintain their autonomy and be more formally engaged in the pain management process. These participants played an active role in their own pain management, and thus the limited engagement of the participants in the discharge education and planning process was problematic. Enhanced Recovery After Surgery (ERAS) initiatives have demonstrated the effectiveness of engaging both adult and pediatric patients in their own recovery through education and collaborative efforts to enhance outcomes, and have revealed the resulting decreases in length of stay and increases in patient satisfaction (Altman et al., 2019; Heiss & Raval, 2018). In terms of engaging adolescent patients, current understanding of adolescent patient education indicates that strategies specific to the learning style and information needs of adolescents may improve their knowledge and skill (World Health Organization, 2018). A number of adolescent-specific novel interventions show promise as methods of increasing skill and knowledge acquisition, including smartphone applications (Mooney et al. 2013), Youtube videos (Harrison, Larocque, Reszel, Harrold, & Aubertin, 2017) and websites (Ingadóttir & Zoëga, 2017). Rabbitts et al. (2017) found that families were interested in ongoing web-based post-operative engagement with members of the healthcare team, as well as greater education on psychosocial pain management. Further research is warranted to determine the effectiveness of these novel Internet based approaches to improve adolescent knowledge and skill in post-operative pain management following inpatient surgery.

In terms of working with adolescents directly, coaching as opposed to traditional discharge teaching may be more effective, as coaching is a more holistic and dynamic process which directly engages the participants in their own learning (Hamric, Hanson, Tracy, & O'Grady, 2014). Studies that examine coaching-style engagement with adolescents focused on building skill in multiple approaches to pain management (e.g. pharmacological, physical, psychological interventions) are needed.

Of particular concern were the participants in the study who met the definition of post-surgical chronic pain. Involvement of these patients with ongoing acute pain with pain transition teams in the post-discharge period may enhance post-operative pain outcomes (Glare, Aubrey, & Myles, 2019). Transitional pain clinics have the clinical expertise to help manage ongoing acute pain and emerging chronic pain as well as referral capacity to involve critical multidisciplinary interventions such as psychology, psychiatry, and other chronic pain services, with the goal of reducing overall pain, disability, and the problematic use of opioids (Katz et al., 2015). Further research is needed to determine the risk factors for developing post-surgical chronic pain in the adolescent population and the role of transitional pain clinics in the care of ongoing post-operative pain in adolescents.

Limitations of the study include the single surgical center; however, the participants were under care of different surgeons and nurses on multiple teams to help offset the practices of one surgical service. Secondly, participants experienced only three different surgical procedures despite the large inclusion criteria, and thus transferability may be limited. Thirdly, many participants were interviewed early in the recovery process (between 2 weeks and 2 months) which, while allowing for improved

experiential recall, inhibited the understanding of the full trajectory of postoperative pain experience as six out of seven participants continued to experience pain.

### **Conclusion**

Most participants reported severe, ongoing pain after discharge following inpatient surgery, with some meeting criteria for post-surgical chronic pain. The adolescents were engaged in their own pain management to varying degrees despite lacking accurate knowledge and skills in some aspects of pain management. Ongoing pain was distressing as it resulted in significant challenges in returning to school, social life, and work. Nurses play a pivotal role in preparing adolescents for discharge. Adolescents could benefit from nurses formally involving them in the discharge process using adolescent targeted educational interventions, nurses supporting the involvement of teachers in the post-operative return to school planning process, and the involvement of a pain transition team for those with ongoing postoperative pain.

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**Tables**

Table 1

*Participant Demographics*

| Alias     | Sex    | Age | Surgery                                          |
|-----------|--------|-----|--------------------------------------------------|
| Brenda    | Female | 13  | Spinal Fusion – Idiopathic Scoliosis             |
| Catherine | Female | 15  | Spinal Fusion – Idiopathic Scoliosis             |
| Eric      | Male   | 16  | Spinal Fusion – Idiopathic Scoliosis             |
| Gabrielle | Female | 17  | Spinal Fusion – Idiopathic Scoliosis             |
| Isabelle  | Female | 16  | Spinal Fusion – Scoliosis r/t Muscular Dystrophy |
| Kyle      | Male   | 17  | Bilateral Open Femur Fracture Reduction          |
| Nathan    | Male   | 16  | Pectus Excavatum Repair                          |

## **Chapter 5**

### **Parents' Management of Adolescent Patients' Post-Operative Pain After Discharge:**

#### **A Qualitative Study**

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This chapter is an unpublished manuscript formatted for submission to

*Qualitative Health Research*

Keywords: *parental; post-operative; pain management; discharge; pediatric; adolescent; inpatient; pain.*

### **Abstract**

Short hospital admission periods following pediatric inpatient surgery leave parents responsible for managing their child's post-operative pain in the community following discharge. Little is known about the experiences of parents caring for their child's post-operative pain after discharge home following inpatient surgery. Research examining parental post-operative pain management following their child's day surgery has found that parents are challenged in their pain management knowledge and practices. This Interpretative Phenomenological Analysis study sought to understand parents' experiences caring for their child's postoperative pain at home. Semi-structured telephone interviews were conducted with seven parents between 2 weeks and 6 months after their child's discharge from hospital. Identified themes were coming home without support, managing significant pain at home, and changes in the parent child relationship. Parents could potentially benefit from nurses optimizing educational interventions, from receiving ongoing support of transitional pain teams, and from assistance with return to school planning.

### **Introduction**

In recent years, research has shown a decrease in length of hospital stay following inpatient surgery (DeSena, Nelson, & Cooper, 2015; Macy et al., 2009), leaving much of the recovery process to occur in the home. This is of particular concern in pediatrics as the burden of the caregiver role most often shifts to the parent (Vincent, Chiappetta, Beach, Kiolbasa, & Latta, 2012). Pain management is a major concern in post-operative care and adequate treatment of pain improves quality of life, reduces complications, and facilitates recovery (Rabbitts, Palermo, Zhou, & Mangione-Smith, 2015). Studies have also indicated that inadequate pain management in children and adolescents can increase morbidity (Peelen, Kalkman, & Meissner, 2013; Stoll, Hansen, Bell, Walsh, & Carlo, 2015) and is a risk factor for the development of chronic pain (Reddi, 2016). Thus, the parental role in post-operative pain management for their child at home is of prime concern.

There is very little research exploring parents' experiences in providing post-operative pain care for their children following inpatient surgeries (e.g. spinal fusion, colectomy), though one study examining pain at home following spinal fusion in 167 parent/patient dyads found that pain catastrophizing (a negative response to actual or anticipated pain) in children, but not parents, was correlated with post-operative pain intensity (Birnie, Chorney, El-Hawary, & PORSCHE Study Group, 2017). The research also found that even at the 6-week follow up appointment the participants continued to experience a mean pain score of 2.51 out of 10 (SD 2.11) (Birnie et al., 2017). This suggests that not only do parents need to manage their adolescent's pain at home for a substantial amount of time following surgery, but that they may also need to be

knowledgeable and skilled in helping their child manage other contributing factors such as pain related catastrophizing. A recent study by Rabbitts et al. (2017) evaluated the post-operative pain experiences of 15 parents and adolescents following spinal fusion, pectus repair, and hip osteotomy using family interviews. Findings indicated that adolescent patients and their parents were unprepared for surgery and the amount of post-operative pain the adolescent experienced, both of which contributed to a challenging recovery at home. The families in the study voiced concerns regarding potential for injury and safety, as well as stress from the adolescent's increased reliance on parents. While these findings are valuable for building our understanding of post-discharge pain management by parents and adolescents, the study interviewed parents and adolescents together, which may have introduced response bias due to presence of the other member of the dyad, and thus exploration of the individual experiences of parents is warranted.

Much of the research on parental post-operative pain management focuses on the care provided by parents whose children underwent outpatient surgery (e.g. tonsillectomy, inguinal hernia repair, myringotomy tube insertion). These studies indicate that post-operative pain management is a significant issue for parents in the home setting. Post-operative pain after day surgery can be both intense and long lasting in children making it necessary for parents to be competent in pain management. In terms of duration of pain following day-surgery, Wilson et al. (2016) examined the duration of pain in 251 patients from birth to 18 years of age undergoing head and neck surgery (e.g. adenoidectomy, myringoplasty, ankyloglossia) and found that their pain lasted on average 9 days post-surgery. In terms of pain intensity, Stanko, Bergesio, Davies, Hegarty, and Von Ungern-Sternberg (2013) followed 100 children post-tonsillectomy to determine the

incidence and intensity of pain on post-operative day (POD) 3 and 7 and found that tonsillectomy was associated with moderate to severe pain at home even into POD 7. Furthermore, an integrative review of 51 articles on the pain management practices for patients undergoing tonsillectomy concluded that post-operative pain peaks on POD 2 and 3 but can last up to 14 days (Howard et al., 2013). These findings suggest that parents of children undergoing inpatient surgeries may also need to manage pain once their child is discharged, as their child's pain may be both intense and last for a significant period of time.

In terms of parent's pain management practices, Fortier, MacLaren, Martin, Perret-Karimi, and Kain (2009) found parents often did not administer any medications following outpatient surgery. Parents have cited a range of concerns including fear of drug tolerance, medication side effects, and addiction to opioids (Fortier, Wahi, Bruce, Maurer, & Stevenson, 2014). Parents have also been found to believe that analgesics should be used as a last resort even in managing post-operative pain at home (Hamers & Huijjer Abu-Saad, 2002). An integrative review by Parker, McKeever, Wiseman, and Twycross (2018) examining parents' post-operative pain management at home concluded that inadequate pain management was most often related to inadequate analgesic delivery and that nurses should directly target parents in their interventions. Exactly what interventions are needed to support parents in their child's post-operative pain management in the home setting remains unclear, as a study by Longard, Twycross, Williams, Hong, and Chorney (2016) found that although parents reported having their educational needs met, they still experienced difficulty managing their child's pain at home following outpatient adenotonsillectomy surgery. Taken together these studies

indicate that parents may benefit from additional resources and strategies to manage their child's pain at home following outpatient surgery, suggesting that parents may experience similar issues following their child's inpatient surgery.

Caring for their child or adolescent's pain following outpatient surgery is challenging for parents as their pain management practices have at times been found to be ineffective. It is unclear how, or if, these findings are different for parents providing post-operative pain to their child following inpatient surgery. This study seeks to better understand this gap in the literature by exploring the experience of this population, to provide insight into their challenges and to develop strategies to support their pain management practices in the home.

### **Methods**

When the topic of inquiry is the lived experiences of participants, particularly in an underexplored area, Interpretative Phenomenological Analysis (IPA) as described by Smith and Osborn (2003) is a valuable approach (Crist & Tanner, 2003). The idiographic focus of IPA targets the unique and personal understandings of a phenomenon while accounting for both the role of the researcher and participant within the construction of knowledge. Given the emphasis on hermeneutical ontology and the resultant social origin of truths, IPA accordingly falls within the constructivist paradigm (Guba & Lincoln, 1994) and thus was an appropriate design to guide this study.

### **Participants**

Recruitment of participants occurred both prospectively and retrospectively, and involved purposeful sampling to recruit parents of adolescents who underwent inpatient surgical procedures at a pediatric tertiary care hospital in Canada. Inclusion criteria were

parents of adolescents who: 1) were between the ages of 12 and 18 years; 2) had surgery for spinal fusion, periacetabular osteotomy, pectus excavatum repair, mammoplasty, ileostomy, colostomy, colectomy, exploratory laparotomy, femoral varus derotational osteotomy, and femur fractures; 3) were hospitalized for over 24 hours post-operatively; 4) had surgery no longer than 6 months prior; and 5) spoke English. Exclusion criteria were parents of adolescents who: 1) had developmental delay; 2) had a major psychiatric diagnosis; 3) experienced significant post-operative complications (e.g. deep vein thrombosis, septic infection); 4) had chronic pain diagnosis prior to surgery; or 5) were hospitalized for greater than 14 days. Exclusion criteria limited the number of possible confounding experiences influencing the adolescent's pain experience and thus their parents.

Recruitment occurred through the Orthopedics team and the Acute Pain Service, where the nurse practitioners (NPs) for each service introduced the study. For prospective recruitment, the NPs provided an introductory study letter and obtained approval for the research team to contact the parents to provide more information about the study and obtain consent from interested parents in hospital during the post-operative admission or at the follow-up appointment. For retrospective recruitment the introductory study letter was mailed to parents whose adolescent had undergone surgery within the last 6 months. The introductory study letter included instructions for contacting the research team if the parent was interested in more information and in possible participation in the study. If the participant was interested in participating (regardless of recruitment approach), consent was confirmed by telephone before the initiation of data collection. Assurances were provided to participants that the healthcare team would not be informed if they

participated or did not participate in the study. From prospective recruitment efforts six parents were approached and five participated. From retrospective recruitment efforts 12 letters were mailed out to potential participants, and two out of two respondents participated.

### **Procedure**

Once consent was obtained by the research team, either during inpatient stay, at follow up, or by phone or email, a time to conduct the interview was arranged no sooner than after their child's two-week follow-up appointment after discharge. This time frame ensured that the pain management course was not altered by serious post-operative complications and allowed for the adolescent's post-operative pain to have peaked and perhaps be declining at the time of the interview, providing parents with a more comprehensive pain management experience.

All interviews took place over telephone and were audio recorded, allowing for the participation of parents who lived a significant distance from the hospital. A semi-structured interview guide was used and included probes to allow the exploration of areas of concern and interest. In order to build trust and rapport, interview questions moved from the general to specific and from less to more personal (Smith & Osborn, 2003). For example, interview questions ranged from "Can you tell me a little bit about yourself and your child?" to "What was the most difficult part of managing your child's pain at home after surgery?" The interview guide was piloted with a parent of a healthy adolescent beforehand to ensure that the questions were understandable and that the interview flowed in a logical manner. No changes to the interview guide were required following

this pilot. Interview times ranged between 30-60 minutes. A professional transcriptionist transcribed each of the interviews.

### **Analysis**

Smith and Osborns' IPA (2003) was used to guide the thematic analysis and followed a four-step process that involved an ongoing and interpretative relationship with the data. The first step included a close reading of the transcript while listening to the interview to ensure accuracy of the transcripts as well as attending to the verbal nuances of the interview. Step two involved the noting and classifying of significant or interesting responses with a word or phrase (code). A code list was developed in collaboration with the second author after the coding of the first two interviews. However, during coding if new codes were needed as more data was collected, earlier transcripts were re-examined with attention to the new code. Step three involved the grouping of codes into emergent themes, which were analyzed for each participant to ensure an idiographic (personal and unique) understanding of their experience. Step four involved collaboration with the research team, as the emergent themes for all transcripts were compiled into larger, major themes to help identify experiences across the participants, including exemplar quotes from the data. Exemplar quotes were reviewed to ensure the analysis was grounded in the data.

### **Rigour**

In order to enhance the “goodness” of this qualitative study as per Tobin and Begley (2004), six elements were taken into consideration in the analysis and discussion of this research: the foundation (the philosophic grounding of the research), the approach (the methodologic soundness of the study), the collection of the data (explicit reference to

the means of collecting data and making decisions regarding it), the representation of voice (reflection of the both the voices of the researcher and of the participants, the art of making meaning (the presentation of insights through the interpretation of the data), and the implication for professional practice (the recommendations implied from the analysis). For example, a constructivist epistemology underpinned the interpretative nature of the phenomenological data analysis, each step in the recruitment and data collection steps had been made explicit, and the inclusion of more than one researcher during the analysis helped to ensure that no participant's voice was dominant within the representation of the data.

### **Ethics**

This research was approved by the Research Ethics Board (REB) of the tertiary care pediatric hospital where the study was held and the REB of its affiliated University. Informed consent was obtained from participants by the researcher before commencing data collection. Data was de-identified at the time of transcription by the removing all names and identifying information. Participants were given a study number and this number was used on the transcripts and collating of data.

### **Results**

Seven participants were recruited; five of the participants were parents of an adolescent who underwent spinal fusion, one was the parent of an adolescent who underwent a pectus excavatum repair, and one was the parent of an adolescent who underwent a bilateral femur fracture repair. Participants included five females and two males, with ages ranging from 41 to 54 years (see Table 1 for details). Length of admission of the adolescents ranged from four days to thirteen days. Interviews were

conducted between September 2018 and March 2019 with interviews between 30 and 60 minutes in duration.

Insert Table 1: Participant Demographics

Through the thematic analysis process, three major themes were identified: *Home Without Support: Transitioning from Hospital to Home*; *We Just Had to Deal With It: The Experience of Caring for a Child's Pain at Home*; and *It Was Like Teamwork: Changes in the Parent-Child Relationship*. These themes illustrate the challenges encountered by participants as they cared for their adolescent child post-discharge. These themes however are to be viewed as abstractions and interpretative delineations made by the research team in order to better communicate and illustrate the idiographic and holistic experiences of the participants to the reader, and thus intersections and overlaps between themes exist.

**Home without Support: Transitioning from Hospital to Home**

A distinctive transition phase occurred between being discharged from the hospital and arriving home. Parents spoke of wariness and anxiety in transitioning from hospital to home, with many parents feeling as though their child was too unwell for discharge citing their child's inability to eat or drink or independently attend to activities of daily living. One parent described this wariness, "I would have liked just to stay one more day because the day we left with her on the Friday she was still, I mean she still couldn't do anything on her own." Moreover, others shared feeling as though they were being forced to leave the hospital to make room for another patient, describing discharge as dependent on the number of days post-surgery and not their child's stage of recovery:

The day to leave was on Thursday and on the Wednesday, she was still very weak, very nauseous, not eating, you know, I could not picture her leaving the hospital, I kept telling the nurses and the doctors and everything that you know, can we stay another day if she needs to stay. So I just felt a lot of pressure and I think that's how it is in hospitals for her to leave... but I'm just saying for other parents out there, just a few days after surgery is quite fast for such a major surgery to ask them to leave, so I guess you know that's how it is.

Furthering the difficulties parents experienced during the transition from hospital to home was the added responsibility of their child's pain management, which was different in hospital where all pain care was provided by the nursing staff, as described by one parent, "Oh in the hospital I didn't do anything." Not surprisingly, parents felt unprepared to take on their new responsibilities. Moreover, feeling forced to leave and not being involved in their child's pain care while in hospital contributed to their feelings of being alone, as one parent expressed, "You come home and you don't have any support."

Perhaps another reason for feeling unprepared and alone at home without support was the fact that the participants spoke of the varying degrees of educational preparation they were given prior to discharge, as some participants reported receiving written instructions while others did not. Despite receiving written instructions it is unclear if their understanding of the material was adequate to care for their child, as those who reported receiving written information said that the information was almost entirely focused on pharmacologic interventions, with no information given regarding psychological or physical approaches to pain control or when to seek further help for

their child's pain, with one parent stating "We received something, I don't remember exactly what it was, but I remember that what we received was for each medication what it does and the pathologies."

It was not solely the parents' feeling their lack of readiness to care for their child at home that was challenging but also their child's difficulties in resuming their activities of daily living. Parents described their child's inability to resume their normal pre-surgery life with significant distress:

She couldn't wear a belt, she couldn't bend over, she couldn't ride a bike, she couldn't ride a bus, she couldn't swim, she has numbness in her feet, burning, her nerves were numb down her legs. Yeah, it was horrible. She couldn't wake up on time, it took her long time to get out of bed, so I had to phone her high school and say 'She will get there when she can' because it was that hard for her to get out of bed.

Pain interfering with returning to school was an unanticipated challenge for most parents. One parent noted that after almost 6 months post-operatively, her child frequently needed to come home from school early, as her pain was unmanageable, stating:

There's been times at school where she had to call home and have her dad come and pick her up because she just can't sit anymore and there's no place to lie down at school... I think it frustrates her.

Being unprepared for their child's slower than expected return to activities of daily living created an environment of significant distress as parents were unsure how to best help their child in pain.

**We Just Had to Deal With It: The Experience of Caring for a Child's Pain at Home**

Most participants within the study reported that their child experienced severe and significant pain, with one parent stating “The pain was unbearable for her and she couldn’t sleep, so we just had to deal with it.” This experience was common, as when participants were using pain scales (which was only reported in two cases), adolescents reported that their pain was at minimum a four and at maximum a ten on a zero to ten pain intensity scale. Being at home with their children was distressing for these parents as although they were aware that their child would experience pain, some parents were unprepared for the severity of pain that their children experienced at home, with one parent describing their child’s pain crisis on return home:

I pulled in the garage and he went to get out of the vehicle and his calf muscle in the right leg spasmed and it was the first time that I heard him scream in pain in this whole situation.

In addition to parents being surprised by the intensity of pain their child experienced at home, they also spoke of the duration of pain, with most parents reporting that their child’s pain was still occurring at the time of the interview. This length of time is disconcerting as most of the interviews occurred between two months to six months post-discharge. Intense pain continued for such an extended period of time that some of the adolescents required their opiate prescriptions to be extended beyond the initial prescription, as described one parent, whose daughter was still requiring opiates four weeks post-operatively:

It took a long time. We were expecting her to be off the morphine after you know, an extra week but it wasn't possible because she was still in a lot of pain overnight. In the fourth week, she was still taking the morphine.

Only two of the seven participants stated that their child's pain was in keeping with their expectations both in terms of intensity and duration, with one stating that their child's pain only lasted four days and the other stating two weeks. One adolescent received no opiate analgesics post-discharge from her spinal fusion, and another only received morphine for the first two days following discharge from his spinal fusion, illustrating that post-operative pain experience, like all other types of pain, are individual in nature.

Parents reported limited experience managing children's pain at home. Only one of the parents had experience managing a child's post-surgical pain before, reporting that the pain her daughter experienced from prior scoliosis corrective surgery was far less intense and more easily managed, stating of the prior surgery "She would just ask for Advil [ibuprofen] and/or Tylenol [acetaminophen] together, to sleep through the night she would take morphine... I don't believe she had dealt with pain like she had with this surgery." Many of the parents' stories spoke of not having the skills and knowledge to manage their child's pain effectively, an experience which one parent described "I was you know, trying to be there for her and trying to support her as much as I could, but sometimes there was nothing that we could do". Another parent, whose child had a pectus excavatum repair, described the distress experienced when she could not protect her son from pain "I was feeling helpless when he was in pain and I couldn't do more for him".

When parents described their pain management strategies they mostly spoke of analgesic administration, which is not surprising considering the pharmacologic focus of

their discharge education. Although parents administered both opiate and non-opiate analgesics, many were instructed to stop opiate analgesics as soon as possible, based more on time than adolescent need, with one parent stating “We were told to stop the morphine on that weekend and we just kept going”.

Parents were creative in their development of strategies to ensure the safe administration of their child’s analgesics. Two of the parents described how they created their own documentation process to track medication administrations, such as a paper chart or whiteboard. These parents voiced how they needed some way to ensure they were administering the analgesics safely and felt that this sort of helpful strategy should be included in the post-operative instructions for parents in the future. As one parent described,

She came home with quite a bit of medications to the point where I had a white board and had to write like the schedule of everything just so that I didn’t mess something up or forget something or give her too much of something else.

Parents voiced a number of concerns regarding caring for their child’s post-operative pain. Opiate analgesics were a common concern, with parents voicing concerns such as addiction and side effects. Some, but not all parents described trying to have their adolescent discontinue medications as soon as possible, with one participant stating “I know the opioids, you know I don’t like giving her those kind of meds knowing what’s going on out there in society”. Some parents voiced an interest or preference for natural and alternative remedies, speaking positively of interventions such as cannabidiol (CBD) but negatively of opiates and other pharmacologic interventions, as one parent described:

I'm wondering about CBD oil for children for pain management and for nausea  
hum, and if hospitals should look into it in terms of you know for surgery for  
children. CBD oil is from cannabis but it's a good pain management remedy  
apparently and there is no side effect as far as people know so far and I'm just  
wondering about that like if that is something the hospitals in the future will be  
looking at for pain management for children.

Not all parents reported using psychological and physical interventions such as  
guided imagery, positioning, heat packs, etc. Many parents did not use formal methods of  
pain assessment, often opting to allow the adolescent to ask for medication if they felt  
they needed breakthrough pain control and using this as a marker of the presence and  
severity of pain, with one parent explaining:

Well I didn't ask him the pain scale because if he said he needed the pain pills,  
then he must have, I didn't care, as a parent I didn't care if it was ten or a four or I  
didn't really care, he was in pain so if he said he needed something I gave it to  
him.

A concerning comment that arose multiple times was the perception of the  
adolescents as "brave" or "tough", potentially indicating an underlying understanding of  
pain as unavoidable, and needing to be faced, with one parent stating "I think she was  
good at managing the pain, she was brave I think". Another parent described a similar  
sentiment, stating "She was a trooper throughout everything and I felt that she, you know,  
she was gonna get through it".

**It Was Like Teamwork: Changes in the Parent-Child Relationship**

The process of caring for a child at home following inpatient surgery involves the changing of roles and responsibilities for both parents and adolescents. This is particularly noteworthy as a key part of adolescence is the development of independence, self-reliance, and autonomy. One parent described his 16-year-old son's need for independence as a significant barrier in his own capacity to provide care, stating "He doesn't like to talk with us, me and his mother, when we give him advice or something he's upset right away, especially from us, when you know when he talks with the nurse he's a different person." Some of the adolescents were forced into a state of higher dependence on their parents due to the severity of their symptoms and their parents were required to adapt to a higher degree of responsibility. This change was noted to be stressful as parents had been trying to support their child to take on more responsibility prior to their surgery. The degree to which this increase in dependence occurred varied amongst the participants, potentially due to the age of the participants, the severity of their pain experience, individual characteristics, and the idiosyncrasies of the parental-child relationship. Nevertheless, all participants experienced their child's increased reliance on them, with some of the adolescents becoming completely reliant on their parents for managing their pain management (e.g medications, positioning), helping them dress, and other activities of daily living, as one parent explained:

We still had to you know, help her get in her bed, lay her down, shift her body because she still couldn't do all that. She was there for quite some time, like I'm gonna say, she needed our assistance at home for a good month.

Meanwhile, other parents spoke of their child's independence:

When she got home, she knew all her meds and what they did so she would get them on her scheduled time unless she needed like some morphine or whatever but she asks for that, I wouldn't offer, like I just wait for her, cause she knows what she needs.

Many of the parents also spoke of a shared decision-making model with their child. In cases with a more shared decision-making process, parents directed scheduled medications and adolescents directed the need for breakthrough medications or interventions and would jointly discuss when to discontinue certain medications. One parent described her collaboration with her son when deciding to discontinue medications, explaining "It was amongst us, like we discussed it, like when we stopped using the morphine, we had discussed it previously, but it was like teamwork, not a dictator". Despite this, parents also spoke of the tenuous balance of supporting their child's autonomy while concurrently describing stress in feeling as though they sometimes needed to override the adolescent's autonomy in order to ensure that they were receiving adequate pain management. For example, one parent discussed how she had to override her daughter's decision not to take medications though she was visibly in pain. This was echoed by other parents. "I mean it was always kind of her responsibility because she is 17 and you know, she can make her own medical decision but you know what sometimes, when the kids aren't rationalizing, [you have to say] 'No you should take that'".

### **Discussion**

Parents described the experience of managing their child's pain post-operatively through the key themes of *Home Without Support: Transitioning from Hospital to Home*,

*We Just Had to Deal With It: The Experience of Caring for a Child's Pain at Home; and It Was Like Teamwork: Changes in the Parent-Child Relationship.* The findings build upon other studies (Gillies, Smith, & Parry-Jones, 1999; Stanko, Bergesio, Davies, Hegarty, & Von Ungern-Sternberg, 2013) which indicate children and adolescents often experience severe pain following discharge. Similar to Rabbitts et al. (2017), parents in this study described feeling unprepared for discharge and the intensity and duration of their child's pain, expressed concern regarding the side effects of analgesics, and spoke of anxiety related to the increased demands their child's treatment would place on them in the post-operative period. Similar to research examining parental pain management at home following day surgery (Stanko et al., 2013), we found that parents were challenged in providing effective pain management for their child. A parent's inability to adequately care for their child has been found to be a highly stressful experience for parents (Goubert, Vervoort, Sullivan, Verhoeven, & Crombez, 2008), which was mirrored by participants in the study.

Unfortunately, our findings continue to align with studies that have discovered that many parents hold misconceptions surrounding the use of opioids (e.g. Fortier et al. 2014; Rony, Fortier, Chorney, Perret, & Kain, 2010). Myths and misconceptions may have ultimately culminated in some parents administering fewer opiates than required to adequately control their adolescent's pain. Standardized accurate messaging from clinicians about opioids and other analgesics is still needed. Although parent's inaccurate beliefs about opioids are not new, the basis of concerns about opioids may also now lie in the current social and media landscape, with a trend towards negative press regarding opiates due to the current misuse of opioids. Alternatively, the voiced interest in other

substances such as CBD may also have been influenced by the media lauding of the potential positive uses of cannabis related to the recent legalization of cannabis in Canada. The effects of social media on parental knowledge and attitudes were not explored within this study but may be of interest for further research.

The duration of pain was a major concern for parents as five of seven reported that their child continued to experience pain at the time of interview with three of the adolescents still experiencing pain more than 3 months post-operatively. This indicates that many of the adolescents met the criteria for post-surgical chronic pain, which is defined as post-surgical pain lasting greater than 3 months (Steyaert & Lavand'homme, 2018; Williams, Howard, & Liossi, 2017). Despite this, none of the parents reported receiving a referral to chronic pain services or any advice at all on treating this type of pain despite all adolescents having ongoing follow up appointments.

Interestingly, none of the parents in the study discussed missing work due to their child's recovery as a source of stress, despite opportunities to do so within the interview. This may demonstrate the extent to which parents were focused on the outcomes of the adolescents rather than work related challenges created by their child's post-operative recovery. Parents instead focused on the difficulty of their child's return to school, which was voiced as a significant concern. Research has demonstrated that adolescents experiencing chronic pain have significantly reduced school attendance, which in turn may lead to poorer academic performance (Dick & Riddell, 2010). Parents in this study voiced concern about their child's difficulty in attending school that was persisting even over five months post-operatively. It is unknown how this would ultimately affect their child's academic performance. Academic interference from postoperative pain warrants

further research including examining the effect of involving teachers and parents in a return to school plan for adolescents undergoing surgery

There were only two parents in this study who, at the time of interview, reported that their child experienced mild pain intensity following surgery, with their pain lasting between 4 days and 2 weeks. Both of these adolescents had spinal fusions as did other adolescents in this study who, in contrast, experienced severe pain that persisted. It is unclear why these two adolescents had a less problematic pain course. Further research examining the severity and duration of pain, along with parental pain management behaviours (e.g. amount of analgesics administered, use of psychological and physical approaches for pain management), across a broader sample size would aid in a greater understanding of adolescent pain trajectories and associated parental pain management strategies.

Parents who participated in the study reported varying experiences that could be interpreted as expressions of powerlessness including the inability to control their child's pain during pain crises, feeling as though there was nothing more they could do, and being unable to effectively advocate for longer stays in hospital for their child. Feelings of powerlessness may have resulted from the underlying belief that pain was unavoidable in addition to the fact that they felt unsupported once discharged. Patient and family centered care is a philosophy that has been purported to guide pediatric healthcare which, in practice, should involve the empowerment of parents to provide care for their children following discharge (Park et al. 2018). Within a family centered care philosophy, parents should also be able to effectively advocate for the needs of their child to the healthcare team and gain the skills necessary for their child to achieve positive outcomes. However,

the parents in this study felt powerless in advocating for a longer stay when their child was still acutely unwell and were unclear as to whom to turn to when they were unable to meet their child's pain care requirements. Studies that explore clinician and parent perspectives on the parent's role in providing postoperative pain care and how best to provide support for this role may provide insight into how family centered care needs to evolve from a concept to embedded practice.

Moving from the hospital to the home and the adoption of the roles and responsibilities of caring for an adolescent during their post-operative recovery marks a transition for parents. Hart (2016) described the consequences of successful transition as "transition-specific skill acquisition, increased self-efficacy and self-confidence, decreased anxiety and positive coping, role mastery, sense of well-being, and identity reformation" (p. 184). Given this definition of a successful transition, the experiences of the parents in this study and their reported outcomes for their child suggest that most did not experience a successful transition. In terms of addressing the unsuccessful nature of this transition, Schumaker and Meleis (1994) identified 6 factors contributing to successful transitions: *meanings, expectations, level of knowledge/skill, environment, emotional and physical level of well-being, and level of planning*. Effective nursing interventions would aid parents in building informed *meanings* of pain and pain management, accurate *expectations* for the recovery process, *a level of knowledge and skill* adequate to meet the needs of the patients, and expand the *level of planning* (e.g. documentation of analgesics, development of a return to school plan). Enhanced Recovery After Surgery (ERAS) initiatives have been shown to improve patient outcomes in the post-operative period through engagement of patients and families in pre,

peri, and post-operative education and collaborative planning and goal setting (Altman et al., 2019; Heiss & Raval, 2018). An ERAS initiative may aid parents in making a successful transition.

This research has implications for clinical practice. Discharge planning needs to be a priority for nurses caring for parents and their children undergoing inpatient surgery. Parents could benefit from written education regarding pain management (Huth, Broome, Mussatto, & Morgan, 2003) including instruction on the assessment of pain, the safe and effective use of opiates in the home setting, currently understood risks of addiction, withdrawal, overdose, an understanding of non-opioid analgesics and psychological and physical pain management strategies. Parents have an interest in gaining more in-depth information regarding post-operative recovery, understanding of pain management including both physical and psychological approaches, as well as their child's associated potential outcomes (Rabbitts et al. (2017). Potential strategies parents have suggested include web-based interactive education in the post-surgical period (Rabbitts et al. 2017). Future interventions could leverage web-based platforms to provide a source of reliable evidence-based approaches readily available around the clock with an ability to contact a clinician to enhance the transition to the home. Parents may also benefit from other styles of novel intervention, such as YouTube videos, webpages, and smartphone applications which have all been shown to aid in knowledge translation (Harrison, Larocque, Reszel, Harrold, & Aubertin, 2017; Ingadóttir & Zoëga, 2017). Parents also spoke of adolescents playing a major role in their own pain management, and thus interventions specifically targeting adolescents need to be examined.

Parents and adolescents may also benefit from the involvement of a pain transition team in order to support the ongoing pain needs of the adolescents post-operatively (Katz et al., 2015). Transitional pain clinics can help in the pain-specific managing and monitoring of patients in the post-operative period while providing access to a range of key related professional resources including physiotherapy, psychology, and addiction services as required, thus improving the pain outcomes of patients (Glare, Aubrey, & Myles 2019).

There are several limitations to this study. Firstly, the children of the parents in this study all received care at a single pediatric surgical center and it is unclear if their experiences would be different at another hospital. However, the participants included those whose children were managed by different services, surgeons and nurses to help improve the representation of others in this study. Secondly, most of the parents were mothers and so this study may be more transferable to the experiences of mothers than fathers. Research has shown that mothers and fathers differ in their interactions with children during cold-pressor tests (Moon, Chambers, & McGrath, 2011), and thus further research could explore the differences in post-operative pain management practices between fathers and mothers. Nevertheless, the experiences of the two fathers who participated did not differ from those of the mothers in this study. Thirdly, five of seven participants had children undergoing spinal fusions, which may limit transferability of findings to other populations. However, the experiences of the other two parents whose children had different surgeries were similar to those of the parents whose children underwent spinal fusions.

### **Conclusion**

Parents experienced many challenges in caring for their child's pain following discharge post inpatient surgery. They spoke of being on their own and feeling unprepared to manage their child's pain at discharge, with many speaking of the desire for a longer inpatient recovery prior to discharge. Parents noted that their children experienced varying degrees of intensity and duration of pain. Parents used mostly analgesics as their pain management approach but cited a number of concerns regarding opioid use including the possibility of addiction and side effects, yet they also voiced interest in what they described as natural alternatives. Some parents did not use psychological or physical approaches to managing their child's pain and were unaware of the use of these approaches. Nurses play a pivotal role in discharge planning and parent discharge preparation. To improve the pain related outcomes for their children postoperatively, parents could benefit from traditional and novel educational interventions including written discharge instructions, the inclusion of physical and psychological pain management approaches in the discharge information, ongoing web-based coaching, and the involvement of a transitional pain clinic for some adolescents and families.

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## Tables

Table 1

*Participant Demographics*

| Participant Sex | Participant Age | Participant's Child's Age | Participant's Child Sex | Surgery Type                                     |
|-----------------|-----------------|---------------------------|-------------------------|--------------------------------------------------|
| Female          | 41              | 13                        | Female                  | Spinal Fusion – Idiopathic Scoliosis             |
| Female          | 48              | 15                        | Female                  | Spinal Fusion – Idiopathic Scoliosis             |
| Male            | 54              | 16                        | Male                    | Spinal Fusion – Idiopathic Scoliosis             |
| Female          | 54              | 17                        | Female                  | Spinal Fusion – Idiopathic Scoliosis             |
| Female          | 49              | 16                        | Female                  | Spinal Fusion – Scoliosis r/t Muscular Dystrophy |
| Male            | 46              | 17                        | Male                    | Bilateral Open Femur Fracture Reduction          |
| Female          | 47              | 16                        | Male                    | Pectus Excavatum Repair                          |

## **Chapter 6**

### Integrated Discussion

## **Thesis Summary**

### **Introduction**

The overall aim of this thesis was to explore the pain management experiences of parents and adolescents following discharge home after inpatient surgery. A literature review was conducted (Chapter 2), followed by two qualitative Interpretative Phenomenological Analysis studies (Chapters 4 and 5). This chapter will summarize the findings, with an integrated discussion of the results of the research, along with the implications for clinical practice and future research.

### **Summary of Thesis Findings**

The review of the literature indicated that pediatric patients experienced significant pain at home following outpatient surgery (Howard et al., 2013; Stanko, Bergesio, Davies, Hegarty, & Von Ungern-Sternberg, 2013). These children and adolescents often received little or no analgesics, with their parents citing concerns related to opioid analgesics such as addiction, and adverse effects (Fortier, Wahi, Bruce, Maurer, & Stevenson, 2014; Rony, Fortier, Chorney, Perret, & Kain, 2010). There is also little research examining the role that children and adolescents play in their own pain management (Sng et al., 2012). Moreover, there is a paucity of research regarding pain management at home following pediatric inpatient surgery. The research that has been conducted on managing postoperative pain at home following inpatient surgery found that these adolescents experienced significant pain (Birnie, Chorney, El-Hawary, & PORSCHE Study Group, 2017), and both parents and adolescents were unprepared to manage pain following discharge home (Rabbitts et al., 2017). These studies

demonstrated the need for further research into the pain management experiences of both adolescents and parents in the post-discharge period.

The findings from the two studies (Chapter 4 and Chapter 5) in this thesis suggested that challenges exist for both parents and adolescents in managing adolescents' postoperative pain at home following inpatient surgery, providing insight into potential nursing interventions. The main themes across both parent and adolescent groups were: challenges in managing significant and ongoing pain, adapting to changes in their respective roles and relationships, and the distress involved in the inability of the adolescents to return to school and regular life. The findings from each study have previously been described. Although each study has its own specific findings, the following will focus on the areas where the findings overlap between the studies.

### **Integrated Discussion**

Both parents and adolescents spoke of the severity and duration of pain experienced by the adolescents, with most still experiencing pain at the time of interview. Similarly, Birnie, Chorney, El-Hawary, and the PORSCHE Study Group (2017) found that adolescents continued to experience significant pain at 6-week follow-up after inpatient orthopedic surgery. The duration of pain experienced by adolescent participants in this thesis is troubling as several of the participants reported ongoing pain three months post-operatively, indicating that these adolescents met the diagnostic criteria for post-surgical chronic pain (Steyaert & Lavand'homme, 2018; Williams, Howard, & Liossi, 2017). Although most parents and adolescents spoke of similar experiences in terms of pain severity and duration, the determination of need for analgesics was inconsistent and relied on either parents perceiving that their child was experiencing pain or the parent

waiting until the adolescent requested analgesics. Previous research has reported that following outpatient surgery, parents significantly underestimate their child's pain, and that children and adolescents may also under-report pain due to emotional distress (Chambers, Reid, Craig, McGrath & Finley, 1998). Inadequate parental assessment of pain severity can lead to lesser dosing of analgesics, and culminate in inferior pain outcomes for pediatric patients (Rony, Fortier, Chorney, Perret, & Kain, 2010).

A concerning finding was that both adolescents and parents focused on the use of pharmacologic pain management strategies and spoke less of psychological and physical strategies. This may be related to the types of education received in hospital, as some participants described receiving only written information pertaining to medications (doses, frequencies, side effects) and no information on psychological or physical interventions. Parents and adolescents have demonstrated interest in education focusing on additional physical and psychological pain management interventions, as established through the research of Rabbitts et al. (2017) and Paquette et al. (2014).

Moreover, despite a focus on analgesics, both parents and adolescents expressed concern about the use of opioids, suggesting that they did not receive information that relieved their misconceptions and fears. Parents who have expressed concerns regarding addiction and side effects were found to deliver far fewer opiate analgesics than necessary to control their child's pain (Fortier et al., 2014). Both parents and adolescents also reported that they were instructed to stop opioid medications relatively soon after discharge, often on a timeline rather than on the basis of pain. Information on analgesics remains a key postoperative pain management priority but needs to include the dispelling of common misconceptions in order to increase parents and adolescents' comfort in

administering opioids and other analgesics. Physicians and surgeons must also provide discharge instructions that do not inadvertently support inaccurate concerns by stopping analgesics on a restricted timeline versus pain management needs.

Although most adolescents spoke to the greater difficulty of managing their pain at home, all adolescents voiced their preference for recovering at home over hospital. Conversely, parents voiced significant concerns regarding the rates of discharge from hospital, preferring adolescents to remain in hospital a day or two longer. Parents framed their need for their child to stay in hospital longer as related to fears associated with caring for their child in the community setting and their child's degree of acuity at the time of discharge. Both the thesis research and the research of Rabbitts et al. (2017) found that parents had significant fears pertaining to caring for their child at home including fragility, injury, and inadequate preparation. Both studies also spoke to the stress experienced by parents due to their child's increased reliance on them and their increased levels of responsibility. Adolescents did not voice similar concerns pertaining to discharge.

### **Implications**

**Clinical Practice.** The findings of this research suggest a number of implications for clinical practice. Parents and adolescents demonstrated significant knowledge deficits pertaining to adequately managing post-operative pain in the community setting. Parents and adolescents focused primarily on use of pharmacologic pain control, and thus moving past a sole focus on analgesics is a key area for intervention. Areas for educational focus include helping parents and adolescents understand how to determine pain intensity (e.g. how to use pain assessment tools) and suggested plans of action for times when pain is

not controlled (e.g. how and when to contact the healthcare team, manage a sudden increase in pain), safe and effective use of pharmacologic analgesics (e.g. opioids, NSAIDs), medication administration tracking, and the use of psychological and physical pain management interventions.

Expanding on the finding by Sng et al. (2012), which suggest that adolescents were significantly engaged in their own pain management, adolescent targeted educational interventions are required. Adolescents learn through various approaches, one of which is modeling (i.e. by watching and emulating nursing staff), which raises the importance of using “teachable moments” in clinical practice (Ingadóttir & Zoëga, 2017). Nurses need to involve adolescents to a greater degree in discussing their plan of care as a way to engage adolescents in developing an understanding of how to manage their pain at home. According to the research of Huth, Broome, Mussatto, & Morgan (2003), written discharge instructions could be beneficial for both parents and adolescents, but given that adolescents may be unable to fully engage in discharge education due to their level of acuity at their particular stage of recovery at discharge and the associated pain, written information may be especially important for adolescents.

However, more innovative approaches that harness the use of the Internet also hold promise as clinical resources for parents and adolescents. For example, studies have demonstrated the effectiveness of Youtube videos as a method of knowledge translation targeting parents to help their infants with needle related pain (Harrison, Larocque, Reszel, Harrold, & Aubertin, 2017), explored the utility of webpages as a means of patient education (Ingadóttir & Zoëga, 2017), and demonstrated the effectiveness of

smartphone applications in engaging adolescents in their own pain management processes (Jibb et al., 2017; Mooney et al., 2017).

Parents in this study expressed feeling unsupported by the healthcare team following discharge home. Rabbitts et al. (2017) have also reported that parents and adolescents were interested in ongoing interactions with a member of the healthcare team post-discharge, potentially utilising a web-based platform, with a particular interest in learning more about psychosocial pain management interventions as their discharge instructions also focused on analgesic use (Rabbitts et al., 2017). This interest could be capitalized upon to build a coaching style intervention, where a pain management specific member of the healthcare team could engage parents and adolescents both pre and post-discharge to provide support for all areas of pain management (e.g. pain assessment, analgesic administration, physical and psychological interventions) by phone or through web-based coaching. Coaching differs from teaching as it engages the participant in their own learning in a holistic and collaborative capacity, dynamically addressing the learning needs of the participant (Hamric, Hanson, Tracy, & O'Grady, 2014).

The parents and adolescents in this study, as well as those in the study by Rabbitts et al. (2017), spoke of significant difficulty in the return to school post-inpatient surgery. Adolescents with chronic pain have been found to have decreased school attendance and poorer academic performance (Dick & Riddell, 2010), with the students often feeling as though their teachers did not support them in the expression of their pain (Logan, Catanese, Coakley, & Scharff, 2007). The findings from this thesis suggest that the adolescents faced some similar issues to those with chronic pain, specifically

experiencing decreases in school attendance, falling behind in their academic work, an inability to take certain analgesics at school, and teachers' lack of understanding of a student's pain tolerance. Given that not addressing ongoing pain symptoms in the classroom may lead to long term educational impairment (Dick & Riddell, 2010), engagement of teachers and school administrators should be a key part of discharge planning in order to facilitate a successful reintegration to school. Logan et al. (2007) suggests that teachers may benefit from education regarding the biopsychosocial model of pain and aid in the development of appropriate pain management strategies for students in the classroom. Nurses have a role to play in assisting parents and adolescents plan their successful transition back into the school environment.

Several parents spoke of their desire to extend the length of time their child remained in hospital following surgery. These parents reported that their children were discharged in states in which they were unable to tolerate oral intake of medication and thus may not have been able to absorb oral analgesic medications. Parents also reported feeling uneasy about the degree of acuity of their child at the point of discharge, stating concerns regarding inability to perform any tasks on their own. A potential intervention at this phase could be a nurse practitioner led follow-up phone call 24 hours after discharge, which Fischer, Hogan, Jager, and von Allmen (2015) found to be an effective method of reducing unexpected clinic visits and improving patient satisfaction. A follow-up phone call could also allow parents and adolescents the opportunity to broach any developing concerns and adjust the treatment course as needed.

**Research.** The two studies in this thesis expand on the current body of research pertaining to adolescent and parent pain management following discharge from inpatient

surgery, however more research is required. Further research is needed to evaluate the effectiveness of novel educational interventions (e.g. YouTube, websites, smartphone apps) in increasing postoperative pain management knowledge and skill amongst adolescents and parents following inpatient surgery. Assessing the impact of these interventions to improve pain related outcomes is also required.

Given the capacity of coaching to improve patient knowledge and skill in the field of postoperative pain management, further research could focus on a coaching style intervention, involving both adolescents and parents. Specifically an examination of whether coaching interventions targeting pain management engage adolescents more effectively than didactic education strategies is needed.

Parents and adolescents both voiced concerns about opioids and other analgesics and both acknowledged the significant pain the adolescents experienced. Further research is needed to explore the pain scores and pain duration at home following inpatient surgery, frequency of administration and effectiveness of opiates, as well as the frequency and effectiveness of physical and psychologic interventions. Addition dyadic studies may aid in understanding the needs of parents and adolescents as a family unit. Research examining the prevalence of post-surgical chronic pain in adolescents following inpatient surgery is also warranted. Finally, considering the difficulty reported by both parents and adolescents in returning to school, research identifying optimal means of incorporating a return to school strategy into discharge planning and pain management is warranted. This area of research should include teachers and administrators so as to ensure that the strategies are in place to support students in a successful postoperative return to school.

**Policy.** The findings in this thesis have implications for policy, specifically in the area of patient education policy. Participants within the study received varying and inconsistent degrees of education, potentially contributing to the severity of pain experienced by the adolescents following discharge. The development of a standardized patient education policy including both educational interventions for parents and for adolescents could improve the consistency and quality of the education provided.

Research has also shown the effectiveness of Enhanced Recovery After Surgery (ERAS) initiatives, which consist of pre-operative, peri-operative, and post-operative educational intervention as well as collaborative goal setting and planning with patients and families. Standardization of ERAS in hospital policy has been shown to decrease length of stay, increase patient satisfaction, and decrease adverse outcomes (Altman et al., 2019; Heiss & Raval, 2018), and thus could be a key intervention to improve outcomes for adolescents following inpatient surgery.

Given that many of the adolescents within the study population met diagnostic criteria for chronic pain but none reported receiving any chronic pain specific interventions, standardized engagement of a transitional pain clinic may benefit patients. Transitional pain clinics are specially equipped to evaluate and treat the needs of patients experiencing ongoing post-surgical pain, with the capacity to incorporate a range of multidisciplinary teams necessary to manage ongoing acute pain, including physiotherapy, psychology, and addiction services (Glare, Aubrey, & Myles, 2019). Hospital policy could also include the standardization of transitional pain clinic referrals for adolescents demonstrating risk of developing chronic post-surgical pain (such as

those with high pain catastrophizing, high peri-operative pain, depression, etc.) to improve potential outcomes (Althaus et al., 2012; Katz et al., 2015).

Finally, there are also opportunities for personnel from hospitals and schools to work collaboratively to better prepare the educational environments to support the healthcare needs of adolescents returning to school postoperatively. Policies that ensure the safe storage of analgesics while on school grounds while allowing adolescents to access needed analgesics at school need to be established.

**Education.** The findings also have implications for nursing education. Nurses play a pivotal role in discharge preparation with both adolescents and parents. Unfortunately, research has found that nursing and medical students in Canada receive less formal pain management education in their pre-licensure programs compared to veterinarian students (Watt-Watson et al., 2009)

Clearly, more robust pain related education is required in pre-licensure programs covering all pain related topics. From this study in particular, nurses' education should include the importance of involving adolescents in all aspects of their pain care including discharge preparation, clarification of myths and misconceptions about analgesics, physical and psychological approaches to pain management, modes of parental support, strategies to help parents with tracking analgesics, and the importance of the implementation of a school return strategy among others.

### **Conclusion**

Following discharge from inpatient surgery, adolescents experienced significant pain that lasted longer than anticipated, with some adolescents meeting diagnostic criteria for chronic post-surgical pain. The experiences of the parents and the adolescents

suggested that both groups held insufficient knowledge and had skill deficits which negatively impacted their ability to manage pain at home adequately. Both groups could benefit from enhanced pre-discharge planning and education, ongoing coaching post discharge, innovative knowledge transfer interventions, and for some, involvement with a transitional pain clinic. Interventions that target adolescents are needed, as they were involved in their own pain management to a significant degree. Parents felt as though adolescents were discharged too early from hospital, and often felt helpless when trying to care for their child's pain. Adolescents encountered barriers in their return to school and a return to school plan needs to be part of their discharge planning and follow up care. As length of stay shortens, being able to manage postoperative pain at home becomes more critical. Nurses are situated to be leaders in improving the postoperative pain recovery of adolescents following inpatient surgery.

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## **Appendices**

**Appendix A****Consent Forms****Assent Form**

**Protocol Title: Parental/Patient Pain Management of Adolescent Post-Operative Inpatients After Discharge: A Qualitative Study**

**Primary Investigator: Bill Dagg, RN, BScN, University of Ottawa, Masters of Science in Nursing Student. Telephone:**

**Secondary Investigators: Paula Forgeron, R.N., Ph.D., Vice Dean Professional Affairs, Faculty of Health Sciences, Associate Professor, School of Nursing, University of Ottawa, Clinical Investigator CHEO RI; Adjunct Associate Professor of Anaesthesia, Dalhousie University CHEO RI.**

**Gail Macartney, RN(EC), PhD, CON(C), Director, Nursing Research & Knowledge Translation, Nurse Practitioner, Concussion Clinic, Children's Hospital of Eastern Ontario.**

**Julie Chartrand, RN, PhD Assistant Professor, School of Nursing, University of Ottawa, Roger-Guindon Hall, 451 Smyth Road, Room 3247B.**

**Address: CHEO, 401 Smyth Road, Ottawa, ON K1H 8L1  
University of Ottawa, 75 Laurier Avenue East  
Ottawa ON K1N 6N5**

**Why is this study being done?**

We would like to ask you to be part of a research study. Research is a way to test new ideas to see if we can do things better.

In our study, we want to know more about what it is like to have pain after surgery when you are at home so we can help other teens have less pain at home.

**Who will take part?**

Teenagers who have had surgery at CHEO and needed to stay in the hospital for at least one day are being asked to join this study. We expect to have 6 to 10 teenagers and 6 to 10 parents join the study over the next 4 months.

**What will happen during the study?**

We meet in person or we will call you on the phone or Skype after your follow-up appointment with your surgeon to do an interview. Interviews are when someone asks you questions and you answer them as honest as you can. There are no right or wrong answers in this type of interview. It is your choice if we use a phone or Skype. We will ask you questions about what it feels like to have pain, what you did to help with the pain, what your parents did to help with the pain, how having pain makes you feel, what you think makes the pain better, and how it felt when you did things to help make the pain better. The interview will be recorded, but nobody will hear the recordings except for the researchers. After the questions are done, you will have time to ask any us questions you have or tell us about anything that worries you about the study. The interviews need to be done in private so we can be sure that you are feel okay talking about how you coped with your pain and how your parents helped with your pain.

**Are there good things that can happen from this study?**

Sometimes good things can happen to people when they are in a study. These good things are called “benefits.” This study will help us better understand teenagers like you,

so that in the future we can help other teenagers have less pain after surgery. That is a benefit. There are no other benefits that we think will happen to you if you decide to join this study.

**Are there bad things that can happen from this study?**

We do not think that anything bad would happen if you decide to join this study.

**What if something bad happens?**

If something does go wrong, your doctor will be able to take care of you.

**What if there is new information?**

Sometimes during a study, we learn new information. We will talk to your doctors about any new information that might be important to you.

**Is this private?**

We will keep your information private whether you decide to join this study or not.

**Can I say no?**

You can decide to be a part of this study or not. You can also decide to stop being in this study at any time once you start. Talk to your parents or your doctor if you want to stop being in the study, and they will tell the researchers. No one will be mad at you if you decide not to take part

**What if I have questions?**

Please ask us and we will do anything we can to answer your questions.

**Assent form Signatures**

If you agree to participate in this research study, please sign the form. I understand the information that was explained to me and I can ask any question that I like about the study.

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Signature of Participant

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Name of Participant

---

Date

**Parental Information & Consent Form**

**Protocol Title: Parental/Patient Pain Management of Adolescent Post-Operative**

**Inpatients After Discharge: A Qualitative Study**

**Primary Investigator: Bill Dagg, RN, BScN, University of Ottawa, Masters of Science in Nursing Student.**

**Secondary Investigators: Paula Forgeron, R.N., Ph.D., Vice Dean Professional Affairs, Faculty of Health Sciences, Associate Professor, School of Nursing, University of Ottawa, Clinical Investigator CHEO RI; Adjunct Associate Professor of Anaesthesia, Dalhousie University CHEO RI.**

**Gail Macartney, RN(EC), PhD, CON(C), Director, Nursing Research & Knowledge Translation, Nurse Practitioner, Concussion Clinic, Children's Hospital of Eastern Ontario.**

**Tel:**

**Julie Chartrand, RN, PhD Assistant Professor, School of Nursing, University of Ottawa, Roger-Guindon Hall, 451 Smyth Road, Room 3247B**

**Address: CHEO, 401 Smyth Road, Ottawa, ON K1H 8L1**

**University of Ottawa, 75 Laurier Avenue East**

**Ottawa ON K1N 6N5**

You are being invited to join in a research study to understand the pain and pain management experiences of parents and teenagers following inpatient surgery after discharge home. You are being invited to join this study because your child is

undergoing or has undergone post-operative care at the Children's Hospital of Eastern Ontario for an orthopedic or surgical procedure for which they will be recovering/have recovered at least in part at home. Before agreeing to take part in this study, it is important that you read and understand this document.

Taking part in this study is voluntary (your choice). Your decision to participate or not in this study will not affect the care you receive at CHEO. You are free to withdraw from the study at any time and there will be no penalty to you or your child.

**Why is this study being done?**

This study is being done because we want to know more about the experiences, beliefs and perceptions of parents and teenagers recovering from inpatient surgery at home. This information may help us understand how to make pain care better when at home.

**How many people will participate?**

At CHEO, we expect to have 6-10 parents and 6-10 teenagers participate. The study is expected to be looking for people to take part for 4 months.

**What will I have to do?**

- The teenager undergoing the surgery and one parent can both be participants, However, children can take part without their parents' taking part and parents can take part without their child taking part.
- Participants will be contacted by the Primary Investigator for an interview after their follow-up appointment with their surgeon.
- Each interview will last between 30 to 60 minutes. Participants will be contacted separately. Interviews may take place in person, by telephone, or by Skype.
- The interview must be conducted in private to make sure no one overhears what

participants say. If you take part you will be asked questions about your thoughts, feelings, beliefs and experiences about your child's pain care at home.

- The interview will be audio recorded, and transcribed (typed) by a professional transcriptionist who has signed a confidentiality agreements with the Primary Investigator.
- As part of your participation, you will be asked to voluntarily share personal information and experiences. This may cause you to feel uncomfortable. You do not have to answer any question you do not want to answer. There will be no negative consequences for deciding to not answer a question. You will be offered a debriefing session after the interview session to allow for any questions or to express any concerns you may have. There is a small risk of a release of information from your research records. Health and research records have been used against patients and their families. For example, in Canada, insurance companies may deny insurance to patients with a certain illness or those that have a genetic risk of disease. Your hospital medical records cannot, however be released unless required by law or if you sign a release of information. The researchers of this study will protect your research records so that your name, address and phone number will be kept private. The transcriptionist will remove your name, names of others, and names of places from the typed interview. They also have signed an agreement with the researchers who are part of the University of Ottawa to not keep any copies (electronic or typed) after giving the typed document to the researchers. Your name will not be used to identify your research data instead we will use a study number. All documents are encrypted and password protected.

**Are there any benefits to participating?**

If you take part in this study you will not benefit directly. However, the information you share could help develop programs and policies that would improve the post-operative care of future teenagers and their patients

**Will I be paid to participate?**

You will not be paid to take part in this study.

**Will I be told about new information?**

We will inform you of any new information that might influence your decision to continue to participate in this research project. We will ask you again if you still want to be in the study.

You can receive a copy of the study results at the end of the study.

**What about confidentiality and privacy?**

Your personal information will be kept strictly confidential except as required or permitted by law. For this study, we will be collecting your name, your child's date of birth, your gender, your child's gender, address, email address, and phone number for the research purposes described in this consent form. A quality reviewer from CHEO research institute or the CHEO Research Ethics Board may look at your records at the site where these records are held, to check that the study is following the proper laws and guidelines.

Your personal information will be kept strictly confidential except as required or permitted by law. Any information that would indicate that a child was being harmed or at risk of such harm, would not be kept confidential and instead be disclosed as appropriate to the appropriate authorities. In the event of the discovery of self-harm, referral to the appropriate mental-health services will be made and the most responsible

physician will be informed.

On discovery of any incidental findings (e.g., pain management techniques or medications outside treatment/indicated use), patients and parents will be directed to refer to their surgeon or primary care physician as appropriate. Incidental findings of risk of harm to oneself or other will be reported as appropriate.

Representatives from the University of Ottawa may receive information for data analysis and/or quality assurance. Any personal information about you that leaves the hospital will be coded so that you cannot be identified by name.

The data (personal information, audio recording and transcription) produced from this study will be stored at CHEO on a secure electronic server under passcode lock. Only information with patient identifiers removed will be shared with the University of Ottawa. Only members of the research team and the individuals described above will have access to the data. Following completion of the research study the data will be kept for 7 years after the last publication of this study. They will then be destroyed.

You will not be identified in any publication or presentation of this study. A copy of the signed consent form will be provided to you.

**Is the research team benefiting from the study?**

The research you will be participating in is part of the requirements for the Primary Investigator, Bill Dagg's Masters of Science in Nursing degree. Mr. Dagg has not conflicts of interest in conducting this study.

**What if I have questions?**

If you have any questions concerning participation in this study, contact: Bill Dagg or Dr. Paula Forgeron

This study has been reviewed and approved by the CHEO Research Ethics Board. The CHEO Research Ethics Board is a committee of the hospital that includes individuals from different professional backgrounds. The Board reviews all human research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board, for information regarding patient's rights in research studies at (613) 737-7600 (3272), although this person cannot provide any health-related information about the study. This study has also been approved by the University of Ottawa Research Ethics Board. You may contact the Chair of the University of Ottawa Research Ethics Board, for information regarding patient's rights in research studies at 613-562-5387 although this person cannot provide any health-related information about the study

**Consent form Signatures**

- The research team members are not benefiting personally, financially or in some other way from this study.

By signing this consent form I agree that:

- I am voluntarily agreeing to participate in this research study;
- I understand the information within this consent form;
- All of the risks and benefits of participation have been explained to me;
- All of my questions have been answered
- I allow access to my personal information as described in this consent form, and;
- I do not give up my legal rights by signing this form.

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Signature of Participant

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Witness to Participant's Signature

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Signature of Person Obtaining Informed Consent

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Name of Participant    Date

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Name of Witness    Date

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Name of Person Obtaining Informed Consent    Date

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**Parental Consent on Behalf of Child: Information & Consent Form****Protocol Title: Parental/Patient Pain Management of Adolescent Post-Operative****Inpatients After Discharge: A Qualitative Study****Primary Investigator: Bill Dagg, RN, BScN, University of Ottawa, Masters of****Science in Nursing Student. Telephone: (****Secondary Investigators: Paula Forgeron, R.N., Ph.D., Vice Dean Professional****Affairs, Faculty of Health Sciences, Associate Professor, School of Nursing,****University of Ottawa, Clinical Investigator CHEO RI; Adjunct Associate Professor****of Anaesthesia, Dalhousie University CHEO RI. Telephone:****Gail Macartney, RN(EC), PhD, CON(C), Director, Nursing Research & Knowledge****Translation, Nurse Practitioner, Concussion Clinic, Children's Hospital of Eastern****Ontario.****Tel:****Julie Chartrand, RN, PhD Assistant Professor, School of Nursing, University of****Ottawa, Roger-Guindon Hall, 451 Smyth Road, Room 3247B. Tel:****Address: CHEO, 401 Smyth Road, Ottawa, ON K1H 8L1****University of Ottawa, 75 Laurier Avenue East****Ottawa ON K1N 6N5**

Your child is being invited to join in a research study to understand the pain and pain management experiences of parents and children following inpatient surgery after discharge into the community setting. Your child is being invited to join this study

because they are undergoing/have undergone post-operative care at the Children's Hospital of Eastern Ontario for a complex surgical procedure for which they will be recovering/have recovered at least in part at home. If they are not capable of consenting on their own behalf, they can sign the attached assent form, and you can consent on their behalf. Before agreeing for your child to take part in this study, it is important that you read and understand this document.

Taking part in this study is voluntary. Your decision to participate or not in this study will not affect the care your child receives at CHEO. Your child is free to withdraw from the study at any time and there will be no penalty to you or your child.

**Why is this study being done?**

This study is being done because we want to know more about the experiences, beliefs and perceptions of parents and children recovering from inpatient surgery at home and/or we hope to find out how to better care for them and improve patient's pain

**How many people will participate?**

At CHEO, we expect to have 6-10 parents and 6-10 children participate. The study is expected to be active for 4 months.

**What will I have to do?**

- The child undergoing the surgery and one parent can both be participants, but children can participate without the participation of their parent and parents can participate without the participation of their child.
- Participants will be contacted by the Primary Investigator for interview following post-discharge follow-up appointment with their physician.
- The interview will last between 30 to 60 minutes per participant. Participants will be

contacted separately. Interviews may take place in person, by telephone, or by Skype.

- The interview must be conducted in privacy to protect the vulnerability of participants in the disclosing of personal experiences, beliefs, and perceptions.
- The interview will be audio recorded, and transcribed by the Primary Investigator.
- As part of your child's participation, they will be asked to voluntarily share personal information and experiences. This may cause them to feel uncomfortable. They do not have to answer any questions they do not want to answer. There will be no negative consequences for deciding to not answer a question. They will be offered a debriefing session after the interview session to allow for any questions or to express any concerns you may have.

There is a small risk of a release of information from your research records. Health and research records have been used against patients and their families. For example, in Canada, any information about child abuse must be reported to Children's Aid or police. Your hospital medical records cannot, however be released unless required by law or if you sign a release of information. The researchers of this study will protect your research records so that your name, address and phone number will be kept private.

**Are there any benefits to participating?**

If you take part in this study you will not benefit directly. However, the information you share could help develop programs and policies that would improve the post-operative care of future teenagers and their patients.

**Will I be paid to participate?**

You/your child will not be paid to take part in this study.

**Will I be told about new information?**

We will inform you of any new information that might change your decision to continue to participate in this research project. We will ask you again if you still want to be in the study.

You can receive a copy of the study results at the end of the study if you like.

**What about confidentiality and privacy?**

Your personal information will be kept strictly confidential except as required or permitted by law. For this study we will be collecting your child's name, date of birth, gender, address, email address, and phone number for the research purposes described in this consent form.

Your personal information will be kept strictly confidential except as required or permitted by law. Any information that would indicate that a child was being harmed or at risk of such harm, would not be kept confidential and instead be disclosed as appropriate to the appropriate authorities

On discovery of any incidental findings (e.g., pain management techniques or medications outside treatment/indicated use), patients and parents will be directed to refer to their surgeon or primary care physician as appropriate. Incidental findings of risk of harm to oneself or other will be reported as appropriate.

Representatives from the University of Ottawa may receive information for data analysis and/or quality assurance. Any personal information about you that leaves the hospital will be coded so that you cannot be identified by name.

The data (personal information, audio recording and transcription) produced from this study will be stored at CHEO on a secure server under passcode lock. Only members of the research team and the individuals described above will have access to the data. Only

information with patient identifiers removed will be shared with the University of Ottawa. Following completion of the research study the data will be kept for 7 years after the last publication of this study. They will then be destroyed.

A quality reviewer from CHEO research institute may look at your records at the site where these records are held, to check that the study is following the proper laws and guidelines.

You/your child will not be identified in any publication or presentation of this study. A copy of the signed consent form will be provided to you.

**Is the research team benefiting from the study?**

The research you will be participating in is part of the requirements for the Primary Investigator, Bill Dagg's Masters of Science in Nursing degree. Mr. Dagg has not conflicts of interest in conducting this study.

**Consent form Signatures**

- The research team members are not benefiting personally, financially or in some other way from this study.

By signing this consent form I agree that:

- I am consenting on behalf of my child as a participant in this research study;
- I understand the information within this consent form; my child understands the information within this consent form to the best of their abilities.
- My child may withdraw their assent and thus consent at any time.
- All of the risks and benefits of participation have been explained to me and my child;
- All of my/my child's questions have been answered
- I allow access to my child's personal information as described in this consent form, and;
- I do not give up my child's legal rights by signing this form.

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Signature of Parent

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Witness to Parent's Signature

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Signature of Person Obtaining Informed Consent

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Name of Participant    Date

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Name of Parent    Date

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**Patient Information & Consent Form**

**Protocol Title: Parental/Patient Pain Management of Adolescent Post-Operative**

**Inpatients After Discharge: A Qualitative Study**

**Primary Investigator: Bill Dagg, RN, BScN, University of Ottawa, Masters of**

**Science in Nursing Student. Telephone:**

**Secondary Investigators: Paula Forgeron, R.N., Ph.D., Vice Dean Professional**

**Affairs, Faculty of Health Sciences, Associate Professor, School of Nursing,**

**University of Ottawa, Clinical Investigator CHEO RI; Adjunct Associate Professor**

**of Anaesthesia, Dalhousie University CHEO RI. Telephone:**

**Gail Macartney, RN(EC), PhD, CON(C), Director, Nursing Research & Knowledge**

**Translation, Nurse Practitioner, Concussion Clinic, Children's Hospital of Eastern**

**Ontario.**

**Tel:**

**Julie Chartrand, RN, PhD Assistant Professor, School of Nursing, University of**

**Ottawa, Roger-Guindon Hall, 451 Smyth Road, Room 3247B. Tel:**

**Address: CHEO, 401 Smyth Road, Ottawa, ON K1H 8L1**

**University of Ottawa, 75 Laurier Avenue East**

**Ottawa ON K1N 6N5**

You are being invited to join in a research study to understand the pain and pain management experiences of parents and teenagers following inpatient surgery after discharge back home. You are being invited to take part in this study because you will

have/have had surgery at the Children's Hospital of Eastern Ontario and will have to/have had to stay in hospital for a day following your surgery. Before agreeing to take part in this study, it is important that you read and understand this document.

Taking part in this study is voluntary. Your decision to take part or not take part in this study will not affect the care you receive at CHEO. You are free to withdraw from the study at any time and there will be no penalty to you.

**Why is this study being done?**

This study is being done because we want to know more about what it was like for teenagers and parents to having to control the pain after surgery at home. This information may help us understand how to make pain care better when at home.

**How many people will participate?**

At CHEO, we expect to have 6-10 parents and 6-10 teenagers participate. We expect that it will take us 4 months to find 6 to 10 teenagers to take part.

**What will I have to do?**

- The teenager who has undergone the surgery and one parent can both take part, but teenagers can take part without their parents taking part. Parents can also take part without their child taking part.
- Potential participants will be contacted by the Primary Investigator (researcher) to arrange an interview after you have had your follow-up appointment with their surgeon.
- The interview will most likely last between 30 to 60 minutes. If you take part and your parents take part we will contact separately. The interviews may take place in person, by telephone, or by Skype. It is the participant's choice which type of interview they want to do.

- The interview will take place in private so that other people do not hear what you say as you will be asked about your thoughts and experience with controlling your pain at home after surgery.
- The interview will be audio recorded, and transcribed by the Primary Investigator.
- You will be asked to voluntarily share personal information and experiences. This may cause you to feel uncomfortable. You do not have to answer any question you do not want to answer. There will be no negative consequences for deciding to not answer a question. You will be offered a debriefing session (time after the interview and not recorded) to allow for any questions or to express any concerns you may have.

There is a small risk of a release of information from your research records. Health and research records have been used against patients and their families. For example, in Canada, any information about child abuse must be reported to Children's Aid or police. Your hospital medical records cannot, however be released unless required by law or if you sign a release of information. The researchers of this study will protect your research records so that your name, address and phone number will be kept private.

**Are there any benefits to participating?**

If you take part in this study you will not benefit directly. However, the information you share could help develop programs and policies that would improve the post-operative care of future teenagers and their patients.

**Will I be paid to participate?**

You will not be paid to take part in this study.

**Will I be told about new information?**

We will inform you of any new information that might change your decision to continue to participate in this research project. We will ask you again if you still want to be in the study.

You can receive a copy of the study results at the end of the study if you like.

**What about confidentiality and privacy?**

Your personal information will be kept strictly confidential except as required or permitted by law. For this study we will be collecting your name, date of birth, gender, address, email address, and phone number for the research purposes described in this consent form. A quality reviewer from CHEO research institute or a member of the CHEO Research Ethics Board may look at your records at the site where these records are held, to check that the study is following the proper laws and guidelines.

Your personal information will be kept strictly confidential except as required or permitted by law. Any information that would indicate that a child was being harmed or at risk of such harm, would not be kept confidential and instead be disclosed as appropriate to the appropriate authorities. In the event of the discovery of self-harm, referral to the appropriate mental-health services will be made and the most responsible physician will be informed.

On discovery of any incidental findings (e.g., pain management techniques or medications outside treatment/indicated use), patients and parents will be directed to refer to their surgeon or primary care physician as appropriate. Incidental findings of risk of harm to oneself or other will be reported as appropriate.

Representatives from the University of Ottawa may receive information for data analysis and/or quality assurance. Any personal information about you that leaves the hospital will

be coded so that you cannot be identified by name.

The data (personal information, audio recording and transcription) produced from this study will be stored at CHEO on a secure server under passcode lock. Only information with patient identifiers removed will be shared with the University of Ottawa. Only members of the research team and the individuals described above will have access to the data. Following completion of the research study the data will be kept for 7 years after the last publication of this study. They will then be destroyed.

You will not be identified in any publication or presentation of this study. A copy of the signed consent form will be provided to you.

**Is the research team benefiting from the study?**

The research you will be participating in is part of the requirements for the Primary Investigator, Bill Dagg's Masters of Science in Nursing degree. Mr. Dagg has not conflicts of interest in conducting this study.

**What if I have questions?**

If you have any questions concerning participation in this study, contact: Bill Dagg

This study has been reviewed and approved by the CHEO Research Ethics Board. The CHEO Research Ethics Board is a committee of the hospital that includes individuals from different professional backgrounds. The Board reviews all human research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board, for information regarding patient's rights in research studies at (613) 737-7600 (3272), although this person cannot provide any

health-related information about the study

**Consent form Signatures**

- The research team members are not benefiting personally, financially or in some other way from this study.

By signing this consent form I agree that:

- I am voluntarily agreeing to take part in this research study;
- I understand the information within this consent form;
- All of the risks and benefits of taking part have been explained to me;
- All of my questions have been answered
- I allow access to my personal information as described in this consent form, and;
- I do not give up my legal rights by signing this form.

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Signature of Participant

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Witness to Participant's Signature

Signature of Person Obtaining Informed Consent 

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Name of Participant    Date

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Name of Witness    Date

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Name of Person Obtaining Informed Consent    

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    Date

**Verbal Consent Script**

This verbal consent is for a research study entitled “*Parental/Patient Pain Management of Adolescent Post-Operative Inpatients After Discharge: A Qualitative Study*”

The purpose of the study is to understand the pain management of parents and teenagers at home following inpatient surgery. Your participation in the study will be limited to a one-time interview with me, Bill Dagg, on the telephone or videoconferencing using Skype. The interview will be audio recorded and then transcribed, meaning our conversation will be typed out, and analyzed at a further date. The questions will be looking at your pain and pain management experience. There are no risks to the study, however, if you become emotionally distressed from speaking about your experience, you can contact my research supervisor Dr. Paula Forgeron for support. If you want to stop or skip questions you may do so at any time. You do not have to share any information with me that you do not want to. If you wish to stop the interview and resume it at another time, we may arrange another time that works best for you. There are no direct benefits to participating in the interview, however the information that you provide me will contribute to helping other teenagers and parents with pain management following surgery. All the information you share with me will remain confidential. Your name and any identifying factors will be removed from the transcript to protect your identity. The transcript will be assigned a participant identification number that will be used to identify you and your demographics. All documents and transcripts related to this study will be stored on the University of Ottawa’s secure server, or computer, and will be password protected and encrypted. You are under no obligation to continue with

the interview, and you may choose to stop the interview at any time. Do you have any questions?

Can you state and spell your name to record your consent.

This serves as documentation of verbal consent for: (participant's name).

On this date (DD/MM/YYYY) at (00:00). Do you (participant's name) understand the study, and give voluntary consent to participate in the above study?

I, Bill Dagg, have made sure, to the best of my abilities, that the participant understands the above study. I confirm that the participant has had the opportunity to ask questions about the study, and that all questions have been answered to the satisfaction of the participant. You have voluntarily verbally consented to this study. A copy of this consent will be mailed to the participant. If you have any questions about the ethical conduct of this study, you may contact the ethics board. Their contact information will be on the consent form mailed to you.

## Appendix B

**Recruitment Materials****Study Information Letter**

Dear Patient and Parents,

You are being invited to take part in a research study called “*Parental/Patient Pain Management of Adolescent Post-Operative Inpatients After Discharge: A Qualitative Study*”. The aim of the study is to explore the pain management experiences of patients and parents after discharge from hospital following inpatient surgery. You are being invited because you or your child has had inpatient surgery at the Children’s Hospital of Eastern Ontario in the last 6 months. This research will help us develop our understanding of how parents and patients control post-operative pain in the community setting. This study has been approved by the Children’s Hospital of Eastern Ontario (CHEO) Research Ethics Board and the University of Ottawa Research Ethics Board.

If you are interested, you will be asked to participate in an interview with the researcher either in person, over telephone, or by Skype, whichever is most convenient. We expect this to take between 30 and 60 minutes as questions are open ended. Both parent and child are welcome to participate, or just parent or child should only one party be interested.

This research is being conducted by Bill Dagg, RN BscN, and Paula Forgeron, RN MN PhD. Bill Dagg is the Primary investigator and is a Masters of Nursing Student at the

University of Ottawa and a Registered Nurse at the Children's Hospital of Eastern Ontario. Paula Forgeron is the Research Supervisor and is an Associate Professor in the School of Nursing at the University of Ottawa.

This information sheet is just a way to introduce you to this study. Taking part is entirely voluntary (up to you). Should you decide to take part or, alternatively, should you decide that you're not interested, this decision will not affect the treatment that you receive from the CHEO in any way.

If you are interested in participating, you can contact Bill Dagg at:

Email:

Phone:

Further information regarding the study will be provided at this time,

Thank you for your time,

Brenda Martelli, NP, Acute Pain Service,

### Study Information Letter

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Email:

Phone:

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Thank you for your time,

Jessica Romeo, NP, Orthopedics

### Study Invitation Letter

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Sincerely,

Juan Bass M.D. FRCSC

**Permission to release contact information**

I give my permission for Brenda Martelli, the Acute Pain Service Nurse Practitioner, to provide my phone number, mailing address, and or email to Bill Dagg (or their research team delegate) for the sole purpose of having Bill Dagg contact me to learn more about the study entitled “*Parental/Patient Pain Management of Adolescent Post-Operative Inpatients After Discharge: A Qualitative Study*”

Even if I am contacted to find out more information about this study it does not mean that I have to take part in this study. The surgical team will not be told if I decide to take part or not take part. I understand that taking part is entirely voluntary (up to me). Should I decide to take part or, alternatively, should I decide that I am not interested; this decision will not affect the treatment that I receive from the CHEO in any way.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Person obtaining permission**

I have explained the nature of allowing permission to the teen (or parents) and judge that they understand that allowing the researcher to contact them in no way commits them to take part in the research.

Name: (Print) \_\_\_\_\_

Signature: \_\_\_\_\_ Position: \_\_\_\_\_

Date: \_\_\_\_\_

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With best wishes,

James G Jarvis MD

Division of Orthopaedic Surgery

Children's Hospital of Eastern Ontario

Ottawa, ON

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With best wishes,

---

Dr. Marcos Bettolli, MD

Physician, Department of Surgery

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With best wishes,

Dr. Claudia Malic

Plastic Surgeon, Department of Surgery,

Children's Hospital of Eastern Ontario,

Ottawa, ON

**Permission to release contact information**

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With best wishes,

Kevin Smit, MD, FRCSC

Pediatric Orthopedic Surgeon

Children's Hospital of Eastern Ontario

**Permission to release contact information**

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Name: (Print) \_\_\_\_\_

Signature: \_\_\_\_\_ Position: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix C

**Semi-Structured Interview Guide**

Thanks for agreeing to participate in this study about the experience of adolescents and parents of adolescents in post-operative pain care. This interview will take 30 - 60 minutes. If there are any questions that you do not want to answer, or if you want to stop at any time, please feel free. This interview is being audio recorded and will later be typed up but your name and anything that can identify will be removed before sharing with others. If you are not sure about what I am asking you, please do not hesitate to ask me any questions. Are you ready to start?

**Adolescent**

1. Can you tell me about yourself?
  - a. What age are you? What grade are you in, what do you like to do when you are not in school (hobbies, sports)?
  - b. What surgery did you have and when?
2. Can you tell me about your experiences with pain before your surgery?
  - a. Have you ever had any injuries that hurt?
  - b. What did you do to help with that pain?
3. Can you describe your experience with pain during your recovery from this surgery?
  - a. Are you experiencing pain now?
    - i. If no, how long did the pain last at home?
  - b. How would you describe the pain you have had since being home? (how strong, where, what it feels like)
  - c. Was the pain more or less than you expected at home?

4. How have you been looking after your pain since being home from the hospital?
  - a. What did you do to control your pain? Did this work when your pain was bad?
  - b. How did your parent's help you with your pain? Did this work when the pain was bad?
  - c. Was there anything other than medication that helped control your pain? If yes, what was it that helped? How?
5. What was the hardest part of dealing with the pain after surgery at home?
  - a. Was it more difficult to deal with the pain at home or at the hospital? Can you tell me a bit more about that?
  - b. Did you have any fears or concerns about pain medications? If yes, what were those fears or concerns?
  - c. Did you feel like the nurses and doctors helped you know how to take care of your pain before you left the hospital?
6. Is there anything that I did not ask that you would like to share with me about what it is like to have pain after your surgery?

**Parent**

1. Can you tell me about yourself and your child?
  - a. What age is your child? Do you have other children, what are their ages?
  - b. What surgery did your child have and when?
2. Can you tell me about your experiences with pain management before your child's surgery?
  - a. Has your child, or any of your other children, had any injuries or medical procedures that hurt?
  - b. What did you do to help with that pain?

3. Can you describe your experience with pain management during your child's recovery from this surgery?
  - a. Is your child experiencing pain now?
    - i. If not, how long did your child's pain last at home?
  - b. How would you describe it? (intensity, location, what it feels like)
  - c. How long did your child's pain last at home?
  - d. Was the pain after discharge more or less than you expected?
4. How have you been looking after your child's pain since they were discharged from the hospital?
  - a. What did your child do to help with their pain? Did this work when the pain was bad?
  - b. What did you do to help with your child's pain?? Did this work when the pain was bad?
  - c. Was there anything other than medication that helped with your child's pain? If yes, what was it that helped? How?
5. What was the hardest part of managing your child's the pain after surgery at home?
  - a. Was it more difficult to manage your child's pain at home or at the hospital? Can you tell me a bit more about that?
  - b. Did you have any fears or concerns about the pain medications? If yes, what were those fears or concerns?
  - c. Did you feel like you were well prepared to manage your child's pain at home at the time you were discharged from hospital?
6. Is there anything that I did not ask that you would like to share with me about what it is like to manage your child's pain at home after your surgery?

## Appendix D

**Ethics Documents**

## Transcriptionist Confidentiality Agreement



Université d'Ottawa University of Ottawa

Bureau d'éthique et d'intégrité de la recherche  
Office of Research Ethics and Integrity

**CONFIDENTIALITY OF INFORMATION AND CONFLICT OF INTEREST****AGREEMENT****THE UNIVERSITY OF OTTAWA RESEARCH ETHICS BOARD**

As a member of the research study: *Parental/Patient Pain Management of Adolescent Post-Operative Inpatients After Discharge: A Qualitative Study*, I understand that all discussions, deliberations, records, and other information generated in connection with this study is privileged information. I agree to respect and maintain the confidentiality of and to make no disclosures of such information, except to persons authorized to receive it such as Bill Dagg (Primary Investigator) or Paula Forgeron (thesis supervisor).

This includes, but is not limited to the following examples:

- I will not disclose information I have transcribed to any other individual otherwise indicated.
- I will not use any information gained during the transcription process to support purposes or initiatives outside of the above study.
- I will not alter or copy any information provided to me, unless during the transcription process.
- Following transcription sessions, I agree to dispose of any paper documents in a secure manner (e.g. 'confidential waste').

I will notify FIRST LAST NAME (PI) or FIRST LAST NAME (thesis supervisor) of any conflicts of interest or potential conflicts of interest that may exist with the study, and will excuse myself from the study if determined necessary.

By signing below, I agree to comply with the requirements as noted above.

\_\_\_\_\_

\_\_\_\_\_  
Name (please print)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_

\_\_\_\_\_  
Witness (please print)

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Participant Information

Name \_\_\_\_\_

Date of Birth \_\_\_\_\_

Gender \_\_\_\_\_

Contact

Phone Number \_\_\_\_\_

Email Address \_\_\_\_\_

Mailing Address \_\_\_\_\_

I hereby authorize the release of this information to the researchers for the expressed purpose of contacting me to provide more detailed study information, answer questions, and determine my interest in participating in the study.

Signature \_\_\_\_\_

Date \_\_\_\_\_

## CHEO Research Ethics Board Approval - Delegated Review

**Principal Investigator:** Mr. Bill Dagg

**REB Protocol No:** 18/25X

**Romeo File No:** 20180113

**Project Title:** CHEOREB# 18/25X - Parental/Patient Pain Management of Adolescent Post-Operative Inpatients After Discharge: A Qualitative Study

**Primary Affiliation:** Clinical Research

**Protocol Status:** Active

**Approval Date\*:** July 05, 2018

**Approval Expiry Date\*\*:** June 15, 2019

### Documents Reviewed & Approved:

| Document Name         | Comments                                                      | Version Date |
|-----------------------|---------------------------------------------------------------|--------------|
| Protocol              | Study Protocol v3 Clean                                       | 7/3/2018     |
| Consent Form          | Parental Consent Form clean v3                                | 7/3/2018     |
| Consent Form          | Patient Consent Form Clean v3                                 | 7/3/2018     |
| Questionnaire/Survey  | Interview Guide                                               | 2/27/2018    |
| Recruitment Materials | Study Invitation Letter - Orthopedics (Dr. Smith)             | 2/27/2018    |
| Recruitment Materials | Study Invitation Letter - Surgery (Dr. Marcos Bettolli)       | 2/27/2018    |
| Recruitment Materials | Study Invitation Letter - Ortho Surgery (Dr. Jarvis)          | 2/27/2018    |
| Recruitment Materials | Study Invitation Letter - Plastic Surgery (Dr. Claudia Malic) | 2/27/2018    |
| Assent Form           | Assent Form                                                   | 2/27/2018    |
| Consent Form          | Parental Consent on Behalf of Child clean                     | 6/13/2018    |
| Consent Form          | Verbal Consent Clean                                          | 6/13/2018    |

This is to notify you that the Children's Hospital of Eastern Ontario Research Ethics Board has granted approval to the above named research study on the date noted above. Your project was reviewed within the delegated stream, which is reserved for projects that involve no more than minimal risk to human participants.

Final approval is granted for the above noted study, with the understanding that the investigator agrees to comply with the following requirements:

1. The investigator must conduct the study in compliance with the protocol and any additional conditions set out by the Board.

2. The investigator is responsible for complying with all applicable guidelines and regulations regarding the ethical conduct of research with humans, as applicable to the research project.
3. Approval for studies that include an investigational device(s) is contingent upon the investigator securing an Investigational Testing Authorization notice from Health Canada.
4. Investigators must obtain annual renewal approval prior to the expiration date stated above.
5. The investigator must not implement any deviation from, or changes to, the protocol, consents or assents without the approval of the REB except where necessary to eliminate hazard to the research subject, or when the change involves only logistical or administrative aspects of the study (e.g., change of telephone number or research staff). As soon as possible, however, the implemented deviation or change, the reasons for it, and, if appropriate, the proposed protocol amendment(s) should be submitted to the Board for review and approval.
6. The investigator must, prior to use, obtain approval from the Board for changes to the study documentation, e.g., changes to the informed consent letters, recruitment materials.
7. Investigators must obtain approval from the Board of French version(s) of the consent/assent form(s), unless a waiver has been granted. An interpreter should be offered to participants as required or at the request of the participant throughout the course of research.
8. The investigator must promptly report to the REB all unexpected and untoward occurrences (including the loss or theft of study data and other such privacy breaches).
9. Investigators must notify the REB of any study closures (closed to accrual, temporary, premature or permanent).
10. Investigators must submit a study closure event form at the conclusion of the study.

Should you have any questions or concerns, please do not hesitate to contact the Research Ethics Board Office at 613-737-7600 ext. 3350 or 2128.

Regards,

**Richard Carpentier, PhD**  
Chair, Research Ethics Board  
Président, Comité d'éthique de la recherche

\* The final approval date for initial delegated study applications approved with or without modifications will be the date the REB has determined that the conditions of approval have been satisfied.

\*\* The expiry date of REB approval for initial study applications will be as follows:

- If the date of approval was **on or before** the 15th of the month, the expiry date will be the 15th of the month prior to the date of review and approval by the Chair and/or delegate *in the following year*;
- If the date of review and approval was **after** the 15th of the month, the expiry date will be the 15th of the month in which the date of review and approval by the REB *in the following year*.

24/08/2018

**Université d'Ottawa**

Bureau d'éthique et d'intégrité de la recherche

**University of Ottawa**

Office of Research Ethics and Integrity

**Lettre d'approbation administrative | Letter of administrative approval****Numéro de dossier / Ethics File Number**

H-08-18-905

**Titre du projet / Project Title**Parental/Patient Pain  
Management of Adolescent  
Post-Operative Inpatients After  
Discharge: A Qualitative Study  
Thèse de maîtrise / Master's  
thesis**Type de projet / Project Type**

CHEO / CHEO

**CÉR primaire / Primary REB**

Approuvé / Approved

**Statut du projet / Project Status****Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)**

24/08/2018

**Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)**

15/06/2019

**Équipe de recherche / Research Team****Chercheur / Researcher Affiliation****Role**

William DAGG

École des sciences infirmières / School of Nursing

Chercheur Principal / Principal Investigator

Paula FORGERON

École des sciences infirmières / School of Nursing

Superviseur / Supervisor

Julie CHARTRAND

École des sciences infirmières / School of Nursing

Co-chercheur / Co-investigator

**Conditions spéciales ou commentaires / Special conditions or comments:**550, rue Cumberland, pièce 154 550 Cumberland Street, Room 154  
Ottawa (Ontario) K1N 6N5 Canada Ottawa, Ontario K1N 6N5 Canada613-562-5387 • 613-562-5338 • [ethique@uOttawa.ca](mailto:ethique@uOttawa.ca) / [ethics@uOttawa.ca](mailto:ethics@uOttawa.ca)  
[www.recherche.uottawa.ca/deontologie](http://www.recherche.uottawa.ca/deontologie) | [www.recherche.uottawa.ca/ethics](http://www.recherche.uottawa.ca/ethics)

24/08/2018

## Université d'Ottawa

Bureau d'éthique et d'intégrité de la recherche

## University of Ottawa

Office of Research Ethics and Integrity

L'Université d'Ottawa a signé une Entente, conforme aux exigences de la plus récente version de l'EPTC et tout autre règlement ou législation applicable, permettant au CÉR ci-haut nommé d'être désigné comme CÉR primaire pour les projets de recherche où

1) les activités principales de recherche sont menées sous l'autorité ou sous les auspices de l'établissement lié au CÉR primaire et

2) Une partie du projet est également réalisé sous l'autorité ou sous les auspices de l'Université d'Ottawa.

Cette lettre confirme que l'Université d'Ottawa a autorisé que le CÉR primaire soit le CÉR officiel pour l'évaluation et la supervision de ce projet de recherche. Ceci n'est pas une approbation éthique.

Afin de nous aider à garder votre dossier à jour, veuillez soumettre une copie de toutes demandes de modification, renouvellement d'approbation éthique etc. soumis à et approuvé par le CÉR primaire dès qu'elles sont disponibles.

Cette approbation administrative est valide pour la durée indiquée ci-haut et est soumise aux conditions énumérées dans la section intitulée « Conditions spéciales ou commentaires ».

The University of Ottawa has signed an Agreement, compliant with current TCPS guidelines and any other applicable guidelines or legislation regarding multisite review, allowing the REB named above to serve as Board of Record (BoR) for research projects where

1) the main research activities are conducted within the auspices or jurisdiction of the BoR's institution and

2) parts of the project are also conducted under the jurisdiction or auspices of the University of Ottawa.

This letter confirms that the University of Ottawa has authorized the REB named above to serve as Board of Record for the review and oversight of this research project. This is not an REB approval.

In order to help us keep your file up to date, please submit a copy of all amendment requests, project renewals or any other changes submitted to and approved by the BoR, as they become available.

Administrative approval is valid for the period indicated above and is subject to the conditions listed in the section entitled «Special conditions or comments».

Catherine PAQUET

Directeur / Director

Pour/For **Daniel LAGAREC** Président(e) du/ Chair of the **Comité d'éthique de la recherche en sciences sociales et humanités / Social Sciences and Humanities Research Ethics Board**

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2018-102

**Data Sharing Agreement ("Agreement")  
Transfer of Data for Research Use**

|                                                                                                                                     |                                                                                                               |
|-------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|
| <b>BETWEEN:</b>                                                                                                                     | <b>AND</b>                                                                                                    |
| Children's Hospital of Eastern Ontario<br>Research Institute Inc. ("CHEO RI")<br>401 Smyth Road<br>Ottawa, Ontario, Canada, K1H 8L1 | University of Ottawa<br>3042-800 King Edward<br>Ottawa, Ontario<br>K1N 6N5<br>("Recipient Institution")       |
| <b>CHEO RI Investigator:</b><br>Dr. Paula Forgeron<br>(together with CHEO RI= "PROVIDER")                                           | <b>Recipient Investigator:</b><br>Dr. Paula Forgeron<br>(together with Recipient Institution,<br>"RECIPIENT") |

**Name of Study ("Study"):** Parental/Patient Pain Management of Adolescent Post-Operative Inpatients After Discharge: A Qualitative Study

**CHEO RI REB Number:** 18/25X

**RECIPIENT REB Number:** H-08-18-905

**Data to be provided:** De-identified data per the REB approved Study Protocol, incorporated herein by reference ("Data").

This Agreement, effective as of the last date of signature below, is entered into between the parties to govern the transfer of the Data from PROVIDER to RECIPIENT for use in the Study, in compliance with applicable laws. PROVIDER retains the right to refuse transfer of the Data requested.

CHEO RI Investigator will prepare and furnish to RECIPIENT the Data in accordance with Ontario's *Personal Health Information Protection Act*. Transfer of the Data by PROVIDER to RECIPIENT will be in compliance with REB approved subject informed consent forms ("ICFs") or terms of an REB Waiver of Consent ("REB Waiver"), as applicable (incorporated herein by reference). The parties shall use a secure method of provision of the Data by PROVIDER to RECIPIENT. Data will not be transferred until each party's REB provides written approval for the Study, to the extent required by their respective REBs. RECIPIENT will not use Data until RECIPIENT receives a copy of the PROVIDER's REB approved ICF or REB Waiver, as applicable.

RECIPIENT shall use the Data in compliance with all applicable laws; and shall specifically only use or disclose the Data for the conduct of the Study in accordance with the permitted uses of the Data specified in the applicable ICFs or REB Waiver, or otherwise as required by law. All Data is owned by CHEO RI. No right, title or interest in and to the Data is granted or implied to RECIPIENT hereunder.

RECIPIENT and PROVIDER shall have the right to use (1) the analyzed, de-identified data derived from the use of the Data, and (2) de-identified results arising out of analysis of the Data, as part of a publication or presentation of the results of the Study. No personally identifying information shall be included in any publication or presentation of Study results. PROVIDER and RECIPIENT shall coordinate publication of the results of the Study and appropriate authorship of any such publication shall be in accordance with International Committee of Medical Journal Editors (ICMJE) guidelines.

RECIPIENT shall use appropriate safeguards to prevent any unauthorized use or disclosure of the Data and shall immediately report to the PROVIDER any unauthorized use or disclosure of which RECIPIENT becomes aware, or of any breach of this Agreement. RECIPIENT shall not use the Data to identify or contact the individuals from whom such Data was collected. RECIPIENT shall securely destroy the Data as required by the Protocol or the PROVIDER and shall provide a written confirmation of the manner of destruction in a form acceptable to PROVIDER. PROVIDER may conduct audits of the RECIPIENT concerning the maintenance of appropriate security safeguards to ensure compliance with this Agreement.