

PARENT/CAREGIVER INVOLVEMENT TO MANAGE PAIN IN CHILDREN WITH
ACUTE LYMPHOBLASTIC LEUKEMIA

by

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DEDICATION

This thesis is dedicated to my family, fellow coworkers, patients and their families. To my husband, Tom who has been supportive of my professional goals. To my daughter Maryn and son Cameron who have taught me the importance of balancing work, family and education. To my father, who has always supported and encouraged me to pursue my goals. To my colleagues including physicians and fellow nurses who have supported me in achieving my personal and educational goals.

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ABSTRACT

Children with Acute Lymphoblastic Leukemia experience pain from the disease, treatment and procedures. Parents can be effective in managing their child's pain but little is known about how they learn to do this.

This study was framed by Appreciative Inquiry (Cooperrider, 2008) and Interpretive Descriptive methods (Thorne, 2008) were used to describe: pain sources, parents' pain care role, and key structures supporting their pain care involvement. Eight clinic nurses and ten parents participated and six key themes per group were identified. Parent themes included: *establishing therapeutic relationships, relearning how to care for my child, overcoming challenges and recognizing pain, learning parent specific strategies, empowered to take active pain care role, and maintaining relationships*. Nurse themes included: *establishing relationships, preparing parents to care for their child, facilitating pain assessment, teaching parents best pain care, empowering parents, and maintaining relationships*. These findings can be used to guide clinical practice and future research.

LIST OF ABBREVIATIONS USED

AI	Appreciative Inquiry
ALL	Acute Lymphoblastic Leukemia
BMA	Bone Marrow Aspiration
FCC	Family Care Coordinator
IASP	International Association for the Study of Pain
LP	Lumbar Puncture
NSAID	Nonsteroidal Anti-Inflammatory Drug
PARIHS	Promoting Action on Research Implementation in Health Services
PI	Principal Investigator
SCMP	Social Communication Model of Pain
STIP	Sensitivity Temperament Inventory for Pain
WHO	World Health Organization

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Chapter One: Introduction

Background of the Problem

Between 2003 and 2007 4,300 Canadian children were diagnosed with cancer and the most common diagnosis, leukemia, accounted for 34% of all new diagnoses (Canadian Cancer Society, Statistics Canada, Public Health Agency of Canada, Provincial/Territorial Cancer Registries, & Public Health Agency of Canada, 2013). Pediatric cancer treatment regimes have made significant gains since the 1960's when most children with cancer were predicted to face death (Patenaude & Kupst, 2005). With improvements in treatment protocols, 5-year childhood cancer survivor rates are as high as 90% in children with leukemia and are predicted to increase in the future with the development of more advanced treatment regimens (Canadian Cancer Society et al., 2013; Inaba, Greaves, & Mullighan, 2013). Because most children are now surviving from cancer, the focus of treatment has transitioned from purely cure-based to understanding the short and long-term impact of cancer treatment on both the child and family involved (Patenaude & Kupst, 2005; Rheingans, 2007). While most children survive from cancer, symptoms at diagnosis frequent medical procedures and treatment side effects can be difficult for the child and family to endure.

Specifically, pain experienced by children with cancer has been recognized as a significant source of parental and child stress (Pöder, Ljungman, & von Essen, 2010). Present pediatric Acute Lymphoblastic Leukemia (ALL) treatment regimes range from two and a half to three and a half years during which time children are exposed to multiple sources of pain including the disease, treatment side effects, and medical/diagnostic procedures (Bossert, VanCleve, Adlard, & Savedra, 2002; Liossi,

2002; Marchesse et al., 2008; McGrath et al., 1990; Redaelli, Laskin, Stephens, Botteman, & Pashos, 2005; Van Cleve et al., 2004). Many parents perceive pain to be one of the most problematic symptoms experienced by their child during cancer treatment (Heden, Poder, von Essen, & Ljungman, 2013; Pöder et al., 2010) and children report the pain associated with cancer treatment and medical procedures to be more distressing than pain resulting from the disease itself (Cline et al., 2006; Hedström, Haglund, Skolin, & von Essen, 2003; Hedström, Ljungman, & von Essen, 2005; Ljungman, Gordh, Srensen, & Kreuger, 2000; Vaudre et al., 2005). As a result, pain management is one aspect of pediatric cancer care that has received increased recognition by researchers and clinicians. In addition, with changes in health care economics, the care of children with ALL has transitioned from inpatient care to most treatment and follow-up being done in the ambulatory care setting (Fortier et al. 2012). This shift from hospital to ambulatory care places parents in a position where they are largely responsible for assessing and managing their child's pain but how parents manage this symptom burden is not documented in the literature.

Many children with ALL begin their cancer experience with significant pain resulting from the disease process with reports that as many as 22-38.3% of these children present at diagnosis with musculoskeletal pain (Ricchio et al. 2013; Sinigaglia et al. 2008). Reports also indicate that up to 16 % of children with ALL develop vertebral compression fractures one half of which are moderate to severe (Halton et al., 2009). In addition, treatment protocols expose these children to ongoing pain from treatment side effects and medical procedures (Jacobsen et al., 1990; Kuppenheimer & Brown, 2002). The ALL pain experience presents a significant symptom burden for the child and parent

involved and reports indicate that up to 64% of childhood leukemia diagnoses have required referrals to specialized pain services (Geeta et al., 2010).

In the 1980's the negative impact of pain experienced by children with cancer became more recognized by researchers and clinicians but we did not have the evidence that we have now to help us reduce pain. During the last several decades knowledge regarding pain management in children has grown exponentially, and as a result, there is strong evidence to support the use of both pharmacological and non-pharmacological strategies to reduce the negative impact of child pain. In addition, this empirical evidence has been integrated into international, national and hospital standards and guidelines (Berry & Dahl, 2000; Canadian Pain Society, 2005; Gordon et al., 2005). Despite these gains in our knowledge about how to assess and manage pain in hospitalized children, numerous reports indicate there is still room for improvement (Ellis et al., 2002; Taylor, Boyer, & Campbell, 2008; Vaudre et al., 2005; Cline et al., 2006; Ljungman et al., 2000; Pöder et al., 2010; Stevens et al., 2011; Stevens et al., 2012) and translating the information is the main issue. The issues point to the need to target all key stakeholders in the translation of evidence-based pain strategies.

In addition, researchers report variability in individual children's pain responses with evidence that some children cope better than others when experiencing similar types of pain (Broome, Rehwaldt, & Fogg, 1998; Chen, Zeltzer, Craske, & Katz, 2000; Cline et al., 2006; Dahlquist et al., 2002; Spagrud et al., 2008). For example, Spagrud et al. (2008) reports wide variability in children's self-reported pain ratings during routine cancer procedures with some children rating low pain (0-2/10, n=11) while other children rate severe pain (8-10/10, n=3) for the same procedure. As a result, it is also necessary to

consider factors that may contribute to individual differences in children's pain. These differences in pain experiences are likely related to a combination of individual child (previous pain, age, cognitive development, sex, anxiety, temperament and coping style), caregiver (parent/caregiver, health care professional) and contextual (parent health care professional interactions, adequate pain management) factors.

Children with ALL receive the majority of their treatment and follow-up in an outpatient setting placing parents in a key position to assess, manage, and advocate for appropriate pain management. Despite parents being in an important caregiving role, limited research has examined parents' actual role in managing children's pain during the treatment of ALL. The majority of research involving the role of parents in oncology pain care has primarily focused on their role during medical procedures and has not examined their role to relieve other significant sources of cancer and treatment related pain. Specific to parents' role during children's medical procedures, researchers have found that what parents do, in response to observing their child in pain, significantly influences pain outcomes.

In addition to assuming medical caregiving roles during a child's ALL treatment, parents have a wealth of experience observing and perceiving pain in their child before diagnosis and as a result are in an optimal position to interpret and react to their children's pain cues (Lynch, Kashikar-Zuck, & Goldschneider, 2010). As a result, parents are key stakeholders that should be considered in our attempts to adequately manage children's pain.

Statement of the Problem

In summary, children with ALL experience a significant pain burden and recent evidence suggests that despite improvements in pain care knowledge, hospitalized Canadian children suffer from inadequate pain assessment and management (Stevens et al. 2012; Stevens et al., 2011). As a result, knowledge translation strategies should focus attention on the role of all key stakeholders, including parents, in the application of pain care evidence. Specifically, parents of children with ALL are in a key position to assess and manage their child's pain but little is known about how they actually manage this symptom burden. Some researchers suggest parents can learn to apply strategies such as distraction during procedures but there is limited guidance regarding parents' actual pain care role during the whole leukemic treatment trajectory.

To better understand and improve parent's pain care role, key stakeholders including parents and nurses should be included in the acquisition and application of knowledge. In this study, the Social Communication Model of Pain (SCMP) was used to describe the child in pain and situate the role of parents in managing children's pain. The SCMP was selected because it is the most comprehensive model that captures the complex interactions between the child, parent and environment in which the child experiences pain. Another theoretical framework that fits well within the SCMP is Appreciative Inquiry (AI) (Cooperrider et al. 2008). AI was used in the present study to frame the research questions using a strengths based approach. There is evidence that parents may be frustrated with their limited passive pain care role (Roberson et al. 2001) and although this research provides important information, there is no constructive way to move forward and improve practice. The current study recognizes that parents may be

challenged in participating in their child's pain care, but, also recognizes that there are strengths that already exist. AI is an innovative framework that has been used to gain knowledge and facilitate positive change in various clinical environments and is based on the premise that every clinical environment and/or social context has existing strengths and processes that work (Cooperrider, Whitney, & Stavros, 2008). If individuals within this environment identify and focus on these existing strengths instead of deficiencies, then improvements are likely to occur as a result. In other words, there are positive pain relieving experiences as a result of parent's involvement and use of evidence-based strategies. By identifying and describing the facilitators of these positive experiences using AI, improved child coping and reduction in one of the most reported distressing symptoms experienced by children with cancer may occur as a result.

Purpose of the Study

The primary purpose of this study was to provide parents of children with ALL and their nurses the opportunity to describe independently, using an Appreciative Inquiry (AI) approach, what parents do well to relieve their child's pain during treatment. A second purpose was to use these descriptions to develop a list of recommendations that may be useful for parents of children undergoing ALL treatment and their nurses.

Research Questions

- 1) What do parents of children with ALL and their nurse's independently prospectively describe as actual and potential sources of pain experienced during treatment?

- 2) What do parents of children with ALL and their nurses describe independently as effective strategies that parents use or can use to relieve pain during treatment?
(AI Cycle-Discovery)
- 3) What do parents of children with ALL and their nurses independently recognize as parents' ideal role in managing child pain during treatment? (AI Cycle-Dream)
- 4) What do parents of children with ALL and their nurses independently identify as key strategies, structures and processes that can be implemented to effectively support parental involvement in managing child pain during treatment (AI Cycles-Design/Destiny)

Chapter Two: Literature Review

Epidemiology of Pain in Hospitalized Children

Despite advancements in pain care evidence, reports indicate that optimal assessment and management strategies are not routinely used in pediatric health care settings (Ellis et al., 2002; Ellis, Sharp, Newhook, & Cohen, 2004; Kozlowski et al., 2012; Stevens et al., 2012; Stevens et al., 2011). In a recent Canadian multisite study, pain-related data from 3822 pediatric inpatient charts, including children receiving care for oncology diagnosis, during a 24-hour period were collected and results from this study highlight the need for improvements in pain assessment and management practices in pediatric hospitals. Specifically, only 28.7% of children (n = 3822) had a documented pain assessment using a validated tool and of these children, 33% reported moderate to severe pain (Stevens et al., 2012). Results from this study also highlight the status of procedural pain management as chart audits found most (78.2%) hospitalized children had undergone at least one painful procedure (mean of 6.3/child who had a procedure) during a twenty four hour period. Of these children, only 28.3% had a documented pain management strategy (84.8% pharmacological, 26.1% physical, and 25 % psychological intervention). This recent large-scale national study provides important information about the present state of pain assessment and management practices in Canadian pediatric hospitals and highlights the need for improvements.

Pain in children with acute lymphoblastic leukemia (ALL). Children with ALL experience a significant pain burden as a result of the disease, treatment side effects, and medical procedures. As mentioned earlier, a substantial proportion of children with ALL present at diagnosis with significant bone pain as a result of the disease process

(Riccio et al. 2013; Sinigaglia et al. 2008). The prevalence of pain in children with ALL is documented in a 1-year longitudinal study that found most (n = 96) children with ALL regardless of age (4-17 years) reported significant pain, with average pain intensity scores in the moderate range, during all of the seven data collection points (Van Cleve et al., 2004). The most common pain locations reported included legs (26.5%) abdomen (16.6%), head/neck (16.6%) and back (14.2%). These pain locations are commonly related to treatment drug side effects and complications related to medical procedures such as lumbar punctures e.g. lumbar headache and/or bone marrow aspirations. Leg pain in leukemia is common and is often related to the administration chemotherapy drugs including vincristine that is known to contribute to the development of peripheral neuropathy. The presence of abdominal pain may be associated with chemotherapy drugs and/or other treatment drugs (e.g. prednisone). This study highlights the common experience of enduring pain during the extensive treatment of childhood ALL.

In addition to disease and treatment related sources of pain, children with leukemia experience pain from numerous tissue damaging procedures including capillary blood draws, venepuncture, central line access, lumbar puncture, and bone marrow biopsy/aspiration (Lioffi, 2002). The diagnosis and initial treatment phases are typically characterized by frequent and repeated procedures. Specifically, during the first five weeks of induction treatment, children with standard risk ALL undergo a minimum of two bone marrow aspirations, three lumbar punctures, and five central line accesses for blood work and chemotherapy administration (Children's Oncology Group, 2010). This minimum number of procedures does not include those required to treat common treatment side effects for example the development of fever, infection, anemia, or

thrombocytopenia. These tissue damaging procedures are stressful for both the parent and child involved and may contribute to child distress, parent anxiety and in some cases have been associated with symptoms of post-traumatic stress disorder in both the child and parent involved (Pöder et al., 2010; Rennick et al., 2004; Stuber et al., 2010).

Vancleve et al.'s (2004) longitudinal study did not address or report the actual incidence of procedural pain. An early study by McGrath et al. (1990) reported that many children reported moderate to severe pain from bone marrow aspirations (73%), lumbar punctures (62%), and venepunctures (59%). Since this early study, there have been substantial gains in procedural pain care knowledge and practice and as a result recent evidence suggests that many children now benefit from procedural sedation for bone marrow aspirations and lumbar punctures (Barbi et al., 2005; Ellis et al., 2003; Hockenberry et al., 2011; Po' et al., 2012). In addition, most children with ALL now have a semi-permanent venous line (port-a-cath) surgically inserted at diagnosis. Although the insertion of this semi-permanent venous access device decreases the number of required venepunctures', frequent needle punctures are still needed to access and use this device throughout a child's treatment.

In summary, despite advancements in pain care knowledge, reports indicate that pain in hospitalized children is poorly assessed and managed. Children with cancer are not immune to the practice of unmanaged pain and reports indicate that many children with leukemia report moderate levels of pain during the first year of cancer treatment. In addition, this gap in pain management practice is concerning for children with ALL because they experience a significant pain burden over an extensive treatment period. As a result, it is important to investigate strategies that involve all key stakeholders,

including the parent and health care professionals involved in supporting parent's pain care role. Specifically parents may have a heightened interest and desire to alleviate suffering in their own child and are in a key position to apply and advocate for pain care strategies to support their child.

Strategies to Manage Pain

Pain is a complex multidimensional phenomenon influenced by cognitive, emotional and social factors (Craig, 2009; McCarthy & Kleiber, 2006; McCarthy, Kleiber, Hanrahan, Zimmerman et al., 2010; Weisman, Bernstein, & Schechter, 1998). The most widely accepted definition states that pain is a subjective “unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (International Association for the Study of Pain, 2009). Traditional biomedical approaches to pain management emphasize sensory physiological mechanisms for pain and fail to highlight the importance of cognitive, emotional and social environmental factors. In order to adequately manage pain, strategies should focus on physical, cognitive, emotional and social environmental factors that influence pain. As a result, researchers have investigated and have established effective pharmacological strategies to target physiological mechanisms of pain and non-pharmacological strategies to target cognitive and emotional aspects associated with pain.

Pharmacological strategies to manage leukemia and treatment related pain.

The gold standard for the pharmacological management of leukemia and treatment related pain involves the use of the World Health Organization's (WHO) analgesic stepladder for pain management (Chauhan, Weiss, & Warriar, 2010; Geeta et al., 2010; Zernikow et al., 2006). This framework provides clinicians with a stepwise evidence-

based approach to prescribing and administering analgesics to relieve cancer and cancer related pain (Neal, 2012). The main goal is to proceed along this ladder using analgesics and adjunctive medications until adequate pain control is achieved. The first step in the ladder is used to manage mild pain and includes non-opioid analgesics such as acetaminophen. Non-steroidal anti-inflammatory (NSAID) medications are also included within the first step but they are not routinely used in children with cancer because they pose a risk for bleeding, gastric and renal injuries (Chauhan et al., 2010). The second step in this analgesic ladder is used to manage moderate levels of pain and includes a combination of step one non-opioid and weak opioids for example acetaminophen with codeine. The third step in this ladder is used to guide management of severe pain and includes strong opioids such as morphine.

Pharmacological strategies to manage procedure pain. In addition to using the WHO step ladder there are pharmacological strategies to manage pain associated with tissue damaging procedures including topical/local anaesthetics (emla/ametop/lidocaine) to numb the skin prior to needle puncture (Bishai, Taddio, Bar-Oz, Freedman, & Koren, 1999; Galinkin, Rose, Harris, & Watcha, 2002; Miser et al., 1994; Rogers & Ostrow, 2004; Stinson, Yamada, Dickson, Lamba, & Stevens, 2008; Taddio, Robieux, & Koren, 1992), and the administration of sedation in combination with topical/local anaesthetics for more invasive cancer procedures (bone marrow aspirations, lumbar punctures) (Broome et al., 1998; Holdsworth et al., 2003; Kuppenheimer & Brown, 2002).

Specifically, topical anaesthetics are efficacious for decreasing pain during venepunctures (Rogers & Ostrow, 2004), immunizations (Cohen, Blount, Cohen, Schaen, & Zaff, 1999), subcutaneous injections (Taddio et al., 1992), intravenous insertions

(Galinkin et al., 2002), and port-a-cath accesses (Bishai et al., 1999; Miser et al., 1994). Despite strong evidence to support the use of topical anaesthetics, reports indicate that this strategy is not widely used in practice. One study found that only 19% of children's needle related procedures during a twenty day period were managed with a topical anaesthetic, the majority of these procedures occurred on the oncology unit (Ellis et al., 2004). There is evidence to suggest topical anaesthetics may be used more frequently in children with cancer with reports that up to 70 % of Canadian pediatric oncology centers use topical anaesthetic at least "some" of the time (Ellis et al. 2003).

In addition to the above needle related procedures, children with ALL also undergo frequent invasive bone marrow aspirations, bone marrow biopsies and lumbar punctures. These procedures, in the absence of pain management, contribute to high levels of pain and distress. Optimal pharmacological management for these procedures consists of a combination of topical/local anaesthetics and moderate/deep sedation (Hockenberry et al., 2011). Fortunately, most pediatric institutions have adopted sedation policies to manage pain and distress associated with these invasive procedures (Barbi et al., 2005; Ellis et al., 2003; Po' et al., 2012). The main goal of sedation is to decrease a child's anxiety and pain during the procedure phase but does not target fear and distress that may result leading up to a procedure. Specifically, Barbi et al. (2005) found that up to 57 % of children with leukemia reported pre-procedural distress and 65% pre-procedural fear prior to undergoing sedated bone marrow aspirations and/or lumbar punctures. In addition, up to 27 % of these children exhibited behavioural distress symptoms pre-sedation. Although sedation protocols are effective for decreasing pain and distress during the actual tissue damaging experience, many children still experience

anticipatory anxiety, fear and distress leading up to the procedure (Dufresne et al., 2010; Hockenberry et al., 2011) and may still benefit from strategies to target the psychological impact of the procedure. In addition, sedation does not manage pain that may result after the procedure including pain at the bone marrow and lumbar puncture sites, and the development of a lumbar headache.

The role of gate control theory in minimizing pain. In addition to pharmacological strategies, researchers have established a strong evidence base to support the use of non-pharmacological strategies to manage children's cancer related pain. The main goal of a non-pharmacological strategy is to target and modify an individual's psychological response to a painful situation (Twycross, Dowden, & Bruce, 2009). Specifically non-pharmacological strategies "reduce pain by activating cognitive controls that influence emotions and beliefs about pain and [provide] a stimulus that competes for attention with the painful stimulus thereby reducing pain perception" (Jacobson, 2006, p. 1032). The gate control theory provides the best explanation for how pain is processed and interpreted and it provides insight into understanding the physiological mechanism of psychological strategies.

The gate control theory is based on the premise that the "brain is an active system that filters, selects, and modifies inputs" such as pain (Melzack & Wall, 1965). This gate can be modified (by opening or closing) to allow or block the transmission of painful stimuli. There are several mechanisms that may close the pain gate and result in decreased pain perception and these include: modifying the pain signal (e.g. pharmacological management), adding competing signals (e.g. massage, heat/cold) and increasing the descending signals from the central nervous system (e.g. distraction)

(MacLaren, Cohen, Larkin, & Sheldon, 2008). Non-pharmacological strategies provide a competing physiological or cognitive stimulus that the central nervous system must filter. During this filtration process, the central nervous system gate must select which stimulus to process, the pain or the non-pharmacological strategy. If a child is anxious, fearful and/or focused on his/her pain the gate will open and allow full pain transmission and the child will experience heightened levels of pain as a result. In contrast, if a child is fully engaged in a non-pharmacological strategy such as distraction, the “gate” will process and allow the transmission of this descending cognitive stimulus and the end result will be decreased transmission of the actual pain stimulus. The gate control theory provides the best explanation for why non-pharmacological mechanisms are effective in managing pain in children.

Non-pharmacological pain strategies. Keeping in mind the underlying mechanism of the gate control theory, there is a large body of evidence to support the use of distraction and hypnosis to improve children’s procedural pain outcomes (Canadian Pain Society, 2005; Gordon et al., 2005; Koller & Goldman, 2012; Landier & Tse, 2010; Stinson et al., 2008; Uman et al., 2013). Both a recent Cochrane Review (Uman et al., 2013) and a summary of systematic reviews (Stinson et al., 2008) report adequate evidence to support the use of distraction and hypnosis to decrease procedural pain and distress in children but they suggest that future research should focus on ways parents can incorporate and use these strategies in practice. Specific to children with cancer, several reviews also support the use distraction and hypnosis during children’s tissue damaging cancer procedures (Landier & Tse, 2010; Rheingans, 2007). Although hypnosis is a

highly effective pain management strategy in children, it requires intensive training and is not easily learned and applied by parents.

Distraction is the most commonly reported non-pharmacological strategy used to manage pain in children and this is an appropriate method to involve parents. The main goal of distraction is to direct a child's attention away from the pain experience (Carlson et al. 2000; Cassidy et al. 2002; Kleiber & Harper, 2006; McCarthy, & Kleiber, 2006) and can be applied by actively or passively redirecting a child's attention away from the pain experience. Specifically, active distraction typically includes several sensory components and includes strategies that encourage a child to actively participate in an activity unrelated to the pain. Active forms of distraction may include the use of interactive toys, counting, deep breathing non-procedural talk, imagery and relaxation (Koller & Goldman, 2012). Passive forms of distraction use external stimuli to shift the child's attention away from the pain and may include the use of music and audio-visual distraction (Koller & Goldman, 2012). Evidence suggests that children of all ages can benefit from using distraction but younger children tend to respond better to passive strategies while older children respond more to active strategies. In addition, distraction strategies should be tailored based on a child's preference and stage of cognitive development (Cavender, Goff, Hollon, & Guzzetta, 2004; Dahlquist, 2002; Koller & Goldman, 2012)

The efficacy of distraction during medical procedures is well established but to date there is limited research to support its use to relieve cancer and treatment related pain. Despite limited evidence, several studies report that children with leukemia commonly use various forms of distraction to assist with the management of non-

procedure cancer pain but the actual effectiveness of distraction in these instances was not measured (Van Cleve et al., 2004). As a result further research is needed to explore the efficacy of distraction as a pain relief method for non-procedure pain in children with cancer.

Several other non-pharmacological pain strategies documented in the literature include thermal heat/cold therapy and massage but there is limited evidence to support the use of these two modalities to reduce pain in children with leukemia (Field et al., 1997; French, Cameron, Walker, Reggars, & Esterman, 2006; Neal, 2012; Post-White et al., 2009). French et al. (2006) explored the use of both heat and cold therapy as a pain relief method in individuals experiencing low back pain and found that heat significantly decreased pain while cold therapy had little effect. Post-White et al. (2009) explored the effectiveness of massage as a pain relief method in children with cancer and found that massage did not significantly decrease pain. These researchers suggest that massage may not be the best strategy to alleviate pain in children with cancer. Despite little evidence to support the use of thermal modalities and massage as pain relief methods, several reports indicate that children with cancer do use these strategies to relieve and cope with pain (Bossert et al. 2002; Vancleve et al. 2004). Although massage and thermal therapies may be beneficial for managing pain in children with cancer, evidence is weak and further research is warranted.

Impact of Unmanaged Pain

If health care providers and parents fail to use evidence-based pain care strategies in practice then children are vulnerable to numerous short and long-term negative consequences including the development of sleep disturbances, decreases in healing,

immune function, and mobility, increases in fear, anxiety, and distress (Twycross et al. 2009). In addition, previous experiences with poorly managed pain have also been linked to non-compliance with medical regimes, avoidance of medical care (Pate et al. 1996), symptoms of post-traumatic stress disorder (Rennick et al. 2004; Stuber et al. 2010) and poor pain tolerance and future responses to pain (Bijttebier & Vertommen, 1998; Chen, Craske, Katz, Schwartz, & Zeltzer, 2000; Weisman, et al., 1998; Young, 2005). There is also increasing evidence to suggest that poorly managed pain can contribute to the development of chronic pain that is more complex and difficult to treat (Berry & Dahl, 2000; Sun-ok & Carr, 1999).

Unmanaged pain may also result in long-term psychological distress and in some cases may contribute to symptoms of post-traumatic stress disorder. Rennick et al. (2004) found that children's exposure to invasive medical procedures, during an ICU admission, was one of the most significant predictors for long-term psychological distress. Specific to children with cancer, Stuber et al. (2010) surveyed 6542 adult childhood cancer survivors and found that treatment intensity was a significant predictor for the development of post-traumatic stress disorder. Although in this study, pain and procedure exposure were not reported, intensive treatment is likely to result in more treatment side effects, pain and medical procedures.

In addition, the need for early pain management in children with ALL is essential as reports indicate that children's memories of early pain experiences influence coping during subsequent pain experiences (Bijttebier & Vertommen, 1998; Chen et al., 2000; Cohen et al., 2001; Weisman, et al., 1998). In other words if a child's pain is inadequately

managed the negative memory of this distressing experience may contribute to heightened levels of distress and poor coping in the future.

In summary, children with ALL experience pain from multiple sources over an extended treatment period and in turn are vulnerable to the many negative consequences of pain. As a result, it is important to use a multi-modal treatment approach to incorporate optimal pharmacological and non-pharmacological pain management strategies early in cancer treatment in order to minimize the associated short and long-term negative outcomes.

Social Communication Model of Pain (SCMP)

The traditional biomedical approach to understand pain emphasizes biological processes, signs and symptoms of disease and treatment strategies to alleviate and treat the underlying physiological cause of the pain (Craig, 2009; Craig, Lilley, & Gilbert, 1996). This traditional biomedical approach ignores important social and contextual factors that contribute to variability in individual pain experiences. The Social Communication Model of Pain (SCMP) was designed to explore the nature of both cognitive and social factors and their influence on the child in pain and caregiver interpretations and reactions to observing the child in pain (Appendix A). The SCMP (Craig, 2009; Craig et al., 1996) conceptual framework was used to situate the important role of the parent in managing child pain. This model was selected because it is the most comprehensive framework available that considers both the child in pain, and the role of a parent/caregiver. For the purpose of this study the caregiver was referred to as the parent and defined as a caregiver, or guardian who identified him or herself as taking on an active role in caring for a child's regular medical needs in and out of hospital.

The SCMP is a comprehensive approach used to understand differences in individual pain experiences. Specifically, this model looks beyond the individual child in pain and considers the role individual child and parent factors and their interaction within the complex social environment in which pain is experienced. The role of parents is important as they are in a key position to provide or withhold comfort measures to alleviate child pain. This model presents a linear sequence of events that begins with the initial presentation of pain/physical trauma experienced by the child, which results in the child's perception, interpretation, and subsequent pain expression (behavioural, verbal self-report, physiological indicators). The parent observes the child in pain and develops an interpretation subsequently reacts according to this interpretation. Parent reactions have the potential to either improve or worsen a child's pain experience. If parent behaviours are positive (e.g. administer/apply/advocate for pain management strategies) then the child's pain may be low; if parent reactions are negative (e.g. withhold pain strategies, reassurance) then the child may experience high levels of pain and distress as a result.

These child-parent interactions are influenced by child and parent interpersonal and intrapersonal factors. Intrapersonal factors include influences specific to the individual and intrapersonal factors consider influences within the social environment. Child intrapersonal factors may include patterns developed from previous pain experiences, levels of anxiety/distress and biological factors such as age, cognitive development, temperament, sex, coping style, and culture. Child interpersonal factors consider variables in the social environment and may include adequate pharmacological and non-pharmacological pain management, and the presence of a supportive or

unsupportive parent. These intrapersonal and interpersonal factors are important and ultimately influence a child's pain and ability to cope when experiencing pain. Similarly, parent's observations, interpretations and reactions to a child's pain are also strongly influenced by parent's intrapersonal (values/beliefs, culture, emotional responses) and interpersonal (opportunities to participate and support child, role negotiation with other health care team members) factors.

Child factors. Consistent with the SCMP (Craig, 2009), several child factors that influence individual pain experiences include child's history of previous pain, age, cognitive development, temperament, sex, coping style and culture. Children's initial experiences with pain influence their reactions and ability to cope with subsequent pain experiences. Specifically, children with high levels of anxiety, fear, distress and pain during a single pain experience may develop exaggerated memories of this experience and may exhibit higher levels of anxiety, fear and distress with subsequent experiences (Bijttebier & Vertommen, 1998; Chen et al., 2000; Frank, Blount, Smith, Manimala, & Martin, 1995; Kleiber, Craft-Rosenberg, & Harper, 2001; Weisman, et al., 1998). These results reconfirm the need to appropriately manage pain early in ALL treatment because these initial experiences influence attempts to manage pain and children's responses to pain in the future.

Child age and cognitive development may also influence children's pain. Specifically, there is a large body of evidence reporting a strong positive association between child age and pain coping and as a result younger children are predicted to experience high levels of fear (Carlson, Broome, & Vessey, 2000; Duff, 2003; Matziou, Vasiliki Chrysostomou, Anthi Vlahioti, Efrosyni Perdikaris, Pantelis, 2013), behavioural

distress (Carlson et al., 2000; Dahlquist, 2001; Dahlquist, Power, Cox, & Fernbach, 1994; Duff, 2003; Fanurik, 2000; Humphrey, Boon, van Linden van den Heuvell, & van de Wiel, 1992; Kazak, Penati, Brophy, & Himmelstein, 1998; Mc Carthy et al., 2010; Miller, Johann-Murphy, & Zhelezniak, 2001) and pain (Carlson et al., 2000; Ljungman et al., 2000; Matziou, Vasiliki Chrysostomou, Anthi Vlahioti, Efrosyni Perdikaris, Pantelis, 2013) when compared with older children. Understanding children's developmental stage may provide context to why these age differences exist (Esteve & Marquina-Aporte, 2011). Specifically, children aged two to seven years, in Piaget's preoperational stage of development, are not able to distinguish between the cause and effect relationship of pain and may view pain as a punishment for something they have done and may become highly distressed when in pain (Lioffi, 2002). In contrast, older children have a greater understanding of what is happening and why they are experiencing pain and may experience less anxiety and distress as a result. Older children may also be better equipped developmentally to adopt and apply appropriate coping strategies to distract themselves from unpleasant pain experiences (Esteve & Marquina-Aporte, 2011). As a result, young children typically show less adaptive pain coping and may benefit from interventions to promote coping.

Temperament is another child factor that influences individual responses to pain. Temperament is considered stable and concerns the way in which an individual behaves and reacts to external stimuli such as pain (Bustos, Jaaniste, Salmon, & Champion, 2008). In the context of pain, temperament influences a child's sensitivity and reaction to pain (Chen, Craske, Katz, Schwartz, & Zeltzer, 2000; Ranger & Campbell-Yeo, 2008). There are several dimensions that make up an individual's temperament including activity level,

rhythmicity, approach or withdrawal, adaptability, intensity of reaction, quality of mood, attention span and persistence, distractibility, and threshold of responsiveness. In a recent systematic review, researchers found that all temperament dimensions influence individual pain responses but activity and mood were reported more consistently (Ranger & Campbell-Yeo, 2008). Temperament and its influence on children's pain have also been measured as pain sensitivity. Chen et al. (2000) used the Sensitivity Temperament Inventory for Pain (STIP) questionnaire to measure pain sensitive temperament and its influence on child distress and anxiety during children's lumbar punctures. The STIP tool is designed to distinguish between pain sensitive and tolerant nervous systems and includes questions related to sensation seeking/pain tolerance, perceptual sensitivity, symptom reporting, and introversion/avoidance sensations. Chen et al. (2000) found that children's pain sensitive temperament accounted for up to 30% of the variance in child distress during lumbar punctures. In addition, higher pain sensitivity was also related to increases in child distress, anxiety and pain ratings. Children with high pain sensitivity also responded better to non-pharmacological interventions such as distraction (Chen et al., 2000).

Reports indicate that sex may also influence children's pain and subsequent pain expression. Specifically, reports indicate that females are more expressive in their pain response and as a result they are more likely to exhibit higher levels of behavioural distress when compared with males (Chambers, Craig, & Bennett, 2002; McCarthy & Kleiber, 2006; McCarthy, Kleiber et al., 2010). These sex differences in children's pain expression have been documented even in early infancy prior to any learned behaviours, which suggests there may be a physiological mechanism for these sex differences

(Guinsburg et al., 2000). There is also evidence that females may respond better to non-pharmacological strategies such as distraction (McCarthy, & Kleiber, 2006).

Coping style is another individual child factor that may influence children's pain. Specifically, children may exhibit one of two coping styles including a blunt/avoidant or a monitoring/approach coping style (Soumitri et al., 2012). Children with blunt/avoidant coping styles typically respond by ignoring or distracting themselves from the unpleasant pain or painful stimuli while children with a monitoring/approach coping style monitor and focus on their experience and may seek out information. Reports indicate that both coping styles respond to using distraction with greater effects noted in children with a blunt/avoidant coping style (Evans, Lu, Tsao, Zelter, 2008; Jaaniste, Hayes, & Von Baeyer, 2007; Soumitri et al., 2012).

Culture is another individual factor that may influence children's pain experiences. Culture is considered a "set of learned behaviours, beliefs, attitudes and ideals that are characteristic of a particular society or population" (Ember, Ember, & Peregrine, 2002, p. 217). As a result, culture may play a role in forming an individual's interpretation and subsequent pain expression. Particularly some cultures value stoicism, for example African and Saudi cultures, and as a result they may deny pain and are less likely to overtly express their pain (Lovering, 2006; Narayan, 2010). In contrast, some cultures are more expressive of their pain, for example Asian, Filipino, Irish cultures, and as a result they may be more likely to report and express their pain as a result (Lovering, 2006; Narayan, 2010). The impact of culture on children's pain is also documented in a recent systematic review that found no cultural differences in children's self-reported pain levels when exposed to similar pain experiences but culture did have an influence on

children's pain expression (Kristjandottir, Unruh, McAlpine, & McGrath, 2012). Specifically, Caucasian American infants tended to exhibit more overt pain behaviours when compared with African American, Chinese American, Hispanic and Dutch. It is not clear why these differences exist but the researchers suggest that they may be related to a combination of cultural socialization and genetics. In addition, Japanese children exhibited less overt pain behaviours but physiologically they had higher cortisol levels suggesting that they still experienced pain but they did not express this pain overly.

In summary, child factors are important to consider as they contribute to individual differences in children's responses to pain. These factors should not be considered in isolation because children's reactions to stressful medical encounters are also highly influenced by parent/caregivers and parent/caregiver's interpretations and actions to alleviate child pain and distress.

Parent factors.

Parental presence. A recent systematic review that examined parent presence during children's painful experiences found conflicting results with some reports linking parent presence to increases in child distress with other reports linking parent presence to improvements in children's pain coping (Piira, Sugiura, Champion, Donnelly, & Cole, 2005). These findings are difficult to interpret and apply in pediatric settings where family centered care is the standard. As a result researchers have expanded their work beyond examining the impact of simply having a parent present to exploring what parents actually do and the impact of these behaviours on the child experiencing pain. There is evidence that some parents may naturally use evidence-based pain strategies such as distraction to help their child cope (Spagrud et al., 2008) while other parents may lack the

appropriate knowledge and skills. Through observations during children's medical procedures, researchers have isolated specific parent behaviours that consistently contribute to poor pain coping and they have also isolated behaviours that are helpful and contribute to children's positive pain coping. In addition to identifying specific parent behaviours, researchers have also explored parent's intrapersonal (attitudes, beliefs, culture, anxiety, catastrophizing) and interpersonal factors (nurse support and opportunities to use pain care strategies) and their influence on children's pain outcomes.

A child in pain attracts the attention of a parent and how the parent assesses and responds to the child in pain can significantly contribute to a child's pain experience. Similar to individual child factors, a parent's assessment, interpretation and reaction to a child's in pain can be influenced by individual parent interpersonal (individual-behaviours, beliefs, culture, emotional response) and social environmental intrapersonal (nurse support and opportunities for participation) factors.

Parent behaviours and child distress. All children encounter stressful situations as a normal part of their growth and development. The manner in which parents respond and behave during children's everyday stressful experiences influences how children appraise and cope when presented with future stressors (Power, 2004). This relationship between parent behaviour and child coping during every day stressful situations also translates to the context of pain experienced during the diagnosis and treatment of a life threatening illness such as ALL. Researchers report that parent behaviours may have a greater influence than health care professional behaviours on children's pain coping (Mahoney, Ayers, & Seddon, 2010) with reports that up to 53 % of the variance in child distress

during children's immunizations was associated with parent behaviours (Frank et al., 1995).

Through systematic observations, researchers have isolated parent behaviours consistently associated with child distress and these include reassurance (Blount et al., 1989; Blount, Landolf-Fritsche, Powers, & Sturges, 1991; Bush & Cockrell, 1987; Cohen, 2000; Kleiber & Harper, 1999; Mahoney et al., 2010; Manimala, 2000; McMurtry, McGrath, & Chambers, 2006; McMurtry, Chambers, McGrath, & Asp, 2010; Spagrud et al., 2008), criticism, apologies, and giving the child control (Blount et al., 1989; Frank et al., 1995; Kleiber & McCarthy, 1999; Manimala, 2000; Power, 2004; Spagrud et al., 2008). As a result, it is important to understand factors that influence parents' ability to appropriately attend to childhood pain.

The most consistently reported distress promoting behaviour used by parents is verbal reassurance (Blount et al., 1989; Kleiber & Harper, 1999; Mahoney et al., 2010) with numerous reports linking parent reassurance to increases in child distress (Blount et al., 1989; Blount et al., 1991; Bush, Melamed, Sheras, & Greenbaum, 1986; Bush & Cockrell, 1987; Chambers et al., 2002; Cohen, 2000; Cohen, Blount, Panopoulos, 1997; Dahlquist et al., 1994; Lamontagne, Wells, Hepworth, Johnson, & Manes 1999; Mahoney et al., 2010; Manimala, 2000; McMurtry et al., 2006; McMurtry et al., 2010; Power, 2004; Spagrud et al., 2008). When parents use reassurance, they make verbalizations intended to comfort a child (e.g. "it will be done soon", "It is okay", "you are almost done", "don't worry") but the outcome of these verbalizations is counterintuitive and instead of comforting a child they result in escalations in child distress. The mechanism of reassurance is not well understood but researchers propose that reassurances focus the

child's attention on the unpleasant pain experience and thus open the central nervous system "gate" to processing the pain. In addition, reassurance may serve as a warning that something bad is happening or is going to happen (Chorney et al., 2009; McMurtry et al., 2006). As a result, parents should be discouraged from using reassurance to comfort their child in pain.

Parent pain relieving behaviours. Although parent behaviours such as reassurance have been linked to child distress, parents may also engage in behaviours that are helpful. These coping promoting behaviours include various forms of distraction. As a result, parents use of distraction has been the major focus of parent procedural pain intervention research and has been documented as an effective strategy for decreasing children's behavioural distress (Blount et al., 1991; Bush et al., 1986; Bush & Cockrell, 1987; Cohen et al., 1997; Dahlquist et al., 1994; Kazak et al., 1998; Kleiber & Harper, 1999; Kleiber et al., 2001; Manimala, 2000; Manne, 1992; Spagrud et al., 2008), fear (Cavender et al., 2004) and pain (Matziou, Vasiliki Chrysostomou, Anthi Vlahioti, Efrosyni Perdikaris, Pantelis, 2013; McCarthy, Cool, Petersen, & Bruene, 1996; Broome, 1994; Pederson, 1996).

There is also evidence that parents use coping promoting behaviours like distraction more often than distress promoting behaviours. Specifically, Kleiber et al. (1999), found that parents' use of distraction occurred more frequently (33% of all parent behaviours) than distress promoting behaviours (23% of all parent behaviours). Non-procedural talk is the most common form of distraction used by parents during children's routine immunizations (Cohen, 2000), bone marrow aspirations and lumbar punctures (Blount et al., 1991) and other procedures including anaesthesia induction (Chorney et

al., 2009). Parents may easily incorporate non-procedural talk as a distraction method because it is easy to apply and it does not require a lot of training and/or supplies.

Evidence suggests that parents may naturally engage in specific behaviours in response to a child in pain and these behaviours can either be helpful or they may contribute to child distress. In an attempt to further understand parent behaviours in response to observing their child in pain researchers have explored individual parent intra-personal and environmental interpersonal factors. Several intrapersonal factors that may influence parent's ability to support a child in pain including parent attitudes and beliefs regarding pain management, culture, and emotional response to seeing a child in pain.

Parents' attitudes and beliefs regarding analgesic use is one important intrapersonal factor that may influence a child's cancer pain experience. In a recent study Fortier et al. (2012) reported that many parents of children with cancer had misconceptions about analgesic use and children's pain expression. These misconceptions and beliefs may influence parents' use of appropriate pain management strategies. Specifically, as many as 76% (n 187) of these parents were concerned about analgesic side effects, 63% had concerns with the potential for addiction, and 42% agreed that children should be given as minimal as possible pain medication. Parents also believed that their child would always tell them when they were having pain (41%) and many (36%) believed that their child would always express pain by exhibiting overt pain behaviours like crying or whining. There are also reported differences in parent ethnicity and beliefs regarding the use analgesics to manage child pain. Fortier et al. (2012) found that English Hispanic parents had more misconceptions regarding pharmacological

management strategies and as a result they tended to avoid giving analgesics. These results are concerning in the context of children with ALL as parent's in this scenario are in a key position to assess and administer analgesics in the home care setting.

Another important factor may influence parent behaviour involves a parent's emotional response to observing the child in pain. Research to date has found a strong relationship between parent anxiety/distress and children's pain outcomes. Specifically, Bearden et al. (2012) found a strong relationship between a parent's pre-procedural anxiety and increases in child anxiety and distress. The relationship between parent anxiety and child pain is even documented in young infants during immunizations, which suggests that even the youngest child learns to pick up on and respond to parent's cues (Bernard & Cohen, 2006). As a result, interventions should target ways to decrease parent anxiety.

One way to address parent anxiety is to empower parents by providing them with the knowledge, tools and opportunities to actively participate in their child's pain care. Improved parent and child coping have been documented when parents of critically ill children were provided with knowledge and opportunities to participate in their child's care during a pediatric intensive care admission (Melnyk et al., 2004). Parents who are provided with the skills and who are encouraged to take on an active role may feel a sense of empowerment and control over their child's medical situation and may experience less stress and anxiety as a result (Cohen et al., 1997; Lamontagne et al., 1999). In addition, many parents report high levels of stress and anxiety when they are uncertain about their pain care role (Lamontagne, 1997; Lamontagne et al., 1999). If parents are provided with the knowledge and tools to actively participate in their child's

care they may themselves experience lower levels of anxiety and their child may also benefit with improved pain outcomes as a result (Cohen et al., 1997; Lamontagne et al., 1999).

Another emotional response documented in the literature involves the role of parent catastrophizing which occurs when a parent develops an exaggerated negative focus on the child's pain. Specifically researchers report that parents who catastrophize about their child's pain, experience high levels of anxiety and distress as a result (Goubert, Vervoort, Sullivan, Verhoeven, & Crombez, 2008; Hechler et al., 2011). In addition, parents who catastrophize may focus more on ways to decrease and alleviate their own distress and they may not adequately apply strategies to alleviate their child's pain and distress (Goubert et al., 2008).

Parent sex may also influence his/her ability to adequately support a child in pain. Numerous reports indicate that children with chronic illness value and prefer the support and comfort provided by their mothers (Decker, 2007; Delois, Kagan, James, & Seboni, 1993) but limited research has explored the role of fathers. The majority of previous research examining parent involvement in children's pain care has primarily recruited and focused on the role of mothers (Moon et al., 2008; Moon, Chambers, & McGrath, 2011). This gap in the literature is important to address as traditional parent caregiving roles have changed with the shift of both parents into the work force. Subsequently, in many cases mothers are no longer the primary child caregivers and many fathers assume child caregiving roles as a result. Most recently, researchers have recognized this imbalance and have begun to explore the role of fathers during children's pain experiences. Despite researchers' primary focus on the maternal role, there is preliminary

evidence to suggest that fathers may in fact be more accurate judges of their child's pain (Moon et al., 2008). Fathers may also be less likely to react emotionally and catastrophize about their child's pain and as a result they may be better able to appropriately attend to their child's pain (Hechler et al., 2011). Although there is evidence to suggest that fathers may play a significant role in children's pain care, further research is needed to explore their role in managing children's pain related to chronic conditions such as cancer.

In summary, parents have a strong desire to be actively involved in their child's pain care but they may lack appropriate knowledge and skills to do so. The main focus of parent involvement in children's pain care has examined parent's role during medical procedures. This focus on medical procedures leaves a gap in understanding parents' role in managing all significant sources ALL treatment related pain.

Parent participation/involvement in pain care. Parents of children with ALL are present during most of their child's pain experiences both in and out of hospital and as a result they are in an important position to use evidence based pain strategies. In addition, many parents have a strong desire to support and comfort their child when they are experiencing pain and many children desire the comfort of their parent (Coyne, 1995; Forgeron, Finley, & Arnaout, 2006; Holm, Patterson, & Gurney, 2003; Jones, Qazi, & Young, 2005; Broome, 1994; Po' et al., 2012; Power & Franck, 2008; Roberson, Franck, & Simons, 2001; von Baeyer, 1997; Woodgate, 2006) but as discussed previously, parents may lack the knowledge and skills to effectively alleviate their child's pain. In addition to individual parent factors described above, social environmental factors may also influence a parent's ability to effectively use pain strategies.

Specific to procedural pain, reports indicate that parents are present for the majority of children's tissue damaging procedures. In fact, Ross and Ross (1984) reported that 99% (n=994) of children aged 5-12 years found it most helpful to have their parent present when they were experiencing pain. Similarly Ellis et al., (2004) indicated that during a 23-day data collection period, parents were present for 75% of all children's (aged <1-20 years) needle related procedures. Parents of children with cancer are also present for a large number of their child's medical procedures and up to 82% of parents are present for anaesthesia induction prior to invasive bone marrow and lumbar puncture procedures (Po' et al., 2012). Jones et al. (2005) found few ethnic differences in parents desire to be present and regardless of ethnicity a large number of parents wanted to be present during highly invasive procedures including fracture reduction (95%) venipuncture (94%), laceration repair (88%), lumbar puncture (81%) and critical resuscitation (81%). Specifically, parents of children with chronic illness, such as cancer, develop expertise in the care of their child and have a strong desire to be present and actively involved in all aspects of their child's medical care (Balling et al. 2001).

Challenges with parental participation/involvement. Although many parents desire participation in all aspects of their child's hospital care, they may face challenges that limit their ability to fully participate. In a recent systematic review, parents of hospitalized children felt strongly supported to participate in their child's basic care but lacked support from the health care team to participate in more complex health care tasks (Power & Franck, 2008). In addition to feeling unsupported, many parents also reported feeling incompetent because they lacked appropriate knowledge, skills, and opportunities to effectively participate in their child's care.

There are also documented inconsistencies between nurse and parent perceptions regarding parents' pain care role. In a study by Polkki et al. (2002), nurses reported adequately teaching parents pain management strategies while only 23% of surveyed parents felt they had a clear pain care role. These inconsistencies in parent-nurse perceptions has also been documented in another study where nurses thought parents' pain care involvement was adequate while parents expressed frustration with their limited passive role (Roberson, et al., 2001). As a result, evidence suggests that communication between nurses and parents is inadequate and better role negotiation needs to occur (Ygge & Arnetz, 2004).

Many pediatric institutions have adopted a family centered care approach that emphasizes involving parents as key stakeholders in the care of their hospitalized child. Specific to children's pain care, accreditation standards and hospital wide policies advocate for parent education and involvement in decision-making and the delivery of pain care strategies (Berry & Dahl, 2000; Canadian Pain Society, 2005; IWK Health Centre, 2012). While this is a positive move, few places have figured out how to fully operationalize this goal. Although parents are encouraged to be present while their child is experiencing pain, evidence suggests that parents are limited in their knowledge and actual pain care role (Daneman, Macaluso, & Guzzetta, 2003). Parents of children with chronic illnesses such as cancer want to be recognized and valued for their expertise and they want to be included as equal partners in care (Ygge & Arnetz, 2004). Specific to children with cancer, there is evidence that health care professionals may be more accepting of parent participation on specialized units such as pediatric oncology (Daneman et al., 2003). In particular, parents of children with cancer become informed

about their child's medical status (e.g. bloodwork interpretation, symptom monitoring) and needs and they become highly involved in assessment and treatment related decisions (Holm et al., 2003). This openness to parent participation in specialized care environments may be related to the enduring nature of a chronic illness and the establishment of long-term relationships between parent and health care professionals that occur as a result.

Nurses' role and parent involvement. Nurses play a major role in implementing and educating parents about specific pain care strategies and they are considered the health care professionals most likely to use pain care strategies in practice (Ellis et al., 2003) but as mentioned earlier, evidence to date reports that these strategies are not routinely implemented in practice (Stevens et al., 2012; Stevens et al., 2011). As a result, if nurses inadequately use pain care strategies, parents may not be provided with appropriate opportunities to learn and effectively apply these strategies.

Nurses have an important responsibility to use evidence-based knowledge to manage pain and distress in hospitalized children and are one of the main stakeholders in the assessment and delivery of adequate pain care (He, Pölkki, Pietilä, & Vehviläinen-Julkunen, 2005; Latimer, Ritchie, & Johnston, 2010; Wood, 2002). Nurses are also important gatekeepers and are in a key position to transfer pain care knowledge to parents (Wood et al. 2002).

Despite strong evidence to support nurses' use of pain care strategies, evidence to date indicates this knowledge is not always effectively translated into practice (Latimer et al., 2010; Twycross, 2010) and as a result parents' knowledge regarding strategies and their participation may be limited. Similar to parent's interpersonal factors mentioned

earlier, nurses are also influenced by individual factors that support their ability to adequately assess pain and apply pain care strategies. Several individual nurse factors that influence his/her ability to apply adequate pain strategies may include knowledge deficits, incorrect and out-dated beliefs about pain and management strategies, decision-making abilities. In addition, the social environment and organizational culture may also influence a nurse's ability to apply evidence-based pain management (Twycross, 2010). Polki et al. (2003) reported several factors that support nurses' ability to apply pain care strategies including nurses' competence, workload/time, child age and ability to cooperate and parent participation. In contrast, factors that may hinder nurses' use of pain strategies may include nurses' insecurity, beliefs regarding parent roles and child ability to express pain, heavy workload and lack of time to adequately apply strategies (Pölkki, Pietilä, Vehviläinen-Julkunen, Laukkala, & Ryhänen, 2002). In addition only 40% of surveyed nurses agreed to "some extent" that they had received adequate education regarding non-pharmacological pain care strategies and only 38% of these nurses' report an adequate workload to support the use of these pain care strategies (Pölkki et al., 2003). Reports also indicate that nurses' knowledge of pain care strategies do not necessarily translate to their actual use in practice. Specifically, Latimer et al. (2009) found many nurses had adequate pain care knowledge (62% venipuncture, 45% heel lance) but only a small number (8% venipuncture, 4% heel lance) actually used this knowledge to manage pain in neonates.

As a result, nurses are challenged in applying pain care knowledge that in turn may limit parents' ability to learn and apply these same strategies (He et al., 2005; He et

al., 2010). As a result interventions that aim to enhance parents' pain care role should include both parents and nurses in the knowledge translation process.

Research Describing Attempts to Involve Parents

As mentioned previously, the main focus of research involving parents in children's pain care has focused on their role during medical procedures. Specifically, numerous researchers have developed and tested interventions to promote parents' use of non-pharmacological distraction strategies. Many of these studies have been conducted in healthy children with non-life threatening illnesses undergoing routine immunizations (Bustos et al., 2008; Cassidy et al., 2002; Cohen et al., 2001; Cohen, Blount, Panopoulos, 1997), venepunctures, and intravenous insertions (Carlson et al., 2000; Cavender et al., 2004; Kleiber et al., 2001; Matziou, Vasiliki Chrysostomou, Anthi Vlahioti, Efrosyni Perdikaris, Pantelis, 2013; McCarthy, Kleiber et al., 2010) laboratory induced pain (McMurtry et al., 2010) and parent administered procedures (Slifer et al., 2009). Researchers have also examined teaching parents distraction strategies to apply during children's cancer procedures including bone marrow aspirations (Kazak et al., 1998), lumbar punctures (Kazak et al., 1998; Broome, 1994; Pederson, 1996), port-a-cath accesses, and intravenous insertions (Dahlquist et al., 2002; Guzzetta, Eshelman, Dale, Sjoberg, & Windich-Biermeier, 2007). Parent intervention studies report mixed results in children's procedural outcomes with some researchers reporting decreases in child distress (Kazak et al., 1998; McCarthy, Kleiber et al., 2010), crying (Bustos et al., 2008) and pain (Broome et al., 1998; Broome, 1994) while other researchers report no changes in child distress (Carlson et al., 2000; Kleiber et al., 2001; Matziou, Vasiliki Chrysostomou, Anthi Vlahioti, Efrosyni Perdikaris, Pantelis, 2013; Slifer et al., 2009). In

addition, most parent intervention researchers have not distinguished between high and low coping children (Broome, 1998; Bustos et al., 2008; Cohen et al., 1997; Kazak et al., 1998; Broome, 1994; Pederson, 1996; Slifer et al., 2009) and parents who already use coping promoting behaviours from parents who engage in distress promoting behaviours (McCarthy, Kleiber et al., 2010). Although previous parent procedural intervention research provides a good starting point for involving parents in children's pain care, further research is required to explore and improve parent's role in relieving other significant sources of cancer and treatment related pain.

Summary

In summary, children with ALL are inevitably exposed to multiple sources of pain, and if this pain is poorly managed, it may result in numerous acute and long-term negative consequences. Evidence to date indicates that pain in hospitalized children is undermanaged and as a result improvements in practice are needed. Parents are a valuable part of the health care team and in most cases they have a strong desire to play an active role in supporting and alleviating their child's pain. Despite this enthusiasm, evidence suggests parents may not be provided with knowledge and opportunities to adequately participate. Previous approaches examining parent's pain care role do not provide an in depth understanding of what parents may already do well to support their child in pain. In addition, previous research does not fully capture the complex context in which pain is experienced and how this context can support and improve the role of parents. The Canadian Pain Society states, "The best pain management involves patients, families, and health professionals" (Berry & Dahl, 2000 p. 20). As a result the present study was designed to further understand the pain experiences of children with ALL and

to identify parents optimal pain care role and key structures and processes necessary to achieve best parent pain care involvement.

Chapter Three: Theoretical Framework

Appreciative Inquiry within the Social Communication Model of Pain (SCMP)

As described earlier, the SCMP was used to guide the present study because the model fits well within the framework of Appreciative Inquiry (AI). The SCMP moves beyond understanding pain from the individual child's perspective and considers important interactions between the child experiencing pain, and individuals who are present in the case of this study the parent and nurse. Parents, who are present, interpret and react to their child in pain and these interpretations and reactions are influenced by a complex interplay between individual parent and environmental factors. Due to the complexity of the circumstances surrounding pain management including individual child, parent/caregiver, social and contextual factors outlined in the Social Communication Model of Pain (SCMP) (Craig, 2009; Craig et al., 1996) an approach such as Appreciative Inquiry (AI), (Cooperrider et al., 2008) was chosen to further understand parents' positive role in managing child pain during ALL treatment. There is evidence that parents may be frustrated with their limited passive pain care role (Roberson et al. 2001) but to date there are no constructive recommendations regarding how they have and how they can be effectively involved. The current study recognized that parents may be challenged in participating in their child's pain care, but also acknowledged that there are strengths that already exist. This study provided a forum for parents and nurses to independently describe these strengths and identify ways that parents' role can be optimized.

AI is a framework that has been used to explore health care professional, patient and caregiver experiences (Reed, Pearson, Douglas, Swinburne, & Wilding, 2002;

Trajkovski, Suza Schmied, Virginia Vickers, Margaret Jackson, Debra, 2013) in various health care contexts from individual hospital units to large multisite settings (Trajkovski, Schmied, Vickers, Jackson, 2013). The basis for AI is about studying, exploring and actively searching out the best practices that already exist within a clinical or social context and it aims to focus and build upon what already works (Carter, 2006).

Cooperrider and Strivasta (1987) first introduced Appreciative Inquiry (AI) as an effective approach to facilitate and initiate change. The underpinnings of AI are related to social constructionism, an approach that recognizes that individuals and groups of individuals create meaning and knowledge through interactions within a complex social system. AI is defined as:

the cooperative, co-evolutionary search for the best in people, their organizations, and the world around them. It involves systematic discovery of what gives "life" to a living system when it is the most effective, alive and constructively capable in economic, ecological, and human terms. AI involves the art and practice of asking questions that strengthen a system's capacity to apprehend, anticipate, and heighten positive potential. (Cooperrider et al., 2008, p. 3)

Hammond (1998) insists that to effectively apply AI, researchers/leaders must recognize that both individual and group interactions within a specific context are central to understanding and generating knowledge. While AI has been used as an intervention method by some researchers, in this study it was not an expected outcome. This study used AI as a framework to frame strengths based research questions to generate knowledge and elicit innovative ideas from parent and nurse perspectives regarding

parents' pain care role during children's ALL treatment. While knowledge generation was the main goal of the study, positive change may have occurred as Cooperrider suggests that by simply asking questions change may occur because "the seeds of change are implicit in the very first questions we ask" (Cooperrider et al., 2008).

In contrast with traditional problem based approaches, AI aims to explore and understand a research problem by identifying and building upon the strengths that already exist within a social system and involves individuals who work and function (in this case, parents and nurses) within this context. As a form of action research, AI works from the "ground up" and is driven by collaboration between the researcher and key stakeholders within a specific context. Specifically, in the present study, this involved separately examining the positive experiences of parents' pain care role from both parent and nurse perspectives.

AI is guided by the 4-D Cycle, a four-step process that includes: **Discovery** (appreciating "what works"), **Dream** (imagining "what might be"), **Design** (designing "what should be"), and **Destiny** (creating "what will be") (Appendix B). Implementing the 4-D cycle provided parents and nurses the opportunity to explore positive experiences of parent's pain care involvement and provided a forum to identify strategies and processes support parents' optimal pain care involvement. The 4-D cycle was used to guide the proposed research questions from a positive lens.

Appreciative inquiry 4-D cycle.

*Discovery: research question 1. What do parents of children with ALL and their nurses describe independently as **effective strategies** that parents use or can use to relieve pain during treatment?*

During the “Discovery” phase, participants engaged in dialogue to identify, explore and appreciate what already works within a social system (Cooperrider et al., 2008). The main purpose of the AI discovery phase was to collect appropriate, useful, strength-based data that can be used as the basis for the subsequent Dream, Design and Destiny phases. Through the discovery process, nurses and parents identified and shared their positive experiences of parent’s involvement in children’s ALL pain care. Discovery phase data is typically collected in the form of one-on-one interviews (Trajkovski, Schmied, Vickers & Jackson, 2013). In the present study parents and nurses participated separately in a single one-on-one interview with the principal investigator (PI) and during the interview they identified and described what parents do or what parents can do to relieve their child’s pain during treatment.

*Dream: research question 2. Based on described experiences, what do parents of children with ALL and their nurses independently recognize as a parent’s **ideal role** in managing pain during treatment?*

During the dream phase, parents and nurses built upon positive outcomes identified in discovery phase and participants took steps to amplify these positive stories by imagining future possibilities (Cooperrider et al., 2008). Data collected during the Dream phase aims to look past “what is” and dream about “what might be” in the future if peak experiences are amplified and occur more often. One goal of the dream phase is to facilitate discussion and story sharing to create positive energy and enthusiasm. During this phase participants were encouraged to share their wishes, hopes and dreams to achieve optimal parental involvement. Another goal of the dream phase is to identify

themes, values and strategies learned in the initial discovery phase. These common themes serve as the building blocks for the last two AI phases.

*Design/Destiny: research question 3. What do parents of children with ALL and their nurses independently **identify as key strategies, structures and processes** to effectively support parent involvement in managing child pain during treatment?*

In the Design and Destiny phases, participants built upon the future vision and identified the “social architecture” or key elements required to achieve this vision. During this phase, participants focused on ways to implement and sustain identified strategies in the future. The primary aims of this study were to describe what parents are already doing well to relieve children’s pain and to identify ways to translate the evidence and actively involve parents in using pain care strategies.

Chapter Four: Methodology

A qualitative approach was selected as the best method to answer the proposed research questions in a complex social environment that is constantly changing. Although there are validated quantitative measures available to capture parent's role during medical procedures there are no validated tools that explore the role of parents in managing multiple sources of child pain in different settings (e.g. home, clinic, inpatient, emergency). The knowledge gained when using a qualitative approach serves an important role in moving forward in-depth clinical information that will enhance clinical practice. Thorne suggests there are limitations to conventional science and as such “ we can know things on the basis of behavioural or attributional patterns that defy measurement” (Thorne, 2014b, p. 100).

Interpretive Description

In the past, qualitative nursing research has been guided by non-nursing methodological approaches including e.g. phenomenology (philosophy), grounded theory (sociology), and ethnography (anthropology) (Hunt, 2009; Thorne, Kirkham, & MacDonald-Emes, 1997). With the expansion of nursing knowledge it has become increasingly apparent that these traditional qualitative approaches are inadequate for addressing the complex clinical, experiential research questions that come from nursing practice (Thorne et al. 2008). As a result, nursing scholars have begun to challenge traditional qualitative approaches and explore methods relevant to applied nursing practice and Thorne and colleagues developed the Interpretive Descriptive approach (Thorne, 2013a). Thorne et al. (1997) believe that nurse researchers can “build methods that are grounded in our own epistemological foundations, adhere to the systematic

reasoning of our discipline, and yield legitimate knowledge for our practice” (p. 172). In contrast with traditional qualitative approaches, ID combines aspects from traditional qualitative methods and is situated within existing research and clinical knowledge and analysis of research findings are based on this expert knowledge (Thorne et al., 1997; Thorne, Kirkham, & O’Flynn-Magee, 2008). ID goes beyond just describing a phenomenon and strives to understand the “so what” and considers the clinical implications, and aims to create knowledge that can be applied in the wider clinical practice (Thorne, 2013; Thorne, 2014).

Consistent with other qualitative methodologies, ID is guided by a philosophical paradigm or a “basic belief system or worldview” (Guba & Lincoln, 1994). ID is aligned with naturalistic constructivist orientations and acknowledges that there are multiple constructed realities and in order to learn about these realities, the researcher must partner with participants and study the phenomenon as it occurs in its natural setting (Hunt, 2009; Thorne et al., 2008). ID also considers the important role of other significant sources of information including policies, clinical knowledge, and existing evidence. Contrary to traditional qualitative approaches, ID considers it impossible to “bracket” or set aside preconceptions because the very nature of the questions asked are founded in the researchers clinical experiences and observations (Thorne, 2013). In other words, ID acknowledges the important theoretical and practical knowledge that the researcher brings to the research and is designed to generate knowledge that is relevant to peoples’ health/illness experiences and aims to identify and understand applications for how nursing or other applied disciplines can improve these experiences (Hunt, 2009; Thorne et al., 2008). Despite being a relatively new qualitative approach, ID has been adopted

and used by researchers in diverse health care settings has demonstrated clinical applicability in nursing research (Lasiuk, Comeau, Newburn-Cook, 2009; Mccord, 2011; Thorne, 2013b). In this research, ID was used to design the study and to guide decisions regarding data collection, analysis procedures and was used to establish and maintain the credibility of study results.

Study Setting

This study was conducted with nurses and parents who were recruited from the outpatient oncology unit at the IWK Health Centre in Halifax Nova Scotia. In 2014 fifty-six Maritime children were diagnosed with cancer at the IWK; fifteen of which were diagnosed with Acute Lymphoblastic Leukemia (ALL). Because treatment duration for ALL ranges from two and one half to three and one half years, in January 2014 there were fifty children undergoing active treatment for an initial ALL diagnosis. Of these children, thirty-four were between one and eight years of age.

There is a large team of health care professionals who care for these children in both the inpatient and outpatient settings. Specifically, six physicians work in both the inpatient and outpatient units and there is no crossover in nursing staff between these two units. The inpatient unit includes fifteen beds and is staffed by forty Registered Nurses (RN's). In addition to this group of inpatient nurses there is one nurse educator, one Clinical Nurse Specialist (CNS), and one Nurse Practitioner (NP). In 2012, the inpatient unit had 378 oncology related admissions. The oncology clinic is staffed with approximately twenty RN's, eleven of which work directly and closely with children with ALL and their families. These clinic nurses provide a combination of care coordination, education, assessment, treatment, emergency care, and follow-up to children with cancer.

There are two nursing roles in the clinic, the Family Care Coordinator (FCC) and the Clinical Care Provider (CCP). Every child diagnosed with cancer is assigned to a FCC, a nurse who consistently follows the child and their family throughout treatment. CCP's are nurses who provide the hands on day-to-day care, which may include administering treatments, supportive/emergency care (chemotherapy, blood products, emergency care, ongoing assessment and follow-up). The group of clinic CCP's is consistent and the child will likely receive care from each of the CCP's throughout their treatment. In 2012 there were a total of 2149 ambulatory oncology clinic appointments and clinic nurses provided inpatient care to patients 809 times. When patients are admitted to the inpatient unit, the clinic nurses continue to follow the child and family and as a result they see the child and family for inpatient visits to provide ongoing patient/parent support, education and coordination.

Children who are acutely ill or require intensive chemotherapy with specialized monitoring are admitted to the inpatient unit. The outpatient setting provides follow-up, continuous assessment, monitoring and treatment to children who do not require hospitalization (e.g. blood work monitoring, blood product and chemotherapy administration). Both the inpatient and outpatient units have access to hospital wide pain policies to guide pain assessment and management practices (IWK Pain Policy) and procedure related pain (Sedation Policy, LP Policy). In addition, the majority of invasive bone marrow aspirations and lumbar punctures are done under sedation in a specific treatment room in the ambulatory clinic. In November 2013, the Oncology service introduced a new practice to decrease the number of needle pokes for children with Central Venous Access Devices (CVAD's). As a result, children with CVAD's have all

routine blood work drawn from their lines when previously blood work required a needle poke (e.g. capillary, venous). The introduction of this new practice has been well received by the staff, patients and parents and has decreased the number of painful procedures these children are exposed to.

There is no formal standardized process for teaching and involving parents in managing children's pain and there are limited parent educational resources to address parent's knowledge deficits related to children's pain care. When new staff nurses are oriented the oncology service, they attend a hospital wide orientation that provides an education session from the IWK Pain Team. During the unit specific orientation, the unit educator provides some education about managing pain in cancer but there is no formal presentation specific to pain management.

Stakeholder Support for Study

Prior to conducting the present study, the PI met with the unit manager to review the study purpose, procedures and obtained a letter of support to conduct the study. Following manager support, the PI submitted an application to the IWK Research Ethics Board (REB) and gained approval. Concurrently with the REB application the PI presented the study plan to the Hematology Oncology Interdisciplinary Committee (HOIC) to seek feedback and gain their approval. The PI also met with the outpatient Clinical Leader to review the study purpose and details. Once approval was obtained from the manager, REB, and HOIC, the PI began participant recruitment using the sampling and recruitment strategies listed below.

Sampling

Purposive sampling was used to strategically select parent and nurse participants for this study. Specifically, purposive sampling in ID research is considered a representative technique that is used to “identify in advance of the study, the main groupings or conditions that you will want to have ensured you include in your study so that the eventual findings you produce have the potential of ringing true or seeming reasonable for your intended audience” (Thorne, 2008p. 91).

Parent sample. Keeping in mind individual’s experiences and ability to inform the study, parents were purposely selected based on the following inclusion criteria: parents (mother, father, grandparent, legal guardian) of eight children aged one to eight years in active treatment up to twelve months post-treatment for ALL; and a parent who identifies themselves as taking an active role in caring for the child’s regular and medical needs; and English speaking. Both parents had the option to participate but this was not an expectation. The PI purposefully recruited participants in all phases of ALL treatment including Induction, Consolidation and Maintenance and follow-up. Induction is the first phase of therapy that typically lasts one-month and the goal is to put the child’s leukemia into remission (American Cancer Society, 2015). Consolidation, the second phase typically lasts one to two months and is more intensive with a goal to eradicate any leukemic cells in the child’s body to decrease the chance that leukemia cells will develop resistance to the chemotherapy drugs. The last and longest phase of treatment is Maintenance and the goal of this phase is to ensure that the child remains in remission.

Parents were excluded based on the following exclusion criteria: child in treatment for relapse, Acute Myeloid Leukemia (protocols differ significantly from ALL), unexpected acute medical, psychological crises (e.g. relapse).

Nurse sample. Eight nurses were also purposively selected and recruited for participation based on the following inclusion criteria: Registered Nurse (RN) (diploma, university, or masters prepared) worked a minimum of one year with the outpatient pediatric oncology setting.

Participant Recruitment

Parent recruitment. There were three main strategies used to recruit parent participants including 1) physician introduction letter sent via postal mail, 2) parent recruitment posters posted in approved areas in the clinic, and 3) a copy of physician letter provided by the child's Family Care Coordinator (FCC) during a child's scheduled clinic appointment or hospital admission. Prior to approaching the parent during a clinic appointment or hospital admission the PI met with the patient's FCC to make sure it was appropriate to approach the parent/guardian on a given day.

Parents were also recruited when the patient came to the hospital for a scheduled clinic appointment. In this case the FCC provided eligible parents with a copy of the physician letter outlining the study to determine parent interest. The FCC informed the PI of interested parents and the PI then met with parent to obtain informed consent.

Nurse recruitment. There were three main strategies used to recruit nurse participants and these included: 1) a manager introduction letter sent to clinic nurses via outlook email, 2) nurse recruitment posters posted in approved areas in the outpatient clinic, and 3) presentation of study in a clinic staff nurse meeting. The manager letter and

posters outlined study details and nurses' role in participating and included the PI's contact information. All of the nurse interviews were done one-on-one in person in the unit's clinic conference room.

In the present study the nurse sample represented IWK clinic nurses who care for children with ALL. The final sample included parents from eight families, with a child who was receiving active ALL treatment as well as children up to twelve months post ALL treatment and eight of their clinic nurses. Of the eight families, there were two where both parents chose to participate. This sample size of eight participants per study group is consistent with other research guided by AI (Barnes, 2009; Lowther, 2012) and ID and fits within a range of six to twelve participants per study group that is considered an appropriate number for conducting meaningful qualitative analysis (Guest, Bunce, & Johnson, 2006). Thirty-six physician letters were mailed out and eleven of the eligible nurses received the manager introduction email. Four parents contacted the PI directly express interest and participate and the other six were purposefully recruited with the assistance of the child's Family Care Coordinator. Two parents who were approached by the FCC declined participation because they thought they were too busy. All of the eight nurse participants contacted the PI to express their interest in participating.

Data Collection Procedures

The primary data collection strategy used in ID includes participation in qualitative semi-structured interviews. In this study parents of children with ALL and their nurses participated in a one-on-one semi-structured interview with the PI. The PI also collected field notes and parent/child and nurse demographic information. In the

following section interview development, interview procedures and data analysis strategies will be outlined.

Interviews. Consistent with ID, each participant partook in a single one-on-one interview that ranged from thirty-five to eighty-five minutes with the PI using the investigator developed Parent and Nurse Appreciative Inquiry Interview Guides (AIIG, Appendix C). All nurse interviews and three of the parent interviews were done face-to-face in the clinic conference room that was a quiet location and free of distractions. For seven of the ten parent participants it was difficult to coordinate the interview during a child's clinic visit and as a result these interviews were done over the phone at a convenient time when the parent was free from distractions. In addition to participating in the interviews, participants completed a brief demographic information form (Appendices D, E).

It was anticipated that there was a small chance that parents could become distressed during or after participation in the interview. As a result during the consent process, the PI provided parent participants with a list of contacts (child's FCC, Social Worker, Family Doctor, Clergy, Child Life Specialist, or someone not listed that the parent identifies as a significant source of social support). Parents were also made aware that they could contact IWK Research Services if they had concerns; and the contact information was provided. The PI did not receive any feedback from the team indicating that any parents became distressed due to their participation in the study.

Appreciative interview guide development. The Parent and Nurse Appreciative Interview Guides (AIIG) for this study were developed by the PI using Cooperrider et al.'s (2008) guidelines, existing literature, previous nursing research that used this

method (Barnes, 2009; Lowther, 2012) and in consultation with committee members and with parent, nurse, and pharmacist input (Appendix C). The interview guide contents were reviewed extensively by content experts and included: two parents of children without chronic illness, one parent of a child who was previously treated for cancer, three nurses with pediatric oncology experience, two nurses with pediatric experience in areas other than oncology, and one oncology clinical pharmacist to ensure that the interview questions were comprehensive and easy to understand and answer. The AIIG's were tested with a small sample of parents and nurses for clarity of questions and time. To enhance the flow of the interviews the order of some of the questions were changed.

Interview guide use. Considering Cooperrider et al.'s (2008) guidelines, these AIIG's included a formal introduction outlining the study purpose and goals followed by three different types of open ended questions including opening, topic and concluding questions. The PI used a paper copy of the AIIG interview guide with sufficient space between questions to take field notes regarding key themes, impressions during and after the interview. One-on-one interviews are considered an effective method to gather in depth accounts of individual's feelings, opinions and experiences related to a subject under study (Milena et al. 2008). The primary goal of the one-on-one interviews was to obtain in depth descriptions of children's ALL pain experiences, and to identify what parents do well to reduce their child's pain; and consequently identify key structures and processes necessary to actively involve parents in the future.

Interview procedure. The AI interview process is considered rhythmic beginning with questions relevant to individual experiences and moves towards identifying generalizations relevant to these individual experiences (Cooperrider et al., 2008). Early

interview questions are meant to allow the individual to share a story about his/her positive experiences related to the topic under investigation. Consistent with the AI process, during the first phase of the interviews, parents and nurses identified and described positive peak experiences of parents pain care involvement through storytelling and included information about individual thoughts and feelings related to these experiences. Once participants shared their stories they identified and made generalisations based on these positive stories. These generalizations aimed to understand how the clinical context facilitated parents' optimal pain care involvement and identified structures, systems, policies, staff and support systems that if put in place that enable these positive experiences to occur more often. During this part of the interview the PI used probing questions to guide the participant in identifying these generalizations.

Interview guidelines. Because AI interviews aim to identify and explore positive experiences the PI planned strategies to deal with, and reframe, any negative talk that might have surfaced during interviews. Cooperrider et al. (2008) outlines several strategies to target and decrease negative talk and these include postponing, listening or redirecting and reframing the discussion. Postponing involves making note of the participant's views so the interviewer can come back and discuss the negative experiences at a more appropriate time for example near the end of interview after all positive stories have been shared. If the participant expresses high intensity regarding these negative experiences the interviewer may have to listen, as appreciative data is unlikely to surface until the participant has expressed himself/herself. When an interviewer chooses to listen to the negative stories the goal is to maintain a caring affirmative positive approach. Redirecting is another strategy to target negative talk and it

involves finding an appropriate opportunity in the conversation to redirect the dialog back to discussing positive experiences. During the interview process, the PI was aware of these strategies but did not need to use them because the research participants spoke of their many positive experiences.

Each interview was audio recorded and the PI's field/handwritten notes (including immediate reflections and information that may not be apparent from solely listening to the audiotaped interview e.g. body language, emotions, interruptions, background noise) was collected during and after the interviews. Shortly after the interviews were audiotaped and reviewed by the PI and adequate field notes were taken, a research assistant transcribed the interviews verbatim. Non-verbal cues and/or background noise were noted in the transcripts. For example if the participant expressed emotions such as laughter or crying it will be noted in parentheses [e.g. (laugh) (cry)]. After the interviews were transcribed and checked with the audio recordings, the recordings were deleted from the encrypted flash drive and then the flash drive was destroyed.

Follow-up review of results. In addition, after the interviews were analyzed, the PI contacted participants individually in person or email to review a summary of the research results; parent results were reviewed with parents and nurse results with nurses (Appendices F, G) The goal of this review process was to confirm that the PI's interpretations adequately reflected the actual experiences of the participants (Thorne, 2008). The PI acknowledged and summarized any new information that arose and this information is included in the study results. This contact with participants was conducted as a step to determine the credibility of the data collected and to determine if the results accurately reflect participant's experiences.

Data analysis. This study collected three types of data including 1) demographic, 2) narrative interview and 3) field notes. The following section will describe how these data sources were analyzed:

Demographic analysis. Parent/caregiver, child and nurse demographic data was analyzed using descriptive statistics such as range and means to describe the parent/child and nurse sample (Appendices D, E).

Narrative and field note analysis. The analysis of the narrative interviews and field notes was guided by ID methods. Specifically, ID provided an analytic framework that is located within existing evidence and expert clinical knowledge and research findings and analysis of these findings were guided by these knowledge sources (Thorne, 2013). In addition, existing knowledge provided a strong theoretical foundation for the questions under study. Throughout the analysis process, the PI was in constant reflection and considered the larger context of evidence-based pain management practice. Consistent with ID, the PI used critical thinking similar to the nursing process and this included a cyclical procedure of engaging, assessing, planning, acting and evaluating throughout the analysis process. The PI's analysis was guided by ongoing critical thinking and asking questions like "so what?" "What is actually happening here" and "How are parents learning to manage their child's pain?" "What is the health care team doing to help support these parents on an ongoing basis?" "What are the important things that we need to know to support parents optimal pain care involvement?" and "How can this information be presented in a way that contributes to furthering our clinical knowledge of involving parents in managing child pain in children with ALL in the future?" Consistent with ID, the study's findings go beyond simply describing parent and

nurse experiences and present them in a way that can be applied in the wider clinical context in the future (Thorne et al., 2008; Thorne, 2013a; Thorne, 2014a).

Thematic analysis. The first step in qualitative thematic analysis involves becoming familiar and immersed in the data (Field & Morse, 1995). The process of immersion is important in qualitative ID research and as a result, repeated immersion is recommended prior to the coding process of classifying and identifying common themes (Thorne et al., 1997). Therefore, soon after each interview the PI reviewed the audiotapes several times and listened closely to the content of the questions asked and participants' responses. The goal of immersion was to gain an intimate understanding of each individual case before extracting common themes based on the work by (Thorne et al., 2008). After the PI reviewed the audiotapes and collected adequate field notes, a research assistant transcribed the interviews verbatim. Once transcribed, the PI reviewed the transcripts several times in consultation with the audio recordings to ensure their accuracy and then began the process of coding and identifying key themes. The main goal in ID analysis was first to intimately understand individual cases through immersion and then secondly to move on and identify and extract common themes and patterns that were common across the individual cases. The PI's supervisor reviewed all transcripts initially and then the PI and supervisor met together to discuss the contents. The PI and supervisor also met with the two remaining committee members to review the broad themes with the sample quotes for review, revision and input. During this meeting, the PI and her committee began to generate interpretive descriptions based on the themes that were applicable in clinical practice based on Thorne et al.'s recommendations (1997; 2008). Initially thematic analysis involved identifying broad themes to understand the

overall picture and considered questions like “What is going on here?” and “ What am I learning about this?” Next, the ID analysis process progressed to the researcher moving beyond identifying the broad themes and worked to develop an understanding and interpretation of the data that is clinically relevant with the support of the committee and then more completely with the PIs supervisor. Parent and nurse perspectives were analyzed separately then comparisons were made between the two group perspectives.

Ethical considerations. Prior to beginning data collection, approval was obtained from the IWK Research Ethics Board (REB). Ethical principles outlined in the IWK REB and the Tri Council Policy Statement (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010) principles were applied throughout the research process. Participants’ privacy was maintained and no identifying information linked participants to their individual study data. Each participant was be assigned a study ID (e.g. Nurse 1, Parent 1) that was included on his or her interview transcript. To preserve anonymity of participants, individual names and identifiers were eliminated from transcripts. A separate password protected excel file was kept that linked participants to their study code but the PI and her supervisor were the only individuals with access to this document which was stored in a separate locked file. Once interviews were transcribed, audio recordings were destroyed and transcripts were kept in a locked cupboard in the office of the PI’s supervisor (Dr. Margot Latimer) in the IWK Centre for Pediatric Pain Research (CPPR) and will be kept there for 5 years post publication of study results at which time they will be destroyed. A \$20 honorarium was given to all

parents and nurses who participated during non-working hours to cover any out of pocket expenses related to study participation (e.g. parking, food).

Chapter Five: Findings

In this study of 10 parents and 8 nurses using a qualitative Interpretive Descriptive (ID) approach, parent and nurse participants moved through the four phases of Appreciative Inquiry (AI) process and 1) provided a description of actual and potential pain sources experienced by children undergoing ALL treatment (AI-Discovery) 2) described pain management strategies that parents use or can use (AI-Discovery/Dream), and 3) identified and described key structures and processes that support parents' optimal pain care involvement (AI-Design/Destiny). Furthermore, parent and nurse perspectives were considered separately and common and contrasting themes were considered and are presented in the discussion.

Parent Demographics

Ten parents aged 31-41 years from eight separate families with a child in active treatment up to one year post-treatment for ALL participated in the interview sessions. There were two families where both parents chose to participate and in these cases the interviews were completed separately with each parent. Of the ten parent study participants, eight were mothers and two were fathers. Eight of the ten parents were Caucasian, one was Aboriginal and one was African Canadian. Parents' highest level of education varied and included two parents with a University degree, one with a college diploma, and three who had completed High School. Purposive sampling strategies effectively captured a wide range of parent experiences throughout the ALL treatment trajectory. Specifically, this strategy enabled the PI to capture the experience of parents whose children were at different ALL treatment stages including Induction, Consolidation, Maintenance, and six to twelve months post treatment. The sample

reflected both sexes (n=5 female, n=3 male) a varied child age range including children aged one to eight years, half of whom were preschool and half school aged. A more comprehensive description of parent/child demographic information can be found in Appendix F.

Nurse Demographics

As projected, eight clinic nurses participated in the study. Because there was a small pool of approximately eleven eligible clinic nurses to draw from, both Family Care Coordinators (FCC's: consistent caregiver for individual child throughout treatment) and Clinical Care Providers (CCP's: nurse who provides hands on care during clinic visits) participated and provided in-depth descriptions of their experiences. Nurses in the sample had a broad range of experience including those who worked in the pediatric oncology setting from one to eighteen years and specifically in the pediatric oncology clinic setting for one to fifteen years. Nurses ranged from 23- 55 years of age with an average age of 41.25 years. Nurses experience with the pediatric oncology population ranged from 1-18 years with an average of 12.38 years. The sample included an equal number of Family Care Coordinators (FCC's) and Clinical Care Providers (CCP's). Four of the nurses had a diploma program and the other four had baccalaureate nursing education. Nurse participants were asked to identify ways that they had learned about pain and they reported learning from multiple sources from most to least common including: colleagues, policies, parents, in-services, and journals, social media, other (personal experiences) and conferences. A comprehensive description of nurse demographic information can be found in Appendix G.

The nurse interviews began with questions meant to establish some trust and comfort with the interviewer and nurses were asked to describe what drew them to the profession and specifically the pediatric oncology population. Nurses responded and described being drawn to the nursing profession for various reasons including: having previous experience caring for someone with a medical condition (e.g. close family member or family friend), encouragement from others to pursue nursing, and some having a vision that they had always wanted to be a nurse even as a young child. Most of the nurses did not have a desire to work with the pediatric oncology population and took a job in the clinic for various reasons including job availability and the need to be further challenged. After working with this patient population, most of the nurses described “loving it” for various reasons including: a preference for treating the whole family and not just the individual, being able to relate to the children, and providing continuity of care to help a child and family cope with a life threatening disease. One nurse considered it a privilege to help support a family going through such a challenging experience and this nurse expressed the sense of fulfillment she experienced by moving families through the childhood cancer experience.

Pain Sources

This section will address the first research question (AI discovery): “*What do parents of children with ALL and their nurses prospectively describe as potential sources of pain experienced during treatment?*” There was overlap in the participant’s responses and both parents and nurses described common pain sources related to three main areas: the disease process, medical procedures and treatment side effects.

Disease related pain. Bone pain, headaches, and abdominal pain were the most common pain sources described by nurses and parents associated with the disease process. Seven of the eight nurses identified bone pain as a common symptom experienced at diagnosis and they reported that between five to nine out of ten children experience bone pain as a result of the disease process. Bone pain was not the only presenting symptom, in fact, two nurses described children who presented with headaches and one nurse identified abdominal pain as another symptom that may occur as a result of the disease process. When nurses were asked to describe what this pain looks like they described a generalized debilitating pain that spreads throughout a child's body making it difficult for them to mobilize, and participate in normal activities and follow normal sleep patterns. When they present to the oncology service with bone pain, they are typically irritable, difficult to settle and may be in so much pain that they curl up into a fetal position and "shut down" as a result. One nurse provides a good description of how a child with bone pain presents at diagnosis in the following quote:

I think when they are first are diagnosed, they are coming in in so much pain that they are often quiet and they are often irritable and are difficult to settle, so I don't necessarily know if they cope very well with it. I think that they are feeling so bad that they don't, I mean the older ones yes cope better than the younger ones, but I am thinking of toddlers who come in with a lot of bone marrow pain with bone marrow involvement. (Nurse 1 line 125-130)

Another nurse provided a description of how a child can present with severe bone and abdominal pain resulting from leukemic infiltrates in the bone and organs. Some of these children with bone infiltrates may also develop fractures as a result:

... you know, one of the common presenting features for kids with ALL can be bone pain. And I've seen kids that, especially the younger ones, with refusal to walk, a few with actually fractures related to boney infiltrates, as well as kids that complain of back or flank pain, and they may have like a kidney infiltrate or something at diagnosis. And it can be quite severe. (Nurse 7 line 47-51)

Similarly, when parents were asked to describe their child's actual pain experiences, five of the eight children had experienced disease related pain at diagnosis. Most of the children experienced pain that began in the legs and over time, spread throughout the child's whole body. For example one parent describes how her child's pain progressed quickly from a limp to the rapid spread of pain throughout her child's body making it difficult for the child to walk:

She was really down and out. She couldn't even walk when she got there because she had woke up early one morning in January and she had a slight limp and the daycare had called me later that day and said she can't even walk anymore.... she was confined to a wheel chair. When she was in bed she was always curled up in the fetal position.... In a short period of time the pain radiated up her left leg to her left hip, and then it seemed to go up to her left shoulder across the back of her neck, right shoulder, down her back, lower back and then right hip, and then right knee, and it just seemed to be throughout her body.... her pain would kind of come and go. (Parent 1 line 63-66, 97-98, 89-92, 79)

Another parent described her child's leg pain as being like "limp noodles" and talked about multiple episodes when her child's legs would just give out from underneath of her. This child also had a difficult time getting comfortable because her whole "body hurt":

It wasn't so much as it was pain as it was like just her legs were just... felt like noodles to her. And it was her bed. It was her bed that was hurting her. Her body was hurting. She was saying "I need a new bed. My body is hurting." I'm like "Ah that's weird." You know, like why does your bed all of a sudden hurt your body, you know? (P4 line 249-253)

Pain related to the diseases also presented as severe headaches in one case. Specifically, this parent described how her child developed severe acute debilitating headaches that came on as a result of leukemic cells infiltrating the central nervous system:

He was scared. Like I have never seen him like that. He was screaming. You could see he was scared. Like he was asking me what was happening.... The first time he had that pain, he was sleeping and he turned. And that's when he started screaming. Like he opened his eyes. I was sleeping with him. I was in bed with him. He opened his eyes like very scared. And you could see it in his face. He wasn't faking. (Parent 3b line 210-211, 231-234)

Not knowing that their child had ALL, many parents attributed the initial bone, abdominal pain and headaches to other causes such as growing pains, infection, and vision problems when in fact the pain was the result of the leukemia (Parent 3a, 4, 5).

Procedure pain. Procedure pain seemed to have two components including actual physiological pain resulting from the procedure itself and a psychological component that included procedural coping. Nurses identified procedures as the most common source of pain experienced by children with ALL including port-a-cath accesses, blood work draws, intravenous insertions, intramuscular injections, lumbar

punctures, bone marrow aspirations and surgical procedures (e.g. dental work, insertion of central line).

The most common procedure was regular port-a-cath accesses and nurses described wide variability in children's individual procedural coping. One nurse provided a good description of varied procedural coping in the following quote: "So that can go anywhere from a hysterical reaction to someone being sad, someone being scared, someone being stoic. I find that most kids, although they have procedure pain and do react, they recover very quickly" (Nurse 1 line 146-148). Another nurse explained that despite children's varied procedural reactions, most children learn to cope over time with repeated exposure. Improved coping occurs as the procedures become routine and the child develops an understanding of what to expect:

...over time some kids get used to those things and they might've been crying and wiggling initially in the beginning days and then when they are towards the end of treatment they may be perfectly still and have no problems with the procedural pain because they are used to it. (Nurse 3 line 124-127)

Similarly, a parent also described how her child's procedural coping improved over time and became "routine". As a result, her child who initially experienced high levels of procedural anxiety and distress learned how to cope: "she was just so used to it being done that we didn't even have to be close to her. We would stand on the other side of the room. The nurses would just go ahead and do it" (Parent 1 line 436-438).

Improved procedural coping is not always the case nurses and parents talked about how they noted it only takes one bad procedural experience to negatively influence children's reactions to subsequent procedures. Specifically, nurses and parents described

scenarios where unsuccessful procedure attempts contributed to heightened anxiety and negative coping with subsequent procedures. One nurse provided a good description of “true” procedure pain in the following quote:

But there are other populations that are difficult port accesses and difficult venous draws that I would say actually experience what I would consider, you know, true procedural pain. Being poked once with an easy port to me at least is different than being poked five times with a deep-seated port that may be in breast tissue, and have to have two nurses. You know, one to kind of stabilize a moving port because I have seen this on a few patients. I would say one to two out of ten actually have these deep seated ... and it's very traumatic, and I can only imagine how uncomfortable that is. And unfortunately that isn't something that I've been able to, you know, well control the pain. (Nurse 7 line 177-185)

Nurses described how even one single negative procedural experience can result in high levels of anxiety and distress with future procedures and it takes time for the child to move past this experience and be able to cope with future procedures.

The ones that have experienced pain tend to be the ones that have stronger reactions when they go in for a procedure.... The ones that do, it creates this fear in them and they are very distressed as they go into the room.... Some of them do really well, again it takes like one painful experience and they'll react that way for the rest, it will take a long time for them to get back to how they reacted before they had difficulty. (Nurse 2 line 156-147, 153-155, 161-163)

Similar to nurses, half of the parents also described how multiple procedure attempts negatively influenced their child's coping with subsequent procedures (Parent 1, 4, 7, 8).

The following is an example of how multiple procedure attempts contributed to heightened levels of anxiety and distress for one child and as a result, it became challenging to perform the procedures and manage the child's anxiety and pain with subsequent procedures:

...the first one was okay. He's just like, "Oh I didn't feel that at all." The second one I think they had to do it twice. Then he started to get a little more apprehensive about it. There was one at one point where they couldn't use... the port wasn't working so they took it out, and I think they accessed the port three times, plus they had to put an IV in him. And I think by the time they were done, they poked him 8 times.... So that was like one of the super traumatizing periods for him where he was literally... you know, for two hours, he was poked 8 times... and every time, it was just a little worse, a little worse. (Parent 8 line 235-243. 246)

This child's anxiety was worsened by multiple procedure attempts to the point that the parent described the experience as "traumatizing" for her child.

Parents and nurses also talked about pain related to sedated bone marrow aspirations (BMA's) and lumbar punctures (LP's). Seven of the eight nurses identified bone marrows and lumbar punctures as a potential source of pain and half of the children actually experienced pain related to these invasive procedures. The pain reported did not occur during the actual sedated procedure but occurred after the procedures in the home setting. Specifically, pain related to BMA's and LP's was described as generalized pain at the site of the needle puncture sites and the pain lasted from a couple of days \to one

week post procedure. One parent described her child's experience with pain after having a bone marrow aspiration:

She does have a lot of pain more from the bone marrow. That lasts about a week I'd say ... She just tells me her back is sore. And she won't let me touch that area. She likes to have her back scratched. That's kind of a thing that we do. But she won't let me touch her lower back. So I know that it's sore for about a week after the bone marrow. And the lumbar punctures are about two days, I'd say. (Parent 7 line 170-173)

Some children developed severe acute debilitating headaches after a LP even if they had not previously experienced pain with these procedures in the past. The following quote provides a detailed description of one child's experience with an acute lumbar puncture headache that presented in the home setting. This child developed a:

Headache from her last... not this last but the time that you seen us two weeks ago from her lumbar puncture, she had ridiculous headaches from that... it lasted for two and a half days.... It was when we got home. It was scary for me because I didn't know if this was like a flu that she was getting or, you know what exactly it was ... And I never want to see that ever, ever again. It was one of the most traumatizing things I have seen in my entire life. ... It would feel like knives. She described it as knives stabbing her in the head. That's how she would describe it. (Parent 4 line 87-88, 105-107, 117-118)

This child's post LP headache was traumatic for the parent because it presented acutely in the home care setting and she was unsure of the cause. This child had previously undergone LP's without experiencing this side effect.

Surgical procedures including port-a-cath insertions and dental procedures were also identified by half of the nurses and only two parents as potential and actual sources of pain. One nurse suggested that compared with all of the other things that these children endure these surgeries are minor:

You know, I think honestly, you know, with these minor procedures, I think post-operative pain is probably the easiest thing that they go through. And that's often an ouchy or walking stiff. You know, a lot of compensatory behaviours. They're really cool, unlike adults who just complain. And they try to do things for themselves as soon as they can. So you can monitor their progress by their want to go to the playroom again and their want to do normal activities. (Nurse 7 line 315-321)

One parent described how it took her child several months to get used to having a port-a-cath and as a result her child was cautious and made accommodations to avoid having any contact or pressure applied to her port site because it was uncomfortable:

Well, it took her a while to get used to it being there. Like she would, when she was snuggling us, eventually, like not the first couple of days, she would just kind of flop on us. But then she realized that that kind of hurt when we would push on her. So she started to give you a hug like this.... She would arch her back and push her shoulders forward to avoid having that being pushed on. And that took a while for her to work out of that. I'd say probably 6 months or so. (Parent 2a line 320-323, 325-327)

Similarly, another parent described how her child was hesitant to have her port-a-cath touched. Close to the surgery this parent made adjustments in how she carried her child

to avoid any unnecessary contact with her port-site, which would cause pain. This child's hesitancy to have her port-a-cath touched continued after the incision was healed.

She did, especially... It was more or less trying to figure out how to, with the port, trying to figure out how we could carry her and lift her without hurting her because of the incision. And still today she doesn't like us to touch it. (Parent 7 line 133-134)

Treatment side effects. All of the nurses and parents reported nerve pain as the most common source of treatment related pain experienced during ALL treatment. Nurses estimated that between six and eight out of ten children develop nerve pain and six of the eight children whose parent(s) were interviewed had experienced nerve pain. Nurses described the child's pain as intense discomfort with joint pain that may or may not radiate in the arms and down the legs and may exhibit as numbness and tingling, pins and needles in the feet and/or hands. Throughout the interviews, nurses talked about how they routinely screen the children for common behavioural manifestations of neuropathies including decreased mobility, changes in the child's gait (tippy toe walking), difficulty using stairs, inability to weight bear and difficulty with fine motor skills in the hands (unable to hold pencil, button shirt). One nurse provided a comprehensive description of neuropathic pain in the following quote and indicates that children often experience:

Pins and needles, a lot of ... You know, kids use different words to describe it as like almost more crampy, especially if they're trying to ... you know, if they have a lot of neuropathy and they're trying to write, like use their hands to write and do homework. I find that's ... But the little kids, they probably complain less but

you notice... I think what we notice is they're either walking funny or not doing activities that they used to do like colouring. Or having kids that are self-sufficient having... I've seen teenagers with difficulty to do zippers and buttons in extreme cases. Or tripping more. That kind of stuff. And then they get pain from related injuries of tripping and falling. But the pain I guess with that is more... it's described as more of like pins and needles kind of pain. (Nurse 7 line 62-71)

In addition, parents described the nerve pain as an ongoing symptom that children experienced throughout treatment with worsening pain that occurs after chemotherapy treatments. One parent provided a raw account of her daughter's actual vincristine induced nerve pain and described it as "torturous" and unrelenting:

Since she's been diagnosed, she's had really bad pain in her legs from her vincristine which she describes to me as torture legs because it feels like but it's not like bad pain but it's happening all the time.... She's still waking up at night and she's still crying. You know, like that they're still hurting and stuff. (Parent 4 line 83-85, 293-294)

Another parent also described the long-term nature her child's neuropathic pain and in this case despite being managed with medication, the child continued to experience increased pain post chemotherapy treatments:

He's had back pain and leg pain since the beginning. And he's on medication for that now. Like he would get to the point where he's so tired and his back hurts or his leg hurts so bad that he just needs to like sit down or lay down for quite a while.... It's more common after he has chemo. Like most of the time he doesn't really notice it because he is on medication for it and that does seem to be helping

quite a bit. But after his chemo that's when he's like "My back hurts a little bit. I'm going to lay down" or "My legs hurt. I'm a little bit tired." And he takes a rest... With his pain, yeah he didn't want to walk anywhere. He had a hard time going up and down the stairs. He would crawl up and down the stairs. Like go down the stairs on his bum. And he would ask me to carry him upstairs to bed, and I would carry him if we went inside of a store. (Parent 5 line 41-44, 68-71, 140-143)

Abdominal pain is another source of treatment-induced pain that was described by both parents and nurses. Four of the eight nurses identified abdominal pain as a common symptom and half of the children had actually experienced abdominal pain during their ALL treatment. In their descriptions, nurses attributed this pain source to medications that these children receive during treatment for example constipation may result from vincristine (chemotherapy drug), and narcotics, nausea/stomach upset that may result from high dose steroids and stomach pain that may result from steroids, vincristine. In one case a child developed constipation that contributed to the development of rectal fissures and increased pain (Parent 7). The following example demonstrates how one child experienced ongoing abdominal pain as a result of her treatment and in this case the parents found it challenging to pinpoint the cause and manage her child's symptoms:

She would cry and tell me her belly is sore. And then she would sleep a lot. And she'd wake up and she'd be a little better. And initially I thought she was constipated because she had those issues too. And so we were trying to get her bowels to move, thinking that was the problem. And her bowels would move, the next day the stomach pain would be back. And so it would just be more or less

crying and then she'd kind of sit down and cry and fall asleep. (Parent 7 line 105-110)

For another child, abdominal pain, the worst source of pain experienced during ALL treatment, was experienced throughout his whole treatment:

Since they started vincristine, he had unbelievably terrible abdominal pain that would last... It was... very... We didn't know if it was just an acute thing. We didn't know if this was ongoing. He wasn't really able to tell us if it was stabbing pain, really where it was in the abdomen, you know.... There were times when he would scream or he would curl up in a ball and just he would say "I can't do this anymore". Why is this happening to me? ... I think it was always there but it was very... it was low and then it would spike up again. So for about an hour he would be like rocking in the bed.... I'd say for the first six months it was when it was at its heightened peak when we would have to get heating pads out at home even. Like I'd be laying in the bed with him and he'd be curled up in a ball crying. (Parent 8 line 49-53, 79-80, 89-91, 130-132)

One nurse identified avascular necrosis as a potential source of pain and one of the eight children actually developed this complication as a result of treatment. The nurse described avascular necrosis as:

...an ongoing throbbing pain. Sometimes it seems that, you know, they kind of say, "Oh it's been bothering me a little bit for a while," and then it becomes significant. And then that's when we actually discover that they had it. Or it can be an acute pain crisis. I've seen both. Where they, you know, go into emerg because they're in so much pain. Or they come into us. (Nurse 7 line 112-116)

The parent described her child's acute presentation of severe pain that was the result of her developing avascular necrosis:

...that night she started screaming with the pain in a restaurant and she couldn't walk, which is exactly how she was at the very beginning when she was diagnosed... she didn't sleep very much through the night. (Parent 1 line 49-52)

In this case, the child was being monitored closely for changes and potential deterioration, as this is a side effect of treatment that is known to not completely resolve. This mother recognized that the avascular necrosis is something that will not go away and has already recognized and has limited activities that aggravate the child's pain symptoms.

In summary, parents and nurses identified several common sources of pain from 1) the disease including bone pain, headaches and abdominal pain, 2) medical procedures including port-a-cath accesses, bone marrow aspirations and lumbar punctures, and 3) side effects of the treatment drugs including peripheral neuropathy, abdominal pain, and avascular necrosis. Both parent and nurse findings were presented together to demonstrate the overlap in the results. Detailed pain sources are presented in Table 1 and 2.

Management Strategies

The following addresses the next two research questions: to identify effective strategies that parents use or can use to relieve pain (AI -Discovery), and to describe parents' ideal role using the identified strategies (AI Cycle). Parents and nurses were asked to describe pharmacological and non-pharmacological strategies used to manage each source of pain. After identifying pain strategies, participants were asked to describe

parents' actual role in applying the strategies. Parent and nurse perspectives were considered separately and there were notable differences between the two perspectives.

Parent report of parent management strategies. Parents described using both pharmacological and non-pharmacological strategies with a particular emphasis on their role in using non-pharmacological strategies to manage the different sources of pain. Parents provided minimal descriptions of their role in managing their child's disease related pain present at the time of diagnosis. The most common pharmacological strategies parents used included administering acetaminophen for disease and treatment related pain and applying topical anaesthetics prior to port-a-cath accesses. Although less common, several parents described their role in administering narcotics to relieve treatment and, less commonly, disease and procedure related pain (Parent 4, 8). The most common non-pharmacological strategies that parents described using to help their child with all pain sources from most to least common included: distraction, preparation, thermal therapy, massage, familiar comfort, being present, remaining calm, having a consistent parenting approach, providing the child with some control. While some of the parents identified their role in administering medications, most of the parents described in depth their role in applying non-pharmacological strategies. For a more comprehensive overview of parent's perspectives regarding their role in using pain management strategies refer to table 1.

Table 1: Parent reports of pain source and their use of pain management strategies	
Pain Source (P: parent participant ID)	Pain Management Strategies (P: parent participant ID)
<p><i>Disease</i></p> <ul style="list-style-type: none"> ✓ Bone (P1, 3a, 3b, 4, 5) ✓ Headache (P3a, 3b) ✓ Abdominal (P4, 7) 	<ul style="list-style-type: none"> • Distraction (P1) • Thermal therapy (heat/cold) (P1) • Medication administration (P4)
<p><i>Procedure</i></p> <ul style="list-style-type: none"> ✓ Port-a-cath access, intravenous, blood draws (P2a, 2b, 3a, 3b, 4, 6, 7, 8) ✓ Bone Marrow Aspiration (P2a, 3a, 3b, 7, 8) ✓ Lumbar Puncture (P3b, 4, 7, 8) ✓ Surgical (P2a, 7) ✓ Tape removal (P1, 2b) 	<ul style="list-style-type: none"> • Distraction (P1, 2a, 2b, 3a, 4, 5, 7, 8) • Preparation (P1, 2a, 2b, 3a, 3b, 7) • Being present (P1, 2a, 2b, 4, 7, 8) • Procedure routines (P1, 2a, 2b, 4, 7) • Apply topical anesthetics (P1, 2b, 3b) • Consistent parenting (P2a, 2b)
<p><i>Treatment</i></p> <ul style="list-style-type: none"> ✓ Nerve (P2a, 2b, 3a, 3b, 4, 5, 7, 8) ✓ Abdominal (P2b, 6, 7, 8) ✓ Headache (P4) ✓ Mouth sores (P6) ✓ Avascular Necrosis (P1) ✓ Bone (rib)(P4) 	<ul style="list-style-type: none"> • Distraction (P1, 2a, 2b, 4, 6, 7) • Thermal therapy (heat/cold) (P1, 3a, 3b, 4, 8) • Massage (P 2a, 3b, 4, 7, 8) • Medication administration (P 4, 7, 8)

Nurse report of parent management strategies. Nurses described parent’s ideal role as providing a combination of pharmacological and non-pharmacological pain strategies. Nurses also described parents’ key role in assessing their child’s pain and determining the effectiveness of pain treatment. The most common parent pharmacological strategies identified by nurses included the administration of acetaminophen and narcotics for all pain sources, gabapentin for treatment related pain, and the application of topical anaesthetics before procedures. Nurses also discussed parents’ key role in using a wide range of non-pharmacological pain management strategies including distraction, thermal therapy, massage, being present with child in pain, and advocating for what works for their individual child. A more comprehensive view of nurse perspectives can be found in Table 2

Table 2: Nurse report of pain sources and parents' use of management strategies	
Pain Source (N: Nurse participant ID)	Parent Pain Management Strategies (N: Nurse participant ID)
<p><i>Disease</i></p> <ul style="list-style-type: none"> ✓ Bone (N1, 2, 3, 4, 5, 6, 7) ✓ Headache (N3, 7) ✓ Abdominal (N3) 	<ul style="list-style-type: none"> • Medication administration (N1, 2, 4) • Pain assessment (N4, 6, 7) • Distraction (N6)
<p><i>Procedure</i></p> <ul style="list-style-type: none"> ✓ Port-a-cath access, intravenous, blood draws (N1, 2, 3, 4, 5, 6, 7, 8) ✓ Bone Marrow Aspiration (N1, 2, 3, 4, 6, 7, 8) ✓ Lumbar Puncture (N1, 2, 3, 4, 6, 7, 8) ✓ Surgical (N1, 3, 7, 8) ✓ Tape removal (N8) 	<ul style="list-style-type: none"> • Distraction (N 1, 2, 3, 4, 5, 6, 7) • Apply topical anesthetics (N 1, 2, 3, 4, 6, 7) • Being present (N2, 7, 8) • Advocate for what works (N7, 8) • Administer medications (N4) • Preparation (N 5) • Procedure routine (N5)
<p><i>Treatment</i></p> <ul style="list-style-type: none"> ✓ Nerve (N1, 2, 3, 4, 5, 6, 7, 8) ✓ Abdominal (N2, 3, 6, 8) ✓ Headache (N4, 5, 6) ✓ Mouth sores (N1, 5, 6) ✓ Avascular Necrosis (N7) 	<ul style="list-style-type: none"> • Administer medications (N1, 2, 3, 4, 6) • Pain assessment (N 5, 6, 7) • Thermal therapy (heat/cold) (N1, 4) • Massage (N1)

Supporting Parents' Pain Care Role

The next section will address the last research question and will discuss in depth from parent and nurse perspectives *the important structures and processes that effectively support parent's pain care involvement (AI -Design/Destiny)*

Parent themes. Six themes emerged from the parent and nurse interviews. A more comprehensive summary is presented in Appendix P. The main *Parent* themes and subthemes include:

P1) First steps: establishing therapeutic relationships

1.1) Developing trust

1.2) Establishing effective lines of communication

P2) Learning how to care for my child diagnosed with ALL

2.1) Beginner knowledge of ALL: a tornado

2.2) Actively seeking information

2.3) Concentrated learning

2.4) Engaging in cycle of information exchange

2.5) Expert knowledge of ALL: being able to anticipate

P3) Overcoming challenges and gaining confidence in recognizing pain

3.1) Difficulty/hesitancy with identifying pain

3.2) Learning what pain looks like

3.3) Mastering pain assessment

P4) Learning parent specific pain strategies

4.1) Child life training in non-pharmacological strategies

4.2) Reinforcement of learned strategies

P5) Putting the pieces together: empowered to take active pain care role

5.1) Non-pharmacological strategies: first step to management

5.1.1) Consistency and following routines

5.1.2) Being honest and remaining calm

5.2) Pharmacological strategies: second step to management

5.2.1) Varied comfort with medication administration

5.2.2) Overcoming challenges with pharmacological management

P6) Maintaining relationships: timely access and meaningful communication exchange with experts

P1 First steps: establishing therapeutic relationships. In all of the parent interviews, parents described the importance of developing meaningful relationships with the health care team with a particular emphasis on the clinic nurses. Specifically, parents talked about developing strong connections with these nurses who worked collaboratively with them throughout their child’s treatment. Several key attributes of a therapeutic relationship included establishing trust, developing effective lines of communication between parent and other health care team members.

1.1 Developing trust. Parents described how they developed a high level of trust and an intimate bond with their nurses to the point that parents considered them a part of their “family”. The following parent quote provides a powerful description of how one parent developed this strong connection with her child’s nurses and how this bond became the foundation of a trusting relationship:

Oh God, the nurses, like they were amazing. Like they're always amazing. I mean the clinic nurses, I guess are... We're seeing them more so they become more of a...kind of like your hospital family. So you get to trust them more. And then they

just get to learn your patterns and the way you are and how you react to his pain. You know, they kind of support you that way. So I mean like just being there. I mean they were always there and they were always helping, and, "What can I do?" You know, they would sit down and... Like before we had the Versed, they would actually sit and think in the room with me what can we do? I mean they were very involved in that kind of planning of it.... They will have even like certain things ready or they will know like, "Oh, okay, [child's name] is my patient today. I'm going to do this." They walk right in the room and they start talking about, you know, "How was your weekend or what did you do? You told me you were doing this." I mean all those little things help ease what's going to happen, right. I mean he really... You know, he really I think cherishes that, and that helps him a lot when he's going through those things. (Parent 8 line 527-535, 547-552)

Another parent described how the nurses came to know her and her child as individuals with specific needs. As a result this parent describes how the nurses viewed her child as a person and not just another child undergoing treatment and as a result the nurses developed an intimate understanding of the child's individual needs and subsequently tailored their care to meet these needs.

...for them to actually look at her kind of individually and see what works for her rather than, you know, she's another kid with ALL, here you go, kind of thing.... As well, like you said, that bond there. She's been in there so much now that she's... they've formed this bond with her that's not just, you know, a patient one. They know her. (Parent 7 ln 339-341, 343-345)

The following parent quote further highlights the important bond parents develop with their nurses or “her girls” with a specific emphasis on the child’s Family Care Coordinator.

The FCC is a phenomenal lady. Phenomenal, FCC, phenomenal. Don’t ever lose that woman.... I have used her as a resource plenty of times. And I’ve used the girls as resources. And if they didn’t have the answer for me then they would find the answer out for me ... I call them my girls because, you know what, they are just as part of everything that is going on as I. You know, everything that I had to experience and learn and do, they had to do the same. And they’ve helped me through a time in my life that... and my child’s life, that just down and out sucks. You know? (Parent 4 line 552-555)

This parent developed such an intimate relationship with her child’s nurses that she felt as though the nurses were going through the experience with her. Parents established therapeutic relationships with their nurses, which they identified as an important factor for moving them through their child’s ALL pain experiences.

1.2 Establishing effective lines of communication. Effective communication was also a consistent pattern that emerged from the parent interviews. Parents specifically recognized and described the important role of establishing effective lines of communication between themselves, and the IWK and primary health care teams in the child’s community. The following parent quote provides an excellent example of how effective communication within the team was important in building and strengthening the therapeutic relationship.

I've been surprised by the level of communication that's up at the IWK. Like in a good way. It was amazing how the whole team seemed to know every little aspect. It didn't matter if it was, you know, if it was a nurse coming in, if it was a doctor coming in, or if it was a nutritionist coming in, they all knew everything about her. What really shocked me was when we came home, we'd been home and been able to get some treatments at our local hospital here, and that the IWK keeps in such good contact with them and me as well. Like they were calling me every day and they were... So that was surprising, the amount of communication. Which is really excellent. (Parent 7 line 36-43)

Through effective communication, the “whole team seemed to know every little aspect” and had expert knowledge of her child’s needs which further contributes to the development and strengthening of a trusting therapeutic relationship. This parent also expressed the important role of having an open line of communication with the IWK team and specifically her child’s FCC who maintained regular telephone contact with the parent in the home care setting.

P2 Learning how to care for my child newly diagnosed with ALL. Parents described moving from being an expert in their child before diagnosis to becoming a novice in caring for their child with ALL. With the assistance of their clinic nurses, parents moved from being overwhelmed and uncertain about their child’s new needs and described how they relearned how to care for their child with ALL. Parents outlined several steps/subthemes that moved them through this learning process including: seeking information, receiving concentrated teaching from nurses, and engaging in a cycle of

information exchange with nurses that included repetition, reminders and reinforcement of teaching.

2.1 Beginner knowledge of ALL: a tornado

During the initial weeks of treatment, all of the parents were overwhelmed and uncertain about their child's diagnosis and their child's new and ongoing health care needs. As a result, in the early stages of treatment, parents relied heavily on the health care team for guidance. Even parents who had previous exposure to other family members with cancer or who had worked in the health care setting were uncertain about what their child's treatment would be like. One parent compared her initial experience to a "tornado" because there was so much happening at once making it difficult to get a good handle on things. Another parent parallels the uncertainty of having a child newly diagnosed with ALL to the experience of bringing home her first newborn:

I was pretty scared to bring him home. To me, I was bringing... Like when you have a newborn, you don't really want to touch him and all that when it's your first kid. Anyway I was like that with my first one. But it was the same.... But anyway, I was feeling... And I still feel like I have a newborn at home. The first time when we got here at home, I was scared. (Parent 3b line 624-631)

Although this parent has learned about her child's diagnosis and treatment there is still a level of uncertainty that she continues to experience throughout her child's treatment.

2.2 Actively seeking information. Despite being overwhelmed with their child's new ALL diagnosis, parents described being motivated to learn what they needed to know to effectively care for their child. As a result initially they relied heavily on the health care team, specifically their clinic nurses, to help them become confident and competent caregivers for their child. One parent provides an excellent example of her

strong desire for more information so she could gain a comprehensive understanding of her child's diagnosis and treatment:

As soon as she gave me the book, I went through it. I read everything in the book. I was done ... within a day I'd say I was probably done with the whole thing. So I was actually kind of like wanting more information ... so have you got time to talk now? And she was kind of waiting to, and I understand now ... We learned what's good and what's not good right away ... I tried to just take little bits of information as I could.... You know, I said, Give me the idea of what's going on. And any time I had a question, I asked....The healthcare team here and my husband and I did a really good job of kind of being ahead of stuff? Like I didn't want to wait to ask about what was going to happen in 3 months. You know, I said, okay lay it all out for me. Give me the idea of what's going on. And any time I had a question I asked. (Parent 2a line 201-203, 205-206, 221, 195-196, 226-229)

2.3 Concentrated learning. Most parents also talked about a period of concentrated learning that occurred during their child's initial hospitalization, which ranged from two to six weeks in length. During this hospital admission, the child was diagnosed with ALL and the parents relied heavily on the health care team to learn what they needed to know about their child's diagnosis, treatment and treatment side effects (e.g. pain) so they would be prepared to meet their child's health care needs at home.

Well, they really explain everything good when we go there. Like especially for the first 2 weeks that we were... like when we got the diagnosis. Like they didn't want to release us until they made sure we knew pretty much everything that

could go wrong. So they were helpful like that. Like they tried to make sure that we don't have any surprises once we're at home. (Parent 3a line 281-285)

Another parent provided an excellent description of how the health care team worked with her to educate and prepare her for what to expect. In this scenario the parent developed a good understanding of her child's treatment and she described how it was helpful to have the health care team available to meet her ongoing information needs.

I think in terms of pain, everything has gone smoothly. They prepared me for everything that he was about to go through. And I didn't really have any questions when he was actually going through the procedure because they had already answered everything before it happened. So they were good at preparing me and supporting me when I had questions. (Parent 5 line 227-231)

2.4 Engaging in cycle of information exchange. Parents described how the health care team went beyond simply providing parents with information and they took steps to engage and ensure parents understood their teaching. Parents worked collaboratively with the health care team and used a cycle of information exchange to ensure they had a good understanding of their child's diagnosis and treatment needs. Specifically, parents shared how nurses provided ongoing education with reinforcement and reminders to ensure they had a good understanding of what they were teaching. The following parent quote demonstrates this parent nurse information exchange process to optimize parent learning:

...even though everyone was giving us a lot of information, just the time to digest. And they'd keep reminding us of things and you know, just... not quizzing me but asking me if I understood and making sure it was all clear, I guess. Which was

excellent because your life is turned upside down. You know, not only just with this child that's sick, if you have another child at home, you know, your work, everything is flipped around. (Parent 7 line 45-50)

Specific to pain, nurses taught parents about common side effects from the treatment drugs including potential pain sources so parents would be prepared and know what to look for when they were in the home setting:

And you know, they would say, "With this specific chemo she gets, she might be feeling this and this and this. Maybe you can try" ... They would recommend trying different things to alleviate whatever she was going through.... The FCC gave us information on the side effects of all of the different drugs. (Parent 6 line 156-159, 204-205)

2.5 Expert knowledge: able to anticipate. Parents moved from not knowing what to expect and how to care for their child with ALL to being able to predict what would happen (e.g. treatment side effects) before it happened. "When she got onto her treatment I could almost tell what was going to happen, like whether it was her counts or whatever" (Parent 1 line 43-45). Several parents also described how once their child started treatment and they had adequate knowledge and as a result they were never really surprised by anything:

You know, I said, give me the idea of what's going on. And any time I had a question, I asked. You know so we didn't really get surprised by any of it. "The healthcare team here and my husband and I did a really good job of kind of being ahead of stuff? Like I didn't want to wait to ask about what was going to happen

in 3 months. You know, I said, okay lay it all out for me. Give me the idea of what's going on. And any time I had a question I asked. (Parent 2a line 226-229)

P3 Overcoming challenges and gaining confidence in recognizing pain.

3.1 Difficulty/hesitancy with identifying pain. Many parents had a difficult time and were hesitant to identify pain in their child and as a result they relied on the nurses to help them with pain assessment. Parents did not recognize their child's pain expression and had difficulty assessing their child's pain for multiple reasons including: if the child was younger and unable to verbalize pain, not asking their child because it would draw attention to child's pain, having the perception that their child has a high pain threshold so they were coping well, or the belief that their child has experienced so much pain they are used to it so it wasn't bothering them.

Several parents had a difficult time differentiating between pain and other symptoms related to treatment. Identifying pain was especially difficult for the parent of an infant whose child was not able to verbalize and describe her pain and as a result this mom relied on behavioural cues to identify her child's pain. This reliance on behavioural cues proved challenging because her child's irritability could also be the result of other causes related to her child's treatment:

I have a hard time distinguishing between pain and just overall, you know, feeling of "yuckiness". Like when she goes through certain chemotherapy, she just feels... she just wants to be held and she just wants to be comforted. (Parent 6 line 102-104)

When her child was irritable and not herself, she expressed how difficult it was to distinguish between pain and other common side effects related to her child's treatment.

Even the parent of a toddler who was verbal expressed how challenging it was to differentiate between pain and other treatment side effects:

Yes. You know, I mean it's like what's pain and what's just rub me because I don't feel right? You know what I mean? Because she didn't exactly say she was hurting but she would say, "Can you rub my legs," or can you rub my feet or whatever. I mean she was very active, you know, the whole time that we were inpatient, right. And she's still active. So it's hard to say when she slows down whether it's tired or cranky or low blood sugar or low hemoglobin. You know, like it was really difficult to kind of nail it down. (Parent 2a line 303-308)

Parents also identified other factors that influenced their ability to assess their child's pain for example one parent described how she avoided asking her child about pain because she has learned that asking about her child's pain draws attention to it and potentially makes the pain worse.

I didn't want to directly ask her because if she's playing around and she's not cranky and fussy and doesn't want to move, I'm not going to specifically ask her to call attention to it. Because I've found like even now, if I ask her if something hurts or something, even if she's not favouring it or something like she's just like. Yeah oh it hurts. (P2a line 703-707)

Another parent perceived that her child had a high pain threshold and as a result she "never complained" about pain". This parent also came to the conclusion that her child did not complain because she had experienced "so much" pain and got used to it.

I think she has a high threshold for pain and he said that I really think that you are right. She never complained about it and I don't ever remember giving her Tylenol or anything like that down there.... I think that she had had it so much maybe her body became used to it that we really never treated with much to be honest. (Parent 1 line 197-201, 205-206)

Although this child did not complain about having pain, she was diagnosed with avascular necrosis, a condition that results in significant pain, and she exhibited clear behavioural manifestations consistent with pain (e.g. decreased mobility).

3.2 Learning what pain looks like. Despite experiencing challenges and being hesitant with identifying their child's pain, several parents talked about how they worked with the nurses to further understand and be able to recognize pain in their child. One parent described how the nurses taught her specific pain assessment questions to use with her child:

I would talk to them [nurses] and they would help me kind of talk to her. Because like I said, when you're 2 or you're dealing with a 2 year old, you know, it's kind of hard. So sometimes they would ask her some questions, you know, and if they agreed with me that yes, okay, maybe we'll give her something, then we'd get her something.... Once they gave me like kind of those questions that I could ask, like where does it hurt, does it hurt a lot, does it hurt a little? (Parent 2a line 791-798)

This parent also mentioned the possibility of using a pain assessment tool to assess her child's pain but she chose not to use one because she had tried it in the past and did not find it effective for assessing pain in one of her other children.

You know, I never used one of the pain scales that I've seen before because I found with my oldest when I would try to use the pain scale, like they had the happy face and the really grumpy face, every time he picked the really grumpy face. So I stopped using those with him, right. So I mean that's kind of coloured my experience with everybody down the line. So I try not to use those. (Parent 2a, line 798-802)

3.3 Mastering pain assessment. With reflective experience and guidance from the health care team, parents gained confidence and expert knowledge about their child's pain and were able to identify patterns and subsequently interpret their child's specific pain cues. The following parent quote captures how one parent worked with her nurses to identify her child's pain. As the parent became familiar with how her child reacted to pain, she was able read her child's specific pain cues with confidence:

So we were trying to figure out is it a mood swing or is she in pain or ... You know, it's like trying to. Because she wouldn't tell us.... And then once we got to know, you know, exactly ... Actually just watching her body language just told us a lot because we'd just watch what she was doing and then we'd know, oh, that's ... she's in pain now, she... you know ... she kind of curls up or shuts down. Like goes in a little.... You know, just kind of curls up, or she wants certain things. Like she wants her blankie and her certain stuffed animal. And the big thing with her is she would play with her hair a lot when she's in pain. (Parent 7 line 71-72, 74-76, 78-81)

In summary, several parents said they were challenged and hesitant to identify what they were seeing in their child as pain. As a result they engaged in an ongoing information

exchange to assist in skill development and worked with their nurses who had expert knowledge in common ways children respond to ALL pain.

P4 Learning parent specific pain strategies.

4.1 Child life specialist training in non-pharmacological strategies. Parents worked in partnership with health care team members to learn and apply pain care strategies with a particular emphasis on non-pharmacological strategies. Specifically, many parents talked in depth about how the Child Life Specialist (CLS) played a primary role in teaching and involving them in using non-pharmacological pain management strategies including: improving parent child communication, providing parents with opportunities to learn about and apply non-pharmacological pain strategies including preparation and therapeutic play and distraction.

One parent shared how the CLS facilitated her ability to effectively communicate with her child. With this improved communication, the child was able to better express how she was feeling and the parent gained a better understanding of the child's actual experience.

Especially I found what really was surprising was (CLS's name), how well that she can get the children to communicate so that you can understand how they're feeling, so that they can start describing to you how they're feeling, and being open. That was a really big surprise for me.... The communication that she set up so that your child learns how to tell you, you know, my body is feeling like this

right now and this is what it's feeling like. It actually gets them trained for down the road of how to, you know, explain what their body is feeling so that you know what to do. It's phenomenal. (Parent 4 line 39-42, 44-47)

This parent recognized the importance of effective parent child communication in order to direct and guide “what to do” and make ongoing treatment decisions.

Parents also talked about how the CLS taught and involved them in using a wide range of procedural distraction strategies.

Like when we are getting port accesses and stuff, we pretty much have it down to a science now because I have had her help of what we need to do to make that less uncomfortable and less scary for your child... I'm not sure what other people have done for things, like for tactics for their child. But I mean those, you know, were learned and we put in place. And I just carry on with them.... So we learned how to do the distraction. We found out what kind of distractions that she needed. How to talk about the procedure before we were going in to do it so it wasn't a very big surprise (Parent 4 line 152-156, 175-177)

The CLS also worked with parents to promote their use of distraction strategies to manage non-procedure pain for example she encouraged socialization and promoted child participation in normal age appropriate activities such as playing and interacting with other children:

It's immeasurable because, yeah, without that, it's quite difficult to ... I mean that's a big distraction, and I think that's helped in helping he... even in dealing with not feeling good and pain-wise, like I think that having that play room just to go to distract her, I think that's... Yeah, that's invaluable. (Parent 6 line 212-216)

The parent described the CLS using developmentally appropriate therapeutic play strategies to engage and prepare children for medical procedures. Specifically, parents referred to the “voodoo doll” to practice/role play and teach and prepare children for procedures so they would know what to expect.

When she was first being explained about getting her port, which that was Child Life, you know, she comes in with that little voodoo doll... We call it the voodoo doll that has the port underneath, you know, and stuff. (Parent 4 line 170-173)

One parent described how she took what she learned from the CLS and was able to incorporate therapeutic play in the home setting by involving siblings. In this case, engaging the whole family in therapeutic play was a strategy used to normalize the child’s treatment.

She likes to play nurse or whatever you want to call it at home. And we would let her put... She would tell us to lay down, we need to have our access done. And she'd go through the whole cleaning. So letting her do that between myself, Mom and her two brothers. Like we had to explain to her two brothers that this is what [child's name]'s life is right now, this is what she sees. And if she thinks that this is wrong to you guys, when she goes and needs to have this done, she's going to feel like it's wrong. So they participated with it every time she asked. (Parent 2b line 105-111)

4.2 Reinforcement of learned strategies. Although CLS’s play a primary role in teaching non-drug strategies, parents also learned about and received reinforcement from the nurses to use these learned strategies:

...at first they [nurses] did tell me what other parents have done with their children when they're getting their port accessed or they're getting finger pokes or they're going in for chemo or anything like that. So they told me to bring his favourite blanket or a stuffed animal or bring a toy that he really enjoys. And each time that we go to the hospital, I make sure that I bring a blanket and a toy and like a stuffy. Or he has an iPad or a DS to play with. And that makes things easier too because he's a little bit distracted and he has things from home that make him comfortable. (Parent 5 line 187-193)

In addition to being taught and receiving reinforcement to use non-pharmacological pain strategies, one parent described the importance of being open and willing to observe and learn from the CLS and nurses

...you know what, there's nothing that I could think of that they could do because I think they do... what they do, they do it very well. And if the parent... I think it depends on the parent. I think if the parent watched what these women are doing and listening to what is being said to them, and apply it to their child, and listen to their child, I think they'll be able to figure it out. You know what I mean: Like I think they would get it. And I think the children would be more comfortable. I think it all comes down to is that you have to realize that you're that team, that support. And you have a lot of input on how your child is going to react. (Parent 4 line 530-537)

This parent described how the health care team provided her with adequate knowledge and opportunities to participate in her child's pain care. In turn, she also described how it build her willingness to take and use the information to enhance her involvement.

Many parents, as explained above, described learning distraction strategies from the health care team while other parents did not make that distinct connection. For example one parent described how her role in using procedural distraction strategies evolved over time with her reflective experience and observations of what worked in the past:

That just kind of evolved. You know like we noticed with her finger pokes sometimes, just talking to her, getting her attention on us rather than her sitting there watching them... She learned that if she was upset and tense and angry and fearful and all that stuff that it was so much worse than if she would just calm down, think about something else, look for the butterflies on the ceiling, look for my soother, play a game (Parent 2a line, 538, 856-859).

P5 Putting the pieces together: empowered to take active pain management role.

Parents gained confidence and were able to piece together and apply learned pain management strategies. They also drew from their own personal reflective experiences with their child with ALL, as well as other children, and themselves and were able to tailor their pain management plan to meet their individual child's needs.

5.1 Incorporating non-pharmacological strategies: first step to management. All parents described routinely using non-pharmacological pain management strategies that they learned from the health care team as well as from their own personal experiences. Several parents also emphasized their preference for using non-pharmacological

strategies as the first line to pain management before considering pharmacological options. The following parent described how she routinely used distraction and provided assistance with mobilization before she considered administering medications:

She never complained about it and I don't ever remember giving her Tylenol or anything like that down there. Even though she couldn't walk sometimes, we'd put her in the wagon or we'd put her on the tricycle. We used to have to kind of hold onto her hands and stuff when she was walking in case she might slip and fall.... I think one of the best things that she had, which was non-medication, was probably her friends and her Child Life Specialist (Parent 1 line 200-204, 337-338)

Another parent also described her preference for starting with non-drug strategies first before moving onto medications to manage her child's pain.

We try to tell our kids, you know, work through it if you can. If you can work through it on your own, work through it. You know if you can't let us know. You know we'll get you something if you need it but if it's just a little pain try some ice. Or you know, like when they scrape their knees, you know we try ice and stuff. Like we don't go straight to Tylenol. (Parent 2a line 765-770)

In addition to parents whose preference was to use non-drug strategies as the first line of management, most parents described their routine use of non-pharmacological strategies they learned from the health care team to help their child in pain (e.g.

distraction, therapeutic play, preparation, socialization, normalization). Once parents were comfortable with what they learned from the health care team, they were creative and used a combination of distraction strategies to manage their child's pain during treatment. The following parent quote provides a comprehensive description of how one parent effectively incorporated a combination of learned distraction strategies to manage her child's non-procedure pain:

She can watch one of her favourite shows. That always seems to be the go to because the kids just kind of like zone out for TV. Like if your kid zones, you're good at this point. If your kid is zoning out and not thinking about what's going on. Crafts. Crafts are huge right now. Getting them to do something with their hands to keep their distraction away from whatever is going on with their body. So we've been doing more crafts in this house than I can ever say that we were doing. She's not much for going outside, because, you know, she can't do it. But those are two of the techniques that we use. Or we'll get talking about something. I'll get her off on some sort of crazy rant about... I just ask her a silly question and then we're off ranting about something else you know. (Parent 4 line 398-407)

In addition to what they learned from the health care team, parents drew from their own experiences and described other non-drug strategies that they found helpful in alleviating their child's pain and includes strategies like providing a familiar comfort, using massage and thermal therapies, using consistent parenting approach, being honest, and staying calm.

Most parents described the importance of incorporating familiar comforts when their child was experiencing pain. Parents expressed the importance of being present both emotionally and physically to comfort their child when they were in pain or undergoing procedures. The following parent quote describes how a parent was emotionally present to comfort her child:

And just check in with her. You know, even just checking in with your child when they're in pain like that makes them feel better. You know like, "Oh she's not forgetting I'm not feeling well" And it just makes them feel better. You know, like when you have a flu and your mom just comes over and touches your forehead even though she knows you still have a fever. But it just feels good to have that touch. You know, to know that your mom didn't forget about you and you're still there. (Parent 4 line 488-493).

For sedated procedures and surgeries, several parents stressed the importance of being physically present with their child during anaesthesia induction. In these scenarios, parents interpreted the health care team as accommodating and supportive of their request to be present to comfort their child.

Normally dad would just carry her in. But when she got older she would walk in and dad would tell the person straight up. I usually hold her until she goes to sleep then I lay her down.... As soon as he walked in, like he would say to them... The anaesthesiologist would introduce himself. He'd say, "Hi, I'm Dad. I usually hold her and lay her down.... They were all pretty understanding. And like I said, you know, like we made sure that they knew upfront what we wanted. And even when... Like when they were going to be taking her to surgery even that first time,

Dad said, "Well, I want to be there. I want to lay her down," because he had done that with one of our other kids. He's like, "I want to be there. I want to be there when she goes to sleep. She's never been away from us." I mean she was 2 at the time. She'd never been away from us. We didn't even know if she'd go with a nurse, you know. (Parent 2a line 613-615, 619-620,627-634)

Another parent described her important role in being present with her child while she was put to sleep for surgical procedures.

With the surgeries, I've been allowed right in the room with her until she's out. The same with the sedations. You know, we hold her until she's out. Yeah they're very accommodating with all that (Parent 7 line 310-312).

Parents also said it was important to provide their child something that soothed and comforted the child before they were diagnosed with ALL. These familiar comforts varied from using breastfeeding to having a family pet present, to providing the child with an object that comforted and soothed them before diagnosis e.g. soother, blankie. One parent described how she routinely used breastfeeding to comfort her infant when she was unwell, irritable and/or not “herself”:

And nursing, like nursing has always helped her.... that was the go-to. Like when she was not feeling well.... It just worked for her before. And just as we were going through her treatment and even before that, like when she wasn't feeling good, that was the one thing that I could always count on to kind of soothe her, you know (Parent 6 line 104-105, 115-116, 226-228).

Another parent used their family dog to comfort their child who was in pain for example “If she couldn't get up to see the dog because her pain was so bad, we would

just bring the dog to her and she was fine” (Parent 1 line 419-421). Parents also used objects including a soother and or special blanket to comfort their child in pain. For example one child was almost completely weaned off a soother until she was diagnosed and exposed to stressful situations which led the child to use the soother regularly as a familiar comfort.

She still had a soother when she first started at two She had almost given it up at that point before we found out she was sick. We found out that she needed it more and more for comfort when she was here. So she did use that. (Parent 2a line 483-486).

Some parents also made sure their child had their familiar special blanket to comfort their child in pain or undergoing stressful procedures such as anaesthesia induction. The following parent quote provides an example of how a child was comforted by his “blankie” during stressful situations when his parents were unable to be physically present:

Now I send the blankie with him because we cannot go in the recovery room either. So he's an hour after the lumbar puncture in the recovery room with nurses. So we send the blankie in all the time now. (Parent 3a line 487-490)

Many parents also described how they routinely incorporated massage and thermal (hot/cold) therapies to relieve their child’s pain even though the health care team had not provided training regarding these strategies. Specifically, massage was used as a key strategy to relieve ongoing bone/neuropathic pain during treatment. One parent

provided a detailed description of how she drew from her own experience of having restless legs and applied massage strategies that worked for her:

I rub her legs. And I have tea tree. And you know how it kind of makes that nice tingly kind of warm kind of feeling but cool at the same time ... And she falls asleep with that. I'm going to be a massage therapist by the time this is all done ... As a massage oil. And I think even just the smell, the smell of tea tree kind of distracts her a little bit. She she's like, "Oh, that's strong. But it's opening my nose up and can I ever smell." You know what I mean? And that's kind of a method of distraction for her that smell ... I have restless legs myself. I've always had restless legs. And I've always put the tea tree on my legs. And it works for me and it feels good for me so I'm like, well, why isn't it not going to feel good for my child whose legs are feeling kind of the same way: Because that's how it was described to me, is it feels like restless leg syndrome. And why wouldn't it work? (Parent 4 line 297-298; 302-303, 460-463, 475-479)

Parents used heat (e.g. warm baths, heating pads) and cold (e.g. ice) therapies to alleviate their child's pain and general discomfort. The following is an example of how one parent used a warm bath to help manage her child's neuropathic pain:

...we do a warm bath at night just on those nights that I know that... It seems to be when it's warmer that it does affect her. Now, that nice hot water just soaking around her body, and then she's coming out, makes the air feel cooler. (Parent 4 line 503-505)

Another parent shared how she applied ice to her child's intramuscular injection sites before and after the procedure "we were putting ice 15 minutes after the injection.... Before and after, and I think that helped" (Parent 3b line 316-317, 321).

5.1.1 Consistency and following routines. Parents described the importance of being consistent in their parenting approach and following procedure routines. The following parent quote reflects one parent's approach to maintain consistent parenting and how this contributed to positive coping in her child:

...you see a lot of it when you have some sick kids, that a lot of parents and stuff a lot of times let the kids get away with a lot. Well, we weren't willing to do that. It was fairly strict and we wouldn't let her get rude with anybody. And if she did, she would be corrected then. And it made a big difference ... if we had let her go then things would have gotten a lot more out of hand and there would have been a lot more screaming and crying and arguing. (Parent 2b, line 236-239, line 242-243)

This parent observed the negative effects of inconsistent parenting on other children and as a result she recognized she needed to use consistent parenting as a strategy to promote her child's coping.

Parents also maintained consistency by developing, following, and advocating for procedure routines. The following is an excellent example of how one parent developed and engaged in a specific procedure routine:

We turned it into a bit of a pattern. It was always that at first she still had her soother. So that was something big that she always wanted to have with her.... And when we would go to have... Well, even for having her port access put on, I

would hold her. She wanted me to be holding her. And when she would be called in for her lumbar punctures, I would carry her in. I would hold her. They would put her to sleep in my arms. And then I would lay her down.... And it's become such a pattern for her. That's always what she was looking for. As soon as they called her in, she knew where she was going, she knew she was going to do this. She would look to me and reach up (Parent 2a line 80-81, 85-88, 90-92)

This parent described how following a routine or “pattern” helped her child know what to expect. Other parents explained how they “pretty much have [procedure routines] down to a science now” (Parent 4 line 152) or in another parent’s words “we’ve kind of come up with a little routine for the port access” (Parent 7 line 264). These procedure routines became particularly important when the child was receiving care in primary care settings where the health care team was unfamiliar with the child as evidenced in the following quote:

...when you go into your other hospitals like we had... They didn't know what to do. There was a few times that I had to stop the doctors there and tell them, this is what you need to do. I'm not trying to take over your job. This is what has to go on.... So it got to the point where all the nurses in there were like “ Oh (patient's name) is coming in. Just listen to what dad has to say. We'll do it” And then because every time before I went in.... They knew she was coming. We knew what we were supposed to do. (Parent 2b line 267-277)

This parent was able to advocate for and guide the home healthcare team in following specific procedure routines. There was also evidence to suggest that once an effective

procedure routine was established, parents and children preferred not to deviate from it because it was predictable and they knew it worked:

Some nurses would try to offer suggestions to her, and sometimes that would be more frustrating for her than not. Like some of them would suggest a deep breath. You know, take a deep breath in and blow it out. And when you blow it out, I'll put the needle in. And that just frustrated her. She didn't like that. I think in her mind, she's like I already have what will work for me. I already know. I don't want to do that. I don't want to do it your way. (Parent 2a line 575-580).

In this scenario, the parent and child had already developed effective procedure routines and when health care team members suggested strategies that deviated from this routine the child became frustrated.

5.1.2 Being honest and remaining calm. Several parents described being honest with their child so they would trust them and know what to expect in the future. The following quote provides an example of how one parent was honest to ensure that her child would trust and believe what she said in the future:

I never told him it would not hurt. I've always told him the truth. I think that's what it has to be. And I am always telling him that it's for his best, it's to heal him. And the pain will go away right after the procedure is done ... If I say that once and he feels pain, well, he won't believe me the next time that it doesn't hurt (Parent 3b line, 345-347, 364-365).

Several parents also stressed the importance of remaining calm in order to instill confidence in their child as one-parent stated, "I think like even staying calm, like us as parents with him. Like when he goes through his needles or anything. I think that kind of

helped too because it put him more in confidence of what's going on" (Parent 3a line 304-306). The following parent described how difficult it was to remain calm but recognized how her reactions would influence her child "The hardest part was trying to stay calm ourselves.... she was okay as long as we were okay. So we stayed calm and, you know, cheerful" (Parent 7 line 69-70, 127-128).

5.2) Pharmacological strategies: second step to management. In addition to using non-pharmacological strategies, parents also described their role in administering pain-relieving medications.

5.2.1 Varied comfort level with medication administration. One pharmacological pain relieving strategy that most parents used and were comfortable using included the application of topical anaesthetics prior to port-a-cath accesses. In some cases, parents tailored this pharmacological strategy to meet their child's individual needs and in some cases applied it for longer than the recommended sixty minutes because they found it more effective.

Most parents were comfortable with applying topical anaesthetics but there was variability in their self-described comfort with administering other pharmacological strategies. Specifically, some parents said they were comfortable using acetaminophen while other parents were hesitant to medicate and preferred to use only non-pharmacological strategies. In contrast, some parents were comfortable with routinely using a combination of acetaminophen and narcotics to manage their child's pain:

So what I do is I give her Tylenol first. After if the pain is enough that she needs Tylenol, "Will Tylenol work?" This is all the stuff I've learned in the hospital from the girls... "Is it Tylenol that you need or is it do you need morphine?"

*“What kind of pain?” “How much pain are you in right now?” And she will tell me if Tylenol will be enough (P4 line 329-332) “ and you know, thinking about putting your kid on morphine is kind of... a normal person would be like why are you putting your kid on morphine: You know? But now it’s just kind of normal” For her legs, she had taken morphine. She has ... only when she’s bawling her head off and asking for it ... “it hurts so bad” You know what I mean? And then “Like how bad does it hurt?” “Does it hurt really, really bad?” “Like do you need” ... “Yeah I need a little bit of my” ... She calls it her soap medicine. And that’s what she calls... She says morphine tastes like soap”.
(Parent 4 line 329-332, 354-356, 511-515)*

Another parent who was comfortable with using medications to alleviate her child’s pain described a scenario when she was able to advocate for better pharmacological management when present treatment was inadequate.

Like they couldn't help him no matter what they did. They got the doll out. We did everything imaginable.... So there was one point where I said I’m not coming into the hospital with him to get his port access until you guys think of something. So whether you give him IV versed or like... I don’t care where you put it. I said put it up his tongue, something. He needs something. And that’s when the girl said “What about intranasal versed?” Like he was the first kid to have it. And it worked wonders. So he doesn’t feel the pain of the procedure. (Parent 8 line 432-433, 215-220)

5.2.2 *Overcoming challenges with pharmacological management.* In contrast with parents who were comfortable with using medications to alleviate their child’s pain, some

parents were hesitant with using medications for reasons including having difficulty getting the child to take medications and misperceptions about analgesics.

Several parents described challenges related to getting their child to take medications. For instance one parent described the traumatic experience of having to hold her child down to administer morphine when her child was experiencing pain. Despite having difficulty administering morphine to her child, this parent was encouraged to continue administering it when she observed the positive effects of alleviated pain in her child. In addition, the child, who did not want to take morphine, also got to the point where she no longer put up a fight to take the medication and began asking for the medication because she knew it would make her feel better.

At first she didn't want to take her medicine because they tasted disgusting, you know. And that was all worked through everybody together ... it still feels weird that it's morphine but at the same time, it's making your child comfortable and not crying and feeling better ... her pain is real and it's something that she is asking for. She's learned from her experience that it's something that helps her.
(Parent 4 line 345-346, 358-359, 360-361)

Some parents also had misperceptions related to common analgesics and these misperceptions influenced their comfort with medication administration. Several parents were fearful with using acetaminophen because they were concerned it would mask a fever and a serious infection even when the child was not neutropenic. For example one parent shared how she “*was scared a little bit to give him Tylenol and hide a fever ... And I would never give it every 4 hours just to make sure I was not hiding a fever*” (Parent 3b line 561, 571). Another parent identified that acetaminophen could be used to manage her

child's pain but she also expressed her hesitation with using it "You know you could use Tylenol but at the same time with using Tylenol, you had to be really careful because of what her temperatures were" (Parent 2b line 354-356). Another parent whose child was near the end of treatment described waiting to treat her child's pain with acetaminophen because if her child's pain worsened she was fearful that her child would need something stronger (e.g. narcotic). As a result this parent was hesitant to use medications and she reverted to non-pharmacological strategies as the first line of pain management.

And you know, like where everything... There's a dosage for everything. So if she is in a little bit of pain right now, not too bad, and we gave her a dose of Tylenol, in an hour if the pain gets really bad and she's already had her dose of Tylenol, we have nowhere to go. Right? Because she would have to wait another 3 hours for another dose of Tylenol. Or we'd have to go to something even stronger. Well, she's 2 years old. We don't want to do that if we can avoid it. Let's start with the rubbing of her legs and then go out from there. (Parent 2a line 781-787).

In summary, many parents relied on a wide variety of non-pharmacological strategies they learned from the health care team and their own experience with their child as the first line of pain management. With respect to pharmacological management, parents described variable comfort levels with administering medications and were hesitant for the following reasons: difficulty getting their child to take medications and misperceptions related to medications.

P6 Maintaining relationships: timely access and meaningful communication exchange with experts. From diagnosis and throughout treatment parents described having easy access to their FCC or an on call physician any time they had questions or

concerns. Maintaining and building upon therapeutic relationships that were established with nurses at diagnosis was important for parents. Parents described how their consistent FCC and physicians developed and maintained an intimate understanding of their individual child's case and as a result when parents called, they never had to explain themselves, the nurse or doctor already knew their story. One parent said that the health care team knows them more than they know themselves.

...if I ever have any questions about anything I can just pick up the phone and they are just a phone call away. They know everything about her and probably know about me more than I know about myself (laugh). (Parent 1 line 529-531)

Parents also talked about how they communicated with their FCC more frequently when their child was first diagnosed and as they gained comfort this contact decreased in frequency for example one parent described how:

every time I had questions, I could call our FCC. I could call even the physician.... At the beginning, I was calling the FCC maybe twice a week. Every little something. But now I check myself and I am not scared anymore. (Parent 3b line 585-586, 638-639)

Parents were reassured by having the health care team only a phone call away if they needed further guidance. The following parent quote provides an excellent example of the easy access and ongoing communication parents have with their nurses:

Yeah, the fact that we have... The fact that it doesn't matter, day or night, I call, I talk to somebody immediately. That's really a huge, huge worry that's lifted ... So I know that like if it's a Monday to Friday, 8 to 5, I call the clinic and I talk to somebody I know and that knows [child's name]. And I don't need to go through

child's name is a 7 year old boy with leukemia. They know my name. And when they hear [participant's name], they know it's [child's name] and they know what's going on. Like I've never heard a nurse or a doctor or somebody come in the room and not know his case or said, "So was he the boy that had that?" Like they're very knowledgeable about that stuff. And even when you call at night, it's the same thing. (Parent 8 line 558-567)

As a result, even though parents take care of their child in the home setting they are never alone and are only a phone call away from receiving further guidance from expert health care team members who know them.

Nurse themes. In the following section the six main *Nurse* themes and subthemes are presented and include:

N1) Getting to know us: establishing meaningful relationships

1.1 Being committed to families

1.2 Providing consistent expert nurse contact

1.3 Partnering with parents

N2) A steep learning curve: preparing parents to care for their child with ALL

2.1 Providing tailored education

2.2 Incorporating ongoing reinforcement, reminders and repetition

N3) Facilitating pain assessment: two-way communication between nurses and parents

3.1 Teaching common signs and symptoms of ALL pain

3.2 Valuing parents expert knowledge: relying on parents' assessment

N4) Involving and teaching parents best pain care from the beginning

4.1 Drawing from multidisciplinary expertise

4.2 Training parents in non-pharmacological management

4.3 Providing guidance with pharmacological management and recognizing challenges

N5) Parents empowered to manage pain

5.1 Taking active procedure role

5.2 Developing routines

5.3 Managing non-procedure pain

5.4 Supporting parent advocacy

N6) Maintaining meaningful supportive relationships with easy access

N1 Getting to know us: establishing meaningful relationships. Similar to parents, clinic nurses recognized the importance of establishing and developing trusting relationships with the parent and child. Several aspects that contributed to the development of therapeutic relationships included: having a consistent clinic nurse dedicated to helping the child and family, providing parents with a key nursing contact, and working in partnership with parents.

1.1 Being committed to families. Nurses in this study emphasized their strong desire and commitment to working with the child and family as they navigate through the whole ALL treatment trajectory as one nurse explains: “I really did enjoy working with the families. I much prefer to treat the entire family versus just the child. I feel like I do a better job when I am treating everybody (Nurse 1, line 29-31).” In addition to having a strong desire and commitment to working with these families as a whole, clinic nurses describe how they prefer to work in oncology because they get the chance to work closely and consistently with these families over an extended treatment period.

Oncology specifically is really nice because you see the same people and you get to watch them grow up and you get to watch their families learn how to cope with something that most families don't get to or have to ... Yes rather than like working in emergency where you may see a child once, you get that continuity and you really get to work with the kids as they grow up (Nurse 2 line 34-37, 42-43).

The long-term nature of cancer nursing differs from other specialty nursing areas where patients are treated for acute illnesses and are discharged home e.g. emergency.

1.2 Providing consistent expert nurse contact. When nurses described how parents navigate through the ALL pain experience they identified the importance of providing parents with one consistent key nursing contact the Family Care Coordinator (FCC) who helps the parent and child navigate through the complex treatment experience. Specifically, the FCC becomes the parent's key nursing contact that has expert knowledge about the ALL diagnosis, treatment and potential and expected side effects. Nurses described the FCC's liaison role with the family, one nurse stated:

I would say the nuts and bolts of it is a liaison... a consistent liaison for families between the healthcare team here, the home resources or home health care team, and the families. We're probably the most consistent go to person for the family.
(Nurse 7 line 22-25)

The FCC develops an intimate knowledge of the individual parent and child and they use this expert knowledge to facilitate communication within the multidisciplinary team:

as the Family Care Coordinator, I know what's been happening. So I can relay a log of that information. I will have had phone calls from parents if there's issues at home. But when the child then comes to clinic, they're seeing a different nurse. But I can let... We have regular meetings with doctors, primary physicians. So you're keeping up to date with other issues that they're having at home that you're not always seeing when they're here because obviously most of the treatment is outpatient. (Nurse 8 line 423-429)

The FCC has accurate and current knowledge of the child and as a result is able to communicate with multidisciplinary team members to ensure the provision of consistent care within the IWK and primary care settings.

1.3 Partnering with parents. In addition to providing families with a consistent nurse contact, nurses also described working in mutual partnership with parents. As a result nurses partnered with and encouraged parent involvement through each stage of the ALL treatment experience:

Well the family is directly involved right from the start. There is never a point where a family is not fully included in anything that we do with their child,

whether it's procedural pain or if it is treatment related pain or diagnosis related pain (Nurse 3 line 298-301).

Nurses collaborated with parents and considered them as equal partners during all phases of the child's treatment. This partnership reflected as a common theme that emerged as parents navigated through their child's ALL pain experiences.

N2 A steep learning curve: preparing parents to care for their child with ALL.

Nurses described how parents are overwhelmed early in their child's treatment and during periods of unpredicted acute illness. As a result, nurses focused on educating and providing parents with adequate knowledge and skills to effectively navigate their child's ALL experience. The following quote provides an excellent example of how nurses move parents from the initial stage of being overwhelmed to gaining expert knowledge and being able to know what to expect as the treatment progresses:

...they're so overwhelmed with the fact that their child has been diagnosed with cancer and then boom, they've got to be looking at all of these papers on study, non-study, what treatment plan, what's the best, so they're very overwhelmed and tunnel visioned with that. As things kind of progress down and they see that things are kind of settling out and they know the routine, then they tend to be very good advocates, they notice things (Nurse 5 line 374-379).

2.1 Providing tailored education. Nurses play a key role in moving parents through this steep learning curve by providing an individualized tailored educational approach to help parents understand “medication side effects, prognosis, protocols” (Nurse 1 line 481). The following quote provides an example of how nurses tailor their educational approach to meet the parents learning needs.

...some parents don't actually read English or have difficulty with it. We do get immigrant parent and families that come here that don't have a take on the language and the language that we use. Sometimes diagrams, pictures, photos is what they need. Sometimes with medications, they all have their medication calendar. We may have to think of colour coordinating a bottle with what's written there. We might have to organize with... We have a great pharmacy department here. They sometimes coordinate with the community pharmacy after the FCC has been able to present a problem with this patient. And they can organize for medications to be blister packed daily for families to pick up. You know, sometimes there's only one parent family. Oh, there's a whole dynamic there. There's a lot of things to think about and potentially work through. (Nurse 8 line 451-461)

Nurses identified that there is no standardized educational approach that works for all parents and as a result they said parent education can be challenging. Some of the challenges are presented in the following nurse quote:

Sometimes our teaching is a bit trial and error because we don't know necessarily how the parents are going to learn information or retain information. So I think we try to do as an effective job as we can, but sometimes what works for one family won't work for another family. (Nurse 2 line 557-560)

2.2 *Incorporating ongoing reinforcement, reminders and repetition.* Nurses engage parents in ongoing education by using repetition and ongoing reminders to ensure that parents have a good understanding for example *“Once treatment has begun, we tell*

them a lot of the side effects of the drugs and we have to keep reinforcing things because it's new to them" (Nurse 3 line 484-485). Specific to pain, nurses taught parents about common ALL pain sources so they would be prepared and know what to look for as one nurse states "with education they're better educated to look for specific types of pain with medications that happen in different phases of therapy. And that's what a big part of what we teach the parents" (Nurse 8 line 488-491). Another nurse reinforced her teaching with parents during regular clinic appointments for example "*when they come in for visits, we kind of are on top of it asking them "do you feel the tingling" because that's the first indication and so we kind of monitor*" (Nurse 5 line 179-183). During regular clinic appointments, this nurse screened for common sources use this screening process as a strategy to reinforce her teaching.

3) Facilitating pain assessment: two-way communication between nurses and parents.

3.1 Teaching common signs and symptoms of ALL pain. Nurses found that many parents had difficulty with recognizing their child's ALL pain for example they "*may not know that their child is in pain or the degree of pain that they are in*" (Nurse 6 line 355-356). In response, nurses engaged parents in a two-way information exchange that drew from parent and nurse expertise. Specifically, nurses drew from their own observations of pain in children with ALL and parent's expert knowledge and ability to recognize changes in their child's behaviour and they worked with parents to assess their child's pain. Nurses recognized the importance of teaching parents how to recognize pain so they would become "*aware of how [their] child behaves when they are in pain, [and so they would be] able to identify the pain at an early point.*" (Nurse 6 line 349-350). The

following nurse quote effectively captures how nurses use their knowledge and build upon a parent's expert knowledge to help them identify and assess their child's pain:

We sit down and we tell them what to look for. So first of all, having the knowledge of what is indicating that their child is in pain because some kids can be in pain and they can still be playing away and you have no idea they've been in pain (Nurse 5 line 467-470).

Two nurses talked about the need to use age appropriate validated pain assessment tools but indicated that they were infrequently used, for example “*we do have the little smiley faces that we see floating around. But do we use them?*” (Nurse 8 line 622-623).

3.2 Valuing parent's expert knowledge: relying on parent's assessment. Nurses specifically relied on common behavioural signs of ALL pain and parents expert knowledge of their child to assess pain. The following nurse quote provides a description of how nurses value and draw from parent's expert knowledge of their child's typical behaviours.

It's funny because I say like you know your child better than anybody else and that's kind of what you have to go by. Like you know when your child is not feeling well, it's very apparent to a mom or a dad if you spend enough time around child you know the second something is off. (Nurse 2 line 350-353)

As children move through ALL treatment, parents draw from their expert knowledge of their child and what they learned from the nurses and they assume the primary role in assessing their child's pain and determining the effectiveness and need for further management. The following example provides a comprehensive description of a parent's key pain assessment role:

I think they are solely responsible for assessing the kid's pain when they are at home. So I think that they are taught how, and they know their child, how to assess pain and to determine whether Morphine or Tylenol is required. Inpatient, I think that they are responsible for monitoring, outpatient as well, monitoring the effect of the Tylenol or Morphine, so a half an hour to an hour after a child has gotten a dose, they need to assess whether the dose was effective or non-effective. If it was non-effective then they need to know to contact their health care provider to seek guidance on what to do about increasing. (Nurse 1 line 227-234)

Even early in a child's ALL treatment, nurses relied on a parent's assessment and ability to recognize and communicate that something is "not right" to guide decisions related to the initiation and ongoing delivery of pain management strategies.

N4 Involving and teaching parents best pain care from the beginning. In addition to working with parents to identify pain in their child, the CLS and nurses taught parents a wide range of non-pharmacological and pharmacological strategies and provided them with opportunities to apply these strategies to manage their child's pain.

4.1 Drawing from multidisciplinary team expertise. The Child Life Specialist (CLS) and nurses taught and involved parents in using non-pharmacological and pharmacological pain management strategies from diagnosis and throughout treatment as one nurse stated "it is something that, you know we try to work with them. And by us I mean the entire team" (Nurse 7 line 279-280). In addition to learning from the CLS, nurses described the importance of using a multidisciplinary pain management approach and as a result "*parents have access to Physio, Psychology, our Pain Team, nursing staff, physicians so that they have access to all of these different things to try if basic pain*

control is not working” (Nurse 1 line 368-370).

4.2 *Training in non-pharmacological management.* Nurses emphasized the important role of the Child Life Specialist (CLS) who becomes involved with each parent and child at ALL diagnosis and continues to follow and provide ongoing support throughout the child’s treatment. The CLS plays a key role in teaching and actively involving parents in applying non-pharmacological pain strategies that parents can use throughout their child’s treatment. Specifically, the CLS takes an individualized approach to each child and works closely with the parent and child to identify and tailor non-pharmacological strategies that work for each individual child.

You know Child Life is involved with every child right from the get go, and helps them find ways that... and not just them but you know, I find nursing helps with this as well. But ways... you know, what distraction techniques and what techniques are going to work for them? You know is having the iPad during the procedure their thing? Or is it playing with a favourite toy? You know, it’s finding what is their... (Nurse 7 line 291-296)

This example demonstrates how the CLS assists parents with identifying and applying procedural distraction strategies. Nurses also described how the CLS expands their parent training to teaching parents about non-pharmacological strategies effective for managing non-procedural pain:

Child Life works with not just the child, but they will work with the parents and say, “here is what I did today and this worked really well maybe you could try this at home”, or maybe they didn’t try something and maybe they can suggest things. (Nurse 2 line 485-487)

4.3 Providing guidance with pharmacological management and challenges. In addition to CLS training in non-pharmacological strategies, nurses described their role in teaching and providing ongoing guidance regarding pharmacological pain management. Nurses described how they used both written and verbal teaching strategies to guide parents' medication administration. Specifically, nurses provide each parent with a paper copy of their child's "medication calendar" that outlines and provides the parent directions about the administration schedule for all regular and as needed medications. In addition to providing parents with this "medication calendar", nurses review and educate parents about how to administer the medications and how to tailor the administration of medications to meet their child's needs. The following quote provides a detailed description of how nurses provide guidance regarding medication administration and how parents can take this education to tailor strategies to meet their child's needs.

The medications we send them home on so they don't have to be here every time they need medication. So parents are responsible for that and responsible when they are at home for reading their child's pain. We kind of give them an arsenal of drugs and explain to them how they can use them and what timeframe and then we, after a while, sort of let the parents give them in a way that works best for their child. Because they see their kid everyday, we don't. So they are way better equipped in some cases to manage their child's pain. (Nurse 2 line 327-333)

Nurses identified parents as the primary caregiver responsible for administering pharmacological pain management strategies as one nurse explains "*they have a big role in it because they would be administering all of medications at home when they're in between visits to the clinic, so their role is kind of big*" (Nurse 3 line 232-234).

Nurses identified acetaminophen as the most common pain medication administered by parents. Despite being the most common pharmacological pain management strategy, nurses talked about its administration should be avoided when child is predicted to be neutropenic for fear of it masking a fever and a life threatening infection for example “we have to check and see if they are neutropenic obviously, but if their counts are good, then we just tell them that it is fine to give them Tylenol” (Nurse 2 line 394-396). One nurse also expressed the possibility that parents may have misperceptions about analgesics and as a result they may limit their administration for example “some parents are very hesitant, they fear addiction or they fear that just by alleviating the pain it’s going to mask a deeper problem that’s going on” (Nurse 4 line 506-508).

N5 Parents empowered to manage pain. Nurses described how parents were able to take what parents learned from their nurses and the CLS and were able to take on an active role in managing their child’s pain.

5.1 Taking an active procedure pain management role. Nurses discussed in detail how parents played a key role in managing their child’s procedure pain by applying a wide variety of distraction strategies.

...a lot of times parents do the distraction with procedural things like Port-A-Cath needles and blood work and stuff like that ... Most parents are good. Most of the time the parents know the kid more than we do because they are there for every port access and sometimes we haven’t accessed the kid’s port in months and we don’t know. I guess with one, the parents will kind of shield the kid a little bit so they can’t see what we are doing or they will keep a game going on the iPad

throughout the procedure so the kids not focusing on what we are doing getting things set up (Nurse 3 line 234-236, 452-457).

5.2 *Developing procedure routines.* Nurses also described how parents, over time and with experience, were able to develop and advocate for step-by-step procedural routines that work for their child. The following is a good example of how one parent took what she learned and implemented distraction routines to help her child cope with her regular port-a-cath accesses:

...a lot of them use very good distraction. There is one, this is all distraction. There is one girl that I can think of that used to like lose her mind over have her port accessed, hated it, had a couple of really bad experiences and really didn't like it. So what the mom ended up doing is we introduced the whole iPad concept and then the mom will snuggle up right behind her, not holding onto her anymore because she does so well. She holds the iPad and holds it right over her face so she can't see what is going on with the port. There's a few like that, there is a lot of that going on. A lot of moms or dads that'll get right up in the child's face and like block off that visual (Nurse 2 line 506-514).

5.3 *Managing non-procedure pain.* Parents also took what they learned from the health care team and their own experiences and were able to apply strategies to manage non-procedure related pain. The following nurse quote describes how parents integrated what they learned from the health care team, their own expert knowledge, and their previous experiences with their child to apply strategies to manage their child's pain.

And of course, you know, parents are usually the best source of information. So we focus a lot on empowering them with education. They're always the ones that know exactly what's going on with their children and what works for their children. So I think as pediatric nurses, we're pretty good at listening to parents (Nurse 8 line 338-342).

Overtime parents develop adequate pain management knowledge and expertise and gain an expert knowledge of what works for their child. As a result parents move from initially being dependant on the health care team for pain management guidance to having the health care team reliant on them to provide specific information about what works for their child.

I usually have them come with the list of this is how we do it. And the same when they go to other health centres. You know, I will send to the nurse in wherever, this is what we tried today, blah, blah, blah. And then the parents will tell them what did and what didn't work based on that. (Nurse 7 line 477-480)

5.4 *Supporting parent advocacy.* Nurses also supported parents in advocating for what they know works for their child. The following describes an instance where a parent drew from her experience and what she learned from the health care team and was able to advocate for better pain management for her child.

So the parent was a very good advocate for her in saying to limit the number of attempts that the child received. She spoke about using Ativan to help her child. She had kind of the experience of Ativan as an inpatient, so she was able to correlate that being effective as an in-patient to maybe it's effective as an outpatient. So I found that helped her. Just giving the parent enough education so

they can be a good advocate for their child I find was very helpful. (Nurse 1 line 415-423)

One of the main goals of parent education is to provide parents with adequate knowledge so they are able to recognize and advocate for what works for their child.

N6 Maintaining meaningful supportive relationships with easy access. Nurses described how parents always have access to their child's FCC or on call physician if they have questions. Nurses encouraged parents to access this resource whenever they needed further guidance.

They have got contact to us as well if they have questions or concerns there is somebody here constantly, like an on-call doctor or a Family Care Coordinator if they need some advice on what to do ... We educate them the best we can. We have available contacts for them to get in touch with anyone if they need to, if they have questions or concerns, that kind of thing (Nurse 3 line 329-331, 508-510).

Specific to pain care, nurses also encouraged parents to contact their FCC to report changes in the child's status that would warrant further intervention or treatment. The following is an example of how one parent effectively accessed her child's FCC when her child developed a new source of pain.

I think of one example in particular where a boy was getting post Vincristine neuropathic pain, but it was in an area that was unusual, it was in his groin. His parents were very astute in calling the Family Care Coordinator and identifying that the boy was having pain. The parents were pretty good at getting him quickly seen and assessed at the IWK and admitted. He was actually put on an infusion to

keep him calm and to help with his pain. So the parents, because of their quick action, they got him seen within a matter of hours and therefore he was assessed and treated very, very rapidly (Nurse 4 line 477-484)

In this example the parent was able to identify a new source of pain, and access her child's FCC to communicate the child's pain and as a result the child was assessed promptly and new pain management strategies were introduced.

Parent and Nurse Review of Themed Results

Parent theme results were sent to all parents through email (Appendix H). Seven of the ten parents responded with their feedback and they were in agreement with the preliminary themes. Parents related to the themes and were encouraged by the common experiences *"Funny how the entire thing describes [child's name] 100%. Honestly it is nice to know that other parents are going through, literally, the exact same things! (Parent 8)"* Another parent, who thought her child's experience was uncommon, was reassured by learning that her experience was "normal".

"I enjoyed reading the parent themes and think you did a great job piecing them together from so many different points of view. I'm amazed by the similarities of all involved. It certainly was an eye opener to read and think, this isn't normal for everybody, but it is normal for us.

Nurse preliminary results were also shared with nurses through email (Appendix I). Similar to parents, nurses were in agreement with the preliminary themes and provided the PI with their feedback in person. Nurses could not think of anything else to add to the themes as they were comprehensive and captured their experiences.

Summary of Findings

In summary, parents and nurses moved through the four phases of the AI process and were able to identify actual and potential pain sources in children with ALL (AI-Discovery), describe positive experiences of parent's pain care involvement (AI-Discovery), identify effective and common evidence-based pain management strategies that parents can use (AI-Dream), and outline key structures needed to achieve optimal parental pain care involvement (AI-Design, Destiny). There were commonalities in terms of most common sources and strategies but some discrepancies between types of strategies, non-pharmacological and pharmacological and parent's primary role.

Chapter Six: Discussion

The following section will discuss the study's findings and how they relate to other research. In addition, implications for practice and research as well as the study's rigour, strengths and limitations will be discussed.

Participant Demographics

Eight of the ten parent participants were mothers and identified themselves as primary caregivers for their child with ALL. These demographics are consistent with other research conducted with parents of children with cancer where mothers identified themselves as their child's primary caregiver (Kars, et al., 2008; Sulkers et al. 2015). Specifically, Kars et al. (2008)'s differentiated between maternal and paternal parenting roles during ALL treatment and found mothers were physically and emotionally present while fathers took on a more practical role such as managing the home. Two fathers participated in the current study and they reported similar pain sources and management strategies but their responses were less descriptive than their partners. These fathers recognized their inability to provide comprehensive descriptions because their spouse participated more in caring for their child's medical needs. Although, father's descriptions did not add to the results, they provided further validation of the mothers' responses.

The final parent sample was representative and included children aged 1-8 years, children in all stages of treatment and captured the experiences of children experiencing each of the common sources of ALL pain. The sample included more parents of female children despite statistics suggesting that ALL is more common in females (Redaelli et

al., 2005). The nurse sample was also representative of the nurses who work closely with children with ALL and included eight of the eleven potential nurse participants.

Pain Sources

Overall parents and nurses provided a comprehensive and consistent overview of the actual and potential ALL pain sources. Consistent with the literature, parents and nurses described common pain sources resulting from the disease, medical procedures, and treatment side effects (Bossert et al., 2002; Marchesse et al., 2008; Van Cleve et al., 2004). Of note, nurse reports of potential sources of pain were consistent with parent reports of their child's pain.

Disease pain. As would be expected, parents provided more detailed descriptions of their child's pain while nurses provided more general descriptions of how children typically exhibit each source of pain. Previous research has found that between 22-38.3% of children present at diagnosis with musculoskeletal pain from the disease process (Halton et al., 2009). However, in the present study, while considered a representative sample, from a quantitative perspective, half of the children actually experienced bone pain at diagnosis. Although reports indicate that up to 16% of children with ALL present with vertebral compression fractures at diagnosis (Halton et al. 2009), no parents reported this as an actual pain experience and only one nurse identified it as a potential source of pain. This overrepresentation of bone pain and underrepresentation of skeletal fractures may be the result of the small sample size consistent with qualitative research.

Procedure pain. Every child was exposed to procedure pain from regular port-a-cath accesses, blood work draws, bone marrow aspirations and lumbar punctures. When

asked to describe their child's pain, most parents did not initially report procedures as a source of pain, but they did discuss the issue when they were prompted. Perhaps this was because these children routinely undergo procedures so they become a normal part of treatment. Parents and nurses described challenges with differentiating among a child's fear, anticipatory anxiety and actual pain. These results are consistent with a recent study that found parents reported higher levels of fear than pain associated with regular port-a-cath accesses (Heden, von Essen, & Ljungman, 2015). Furthermore, parents and nurses considered the psychological component to be more problematic than actual pain experienced. As a result, medical procedures in particular have a strong psychological component (anticipatory anxiety) that should be considered when planning pain management strategies. It is also important to note that parents described how their child's procedural anxiety and distress was reduced over time as they became familiar with the procedure process and learned and applied non-pharmacological pain strategies. These results are consistent with a meta-analysis that found children who engaged in avoidance coping (e.g. distraction) over-time experienced better adjustment and lower levels of distress as they progressed into their treatment (Aldridge, & Roesch, 2008). These findings are also consistent with reports that children's pain coping improves over time with repeated exposure because the child and parent learns what to expect and they learn apply effective coping strategies (e.g. pharmacological and non-pharmacological strategies) (Dahlquist et al. 2002; Sposito et al. 2015).

As children progressed through ALL treatment, their procedural coping improved but this was easily changed if they experienced one negative procedure. This finding is consistent with reports that negative procedure experiences contribute to high levels of

anxiety, fear, distress and pain with subsequent procedures (Bijttebier & Vertommen, 1998; Chen et al., 2000; Cohen et al. 2001; Frank et al., 1995; Kennedy, Luhmann, & Zempsky, 2008; Kleiber et al., 2001; Pate et al 1996; Weisman, et al., 2001; Willemsen et al., 2002; Young 2005). Nurses identified that “true procedural pain” occurs when a child undergoes multiple unsuccessful procedure attempts. One of the eight children whose parents were interviewed experienced “true procedure pain”. Specifically, this child’s had a port-a-cath that was difficult to access and as a result he routinely endured multiple unsuccessful procedure attempts along with heightened level of anxiety and distress. This child’s level of anxiety and distress was consistent with “needle phobia”, however, despite applying pharmacological and non-pharmacological strategies and involving the psychologist this child’s anxiety and distress persisted. Needle phobia is an emotional reaction that results in “a fear of needles syringes, injections, and injection paraphernalia”(Kettwich et al., 2007). The treatment of needle phobia is challenging for children undergoing cancer treatment who require regular needle procedures. This one case of “true procedure” pain/needle phobia provides important information for future research and clinical practice.

Children also experienced pain from invasive bone marrow aspirations (BMA’s) and lumbar punctures (LP’s) despite using topical anaesthetics and being sedated during the procedure. Most research to date has focused on establishing effective sedation protocols to decrease anxiety and pain during the actual procedure with little focus on pain that may occur post procedure (Barbi et al., 2005; Po' et al., 2012). The most common complication related to lumbar punctures (LP) is the development of a post LP headache that is predicted to occur in 7-11% of children undergoing oncology

surveillance/treatment with reports that symptoms persist for up to seven days post-procedure (Lowery & Oliver, 2008). In the present study three of the eight children experienced a post LP headache and its presentation occurred primarily in the home setting. According to parents, their child developed a severe acute debilitating headache that was difficult to manage. When nurses described pain related to bone marrow aspirations (BMA), they focused mostly on potential acute pain at the needle puncture site but did not describe the duration of this pain, suggesting they may not have a good understanding of how this pain persists in the home setting. On the other hand, parents reported that pain post BMA may last for up to one-week post-procedures. Parents describe the pain as a generalized discomfort at the puncture site and while children were still able to perform normal activities they avoided any contact with the puncture site. There is limited research exploring the actual experience of pain post BMA and LP in the home setting leaving a gap in this area.

Treatment related pain. Also consistent with existing research, the most common sources of treatment related pain reported by parents and nurses included peripheral neuropathies and abdominal pain (Jain et al., 2013; Lavoie-Smith et al., 2013; Ramchandren, Leonard, & Moody, 2009; Van Cleve et al., 2004). Research indicates most children undergoing ALL treatment will experience some degree of peripheral neuropathy as a result of regular administration of vincristine, one of the chemotherapy drugs (Lavoie-Smith et al., 2013). Participants described how vincristine induced peripheral neuropathies are manifested as abnormal sensations including pins and needles, sensory loss, suppression of deep tendon reflexes, difficulty with balance and coordination, and muscle weakness (Ramchandren et al., 2009). When medications such

as gabapentin were introduced to treat neuropathic pain, nurses reported almost complete resolution of symptoms while parent's described improvement in symptoms but not complete resolution. Specifically, parents described persistent pain that worsened at night. Future research could try to build a better understanding of children's actual experiences with neuropathic pain to identify and describe the long-term experience of neuropathic pain from the parent and child's perspectives.

Although rare, one parent described her child's experience with avascular necrosis related to treatment and one nurse identified this as a potential pain source. Sinigaglia et al. (2008) found that only 3.3% of children with leukemia develop avascular necrosis. Specifically, avascular necrosis is a common side effect from long-term treatment with high dose steroids and results in bone destruction pain and loss of joint function (Tofferi & Gilliland, 2014). Although avascular necrosis is uncommon during ALL treatment, it has long-term implications including ongoing pain and the need for joint replacement in the future.

In summary, parents and nurses reported pain sources consistent with the literature. It is important to note that parents and nurses considered procedural anxiety and distress to be more significant than the pain associated with the actual procedures. Parents and nurses also described how children's procedural coping increased over time with repeated exposure and with the application of pain management strategies. In addition, there is a gap in the literature describing children's pain experiences post sedated procedures such as BMA's and LP's with parents in the present study describing pain that lasts for up to one week post-procedure. As a result, little is known about the actual pain experience of these invasive procedures when the child is in the home setting

where parents assume primary responsibility for assessing and managing their child's pain. Parents also described the ongoing nature of neuropathic pain despite receiving treatment with pharmacological strategies, and as a result future research should explore the long-term nature of this pain source from the child and parent perspectives.

Factors Influencing Child Coping

Consistent with the Social Communication Model of Pain (SCMP), this study found several individual child factors that influenced children's pain and these included the child's age, temperament, and previous pain experiences (Craig, 2009; Craig et al., 1996). Parents and nurses both described challenges with identifying and managing pain in younger, non-verbal children because they were unable to verbally express their pain. Nurses reported younger children had a more difficult time coping with pain at diagnosis and as a result they were more irritable. These results are consistent with research that reports higher levels of fear, anxiety and distress in younger children (Matziou et al., 2013; McCarthy et al., 2010). In contrast, older children seemed to have a better understanding of their procedures; they experienced minimal distress when their procedures went smoothly and they were able to effectively engage in procedural coping strategies.

Consistent with previous research, temperament also seemed to influence children's pain experiences (Bustos et al., 2008; Chen et al., 2000; Ranger & Campbell-Yeo, 2008). Parents described that children who coped well with pain prior to their ALL diagnosis tended to cope well with pain during ALL treatment. In contrast, children, who were sensitive to pain and exhibited poor pain coping prior to diagnosis, exhibited poor coping when experiencing pain during treatment. Although children's temperament was

not measured in the present study, findings appear to be consistent with research that a child's temperament influences their ability to cope when experiencing pain (Bustos et al., 2008; Chen et al., 2000; Ranger & Campbell-Yeo, 2008).

The SCMP factors including the child in pain, the parent and the health care team present to support parent's pain care involvement were considered throughout the study process. This study's findings are consistent with this model and the complex nature of an individual's pain was further highlighted in the results.

Parent and Nurse Views of Parent Pain Strategies

There were notable differences between parent and nurse perspectives on the wide range of strategies. Specifically, parents provided a list of pharmacological and non-pharmacological pain strategies but when they described their actual role in implementing these strategies, they provided more in-depth descriptions of their primary role in using non-pharmacological strategies. In contrast, nurses described parents' role as comprehensive including pain assessment and the application of both types of pain management strategies. Parents may not see their primary role in medication administration because it is a strategy that is directed by physicians and nurses. As a result, future research should seek to understand more clearly parents' actual role in applying pharmacological strategies.

Nurses' evidence-based pain care knowledge. Despite differing views between parents and nurses, findings from this study are encouraging and suggest that nurses have relevant and useful evidence-based pain management knowledge to guide their practice and parent education. Specifically, nurses described involving parents in using pharmacological strategies consistent with the WHO's analgesic stepladder (Chauhan et

al., 2010; Geeta et al., 2010) and evidence-based non-pharmacological strategies such as distraction (Uman et al., 2013). Even a nurse with only one-year experience with the pediatric oncology population and only two years total experience as a nurse, had adequate evidence-based pain management knowledge (Nurse 2). Previous research suggests that nurses may have adequate pain care knowledge but they struggle to implement this knowledge into practice (Latimer, 2010; Twycross, 2010). In this study, both parents and nurses had adequate knowledge of non-pharmacological strategies and nurses provided specific scenarios where parents effectively implemented these strategies in practice. These findings suggest nurses have the knowledge and ability to effectively translate evidence-based pain care information to the parents who are in a key position to manage their child's pain. The strategies may need to be augmented for pharmacological strategies to provide fully effective treatment and future research could focus on exploring parents' perspectives of their actual role in applying pharmacological strategies.

Processes to Optimize Parent's Pain Care Role

The first three main Nurse study themes provide an excellent example of how the health care team can facilitate parent empowerment by working in partnership to: 1) establish and maintain trusting therapeutic relationships with parents, 2) provide parents with adequate knowledge and tools to assess and manage their child's pain, and 3) provide parents with opportunities to draw from their own experiences and what they learned from the health care team to apply and advocate for pain management strategies.

Working in partnership. One of the strengths that emerged from the parent and nurse interviews was the importance of parents working in partnership with the health

care team to meet the child's pain care needs. Consistent with previous research, parents in this study had a strong desire to learn about and participate in their child's pain care (Po' et al., 2012; Power and Franck, 2008; Woodgate, 2006). In contrast with previous research that reported parents' frustration with their limited pain care role, parents in this study described being provided adequate knowledge and opportunities to assume the primary pain management role (Daneman et al., 2003; Pölkki et al., 2002; Roberson, et al., 2001). Parents could not think of anything else that the team could have done to better support them because from their perspective they were well supported. Results from this study further support the theory that health care professionals are more supportive of parent involvement in the context of specialized oncology care (Daneman et al., 2003). As a result, many parents developed expertise and had the appropriate knowledge and skills necessary for assessment, applying pain management strategies, and advocating for what works best to manage their child's pain.

Key nursing role: Developing and maintaining parent-nurse therapeutic relationship. Early in the pediatric ALL pain experience, nurses and parents acknowledged the importance of parents developing therapeutic relationships with their clinic nurses. These results are consistent with a study that found children with ALL and their parents valued meaningful relationships with their nurses who worked closely with them and got to know them as individuals (Darcy, Knutsson, Huus, & Enskar, 2014). A therapeutic relationship is defined as a "helping relationship that is based on mutual trust and respect, the nurturing of faith and hope, being sensitive to self and others and assisting with the gratification of your patients physical, emotional and spiritual needs" (Watson, 2005). In this study, parents establish a therapeutic relationship with their

nurses when the child is diagnosed and this relationship develops and strengthens as the child's treatment progresses to the point that some parents considered the nurses a part of their family and they felt like the nurses went through their experience with them.

The care of children with cancer has become increasingly more complex making it difficult for families to navigate on their own (Campbell, Craig, Eggert, & Bailey-Dorton, 2010). As a result, to maintain consistent and seamless care, many cancer centers have established a key nursing contact to help the family navigate the complex treatment (Campbell et al., 2010; Howitt, 2010). In this study, the important role of the child's Family Care Coordinator (FCC) was highlighted as an invaluable resource that was easily accessible and provided ongoing tailored education and support to facilitate parents' ability to effectively navigate through the ALL pain experience.

In addition to establishing relationships with their child's FCC, parents also valued the relationships they developed with the group of consistent clinic nurses who provided their child's ongoing hands on care during regular clinic appointments. Both the FCC and the clinic nurses worked closely with the parent and child and developed an intimate understanding of child and parent which formed the basis of a strong bond that continued to develop throughout the child's illness trajectory. This parent-nurse relationship shares many attributes noted in the family centered care philosophy where parents are considered equal partners and valued for their expert knowledge of their child (Mackay & Gregory, 2008) and is the guiding principles of care for the study site. When establishing this initial parent-nurse relationship, nurses can communicate openly with parents to identify describe what parents' see as their role and how the health care team can work with them to facilitate and empower them in their role. Clear communication

and role negotiation should occur early in this relationship so parents can recognize and feel confident in their caregiving role and nurses can facilitate and support this important role.

Educating parents about disease, treatment, and side effects including pain.

When a child is diagnosed with a life-threatening illness like cancer they are forced to navigate an unfamiliar experience with limited knowledge about what to expect. This initial diagnosis experience is referred to as “psychosocial crisis” or what was referred to by a parent as a “tornado” in the present study. This initial crisis phase disrupts a parent’s role and, as a result, parents become overwhelmed and must go through a period of adjustment to understand their new parenting role (Davidson, 2009; Howitt, 2010). Despite experiencing high levels of distress at diagnosis, recent evidence suggests that parents of children with cancer move past this initial “crisis” period. Specifically they adapt and learn what they need to know to assume their new parenting role (Lindwall et al., 2014). Likewise, parents and nurses in the present study described how parents were overwhelmed when their child was first diagnosed with ALL. Specifically, parents relied on their nurses to provide them with essential information needed to understand the diagnosis, the treatment and treatment side effects including pain.

Consistent with previous research, parents in this study moved past being overwhelmed and were eager to seek information and learn what they needed to know to effectively manage their child’s pain (Davidson, 2009). Parents and nurses talked about how nurses provided ongoing individualized education to ensure parents understood their child’s diagnosis, treatment and side effects including pain. Specifically, parents described how nurses went beyond simply providing them with information and they

took steps (e.g. reinforcement and reminders) to ensure parents understood and were able to apply what they were teaching. The knowledge exchange process that nurses used is similar to what has been described in recent knowledge translation pain initiatives that involved tailored educational approaches with ongoing reinforcement and reminders (Stevens et al. 2014; Stevens, Yamada, Promislow et al. 2014). When nurses provided parents with reminders and reinforcement they did it in a non-threatening way and parents were receptive to learn about common ALL pain sources (e.g. peripheral neuropathy), pain assessment, and evidence-based pharmacological and non-pharmacological pain management strategies. Nurses provided parents with adequate knowledge, skills and opportunities to assume the primary pain management role. The effectiveness of knowledge translation strategies can be further understood within the Promoting Action on Research Implementation in Health Services (PARIHS) framework where evidence (knowledge of pain sources, pain care strategies), context (environment supportive of parent's involvement, therapeutic relationship with nurses), and facilitation (nurses who provide parents with tailored education and opportunities) are key steps to translate evidence-based pain care into practice (Kitson et al. 2008; Ulrich, Sahay, & Stetler 2014).

Facilitating Pain Assessment. In addition to teaching parents about their child's treatment and what to expect (e.g. potential sources of pain) nurses facilitated parent's pain assessment. However, based on the results, it appears there is a need to provide more specific information to guide accurate pain assessment. Initially, parents were challenged and hesitant with identifying pain in their child. These results are consistent with recent findings that found many parents (n=187) of children with cancer have misperceptions

about how children express pain (Fortier et al., 2012). Specifically up to 41% of parents assumed that their child would always tell them if he/she was in pain, 36% believed that their child would always express pain by crying or whining, and 28% believed that their child would immediately report their pain as it occurs. Children in the present study showed variable pain expression, with some children not complaining despite showing clear behavioural indications of pain (e.g. not mobilizing) while other children verbally expressed and exhibited overt distress that indicated they were in pain; for example when the parent described placing her child in a wagon to get around because the pain prevented the child from walking. In the present study, many parents were challenged with identifying pain in their child, from a traditional or expected overt pain cue perspective and, as a result, they relied on their nurses to help them assess their child's pain. Nurses also routinely screened for common sources of ALL pain with each clinic visit and they used these opportunities to reinforce teaching about common sources of pain and common behavioural indications consistent with pain.

Guiding pharmacological management. While nurses described a key role in teaching parents about pharmacological strategies, parents did not describe learning about pharmacological pain management. The only guidance parents described was learning about acetaminophen and when its use would be appropriate. Nurses described how the health care team directs medication administration by providing parents with a “medication calendar” that outlines the child's regular, and as needed, medications and included specific guidelines about timing and frequency of medications. Nurses suggested that, over time, parents are able to adjust as needed medications to meet their child's individual pain care needs. While this seemed important from a nurse

perspective, parents did not describe their role in administering and tailoring the administration of medications. From nurse descriptions, the administration of medications was structured with minimal opportunities for deviating from what was recommended. It is possible that parents perceived medication administration to be something that was not their role as it was that of the health care team. As a result, future research should focus on further understanding parents actual role and understanding in medication administration.

Child life specialist: training in non-pharmacological management.

Parents and nurses both identified the Child Life Specialist (CLS) as an invaluable resource that taught and involved parents in using a variety of non-pharmacological pain strategies. Researchers have recently recognized the important role of the CLS in teaching and applying non-pharmacological strategies to improve children's pain outcomes but minimal research has investigated the role of the CLS in parent teaching (Bandstra et al., 2008). In this study, the CLS used therapeutic play, a preparation strategy known to reduce parent and child anxiety levels, to prepare the parent and child for medical procedures (Cheung, Li, & Lopez, 2008; Moore, Bennett, Dietrich, & Wells, 2015). The CLS also taught and involved parents in using a variety of evidence-based active (e.g. interactive toys, counting, deep breathing, non-procedure talk) and passive distraction (e.g. television, books) strategies to manage procedural and non-procedural pain (Uman et al., 2013). Nurses also reinforced parents' use of CLS taught strategies. As parents learned and applied strategies, they were able to identify, tailor and advocate for strategies and they developed procedure routines that work for their individual child

and parents who previously relied on the CLS and nurses now had the health care team looking to them for guidance.

One parent also described how the CLS facilitated parent child communication and how the CLS worked with the child to facilitate her expression of how she was feeling. Facilitating parent child communication is an important aspect of pain care. Specifically, these findings really highlight how important a role the CLS plays in helping children describe and communicate their pain clearly in developmentally appropriate ways.

Parents drawing from own personal experience: transferable knowledge using strengths based approach. Parents were also creative and drew from their own personal experience to apply a variety of other non-pharmacological strategies. The most common strategies included being physically and emotionally present, and using strategies such as massage, thermal therapies, familiar comfort, consistent parenting. Some nurses described parent's role in using massage and thermal therapies but did not identify or describe how they learned about and how they actually applied these strategies.

One highlighted area was the importance parent presence when a child was undergoing invasive medical procedures. According to parents, the medical team was supportive and made accommodations to ensure that parents could be present with child during anaesthesia induction for lumbar punctures, bone marrow aspirations and surgical procedures. Although not empirically measured, children appeared to benefit from having their parent present when they were experiencing pain. Similar to other research,

mothers in this study were the most consistent parent who was present during most of their child's treatment (Decker, 2007).

Massage was another important pain relief strategy used by parents. Several nurses also identified massage as a potential strategy that parents could use to alleviate their child's pain but they provided minimal descriptions of what this actually looked like. In adults with cancer, massage has been found to promote relaxation, relieve muscle spasms, and reduce pain (Haughn, Graham-Pol, & Shortley, 2009). Although there is limited evidence to support the use of massage to relieve pain in children with cancer (Neal, 2012; Post-White et al., 2009), parents in this study routinely relied on this strategy to comfort and alleviate their child's pain. Despite limited evidence, recent reports indicate that massage is the most common complementary therapy used among children with cancer to provide comfort and relieve symptoms such as pain (Ackerman et al., 2012; Haughn et al., 2009; Hughes, Ladas, Rooney, & Kelly, 2008). Massage may also play a role in enhancing the intimate connection between a parent and child and as a result has the potential to benefit both the parent and child (Ackerman et al., 2012). Only one parent described having formal training in massage prior to her child's diagnosis suggesting that others applied this strategy without any specific training. Future research should investigate if children's pain outcomes could be improved by implementing parent massage training to teach specific massage techniques.

Several parents also described using consistent parenting practices and remaining calm so that their child would feel secure and confident with what was happening. This is consistent with previous research that shows a strong association between parent anxiety, catastrophizing and its negative impact on child coping (Bearden, Feinstein, & Cohen,

2012; Bernard & Cohen, 2006; Goubert et al., 2008; Hechler et al., 2011). In the present study, while some parents recognized the importance of their ability to remain calm and consistent, many parents did not make this distinct association. As a result, parents could benefit from interventions and research targeted at decreasing their anxiety levels which in turn may improve their child's pain coping.

Putting pieces together. As parents gained knowledge and comfort in assessing their child's pain and applying pain management strategies, they took on the primary role in implementing and advocating for strategies proved effective with their child. Specific to procedures, parents gained knowledge and were able to identify strategies that had worked previously to alleviate their child's procedural pain and anxiety. Parents also developed, advocated for, and followed procedural routines. In addition, parents quickly learned about the effectiveness of topical anaesthetics and, as a result, they assumed the primary role for applying them prior to port-a-cath accesses and in some cases they tailored their application to meet their child's needs (e.g. apply for 90minutes instead of recommended 60 minutes).

Parents moved from being novice in understanding their child's diagnosis, treatment and pain care needs to becoming the expert in their child and his/her pain care needs as the treatment progressed. As parents gained expert knowledge, the health care team began to rely on parents to communicate what works for their individual child. This movement from novice to expert provider suggests the health care team provided parents with adequate knowledge and opportunities to manage their child's pain and as a result parents were empowered and supported to take on a primary pain care role.

Clinical implications and areas for improvement. This study provides an in-depth understanding of parents ALL pain care role and outlines, from parent and nurse perspectives, key structures that facilitate parents pain care involvement. Although this study highlighted numerous strengths there were several areas of practice that could be improved including using evidence-based pain assessment tools, addressing parents' misperceptions and teaching them how to balance pharmacological management to relieve their child's pain.

Gaps in pain assessment. Despite having hospital and accreditation guidelines to guide pain assessment, nurses did not describe routinely using age appropriate validated pain assessment tools in their practice and, as a result, they did not incorporate these tools in their teaching with parents (Berry & Dahl, 2000; Canadian Pain Society, 2005; Gordon et al., 2005). Instead, nurses drew from other sources when they assessed pain including, their previous experience and observations of other children with ALL who experienced pain, and parent and child reports of behavioural changes in a child that would indicate that the child would be in pain. As a result parents did not learn how to assess their child's pain using these recommended evidence-based tools. These findings are consistent with reports that health care professionals infrequently use validated, age appropriate pain assessment tools to assess pain in children (Stevens et al., 2012). Indeed, research to date has demonstrated that children as young as two years old can effectively use validated self-report pain measurement tools (Zisk-Rony, Lev, & Haviv, 2014) and younger non-verbal children can have their pain assessed with validated observational measures (Stevens et al. 2012).

Despite numerous attempts to increase the use of validated pain assessment tools in practice, numerous reports indicate that nurses infrequently use them and this was true for this study. In response to this problem, Zisk-Rony et al. (2014) sought to further understand why nurses are resistant to the “gold standard” of pain assessment and nurses described how the recommended uni-dimensional self-report measures are overly simplistic and “irrelevant in certain settings”. In addition, these nurses thought that pain assessment should be more multidimensional and should consider the child’s culture, language, communication and previous experiences. Nurses approach to pain assessment for the most part is in line with recommendations from the International Association for the Study of Pain (IASP, 2014). The IASP recommends that health care professionals assess pain using a multidimensional approach consistent with what nurses described and nurses with the addition of incorporating validated tools as a regular part of pain assessment. As a result, nurses tended to rely on a multidimensional assessment approach that included the child and parent’s report of the child’s pain, as well as the nurse’s own impression of the child’s pain. Based on the PI’s reflections, nurses within the study context routinely assess pain but they do not use recommended validated tools. Based on the PI’s experience some reasons for this may include having a parent or child who does not want to use the assessment tool. Children with cancer experience repeated pain and based on the PI’s experiences, some children do not want to repeatedly report their pain using one of these tools. In addition nurses who work in this setting quickly gain experience identifying in managing children’s pain and they develop clinical expertise in in this area.

According to the PARHIS framework, evidence is more than research and can include experience, research and local data so the nurses' approach may make more sense in a specialized oncology setting (Kitson et al., 2008). Nurses with clinical experience in this area may have important information on why this gap in knowledge translation is present. In addition, it would also be important to explore parent's perceptions of the utility of these tools to assess their child's pain during ALL treatment and what they view as meaningful.

Balancing pharmacological management. This study also found variability in parents' comfort level regarding the administration of medications to relieve their child's pain. Specifically, some parents had a high level of comfort with administering a combination of medications (e.g. acetaminophen, narcotics) while other parents were hesitant or had misperceptions about analgesics.

In a recent study, Fortier et al. (2012) explored attitudes of parents with children with cancer regarding analgesia and found many parents were hesitant to use medications to manage their child's pain. Specifically, 64% of parents (n=187) believed that pain medications are addictive and 54% were concerned with the side effects, 42% thought that children should be given as little as possible and 38% believed that the less often children receive analgesia the better it works. In a later study, Fortier et al. (2014) also found that many children with cancer who experienced significant pain received minimal pharmacological management in the home setting. Some of the reasons parents limited analgesic administration included the child's refusal to take the medication, parent preference for non-pharmacological strategies such as massage or thermal therapies or the parent's belief that their child was not in enough pain to require treatment. These

researchers also found children who were outgoing, more social, and/or more anxious were more likely to have analgesics administered. Fortier et al.'s (2012, 2014) findings are consistent with the experiences of parents in the present study. Specifically, some parents reported having difficulty getting the child to take medications, having misperceptions about analgesics, and believing that one should wait until child's pain is "bad enough" before administering medications. In addition, parents did not administer medications because their child was not complaining despite exhibiting clear behaviour signs of being in pain (e.g. difficulty mobilizing). Children who were outgoing and who were able to verbalize their pain, or showed clear indications of anxiety and distress, tended to receive more pharmacological management from their parent.

With the exception of learning about acetaminophen and when to avoid its administration, parents did not describe how they learned about pharmacological management. In contrast, nurses described how they routinely educate parents about pain medications and how they provide guidance regarding when and how to administer medications. It is not clear why these differences occurred between parent and nurse perceptions. Parents focused more on non-pharmacological strategies in which they had more independence and control. It's possible their lack of comprehensive understanding about how to assess pain and effectively use medications in conjunction with non-pharmacological strategies may be an area of important focus to shorten the gap and improve practice. Only one nurse identified the possibility that some parents may have misperceptions that limit their use of pharmacological pain management strategies. Although this theme was not present in many of the nurse interviews, it is worth noting because some parents do have these misperceptions and the health care team should be

aware of the negative impact of parent anxiety so targeted education can be done in these situations.

Several parents were also hesitant to use acetaminophen to manage their child's pain because they were taught to avoid it during times when their child was neutropenic. Even though parents took this teaching, they were hesitant to administer acetaminophen anytime even when it was safe to do so. One of the most common side effects of chemotherapy is immune system suppression or neutropenia. When a child is neutropenic they are at risk for life threatening infections. Nurses indicated that acetaminophen is one of the most common analgesics used by parents but they also described how they educated parents about avoiding its administration when the child is predicted to be neutropenic. Several parents were afraid to use acetaminophen anytime for fear of missing an important fever. These results indicate that nurses and physicians working with this specific population should address these fears and implement education strategies to teach parents how to balance the administration of acetaminophen as an effective analgesic. As a result, health care professionals should be aware of these misperceptions in order to develop educational interventions to identify and target some of these parent misperceptions.

Paternal role. Although this study did not specifically recruit fathers, two fathers chose to participate. These two fathers described their experiences and suggested their partner would be able to provide more comprehensive descriptions of their child's pain and parental role. These findings are consistent with findings that mothers in many cases take on the primary caregiver role during child cancer treatment (Hill et al., 2009; Kars et al. 2008). Reports indicate that in many cases parenting roles in the midst of child cancer

conform to traditional “gender based” parenting approaches. As a result, mothers assume the primary caregiving role while fathers assume a practical approach by maintaining the household (Hill et al. 2009; Kars et al. 2008). Findings from these studies also suggest that mothers and fathers tend to differ in their coping response to a child cancer diagnosis and as a result mothers tend to rely more on emotional coping strategies while fathers rely more on active practical coping strategies such as caring for the house and other children by maintaining some normalcy. This paternal active coping approach appears to provide fathers with a sense of normalcy and control. While it wasn’t clearly expressed in words but was in actions, the findings may suggest that the paternal role is limited due to maternal preferences to be present and “maternal gate-keeping” where mothers take on the primary caregiving role leaving fathers on the periphery. Previous reports indicate that some fathers are dissatisfied and have had feelings of resentment related to their limited caregiver role, but in an attempt to facilitate their partner’s coping they chose to accept their limited role (Hill et al. 2009; Kars et al. 2008). Findings from these studies also suggest that medical staff reinforce father’s limited role. As a result, future research should look at ways to better support and involve fathers in the care of their child with ALL.

In summary, there are several areas of practice where there is the potential for improvement including the need address parents misperceptions about medications and implement educational strategies that expedite the rate at which parents learn and apply pharmacological pain management strategies. Also, future practice should consider ways to consider and improve paternal involvement. Nurses and parents can also improve pain

assessment by implementing and routinely incorporating validated pain measures as a component of their multi-dimensional pain assessment

Methodological Considerations

The Appreciative Inquiry (AI) strengths based approach was useful for identifying and building upon the strengths that already exist to facilitate parent's ALL pain care involvement (Cooperrider et al., 2008). Findings suggest that parents and nurses work collaboratively to meet children's ALL pain care needs. In addition to identifying strengths, there were several areas where clinical practice can be improved e.g. assessment and pharmacological management. Time for relationship building and communication/information exchange is essential. Although knowledge generation was main goal of this research, sharing these findings with parents and clinicians may stimulate interest and discussion that may result in positive change in the future. During the analysis process, the PI, committee members, and the PI's supervisor worked together to interpret the results and identify key themes and it became evident that the findings fit well within the Social Communication Model of Pain (SCMP, Craig 2009; Craig et al. 1996). Specifically, children's ALL pain was influenced by individual child factors (e.g. age, temperament, previous experiences) and the presence of a parent who was able to assess and manage their child's pain (e.g. pharmacological and non-pharmacological strategies). Parent's actual role in managing their child's pain was influenced by individual parent factors (e.g. previous experience, beliefs, misperceptions) and a supportive environment that facilitated parent's involvement (nurses, child life specialist who educated and provided opportunities). Findings from this study provides further

validation for this model that provides a comprehensive framework for understanding an individual's pain and the role of parents in managing their child's pain.

Evaluative criteria/credibility. This study followed several ID evaluative criteria/credibility guidelines to ensure and optimize the quality and credibility of the research and its findings and included: 1) epistemological integrity, 2) representative credibility 3) analytic logic, and 4) interpretive authority (Thorne, 2008).

Epistemological integrity. Qualitative inquiry is expected to identify and maintain epistemological integrity throughout the research process. Epistemological integrity provides a defensible line of reasoning consistent with an individual's assumptions about the nature of knowledge and guides methodological decisions throughout the research process. This study was consistent with the epistemological foundations of nursing practice and, as a result, aimed to obtain information that would be relevant and applicable in the clinical context. In addition, findings were consistent with the SCMP which further strengthens the integrity of the study (Craig 2009, Craig et al. 1996).

Representative credibility. To establish credibility, the PI used purposive sampling and multiple data sources including narrative interview data from nurse and parent perspectives, and field notes to enhance its representative credibility. There was significant overlap between parent and nurse themes, which indicates participants had adequate experience to inform the study. Also, in follow up parents and nurses were in agreement with the themes and they expressed how they reflected their actual experiences.

Analytic logic. Analytic logic recognizes the importance of considering existing knowledge in the analysis process "so that findings can be constructed on the basis of

thoughtful linkages to the work of others in the field” (Thorne et al., 1997, p. 173). The development of the research purpose and questions in the current study and analysis of study findings were guided by the PI’s experience as a clinician, parent, and in consultation with existing research and clinical based literature.

Interpretive authority. Interpretive authority decreases bias and assures that the researcher’s interpretations are trustworthy and accurately reflect participant’s experiences. As a result, the PI built systems within this research to check preliminary findings with research participants (Thorne, 2008). Thorne and colleagues (1997; 2008) discourage taking “raw data” (individual transcripts) back to participants to check their credibility but instead review preliminary results from the entire sample to obtain individual participant considerations (Thorne et al., 1997; Thorne et al., 2008). In this study, the PI individually reviewed preliminary results by group (nurse and parent) and participants were in agreement with study the findings. The PI’s supervisory committee met with the PI and her supervisor to review and provide feedback related to preliminary themes. The PI’s supervisor also read all the transcripts and in detail themed 20% to identify themes and ensure the accuracy of the PI’s analysis. The transcripts that considered by the PI to be most representative of the themes and patterns were selected for the supervisor to code. The PI and supervisor initially identified broad patterns, then the supervisor worked with the PI to develop accurate interpretive descriptions of each. There were no specific discrepancies in two reviewers overall interpretation and as the analysis process advanced, clinically relevant patterns consistent with the ID process were identified.

Purposive sampling and sample size. Initially recruitment strategies targeted all eligible parent and nurse participants, and based on recruitment, the PI employed purposive strategies to capture the diverse range of demographics and experience of both parents and nurses. The PI worked with the Family Care Coordinators (FCC's) to identify specific cases not yet captured in the sample (e.g. child sex, age, stage of treatment). In these instances where purposive sampling was used, the FCC met with the parent during their child's routine clinic visit to determine parent interest. The FCC then provided the PI with the interested parent's contact information who then made contact. As there were only eleven potential nurse participants, purposive strategies were not needed as recruiting eight of these nurses provided an adequate range of experience from both the Family Care Coordinator (FCC) and Clinical Care Provider (CCP) perspectives. ID does not dictate a specific sample size and suggests that sampling decisions should be consistent with study questions and the overall goals of the study.

Strengths and Limitations

It is a strength that this study considered perspectives from two key stakeholders including parents of children with ALL, and their clinic nurses. This is an addition to the literature on pain in children and specifically for children with cancer. In addition, study participants were representative of the study population and included eight out of eleven potential clinic nurses and the parents of eight children out of a potential thirty-six. This means for this group of participants there is a good chance that results accurately reflect the experiences of parents of children with ALL and their IWK clinic nurses. This study also contributes to research to date by obtaining in depth descriptions using a qualitative approach and captured important detailed descriptions that would be captured using a

quantitative approach. The PI's experience as a mother and nurse in the oncology clinical area is also a strength that should be considered. The PI's clinical experience with the ALL population was strength because she had a comprehensive knowledge of the clinical context in which ALL pain is experienced. Throughout the interview process the PI was able to use this expert knowledge to guide the interviews and gain more comprehensive participant descriptions. The PI has a strong desire to facilitate and improve parent's involvement in practice. In addition, through her experience as a clinician the PI was able to design and conduct a study and extract findings that are relevant and applicable to the needs of parents and children undergoing ALL treatment in the future.

Although this study has numerous strengths, there are several limitations that should be considered when interpreting research findings. Firstly, because the PI was a nurse that worked in the area where the research was conducted, it is possible that parent and nurse participants may have been subject to social desirability bias when responding to the interview questions. Social desirability bias refers to the "tendency for people to present a favourable image of themselves... creating false relationships or obscuring relationships" (Mortel, 2008). Although possible, response bias in this study is unlikely because both parents and nurses described similar structures and processes that facilitated parent involvement. The fact that both parent and nurse responses were similar adds to the validity of the research findings. Specifically, nurses provided in depth descriptions of how parents learn to manage their child's pain and parent reports were consistent with these nurse reports. It is unlikely that parents would be able to provide such in depth descriptions consistent with nurses without nurses actually doing what they said. As a result, I would predict that social desirability response bias was minimal in this study.

Another limitation was this study recruited parents from a small population of parents of children with ALL and their clinic nurses and although in-depth descriptions of their experiences were obtained, results cannot be transferred to the wider pediatric and pediatric oncology populations but could be considered a robust qualitative perspective of ALL families and nurses at the study site. In addition, it is important to note that this study was conducted in a small hospital with limited cultural diversity and as a result most of the participants were Caucasian. Study results may not be consistent with larger urban pediatric centres that provide care for more culturally diverse populations.

Participants in this study also self-selected themselves for study participation and may have chosen to do so for a particular reason. For example, this study may have attracted the attention of parents who had positive experiences and who felt empowered to manage their child's pain. In contrast, parents who were struggling or struggled with pain management may have declined participation, leaving a gap in this perspective. During recruitment, two of the parents who were approached, declined participation because according to their FCC they were too "overwhelmed" to take time to participate. As a result, this study may not capture the experiences of all parents of children with ALL and may be missing the experiences of parents who are struggling.

In summary, this study had several key strengths and limitations that should be considered when interpreting the results.

Summary and Conclusions

In conclusion, this study effectively used qualitative Interpretive Descriptive (ID) methods to move parents through the four Appreciative Inquiry (AI) phases and generated knowledge consistent with the AI process and provided a description of ALL

pain sources (AI-Discovery), pain management strategies parents use or can use (AI-Discovery/Dream), and key structures and supports that facilitate parents pain care involvement (AI-Design/Destiny). Pain management in children with ALL is complex, influenced by multiple factors identified in the SCMP including the child, the parent, and the health care team. As a result, when trying to understand and develop strategies that optimize a parent's pain care role it would be helpful to consider the different components of the SCMP. In this study the SCMP provided an excellent framework to understand the complex child pain experience and the factors that influence parent's involvement. This study identified several strengths but also highlighted areas for improvement that may be helpful for nurses and other health care professionals working with the pediatric ALL population.

Findings from this study highlight the common experience of pain in children with ALL. Although parents and nurses described similar pain sources there were some differences in how they described some sources of pain. One difference related to their description of neuropathic pain once pharmacological management was initiated; nurses reported resolution of pain while parents described improvements but ongoing pain. As a result it would be beneficial to further explore these pain sources from both the parent and child's perspectives to gain a better understanding of their experience and to identify if there are potential areas where parents could be better supported.

Parents relied on several key resources to learn how to identify and manage their child pain care needs and they identified the key role of nurses and the Child Life Specialist. Parents established and maintained therapeutic relationships with their nurses who helped them navigate their child's pain experience. Nurses recognized that parents

were overwhelmed when their child was diagnosed and as a result they tailored their educational strategies to meet parents information needs. They did this through effectively communicating with parents and by providing parents with ongoing, education repetition of information and reminders. These nurses had a strong level of evidence-based pain care knowledge that they could transfer to parents and although there is room for improvement in some areas (e.g. pain assessment, balancing pharmacological management) they provided ongoing communication and education to help parents learn what was necessary for caring for their child. The nature of this parent nurse relationship was a partnership where parents valued nurses knowledge and experience and nurses valued parent's expert knowledge of their child. Nurses were supportive of parent's involvement and they saw parents role as comprehensive including pain assessment, using non-pharmacological strategies and medication administration while parents focused more on their role with using non-pharmacological strategies leaving a gap in our understanding their actual role in pharmacological management. Parents also relied on the Child Life Specialist as a key resource who taught and provided them with opportunities to prepare their child for procedures and apply non-pharmacological strategies to manage procedure and non-procedure pain.

Pain assessment was challenging and although parents relied on their nurses to help them identify and assess their child's pain, findings suggest there is room for improvement including teaching parents how to use evidence based validated pain measures and reviewing the different ways that children may cope with pain which may be different from what they expect (e.g. child not complaining of pain but not mobilizing because of pain). In the area of pain assessment nurses can help parents to look at the

whole picture by integrating age appropriate pain assessment tools, teaching parents how to recognize and identify behavioural indications of pain, and identifying the different ways children cope with pain (e.g. some more verbal than others, some do not complain but show behavioural signs of pain). The ability to recognize pain is the first step to management and if parents are able to confidently identify pain then better pharmacological management may follow as a result.

Nurses had a key role in engaging parents in pain care and with the ongoing support of their nurses and child life, parents moved from being novice in their ALL pain care role to being able to advocate for pain care strategies work for their child. Although physicians are involved with the parent and child throughout, parents mainly focused on the role of their nurses and the CLS. In addition this study provides direction for future research (e.g. parent role in pharmacological management, misperceptions regarding pharmacological management) and provides recommendations for improvements in clinical practice (e.g. pain assessment using validated measures, balance regarding pharmacological strategies including acetaminophen).

Knowledge Translation

The PI will use several knowledge transfer strategies to disseminate research findings and will include publication of results in peer-reviewed journal (e.g. Journal of Pediatric Oncology Nursing), presentation of results in the study site, for clinicians and leadership; at conferences and education sessions with clinicians who work with children who have ALL and University learners. Dissemination strategies will also target parents of children with cancer and the results and recommendations that come from this study will be made available to the parents of children undergoing cancer treatment presently

and those who are diagnosed and receive treatment in the future. The PI will develop plain language handouts for parents providing guidance with pain assessment and management. The PI will also use social media dissemination strategies such as posting results on the IWK Centre for Pediatric pain website.

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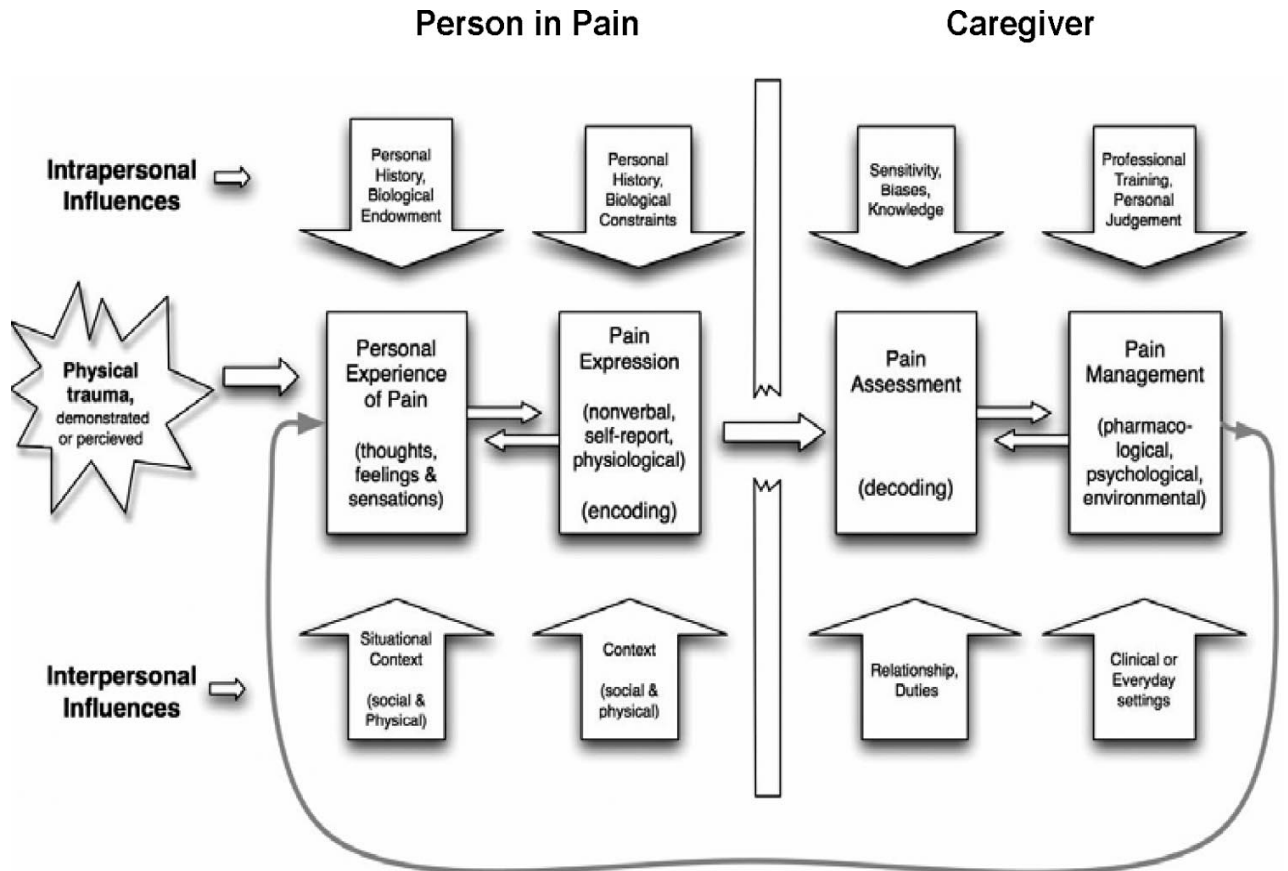
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Appendix A

Social Communication Model of Pain



(Craig, 2009)

Appendix B

Appreciative Inquiry (AI) 4-D Cycle



(Cooperrider et al., 2008)

Appendix C

Parent Nurse Appreciative Inquiry Interview Guide

Parent Introduction

Before we start, I would like to explain what we are going to do because it may be a little different from what you are used to. I am asking you to participate in this study because I believe that your experiences are important and can help me learn more about how parents of children with Acute Lymphoblastic Leukemia (ALL) support and manage their child's pain during treatment.

The purpose of this interview is not to focus on what has not worked in the past but to identify and describe what has worked. I am going to ask you questions about times when you saw things working at their best when your child was being cared for in hospital and at home.

Specifically, I want to learn more about what parents do well to relieve their child's pain during treatment. I would also like to learn more about how the health care team has and can involve parents in managing their child's pain in hospital and at home during treatment.

Before proceeding with the interview I would like to remind you that this interview is confidential and your individual results will not be shared with the health care team. I would also like to clarify that while I am a nurse, the purpose of this interview is for a research study and therefore I will not have a clinical or counselling role. If you have concerns or ideas that could work for your child you should discuss these with your Family Care Coordinator or Oncologist.

Nurse Introduction

Before we start, I would like to explain what we are going to do because it may be a little different from what you are used to. I am asking you to participate in this study because I believe that your experiences are important and can help me learn about how parents of children with Acute Lymphoblastic Leukemia (ALL) support and manage their child's pain in hospital and at home during treatment.

The purpose of this interview is not to focus on what has not worked in the past but to identify and describe what has worked. I am going to ask you questions about times when you saw things working at their best when working with parents and children with ALL.

Specifically, I want to learn more about what parents do well to relieve their child's pain during treatment. I would also like to learn more about how the health care team has and can involve parents in managing children's pain.

Before proceeding with the interview I would like to remind you that this interview is confidential and your individual results will not be shared with the health care team. I would also like to clarify that while I am a nurse, the purpose of this interview is for a research study and therefore I will not have a clinical or counselling role. If you have concerns or ideas that

could work for your child you should discuss these with your Family Care Coordinator or Oncologist.

AI Phase	Parent/Caregiver Interview Guide	Health Care Professional Interview Guide
	<p>Opening Questions</p> <ol style="list-style-type: none"> 1) Can you tell me about how this experience with leukemia began for [child's name] and your family? 2) Did you have any pre-conceived ideas about what to expect from the treatment? 3) Was it as you expected? Or were you surprised by anything you experienced or learned? 	<p>Opening Questions</p> <ol style="list-style-type: none"> 1) Can you tell me a little bit about yourself and what drew you to the nursing profession? 2) Did you always want to work with families who have a child with cancer? Can you describe what drew you to working with this specific population? 3) Can you briefly tell me about your role in taking care of children with leukemia and their families?

AI Phase	Parent/Caregiver Interview Guide	Health Care Professional Interview Guide
<p>Discovery (Explore positive experiences of parent involvement)</p>	<p>From your experience of having a child with leukemia, you may recall some high points and low points related to your child’s course of treatment. For the purpose of this interview we will focus on what has worked well to relieve your child’s pain.</p> <p>Topic Questions</p> <p>1) Has your child experienced pain as a result of the leukemia, medication side effects and/or medical procedures?</p> <p>Depending on participant’s answer the interviewer will use the following probe to target potential sources of pain that were not discussed: “For example some children with leukemia also experience”:</p>	<p>From your experience of caring for children with ALL you may recall both high and low points related to children’s pain experiences. For the purpose of this interview we will focus on what works or has worked well to relieve all types of pain in children with ALL.</p> <p>Topic Questions</p> <p>1) From your experience of working with children with ALL, can you tell me about the types of pain you see in these children?</p> <p>Depending on participants answer the interviewer will use the following probe to target potential sources of pain that were not discussed: “ Some children with leukemia also</p>

AI Phase	Parent/Caregiver Interview Guide	Health Care Professional Interview Guide
	<p>1.1) Bone pain at diagnosis related to the leukemia. Was this true for your child? If so can you describe?</p> <p>1.2) Pain related to treatment drug side effects including mouth sores, muscle pain, abdominal pain, neuropathy (leg/foot pain). Has your child experienced any of these sources of pain? If so can you describe?</p> <p>1.3) Pain related to procedures including finger pokes, surgical insertion of Port-a-cath and PAC accesses, BMA's, LP's? Has your child experienced pain related to these procedures or other procedures? If so can you describe?</p> <p>1.4) If you identified any sources of pain, what type(s) of pain occurred most frequently?</p> <p>2) Can you tell me about how [child's name] copes with</p>	<p>experience”:</p> <p>1.1) Bone pain at diagnosis related to the leukemia? Have you observed children with this type of pain? If so can you describe?</p> <p>1.2) Pain related to treatment drug side effects including mouth sores, muscle pain, abdominal pain, neuropathy (leg and foot pain). Have you observed children with this type of pain? If so can you describe?</p> <p>1.3) Pain related to procedures including finger pokes, surgical insertion of Port-a-cath and PAC accesses, BMA's LP's? Have you observed children with this type of pain? If so can you describe?</p>

AI Phase	Parent/Caregiver Interview Guide	Health Care Professional Interview Guide
	<p data-bbox="581 268 651 300">pain?</p> <p data-bbox="532 510 927 793">3) Were there different strategies (medication and non-medication) used by yourself, [child's name] or other health care professionals to manage your child's pain and help them cope?</p> <p data-bbox="483 940 688 972">3.1) Leukemia?</p> <p data-bbox="483 1077 846 1108">3.2) Treatment side effects?</p> <p data-bbox="483 1213 704 1245">3.3) Procedures?</p> <p data-bbox="483 1350 911 1423">Did these strategies differ depending on the source of pain?</p> <p data-bbox="532 1665 938 1885">4) As a parent/caregiver, what did you or your child feel was most helpful to relieve your child's pain related to (focus on previous sources of pain identified):</p>	<p data-bbox="976 331 1430 583">2) In your experience do parents want to know how to relieve their child's pain? Do they want to participate in helping to manage their child's pain? Do they ask specific questions related to this matter?</p> <p data-bbox="976 730 1430 867">3) From your experience what drug and/or non-drug strategies work well to relieve pain related to:</p> <p data-bbox="1068 982 1268 1014">3.1)Leukemia?</p> <p data-bbox="1068 1129 1425 1161">3.2)Treatment side effects?</p> <p data-bbox="1068 1276 1284 1308">3.3)Procedures?</p> <p data-bbox="976 1864 1414 1896">4) From your experience can you</p>

AI Phase	Parent/Caregiver Interview Guide	Health Care Professional Interview Guide
<p>Dream (Identify and describe parents' ideal role in of pain care)</p>	<p>4.1)Leukemia?</p> <p>4.2)Treatment side effects?</p> <p>4.3)Procedures?</p> <p>5) Can you describe any strategies that have not been used to relieve your child's pain that you think may be helpful?</p> <p>1) As the parent/caregiver of a child with ALL, your child receives care in a variety of settings including the clinic, the inpatient unit and home. The majority of this care will/or has occurred in the outpatient setting with you or another parent/caregiver present. Are there things we could be doing as health professionals to make sure you feel like you are doing everything to support your child when</p>	<p>describe how parents have been effectively involved in relieving children's pain related to (consider role at home and in hospital):</p> <p>4.1)Leukemia?</p> <p>4.2)Treatment side effects?</p> <p>4.3)Procedures?</p> <p>5) Can you describe any strategies that are not routinely used in your practice to relieve pain in children with leukemia that you think may be helpful?</p> <p>1) Our hospital has a family centered care philosophy. Does this apply to their involvement with pain care? What would that look like?</p> <p>2) How does family centered care apply in</p>

AI Phase	Parent/Caregiver Interview Guide	Health Care Professional Interview Guide
<p>Design/Destiny (identify key strategies, structures and processes to achieve optimal parent pain care involvement)</p>	<p>he/she is experiencing pain?</p> <p>2) If you could do anything you wanted what would you do to manage your child's pain:</p> <p>2.1) At home?</p> <p>2.2) In hospital?</p> <p>1) From your experience, can you describe a "positive" story of when you or someone else was involved in relieving your child's pain related to:</p> <p>1.1)Leukemia?</p> <p>1.2)Treatment side effect?</p>	<p>the context of managing pain related to an ALL diagnosis:</p> <p>2.1)In the home setting?</p> <p>2.2)In hospital?</p> <p>3) Considering Family Centered Care, describe how parents can be involved in managing pain related to:</p> <p>3.1)Leukemia?</p> <p>3.2)Treatment side effects?</p> <p>3.3)Procedures?</p> <p>1) From your experience, can you describe a "positive" experience/story when a parent was involved in relieving pain related to</p> <p>1.1)Leukemia?</p>

AI Phase	Parent/Caregiver Interview Guide	Health Care Professional Interview Guide
	<p>1.3) Procedure?</p> <p>2) Based on these experiences/stories can you break them down step by step to describe what happened and who was involved to make them positive? (e.g. who was involved, what did they do, what steps were taken, what supports were needed?)</p> <p>2.1) Leukemia experience/story (described above)?</p> <p>2.2) Treatment side effects?</p> <p>2.3) Procedure?</p> <p>3) If there were no limitations on what the health care team could do, do you have suggestions/ideas on how we can support parents who want to be involved in managing their child's pain?</p>	<p>1.2) Treatment side effect?</p> <p>1.3) Procedure?</p> <p>2) Based on these experiences/stories can you describe step by step what happened and who was involved to make them positive? (What did the parent do? What did other team members do to support parent, what made these experiences positive)?</p> <p>2.1) Leukemia experience/story (described above)?</p> <p>2.2) Treatment side effects?</p> <p>2.3) Procedure?</p> <p>3) What would our practice look like if we provided all parents with knowledge and opportunities to relieve their child's pain?</p>

AI Phase	Parent/Caregiver Interview Guide	Health Care Professional Interview Guide
		<p data-bbox="1024 485 1422 625">4) With many competing priorities, how important is pain control in the overall management of the child?</p> <p data-bbox="1117 743 1403 848">4.1) If participant identifies pain control as a priority in 4)</p> <p data-bbox="1117 890 1422 1251">If you had no limitations to what you could do, what processes, supports and strategies should be implemented to make sure parents have the knowledge and skills to manage their child's pain?</p> <p data-bbox="1070 1293 1422 1541">5) Do you have any suggestions/ideas on what we can do in the future to support parents who want to be involved in managing their child's pain during leukemia treatment?</p>

Appendix D

Parent Demographic Information Form

Study ID _____

Parent/Caregiver Demographics

1) Relationship with child: Mother _____ Father _____ Other _____ (specify)

2) Sex _____

3) Age _____

4) Ethnicity: Aboriginal _____ Asian _____ African Canadian _____

Caucasian _____ Hispanic _____ Other _____ (specify)

5) Education level achieved: High School _____ College Diploma _____

University Degree _____ Other _____

Child Demographics

1) Age _____

2) Sex _____

3) Diagnosis Date _____

4) Education Level achieved: Preschool _____ Grade _____ (specify)

5) Treatment Stage _____

Appendix E
Nurse Demographic Information Form

Study ID _____

1) Age: _____

2) Highest Level of Education: Diploma _____ Bachelors _____

Masters _____ Other _____

3) Number of years worked as an RN _____

3) Number of years worked in Outpatient Oncology Clinic _____

4) Number of years worked in Inpatient Oncology Unit _____

5) Employment type: Full-time _____ Part-time _____ FTE _____

6) Number of years worked with pediatric oncology population _____

7) What are the different ways you may have learned about pain care?

Check all those that apply.

Hospital policy _____

Pain Education In-service _____ if yes, within the last year _____

Pain conferences _____

Colleagues _____ Nursing _____ Physician _____ other _____

Journals _____

**Appendix F
Parent Demographics**

Parent Characteristics (N=10)	n	Range	Mean
Age (yrs.)		31-41	35.7
Mothers/Fathers	8/2		
Ethnicity			
• Caucasian	8		
• Aboriginal	1		
• African Canadian	1		
Education			
• University/College/High School	2/5/3		
Child Characteristics N=8			
Age (yrs.)		1-8	5.4
Male/Female	3/5		
Education			
• Preschool/School age	4/4		
Treatment Stage			
• Induction/Consolidation/Maintenance	1/2/3		
• Post treatment 6 mos./1year	1/1		

Appendix G
Nurse Demographics

N=8	n	Range	Mean
Age		23-55	41.25
Total Yrs. Worked		2.5-35	19
• Pediatric Oncology		2-18	12.38
• Pediatric Ambulatory Oncology		1-15	6.63
• FCC/CCP	4/4		
Bachelor/Diploma	4/4		
Pain Education			
• Colleagues	8		
• Policies	7		
• Parents	7		
• In-services	5		
• Journals	4		
• Social Media	3		
• Other	2		
• Conferences	1		

Appendix H

Parent Preliminary Result Review

Common Sources of ALL Pain

- **Disease Pain:** (bone pain, headache, abdominal pain): Five of the eight children experienced disease related pain when their child was first diagnosed
- **Procedure Pain:** All of the children were exposed to procedures (e.g. port-a-cath accesses, bloodwork, lumbar punctures, bone marrow aspirations). Parents had difficulty differentiating between pain and the child being anxious and fearful of the procedures. Parents described scenarios of when their child required multiple procedure attempts (e.g. port a cath access was not successful so child needs to be poked more than once) and in these instances their child' anxiety and distress increased for the actual procedure and for future procedures. Four out of the eight children experienced pain related to the sedated bone marrow aspirations and/or lumbar punctures. Most of these children experienced pain after the bone marrow aspiration and/or lumbar puncture sites and the pain was described as a generalized discomfort that lasted from a couple days up until one-week post procedure. Three of the eight children developed a severe headache after a lumbar puncture.
- **Treatment Side Effects:** Nerve pain (commonly experienced in the legs, back) and abdominal pain were the most common sources of treatment related pain. Six out of eight of the children experienced nerve pain and four of the eight children experienced abdominal pain as a result of the treatment drugs.

The following list will outline six common parent themes that “describe the important structures and processes that effectively support parent’s pain care involvement” that came from the parent interviews.

- 1) **First Steps: establishing therapeutic relationships:** Parents established meaningful relationships with their clinic nurses who helped them move through their child’s ALL treatment experience
 - **Developing Trust:** parents established strong connections with their clinic nurses. The nurses gained an intimate understanding of the parent and child’s individual needs.
 - **Establishing effective lines of communication:** parents communicated with and relied on their Family Care Coordinator to communicate their child’s needs to other health care team members at the IWK and in the home hospital setting.
 -
- 2) **Relearning how to care for my child with ALL:** Parents moved from being an expert in their child (before diagnosis) to a beginner in caring for their child newly

diagnosed with ALL. Over time and with the assistance of the health care team, parents gained expert knowledge of their child's diagnosis and treatment.

- Novice: when their child was first diagnosed parents had a beginner knowledge of ALL
- Feeling overwhelmed with information: dependent on Health Care Team
- Steps to gain confidence and expert knowledge:
 - Information seeking
 - Concentrated learning during hospital admission when child was first diagnosed (2-6 weeks)
 - Cycle of information sharing- Parents worked with their nurses to learn what they needed to know to care for their child with ALL. Nurses reinforced information and provided ongoing reminders to make sure parents had a good understanding of their child's diagnosis and what to expect.
 - Expert knowledge: ability to anticipate- Parents were able to get to a point where they had a good understanding of their child's ALL diagnosis, treatment and treatment side effects. Parents used this expert knowledge to anticipate predict treatment side effects before they even happened.

3) Overcoming challenges and gaining confidence in recognizing pain: Parents experienced challenges with recognizing pain in their child and relied on nurses to help them assess their child's pain.

- Difficulty identifying pain:
 - Perception that child has high pain threshold
 - Young child not able to verbalize pain, is their child fussy because he/she is in pain or is it a general "yucky" feeling
 - Perception that child is used to pain because he/she has experienced so much pain
 - Not wanting to draw attention to pain if child is not complaining of pain
- Learning what pain looks like
 - Parents learned from their nurses how to ask specific questions to assess their child's pain
 - Mastering Pain assessment: Over time, parents took what they learned from the nurses and their own experience with their child and they gained confidence in identifying pain in their child.

4) Learning parent specific pain management strategies: Parents described working with the Child Life Specialist and their nurses to learn non-medication strategies to help manage their child's pain.

- Child Life training in non-medication strategies
 - Assisting communication between parent and child

- Teaching distraction strategies: finding distraction strategies that work for individual child e.g. I Pad, books, television, playing, being around other children
- Procedural preparation/therapeutic play: giving the child and parent information about procedures (e.g. port-a-cath, blood work, surgeries) and the opportunity to play and act out the procedures a non-threatening environment (e.g. the use of the doll some parents referred to it as the “voodoo doll”
- Reinforcement of non-medication strategies from nurses- nurses also teach and reinforce strategies that were learned from the Child Life Specialist.

5) **Putting the pieces together: empowered to take active pain care role:** Parents pieced together what they learned from the health care team, and their own experiences with themselves, their child with ALL, and other children and they were able to use a combination of strategies to help manage their child’s pain.

- Non-medication: first line to manage pain-many parents used non-drug strategies before considering medications to treat their child’s pain
 - Using strategies they learned from Child Life Specialist and Nurses
- Drawing from own experience and using other non-medication pain strategies
 - Being present
 - Massage, heat, cold (ice)
 - Providing familiar comfort e.g. soother, blanket, stuffed animal, breastfeeding
 - Being consistent and following routines
 - Being honest and remaining calm
- Medications: second line to management
 - Application of topical anesthetic (freezing cream before port access)
 - Overcoming challenges with pharm management
 - Fear of masking fever with Tylenol
 - Difficulty getting child to take medication
 - Advocating for other medication strategies when present medications are not working

6) **Maintaining Relationships: timely access and meaningful communication exchange with experts:** Parents rely on having 24/7 access to their Family Care Coordinator or on call Doctor if they have questions or require further guidance.

- Nurse/Dr. Intimate understanding of individual child
- Approachable
- Mutual trust and commitment to parent and child throughout treatment

Appendix I

Nurse Preliminary Result Review: Nurse Themes

The following list will outline six common themes that “describe the important structures and processes that effectively support parent’s pain care involvement” that came from the nurse interviews.

- 1) **Getting to know us: establishing meaningful relationships:** Consistent nurse contact introduced to parent and child at diagnosis, becomes the go to person for the parent and health care team. There is also group of consistent clinic nurses who provide ongoing clinical care. Nurses work in partnership with child and family to move them through the ALL experiences.
 - Being committed to patients and families
 - Providing expert nurse contact
 - Working in partnership with parents
- 2) **A steep learning curve: preparing parents to care for child with ALL:** Nurses recognize how much parents need to learn to understand their child’s diagnosis, treatment and side effects and as a result they provide tailored education based on each individual parent’s needs. Nurses use cycle of information exchange to educate, reinforce, remind, and revise education strategies.
 - Providing tailored education
 - Incorporating ongoing reinforcement, reminders and repetition
- 3) **Facilitating pain assessment: two-way communication between nurses and parents:** Nurses work in partnership with parents to identify and assess a child’s pain.
 - Valuing parents expert knowledge
 - Teaching common signs and symptoms of ALL pain
 - Relying on parents assessment to guide treatment decisions
- 4) **Involving and teaching parents best pain care from the beginning:** Multidisciplinary team-involves parents in the application of evidence-based management strategies from diagnosis and throughout treatment.
 - Drawing from multidisciplinary expertise e.g. Child Life, nurses, psychology
 - Training parents in non-pharmacological management (Child life, nurses)
 - Providing guidance with pharmacological management
 - Challenges with pharmacological management e.g. Tylenol masking fever, parent misperceptions
- 5) **Parents empowered to manage child’s pain:** As parents gain knowledge and confidence they draw from what they have learned from the health care team, actual experiences with child and are empowered to take on active management role and advocate for what works for their child.
 - Taking active procedure role

- Developing procedure routines
 - Managing non-procedure pain
 - Encouraging parent advocacy
- 6) **Maintaining meaningful supportive relationships with easy access:** The FCC or on call physician who knows the child is accessible to parent and family 24/7 if they have questions.

Appendix J
Parent Themes and Quotes
Purpose-describe structures and processes that optimize Parent’s pain care involvement

Theme	Definition	Supporting Quotes
<p>1) First Steps: Establishing therapeutic relationships</p>	<p>The establishment of a therapeutic relationship with clinic nurses is invaluable for the Parent as they navigate their child’s ALL pain experience. Parents develop strong connections with these clinic nurses and work in partnership with them throughout their child’s treatment.</p> <p>Key Attributes of Therapeutic Relationship:</p> <ul style="list-style-type: none"> ✓ Developing trust ✓ Establishing effective lines of communication 	<ul style="list-style-type: none"> • The FCC is a phenomenal lady. Phenomenal, FCC, phenomenal. Don’t ever lose that woman”. ... “I have used her as a resource plenty of times. And I’ve used the girls as resources. And if they didn’t have the answer for me then they would find the answer out for me” ... I call them my girls because, you know what, they are just as part of everything that is going on as I. You know, everything that I had to experience and learn and do, they had to do the same. And they’ve helped me through a time in my life that... and my child’s life, that just down and out sucks. You know?” (Parent 4 line 552-555) • Between “Child Life” and the nurses... The nurses are phenomenal over there too. I

Theme	Definition	Supporting Quotes
		<p>can't praise them enough. I really can't. Like between all of those people, you figure out what works for your child, and you do it quickly. Like everything is very fast-paced over there. And you do it quickly. You figure things out. “ (Parent 4 line 209-213)</p> <ul style="list-style-type: none"> • So the kids become very comfortable with the nurses that work in the clinic, and they have their own special routine. So [child’s name] knows that when he’s with (nurse’s name), he does this and this. When he’s with another nurse he knows he does... And there’s specific things that they just do together.” (Parent 8 line 277-282) • Oh God, the nurses, like they were amazing. Like they're always amazing. I mean the clinic nurses, I guess are... We're seeing them more so they become more of a...kind of like your hospital family. So you get to trust them more. And then they just get to learn your patterns and the way you are and how you react to his pain. You know, they kind of support you that way. So I mean like just being there. I mean they were always there and they were always helping, and, "What can I do?" You know, they would sit down and... Like before we had the Versed, they would actually sit and think in the room with me what can we do? I mean they were very involved in that kind of planning of it. (Parent 8 line 527-535) ... “Yeah, very much.

Theme	Definition	Supporting Quotes
		<p>They will have even like certain things ready or they will know like, "Oh, okay, [child's name]'s my patient today. I'm going to do this." They walk right in the room and they start talking about, you know, "How was your weekend or what did you do? You told me you were doing this." I mean all those little things help ease what's going to happen, right. I mean he really... You know, he really I think cherishes that, and that helps him a lot when he's going through those things." (Parent 8 line 547-552)</p> <ul style="list-style-type: none"> • " I've been surprised by the level of communication that's up at the IWK. Like in a good way. It was amazing how the whole team seemed to know every little aspect. It didn't matter if it was, you know, if it was a nurse coming in, if it was a doctor coming in, or if it was a nutritionist coming in, they all knew everything about her. What really shocked me was when we came home, we'd been home and been able to get some treatments at our local hospital here, and that the IWK keeps in such good contact with them and me as well. Like they were calling me every day and they were... So that was surprising, the amount of communication. Which is really excellent" (Parent 7 line 36-43) "for them to actually look at her kind of individually and see what works for her rather than, you know, she's another kid with ALL, here you go, kind

Theme	Definition	Supporting Quotes
		<p>of thing” (Parent 7 line 339-341) “they’ve told me what works for other parents in the past. And if I do have a question, they’re really quick to get me an answer. As well, like you said, that bond there. She’s been in there so much now that she’s... they’ve formed this bond with her that’s not just, you know, a patient one. They know her” (Parent 7 line 341-345)</p>
<p>2) Learning how to care for my child diagnosed with ALL.</p>	<p>Parents who were experts in their child pre ALL diagnosis were unsure about how to care for child with ALL. Initial high reliance on health care team to learn how to effectively care for their child. Parent moves from expert in child (pre-diagnosis) to novice in caring for Child with ALL (beginning of treatment) to expert in child as treatment progresses and they become confident.</p> <p>✓ Beginner knowledge of ALL: parent overwhelmed/ uncertain at diagnosis and periods of acute illness. Reliance on Health Care Team</p>	<ul style="list-style-type: none"> • When we got to IWK, I’ve never seen things happen so fast for a child in my entire life. And for myself, it just seemed like everything was like a tornado. You know what I mean? And people were coming in and out.” (Parent 4 line 21-23) • “I was pretty scared to bring him home. To me, I was bringing... Like when you have a newborn, you don’t really want to touch him and all that when it’s your first kid. Anyway I was like that with my first one. But it was the

Theme	Definition	Supporting Quotes
	<p>Steps to Gain Confidence and expert knowledge:</p> <ul style="list-style-type: none"> ✓ Actively seeking information: strong desire to learn what is needed to effectively care for child ✓ Concentrated (2-6 week hospital admission) learning from experts. Learning what we need to know (diagnosis, treatment, side effects e.g. pain) 	<p>same.... But anyway, I was feeling... And I still feel like I have a newborn at home. The first time when we got here at home, I was scared.” (Parent 3b line 624-631)</p> <ul style="list-style-type: none"> • “As soon as she gave me the book, I went through it. I read everything in the book. I was done... within a day I’d say I was probably done with the whole thing. So I was actually kind of like wanting more information” (Parent 2a line 201-203) “ so have you got time to talk now? And she was kind of waiting to, And I understand now” (Parent 2a line 205-206) “We learned what’s good and what’s not good right away” (parent 2a line 221) I tried to just take little bits of information as I could” (Parent 2a line 195-196) “You know, I said, Give me the idea of what’s going on. And any time I had a question, I asked. You know so we didn’t really get surprised by any of it. “The healthcare team here and my husband and I did a really good job of kind of being ahead of stuff? Like I didn’t want to wait to ask about what was going to happen in 3 months. You know, I said, okay lay it all out for me. Give me the idea of what’s going on. And any time I had a question I asked. (Parent 2a line 226-229) • Well, they really explain everything good when we go

Theme	Definition	Supporting Quotes
	<p data-bbox="532 743 867 884">✓ Engaging in cycle of information exchange: Reinforcement and reminders</p> <p data-bbox="532 1717 867 1787">Expert knowledge: able to anticipate</p>	<p data-bbox="1003 268 1432 667">there. Like especially for the first 2 weeks that we were... like when we got the diagnosis. Like they didn't want to release us until they made sure we knew pretty much everything that could go wrong. So they were helpful like that. Like they tried to make sure that we don't have any surprises once we're at home." (Parent 3a line 281-285)</p> <ul data-bbox="959 674 1432 1875" style="list-style-type: none"> <li data-bbox="959 674 1432 1360">• "They told me that with the type of chemo that he was getting, that he would experience pain in the nerves in his legs and his back. And it all made sense from there" (Parent 6 line 154-156) " I think in terms of pain, everything has gone smoothly. They prepared me for everything that he was about to go through. And I didn't really have any questions when he was actually going through the procedure because they had already answered everything before it happened. So they were good at preparing me and supporting me when I had questions" (Parent 5 line 227-231) <li data-bbox="959 1367 1432 1875">• "even though everyone was giving us a lot of information, just the time to digest. And they'd keep reminding us of things and you know, just... not quizzing me but asking me if I understood and making sure it was all clear, I guess. Which was excellent because your life is turned upside down. You know, not only just with this child that's sick, if you have another child at home, you know, your work, everything is flipped

Theme	Definition	Supporting Quotes
		<p>around” (Parent 7 line 45-50)</p> <ul style="list-style-type: none"> • And you know, they would say, “ With this specific chemo she gets, she might be feeling this and this and this. Maybe you can try...” The would recommend trying different things to alleviate whatever she was going through” (Parent 6 line 156-159) “The FCC gave us information on the side effects of all of the different drugs” (Parent 6 line 204-205) When she got onto her treatment I could almost tell what was going to happen, like whether it was her counts or whatever” (Parent 1 line 43-45) • When she got onto her treatment I could almost tell what was going to happen, like whether it was her counts or whatever” (Parent 1 line 43-45)
<p>3) Overcoming challenges and gaining confidence in recognizing pain</p>	<p>Parents experienced challenges with identifying pain and relied on nurses to help with assessment. Over time Parents gained comfort and confidence and were able to recognize child’s specific pain cues.</p> <p>Challenges with identifying pain:</p> <ul style="list-style-type: none"> ✓ Difficulty/hesitancy with identifying pain 	<ul style="list-style-type: none"> • “I had this conversation with the orthopaedic surgeon, like when he looked at her avascular necrosis, when he had diagnosed her, I said to him that I think she has a high threshold for pain and he said that I really think that you are right. She never complained about it and I don’t ever remember giving her Tylenol or anything like that

Theme	Definition	Supporting Quotes
	<p>✓ Learning what pain</p>	<p>down there.” (Parent 1 line 197-201)</p> <ul style="list-style-type: none"> • “I think that she had had it so much maybe her body became used to it that we really never treated with much to be honest” (Parent 1 line 205-206) • “I have a hard time distinguishing between pain and just overall, you know, feeling of “yuckiness”. Like when she goes through certain chemotherapy, she just feels... she just wants to be held and she just wants to be comforted.”(Parent 6 line 102-104) • Yes. You know, I mean it's like what's pain and what's just rub me because I don't feel right? You know what I mean? Because she didn't exactly say she was hurting but she would say, "Can you rub my legs," or can you rub my feet or whatever. I mean she was very active, you know, the whole time that we were inpatient, right. And she's still active. So it's hard to say when she slows down whether it's tired or cranky or low blood sugar or low hemoglobin. You know, like it was really difficult to kind of nail it down. So we just kind of told her that, you know, if you don't feel right, just let us know. You know. And she didn't... Like I said, she didn't really complain a lot. Often she would just be like snuggly, you know. Like she was that way before but... It's just hard to say how much was what was going on and how much was just typical little kid stuff. (Parent 2 a

Theme	Definition	Supporting Quotes
	<p>looks like</p> <p>✓ Mastering pain assessment</p>	<p>line 303-312)</p> <ul style="list-style-type: none"> • “I didn’t want to directly ask her because if she’s playing around and she’s not cranky and fussy and doesn’t want to move, I’m not going to specifically ask her to call attention to it. Because I’ve found like even now, if I ask her if something hurts or something, even if she’s not favouring it or something like she’s just like. Yeah oh it hurts” (Parent 2a line 703-707) • “I would talk to them (nurses) and they would help me kind of talk to her. Because like I said, when you’re 2 or you’re dealing with a 2 year old, you know, it’s kind of hard. So sometimes they would ask her some questions, you know, and if they agreed with me that yes, okay, maybe we’ll give her something, then we’d get her something.... Once they gave me like kind of those questions that I could ask, like where does it hurt, does it hurt a lot, does it hurt a little” (Parent 2a line 791-798) • So what I do is I give her Tylenol first. After if the pain is enough that she needs Tylenol, Will Tylenol work? This is all the stuff I’ve learned in the hospital from the girls- Is it Tylenol that you need or is it do you need morphine? What kind of pain? How much pain are you in right now?” (Parent 4 line 329-332) • So we were trying to figure out is it a mood swing or is she in pain or ... You know, it’s like trying to.... Because she wouldn’t tell

Theme	Definition	Supporting Quotes
		<p>us.”(Parent 7 line 71-72).. And then once we got to know, you know, exactly ... Actually just watching her body language just told us a lot because we’d just watch what she was doing and then we’d know, oh, that’s ... she’s in pain now, she... you know” (line 74-76) ...”she kind of curls up or shuts down. Like goes in a little... You know, just kind of curls up Or she wants certain things. Like she wants her blankie and her certain stuffed animal. And the big thing with her is she would play with her hair a lot when she’s in pain” (line 78-81) “With the actual leg pain, she didn’t really complain too, too much. We just kind of noticed that she was walking a bit different” (Parent 7 233-235)</p>
<p>4) Learning parent specific pain management strategies</p>	<p>Parents primarily describe working with the Child Life Specialist to learn non-pharmacological pain management strategies. Focus on involving and teaching Parents what they can do to help child in pain.</p> <p>✓ Child Life Training in non-pharmacological strategies</p>	<ul style="list-style-type: none"> • So they helped us out a lot with that. The Child Life specialist would get out the whole star chart program for her. They got the child psychologist in to teach her ways to calm down. You know, like breathing techniques. (Parent 7 line 152-155) And getting, again, the Child Life specialist, they get “the CLS” in, and distracts her and uses an iPad with her and puppets and all that stuff. (Parent 7 line 166-167)

Theme	Definition	Supporting Quotes
		<ul style="list-style-type: none"> • Especially I found what really was surprising was “person’s name”, how well that she can get the children to communicate so that you can understand how they're feeling, so that they can start describing to you how they're feeling, and being open. That was a really big surprise for me. (Parent 4 line 39-42) The communication that she can set up so that your child learns how to tell you, you know, my body is feeling like this right now and this is what it's feeling like. It actually gets them trained for down the road of how to, you know, explain what their body is feeling so that you know what to do. It's phenomenal. (Parent 4 line 44-47) • When she was first being explained about getting her port, which that was ”Child Life”, you know, she comes in with the little voodoo doll... We call it the voodoo doll that has the port underneath, you know, and stuff... we learned how to do the distraction. We found out what kind of distractions that she needed. How to talk about the procedure before we were going in to do it so it wasn't a very big surprise. (Parent 4 line 170-177) • Like within a few days she met Child Life Specialist, and then the Child Life Specialist, of course she had given her that doll... that was a great resource as well, because she could say okay, this is what we do next and so that was a great learning tool for her and also a comfort as

Theme	Definition	Supporting Quotes
	<p>✓ Reinforcement of learned strategies</p> <p>✓ Parent willingness to work with team and learn strategies</p>	<p>well, but then she also, if she knew of other little children who were of an age of (<i>child's</i>) or whatever, then she would introduce them and the two of them and they'd all match up and they'd all be a great little group of friends or whatever and so knowing that to. (Parent 1 line 476-487)</p> <ul style="list-style-type: none"> • I think one of the best things that she had, which was non-medication, was probably her friends and her Child Life Specialist. At first like when she didn't want to have procedures done, if the Child Life Specialist was in the room, there was no question; she would just be like let's do it so we can go play or whatever. So that seemed to be a great resource. (Parent 1 line 336-340) • It's immeasurable because, yeah, without that, it's quite difficult to... I mean that's a big distraction, and I think that's helped in helping her. Yeah, I never thought to bring it up but yeah, even in dealing with not feeling good and pain-wise, like I think that having that play room just to go to to distract her, I think that's... Yeah, that's invaluable, very. (Parent 6 line 212-216) • at first they did tell me what other parents have done with their children like when they're getting their port accessed or they're getting finger pokes or they're going in for chemo or anything like that. So they told me to bring his favourite blanket

Theme	Definition	Supporting Quotes
		<p>or a stuffed animal or bring a toy that he really enjoys. And each time that we do go to the hospital, I make sure that I bring a blanket and a toy and like a stuffy. Or he has an iPad or a DS to play with. And that makes things easier too because he's a little bit distracted and he has things from home that make him comfortable. (Parent 5 line 187-193)</p> <ul style="list-style-type: none"> You know what, there's nothing that I could think of that they could do because I think they do...what they do, they do it very well. And if the parent... I think it depends on the parent. I think if the parent watches what these women are doing and listening to what is being said to them, and apply it to their child, and listen to their child, I think they'll be able to figure it out. You know what I mean? Like I think they would get it. And I think the children would be more comfortable. I think it all comes down to is that you have to realize that you're that team, you're that support. And you have a lot of input on how your child is going to react. (Parent 4 line 530-537)
<p>5) Putting the pieces together: empowered to take active pain management role</p>	<p>Parents pieced together what they learned from HCT and their own experiences with child, other children and self and took on active role in managing child's pain</p> <ul style="list-style-type: none"> ✓ Non-pharmacological strategies: first step to management 	<ul style="list-style-type: none"> I really didn't use much here. I know before she was diagnosed they had used Naprosyn, but again, that was before she was receiving treatment. I think one of the best

Theme	Definition	Supporting Quotes
		<p>things that she had, which was non-medication, was probably her friends and her Child Life Specialist. At first like when she didn't want to have procedures done, if the Child Life Specialist was in the room, there was no question; she would just be like let's do it so we can go play or whatever. So that seemed to be a great resource. Also, other kids that were around, she seemed to take comfort in lot of them, if they were explaining things to her that they had done to them, whether was port access or whatever, it seemed to calm her and reassure her, but as far as medication, not really... If she needed me, especially at first when it was the fear of the unknown for her, as far as procedures and whatnot, but once she got to know what was going to be coming or what was expected next, she was fine, but it was just I guess more or less for her at first the fear of the unknown and as long as we were present, whether it was holding her hand when they were doing the port access or anything like that she was fine. I remember (laugh) she always said she didn't like the milky medicine when she used to have the LP's, and we used to stay with her and as long as we sang "the wheels on the bus go round and round," she was out before we were done singing, but as long as we stayed there until she was asleep, she was fine (Parent 1 line 334-343, 432-442)</p> <ul style="list-style-type: none"> <li data-bbox="954 1644 1438 1896">• We try to tell our kids, you know, work through it if you can. If you can work through it on your own, work through it. You know if you can't let us know, you know we'll get you something if you need it but if it's just a little pain try some ice. Or you know, like when they scrape

Theme	Definition	Supporting Quotes
	<p>✓ Incorporating learned strategies</p>	<p>their knees, you know we try ice and stuff. Like we don't go straight to Tylenol" (Parent 2a line 765-770)</p> <ul style="list-style-type: none"> • "There was really nothing that we could do directly other than distract her, keep her busy, tell her we know her legs are bothering her ... it kind of got to the point where we would be busy enough that it would take away from it" (Parent 2b line 184-188) • I think one of her greatest therapies was having other children around to be with.... Once things got going with her treatment, she wanted to be out and about and I think being with other kids was kind of one of her greatest therapies" (Parent 1 line 271-277)... Other than that, there was really no medications as such or whatever that we used" (Parent 1 line 409-414) • "That just kind of evolved. You know like we noticed with her finger pokes sometimes, just talking to her, getting her attention on us rather than her sitting there watching them" (Parent 2a line 538) "She learned that if she was upset and tense and angry and fearful and all that stuff that it was so much worse than if she would just calm down, think about something else, look for the butterflies on the ceiling, look for my soother, play a game" (Parent 2a line 856-859) • "being creative enough to try and find our own ways to do things with her, and openly communicating with the whole treatment team, any questions, any ideas, they were able to pass things along" (Parent 2b line 228-230) • "we used distraction. Like we tried to keep her from watching them because she would try to watch. And a lot of times that would make it worse for her" (Parent 2a line

Theme	Definition	Supporting Quotes
	<ul style="list-style-type: none"> ✓ Drawing from own experience and using other strategies <ul style="list-style-type: none"> ○ Providing familiar comfort (parent presence, familiar object, breastfeeding) 	<p>487-488)...”they have something on the ceiling right. So it was like, Oh look up there. And if we were in a clinic room where it didn’t have anything like that, my husband would sometimes put his hand up here or I’d make funny faces at her of something to have her looking up, not trying to look down and what them do the port.” (Parent 2a line497-501)</p> <ul style="list-style-type: none"> • “ So basically my strategy for that was I try to keep her calm. You know, get her to do her deep breathing, stuff like that. Like do her deep breathing, try to distract, have a distraction for her. Which is all the stuff that I’ve learned from the Child Life Specialist” (Parent 4 line 129-131) • “She can watch one of her favourite shows. That always seems to be the go to because the kids just kind of like zone out for TV. Like if your kid zones, you’re good at this point. If your kid is zoning out and not thinking about what’s going on. Crafts. Crafts are huge right now. Getting them to do something with their hands to keep their distraction away from whatever is going on with their body. So we’ve been doing more crafts in this house than I can ever say that we were doing. She’ not much for going outside, because, you know, she can’t do it. But those are 2 of the techniques that we use. Or we’ll get talking about something. I’ll get her off on some sort of crazy rant about... I just ask her a silly question and then we’re off ranting about something else you know.” (Parent 4 line 398-407) • The thing that helped her the most was we’d lay on the bed with her and read her books or sing her songs” (Parent 7 line 63-64) “Yes it

Theme	Definition	Supporting Quotes
	<ul style="list-style-type: none"> ○ Consistency and following routines 	<p>was more of a distraction And I mean the nurses were really good to do the whole you know anti-nausea medication and all that stuff very promptly and everything. It was good. But just in the meantime for them to... for us to try to figure out what was bothering her, we read a lot of books.” (Parent 7 line 66-69)</p> <ul style="list-style-type: none"> • “I definitely had to physically be a part of it. Like I had to lay in the bed with him. So it was definitely the close contact of a Parent, and more the mom, that helped I think relieve it a lot.” (Parent 8 line 407-409) • “I was there when she needed me, I shouldn’t say when she needed me, I was there all the time” (Parent 1 line 431-432) • “And just check in with her. You know, even just checking in with your child when they’re in pain like that makes them feel better. You know like, “Oh she’s not forgetting I’m not feeling well” And it just makes them feel better. You know, like when you have a flu and your mom just comes over and touches your forehead even though she knows you still have a fever. But it just feels good to have that touch. You know, to know that your mom didn't forget about you and you're still there.” (Parent 4 line 488-493) • ‘Normally dad would just carry her in. But when she got older she would walk in. and dad would tell the person straight up. I usually hold her until she goes to sleep then I lay her down” (Parent 2a line 613-615) • “with the surgeries, I’ve been allowed right in the room with her until she’s out. The same with the sedations. You know, we hold her until she’s out. Yeah they’re very accommodating with all that” (Parent 7 line 310-312)

Theme	Definition	Supporting Quotes
		<ul style="list-style-type: none"> • “We actually show her little videos of animals or anything like that that we find on YouTube or any of that kind of stuff. And books. Again, books is a big thing that we use a lot. And she gets to take her favourite stuffy” (Parent 7 line 184-187) • the other thing was her dog too. If she couldn’t get up to see the dog because her pain was so bad, we would just bring the dog to her and she was fine” (Parent 1 line 419-421) • She still had a soother when she first started at 2” She had almost given it up at that point before we found out she was sick. We found out that she needed it more and more for comfort when she was here. So she did use that” (Parent 2a line 483-486) • And nursing, like nursing has always helped her” (Parent 6 line 104-105)... “that was the go-to. Like when she was not feeling well” (line 115-116) “It just worked for her before. And just as we were going through her treatment and even before that, like when she wasn’t feeling good, that was the one think that I could always count on to kind of soothe her, you know” (line 226-228) • “Now I send the blankie with him because we cannot go in the recovery room either. So he's an hour after the lumbar puncture in the recovery room with nurses. So we send the blankie in all the time now.” (Parent 3a line 487-490) • We turned it into a bit of a pattern. It was always that at first she still had her soother. So that was something big that she always wanted to have with her. Like right when this started we were getting away from that. But then once

Theme	Definition	Supporting Quotes
		<p>you're in here, it's like just let them take that. It's not going to hurt them. (Parent 2a line 80-83).... And wen we would go to have... Well, even for having her port access put on, I would hold her. She wanted me to be holding her. And when she would be called in for her lumbar punctures, I would carry her in. I would hold her. They would put her to sleep in my arms. And then I would lay her down" (line 85-88).. And it's become such a pattern for her. That's always what she was looking for. As soon as they called her in, she knew where she was going, she knew she was going to do this. She would look to me and reach up" (line 90-92) " And we were very involved. Like you know, you can come into this position and be willing... Some people might not be able to but if you're willing and able to talk all the instruction and the information from here, and learn, then when you go into your other hospitals like we had... They didn't know what to do. There was a few times that I had to stop the doctors there and tell them This is what you need to do. I'm not trying to take over your job. This is what has to go on. And they wouldn't do it. And then all of a sudden, you'd get frustrated enough with them. And you'd tell them , you know you're going a little too far. And now they would listen . So it go to the point where all the nurses in there were like " Oh (patient's name) is coming in. Just listen to what dad has to say. We'll do it" And then because every time before I went in , I was already on the phone with the IWK. They knew she was coming. We knew what we were supposed to do" (Parent 2b line 267-277)</p> <ul style="list-style-type: none"> • " Like when we are getting port

Theme	Definition	Supporting Quotes
	<ul style="list-style-type: none"> ○ Being honest and remaining calm 	<p>accesses and stuff, we pretty much have it down to a science now because I have had her help of what we need to do to make that less uncomfortable and less scary for your child. It's not so much that it's hurting your child, it's they're scared. They're scared of what people are doing to them, and they don't understand" (Parent 4 line 152-156)</p> <ul style="list-style-type: none"> • "I'm not sure what other people have done for things, like for tactics for their child. But I mean those, you know, were learned and we put in place. And I just carry on with them" (Parent 4 line 421-423) "There's verbal and what are we going to do? And acknowledgement. Okay, so this is what's going on. Now you've acknowledged that this is going on. Now we're going to come up with a plan of what we're going to do about it. And then the follow through. And that is all the stuff that we've learned from you guys" (Parent 4 line 442-446) • "we've kind of come up with a little routine for the port access where she sits in front of me and leans back on me. And that kind of comforts her a bit" (Parent 7 line 264-266) • "She likes to play nurse or whatever you want to call it at home. And we would let her put. She would tell us to lay down, we need to have our access done. And she would go through the whole cleaning. So letting her do that between myself, Mom, and her two brothers. Like we had to explain to her two brothers that this is what [child's name] is like right now, this is what she sees. And if she thinks that this is wrong to you guys, when she goes and needs to have this done,

Theme	Definition	Supporting Quotes
	<ul style="list-style-type: none"> ○ Using massage and/or thermal therapies 	<p>she's going to feel like it's wrong. They participated with it every time she asked" (Parent 2b line 105-111)</p> <ul style="list-style-type: none"> • "She has chosen that she wants me to be behind her and with her because I told her every step of the way, I'm with you, I'm here for you. I am here, I am with you. So she always wants me... If you would come in, you would see me sitting behind her. And I am here for her. And she wants my thumb. She wants my thumb in her mouth and she wants to bite my thumb"... She bites down on it. But what she does is she tries not... She tries not to hurt me. So she's thinking about not hurting me but still trying to bite my thumb" (Parent 4 line 182-192) "She focuses on not hurting my thumb even though she thinks she's being hurt" (Parent 4 line 195) • This is going to sound kind of funny. She was really young at the time. She was 2. But we kind of sat her down and told her, "Well, this has to happen. You can fight it and it's going to make it worse or you can cooperate, get it done, and the faster you get it done, the faster it's going to be over." I don't know if she understand or not at that point, really and honestly. But she did it. You know, it seemed to me like she just kind of sucked it up and just went with it. (Parent 2a line 353-358) • you see a lot of it when you have some sick kids, that a lot of Parents and stuff a lot of times let the kids get away with a lot. Well, we weren't willing to do that. It was fairly strict and we wouldn't let her get rude with anybody. And if she did, she would be corrected then. And it made a big difference" (Parent 2b line 236-239) "if we had

Theme	Definition	Supporting Quotes
	<p>✓ Pharmacological strategies: second step to management</p> <ul style="list-style-type: none"> ○ Tailored application of topical anaesthetics 	<p>let her go then things would have gotten a lot more out of hand and there would have been a lot more screaming and crying and arguing” (Parent 2b line 242-243)</p> <ul style="list-style-type: none"> • “I never told him it would not hurt. I’ve always told him the truth. I think that’s what it has to be. And I am always telling him that it’s for his best, it’s to heal him. And the pain will go away right after the procedure is done.” (Parent 3b line 345-347) “If I say that once and he feels pain, well, he won’t believe me the next time that it doesn’t hurt” (Parent 3b line 364-365 • “But what we found with her is she likes to know everything that’s going to happen, as much as she can. And then that kind of alleviates a lot of the anxiety. She was getting a lot worked up over not knowing what’s going to happen” (Parent 7 line 128-131) “She needs to know what is going to happen. Yeah, it goes much better.” (Parent 7 line 322) • “we try to prepare her in advance to let her know that she’s got to do it” (Parent 2a line 409)...”it’s worse if we get there and tell her you’re going to have a finger poke because then she’s like, “well, I thought I was just coming for a check-up. I didn’t think I was going to have bloodwork”. You know so we try to prepare her in advance” (Parent 2a line 410-413). “she wanted to know what was going on . So she knew all of the steps, right , and she would practice them at home with us, right” (P 2a line 511-513), • I think like even staying calm, like us as Parents with him. Like when he goes through his needles or anything. I think that kid of helped too because it put him more in confidence of what’s going on”

Theme	Definition	Supporting Quotes
	<ul style="list-style-type: none"> ○ Advocating for better management 	<p>me that her legs hurt, I'd start with like doing some squeezing and kind of going like that. But after maybe 10 minutes or so, it just kind of got to the point where I was just more going over the skin and just kind of soothing at that point. Like she wouldn't say, "They still hurt, keep rubbing." So I would just kind of slowly stop. You see, I took training in massage. So they taught us at the very end to just kind of do light touching. So that's kind of what I would do towards the end, to kind of let her know that I was going to stop. And she would usually leave it at that. (Parent 2 a line 294, 356-363)</p> <ul style="list-style-type: none"> • “we do a warm bath at night just on those nights that I know that... It seems to be when it's warmer that it does affect her. Now, that nice hot water just soaking around her body, and then she's coming out, makes the air feel cooler.” (Parent 4 line 503-505) “ • “One thing that I kind of found that worked is if we kind of just lightly scratch her back, that kind of helps her. And massaging her feet helps her a lot.” (Parent 7 line 232-233) • we were putting ice 15 minutes after the injection” (Parent 3b line 316-317) • “I have a heating pad. So I was putting the heating pad on. And the 2 last times that he said he had leg pain, I didn't even give him Tylenol. I would just rub and gave him the heating pad. And he fell asleep and I never heard about it after” (Parent 3b line 275-277) • We were putting the EMLA cream for 15 minutes on his site before the injection. I don't think that changed anything but just in his head maybe a little bit. Because really the pain

Theme	Definition	Supporting Quotes
		<p>was inside, not on the skin. (Parent 3b line 309-311)</p> <ul style="list-style-type: none"> • “before we access his port, we put emla cream on” (Parent 3a line 263) • we found for her that she needed a little bit longer for it to work to be effective” (Parent 2a line 529-530) • So what I do is I give her Tylenol first. After if the pain is enough that she needs Tylenol, Will Tylenol work? This is all the stuff I’ve learned in the hospital from the girls- Is it Tylenol that you need or is it do you need morphine? What kind of pain? How much pain are you in right now? And she will tell me if Tylenol will be enough” (Parent 4 line 329-332) “ and you know, thinking about putting your kid on morphine is kind of... a normal person would be like why are you putting your kid on morphine: You know? But now it’s just kind of normal.” Line 354-356) “ For her legs, she had taken morphine. She has. Only when she’s bawling her head off and asking for it. “it hurts so bad:. You know what I mean? And then “Like how bad does it hurt? Does it hurt really, really bad? Like do you need ... “Yeah I need a little bit of my ... She calls it her soap medicine. And that’s what she calls... She says morphine tastes like soap”. (Parent 4 line 511-515) • “ you know, over time you know medicine stops working if you use it to much right. So you’re going to take more and more and more right” So if you can start with nothing and work from there, you know, it works better (Parent 2a line 775-778) “if she is in a little bit of pain right now, not too bad, and we gave her dose of Tylenol, in an hour if the

Theme	Definition	Supporting Quotes
		<p>pain gets really bad and she's already had her dose of Tylenol, we have nowhere to go. Right. Because she would have to wait another 3 hours for another dose of Tylenol. Or we'd have to go to something even stronger. Well she's 2 years old. We don't want to do that if we can avoid it. Let's start with the rubbing of her legs and then go out from there " (Parent 2a line 781-786)</p> <ul style="list-style-type: none"> • "I was scared a little bit to give him Tylenol and hide a fever" (Parent 3b line 561) "And I would never give it every 4 hours just to make sure I was not hiding a fever" (line 571) • "....."You know you could use Tylenol but at the same time with using Tylenol, you had to be really careful because of what her temperatures were." (Parent 2b line 354-356) " if she was really saying repeatedly that it was bugging her then we would see about using something. But if it wasn't too bad then we would kind of let her go through it" (Parent 2b line 361-362) • "she is someone that in the beginning would not take oral medication. She refused. So we were holding her down to get it in. So it was kind of more...." (Parent 7 line 143-144) • "At first she didn't want to take her medicine because they tasted disgusting, you know. And that was all worked through everybody together" (Parent 4 line 345-346) "it still feels weird that it's morphine but at the same time, it's making your child comfortable and not crying and feeling better" (Parent 4 line 358-359)... "her pain is real and it's something that she is asking for. She's learned from her experience that it's something that

Theme	Definition	Supporting Quotes
		<p>helps her” (Parent 4 line 360-361)</p> <ul style="list-style-type: none"> • “Like they couldn't help him no matter what they did. They got the doll out. We did everything imaginable.” (Parent 8 line 432-433) “So there was one point where I said I’m not coming into the hospital with him to get his port access until you guys think of something. So whether you give him IV versed or like... I don’t care where you put it. I said put it up his tongue, something. He needs something. And that’s when the girl said “What about intranasal versed?” Like he was the first kid to have it. And it worked wonders. So
<p>6) Maintaining Relationships: timely access and meaningful communication exchange with experts</p>	<p>Parents rely on having 24/7 access to their nurse or a Doctor if they have questions or require further guidance.</p> <ul style="list-style-type: none"> ✓ Nurse/Dr. Intimate understanding of individual child ✓ Approachable <p>Mutual trust and commitment to Parent and child throughout treatment</p>	<ul style="list-style-type: none"> • Yeah, the fact that we have... The fact that it doesn’t matter, day or night, I call, I talk to somebody immediately. That's really a huge, huge worry that's lifted. And the fact that my home hospital is the IWK. Well, you can't get any better than that. So you know, that's an extra thing that I don't have to think about. So I know that like if it's a Monday to Friday, 8 to 5, I call the clinic and I talk to somebody I know and that knows “Sam”. And I don't need to go through “Sam” is a 7 year old boy with

Theme	Definition	Supporting Quotes
		<p>leukemia. They know my name. And when they hear [participant], they know it's "Sam" and they know what's going on. Like I've never heard a nurse or a doctor or somebody come in the room and not know his case or said, "So was he the boy that had that?" Like they're very knowledgeable about that stuff. And even when you call at night, it's the same thing. " (Parent 8 line 558-567)</p> <ul style="list-style-type: none"> • "every time I had questions, I could call our FCC. I could call even the physician" (Parent 3b line 585-586) "At the beginning, I was calling the FCC maybe twice a week. Every little something. But now I check myself and I am not scared anymore" (Parent 3b line 638-639) • like at 3:00 in the morning when I had phone calls, you know, the oncologist answered the phone and talked" (Parent 2b line 255-256) " I wouldn't always wait for our FCC to be available" (line 258) • "if I ever have any questions about anything I can just pick up the phone and they are just a phone call away. They know everything about her and probably know about me more than I know about myself (laugh)" (Parent 1 line 529-531) • "she had to get her PAC access in the middle of the

Theme	Definition	Supporting Quotes
		<p>night because of a fever and they didn't have her information up here. They could call down there in the middle of the night and they knew exactly what I was looking for. It was just wonderful" (Parent 1 line 510-513)</p>

**Appendix K
Nurse Themes and Quotes**

Purpose-describe structures and processes that optimize Parent’s pain care involvement

Theme	Definition	Supporting Quotes
<p>1) Getting to know us: establishing meaningful relationships</p>	<p>A group of clinic nurses work consistently with the parent and child throughout treatment and establish and develop meaningful relationships. The Family Care Coordinator becomes the “go to” person and provides seamless communication between child, family and other health care team members.</p> <p>Key Nurse Attributes that contribute to meaningful relationship:</p> <ul style="list-style-type: none"> ✓ Being committed to families ✓ Providing consistent expert nurse contact (FCC) ✓ Partnering with parents 	<ul style="list-style-type: none"> • I really did enjoy working with the families. I much prefer to treat the entire family versus just the child. I feel like I do a better job when I am treating everybody. (Nurse 1 line 29-31) • “Oncology specifically is really nice because you see the same people and you get to watch them grow up and you get to watch their families learn how to cope with something that most families don’t get to or have to.” (Nurse 2 line 34-37) “Yes rather than like working in emergency where you may see a child once, you get that continuity and you really get to work with the kids as they grow up” (line 42-43) • “started working here, loved it, and have been here ever since. Never ever thought I would love it as much as I do, but it’s a good place to work, it’s rewarding, at times.” (Nurse 3 line 24-26)

Theme	Definition	Supporting Quotes
		<ul style="list-style-type: none"> • “initially was quite nervous with children that have cancer. Emotionally very nervous. I was thinking that maybe I wouldn’t be able to handle what the children are going through and what their families go through, but after a couple of weeks, I realized that I couldn’t change the fact that the children were unwell and if I had chosen not to work in the clinic, the children were not going to go away. It wasn’t like a peek-a-boo type of game (<i>laugh</i>) and I figured that somebody had to take care of them and I figured I would allow myself the opportunity to challenge myself to see if I could handle working in the setting. I actually quite enjoy the work right now.” (Nurse 4 line 22-30) • “And once I went to the children’s hospital and met the oncology folks, I thought that that was the right place for me. And once I started, I absolutely loved it. So that’s pretty much where I’ve been since.” (Nurse 7 line 12-15) • “I am responsible for teaching the parents for present treatment and upcoming treatment, including side effects. If the kids are not local, I am responsible for setting up schedules for care in outside facilities, as well as doing any education with the nurses that they might request.” (Nurse 1 line 37-40) • “I am a Family Care Coordinator, so I meet the families at diagnosis and are their contact person, coordinating their care with the rest of the team and home hospitals. Give them education and help them

Theme	Definition	Supporting Quotes
		<p>with understanding the disease and the side effects of the disease and how they can support their child.” (Nurse 6 line 21-25)</p> <ul style="list-style-type: none"> • “I would say the nuts and bolts of it is a liaison... a consistent liaison for families between the healthcare team here, the home resources or home health care team, and the families. We’re probably the most consistent go to person for the family (Nurse 7 line 22-25) • “as the Family Care Coordinator, I know what’s been happening. So I can relay a log of that information. I will have had phone calls from parents if there’s issues at home. But when the child then comes to clinic, they’re seeing a different nurse. But I can let... We have regular meetings with doctors, primary physicians. So you’re keeping up to date with other issues that they’re having at home that you’re not always seeing when they’re here because obviously most of the treatment is outpatient” (Nurse 8 line 423-429) • Yes. So I take that concern to the physician who is clinic for the day and they often will call an increase to the pharmacy or they will just tell me to tell the parent to increase the dose and I will write it because they already have the drug at home, I’ll write the change on the flow sheet and the drug calendar.” (Nurse 1 line 269-272) • I don’t know how you would do it, but to make it known to the parents that their opinion is very important when it comes to pain because sometimes they come here and they think that we are the be all

Theme	Definition	Supporting Quotes
		<p>and end all and they don't realize that we rely on them for assessment and we take their ideas sometimes and use their ideas." (Nurse 1 line 527-531)</p> <ul style="list-style-type: none"> • Well the family is directly involved right from the start. There is never a point where a family is not fully included in anything that we do with their child, whether it's procedural pain or if it is treatment related pain or diagnosis related pain. (Nurse3 line 298-301)
<p>2) A steep learning curve: preparing parents to care for their child with ALL</p>	<p>FCC and clinic nurses recognize parents have a steep learning curve to understand child's diagnosis, treatment and potential treatment side effects. HCT provides tailored education based on parent's needs and ability to process information. Use cycle of information exchange to educate, reinforce, remind, revise education strategies then repeat.</p> <ul style="list-style-type: none"> ✓ Providing tailored education and treatment ✓ Incorporating ongoing, reinforcement, reminders, repetition and re-evaluating parents information needs 	<ul style="list-style-type: none"> • Because the first stage of treatment, including diagnosis, is too overwhelming. There is a lot of teaching being done in that first stage in terms of medication side effects, prognosis, protocols." (Nurse 1 line 481) • if their child is not feeling well that day, then I don't think that they take any of the education in because they are trying to settle that child. If everything is perfect and their child is happy, then I think they do take some of the information in. (Nurse 1 line 504-507) • "Yes, it's overwhelming for them and it's a lot because sometimes the diagnosis takes them awhile to piece together that this is the

Theme	Definition	Supporting Quotes
		<p>diagnosis and they are having pain and this is why and we are going to give them this treatment and eventually they are going to feel better again,” (Nurse 3 line 384-387)</p> <ul style="list-style-type: none"> • “they’re so overwhelmed with the fact that their child has been diagnosed with cancer and then boom, they’ve got to be looking at all of these papers on study, non-study, what treatment plan, what’s the best, so they’re very overwhelmed and tunnel-visioned with that. As things kind of progress down and they see that things are kind of settling out and they know the routine, then they tend to be very good advocates, they notice things.” (Nurse5 line 374-379) • I think that some parents just become so overwhelmed with everything that’s going on that they need our guidance and support and us reminding them about things. Some families have a lot going on outside of here that they can’t always focus everything on their child’s pain. I think we are pretty important in helping the families to recognize pain, especially when it becomes a treatment sort of thing. Once treatment has begun, we tell them a lot of side effects of the drugs and we have to keep reinforcing things because it’s new to them. (N3 line 478-485) • “Sometimes our teaching is a bit trial and error because we don’t know necessarily how the parents are going to learn information or retain information. So I think we try to do as and effective job as we

Theme	Definition	Supporting Quotes
		<p>can, but sometimes what works for one family won't work for another family" (Nurse 2 line 557-560)</p> <ul style="list-style-type: none"> • "Once treatment has begun, we tell them a lot of the side effects of the drugs and we have to keep reinforcing things because it's new to them" (Nurse 3 line 484-485) • "But you know, with education they're better educated to look for specific types of pain with medications that happen in different phases of therapy. And that's what a big part of what we teach the parents" (Nurse 8 line 488-491) • But you know, with education they're better educated to look for specific types of pain with medications that happen in different phases of therapy. And that's what a big part of what we teach the parents" (Nurse 8 line 488-491) • "Well they typically start off with, when they come in for visits, we kind of are on top of it asking them "do you feel the tingling" because that's the 1st indication and so we kind of monitor " (Nurse 5 line 179-183)
<p>3) Facilitating pain assessment: two-way communication between nurses and parents.</p>	<p>Nurses work in partnership with parents to identify and assess child's pain. Parents may not always recognize changes in their child's behaviour as pain. Nurses teach parents how to assess and recognize signs and symptoms of pain then rely on parent's assessment to</p>	<ul style="list-style-type: none"> • You know we can kind of lead them with. You know, with them saying, "Well how do I know if this drug is working?"

Theme	Definition	Supporting Quotes
	<p>guide initial and ongoing management.</p> <p>Parent and nurse work as a team to identify and assess pain:</p> <ul style="list-style-type: none"> ✓ Valuing parent’s expert knowledge ✓ Teaching common signs and symptoms of ALL pain ✓ Relying on parent assessment 	<p>Well you know, what would your child normally be doing? You know, to help them get back to their normal ADL’s or their normal activities. Are they sleeping through the night? Like you know we can kid of prompt them with questions.” (Nurse 7 line 395-399)</p> <ul style="list-style-type: none"> • “We sit down and we tell them what to look for. So first of all, having the knowledge of what is indicating that their child is in pain because some kids can be in pain and they can still be playing away and you have no idea they ‘ve been in pain” (Nurse 5 line 467-470). • Just to be aware of how the child behaves when they are in pain, being able to identify the pain at an early point.” (Nurse 6 line 349-350)...” Often times they may not know that their child is in pain or the degree of pain that they are in.” (line 355-356) • “So again being able to identify what pain looks like in their child, anything that might trigger pain, and anything that may help the pain, being able to identify what relieves the pain.” (Nurse 6 line 395-397) • Yes, parents are often the only line of assessment that you have, so they’re where you go first. A lot of times if the kids are not able to describe their pain effectively, we count on the parents to come in and say our child is not acting how they normally do. So their assessment is a huge part of

Theme	Definition	Supporting Quotes
		<p>what we end up or how we end up treating pain.” (Nurse 2 line 318-322)</p> <ul style="list-style-type: none"> • Sometimes kids will only tell their parents they have pain. Sometimes they won’t tell the healthcare provider. Sometimes the parents are the communicating body to let us know that the child is uncomfortable or in pain and if they are too young to express it, the parents can pick up on the kid’s nonverbal cues that they are in pain. Sometimes it’s just that, they are kind of advocating for their child. (Nurse 3 line 202-206) • It’s funny because I say like you know your child better than anybody else and that’s kind of what you have to go by. Like you know when your child is not feeling well, it’s very apparent to a mom or a dad if you spend enough time around child you know the second something is off. “ (Nurse 2 line 350-353) • “I would say most parents are pretty good at identifying and I think for a lot of parents if the child is crying or irritable or if the parent notices any change in the child’s behavior from what they’re normally like, the parent kind of clues in that there is something wrong, that the child is not feeling well. (Nurse 4 line 350-353) “The biggest thing with parents is letting them know what needs to be done, what to watch for, and to always be an advocate,

Theme	Definition	Supporting Quotes
		<p>to always trust your gut, and let the medical staff know if there is a need to correct either the medication or the therapy or whatever when the child's in pain." (line 366-369)</p> <ul style="list-style-type: none"> • "I am entirely dependent on... Well, I would say mainly dependent on because they also get assessed by physicians and nurses, of course, but most of our assessment is the parents' report of how they're coping and how well their pain seems to be controlled." (Nurse 7 line 387-390) • "they watch for the signs because they've been taught what signs to look for, then if it gets to the point that they need to be on the medication, then we will put them on medication. If the medication is not working, then they will communicate with the Family Care Coordinators, who will communicate with the physicians on whether they need to go up on the dose. So, they are a big advocate in letting us know if they're being controlled or not. That's with all of the pain." (Nurse 5 line 351-357) • "Out they definitely do because I think they are solely responsible for assessing the kid's pain when they are at home. So I think that they are taught how, and they know their child, how to assess pain and to determine whether Morphine or Tylenol is required. Inpatient, I think that

Theme	Definition	Supporting Quotes
		<p>they are responsible for monitoring, outpatient as well, monitoring the effect of the Tylenol or Morphine, so a ½ an hour to an hour after a child has gotten a dose, they need to assess whether the dose was effective or non-effective. If it was non-effective then they need to know to contact their health care provider to seek guidance on what to do about increasing.” (Nurse 1 line 227-234)</p> <ul style="list-style-type: none"> • “So I think for nerve pain, parents are mostly involved in looking at how effective the pain med that the child was put on in the hospital. So if they were put on Gabapentin, it is kind of their job to assess how the Gabapentin is working and I have had a lot of parents able to do that, to call in and say this dose doesn’t seem to be enough.” (Nurse 1 line 262-265) • “Probably the first step would be for them to actually identify that the child is in pain and to take action such as contact either their FCC or the Oncologist on-call if it’s after hours,” (Nurse 4 line 338-340)
<p>4) Involving and teaching parents best pain care from the beginning</p>	<p>Multidisciplinary team-involving parents in the application of evidence-based management strategies.</p> <ul style="list-style-type: none"> ✓ Drawing from multidisciplinary expertise 	<ul style="list-style-type: none"> • Parents have access to Physio, Psychology, our Pain Team, nursing staff, physicians so that they have access to all of these different things to try if basic pain control is not working” (N1 line 368-370) • “it is something that, you know we try to work with them. And by us I

Theme	Definition	Supporting Quotes
	<p>✓ Training parents in non-pharmacological management</p>	<p>mean the entire team (Nurse 7 Line 279-280)</p> <ul style="list-style-type: none"> • “And I think we always strive to look to see what we can do to try and improve all of that, whether it’s involving Child Life specialists” (Nurse 8 line 165-167)...”involving other HCPS’ when appropriate, try to get a good handle on pain early to prevent long term negative consequences.”(Nurse 8 line 173) • “I think the biggest one is if it’s not meds, it’s Buddington, it’s Child Life, and it’s giving them the knowledge of what to expect or how we are going to deal with it, so those are the big things.” (Nurse 5 line 526-528) • We have just sort of little bits of lots of different areas but we can tap into more expertise areas who can spend more time and more in-depth education with families” (Nurse 8 line 299-301) • “You know Child Life is involved with every child right from the get go, and helps them find ways that... and not just them but you know, I find nursing helps with this as well. But ways... you know, what distraction techniques and what techniques are going to work for them. You know is having the iPad during the procedure their thing? Or is it playing with a favorite toy: You know, it’s finding what is their...” (Nurse 7 line 291-296) • “Yes usually because parents are the most familiar face in the room usually and if you are going to have anyone distract them it’s

Theme	Definition	Supporting Quotes
		<p>almost always better to have a parent.” (Nurse 2 line 343-345)</p> <ul style="list-style-type: none"> • “Child Life works with not just the child, but they will work with the parents and say, here is what I did today and this worked really well maybe you could try this at home, or maybe they didn’t try something and maybe they can suggest things. So one of the things that we do with parents sometimes is we suggest like find something at home that your child really likes and give it to them specifically when they are going to do something that is painful, so that way they have something good to look forward to that they don’t get otherwise.” (Nurse 2 line 485-493) • “Sometimes Child Life is involved to help us with strategies to help people cope with either pain from procedures or pain from other sources.” (Nurse 3 line 155-157) • We also use Child Life, who has various amounts of distraction tools or toys that they use. Just reassurance, having the comfort of having their family member, their parent, there with them can also help. Routine, as long as you got a nice little routine of how and letting them be involved in the decisions that they are able to make is a wonderful thing.” (Nurse 5 line 219-224) “Child Life is present when the child has just been so traumatized with the Port-A-Cath insertions because they’ve obviously gone wrong and they have had to access it on a few occasions, or if it’s their 1st change of their needle they would be involved.” (line 233-236)

Theme	Definition	Supporting Quotes
	<p>✓ Providing guidance with pharmacological management (verbal and written instructions)</p>	<ul style="list-style-type: none"> • So often times there's a lot of distraction used with support of Child Life." (Nurse 6 line 205)... "Children that are at a point in their development that they can engage in activities with Child Life and distractions. Some children don't require, they're able to cope on their own without Child Life." (line 214-216)... "I think Child Life and nursing do a really good job of helping them sort out what works best in terms of distraction and they also come with a lot of good ideas themselves." (line 514-515) • sometimes the distraction might be like "look over there" or something like that or just talking to them. Sometimes it's parents will like come up and just squeeze their kids hands and tell them to focus on that or something like that." (Nurse 2 line 419-421) • "teaching and guidance mostly from the nurses because we are the ones that are doing the port accesses (Nurse 4 line 424-425) • "The medications we send them home on so they don't have to be here every time they need medication. So parents are responsible for that and responsible when they are at home for reading their child's pain. We kind of give them an arsenal of drugs and explain to them how they can use them and what timeframe and then we, after a while, sort of let the parents give them in a way that works best for their child. Because they see their kid everyday, we don't. So they are way better equipped in some cases to manage

Theme	Definition	Supporting Quotes
	<p>✓ Recognizing challenges with management</p>	<p>their child’s pain.” (Nurse 2 line 327-333)</p> <ul style="list-style-type: none"> • One of the things we do is we give the families a medication calendar and quite often that will include management of pain in whatever form it takes.” (Nurse 2 line 485-486) • Yes. They would have a calendar and it would tell them what to give and when to give it. (Nurse 3 line 412-413) • “Yes they are taught to and are eventually are the ones giving the medications at home.” (Nurse 6 line 376-377)...” Whatever medications they are prescribed” (line 381)...” So they’re taught about the medication and the best way to give it.” (line 411) • “So they would be the people that know their child the best so they’d be able to, with discussion and with education, the goal would be for them to be able to identify that their child is in pain and what relieves their pain.” (Nurse 6 line 422-425) • they just probably need our guidance of how frequently they can give them pain medication or how much they should give them and those kind of things, dosing. If they’re at home looking after them, if they were in hospital it would be different, we would be more guiding a lot of that, but if they are at home we would give them the support that they need to know what to give them I guess. (Nurse 3 line 220-225) “The parents I guess they have a big role in it because they would be administering all of medications at home when they’re

Theme	Definition	Supporting Quotes
		<p>in between visits to the clinic, so their role is kind of big. (line 232-234)</p> <ul style="list-style-type: none"> • “Another important part for parents at home would be to administer pain medications according to the med schedule that they are given to try to not miss doses of regular meds, like say if their child is on Morphine for severe leg pain, to try and give the Morphine according to the schedule.” (Nurse 4 line 342-345) • “usually it is just Tylenol and usually we have to check and see if they are neutropenic obviously, but if their counts are good, then we just tell them that it is fine to give them Tylenol.” (Nurse2 line 394-396) • “Sometimes Tylenol, again, if the kid is not neutropenic.” (Nurse 3 line 148) • “As I said earlier, some parents are very hesitant, they fear addiction or they fear that just by alleviating the pain it’s going to mask a deeper problem that’s going on” (Nurse 4 line 506-508)
<p>5) Parents empowered to manage child’s pain</p>	<p>As parents gain knowledge and confidence with pain management strategies, they draw from what they learned, their actual experiences with their child and are empowered to confidently take active management role and advocate for what works for</p>	<ul style="list-style-type: none"> • Once after the first couple of visits and they start to understand it and they take full responsibility in putting freezing cream on” (N1 line 325-326) “So parents are

Theme	Definition	Supporting Quotes
	<p>their child.</p> <ul style="list-style-type: none"> ✓ Taking active procedure role 	<p>advocates for the kids asking the nurse for Ametop and EMLA. Often they'll go home with an extra dose and know to apply it before they come to the clinic." (N1 line 301-303) " I think parents are really aware of timings, so they don't want to be here any longer than they have to be. Once after the first couple of visits and they start to understand it and they take full responsibility in putting freezing cream on to decrease the amount of time that they are here." (Nurse 1 line 324-327)</p> <ul style="list-style-type: none"> • "So we try to get the parents to be. You know, if Child Life is there then they sometimes do the holding of the iPad or whatever. But if not, it's often the parents that do that. We try not to have parents actually involved in the procedural components. And by that I mean, you know, the holding or stabilizing of patients. We try to have them more involved in the actual distraction components- talking to their child or doing whatever" (Nurse 7 line 554-558) • "parents will often almost mimic those coping strategies or give the child encouragement to use them. If they haven't been involved with Psychology, parents I think would use whatever seemed to work in the past at home to calm the child down or to get them through the short amount of time that the procedure takes. So often just giving them their support. Sometimes they just give them their hands to squeeze or to help stay still. I've had parents who kind of lay beside the kid's face so

Theme	Definition	Supporting Quotes
	<p>✓ Developing routines</p>	<p>that the child can turn their face into their parent's face until do whatever they need to do, and just snuggling afterwards. Often the parents if there is any holding down involved, once that all finished, the parents will pick the children up to give them a snuggle." (Nurse 1 line 331-341)</p> <ul style="list-style-type: none"> • "the families have an idea of what's going on so then the families can talk to the children beforehand and say "this is what we've done before, it's the same routine, we are going to do this, this, and this." This helps to prepare the child so that when they come here then they know what to expect. I find with some of the children that you need to give them a lot of preparation before you do it and then other kids it's just boom let's get it done now, and then again, involving Child Life." (Nurse 5 line 291-302) • Definitely by helping with the application of the topical freezing cream and trying to be supportive of their child, helping them maybe to use deep breathing, counting, recognizing what seems to work for their particular child to take away the stress and the pain that can be associated with port accesses I would say." (Nurse 4 line 408-411) • "I usually have them come with the list of this is how we do it. And the same when they go to other health centres. You know, I will send to the nurse in wherever, this is what we tried today, blah, blah, blah. And then the parents will tell them what did and what didn't work

Theme	Definition	Supporting Quotes
		<p>based on that. (Nurse 7 line 477-480)</p> <ul style="list-style-type: none"> • “Well parents get, and kids as well, they get very set in how the routine to the point of they prefer this dressing, they prefer this technique, right down to how it’s cleaned, what it looks like, what device you’re using, how many minutes you do this.” (Nurse 5 line 430-433) • “After awhile they do. I think at first probably not. I think it’s a learned thing. They probably haven’t needed to use it until their kids get here.” (Nurse 2 line 425-426). “Yes the first couple are always bad because they don’t really know what to expect and it’s very traumatic for parents as much as it is for kids.” (line 430-431) “a lot of them use very good distraction. There is one, this is all distraction. There is one girl that I can think of that used to like lose her mind over have her port accessed, hated it, had a couple of really bad experiences and really didn’t like it. So what the mom ended up doing is we introduced the whole iPad concept and then the mom will snuggle up right behind her, not holding onto her anymore because she does so well. She holds the iPad and holds it right over her face so she can’t see what is going on with the port. There’s a few like that, there is a lot of that going on. A lot of moms or dads that’ll get right up in the child’s face and like block off that visual” (N2 line 506-514) • a lot of times parents do the distraction with procedural things

Theme	Definition	Supporting Quotes
	<ul style="list-style-type: none"> <li data-bbox="578 936 821 1003">• Managing non-procedure pain <li data-bbox="578 1230 878 1297">• Encouraging parent advocacy 	<p data-bbox="976 275 1433 890">like Port-A-Cath needles and blood work and stuff like that.” (Nurse 3 line 234-236) Most parents are good. Most of the time the parents know the kid more than we do because they are there for every port access and sometimes we haven’t accessed the kid’s port in months and we don’t know. I guess with one, the parents will kind of shield the kid a little bit so they can’t see what we are doing or they will keep a game going on the iPad throughout the procedure so the kids not focusing on what we are doing getting things set up.” (Nurse 3 line 452-457)</p> <ul style="list-style-type: none"> <li data-bbox="932 898 1433 1220">• “So we have one family that the dad sings to his little girl every time she has her Port-A-Cath inserted, they sing a song together and the distraction of that has really helped her identify this as a positive experience. They will giggle and laugh. (laugh) It’s cute.” (Nurse 6 line 492-495) <li data-bbox="932 1228 1433 1591">• “it’s something that they learn over time, especially when they’re making frequent outpatient visits and the port is being access more frequently. The quickly learn that the freezing cream really does help and usually the parent and the child together are able to come up with a strategy that will work” (Nurse 4 line 415-419) <li data-bbox="932 1633 1433 1875">• “after a while, sort of let the parents give them in a way that works best for their child. Because they see their child everyday, we don’t. So they are way better equipped in some cases to manage their child’s pain” (Nurse 2 line

Theme	Definition	Supporting Quotes
		<p>331-333)</p> <ul style="list-style-type: none"> • I think they know their child the best and they know what seems to give them the most comfort and I think that they go back to those kind of things that have worked in the past to see if that will give them some comfort. (Nurse 1 line 255-257) • “And of course, you know, parents are usually the best source of information. So we focus a lot on empowering them with education. They're always the ones that know exactly what's going on with their children and what works for their children. So I think as pediatric nurses, we're pretty good at listening to parents.” (Nurse 8 line 338-342) • So the parent was a very good advocate for her in saying to limit the number of attempts that the child received. She spoke about using Ativan to help her child. She had kind of the experience of Ativan as an inpatient, so she was able to correlate that being effective as an inpatient to maybe it's effective as an outpatient. So I found that helped her. Just giving the parent enough education so they can be a good advocate for their child I find was very helpful.” (Nurse 1 line 415-423) • “I think of one example in particular where a boy was getting post Vincristine neuropathic pain, but it was in an area that was unusual, it was in his groin. His parents were very astute in calling the Family Care Coordinator and identifying that the boy was having

Theme	Definition	Supporting Quotes
		<p>pain. The parents were pretty good at getting him quickly seen and assessed at the IWK and admitted. He was actually put on an infusion to keep him calm and to help with his pain. So the parents, because of their quick action, they got him seen within a matter of hours and therefore he was assessed and treated very, very rapidly.” (Nurse 4 line 477-484)</p>
<p>6) Maintaining meaningful supportive relationships with easy access</p>	<p>The FCC or on call physician is accessible to parent and family 24/7 if they have questions. Parents are encouraged to access this resource. Parent’s reliance on this resource changes over time as they gain confidence.</p>	<ul style="list-style-type: none"> • “ I always say to families. You know, we also have oncologist’s coverage 24 hours a day. So you know they always have somebody they can reach” (Nurse 7 line 631-633) • “So there’s always one person that the family can call. And you are the main hub of being able to answer and coordinate anything that the parents are asking. That sort of reduces miscommunications and allows for more seamless process” (Nurse 8 line 53-56) • “the phone calls from being very frequent do tail off because the parents start feeling comfortable because they know and they know what to expect. They often then know how to manage things themselves.” (Nurse 8 line 507-509) • I have some patients that call me every day just to run ideas past me. I do have parents that call me more often than others.

Theme	Definition	Supporting Quotes
		<p>Some I see just at the beginning of the course and not again for 3 months, or I hear from them just at the beginning of the course and not again until the end of the course when they are coming back to the IWK. But more often, most of them I hear from pretty much weekly. I do have one parent that seems to call me everyday (laugh). So it depends on whether the parents require more support, and if they do, I am here for them to call me. (Nurse 1 line 45-51)</p> <ul style="list-style-type: none"> • “we reinforced that if you are ever in trouble or if you feel like you don’t know the answer to something, just call us and we are here. It makes a lot of the families feel a lot better to know that we don’t feel that bad when they call us.” (Nurse 2 line 541-544) • “They have got contact to us as well if they have questions or concerns there is somebody here constantly, like an on-call doctor or a Family Care Coordinator if they need some advice on what to do.” (Nurse 3 line 329-331) We educate them the best we can. We have available contacts for them to get in touch with anyone if they need to, if they have questions or concerns, that kind of thing. “ (line 508-510) • “The parents right from the very beginning from diagnosis they meet their Family Care Coordinator and that person basically becomes their lifeline

Theme	Definition	Supporting Quotes
		<p>during business hours, but there is always a Hematology/Oncologist on-call for after hours and for weekends. The parents are not discouraged from calling with their concerns and I think they have an excellent contact system for the families.” (Nurse 4 line 489-493)</p>