

Examining Conditions that Facilitate Parental Involvement in Procedural Pain  
Management

by

Shelley P. Lowther

Submitted in partial fulfillment of the requirements  
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Dated: December 10, 2012

Supervisor: \_\_\_\_\_

Readers: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

External Examiner: \_\_\_\_\_

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AUTHOR: Shelley P. Lowther

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## Dedication

*“Feeling gratitude and not expressing it is like wrapping a present and not giving it”  
~William Arthur Ward*

I want to dedicate this work to my wonderful family and friends – especially my husband Rob, my son Ben, and my furry daughter Sidney. I have missed some valuable quality time with you, hiking, watching movies, doing homework (except for when we did it together Ben), and attending fieldtrips, medal ceremonies, weddings, and funerals. Rob, I know I have also missed some not so valuable quality time doing household chores and errands, but you were always there to support me and pick up the slack. I hope that I was happier because I was doing something that I really wanted to do (even when it seemed like I didn't). I hope that I made you proud and that I can give something extra back to the IWK and the patients that are so meaningful to me. I hope that by doing day shifts, I was little more human and humane to all of you (and I never missed a hockey game). Thank you doesn't begin to express the appreciation and love that I have for you.

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## Abstract

Procedural pain is still under managed in practice, resulting in immediate and long-term negative sequellae for children. Accreditation guidelines identify health care professionals as responsible for providing procedural pain management, however recent evidence supports the idea that parents can be assisted to provide effective pain management through non-pharmacological strategies. Using Appreciative Inquiry, twelve nurses were interviewed about their knowledge of the evidence, work context, and factors that facilitate their ability to engage parents in procedural pain management. Focus groups verified the findings and made suggestions for practical application. From the data, four predominant patterns emerged: *1) Establishing meaningful interpersonal connections; 2) Fostering a culture of collaboration; 3) Pain as a priority – moving from a philosophy to a standard; 4) Sustaining practices through advanced knowledge and skills.* Findings will contribute to the literature that guides education, policies, and standards that engage all resources to promote more effective pain relieving practices.

## **List of Abbreviations Used**

PICH	Pain in Child Health
CIHR	Canadian Institutes of Health Research
N-PPMSs	Non-Pharmacological Pain Management Strategies
AI	Appreciative Inquiry
PI	Principal Investigator
CNS	Clinical Nurse Specialist
NICU	Neonatal Intensive Care Unit
FCC	Family-Centered Care
JCAHO	Joint Commission on Accreditation of Healthcare Organizations
4-D	Discovery, Dream, Design, Destiny
AIIP	Appreciative Inquiry Interview Protocol
PARIHS	Promoting Action on Research Implementation in Health Services
CLS	Child Life Services
PICC	Peripherally Inserted Central Catheter
APN	Advanced Practice Nurse
NP	Nurse Practitioner

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## **Chapter One**

### **Introduction**

The research and knowledge of pediatric pain has grown exponentially over the past 20 years (Young, 2005). Yet, despite the expanding body of evidence on pediatric pain, procedural pain is still largely under managed in practice (Kortesluoma, Nikkonen, & Serlo, 2008; Latimer, Ritchie, & Johnston, 2010; Stevens, 2009; Van Hulle Vincent, 2007). A review of epidemiologic studies suggests that 49-64% of hospitalized children receive inadequate pain management (Stinson, Yamada, Dickson, Lamba, & Stevens, 2008). Pediatric patients often experience acute pain from multiple procedures without adequate interventions to minimize pain and the pain from these procedures is often worse than the pain from the condition itself (Cregin et al., 2008; Maccagno, 2009).

Multiple procedures are experienced daily by hospitalized children (Stevens, 2009). The diagnosis and treatments of many conditions rely on invasive procedures such as venipuncture, intravenous cannulation, capillary sampling, and injections to deliver and monitor the effects of curative therapies (Young, 2005). In a recent study of the incidence of painful procedures in Canadian pediatric hospitals, a mean of 6.3 procedures were experienced per child who had any painful procedure in a 24 hour period, and only 28.4% of those children received one or more types of pain management intervention for that painful procedure (Stevens et al., 2011). High levels of untreated pain in infants and children can cause detrimental neurophysiological, physiological, and psychological consequences (Blount, Piira, Cohen, & Cheng, 2006).

The immediate and long-term consequences of untreated pain result in demands on resources and costs to the health care system. In an already strained health care

system, it is necessary to find creative and cost-effective ways to effectively manage pain. Accreditation standards, professional guidelines, and policy statements have been influential in the structuring and delivery of pain care practices by making organizations and health professionals accountable for their pain care delivery (Latimer et al., 2010). Parents also have an obligation to provide the best pain care for their child. Parents' use of non-pharmacologic pain management strategies (N-PPMSs) can significantly decrease the costs and risks associated with painful procedures by enhancing the quality of care and increasing the child and parents' coping skills (Christensen & Fatchett, 2002; Polkki, Vehvilainen-Julkunen, & Pietila, 2002). Patient/family satisfaction and preference for safe and effective pain reduction strategies have driven the application of non-pharmacological interventions in research and practice. Nurses are challenged more than ever to optimize pain management and negotiate roles with parents in a way that uses health resources wisely and produces the best possible health outcomes.

Nurses tend to be involved in many of the painful procedures in hospitalized children and they play a major role in the management of procedural pain (Latimer et al., 2010). Nurses are frequently involved in the administration of analgesics and are responsible for monitoring the effectiveness of these treatments. N-PPMSs may be used as an alternative to pharmacotherapy or as an adjuvant to sedatives/analgesics for procedural pain and their use is usually driven by nurses as a way to promote safety and comfort for the patient. Non-pharmacological pain management strategies are methods that do not involve the use of drugs, but can change patients' perceptions of pain and alter pain behaviour. These methods are typically divided into categories, which may include but are not limited to the following: cognitive-behavioural, physical, emotional support,

helping with activities of daily living, and creating a comfortable environment (He et al., 2010).

Parent involvement in N-PPMSs is often limited and inconsistent. Involvement is positively related to the level at which information is provided and the provision of support by nursing staff (Polkki, Vehvilainen-Julkunen, et al., 2002). Nurses can play a key role in engaging parents in the use of N-PPMSs with their child (Simons, Franck, & Roberson, 2001).

Recent literature supports parent involvement in N-PPMSs to reduce their child's pain from procedures (Polkki, Pietila, Vehvilainen-Julkunen, Laukkala, & Ryhanen, 2002). Providing parents with a specific role and educating them about evidence-based strategies can be very helpful for procedural pain management (Young, 2005). Parents can be trained to engage in interventions that benefit their child's coping rather than those that have been shown to increase child distress, such as providing reassurance, being apologetic, or being overly empathic about the child's pain (Blount et al., 2006). Effective collaboration between the nurse and parents has been demonstrated to improve children's pain care by promoting comfort and decreasing anxiety and procedural pain in their child (Simons et al., 2001). When parents become confident in their pain management role, it is likely that they will play a role in their child's pain experiences even after discharge (Baulch, 2010).

Parent engagement is a cost-effective, opportunistic, and beneficial way to help with pediatric procedural pain. Parents want to be involved (Jones, Qazi, & Young, 2005; Polkki, Pietila, et al, 2002) but need direction on how to best assist their child during painful procedures (Christensen & Fatchett, 2002). Parents may wish to be involved at

various levels and nurses can work with them to establish common and relevant goals related to pain management. Nurses need to be proactive in establishing effective communication in order to negotiate parents' roles and level of involvement. Parents often express a desire to be involved in their child's care but are unsure of how to communicate and negotiate roles with nurses to participate in their child's care at a level that is right for them (Corlett & Twycross, 2006). Nurses' and parents' perceptions of parent engagement in pain care often differ (Polkki, 2002; Simons et al., 2001).

There is definitely inconsistency between nurses' and parents' perception of the levels of information regarding parents' roles and the level of actual parent engagement (Polkki, 2002). Nurses often perceive that parents are well informed about their child's procedures and non-pharmacological interventions and that parental engagement in pain management strategies for their child is adequate (Polkki, 2002; Simons et al., 2001). Parents often perceive they have limited involvement in pain management strategies for their child and have expressed feelings of frustration related to their passive role (Simons et al., 2001). Most parents would prefer to be present for procedures and participate in pain management strategies, even if procedures are highly invasive (Jones et al., 2005; Polkki, Pietila, et al., 2002). It would be meaningful to learn more about how nurses think about and respond to procedural pain in children and how they may engage parents in non-pharmacological interventions.

By interviewing nurses about their positive experiences and what they consider (i.e. context, evidence, facilitation) when engaging parents, we can learn about what works and build on this. Findings will inform our clinical practice and may stimulate further research in the area of parent engagement in procedural pain management

strategies. Innovative strategies to engage parents in procedural pain management can then be identified and examined through implementation studies. It should be noted that throughout the paper, the terms “child” and “patient,” “parents” and “family,” and “nurse” and “participant” will be used interchangeably to avoid constant repetition. “Parents” or “family” could also refer to the primary caregiver(s) or guardian(s) of the child.

### Purpose of the Research

The purpose of this study is twofold: 1) Provide pediatric nurses with the opportunity to articulate the positive conditions that facilitate parents’ active engagement in procedural pain management strategies with their hospitalized child; and 2) Interpret their experiences in order to present a new understanding of the structures and processes to improve the management of pediatric procedural pain by engaging parents.

The study uses Appreciative Inquiry (AI) as a philosophy of inquiry and research methodology. The primary goal of the research is to articulate and promote an understanding of an affirmative topic through positive inquiry with stakeholders to explore an area’s strengths and how to build on them. This form of action research is effective to generate knowledge or ideas to initiate a dialogue that will eventually lead to a reflection of values and practices (Kavanagh, Stevens, Seers, Sidani, & Watt-Watson, 2008). The approach is unique in that it focuses on strengths of an organization rather than weaknesses. It is suited to generating positive group dynamics and creating innovative ways to improve practices.

### Reflexivity

The principal investigator (PI) has worked in many nursing roles in a tertiary care hospital caring for women, children, and families. These roles included staff nurse,

clinical nurse specialist (CNS), nurse research coordinator, and graduate student. In all of these roles, the PI has been involved with pain assessment and/or management of infant's and child's pain. As a staff nurse in the Family Newborn Unit, she worked in direct contact with healthy infants receiving routine immunizations and bloodwork. For over a decade as a staff nurse in the Neonatal Intensive Care Unit (NICU), she cared for sick infants receiving multiple painful procedures plus routine immunizations and bloodwork. A few years ago as a CNS in NICU, she led an initiative to promote the utilization and communication of a validated pain measurement tool. In her current position as a nurse research coordinator of a large multi-site study, she worked to facilitate an interactive knowledge translation intervention in pain assessment and pain management on different pediatric units. In her other position as a CNS for the Complex Pain Team, she is involved in assessing and managing acute and chronic pain patients and collaborating with families in the use of pharmacological and N-PPMSs.

The PI has carefully considered her clinical practice and the gaps in patient care. She found that procedural pain practice may not be consistent with the evidence to support optimal care and believes that pediatric procedural pain is still under assessed and under managed in the hospital setting. The PI has always been interested in ways to manage pediatric procedural pain, especially non-pharmacological pain management strategies. Through various nursing positions she has practiced and promoted developmental care and non-pharmacologic methods to reduce pain.

In her present research nurse coordinator position, the PI has been involved in assessing the pain intensity of 120 children during various painful skin-breaking procedures. It was during this phase of that study that her own research questions became

more apparent. Very few non-pharmacological pain management strategies were utilized during these painful procedures. The children who experienced these procedures were sometimes in obvious distress and their parents were present, often looking bewildered and asking what could they do to help with the pain. The most frequent and probably innate response from parents was to provide comfort/reassurance to their child.

During these 120 pain assessments, parents never said they wanted to leave the room because they did not want to see their child in pain or because they were too anxious to watch. Children never once asked their parents to leave the room during their procedure. When parents are present for procedures, they are accessible, available, and often willing to help provide pain care. Parents often try to help comfort their child, but are not aware of effective pain management strategies and may even cause their child further distress. Parents need appropriate guidance in providing effective procedural pain management strategies and skilled nurses could provide guidance in effective pain management through communication and negotiation.

The PI is able to integrate academic and clinical knowledge of pain and pain management strategies with her own family and friends, and these experiences have created meaning and value related to the positive effects of parental involvement in reducing pediatric pain and distress.

This experience has led the PI to think critically; parents are a valuable resource for the delivery of pain care and they want to be involved so how can we facilitate their involvement in more effective pain strategies? Nurses could provide valuable perspectives of the ideal conditions to engage parents and this information could be used to improve the procedural pain care.

## **Chapter Two**

### **Literature Review**

#### Theoretical Perspective

Procedural pain is often experienced during the treatment or management of a disease or condition and is one of the greatest sources of distress for children and their families during their hospital stay (Blount et al., 2006; Megel, Hesel, & Matthews, 2002; Murat, Gall, & Tourniaire, 2003; Slifer et al., 2009). Despite solid evidence and medical advancements, many children still experience unacceptable levels of pain and distress from procedures during their hospitalization (Blount et al., 2006; Harvey & Morton, 2007; Kavanaugh et al., 2008; Latimer et al., 2010; Van Hulle Vincent, 2007).

Optimal pain management is a right of all children and the legal and professional responsibility of all health professionals (Baulch, 2010; Maccagno, 2009). The prevention and treatment of pain and suffering should be a priority for all health professionals, as it is the moral and ethical obligation of health professionals to effectively manage pain (Maccagno, 2009; Murat et al., 2003; Ramponi, 2009). Nurses have a primary responsibility to reduce pain and anxiety from procedures in the hospital (Wood, 2002).

Parents of hospitalized children have expressed sincere interest in being involved in reducing their child's pain (Jones et al., 2005; Simons et al., 2001). Because of the ongoing care they provide, nurses are in an ideal position to empower parents to support their children during painful procedures by engaging them in effective N-PPMSs (Wood, 2002). Parents can use non-pharmacological techniques effectively with their children if provided with appropriate guidance (Blount et al., 2006; Polkki, 2002; Polkki,

Vehvilainen-Julkunen, et al., 2002; Power, Liossi, & Franck, 2007; Simons et al., 2001; Wood, 2002). A family-centered care (FCC) approach that considers both pharmacological and non-pharmacological pain management strategies is needed to optimize pain care in hospitalized children (Blount et al., 2006; Harvey & Morton, 2007; Young, 2005).

### Pain in Hospitalized Children

This literature review will present evidence about the incidence of painful procedures in hospitalized children, inadequate management of procedural pain in hospitals, and the immediate and long-term sequelae of under managed pain. The nurses' and parents' role in managing children's procedural pain and the effectiveness of N-PPMSs will be discussed. The discussion will also include factors that facilitate parent engagement in N-PPMSs, as identified in the literature. Specific emphasis will be placed on the parent-nurse relationship and the characteristics that facilitate parental engagement in N-PPMS with their child in the hospital setting.

Keywords entered in the search strategy included pain, parent, mother, father, children, pediatric, participation, involvement, procedure, non-pharmacological, and hospital. Relevant studies between the years 2000-2012 were included in this literature review. The literature search was conducted on MEDLINE, CINAHL, PUBMED, EMBASE, PSYCHINFO, and the Cochrane Library. The IWK library electronic database was also searched for relevant literature. Bibliographies and recent pediatric and pain journals were hand searched for relevancy. A number of relevant research articles were found that supported parent participation in pain management strategies and/or the effective use of N-PPMSs with chronic or surgical pain. Limited information was

retrieved on the factors that facilitate parent participation in the use of N-PPMSs for procedural pain with their hospitalized child. Additional articles were used to provide background information on the topic and add to the discussion.

### *Background*

#### *Incidence of Painful Procedures*

Hospitalized children are increasingly subjected to painful procedures for the diagnosis and treatment of a wide variety of disorders (Harvey & Morton, 2007). On 32 patient units in eight Canadian pediatric hospitals during one 24-hour period, 2987 children experienced 18,929 painful procedures (a mean of 6.3 per child who had any painful procedure) (Stevens et al., 2011). Only 28.4% of the 2987 children received one or more pain management intervention specifically for the painful procedure (Stevens et al., 2011). Despite the recognition of the importance of pain management and research, children are still experiencing unacceptable levels of pain and procedural pain (Cohen, 2007; Kavanagh et al., 2007; Kortessluoma et al., 2008; Van Hulle Vincent, 2007).

#### *Inadequate Management of Procedural Pain in Hospitals*

Children's pain has historically been under treated and under recognized (Blount et al., 2006). It has been consistently recognized over the past decade that a significant proportion of hospitalized children (49 to 64%) have pain that is under managed (Stinson et al., 2008; Twycross, 2010). Pain continues to be an issue for pediatric patients and their families because of long-standing myths and misconceptions, costs, risks, and/or just the time and effort it takes to manage pain (Murat et al., 2003; Pillai Riddell, Horton, Hillgrove, & Craig, 2008). All age groups can experience pain and inadequately managed pain can lead to short and long-term consequences for children of all ages. Recent

evidence has shown that even premature infants can suffer long-lasting effects from painful experiences (Blount et al., Cohen, 2007; Young, 2005).

It was once believed that infants lacked the ability to feel pain or the cognitive capacity to remember pain. It was also believed that since children had immature nervous systems, they would not experience long-term adverse consequences from untreated or under managed pain and did not experience pain like adults (Blount et al., 2006; Cohen, 2007). Such assumptions contributed to years of mismanagement of pain from procedures (Pillai Riddell et al., 2008).

Today some still believe that pain is a normal part of life and that it builds character (Ramponi, 2009). Even some health professionals believe pain is to be expected during hospitalizations (Twycross, 2010). Analgesia is often underused in pediatrics because of fears of respiratory depression, addiction, and other perceived dangers (Pillai Riddell et al., 2008). Pain medication and management strategies are often avoided because of the added cost and the extra time and effort it takes (Ramponi, 2009). Pain management is not seen as a priority, as reflected in observational data, interviews, or questionnaires with nurses (Twycross, 2010). However, pain is one of the common reasons for hospital admissions, and can have a widespread impact on all aspects of life, costing society billions of dollars each year (Cohen, 2007).

Children's procedural pain continues to be largely under managed in hospitals (Stevens, 2009; Stinson et al., 2008). Even minor procedures can result in significant pain and distress for children and these procedures are often performed without any real strategies to manage the child's pain (Ramponi, 2009; Young, 2005). Common invasive procedures such as lumbar puncture, venipuncture, immunizations, intravenous access,

and blood collection are performed daily and often without analgesics or psychological coping methods (Cregin et al., 2008). Inadequate pain management can have significant individual and societal costs (Cohen, 2007; Young, 2005). We now know that infants and children experience detrimental short and long-term repercussions to untreated and under managed pain (Blount et al., 2006; Cohen, 2007; Latimer et al., 2010; Ramponi, 2009).

#### *Immediate and Long-Term Sequellae of Under Managed Pain*

Both animal and human studies have shown there are detrimental short and long-term effects from untreated pain (Cohen, 2008; Harvey & Morton, 2007; Pillai Riddell et al., 2008; Stifer et al., 2009; Young, 2005). The pain response is very individual and the pain experiences that occur in early life are instrumental in shaping the pain response to future events (Young, 2005). Procedural pain distress can disturb necessary medical care, decrease quality of life for the patient, and cause unnecessary psychological stress for families (Stifer et al., 2009). Short-term effects include hypoxemia, altered metabolic stress responses, and even mortality (Young, 2005). In infants and children that experience repeated and untreated painful procedures, the neuronal architecture of the brain may be permanently changed (Blount et al., 2006; Young, 2005). As a result, pain responses and autonomic cardiovascular responses may be altered (Blount et al., 2006; Young, 2005).

Repeated procedural pain may put the child at risk for behavioural or psychological disturbances inside or outside of the medical context (Stifer et al., 2009). Long-term effects include altered pain responses, increased anxiety, heightened medical fears, higher risk for attention deficit disorder, higher risk for posttraumatic stress disorder, and avoidance of health care (Blount et al., 2006; Young, 2005). Unmanaged

pain can have damaging effects on multiple body functions, resulting in slowed recovery, prolonged hospitalization, and worsening conditions (Van Hulle Vincent, 2007).

Untreated pain can also lead to the development of chronic pain and neuropathic pain (Baulch, 2010).

#### *Nurses Role in Managing Pediatric Procedural Pain*

The nurse usually assumes primary responsibility for the child's pain management while in the hospital (Latimer et al., 2010; Simons et al., 2001). Because of the nature of their relationships with patients and families, nurses tend to act as gatekeepers to parental participation by deciding whether or not to negotiate with parents (Tomlinson, Tomlinson, Pedine-McAlpine, & Kirschbaum, 2002). Nurses need to be aware of the role they play and how their actions can influence parental presence and participation (Young, 2005).

Nurses have a responsibility to empower parents to support their children during painful experiences (Wood, 2002). Parents may benefit from specific instruction and training from nurses in how to help their children with non-pharmacological pain management strategies (Blount et al., 2006; Ramponi, 2009; Young, 2005). Children may also benefit when parents are educated about behaviour management and behaviour modification (McMurtry, McGrath, Asp, & Chambers, 2007; Power et al., 2007; Wolff et al., 2009). Effective collaboration between nurse and parents has been demonstrated to improve children's pain care (Simons et al., 2001).

#### *Parent Interest in Engaging in N-PPMSs*

Parent's desire to be present during painful procedures with their hospitalized child is well supported in the research (Christensen & Fatchett, 2002; Gilboy &

Hollywood, 2009; Melhuish & Payne, 2006; Young, 2005). Parent participation in pain care is also supported in recent research (Blount et al., 2006; Cohen, 2008; He, Polkki, Pietila, & Vehvilainen-Julkunen, 2005; Power et al., 2007; Simons et al., 2001). Most parents would prefer to be present for procedures and participate in pain management strategies, even if procedures are highly invasive (Jones et al., 2005; Polkki, Pietila, et al., 2002). Pediatric patients would generally prefer for their parents to be present for procedures (Cohen, 2008; Garland & Kenny, 2006). It is well documented in the literature that parent engagement in procedural pain management strategies is beneficial to coping in both the child and the family (Polkki, Pietila, et al., 2002; Power et al., 2007; Ramponi, 2009; Young, 2005).

A study by Jones et al. (2005) examined ethnic differences in parent preference to be present for painful medical procedures; parents from four ethnic groups were surveyed. The vast majority of parents indicated they would prefer to be present and actively participate during procedures to coach and soothe their child (94% - venipuncture, 88% - laceration repair, 81% - lumbar puncture, 81% - fracture reduction) and there were no differences across the four ethnic groups.

Evidence suggests that parents are the greatest support to children during painful procedures and their involvement is fundamental to effective pain management (Polkki, Laukkala, Vehvilainen-Julkunen, & Pietila, 2003; Wood, 2002). Parents have a significant expertise in detecting subtle changes in their child's behaviour and thus can make a significant contribution to their child's pain care (Blount et al., 2006; He et al., 2005; Pillai Riddell et al., 2008; Polkki, Vehvilainen-Julkunen, et al., 2002; Simons et al., 2001). Parents have an increased level of understanding and history of previous pain

experiences, strategies, and responses (Polkki, Vehvilainen-Julkunen, et al., 2002).

Parents are more likely to know the child's pain cues and typically rate their child's pain closer to the child's ratings than the nurses' ratings (Simons et al., 2001; Garland & Kenny, 2006; Rajasagaram, Taylor, Braitberg, Pearsell, & Capp, 2009) and their participation may have a positive impact on their child's anxiety, pain, and sleep (Polkki, 2002).

Parents can advocate for their child's pain and collaborate with the nurse to meet their child's pain management needs (He et al., 2005). When parents are involved in their child's care and pain management strategies they experience continuity in their role, which can enhance coping during the hospitalization (Christensen & Fatchett, 2002; Polkki, Pietila, et al., 2002).

However, parents' involvement in non-pharmacological procedural pain management is often varied and limited (Simons et al., 2001). Parent anxiety and distress often result from uncertainty related to how to best assist their child during a painful procedure. Parental stress increases when parents are not involved in their child's care to the extent of their wishes (Franck & Bruce, 2012). Involving parents in the assessment and management of pain would improve the effectiveness of pain management strategies and improve coping for both parents and the child (Blount et al., 2006; Christensen & Fatchett, 2002; Simons et al., 2001).

#### *Parents as Facilitators for N-PPMSs*

Parents can play a significant role in helping to manage their child's pain, especially in the use of non-pharmacological strategies (Blount et al., 2006; Christensen & Fatchett, 2002; Polkki, 2002; Polkki, Pietila, et al., 2002; Power et al., 2007; Simons et

al., 2001; Wood, 2002). Christensen & Fatchett (2002) have suggested that N-PPMSs are more effective when implemented and reinforced by someone who is “interpersonally warm” such as a parent. Parents can play a large role as coaches for N-PPMSs with their child, as children rarely engage in coping behaviours without the use of coaches (Cohen, 2008). When parents are confident in pain management with their child, there is a greater likelihood they will play a role in their child’s pain experiences even after discharge (Baulch, 2010).

Nurses have also reported that parents’ participation in their child’s care facilitated the use of non-pharmacological methods (Polkki et al., 2003). However there is still a lack of knowledge as to how nurses guide parents in the application of non-pharmacological methods with procedural pain care (Polkki, 2002).

A study by He et al. (2005) used structured questionnaires to examine how nurses used preparatory information for procedures and what N-PPMSs were recommended to parents. This study targeted nurses on a surgical ward and the response rate for completion of the questionnaire was high (98%). The study concluded that parents were often not guided in N-PPMSs with their hospitalized children.

A study by Polkki, Vehvilainen-Julkunen, et al. (2002) used questionnaires to examine parents’ roles in using non-pharmacological methods in their child’s postoperative pain alleviation. The methods that were frequently reported as being used were instinctive and natural care-giving tasks such as emotional support and helping with daily activities; cognitive-behavioural and physical methods were used less frequently (Polkki, Vehvilainen-Julkunen, et al., 2002). Providing parents with a specific role and educating them about evidence-based techniques can be very helpful for procedural pain

management (Young, 2005). Non-pharmacological procedural pain management strategies, such as cognitive and behavioural techniques, are ways parents can effectively help their children (Christensen & Fatchett, 2002; Power et al., 2007; Sinha, Christopher, Fenn, & Reeves, 2006).

### *Effectiveness of N-PPMSs*

Alternatives to potent analgesics and other pharmacologies are gaining attention in the medical community. N-PPMSs have been used effectively as a substitute for potent pharmacological therapies and as an adjuvant to sedative/analgesic therapy for pediatric procedural pain. Many recent well-conducted studies have reported effectiveness with N-PPMSs and their possibilities for use in clinical practice (Cohen, 2008; Murat et al., 2003; Lawes et al., 2008; Sinha et al., 2006; Stinson et al., 2008).

A recent systematic review and meta-analysis on the effectiveness of psychological interventions in children concluded that there was strong evidence to support non-pharmacological techniques such as distraction, hypnosis, and coaching to help children in coping with painful procedures (Uman, Chambers, McGrath, & Kisley, 2006; Christensen & Fatchett, 2002; Sinha et al., 2006). Distraction and breathing techniques, desensitization, relaxation, memory change, hypnosis, parent coping styles, staff behaviour and increase in child control during the procedure have been studied and proven to reduce patient distress associated with painful procedures (Lawes et al., 2008; Murat et al., 2003).

Uman et al. (2006) also report that there is sufficient evidence to support parent participation in many cognitive and behavioural techniques to effectively manage pain with their child when they have received training in these areas. The use of N-PPMSs to

control distress, pain, and anxiety associated with procedural pain can also benefit children and their parents over the course of their treatment and/or recurrent hospitalizations by adding to their repertoire of pain management skills (Christensen & Fatchett, 2002).

### *Factors Related to Pain Care Delivery*

#### *Nurse Characteristics (Age, Education, Experience, Attitudes, Values, Beliefs)*

There have been a wide variety of factors identified in the literature that could influence better pain care delivery including experience, educational preparation, expectations, attitudes, values, and beliefs. Latimer et al. (2010) identifies individual nurse characteristics such as educational preparation, critical thinking disposition, knowledge of current pain care, years of experience, empathy, and mental/physical wellness as factors that may better predict pain care practices. He et al. (2005) used structured questionnaires with surgical nurses to examine the factors that influenced the provision of preparatory information and methods/guidance in pain management to parents. Nurses, who were older, more educated, more experienced, held advanced nursing positions, or had children, tended to provide information and guidance more than nurses without those characteristics. There is conflicting evidence about the influence of various nurse characteristics on the application of strategies in children's pain management and work with parents.

In a study by Polkki (2002), nurses completed surveys related to their perceptions of how they guide parents to help relieve their child's surgical pain in the hospital. Similar to the work of He et al. (2005) nurses who were older, more educated, more experienced, and had two or more hospitalizations with their own children were more

willing to provide information about pediatric pain management than the nurses without these characteristics. Corlett & Twycross (2006) suggests that senior nurses are better able to negotiate care with parents than junior nurses. In contrast, Meluish & Payne (2006) suggest that demographic factors such as nurse's age, education, and experience had no influence on nurses' pain management practices.

There is also conflicting evidence related to the influence of nursing education on pain management practices with children and their families. Twycross (2010) suggests that there are still gaps in nursing knowledge of managing pediatric pain with non-drug methods. However, there is no evidence of a positive correlation between the nurse's level of knowledge and their pain management practices. Even when nurses are knowledgeable about pain and pain management, this knowledge does not seem to be effectively translated in practice (Latimer et al., 2010; Twycross, 2010).

Pain education related to the parents' role in children's pain management might be an important first step in increasing parents' participation in N-PPMS (Garland & Kenny, 2006; Gimbler-Berglund, Ljusegren, & Enskar, 2008; He et al., 2010). Education may have a positive effect on nurses' use of N-PPMSs with pediatric patients and their families but often it is the attitudes, values, and belief of patients, nurses, and organizations that influence the outcomes of education and often act as barriers to optimizing pain management practices (He et al., 2010).

Nurses' attitudes, values, and beliefs can either facilitate or impede parent participation in their child's pain care (Twycross, 2010). Personal or cultural values associated with pain and pain management may play a role in nurses' pain management practices (He et al., 2010). Nurses seem to have preconceived ideas about what types of

care that parents could be involved in (Corlett & Twycross, 2006). For example, when a nurse believes the family could be a positive and pivotal influence in their child's care they may be more receptive to involving them. On the other hand, nurses who feel ambivalent or threatened by the family's knowledge or role in their child's pain care may choose not to involve them or limit their involvement (Espezel & Canam, 2003).

Nurses may change their attitudes about parents over the course of their relationship, when they believe that the family is competent to set realistic and meaningful goals for the child's care (Espezel & Canam, 2003). Van Hulle Vincent (2007) conducted a pilot study to better understand how pediatric nurses think about and respond to pain through examination of their cognitive representations. Cognitive representations are how individuals perceive a situation based on previous experiences that are stored in memory. Cognitive representations were identified through qualitative interviews using open-ended technique cognitive and those cognitive representations were compared to decisions about pain assessment and management in relation to case study vignettes. The majority of participants (80%, n=16) identified a role for family involvement in pain assessment but only 35% (n=7) of participants indicated they should be involved in management. More research is needed in this area, but the results of this study suggest that when attempts to involve parents are unsuccessful, nurses may develop the perception that parents are not essential in their child's pain management.

Though nurse characteristics are largely unmodifiable (age, education, experience), creative strategies such as mentoring programs and parent/family-designed workshops could be focused on nursing development in the delivery of pediatric pain management practices.

### *Child Characteristics (Severity of the Illness, Age)*

Child's age and acuity are factors that may influence pain care. A survey of nurses on medical and surgical wards in a children's hospital revealed that nurses believed that infants and toddlers feel more pain than older children (Melhuish & Payne, 2006). There is other evidence that young children experience more distress as a result of painful procedures (Murat et al., 2003). Acuity and diagnosis may also affect nurses' pain management practices (Garland & Kenny, 2006).

Nurses may limit their interactions with parents when their child is acutely ill, but involve parents more often or at a higher level when the child's condition improves (Espezel & Canam, 2003). Parents perceived that nurses did not converse with them when their child was very ill (Espezel & Canam, 2003). Interactions were mainly brief, factual, or more technologically focused during times of highest acuity. As the child's condition improved the relationship became more positive (Espezel & Canam, 2003). Though age and acuity are also not modifiable factors, they should be considered when making up patient assignments to highlight nurses' expertise and skill mix (Latimer et al., 2010).

### *Parent Characteristics (Existing Behaviours, Confidence, Other-Oriented)*

The way that parents react and behave in relation to their child's pain can greatly influence their child's response to painful experiences and thus their role in pain care management (Blount et al., 2006; McMurtry et al., 2007; Power et al., 2007). Parent emotions such as anxiety and fear can obstruct effective N-PPMSs and behaviours such as empathy, criticisms, apologies, giving control to the child, and reassurance are associated with child distress (McMurtry et al., 2007; Plumridge, Goodyear-Smith, &

Ross, 2009). When parent's behaviours and emotions are linked to increased distress in the child, nurses may or may not be hesitant to involve them in pain care delivery. This is a gap in the literature.

Goubert, Vervoort, Sullivan, Verhoeven, & Crombez (2008) sampled 650 parents (325 mothers; 325 fathers) who read eight vignettes about their child in varying types, intensities, and frequencies of pain and stressful situations. The study found preliminary evidence that linked parental characteristics to parental helping pain related behaviours. The authors hypothesize that parents who catastrophize about their child's pain are more likely to focus on reducing their own distress rather than their child's. On the other hand, parents who have greater empathy may be more flexible in providing care, stimulating coping, and attending to the needs of their child. It was concluded that further studies are needed to test this study's hypothesis.

#### *Organizational Culture of Care Area*

Organizational culture is a factor that positively or negatively influences pain management practice. The social context of each nursing unit can be different, affecting the way that nurses' conduct their pain management practices related to parent participation. Cultures that encourage collaboration, support, and autonomous decision-making promote evidence-based pain practice by health professionals (Stevens et al., 2011). Quality improvement strategies and pain management programs have been implemented in hospitals to improve pain assessment and management practices with success in the short-term, but these practices have not been studied over a prolonged period (Twycross, 2010). It is not clear how these factors directly influence parental involvement in pain practices.

## *Resources*

Resources can play a significant role in the delivery of adequate pain care. Such resources may include adequate staff, staff with pain expertise, supplies (topical anaesthetic, videos), and equipment (patient controlled analgesia pumps, distraction tools). Adequate workload requires enough staff with the appropriate expertise to do the necessary work. Pressures of workload can influence nurses' pain management practice (Garland & Kenny, 2006). Nurses report that lack of time and lack of routines negatively affect their ability to manage pain in children (Gimble-Berglund et al., 2008; Latimer et al., 2010). Parents reported that consistency of staff and fewer turnovers of staff are factors that promote shared care with nurses (Espezel & Canam, 2003).

The resource of a hospital pain team often enables staff members to facilitate parental engagement and model coping-promoting behaviours (Blount et al., 2006). A pain team can present seminars and provide guidance to staff on the roles of the pain team members, how to prepare a child for a procedure, how to respond to the child during a procedure, and how to use the assistance of a child's parents for a procedure (Blount et al., 2006). Several studies have found that the introduction of a pain service can significantly reduce patients' pain scores (Blount et al., 2006; Twycross, 2010). A CNS specializing in pain can provide educational support and guidance on pain management and is considered to be a valuable human link to pain management services, forming relationships between the parent and child, units, and the hospital pain team (Twycross, 2010).

*Organizational Standards (Pain Guidelines and Standards, FCC)*

Extensive research in the area of pediatric pain has prompted the development of pediatric pain standards and guidelines. The policies and guidelines put forth by professional organizations and pain societies may impact pain care by changing work-life conditions and patient outcomes (Latimer et al., 2010). Care standards for pain assessment and management by authorities such as the Joint Commission of the Accreditation of Healthcare Organizations (JCAHO, 2003) and the Canadian Council of Health Service Accreditation (2005) may have made an impact on pediatric pain management and are credited with directly influencing nurses' pain care practices (Latimer et al., 2010; Stinson et al., 2008).

Today most pediatric hospitals boast philosophies of FCC and are equipped with facilities to accommodate parents. FCC is a basic tenet of pediatric nursing and involves shared decision-making and negotiation of roles between health professionals and the family (Corlett & Twycross, 2006). Most parents want to be involved in their child's pain care but are not sure how they can help to reduce their child's pain or negotiate a role for themselves in sharing the care of their hospitalized child. The relationship between the family and the nurse is critical to this negotiation process and the interactions that result (Corlett & Twycross, 2006). Much of the literature on FCC describes inconsistencies surrounding the decision making and negotiation process, parental expectations of participation, and issues relating to power and control, particularly with nurses (Corlett & Twycross, 2006).

### *Nurse-Parent Relationship*

The most prominent and promising literature on the topic of parent's involvement in N-PPMSs is related to the potential successful working relationship between parents and health professionals, primarily nurses. The nurse-parent relationship is probably the biggest modifiable influencing factor in facilitating active engagement of parents in N-PPMSs with their hospitalized child.

#### *Empathy*

Empathy may be helpful to motivate nurses to engage parents or use other strategies to reduce pain. Empathy is “a cognitive-emotional process that fosters an understanding of others’ emotional states and leads to helping, altruism, and prosocial behaviour” (Drwecki, Moore, Ward, & Prkachin, 2010, p. 1001). It has been hypothesized that nurses’ empathetic ability is essential for high quality care related to pain management in children (McCabe, 2007; Yu & Kirk, 2008). When nurses imagine what parents and their child are feeling, they are more empathetic and motivated to initiate helping and lessen distress and suffering with parents and their child (Decety, 2011).

It has been suggested that empathetic nursing care may be affected by factors such as nurses’ characteristics (i.e., age, nursing education/ experience, pain knowledge/beliefs) and patients’ characteristics such as age, and situational context (Watt-Watson, Garfinkel, Gallop, Stevens, & Streiner, 2000), but this relationship is not fully understood because there is little known about how to accurately measure empathy. Greater empathy may play a role in delivery of better pain care, but it has not been shown consistently in the literature (Latimer, Jackson, Johnston, & Vine, 2011). Nurses have

unique knowledge and sensitivity related to the pain, but this does not translate into better pain management for their patients (Latimer et al., 2011; Watt-Watson et al., 2000).

Latimer et al. (2011) suggest that nurses' ability to empathize or be sensitive to pain might be impaired or compromised as a result of repeatedly viewing pain and this may play a role in under management.

#### *Rapport/Communication*

Establishing rapport and clear communication are necessary elements for collaboration between parents and nurses for pediatric pain management (Corlett & Twycross, 2006; Espezel & Canam, 2003; Simons et al., 2001). Rapport is defined as a relationship of mutual understanding or trust and agreement between people. In a qualitative study by Espezel & Canam (2003), parents provided in-depth interviews about their experiences with nurses in a hospital setting related to the care of their children. Parents identified the key aspects in establishing rapport were the reciprocal interchange of knowledge, skills, and coaching and the nurse's demonstration of interest in learning about their child and their individual experience.

Both parents and nurses felt it was essential to spend time together in order to establish rapport. Consistency of staff and an increased familiarity with the hospital environment and routines promoted rapport; allowing parents and nurses time to interact and work together to provide care for the child (Espezel & Canam, 2003).

Clear communication can also set the tone for collaborative relationships and advance the determination of care needs and mutual goals. Communication skills are core to professional nursing practice and allow nurses to align with parents and avoid miscommunication and misunderstandings. When nurses and parents work together to

establish a common and relevant goal, they can work together to provide more individualized pain care that suits the child and family (Espezel & Canam, 2003; Plumridge et al., 2009).

#### *Sharing Health Information*

Nurses and parents often differ in their perceptions of whether parents receive adequate information to help their child with N-PPMSs with their child. Polkki (2002) measured nurses' perceptions and the findings of this study showed that nurses believed parents were well informed about their child's procedure and the N-PPMSs to relieve their child's pain. In another study by Polkki, Pietila, et al. (2002) parents expressed a need for sufficient and understandable information related to their child's pain. Less than half (33%) of the parents in this study agreed that they had received adequate information about N-PPMS and only 31% had been taught methods for alleviating pain in the hospital.

According to Polkki (2002), only 39% (n=63) of nurses reported routinely providing parents with information about the use of N-PPMSs such as imagery, positive reinforcement, thermal regulation, and massage. Polkki (2002) and Twycross (2010) conclude that nurses had knowledge deficits related to non-drug methods of pain relief and suggest they may lack the confidence in their ability to use N-PPMS, let alone how to teach these strategies to parents.

#### *Parent-Professional Collaboration*

Parent-professional collaboration is an essential component of quality children's pain management (Espezel & Canam, 2003; Gimpler-Berglund et al., 2008). Collaboration has been described as working together to achieve mutual goals. Nurses

and parents must develop relationships of mutual trust and goal setting in order to fully collaborate in pediatric pain care.

Espezel & Canam (2003) examined the experiences of parents who interacted with nurses in a hospital setting while caring for their child. Qualitative interviews with parents described the exchanges between parents and nurses as mostly positive but not collaborative. This study concludes that parents and nurses may establish rapport but often do not develop collaborative relationships in the current health care environment. They suggest that the nurse-parent relationship is developed in stages that may overlap, and individual/contextual characteristics may influence this relationship building.

### *Negotiation*

The nature of the nurse-parent relationship may affect the negotiation of care roles. Negotiation has been described as mutual discussion and arrangement of the terms of a transaction or agreement. When care tasks are negotiated between health professionals and family, shared decision making about the child's care and what their participation will involve occurs (Corlett & Twycross, 2006). Parents wish to participate in their child's care, but at a level of their own choosing (Polkki, Vehvilainen-Julkunen, et al., 2002).

Espezel & Canam (2003) describe a negotiation process that needs to happen between the parents and nurse in order to facilitate parents' active engagement with their hospitalized child. It is believed there is a continuum of care that seems to emerge as parents and nurses care for a sick child and this directly affects the negotiation process. Once hospitalized, a child's care seems to become almost exclusively provided by the nurse. Parents seem to accept this and describe it as "necessary" when a child is severely

ill. Usually once the child's condition is stabilized, the care giving responsibilities tend to become more balanced and parents describe this as "positive". In some cases, parents feel they are expected to provide most of their children's care. When care is no longer shared and there is an expectation that they will provide the majority of care, parents describe this as a "negative" experience.

Nursing staff often has clear views of what they want parents to do and parents are expected to cooperate with those. As parents develop knowledge and proficiency in the care of their hospitalized child, and become more experienced in their interactions with health professionals, they become more assertive in negotiating their desired role and are able to refuse roles they think are inappropriate. This new confidence enables parents to negotiate with health professionals and allows for more of a power balance between parents and nurses (Corlett & Twycross, 2006) however power remains a real issue/struggle between parents and nurses.

#### *Power and Control Issues*

When parents express a desire to increase or decrease their involvement in the care of their child, nurses usually respond in one of three ways: encouragement, explanation, or negotiation. This response can act as a facilitator or barrier to parent involvement in the pain care of their child, and may affect future health care experiences for the parents and child.

Health care professionals are in a position of power and parents often report feeling disempowered and deskilled in the hospital environment (Kirk, 2001). Parents often feel ignored and under-used as a resource for pain management with their child (He et al., 2010). Parents want information to be able to make decisions about what their level

of participation in their child's pain care will be (Corlett & Twycross, 2006). When parents are not given enough information to make decisions or participate in care it is a power and control issue.

Parents feel that nurses were not always willing to relinquish their control over the part of the child's care that has been historically seen as the "nursing care". Consciously or unconsciously, nurses act as gatekeepers to parental participation, choosing whether or not to negotiate with parents about their level of participation in their child's and information relating to the child's condition (Corlett & Twycross, 2006).

#### Gaps in the Knowledge Base

There are several factors that appear in the literature that potentially influence parental involvement in N-PPMSs. These include nurse, child, and parent characteristics, organizational culture, resources, and standards, and factors related to the nurse-parent relationship (i.e., empathy, rapport/communication, sharing health information, parent-professional collaboration, negotiation, and power and control issues). Gaps in the knowledge base related to parental involvement in pain care have been identified.

One of the gaps is related to the discrepancy between parents and nurses' perceptions of level of parental involvement and information sharing. Nurses often perceive that parents are adequately involved in pain management with their child (Polkki, 2002; Simons et al., 2001), yet parents often express frustration and describe having a superficial and passive role (Polkki, 2002). Nurses generally perceive that parents are well informed about their child's procedures and non-pharmacological methods of pain management (Polkki, 2002) yet parents often report a lack of information about their child's condition and pain management strategies as a barrier to

their involvement (Polkki, Vehvilainen-Julkunen, et al., 2002). It is unclear why there is such an inconsistency between nurses' and parents' perceptions of parental involvement in pain care (Polkki, 2002). Simons et al., (2001) describe a definite need to implement creative strategies to promote effective relationships between parents and nurses where roles are negotiated and information is shared to promote effective pain management in hospitalized children. Another gap in the knowledge relates to how N-PPMSs and parental participation is used in practice by health professionals.

As identified in several studies by one researcher (Polkki, 2002; Polkki, Pietila, et al., 2002; Polkki, Vehvilainen-Julkunen, et al., 2002), there is a need to do research that examines the factors influencing parental participation in the application of pain management strategies and care of their hospitalized child. Very little is known about how parents are engaged in N-PPMSs with their hospitalized child and what is known mainly comes from a parent perspective (He et al., 2005; Polkki, Pietila, et al., 2002). It would benefit practitioners to understand the factors that nurses consider when making decisions about involving parents in N-PPMSs, since they are seen as the gatekeepers of care and care decisions.

Much of the current literature on parent participation discusses the barriers, rather than the facilitators to shared decision-making and parental involvement in their child's pain care (Corlett & Twycross, 2006). This study examines the positive conditions that facilitate parental engagement in N-PPMSs with their hospitalized child. Through qualitative interviews and AI, pediatric nurses identify facilitators to parents' active engagement in procedural pain management strategies.

## **Chapter Three**

### **Methodological Framework**

#### Introduction

A qualitative research approach was used involving in-depth interviews with nurses to gain understanding of the positive conditions that facilitate parent engagement in N-PPMSs with their hospitalized child. Qualitative research fits within an interpretivist tradition which is based on the assumption that in order to make sense of the world, human behaviour and social processes we need to understand interactions between people (Gerrish & Lacey, 2010). This approach is used to explore an experience, culture, or situation in depth, taking account of context and complexity, and is a valid way of advancing nursing knowledge (Creswell, 2007; Gerrish & Lacey, 2010). Qualitative methods are appropriate when little is known about a subject and the purpose of the research is to explore a problem or issue (Creswell, 2007).

The Theory of Social Constructivism (Vygotsky, 1978) and the methodology of AI (Cooperrider & Whitney, 2005) were employed in this study. The Theory of Social Constructivism (Vygotsky, 1978) is a worldview where individuals seek to understand the human interaction with the world in which they live and work. The goal of research under this worldview is to understand the participant's view of the situation, issue or problem through their experiences. Participants have developed subjective meanings of their experiences through their interactions with others and through historical and cultural norms that operate in their individual lives. Subjective information set in the context or natural setting is essential to construct knowledge and understanding of the issue (Patton, 2002). In this study, the significance of social interactions between nurses and parents,

and culture and context of where parental involvement in procedural pain management occurs was examined through a social constructivist view and analyzed with the positive lens of appreciative inquiry to create practical recommendations for engaging parents in N-PPMSs.

Constructivist researchers use open-ended questions and “position themselves” in the research, to interpret their findings, which are shaped by their own experiences and background (Creswell, 2007). The PI has been connected with children’s pain experiences as a NICU nurse, Pain Management Team nurse, mother, and as a research nurse involved with a large multi-center study actively examining strategies to reduce children’s pain. The personal and professional experiences described in the Reflexivity section of Chapter One have created meaning related to the positive effect of parental involvement in reducing pediatric pain and distress. Knowledge constructed from these pain strategies and experiences have been utilized and applied to the research findings to create a mutual interpretation of how Appreciate Inquiry and the resulting themes can be used to improve pain practices with children and their parents.

### Appreciative Inquiry (AI)

AI is premised on the social constructivist view that social reality is a creation of shared meanings within a social system (Kavanaugh et al., 2008). AI is fundamentally based on the idea that organizations are centers of human connectedness and potential through their relationships, partnerships, alliances, and networks. 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 an organization or a community when it is the most effective and most capable in economic, ecological, and human terms (Cooperrider & Whitney, 2005, p. 8).

AI is a philosophy and methodology that has been used to promote positive change in social systems (Havens, Wood, & Leeman, 2006). AI challenges the traditional problem-oriented approach used in organizations, and explores the issue through a positive lens at what is possible. When using a positive, strengths-based process of inquiry, systems can grow in a positive direction and consciously create a better future.

AI is a complement to more conventional forms of action research and is effective to generate knowledge or ideas to initiate a dialogue that will eventually lead to a reflection of values and practices (Kavanagh et al., 2008). AI is also characterized by its ability to unite researchers and clinicians for the purpose of mutual learning about what works best in an organization and how to build on these positive ideas and images (Richer, Ritchie, & Marchionni, 2009). This research is not organization based per se, but has drawn on the perspectives of a sample of nurses who work in four pediatric care areas in one particular organization. It is suited to generating positive group dynamics and innovative ways to improve nursing practice. This method has been used as an intervention strategy to change practice; however, this is beyond the scope of this research.

AI can bring together the nurses' knowledge, core values and attitudes, and mutual goals and aspirations through a four-phase process. The process can guide and challenge nurses to be self-reflective and identify existing inspiration and facilitators that drive practices forward (Ruhe et al., 2011). At the heart of this process is the appreciative interview, where nurses are engaged in a deep dialogue about strengths, resources, and capabilities so they can imagine the bold possibilities and dreams for the future and the relevant structures and processes to realize those dreams.

AI has been used to elicit positive innovative ideas from the nurse's perspective, for example, Barnes (2009) determined that AI was used successfully to gather rich, descriptive data and advance current knowledge in palliative care practices. Richer et al. (2009) determined that AI could be used with individuals and teams, as an important first step toward reorganizing health care services by uncovering their strengths/successes and creating innovative ways to improve care. Similar to the work of Barnes (2009), Kavanagh et al. (2008), Richer et al. (2009) & Stefaniak (2007), AI was used to gather information from nurses about the positive conditions that facilitate parents' active involvement in effective procedural pain strategies with their hospitalized child. The AI process includes a 4-D cycle (Appendix A).

#### *4-D Cycle*

The four D's are Discovery, Dream, Design, and Destiny. Using AI and the 4-D cycle can help individuals and groups to think strategically and imaginatively about their future and initiate change in the practice environment based on the strengths and evidence of past successes. The AI process is captured in the 4-D cycle: Discovery leads to Dream, is followed by Design, and eventually creates Destiny (Cooperrider & Whitney, 2005). The interview process addressed all phases of the 4-D cycle through mutual learning about what works best in their units, how it could inspire future innovations, and how structures and processes could be built on to advance parental involvement in pain practices.

The content of the questions was developed from a number of areas; the PI's experience as a clinician and a parent, literature on nurses, parents, and pain, and other research studies specifically using this methodology. The questions were developed to

guide participants in the process of reflection and self-discovery about strengths and capabilities, and then lead them to forward thinking about dreams and possibilities. The positive framing of the questions seemed to provide a positive atmosphere to inspire imagination and creativity. The questions were arranged according to the 4-D cycle to guide the AI process and to draw out responses in a story-like format; each phase builds on the one before.

### *Discovery*

The purpose of this phase was to discover the positive capacity of nurses and the environments in which they work. In this phase the appreciative interview guide was used to initiate conversation about the strengths and accomplishments of the nurse participants and their respective pediatric units.

The first series of research questions provided nurses with an opportunity to identify positive experiences when they engaged parents in pain care practices. Participants were asked to identify what is most meaningful and valuable about their individual work and the most important assets of the team. For example, one of the interview questions asked “What are some of the things that you value the most about yourself and your position as a nurse, the unit that you work on, and the organization as a whole?” Participants were also asked about what they valued as their role in involving parents in pain management during painful procedures and to identify the most significant contributions and practice achievements. Information gained in this phase often inspires creativity, motivation, and enthusiasm among participants (Cooperrider & Whitney, 1999).

### *Dream*

Cooperrider & Whitney (1999) state that positive real life experiences and insights can inspire hopes and dreams for the future. In the dream phase, dreams are envisioned through the further exploration of the stories that were shared in the first phase. Through mutual learning and positive discussion about past practices and potential for the future, participants may imagine the possibilities based on common values (Cooperrider & Whitney, 2005).

A second series of research questions encouraged participants to dream of what could be. Participants were encouraged to discuss the individual and contextual factors that would exist for the ideal conditions for engaging parents in procedural pain management to be realized. Questions to guide participants included “Based on this particular experience of involving parents, what do you think happened to make it so positive and what sorts of things happened on your unit to make this experience possible?” and “If you had three wishes related to improving the effectiveness and involvement of parents in their child’s pain care, what would they be?” Through exploration of their experiences and expanding on future possibilities, participants were able to articulate strengths and best practices for engaging parents in N-PPMS with their child.

### *Design*

Once the dream is articulated and the future is envisioned, the ideal environment can be appreciated and proposed in the design phase. This proposed creation should be based on successful real life experiences and innovative ideas for the future (Cooperrider & Whitney, 2005). In the design phase, participants are encouraged to design the

processes and structures needed for the dream they proposed to become a reality (Cooperrider & Whitney, 1999).

The third series of questions engaged participants in an in-depth dialogue about the best individuals, practices, structures, and processes that would support parents in procedural pain management. Participants were asked to propose a clear vision for engaging parents, including a hypothetical plan and implementation strategies and including questions such as: “What do you identify as the key strategies and processes to achieve optimal parent involvement in pain care with their child?” and “Who do you think should be involved?” These questions encouraged participants to think about how they would design an environment that is based on values and past successes.

### *Destiny*

This phase is an opportunity to think about action after contemplating the discovery, dream, & design aspects. The goal of this phase is strengthen the positive capability of the system through commitment to planning the improvement through conversations about how to build relationships, redesign structures, and sustain processes (Cooperrider & Whitney, 2005). Outcome measures should also be identified in this phase (Stefaniak, 2007).

The fourth series of questions invited participants to identify strategies and support systems to sustain the “dream” practice environment (Cooperrider & Whitney, 1999). Interventions and evaluation were not part of this study but participants were still asked to think strategically about how they would make and measure improvements and sustainability in their practice environment. Stakeholder input is vital for appreciating what already works well and how it can be built on and identifying appropriate outcome

measures based on their practical experiences with the patient population and work environment (Stefaniak, 2007).

Through a qualitative approach using in-depth interviews, nurses were able to articulate valuable information about their interactions with parents and the context of these experiences. AI and the 4-D cycle were used to examine their experiences through a positive lens.

### Setting

The study was set in four pediatric units at the IWK Health Centre in Halifax, Nova Scotia: medical, medical/surgical, neonatal intensive and hematology/oncology. The numbers of patient beds in each of these respective areas are as follows: 24 (medical), 24 (medical/surgical), 40 (neonatal intensive care), and 15 (hematology/oncology). These units were chosen because the PI is involved in a larger research study that includes all four of these units for data collection related to pain and pain management strategies. Some of the data collected from these units for the larger study is accessible from a large database and could be used in the future to compare and discuss the findings.

The patients on these units range from newborn infants to teenagers. All age groups experience painful procedures such as lumbar puncture, venipuncture, immunizations, intravenous access, and blood collection. There are non-pharmacological evidence-based strategies that can be used by health professionals to effectively reduce procedural pain in all of these age groups (Cohen, 2008; Murat et al., 2003; Lawes et al., 2008; Sinha et al., 2006; Stinson et al., 2008).

## Sample

Purposeful sampling was used as the sampling method for this study. Purposeful sampling adds credibility to the sample when the potential sample is too large (Creswell, 2007). This was thought to be the best method to inform an understanding about the research topic under question. Participants included three nurses from each of the four identified areas (medical, medical/surgical, neonatal intensive care, and hematology/oncology units) of the IWK Health Centre for a total of twelve nurses. The sample was based on other health research using this methodology (Richer et al., 2009; Stefaniak, 2007). A sample of 12 nurses is acceptable to conduct a qualitative analysis, as the intent is not to generalize the information but to elicit details about a particular problem or issue (Creswell, 2007).

Nurses are the largest professional group working in each of these areas and the numbers of nurses in each of the four pediatric units are as follows: 45 (medical), 50 (medical/surgical), 150 (neonatal intensive care), and 33 (hematology/oncology). The IWK Health Centre is the tertiary care centre for the Maritime Provinces and each of these areas has a large number of inpatients that are acutely ill. Nurses were chosen as the participants in this study because they could provide perspectives on their experiences to add to the current knowledge about involving parents to reduce children's pain.

Nurses in each of these areas receive various types of training and orientation to care for different acuity levels of ill infants and children. To appreciate nurses' diverse perspectives of involving parents of children experiencing various conditions, procedures and levels of pain this study excluded nurses who have worked in a specific area for less than two years. Based on the personal experience of the PI and consultation with unit

educators, it may take up to two years to receive the comprehensive training needed to work with the most critically ill patients. The PI acknowledges the importance of obtaining parent perspectives on the research issue but this study focused only on the nurse's considerations when engaging parents in N-PPMSs.

### Procedure

The process of obtaining ethical approval and support to conduct research on this topic, recruiting participants, and collecting and analyzing data using the AI process will now be discussed.

#### *1. Obtained Ethical Approval*

Prior to data collection, ethical approval was obtained from the Research Ethics Board at the IWK Health Centre. Ethical principles outlined in the institutional ethics board guidelines (such as: respect for human dignity; respect for free and informed consent; respect for vulnerable persons; respect for privacy and confidentiality; respect for justice and inclusiveness; balancing harms and benefits; minimizing harm; and maximizing benefits) were considered throughout the research process.

#### *2. Consulted Managers and Obtained Support*

Concurrently, the PI met with unit managers to seek a letter of support to state that their unit was able to accommodate the project and requested permission to approach unit nurses for potential recruitment. The unit managers were given a detailed verbal and written description of the study including purpose and description of the research, methodology and methods, and ideal participants for the study. Participants were recruited through email communication, posters, face-to-face contact, and word of mouth.

### 3. *Participant Recruitment*

The PI asked each of the unit managers to send an email message (Appendix B) to nursing staff describing the study's objectives, purpose, and participant expectations. The email was sent using eSource, the hospital's electronic communication tool which is frequently used by nurses. With the unit managers' permission, invitations to the study (Appendix C) with a detailed description of the research, participant's role, and time commitment were posted on the four units in a paper poster format as well as electronically on the eSource communication tool. Potential participants were asked to call or email the PI to express their interest in the study. As participants were available for the study on each unit, dates and times were arranged for the interviews. Therefore interviews were done on a first come, first serve basis. When there were more than three nurses recruited for the study on a unit, interested participants were contacted and told that their names would be kept in case someone withdrew from the study. Recruitment and all interviews were done over a five-week period. Recruitment strategies were effective; with no need to send a second round of emails or reminders to recruit participants.

Once nurses expressed a desire to participate and signed the consent form outlining study details such as description of the research, purpose of the research, potential harms and benefits, and considerations to protect the participant, an interview time convenient to the nurse was set. Nurse participants were told that confidentiality would be maintained and that they were free to share their experiences openly without being linked to the data. A copy of the consent (Appendix D) was provided to each participant with phone number/email address information to contact the PI at any time

with questions. Participants received a small honorarium, a gift card for the movie theatre, for their time.

#### 4. *Data Collection*

Nurse study participants were clearly informed of their role in the study and permission to audiotape the interview was obtained. Participants were informed that audiotapes would be destroyed after they were transcribed and transcripts would be identified with a study number, but no other personal identifiers. It was also mentioned that a separate linking document with participants' names and numbers pertaining to the study would be kept in a locked cabinet in the Centre for Pediatric Pain Research at the IWK Health Centre for five years after publication, as per the IWK guidelines. The PI assured the participants that their participation in the study was voluntary and that confidentiality would be maintained. A copy of the study results was offered to participants by checking a box on the consent form.

Two datasets were obtained from this study: a) information provided by nurses in the one-on-one interviews, b) information provided by nurses in collective focus groups in response to the themes generated from the interviews. AI encourages dialogue and learning through the process of appreciative interviewing. The appreciative interview is considered the heart of AI, and is used to uncover what is valued, wished for, and gives life to an organization when it is at its best. Focus groups were also used to determine the participants' views of the credibility of the findings and interpretation and to create strategies that represented the themes/sub-themes and were used because focus groups are often advantageous when the interactions among interviewees will likely yield the best information (Creswell, 2007). The overall goal of the interviews and focus groups

was to examine the nursing perspective, individually and then collectively, related to the conditions that support parent involvement in N-PPMSs with their child from a nursing perspective.

*a. Interviews*

Interviews began with a discussion of the intent and purpose of the study and the background of the researcher, the tentative timeline for the interview, and the plan for the study results before obtaining informed consent. Although the interview consisted mainly of questions related to the 4D cycle of AI, some descriptive demographic data was collected including: years of nursing experience, years of nursing experience in current unit, and nursing education. An interview protocol was used to guide the discussion between the interviewer and the participant.

The AI Interview Protocol ([AIIP] - Appendix E) was developed by the PI and based on Cooperrider and Whitney's (2005) format and other AI research conducted with nurses (Barnes, 2009; Richer et al., 2009). The protocol includes open-ended questions and time for the interviewer to write down comments, impressions, insights, questions, and areas for clarification.

At the time of data collection, interview and focus group sessions were audio taped and the PI occasionally wrote field notes. Field notes included impressions related to emotions, expressions, and context (Gerrish & Lacey, 2010). Reflecting after each interview was important to determine the quality of the content as related to the questions asked and the participant's response. The interviews were standardized through the AIIP and all interviews were conducted in a similar manner. A few of the questions seemed repetitive and as a result one of the questions was removed from the AIIP after the first

two interviews in order to maximize the quality of the data obtained during the 45 minute interview time. The PI had no previous experience with conducting interviews.

A general statement was rehearsed to address any negative responses by the participant and will be phrased “I am sure that you are knowledgeable about the barriers to parental involvement in pain management strategies but this study is intended to examine the subject in a positive manner. Could we talk about the positive ways that parent involvement might work in your unit?” If the PI was unable to steer the participant in a positive direction, the plan was to collect and transcribe the data in its entirety. In all interviews, participants were steered or steered themselves in a positive direction, even when the tone of the interview became negative.

*b. Focus Groups*

After the interview data was analyzed and themed, participants were invited to attend one of two focus groups. All participants were contacted by email with a list of four potential dates/times and they were asked to respond about their availability. A table was created to organize the availability of each participant.

The dates chosen for the focus group sessions were based on the availability of the majority of participants. The first focus group involved four participants and the second focus group had three participants. A focus group should be between five to twelve members to ensure diversity of perspectives but be small enough to ensure that everyone has an opportunity to participate (Gerrish & Lacey, 2010). An attempt was made to have one larger focus group but there was no time identified that could accommodate both groups of participants. The focus groups lasted 60 to 90 minutes and took place in the IWK Centre for Pediatric Pain Research and a nursing unit conference

rooms. Coffee and sweets were offered to participants that were seated around a round table.

Focus groups began with the PI reminding participants of the study's purpose and objectives and of the purpose and objectives of the focus groups. Participants were presented with a brief overview of AI and the four phases that describe the processes of constructive thinking about parental involvement in N-PPMSs. Direct quotes were taken from the interviews and any identifiers were removed. Participants were reminded to maintain confidentiality on other participants' ideas or views.

The goals of the focus group sessions were presented in the focus group guide (Appendix F) and were used to review common threads or ideas and generate discussion. Direct quotes were chosen as those that represented examples of the themes identified. These quotes were written on pieces of paper and participants worked together to sort them into one of the four headings and then place them under one of the sub-themes identified by the PI. This was an opportunity to determine the trustworthiness of the data. It was also an opportunity for nurse participants to learn about other's experiences and share creative ideas about practical ways to involve parents. Focus groups are beneficial when the cumulative interaction among interviewees can yield new information or provoke more information when some interviewees are hesitant to speak and share ideas (Creswell, 2007).

#### *Risk Benefit Analysis*

Since all data collection standards were put in place for this study and there was very little potential for harm with the study topic and design, the potential benefits outweighed the risks. By providing nurses with the opportunity to reflect on positive

experiences of engaging parents in N-PPMSs for procedural pain with their hospitalized child they were able to provide rich data that will inform a strengthened practice environment and pain delivery system for pediatric patients.

#### 5. *Data Analysis*

Cooperrider and Whitney (2005) discuss data analysis as mapping the positive core of strengths through repetition of themes related to the best features of the practice environment, envisioning what might be, and, dialoguing what should be. Interview and focus group data was analyzed using the following format.

##### Analysis Plan

The analysis was conducted by grouping the data in two separate categories: interview data and focus group data. The data obtained from focus groups was eventually added to the interview data for analysis. All interview and focus group responses were grouped together by AI cycle including: discovery, dream, design, and destiny.

Interview and focus group data was analyzed for common threads using thematic analysis. Thematic analysis involves a number of steps including data transcription, identification of themes, organization of results into tables, and verification of findings with the participants.

##### *Data Transcription*

After each session the audiotape was transcribed to an electronic copy by an independent transcriptionist and assigned a number but no identifiers. The transcriptionist was asked to sign a confidentiality agreement (Appendix G) before the interviews were transcribed. Interviews were transcribed verbatim from the audiotapes into a computer program. As soon as possible after the interview, the PI reviewed each audiotape and

began the process of “immersion” in the data (Gerrish & Lacey, 2010). Immersion included listening to the audiotapes and reading each transcript several times to become very familiar with the content of the data. Memos were written on the interview transcripts to note any impressions, ideas, or possible themes that came out while reading the transcript. Field notes taken during the interviews were also be transcribed and added to the interview transcript.

### *Thematic Analysis*

Thematic analysis focuses on the content of the participant’s stories and the recurrent themes that come up time and time again in an individual interview or a set of interviews (Morse & Field, 1995). After immersion in the data, the PI worked to organize, label, and group to aggregate data into themes and provided details to support the themes with quotes from participants and excerpts from stories told (Creswell, 2007; Gerrish & Lacey, 2010).

Through the process of interviewing, listening to the audiotapes, and reading the data, the PI was able to group the data and attach possible themes when there were repetitive words/phrases or concepts. Pertinent data was identified in the transcripts and was then organized by question and answer into a table format. Key themes were then identified with different colour highlighters and a key was created to reference those themes by colour.

Synthesizing is also an important stage of analysis, and is reached when the investigator gets a feel for the data within the setting, the norms, and the context (Gerrish & Lacey, 2010). The PI was able to identify patterns, theme the data, and place the results in the context of established knowledge based on her experience as a nurse and a parent,

and on relevant literature. Analysis was complete when there was enough data to write a complete, detailed description of the conditions that facilitate parent engagement in N-PPMS for procedural pain with their hospitalized child.

### *Verification*

After the interview data was analyzed and organized, it was prepared for verification within the focus groups. Inter-participant analysis, or member checking, is helpful for the researcher to synthesize, interpret, and link the findings (Gerrish & Lacey, 2010). Quotes from the interview data were organized by the focus groups participants under the themes and then sub-themes. They were organized similarly to the way the PI arranged them. A discussion revealed there was some definite overlap between the themes but the participants verified the authenticity of the themes.

### Trustworthiness

Rigor refers to the strength of the research design as it relates to the conscientious execution of procedures, the elimination of all confounding factors, and the formation of dependable conclusions (Gerrish & Lacey, 2010). Creswell (2007) describes characteristics of a good qualitative study as having an emphasis on rigorous methods. Methods used in this study include detailed description of the data collection procedures, data analysis and report writing methods, framing the study with the assumptions and characteristics of the qualitative approach chosen, addressing the entire ethical standard through all phases of the research study, and verifying an accurate interpretation of the personal experiences of the participants. Lincoln & Guba (1985) describe the following four criteria to judge the trustworthiness of a qualitative study: credibility, transferability, dependability, and confirmability

### *Credibility*

The PI's most important job is to accurately interpret the perspectives of the participants. In the findings, quotes will support the themes and ideas presented. Lincoln & Guba (1985) recommend that two or more data sources be used to reduce the uncertainty of interpretation. Triangulation through individual interviews and focus groups and verification of findings with the participants added to the credibility of the study. The thesis committee and supervisor are topic experts and have supported the creation of themes and interpretations. Input from participants in the focus groups was used to create an accurate portrayal of their experiences.

### *Transferability*

Transferability refers to whether the study's findings can be applied in other contexts or settings or with other groups. By interviewing nurses who differed in age, experience, gender, and work context, findings may be applicable with other groups or in other contexts or settings. Lincoln & Guba (1985) recommend collecting data rich in detailed descriptions of the research process, to allow readers to make decisions related to the transferability of the study results. Descriptive data was obtained from four different units and common themes and ideas are presented in the findings and discussion.

### *Dependability*

Dependability is described as the transparency of the decision trail and the research process in all its stages. Concurrent data collection and analysis, detailed field notes and side notes, and description of the analysis process were utilized in this study to increase dependability. Dependability is apparent through the use of multiple quotes and excerpts to support themes from the interviews and focus groups.

### *Confirmability*

In qualitative research, confirmability occurs when the PI identifies their own biases and clearly establishes that the data, findings, and interpretation are all clearly linked. The PI identified her location in the study and acknowledged any biases throughout the process. Notes related to subjective interpretations were recorded to remain aware of potential biases. An audit trail was kept to clearly document any decisions, choices, and insights about the research process.

### Framework for Analysis

In the analysis of the data, the Promoting Action on Research Implementation in Health Systems (PARIHS) framework was also used to consider the relationship between the nature of the evidence, work context and facilitation factors that are thought to influence parent engagement in effective N-PPMSs (Rycroft-Malone, 2004). The PARIHS framework is an appropriate framework to examine the social processes that contribute to everyday practices and how the factors play a role in promoting and sustaining evidence-based pain practices in pediatric nursing. The findings were organized into the three elements identified by the framework to identify areas that should be developed in to enhance research utilization on parental involvement in N-PPMSs in practice.

## **Chapter Four**

### **Discussion**

Participant demographics, narrative descriptive demographics, general themes and sub-themes from the interviews and focus group data will be presented and discussed in this chapter. Themes and sub-themes were organized and presented using the AI 4-D model according to the headings Discovery, Dream, Design, and Destiny and discussed using the PARIHS framework.

#### **Participant Demographic Data**

Twelve nurses participated in one-on-one interviews, as the study projected. Seven of those twelve participants participated in two separate focus group sessions. All participants were nurses working on pediatric inpatient units at the IWK. Eleven of the nurses were female and one was male. The sample had a broad range of experience, from four years to forty-two years of nursing. All participants had at least two years working on their present unit. Three of the twelve nurses were educated through a diploma program and the other nine had baccalaureate nursing preparation. Two of the twelve nurses are currently enrolled in a graduate nursing program. Three of the participants won the Eileen Boland Preceptor Recognition Award, where recipients have been nominated by colleagues to recognize their outstanding contributions to learning and professional practice at the IWK Health Centre.

Participants were asked to describe their experience in nursing and their educational background as a starting point to the interview in order to gain knowledge about the sample. In an effort to gain trust and build a relationship, participants were asked to describe their attraction to nursing and what they felt was the most meaningful

about working with children and families. Participants said they were attracted to nursing for many reasons including: job availability, focused educational program, familiarity with the role (women in the family were nurses), desire to work with children/vulnerable population, desire to help people and have a fulfilling job, and interest in relationships and family dynamics. When asked what was most meaningful about working with children and families they described their up-close involvement with children and families through their journey from sickness to wellness or sickness to managing their illness, ability to help and make a difference, empowerment of patients and families, and interpersonal connections with patients and families.

Participants described stories that were most memorable, most challenging, or most exciting to them. Descriptions included experiences that exemplified interpersonal connections, extraordinary experiences, teamwork, collaboration, validation by colleagues, and best care. Participants described their experiences in detail.

#### AI 4D Model

The AI model was used to provide nurses with a positive framework to reflect on their practice, identify what works in their practice environment, explore how to expand on what already works well, and then contemplate how changes could be evaluated and sustained.

Findings from the interviews and focus groups were consistent and so the content was woven together in the themes and sub-themes. Focus group participants thought the themes were accurate but idealistic and did not reflect the current environment. Participants were reminded that AI and the 4-D cycle were used to discover their values, identify their dream for best practice with parents and N-PPMSs, and comprehend their

perspectives about how to achieve and sustain the dream. Four major themes were identified from the data and they are described in rich detail in this chapter. There is definite overlap between the themes and sub-themes because of the nature of the content, so major themes are supported by a published definition.

### Findings

A summary of the themes and sub-themes derived from the content of the interviews and focus groups are presented (Table I) and will be discussed in the following section. Quotes from participant interviews and focus group sessions will support the themes and sub-themes where applicable. Additional quotes that support the themes and sub-themes are included in Appendix H.

Table I - *Themes and Sub-Themes from the Interview and Focus Group Data*

Themes	Sub-themes		
<b><i>Discovery theme</i></b> – Establishing meaningful interpersonal connections	1.1 Active implementation of the interprofessional care team with a FCC philosophy	1.2 Development of effective therapeutic relationships with the patient and family	1.3 Individualized, needs-based care to establish active partnerships
<b><i>Dream theme</i></b> – Developing a culture of collaboration and teamwork	2.1 Physical infrastructure to accommodate families	2.2 Patient and family recognized as an integral part of the team	2.3 Consistent parental involvement at their desired level
<b><i>Design theme</i></b> – Committing to pain management as a priority – moving from a philosophy to a standard	3.1 Adequate clinician time and resources to foster parental involvement	3.2 Patient and parent contribution beyond the bedside	3.3 Demonstrated leadership and organizational commitment to an “interprofessional pain plan”
<b><i>Destiny theme</i></b> – Sustainability through advanced knowledge, skills, and practices	4.1 Expert clinicians as pain care facilitators	4.2 Key role of clinician empathy in facilitating optimum pain care	4.3 Evidence-based education, research, and policies/practices

*Discovery Theme - Establishing Meaningful Interpersonal Connections*

“Interpersonal connections or interpersonal relationships may be defined as the reciprocal social and emotional interactions between the patient and other persons in the environment. Interpersonal communication is the primary tool used for exchanging information between health professionals and patients and families for negotiating care” (Jones, Woodhouse, & Rowe, 2007, p. 206). Participants described how they established meaningful connections because of the FCC they provide, the therapeutic relationships they are involved in, and the nature of the partnerships they establish when working with patients and families to provide individualized and need-based care.

In all of the interviews, participants referred to meaningful connections and relationships they formed with patients and families. They often described these special connections or relationships in a general way, but sometimes they referred to a specific approach or behaviour. Ten of twelve participants described an interaction with a patient and/or family when asked to share a story that was most memorable, challenging or exciting to them. Descriptive phrases from the interviews that highlight the nature of these relationships include “caring for”, “helping them through”, “getting to know their needs”, “communicating with them”, “hearing them”, “letting them take the lead”, and “reassurance and explanation”. One nurse adds a powerful description of what is most valued about being a nurse:

What I value most in my position as a nurse...is helping families. I got into nursing because I like the caring aspect, it is kind of what defines nursing is care. It's what makes nursing so hard to define sometimes, what is caring? But it's having empathy...caring about people and how they do, try to help them get better when they're sick and trying to make things better when they're not going to get better, but to increase comfort. We have quite a lot of kids who die on our unit and trying to help those

families and those children to cope with that, to make that experience the least traumatic possible or the least unpleasant possible. I don't think it's unfair to say that nurses spend the most time with patients; I think that's just a fact. We get to know them, and we get to know their needs, and I think we have a real role to play in that, in terms of letting other members of the team know, what's necessary for families, to have the best experience possible, to get better, things like that.

Throughout the interviews it was highlighted that nurses value their nursing role because of the meaningful connections that they make with patients and families. When asked to describe a memorable, challenging, or exciting experience nurses often told stories that represented meaningful connections made with patients and families during their hospitalization.

Other connections may occur because of the nature of the illness and role the nurse played in helping a patient and family through a traumatic time in their life. One participant recalled an experience involving an oncology patient who spent a significant amount of time on the unit because of the prescribed treatment regime. This patient visited the unit eight years later to connect with specific nurses that cared for him during his hospitalization and show how he was doing and give out graduation pictures.

Nurses often go into the profession because they genuinely want to care for and help people. Nurses in this study said they stay in the profession because of the connections they make with patients and families and because they find work very fulfilling. Nurses described how FCC practices, effective communication, and working with the patient and family to meet their individual needs, could contribute to meaningful relationships that facilitate parental involvement in N-PPMSs.

### *1.1 Active Implementation of the Interprofessional Care Team with a FCC Philosophy*

FCC is considered the “gold standard” in pediatric care. FCC is defined as “an innovative approach to the planning, delivery, and evaluation of health care grounded in mutually beneficial partnerships among health care providers, patients, and families” (Abram & Moretz, 2012, p. 44). An example of FCC was presented in one participant’s story of caring for an infant who was palliative but the parents wanted to be involved in providing N-PPMSs. This example shows how the nurse, respiratory therapist (RT), and physician were creative in their approach to provide care to meet the family’s needs. The nurse commented that sometimes you need to “think outside the box” to provide exceptional FCC in difficult situations.

I cared for a baby that was terminal, and that baby was very, very ill. We knew that the baby was not going to survive and was probably going to die on support. Mom was really unwell, and myself as well as an RT and a physician managed to get that baby taken upstairs to be with that mom, which was kind of unprecedented, they had never really done that before...and I’ve never really forgotten that because essentially we took the baby off the ventilator and we just bagged the baby all the way up and we actually took the tube out in mom’s arms up on a completely different floor, so I’ve never forgot that. It’s always made me realize, that sometimes when you think you can’t do anything, there’s a lot that you can.

All participants mentioned that family-centered values were integral when working with children and families, and five of the participants identified the family-centered philosophy was what they valued most about the hospital they work in. One participant explains, “I value what the IWK stands for. I do think FCC is huge. I think that’s probably one of the most valuable things, that we involve families like we do.”

Nurses explained that a family-centered philosophy is integral when working with patients and families to provide optimal care. Nurses also said they need to establish therapeutic communication in order to facilitate successful parental involvement.

### *1.2 Development of Effective Therapeutic Relationships with the Patient and Family*

Therapeutic relationships in nursing are defined as “a meaningful and purposive action-reaction exchange with the nurse displaying competence, developing relationships through effective communication, indicating availability, providing information and acting verbally and non-verbally” (Tejero, 2011, p. 995). Communication is the process of sharing information, thoughts, and feelings between people through verbal and non-verbal interactions or writing. Effective communication extends the concept to require that transmitted content is received and understood by someone in the way it was intended (Tejero, 2011).

All participants mentioned effective communication as an attribute they valued in their position as a nurse or their role in involving parents in pain management. Participants describe the value of trust and respect in establishing therapeutic relationships, by providing parents with information and opportunities to ask questions to facilitate informed decision making for their child.

An example of how communication was a major factor in a positive interaction with a parent about her infant’s pain management is described.

I think most recently we had a very complicated patient who had multiple issues, and his mom was super active in his care and she was so knowledgeable about him and she really noticed his cues. I think she was so on top of things, and he had been back and forth to surgery multiple times. I hadn’t looked after this baby in a couple of weeks, and was just talking to her and saying “this is what I’m seeing, what are you seeing?” and we really talked a lot about how the baby was coping, and eventually turned it into

going to the physician or resident who was on saying, this is what we're seeing and we think that his pain isn't being adequately managed...we noticed his heart rate decreased and his oxygen requirements decreased, and so it was mostly through talking to her. There were no huge signs that he was in pain, but there was just a lot of subtle cues that he exhibiting, and so I was glad that we had that conversation and the baby seemed to improve.

In the following quote the same nurse described how she thought that effective communication was a factor that made that interaction and outcome so positive.

I just think effective communication and I think the mom felt that she was heard and I think that's really important and I think it was, involving her and not just you know, putting her to the side and saying I'm the nurse, I'm the caregiver, I know best and you just sort of sit there. I think including her as part of the team approach, and being supported and being listened to, you know, by the people we brought our concerns to.

Nurses indicated they want to provide relevant information, education, and resources and allow patients and families to have input in short and long-term plans. By keeping the lines of communication open, nurses and patients/families could work together to provide care that is individualized and need-based.

### *1.3 Individualized, Needs-Based Care to Establish Active Partnerships*

Partnerships are defined as “negotiation between the patient/family and the nurse, for the purposes of strengthening their relationship, building trust, and increasing communication regarding health issues...” (Ford, Davenport, Meier, & McRee, 2011, p. 53). In the present study, participants said it was important to provide individualized and needs-based care that is based on interactions and discussions with the patient and family.

When parents are willing to participate in N-PPMSs, nurses say they negotiate roles with parents about how they could support their child during a procedure. One participant described an experience where a mom expressed interest in participating in

pain strategies for her child. Child Life Services (CLS) provided an iPad for use during the initiation of a peripherally inserted central catheter (PICC) and showed the mom some of the programs that could be used based on the child's individual interests. CLS are certified, trained professionals whose role is to promote the well being of patients and families by assisting them to cope with the stresses of hospitalization through play, education, and other strategies. The nurse provided education related to staying on task and the importance of keeping their child distracted during the procedure. The guidance and education that was provided was individualized to the patient's and family's needs at the time.

Participants identified the desire to meet patient's individualized needs, including pain management strategies that would be effective for patients who are blind, deaf, and non-communicating. One participant discussed how she was challenged to individualize pain care for a child that was blind. She outlined the importance of considering the parent's expertise in all situations.

Mom knew exactly what he needed because she's the one who educated us in that sense. We don't see very many kids that are blind. She explained that he gets very uncomfortable and anxious when he doesn't know your voice ...so when I went in I just said, 'hey buddy, I'm one of the nurses'...and mom had said it's better if you just kind of go in slowly. Then for the procedure I said, 'does he like to listen to, like even if I turn the TV on, is there a show he likes to listen to?'...Because really, I didn't know what to do for distraction because I was used to jumping around or putting an iPad in front of a child, you know, something like that, and you don't have that with him...

This participant described how she really had to consider how she would use N-PPMSs for procedural pain. Other participants discussed effective "unconventional techniques" such as: using Buddington the therapeutic clown, playing an audiotope of a grandmother's singing, and bringing in a pet fish for distraction from procedural pain.

Probably when I was changing a dressing...the mom was really good. She had the TV going...she had a fish at the bedside and he really focused in on the fish. Everything that she had learned over the last several weeks...she was bringing it all. She was doing a great job. He didn't even budge and didn't have any complaints the whole time...They went to a restaurant and mom had told the waitress what he was going through and she was taking pictures of the fish tank because he had a fish tank at home. And when she went to pay the bill, they came out with a fish from the fish tank for him in a little bowl and everything... So that's what he had in the room. It was amazing.

One nurse recommended that health professionals be educated on how to individualize pain care, and consider ethnicity, cultural values, and spiritual beliefs. Focus group participants also mentioned the importance of pain care to all patients and families and suggested that diversity training should be ongoing for staff.

Participants talked about providing needs-based education so families "could learn as they go", instead of being overwhelming with a huge amount of information all at once. One participant explained that pain management strategies may need to be modified as an infant gets older, a child's developmental needs change, an infant or child's condition improves or declines, or a child has special needs.

Most participants described the importance of planning and preparing for procedures through individualized and needs-based management as "setting up for success".

I think a lot of times parent involvement or distraction or any of these techniques for dealing with pain are often an afterthought but if a procedure doesn't go well then it's like, 'what could I have done to make it better?' I think it is important to plan and communicate with the family and see what's going to make this the best that it's going to be right now.

One nurse gave a detailed explanation of how to plan for a procedure. This plan involved talking to the parents, providing a tentative time for the procedure, asking parents how they want to be involved, figuring out what supplies are needed, providing anticipatory guidance and education, and pre-medicating if appropriate. She said health professionals should consider even routine procedures (such as catheter removal, nasogastric tube removal, capillary blood work) as potentially painful because pain is very individual, and previous experiences with pain are very individual.

Participants thought parents could benefit from information about the importance of parental involvement in N-PPMSs and specific strategies through educational materials such as: pamphlets, videos, and demonstrations from nursing and CLS. One participant thought verbal explanations and education should not be the only way that education is provided to patients and families. Focus group participants suggested supplemental educational materials on parental involvement and N-PPMS should be available in paper format, on an IWK parent website, and maybe a link to these materials could be provided in a pre-admission/admission email or letter. Participants cited rationale for supplemental materials as: concerns that sometimes things get missed and forgotten, everyone learns in different ways, and patients and families are often overwhelmed with information and need other reinforcements to learn about parental roles and methods of procedural pain management.

Participants identified that nurses and other health professionals can serve as role models; adding to the patient's and family's learning over time. This participant explained when parents see something work, it is powerful, and worth

repeating. She said nurses are also more likely to use N-PPMSs when they have seen them be effective.

One participant elaborated on how education and role modeling on advocacy is a tool that parents can use beyond the immediate hospitalization. This participant described how families could advocate for optimum pain management, using knowledge and skills that they may not have realized they had. Another participant explained that it is necessary to inform parents of the resources that are available to help with pain management to meet their needs.

Nurses said they need experience and comfort with strategies before they can teach them to parents. One participant said she uses the strategies that she is most comfortable with more often than others. Nurses identified the N-PPMSs they think are the most effective, and also the strategies they think are most effective when parents are involved (Appendix I). Another participant described professional growth with time and experience and how she has learned to provide pain management based on needs, with a more individualized and holistic lens. She explained that when she was a novice nurse, she was so focused on tasks and getting things done that it was difficult to think about N-PPMSs or involving parents.

One participant provided a great comment describing how individualized and needs-based care should be used to promote good outcomes using N-PPMSs.

I think we have great potential to incorporate parents more and pain management can be broadened with a team approach and really moulding a plan to a specific child. Everyone here is unique and there's no strategy that's going to work for everyone so I think individualizing care... which I think we do, but I don't think we do it to our potential. I think that would benefit all patients and families and staff...I don't think you're going to treat with meds and not have other forms of coping. If you require meds

for a particular procedure then likely you're going to need more support than just that...

Nurses describe their best experiences as those when they have developed meaningful connections and effective working relationships with patients and families. Participants value the family-centered approach to care and effective communication and use it to individualize care and meet the needs of the whole family. With time and experience, participants believed they are better equipped to involve parents in N-PPMSs.

*Dream Theme – Developing a Culture Dedicated to Collaboration and Teamwork*

Interprofessional collaboration is defined as “an active and ongoing partnership, often between people from diverse professional backgrounds, who work together to solve problems and provide services” (Gum, Prideaux, Sweet, & Greenhill, 2011, p. 21). Parent-professional collaboration is also relationship-based and combines the expertise of the parents and professionals in helping children to meet their goals. Interprofessional and parent-professional collaboration is what participants identified as the dream, or what needs to happen consistently in order for parents to be involved in N-PPMSs on a regular and ongoing basis to accomplish mutual goals.

Teamwork is defined by Webster's New World Dictionary (1994) as “joint action by a group of people, each doing a part but all subordinating personal prominence to contribute to the group unity and efficiency of the whole” (p. 1459). The focus of teamwork is the goal; the process is just a means to an end. Teamwork was described by participants as “everyone knows what is going on and is there to help when needed”, “everyone came together and teamwork made the difference in the way the situation was handled”, and “helping each other out – across units and throughout the hospital”.

Teamwork adds to camaraderie, a positive environment, and cohesion. Some participants

suggested interprofessional teamwork could be a great example to families on how to work together for better outcomes and more efficient services.

Working together toward common goals was something that was valued by all interview participants. Four of twelve participants described these relationships as collaborative. All twelve participants used the words “collaboration” and/or “teamwork” to describe important relationships with other health professionals and families that were necessary to meet mutual goals and provide optimum pain care through N-PPMSs. Although the PI defines these terms differently, the participants used the terms interchangeably to describe positive interactions that promoted patient and parental involvement in procedural pain care.

One participant worked with a parent to support her infant through blood sampling described parent-professional collaboration. The participant described how supporting the parent decreased her stress and the infant’s stress and optimized pain care.

So it’s the explanation of the different comfort measures that we do, why we use them, and what difference it makes for their babies. I think that when they can negotiate those roles, it relieves some of their stress, and I think certainly once we do those things and the babies seem less stressed, the more comfortable they are. Certainly I am never one to put parents off when I’m doing a painful procedure, I want to involve them if they want to be involved; if they want to hold the soother or if they want to hold their baby... whatever they think is most effective for their child. I am there to prepare them and support them in whatever they want to do.

One of the participants described a personal experience of being involved in using N-PPMSs while in the hospital as a parent, and how one team member made the difference in this experience. This participant explained that all team members should work toward the goal of parental involvement in pain management strategies and outline how they can promote this in their role.

Just a personal experience we had while in the family newborn unit...we had a lab technician come up who was completely supportive, who said, 'oh I encourage it, I do this all the time'. That was so helpful to us, to talk about getting parents involved...Just having the baby on my chest while he did the heel lance really helped and it was helpful for him to be so supportive and say 'yes you should definitely do that and I prefer to do it on you than in the bassinet'...and he talked about how a lot of his colleagues weren't comfortable doing what he did...getting on his knees at the bed to do the heel stick. There's some education that needs to be done there, maybe some training, some extra training for lab staff. I understand some of the lab concerns, because they have ergonomic concerns, certain things can be awkward if they're doing them the same way over and over...but I think there are strategies to try and help with that.

Some participants thought teamwork already existed on their units, but most participants thought interprofessional and parent-professional collaboration and teamwork needed to improve to optimize pain care through parental involvement in N-PPMSs. One participant explained this would require the reframing of ideas; that everyone has a role to play in pain management and figuring out what is needed for that to play out. Participants explained with the shift to primary care, nurses often feel they need to do everything for their patients on their shift and it is almost taboo to ask your colleague to do your work. This participant suggested nurses could provide pain education and support to patients and their families for procedures, and nursing colleagues could cover other duties in order for this to happen.

Everyone has things they have to do, but if we were able to say...'no, you go have that conversation, you go figure that out and I'll take care of this right now'...sort of that kind of conversation...and to be able to ask for someone to do that too. A lot of people, they don't want to relinquish the control over their own patients, so they don't ask, 'can you go get this while I go have this conversation?'...Just being able to change the way we think about that sort of thing.

Participants explained that collaboration and teamwork occurs when parents and professionals work together to achieve common goals toward optimal pain care outcomes

during the child's hospitalization. For interprofessional and parent-professional collaboration to occur, participants said parents need to be present, considered an integral part of the team, and encouraged to participate in N-PPMSs at their desired level.

### *2.1 Physical Infrastructure to Accommodate Families*

Single family rooms, private bathroom facilities, spaces to cook/store food, wireless networking and capacities to work in the hospital room/unit, and places in the hospital for social interactions between families were identified by seven of twelve participants as factors that would enhance parental involvement and parent-professional collaboration. One participant describes how single family rooms would make it easier for families to stay at the hospital and be involved in their child's care.

I think in our particular unit, we're going to single room care so that parents can stay and have better access to their children on a more consistent basis. It will be a more comfortable environment for them, because right now with particular sites, sometimes space is an issue. I think the more space that they have and more room to move around...then they're more apt to stay and be involved in their child's care.

In contrast, one participant expressed concern about the lack of social interaction within the single room design of the present unit (as the pediatric units have already transitioned to single family rooms).

The way that the physical unit was set up there seemed to be a lot more integration of families with families...a lot more chatting. Now each of the rooms have their own fridges so they (families) don't spend a lot of time socializing down the hall. I think if the unit was set up in a physical manner where patients and families have more time together, that maybe they would be able to support each other in what has worked with procedural pain.

Nurses said patients and families would benefit from social interactions with other patients and families and that they often encouraged them to go to the Ronald McDonald room, the playroom, and the play garden.

The majority of participants thought that single room care would facilitate parental involvement in pain management strategies. By making it easier to be present and available, parents could be involved in decision making about pain management strategies. Participants suggested families receive better quality care and efficient services when they are present and exposed to a consistent culture of teamwork and positive interactions.

## *2.2 Patient and Parents Recognized as an Integral Part of the Team*

One participant, who had worked for another organization for several years, explained in her prior work experiences parents were more involved and considered an integral component of the team. This participant said parents should be recognized for their important role in their child's care and the benefits of their involvement in pain management strategies. She believed this information should be presented to parents prior to admission or on admission, and then followed up on an ongoing basis during hospitalization. Participants had ideas about how to send messages to parents about their integral role in pain management, which included posters in the units and main thoroughfares saying things like, "You're part of the team that is caring for your child in the hospital – we can help you get comfortable with managing pain", "We can help you to learn ways to lessen your child's pain from procedures", "You can provide valuable information about what works for your child".

Participants describe how families have intimate knowledge of their child and are an integral part of the pain management team. Parents are the consistent person in their child's life and know their child best, are their best advocate, and can use this knowledge to facilitate care for the child for the rest of their life. Nurses recognized the need to

provide a welcoming space to the parents and spend time with families to get input and guidance about the best way to approach the patient.

### 2.3 *Consistent Parental Involvement in N-PPMSs at Their Desired Level*

All participants thought parents should be involved in N-PPMSs if they want to be. Most participants said an important part of their role was to determine what extent parents want to be involved. Participants expressed the importance of respecting parents' decisions about participating or not participating in pain management strategies with their child. One participant explained that this should be an informed decision though.

I think recognizing that parents have their own feelings about being present during painful procedures, or anything that makes feel uncomfortable. Some people derive personal comfort by being present during those difficult situations but for some people it's very anxiety producing. If there's evidence that supports that it is better for their child or baby then I think they need to be made aware of that and that's my role to make them aware of that. I think most parents want to do whatever they can to make things better for their baby, and I think even parents who have difficulty being present for painful procedures, probably still want to support their child.

This participant said if a parent does not want to be involved in pain management strategies, maybe the idea of having a "comfort person" should be adopted. This could be a consistent person in that patient's life or a member of a core group or pain support team that could be present if the patient/parent wishes.

Adopting the idea that it doesn't have to be a parent...I know we're talking about parent support but does it really have to be a parent?...or does it just have to be somebody that is a consistent comfort in that person's life? If you were considering the pediatric population, even having a core group, a support team that makes connections with children from the initial admission and builds a rapport so that there is someone that could be called upon to provide that support.

Even after being informed of the benefits of involvement, parents may still opt out. One participant suggested parents could still be involved in comfort care after the procedure.

Participants said some parents might know of ways to help their child with procedures but still need to be supported through it, while other parents may need education, guidance and support to provide N-PPMSs. One participant talked about how it was important to help parents be involved in procedural pain strategies while they are in the hospital and in a “safe” environment where they can ask questions and receive support and guidance until they are comfortable and confident in providing N-PPMSs on their own.

Another nurse said that it was important to normalize the hospital experience as much as possible and tell parents to comfort their child and do what normally works at home. Interview participants thought that parents might think that it is the nurse’s role to manage pain and that maybe some work needs to be done around clarification of roles.

Participants said that it is necessary to have physical infrastructure for parents to stay in the hospital and be present and establish relationships with the team. Parent-professional collaboration is fostered when the team members recognize parents’ important contribution to pain management and allow them to participate in N-PPMSs at their desired level. No matter what parents decide about their involvement in strategies, it is important to establish standard practices to implement consistent and quality pain management and communicate the effectiveness of strategies.

*Design Theme – Committing to Pain Management as a Priority (Moving from a Philosophy to a Standard of Care)*

Webster’s New World Dictionary (1994) defines standard as “a level of excellence, attainment, etc. regarded as a measure of adequacy” (p. 1387). Standards of

care are written statements describing the rules, actions, and conditions that direct patient care. Standards of care guide practice and may be used to evaluate performance.

Participants said involving parents in procedural pain management is a major priority but organizational change is needed to make it a reality. One participant explained if parental involvement were implemented consistently it would become a standard.

I think that it needs to be just standard, the institution as a whole needs to hold it in high priority and it needs to be standard practice and those delivering care to any one of our clients in this institution, to provide the same comparable care.

Participants repeatedly described the need for more clinician time and resources, a meaningful patient-parent voice advocating for better pain management, and demonstrated leadership and organizational commitment to developing a “pain plan”. They identified these components as necessary to move parental involvement in N-PPMSs from a philosophy to a standard of care.

### *3.1 Adequate Clinician Time and Resources to Foster Parental Involvement*

All nurses emphasized the need for adequate time and resources to involve parents and provide optimum pain care. Participants said more time was required to spend with families to provide education, support, and guidance about pain management strategies and get input from parents about their child’s experiences with pain and pain management. Participants repeatedly expressed concerns about budget and resource losses that have affected available time and way they provide pain care.

Participants recognized the following resources as those that would enhance the delivery of services related to pediatric procedural pain: more nursing and CLS, playroom access, toys and electronics for N-PPMSs, Pain Management Team support,

increased access to supportive resources (Palliative Care, Spiritual Care, pharmacy, physiotherapy, psychology, technology support) and, evidence-based educational materials for staff and patients/families.

Many participants described how nurses often become task-oriented because of the demands on their time. Participants said patients and parents would benefit if nursing staff had more time to learn about individual needs, set goals, and provide teachable moments. Participants thought if they could spend more time preparing patients and families for procedures there would be less negative outcomes that result in fear and anxiety.

Sometimes you get a kid in and you're like what happened? What happened that this is so traumatic? And I mean sometimes I think that can't be avoided and it's just the nature of how some things have to happen but if someone took the time to plan it before it happened... Time is an issue too... we don't think to do that, sometimes we're task-oriented because we're forced to be.

Discussions about resources identified the need for more psychology resources to help patients and families through feelings such as anxiety, anger, and denial so they can participate in procedural pain care.

All participants from the pediatric units discussed the important role of CLS in procedural pain management. Most participants suggested there was need for more nursing and CLS resources to realize the dream of involving parents in procedural pain management on a consistent basis. One participant said "I'd be in a dream setting if Child Life was involved every time something was going on that was painful".

Participants identified CLS as a huge support to nurses, patients, and families during lengthy procedures.

Having a Child Life specialist there full-time would definitely be beneficial...or even two or three...especially on days when we're full and we have 24 kids...we may have procedures going on everywhere. So having them available at our beck and call to go to a procedure...whether it's an MRI, CT, a PICC procedure, an x-ray...because sometimes like skeletal survey x-rays where they do 26 x-rays on a baby...things like that...

According to participants, CLS or trained volunteers are required for access to the playroom and resources like toys and electronics such as iPads, DVD players, and video games and access is limited because the playroom is open just a few days a week.

Participants suggested it would be ideal to have access to toys and electronics when CLS are unavailable or when patients are unable to travel to the playroom or treatment room.

All of the nurses on the pediatric units repeatedly cited the importance of the playroom and teen lounge and their desire for increased staffing and increased hours of operation for these resources. Two participants proposed a trip to the playroom could be used as distraction before a procedure and a reward after a procedure. One participant suggested there was a need for more age appropriate resources, especially for teens.

Right now we pretty much have the box of toys, which is all great for the younger kids, but there's a huge teen population that have to deal with painful procedures as well. So I do think more teenage-related supports for dealing with pain would be wonderful, like the iPad. That's a great one. Even the older school age kids love the iPad too.

Participants said the link between parental involvement and the use of N-PPMSs should be identified in the annual telethon to raise awareness and money for distraction tools, maintenance, and replacement costs. One participant suggested that having a technology person to support the teams with maintenance of the electronics would be timesaving to the nurses and CLS. She stressed the importance of "having the right

person, at the right time, doing the right job”, so that nurses and CLS would have more time to support patients and parents.

This is going to sound strange, but it could be a technology person...because Child Life uses a lot of videos, DVDs, and machines. So if the machine isn't working or something for whatever reason, they're the go-to person because they're the ones that might have the extra machine or whatever. So even to support Child Life and the teams with a technology person so that Child Life and nurses can actually do their job...

One participant thought it would be helpful to have someone available that works as part of a team dedicated to pain management (not specifically the Pediatric Pain Management Team), that is assigned to talk to parents about painful procedures, pain management strategies, and what has worked for their child in the past.

The most common “design” suggestion or wish was for more time and resources to facilitate parental involvement in N-PPMSs. Participants believed that when patients, families, and health care professionals present a strong voice that pain is a priority; leaders and the organization are more likely to respond with a demonstrated commitment to pain management.

### *3.2 Patient and Parental Contribution Beyond the Bedside*

Several participants suggested patient and parent representation on committees and hospital boards would provide a valuable perspective on what is needed (e.g., resources, peer support groups, quality improvement initiatives) to promote quality care in an area such as procedural pain management. One participant said:

I know they're starting to do these groups where there will be a board of parents...a peer kind of thing, and I think those are great to support parents...and peers kind of give the most information they can. Sometimes it means knowing someone's been through the procedure and is able to give you some advice on what happens. So maybe just having more supports out there from parent to parent...

Participants said peer support networks are important because patients/families possess valuable information and they can share this with other patients/families so they may learn from their pain care experiences. The participants articulated that patient and family contributions would drive leaders and organizations to examine their current practices and develop necessary structures and networks to improve pain management.

### 3.3 *Demonstrated Leadership and Organizational Commitment to an “Interprofessional Pain Plan”*

Building on the previous themes, nurses thought the hospital should commit to making pain management a priority by ensuring adequate staffing, appropriate resources, parent involvement beyond the bedside, and demonstrated leadership by physicians and management. One participant said, “the message needs to be sent from the top, so everyone will take it seriously and understand the relevance. I think just having the support from your managers, and support from higher up that they’re giving you the okay to spend that time to do it.” She also explained that physician support is necessary to individualize pain management and promote optimum pain care.

We’d have to have the ability of the frontline staff to be present and to follow through on what we have deemed as a priority...not just nursing staff either, I mean I think all support staff and medical support staff as well...that would have to be a priority, there would have to be a flexibility from the medical staff to just first and foremost, deliver safe care in an individualized way instead of just a standardized way.

Participants said the hospital should be committed to an interprofessional pain plan that includes standards and a hospital-wide pain committee. They said if all leadership and staff understood the significance of parental involvement in N-PPMSs and supported it; it would be successfully integrated in practice. One participant said N-

PPMSs should be treated just a like medication, by documenting their use and effectiveness, what procedures they were used for, who was involved, and so on.

Somehow you have to transform the culture of a place. It's so normalized to look at what medications you have to give and make sure that you're giving them at the right time and signing them off. That's a task that just seems engrained in the culture of nursing, where perhaps non-pharmacological pain management strategies aren't that way yet. Perhaps there's a need for education...perhaps it's framing pain as an issue that's just as important as the medication that kids get. One of the most important parts of a child's hospital stay is how painful procedures are dealt with. That can change if it was part of a strategy for change, then we might be the best we can be in terms of pain management and getting parents involved. That's the hard part, is how do we change so that nurses and other people in positions of authority like managers and physicians take it seriously...how do we change the culture of this unit so that everybody is working towards helping parents to help their children during painful procedures?

All nurses explained how the organization should to be committed to documentation and communication of a pain plan to facilitate parental involvement. Most nurses recommended that this be done using an “interprofessional pain plan” and routine evaluation of its use and clinical utility.

A few participants suggested using a tool that is already in place, such as the kardex (a card-filing system usually kept in the patient's chart that allows quick reference to the particular needs of a patient for certain aspects of the care plan). They already used this tool to communicate with other health professionals, but thought that a specific section on pain should be added. One nurse suggested it would be to everyone's advantage to develop, implement, and communicate the plan and continually update it with what is effective and what is not.

It would be to our advantage to use a pain plan for our patients. It will make everyone's day better if the procedure goes as well as it possibly could. So I think that's important...if it becomes the norm and not the exception to make a 'pain plan'...it would be an efficient way to communicate things...and I don't think this plan should be limited to the

nurses. It's not always the nurse that heard what did or didn't work and the team as a whole can communicate on this plan and learn from it. They can read it too and see what worked or didn't... Everyone needs to be on board and on the same page.

This nurse continued to say that it was important to continually update and communicate the pain plan based on the patient's development, needs, and effective strategies.

One participant predicted an electronic health record with flags or alerts on procedures could prompt the clinician to "consider the use of N-PPMSs" or when charting that a procedure was done, there could be a space to document N-PPMSs that would not let you bypass until you chart "none" or "specify what was used". This participant suggested this would be valuable tracking data that could support clinical research and patient outcomes related to N-PPMSs.

Resources, time, parental contributions to hospital committees/boards and pain groups, and leadership and organizational commitment to pain management as a priority would create opportunities for parental involvement.

#### *Destiny Theme - Sustainability through Advanced Knowledge, Skills, and Practices*

Webster's New World Dictionary (1994) defines sustainability as: "the ability to keep up or keep going, as an action or process" (p.1435). Education was identified as needed to sustain the dream of a collaborative culture where parents are a fundamental part of pain management, participating in care at their desired comfort level. Participants suggested that education could be facilitated in a "train-the-trainer" method, where experts build capacity within the team (i.e., Pain Management Team could educate Clinical Leaders/Educators/Advanced Practice Nurse (APNs) who then educate front line staff on how to educate, support, and guide patients and families through N-PPMSs).

#### *4.1 Expert Clinicians as Pain Care Facilitators*

Participants suggested the Pain Management Team would be a knowledgeable resource that could be utilized to educate leaders and management about the importance of optimum procedural pain management and the benefits of clinician knowledge development and facilitated application to practice.

Some participants recommended the Pain Management Team should present the evidence-base on N-PPMSs and provide expert advice to facilitate and sustain improved procedural pain care practices. Some participants were not aware there was a team dedicated to pain management or were unclear about the Pain Management Team's mandate and whether they dealt with acute or chronic pain or both. Participants thought of the Pain Management Team as a "medicinal" service and did not associate them with N-PPMSs. Participants were also uncertain how the Pain Management Team could be utilized for parental involvement in N-PPMSs, and proposed the pain presence on the unit could take the form of a pain champion such as a physician, nurse practitioner (NP), or a staff nurse that brings new evidence and/or new strategies forward to the rest of the group. Two participants suggested that preceptors of students or new staff could be trained to be pain champions.

If all nurses that were preceptors of incoming students or new nurses, were somehow trained to be pain management champions, or have good training from (the educator) or the pain team in the hospital...if that was part of their training as preceptors. Pain is a really important issue. I think it could start there because that first mentor makes a big impression on a new nurse and when they take pain seriously and they put a lot of thought into how they're going to manage pain in children I think that has an effect.

Participants thought a consistent message to both nursing and medical staff would support sustainability of N-PPMSs with parent involvement. Strategies suggested by

participants to increase parental involvement and optimize procedural pain management included a formal mentorship program and a hospital-wide pain committee to create and discuss pain initiatives and strategies. They recommended the committee should meet regularly and consist of interprofessional, hospital leaders, pain champions, and preceptors, with representation from each unit/department.

Participants said clinician comfort and confidence with performing procedures and doing them in front of parents is important. They thought comfort and confidence might improve if pain care facilitators provided education about procedural pain management strategies through practical scenarios and simulations. Nurses indicated it was important to find a balance between pain care facilitators with knowledge and skills and parents with expert knowledge of their child.

Parents know their kids best and there's no denying that. If they've had that procedure done ten times before, parents have been there those ten times when maybe you've been there once. I value parents' knowledge and their knowing their child and advocating for their child. Sometimes the child doesn't have a voice because maybe they're eight months old or two years old or maybe they're really anxious about the procedure and scared to tell you what they want...but it's parents who often communicate a need for a child for a particular procedure whether it be freezing cream or distraction techniques...or just the person that's there for the child at the time. It's all very important to have the parent involved.

The combination of clinician and parent expertise is necessary to facilitate optimum procedural pain care. Knowledge and skills are necessary for quality pain management but the impetus to help patients and families with pain comes from clinical empathy.

#### *4.2 Key Role of Clinician Empathy in Facilitating Optimum Pain Care*

Empathy is defined as a “predominantly cognitive (rather than emotional) attribute that involves an understanding (rather than feeling) of experiences, concerns and

perspectives of the patient, combined with the capacity to communicate this understanding (McKenna et al., 2012, p. 247). Clinical empathy is defined by Neumann et al. (2009) as “the ability to i) understand the patient’s situation, perspective and feelings (and their attached meanings), ii) communicate that understanding and check its accuracy and iii) act on that understanding with the patient in a helpful (therapeutic) way” (p. 342). Many participants described how they strive to understand the patient’s and family’s experiences and how clinician empathy is necessary to facilitate and sustain quality pain management.

Trying to make their stay here better or just helping them through it all, and navigate the whole (particular unit) culture...trying to make that easier for them and especially trying to make kids’ stays a little better...because they're sick, they're feeling miserable, they don't want to be here. They're undergoing lots of painful procedures...unpleasant procedures and I like to help out, to try to ameliorate that or do what I can to make those situations better because sometimes there's not much you can do to make things better. Kids are going to go through some pretty awful things here...

Participants expressed concerns about how their ability to care is affected when they are constantly overworked and understaffed, and working with very sick patients. One participant recognized that high levels of stress or burn out would affect her ability to empathize or care for patients.

What I value in myself as a nurse is...I guess my ability to care, and not burn out on a unit like I’m on...because it can be very intense, there’s a lot of chronic kids. I like to think that I value that if I ever feel like I don’t care or that it just doesn’t matter, that I’ll recognize that that’s time for me not to stay anymore. So I think that’s something that’s really important for myself.

Participants said that it would be important to find ways to stay fresh and not get jaded or burnt out with patients in pain; maybe through some discussion in the ongoing education that is needed to sustain procedural pain management practices. Participants

said evidence-based education and research on parental involvement in N-PPMSs is needed to support policies and sustain practices.

#### *4.3 Evidence-Based Education, Research, and Policies/Practices*

All participants thought evidence-based research was the key to a strong foundation and sustainable quality pain practices in the pediatric population. One participant supported the need for current, evidence-base research to support practice by saying she thought continued education should include regular updates on ‘this is new’, ‘this is the best’ and ‘this is shown to be effective to do it this way’.

One participant thought even short, regular education sessions would keep the topic on the minds of staff and have nurses talking about N-PPMSs, thinking about, and placing value on them.

Anything we can do to help put more value on it. Whenever you go to an education day and they talk about something, everyone kind of talks about it on the unit. So maybe just every so often have a reminder about it...not necessarily a full day about it but if we talked about it for 15 minutes or 30 minutes during an education day...that would probably help.

All participants believed that evaluation and feedback are necessary to sustain and continually improve practices and strategies to decrease procedural pain. All participants said patient and family input through interviews, surveys or questionnaires was necessary to evaluate the extent of parental involvement and the effectiveness of the strategy or strategies. Participants thought practices should be monitored and evaluated on a regular basis to sustain quality pain care.

Participants identified other evaluation measures of parental involvement and effectiveness of N-PPMSs in the neonatal population such as: patient stay, infection rate, and growth rate. In pediatrics, other evaluation measures suggested were: physiologic

parameters (heart rate, blood pressure, and oxygen saturations), behavioural signs (length of crying time, grimacing, tensing), and pain assessment scores. Participants suggested patient and family feedback was the best way to evaluate parental involvement in N-PPMSs in the short-term, but that other measures should also be studied in the long-term.

Participants thought evidence-based policies and practice guidelines were necessary to sustain consistent pain management practices and maintain effective relationships with the patient and family. One participant voiced the need for consistency through pain policies and guidelines so everyone is accountable to provide the same standard of care. Nurses suggested benchmarking be used, to find out what is being used effectively in other pediatric hospitals. Some of the participants knew there was a new pain management policy being developed and were cautiously optimistic about how it would affect their practice considering the present demands on their time. All participants said pain management was a huge priority and should be treated as such, in terms of staffing, resources, and initiatives.

In this study, four main themes related to parental involvement in N-PPMSs emerged. The themes included 1) Establishment of meaningful interpersonal connections 2) Development of a culture dedicated to collaboration and teamwork 3) Commitment to pain management as a priority – from a philosophy to a standard of care 4) Sustainability through advanced knowledge, skills, and practices. Though these themes are not new to research, they have been expanded on and described in rich detail related to parental involvement in N-PPMSs in this study.

## Comparing and Contrasting the Literature and the Findings

In this section I will compare and contrast the study findings with related literature and within the PARIHS framework to explore how contributing factors may determine the extent of research utilization in practice.

### *Factors that Contribute to Parental Involvement in N-PPMSs as Related to PARIHS*

The PARIHS framework considers the relationship among three elements for successful research implementation: context, evidence, and facilitation (Appendix J). The framework is being used to determine how the factors identified by participants influence the application of evidence-based practice related to parent involvement in N-PPMSs in the clinical setting. In order to discuss the results in a relevant manner the findings are organized into the three PARIHS elements of evidence, context, and facilitation (Table II), while considering the AI 4D model outcomes. The discussion also includes some subheadings to highlight the major sub-themes.

Table II - *Findings Placed in PARIHS Headings*

<b>Context</b>	<b>Evidence</b>	<b>Facilitation</b>
<ul style="list-style-type: none"> <li>• Family-centered environment</li> <li>• Communication and partnerships</li> <li>• Empathy</li> <li>• Goal-oriented Relationships</li> <li>• Physical space Considerations</li> <li>• Competency</li> <li>• Organizational resources and support</li> <li>• Quality improvement initiatives</li> </ul>	<ul style="list-style-type: none"> <li>• Practice-based evidence</li> <li>• Evidence-informed policies and guidelines</li> <li>• Input and feedback from clinical experiences</li> </ul>	<ul style="list-style-type: none"> <li>• Leadership and expertise</li> <li>• Patient and parental consciousness</li> <li>• Pain champions and other supports</li> </ul>

### *Context*

Participants describe an ideal context that would facilitate parental involvement in N-PPMS. Collectively, they say successful implementation in practice would include: family-centered environment, communication and partnerships, empathy, goal-oriented relationships, physical space considerations, competency, organizational resources and support, and quality improvement initiatives.

### *Family-Centered Environment*

According to Abraham & Moretz (2012), the four core concepts of FCC include: dignity and respect for family perspectives and choices, information sharing and decision-making, participation in care planning and decision making at a level they choose, and parent-professional collaboration in pain initiatives. Participants also presented these concepts and they are clearly represented in the themes and sub-themes.

When practicing with a FCC philosophy, it is necessary to explore concerns and solutions with families, and share complete information with them so they can make informed decisions. The needs of patients and families may change as they progress through their hospitalization, therefore FCC requires planning and creative individualized approaches to meet families where they are and help them to get where they want to go (Goldfarb et al., 2010; McKenna et al., 2010).

Unfortunately there is a wide variability in how FCC is approached and provided, and what necessary clinician skills are needed to provide it. Many nurses face challenges in implementing FCC on a consistent basis but when there is a vision and strategic plan for FCC and an interprofessional approach to creating, implementing, and evaluating organizational policies there will be a strong foundation for this standard of care. In a

setting where health professionals and families work together, organizational policies are reflective of the culture of FCC. Families and health professionals value FCC because it contributes to effective therapeutic relationships and positive outcomes (Abraham & Moretz, 2012). Participants in this study say they value FCC, but are often too time and resource-challenged to have meaningful discussions with patients and families about pain management.

#### *Communication and Partnerships*

Jones et al. (2007) provide parents' perspectives of effective communication skills. These skills include listening to parents, asking for input and suggestions from parents, giving direct and honest feedback, and maintaining respect and appropriate levels of reassurance. Parents would like more information about all aspects of care, improved timing of information giving, and involvement opportunities.

Parents express that effective communication and support from staff influence their ability to achieve their desired level of involvement with the actual procedure (Franck Oulton, & Bruce, 2012). N-PPMSs are often mother-driven, but they are ultimately nurse-enabled, therefore effective communication and meaningful relationships between nurses and patients/families are necessary for successful implementation and collaboration (Campbell-Yeo, Fernandes, & Johnston, 2011).

Nurses are a primary source of information and support for parents during hospitalization for effective nursing communication is highly valued by parents (Jones et al., 2007). Nurses should adapt their communication style to parents' desired levels of information exchange and their choices related to decision making (Jones et al., 2007). The positive effects of therapeutic relationships and effective communication are not just

limited to parents. Swartz, Perry, Brown, Swartz, & Amiram (2008) report that therapeutic relationships and effective communication enhanced patients' mental health, decreased nurses' stress, and increased job satisfaction among nurses. Nurses value these relationships with parents as well and this is clearly recognized in the participant's responses.

Eden & Callister (2010) conclude that parents build trust and reduce stress by establishing therapeutic relationships and effective communication with health professionals. Furthermore, when accurate information is provided and therapeutic relationships are positive and parents believe that the health professional truly cares about their child, they are more likely to trust the information that is provided to them. Parents can be educated about how to establish effective communication with health professionals (Eden & Callister, 2010).

Interventions and treatment regimens do not fully account for positive patient outcomes, and the effect of interventions is often mediated by factors such as therapeutic relationships and effective interpersonal communication (Tejero, 2011). Effective communication is well accepted as necessary for quality care, patient safety, and financial performance (Baird, Funderbunk, Whitt, & Wilbanks, 2012).

Nurses say it is important to provide individualized, needs-based care through communication and partnerships with the patient and family. Partnership in care is "the recognition that caring for a child includes respecting the parents' knowledge about their child and their right to be involved in decision making and the caring process, thereby enabling the family to retain control over this aspect of their lives" (Ford et al., 2011). When health professionals provide information, parents perceive support, and this is

associated with enhanced relationships with patients and families and increased parent satisfaction with decision-making and involvement (McKenna, Collier, Hewitt, & Blake, 2010; Tejero, 2011). Nurses say effective communication and relationships are valuable and necessary for positive outcomes in procedural pain management with parental involvement.

### *Empathy*

Clinician empathy is widely accepted as a necessary component of a supportive relationship (Cunico, Sartori, Marognolli, & Meneghini, 2012). Many researchers believe that clinician empathy may benefit patient and health professionals by improving quality of care through patient satisfaction and better pain management (Abbott Moore, 2010; Cunico et al., 2012; Neumann et al., 2009).

However, there are research studies that find little to no correlation between empathy and better pain management (Moore, 2010; Watt-Watson et al., 2000). This could be because there are no reliable and valid self-report measures for clinician empathy (Yu & Kirk, 2008).

Neumann et al. (2012) describe how the ability to empathize can suffer from experiences of heartlessness and brutality, pressure and stress. An example of this would be when nurses are exposed to patient experiences of procedural pain that are untreated or undertreated. When a clinician imagines how a patient may feel, when they are in pain or distress, similar neural circuits are activated in both the patient and the health professional. If clinicians are exposed to untreated or undertreated painful pain repeatedly, this empathetic response might be dampened. Clinician's lack of empathy could actually jeopardize the health professional's

ability to provide quality care. Decety & Jackson (2006) explain that a certain level of executive control is needed as a protective mechanism to inhibit the pain/distress felt by the patient and detach oneself from it.

Training health professionals, especially front line staff, in the use of coping/emotion regulating strategies may reduce distress and prevent against burnout. Clinician empathy may be also influenced by situational factors; effective collaboration may improve parental involvement in N-PPMS and protect nurses from decreased empathy and burnout (Neumann et al., 2009). Nurses in this study fear they may burnout because of work stress and the nature of the patients they care for. Nurses describe how they try to understand the experience of patients and families and how clinician empathy contributes to better quality pain management.

#### *Goal-Oriented Relationships*

An increased focus on best practice in collaboration has called for interprofessional collaboration across departments, patient and family contributions to patient care initiatives, conducive organizational culture and executive-level support, based in a nurturing interpersonal environment (Nicholas, Fleming-Carroll, & Keatings, 2010). The magnet hospital research shows better collaboration increases better care outcomes (Latimer et al., 2010; Nicholas et al., 2010; Rawe et al., 2009).

Collaborative models are being introduced into academic curriculums to support learning and prepare students for clinical practice in team-based health care environments (Bandali, Niblett, Yeung, & Gamble, 2011). These advancements also align with the core values of FCC and highlight the importance of organizational context and consideration of stakeholders in the process of pain management (Nicholas et al., 2010). Although

some participants describe their work context as collaborative, most participants identify a need for a more collaborative environment to improve parental involvement in procedural pain management. Participants say time and resource constraints make it difficult to collaborate and to find creative ways to collaborate with patients and families.

Interprofessional teams that work collaboratively can improve patient safety and quality patient care (Gum et al., 2012). Parent-professional collaboration can provide parents with the knowledge skills and resources to become active participants who make decisions about their child's services, and work together to improve pain outcomes (Goldfarb et al., 2010).

Parents, particularly mothers, have expressed concern about the loss of their parental role and the ability to provide comfort to their child in the hospital. Fathers also feel they are excluded from pain care and would like to be more involved (Campbell-Yeo et al., 2011). Parents have expressed a desire to participate in pain management strategies even though this may cause them distress. Parent distress may decrease when they are provided with information about pain, are actively engaged in parenting and providing comfort to their child, and receive support and encouragement from health professionals to be involved in pain care (Franck et al., 2012; Yates et al., 2004). Nurses in this study say that parents should always be involved in N-PPMSs if they want to be, but at their desired level.

#### *Physical Space Considerations*

Single family rooms are growing in popularity and are often associated with improved outcomes (Shahheidari & Homer, 2012). In a recent systematic literature review, key factors related to improved pain management outcomes with single family

rooms were identified: increased comfort and privacy, increased parental involvement in patient care, assistance with infection control, noise control, improved sleep, decreased length of hospital stay, and decreased rates of re-hospitalization (Shahheidari & Homer, 2012). Single family rooms also ensure that patients and families are not directly exposed to distressing situations that can cause further stress and anxiety (Rose & Blythe, 2009).

There is some debate as to whether single room setups interfere with interprofessional collaboration. Because of the layout, there are less opportunities for discussion, support, and informal education, which could influence the extent of parental involvement in N-PPMSs (Shahheidari & Homer, 2012) Rose & Blythe (2008) conclude that measures should be taken to ensure that patients and families in single room care have opportunities for play and interaction with other families on the unit, because interaction with peers is an important aspect of support and informal information sharing about pain management strategies. Participants in this study identified geographical/physical space issues as an important contextual factor for improved parental involvement in N-PPMSs. However, a few of the participants expressed concerns about social isolation and lack of opportunities for parent-to-parent support.

### *Competency*

Twycross (2010) identified gaps in nurses' knowledge and skills related to N-PPMS. However, there are no real links to nurses' level of knowledge and how well they manage pain (Twycross, 2010). Cramton & Gruchala (2012) state the key to managing a patient's procedural-related pain is preparation, and achieving a balance between having time to process information and without too much time where anxiety ensues. Nurses in

this study describe competency in managing procedural pain as having the knowledge and experience, and being prepared and confident.

#### *Organizational Resources and Support*

Nurses in the current study identify that adequate time and resources are needed to provide optimum pain care. This is consistent with the literature identifying increased work demands for nurses (Gum et al., 2012; Shahheidari & Homer, 2012). Adequate time and resources are required to meet work demands and provide quality patient care. Balancing work demands and skill mix will likely decrease pain experiences in children and increase evidence use in pain care (Latimer et al., 2010).

#### *Quality Improvement Initiatives*

An organizational commitment to pain management should be part of an organization's quality improvement program and is a critical element for successful accreditation (Curtiss, 2001; Twycross, 2012). Implementing hospital-wide initiatives, such as an individualized pain plan can enhance the psychosocial and physical outcomes of patients (Czarnecki, Turner, et al., 2011). An individualized, interprofessional pain plan should include procedural pain management, including pharmacological and non-pharmacological interventions based on the patient's unique characteristics, treatment setting, procedure being performed, patient and family preferences and input (e.g., what was effective/not effective in the past), and ethnicity and cultural considerations (Czarnecki, Turner, et al., 2011). Nurses in this study say that leadership and an organizational commitment to an "interprofessional pain plan" would enhance individualized pain management and better procedural pain care. They also say if the pain plan is integrated into a tool

that is already established (e.g., the kardex), used by the whole team, and updated regularly, that is could be a valuable communication tool related to pain management.

For this to work, health professionals must realize that many of the procedures that are inflicted on children in the hospital have the potential to be painful (Stapelkamp, Carter, Gordon, & Watts, 2011). Even routine procedures like x-rays and physiotherapy can produce pain and steps should be taken to prevent or relieve procedural pain and N-PPMSs should be documented in a pain plan to communicate what was or was not effective (Tupper & vonBaeyer, 2010).

High context occurs when the environment is receptive to change with ‘learning’ cultures, strong leadership, and appropriate monitoring and feedback systems. Quality improvement is an appropriate way to continually monitor and evaluate progress toward effective pain management, documentation, and communication (Curtiss, 2001).

Participants believe there should be a commitment by leaders and the organization to participate in quality improvement initiative such as an “interprofessional pain plan”. In order to successfully implement evidence-based practices, all stakeholders should be informed and aware of how to best support parents in N-PPMSs.

### *Evidence*

Participants describe high quality evidence consisting of practice-based evidence, evidence-informed pain policies and practices, input and feedback from patients and families, and clinical experiences that resulted in effective pain management.

### *Practice-Based Evidence*

The growing body of research underscores the importance of pediatric pain management over the last three decades; however, research evidence can only guide practice (Harvey & Morton, 2007; Stapelkamp et al., 2011). The ultimate decision to use it depends on health professionals, the organizations in which they work, and the implementation and evaluation of robust pain management policies and practices (Stapelkamp et al., 2011). These are also dependent on the content factors discussed in the first section.

### *Evidence-Informed Policies and Guidelines*

There is a need to examine the current state of pain management in an organization, then implement a standard of practice based on national standards and guidelines and specify in articulated, written policies the accountability for pain management. Health professionals need to collaborate to develop policies and procedures that outline goals and expectations for procedural pain management (Czarnecki, Turner, et al., 2011). New and updated policies and practice guidelines can assist in providing a basis for standardization (Curtiss, 2001). Pain standards outlined by JCAHO (2001) are credited with improving pain care practices for nurses (Latimer et al., 2010). A study by Van Hulle Vincent, Wilkie, & Wang (2011) demonstrated how the provision of evidence-based education could improve nurses' beliefs, knowledge, and intention to treat. All nurses in the study thought evidence-based research was the basis for facilitating and sustaining optimum procedural pain practices.

### *Input and Feedback from Clinical Experiences*

Nurses' practice can be influenced by clinical experiences with parental involvement in N-PPMSs. As stated in the literature review, it is unclear whether nurses respond to positive or negative experiences past experiences with parental involvement in N-PPMS by either involving or not involving them in future procedural pain strategies. Nurses in this study said that when they saw effective pain management strategies, it was powerful and worth repeating.

High evidence occurs when evidence is high quality and appropriate and it matches professional consensus and patient preferences, and local information is considered. There are a multitude of studies that support parental involvement in procedural pain management and N-PPMSs (Campbell-Yeo et al., 2011; Franck et al., 2012; Pillai Riddell et al., 2012; Power et al., 2007), however there are gaps in the research.

### *Facilitation*

Nurses in this study recognize high facilitation factors that will enhance parental involvement in N-PPMSs and they include: leadership and expertise, patient and parental consciousness, pain champions, and other supports.

#### *Leadership and Expertise*

Many organizations state that pain is a priority but need to take steps to make pain management a standard of care by increasing development of groups dedicated to pain management in the pediatric population, establishment of pain accreditation standards, and increasing patient and family involvement in shaping organization policy and programs (Cramton & Gruchala, 2012; Twycross, 2010).

Organizations should appoint lead facilitators to promote and support the planning, implementation, and evaluation of family-centered, high-quality, consistent pain management practices (Stapelkamp et al., 2011). Key stakeholders, such as physicians, nurses, nursing management, and clinical educators can help to implement policies and guidelines into clinical practice but must recognize their importance and the need to have evidence-based guidelines to provide quality pain management.

A change agent, such as an APN, could provide commitment to the guidelines and the practice outcomes, and serve as expert facilitator for direct care providers. Involving the targeted staff will promote ownership of the guidelines and help to ensure that best practices occur as a result of their implementation (Stapelkamp et al., 2011). APNs are in an ideal position to act as pain care facilitators by supporting other health professionals, especially staff nurses, in the provision of effective pain management strategies (Kohr & Sawhney, 2005).

Nurses often consult APNs when they care for patients who they predict will have significant procedural pain. Nurses in advanced practice can build capacity by helping staff to work through practice issues through critical evaluation, research, and planned change and providing guidance and support in procedural pain management to staff and parents (Rawe et al., 2009). In Czarnecki, Simons, et al. (2011) nurses provided perspectives of pain management, supporting the importance of APNs in providing quality patient care, educational and improvement initiatives.

Nurses in this study recognize their own role in facilitating parental involvement in N-PPMSs. Staff nurses are direct care providers of pediatric pain management and

they can provide valuable insight into the barriers and facilitators to optimal pain management. This insight is necessary to making meaningful improvements and therefore nursing involvement in the development and revision of pain care policies and procedures and patient care initiatives at all levels is crucial (Czarnecki, Simons, et al., 2011).

#### *Patient and Parental Consciousness*

The intimate nature of the relationship between a child and their family may enable family members, particularly parents, to recognize subtle signs of pain and to provide expert knowledge about what strategies may be effective with their child. Parents are experts in their child and should be encouraged to actively participate in pain management (Alspach, 2010). Nurses in this study say parents are the constant in their child's life and they often draw on parent's expert knowledge of their child.

Over the years philosophies have changed and our system has improved because of input from families. Recent studies highlight the important role of patients and families in the planning, implementation, evaluation and follow-up of initiatives related to FCC and interprofessional collaboration, peer support, and health professional education and training (Bandali et al., 2011; Goldfarb et al., 2010; Nicholas et al., 2010; Stapelkamp et al., 2011). The quality of health care and pain management improves when families are involved (Ford et al., 2011; Muething & Tietjen, 2007). Patients and family members can help to identify areas that need improvement because they can provide a different perspective (Muething & Tietjen, 2007). Nurses in this study suggest that parents could provide important

contributions to pain management even beyond the bedside. They also say parents have a strong voice and can influence change and improvements at all levels.

#### *Pain Champions and Other Supports*

Pain Management Teams and other pain champions and supports can improve pain management on a daily basis. Having the right expertise and support could assist nurses caring for children in pain. However, much of the literature on pain services is adult based (Twycross, 2010). CNSs and pain champions can provide educational support and advice on pain-related issues to staff (Kohr & Sawhney, 2005; Twycross, 2010). CLS are also highly involved in providing N-PPMS and supporting parental involvement in their provision (Bandstra et al., 2008). Nurses in this study mentioned the importance of pain care facilitators such as the Pain Management Team, APNs, pain champions, and many other supportive resources to facilitate parental involvement in N-PPMSs.

High facilitation of evidence into practice occurs when there is appropriate support to achieve a specific task (parental involvement in N-PPMSs). There are expert pain care facilitators who possess the knowledge and skills to implement evidence-based practice but resources and time may limit them.

The most successful implementation of evidence-based research occurs when the work context is receptive to change, the evidence is high quality, and the change process is facilitated appropriately (Kavanaugh, Watt-Watson, & Stevens, 2007; Rycroft-Malone, 2004). When comparing the findings to the literature, the nurses description of the attributes within their work context are low to moderate in strength and potential to actually implement the practice of engaging parents in N-PPMSs. There is consistency in

the findings that there is a significant lack of resources and time, which play a major part in facilitating parental involvement in N-PPMSs. Instituting true FCC, and establishing partnerships and communication/collaboration is a challenge in the current health care environment. It is also not clear how or if hospital leaders show active support for parental involvement in N-PPMSs. The organization deems pain management is a priority but has provided little more than lip service to the issue. The test will come with a new pain policy implemented in 2012, but with so many competing issues it is hard to predict whether the policy will be taken up. The policy is based on recent, high quality evidence but parental involvement was not acknowledged. Nurses express concerns related to burnout affecting their ability to empathize as financial, physical, and personnel resources are often enable them to provide just the “basic” care.

Evidence-based research related to parental involvement in procedural pain is moderate to strong. There is strong evidence that parent involvement and N-PPMSs are effective but best practices have not been identified. Nurses describe practice-based evidence from their work experiences with patients and families but there are no formal evaluation measures in place to evaluate N-PPMSs at this time.

Participants’ descriptions of facilitation factors that would contribute to parental involvement in NPPMSs are low to moderate. The Pain Management Team and APNs do act as pain champions but resources and time limit the scope of their involvement. Nurses are supportive of parental involvement in strategies but they are also limited by resources, time, and their knowledge and skills related to N-PPMSs. There are no pain committees that involve parents at this time. Participants identify other resources (e.g., psychology, palliative care, spiritual care, technology person) as facilitators to parental

involvement in N-PPMSs, but these resources are often limited too. However as this research is shared, there will be an increased in awareness of the importance of parents' role and the context, evidence, and facilitating factors that influence parental involvement in N-PPMSs.

AI was effective to gather nurses' perspective of clinical experiences with parental involvement in N-PPMSs. With the 4-D process of AI, nurses can critically appraise their clinical practice through reflection, examination, and projection. This positive inquiry gives nurses an opportunity to celebrate personal and professional successes and create ways to build on them.

PARIHS fits nicely with AI and this particular research question that examines the conditions that facilitate parental involvement in procedural pain management. Strengths and limitations to successful implementation of evidence-based research into practice can be recognized by identifying the factors that contribute to parental involvement and placing them in the PARIHS framework.

## **Chapter Five**

### **Conclusion**

The experience of pain is not a new concept to hospitalized children and their families. What is new and emerging is the breadth and depth of how parental involvement in N-PPMSs can be used for optimum procedural pain care. Evolving research in parental involvement in the management of pediatric pain tells us that the majority of parents want to be present in the hospital and participate in N-PPMSs with their child at a level they are comfortable with. In this study, all the nurse participants strongly supported the idea of involving parents in strategies and acknowledged the benefits of N-PPMSs in effective pain management and decreasing stress/anxiety in patients and families. Nurses in this study who have used N-PPMSs have seen the benefit in using them in practice.

Nurses in this study have provided valuable, practice-based knowledge related to the conditions that could facilitate and sustain procedural pain practices by involving parents. The detailed descriptions of their experiences with patients and families and their first-hand knowledge of the patient populations, pain care practices, and how to engage parents provided the basis for the creation of themes and sub-themes in this paper.

Participants identified facilitators to parental involvement in N-PPMSs including: 1) establishing meaningful relationships and effective communication to provide individualized and needs-base care, 2) developing a culture of collaboration where parents are present, seen as an integral part of the pain management team, and involved at their desired level, 3) committing to organizational pain management as a priority

through demonstrated leadership, adequate clinician time and resources, and patient and parent contributions, and 4) sustaining ideal pain practices through pain care facilitators, clinician empathy, and evidence-based education, research, and practices.

Clinical research is the foundation for evidence-based practice. Given the evidence-based benefit of parental involvement in N-PPMSs, it is important to consider how to facilitate these interventions for all infants and children having procedures. It is important for nurses to develop their practices based on the best available scientific knowledge. These study findings may be useful to consider when creating strategies to support health care professionals and parents to provide effective procedural pain care.

By understanding nurse's perceptions guided by the conceptual framework of the PARIHS model, the actual evidence, work context, and facilitation factors, efforts and resources to support change and development strategies can be identified more comprehensively as facilitators. Strengths and limitations of the study method, clinical and research implications for practice, suggestions for future research, and planned dissemination of findings will also be discussed.

#### Strengths and Limitations of the Study

The methodology of AI was appropriate to examine nurses' perspectives of involving parents in N-PPMSs for procedural pain. The research question fit well with this methodology as it allowed the researcher to explore the topic through positive inquiry and led participants through an evolving process of discovery, dream, design, and destiny. The interviews and focus groups led participants to reflect and explore their perceptions and personal experiences on the topic, discuss how context, evidence, and facilitation contributes to parental involvement in N-PPMSs in practice, and describe

strategies and recommendations that may be implemented to facilitate parental involvement in pain strategies. AI is a novel way to examine practice issues since it looks at the facilitators, and how to build on what works already in practice.

As with many qualitative research studies, variability in the sample is a limitation in this study. The study site currently has 200-300 nurses (full-time and part-time) working within the four participating units. The data collected from the study revealed patterns, although consistent among twelve nurses, may not be representative of all nurses. It is believed that the findings from this study reflect ideas and practices documented in other evidence, which are outlined in the discussion section. The study used purposive sampling; therefore the research may not be transferable to other sites or disciplines.

Interviewing and focus groups were used as the main methods of data collection. The interview participants provided rich, detailed data that may lead to further research using other methodologies. The interviews provided respondents with some flexibility to answer and share their experiences as they wish; yet there may be limitations to the questions that are asked and the way they are asked. The interviewer or the interview protocol may influence the richness of the data; this may be seen as a limitation to the study.

The focus group format worked well and all participants had an opportunity to share their perceptions, experiences and thoughts on parental involvement in N-PPMSs. All participants took part in the discussion. One limitation of the focus groups was that only seven of the twelve participants were available to attend due to scheduling conflicts. This became a study limitation, as not all study participants were available to confirm the

findings. It is likely that even with more participants, there would be agreement on the finding/themes since there was representation from all four units and all seven participants agreed with the PI's interpretation.

Finally, the PI is a health professional and nurse research coordinator who is directly associated with the four participating units so the participants may have been hesitant to disclose information and may have been a limiting factor of the study. On the other hand, this could be considered a strength because the participants are familiar with her and her association with pain research and practice may have felt more comfortable discussing their experiences.

#### Clinical and Research Implications

This study provides new understanding related to nurses' perceptions of how parental involvement in N-PPMSs facilitates optimal management for procedural pain. The study has generated knowledge related to the positive facilitators that promote parent involvement in procedural pain management. These findings contribute to the body of literature that guides practices and strategies for involving parents in N-PPMSs on a consistent basis. This study is the first examination of nurses' perspectives using AI on parental involvement in N-PPMSs.

The PI has created recommendations based on research evidence and participants' experiences and input. Information may inspire better pain practices and plans to build on present strengths. It is anticipated that there will be a deeper appreciation from health care providers of the significance of parental involvement in procedural pain strategies. This research has the potential to raise consciousness and discourse potentiating change in pediatric pain care by influencing health care practice and policy. The research may

heighten health care professionals' awareness to consider all aspects of parental participation in pain management thereby positioning them as equal partners in pain management with their child. This research will lay the groundwork for future research based guidelines in this area. The long-term goal of this research is to improve health services to children and their families, specifically to improve procedural pain management.

Provisions should be made to respect the privacy of patients and families; for instance, private rooms allow parents to participate in N-PPMSs without feeling like they are under a microscope. Resources need to be allocated to support parental involvement and N-PPMSs.

Evaluation and feedback of N-PPMSs is necessary to find out what strategies are effective and how parents felt about implementing them. Furthermore nursing education opportunities may be designed that focus on clinical empathy, parental involvement, and N-PPMSs, which may improve consistent and standard use of strategies for painful procedures. Interprofessional and intraprofessional collaborative opportunities to explore families' desires in terms of pain management would enhance the likelihood this level of care will be provided. Team based workshops would also facilitate better processes of care delivery.

#### Future Research

The findings and recommendations for future studies may stimulate further research in the area of parent involvement in procedural pain management strategies. Through the experiences of the nurses, this study offers strategies to enhance or facilitate research utilization thereby guiding and improving clinical practice and potentially

stimulating future research. Little research exists on specific N-PPMSs and their effectiveness with specific procedures or children of various ages. Research is needed on how to implement parental involvement in N-PPMSs in an effective and efficient manner. The next step could be implementing a protocol for procedural pain in the hospital.

The development of guidelines to standardize parental involvement in procedural pain would be pivotal in facilitating its use. Unit standards or guidelines could be created to guide nurses in how to involve parents and use N-PPMSs as a primary procedural pain management strategies or adjuvant to pharmacological therapy. The CLS's role was seen as pivotal to successful use of N-PPMSs, and further research is needed to examine how they involve parents in strategies. Conducting research that focuses on the parental perspective and/or experience of using N-PPMSs with their child could help health care professionals to empathize with families and help to decrease parental anxiety. Human resources and physical comfort issues require some further exploration as well.

#### Dissemination of the Findings

Knowledge transfer is an essential component of the research process. Effective knowledge transfer involves an ongoing exchange between researchers and research users, often by means of traditional formal and informal methods. Some of these methods include journal submissions, formal educational seminars, informal unit-specific education such as lunch and learns and education days, conferences presentations, and posters. In knowledge dissemination it is important to use an approach that targets all levels including management, researchers, nurses, other allied health staff, patients and

families, and the public. Even parents who use the strategy may be a potent knowledge transfer agent.

Traditional methods of dissemination to inform health care providers will include poster and/or oral presentations at local and national conferences, Dalhousie University School of Nursing Scholars Seminar and Pain in Child Health seminars, in addition to publication in peer reviewed journals (i.e. Journal of Child Health Care, Neonatal Nursing) as well informal parent based magazines or newspapers. Informal conversations, such as lunch and learns, with health professionals and patients/families will facilitate discussions that may increase the use of N-PPMSs for procedural pain.

The results of this study will be shared with the managers working within the Children's Health Program and participating units so that current nursing practice may be appreciated through the recognition of their strengths and accomplishments. By disseminating the findings to participating units and other units in the hospital where children experience procedural pain, clinicians will realize the benefits of involving parents and the conditions that facilitate their involvement in N-PPMSs. All of these strategies will be considered as effective ways to disseminate the results of this study and increase knowledge about the factors that contribute to parental involvement in N-PPMSs.

Through AI, twelve nurses with diverse backgrounds and varying levels of experience provided rich, descriptions about their perceptions of parental involvement in N-PPMSs. Trustworthiness was established through the analysis of two datasets, and the integration of the findings with literature specific to the themes. Interview and focus group data aligned with previous literature, enhancing the credibility of this study.

The study goals were achieved and nurses were able to articulate the positive conditions that facilitate parents' active involvement in procedural pain management strategies with their hospitalized child. A new understanding of the structures and processes to improve the management of pediatric procedural pain by engaging parents is the result. Using AI, nurses were able to provide their perspectives of the current conditions and propose structures and processes to improve and sustain practices that facilitate parental involvement in N-PPMSs.

Nurse participants have reflected on their practice and shared stories of their work with patients and families. Meaningful interpersonal relationships and collaboration with patients and families about their involvement in N-PPMSs is established through interactions and identification of needs. Parents need to be present and considered an integral part of the pain management team, yet participating at their desired level. Clinicians, parents, and hospital leaders need to work together to implement an "interprofessional pain plan" in order to move pain management from a philosophy to a standard of care. Nurses suggested consistent parental involvement in pain management could be sustained through expert pain care facilitators, clinician empathy, and evidence-based education, research, and practices.

The findings provide a solid direction to guide practice and for future research including studies exploring parent and CLS experiences with N-PPMSs, and identifying and evaluating current practices related to parental involvement in procedural pain management strategies. Furthermore, intervention studies where initiatives are implemented and evaluated to promote parental involvement in N-PPMSs strategies are needed.

Appendix A

*4-D Cycle*



Cooperrider & Whitney (2005)

## Appendix B

### *Email Message from Manager to Support Study*

**Subject: Nurses' Experiences with Helping Parents to Comfort their Child during Painful Experiences in the Hospital**

A Master of Nursing student is interested in learning more about nurses' positive experiences in helping children and their parents during painful procedures. Participants will be asked to share their stories in an interview that will take approximately 45 minutes. Participants will also be invited to join a focus group session to share experiences and perspectives and this will take approximately 90 minutes. Participants will be offered a small honorarium and reimbursement for parking.

This study will help to understand how parents can be actively involved in provide comforting strategies during procedures with their child. Parent involvement in pain care can result in better health outcomes for their child and overall better pain care delivery.

If you are interested in participating in the study or have any questions related to the study, please contact Shelley at 470-7705/Shelley.lowther@iwk.nshealth.ca or her supervisor Margot Latimer at 431-8648/mlatimer@dal.ca

## Appendix C

### *Invitation Letter to Participate in Study*

Dear Nursing Staff of NICU, PMU, MSNU, & 6Link

Shelley Lowther is student in the Master of Nursing program at Dalhousie University and has decided to focus her thesis work on parent involvement in pediatric pain care practices. Shelley is passionate about ways to reduce pain through developmental care and non-pharmacologic pain management strategies. She is interested in ways to engage families in care related to procedural pain.

The study's title is: **Examining the Conditions that Facilitate Parents' Active Engagement in Procedural Pain Management with their Hospitalized Child**

The goal of the study is to explore nurses' positive experiences related to involving parents in non-pharmacologic procedural pain management strategies. Participants will share their positive perspectives and stories through a one-on-one interview that will take approximately 45 minutes. Participants will be invited to join a focus group session with other participants to discuss preliminary findings from the interviews and to share experiences and perspectives. The focus group session will take approximately 90 minutes. Participants will receive a small honorarium and reimbursement for parking.

If you are interested in participating in the study or have any questions related to the study, please contact Shelley at 470-7705/Shelley.lowther@iwk.nshealth.ca or her supervisor Margot Latimer at 431-8648/mlatimer@dal.ca

Sincerely,

(Manager's name)

*Consent Form for Participants*

**Research Title:**

**Examining the Conditions that Facilitate Parents' Active Engagement in Procedural Pain Management with their Hospitalized Child**

**Researchers:**

Shelley Lowther  
Principal Investigator (PI)  
Master of Nursing Student  
Dalhousie University  
470-7705

Dr. Margot Latimer  
Thesis Supervisor  
Associate Professor  
Dalhousie University  
494-2391

**Introduction:**

Despite an expanding body of evidence on pediatric pain, procedural pain is still largely under managed in practice. Hospitalized children experience a large number of procedures and the pain from these procedures is a stressor for parents and children. Children who experience inadequate pain management for medical procedures may have immediate and long-term negative effects. Recent evidence supports the idea that parents can provide important and effective pain management through non-pharmacological strategies. Nurses have a key role in engaging parents in using procedural pain management strategies.

**Purpose:**

The purpose of the research is twofold:

1. To examine nurses' perspectives on the individual and contextual conditions that facilitate parents' active engagement in procedural pain management strategies, and
2. To interpret their experiences in order to determine the processes that will improve parent involvement in managing their child's pain.

Findings will add to the body of literature related to children's pain and may inform better pain practices or further research related to parent involvement.

**Description of the Research:**

This voluntary research study will be carried out in four pediatric units at the IWK Health Centre.

If you agree to participate in this study, you will be invited to attend one 45-minute interview about your positive experiences of engaging parents in procedural pain management strategies with their hospitalized child. Later on, when all the interviews are complete, you will be invited to attend a 90-minute focus group session

You will be reimbursed for your parking and provided with a small honorarium for participation in the study. A private area within the hospital will be chosen for the interview location. The information shared during interviews will be kept confidential, however it is requested that the information could be shared anonymously during the focus groups.

**Potential Harms:**

There are no burdens or harms anticipated from participation in this research study.

**Potential Benefits:**

By participating in this study participants may benefit by being inspired by or learning about conditions that facilitate parent involvement in pain care strategies with their child. Participants will have an opportunity to discuss relevant experiences related to pain management and it is hoped that what is learned will benefit families receiving pain care at the IWK and the staff providing care for those families.

**Confidentiality:**

All interviews and focus group sessions will be audio taped and transcribed. A research assistant will transcribe the interview and focus group data and sign a confidentiality agreement. Your privacy will be respected. No personal information or identifiers will be given to anyone or be published without your permission, unless required by law. Direct quotes may be used to strengthen the analysis of data; these quotes will not be linked with any personal information or identifiers.

Only the PI, thesis supervisor, and IWK Research Ethics Audit Committee will have access to study records. No personal identifiers will be linked with the data. All tapes and transcriptions will be kept in a locked filing cabinet in Dr. Latimer's office in the Centre for Pediatric Pain at the IWK. Audiotapes will be destroyed after transcription. Study information will be kept for 5 years after publication as per the guidelines for research services. Any published study results will not reveal your identity.

**Participation:**

Participation in this study is voluntary and it is your choice to take part in this study. You may withdraw from the study at any time. Withdrawal from the study will not affect your employment at the IWK in any way by whether you take part in this study. Please contact the PI at 470-7705 if this option is anticipated.

**Research Rights:**

Signing and returning the consent form indicates that you have agreed to take part in this research study and have your responses used as data related to the research topic. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institution from their legal and professional responsibilities. If you have any questions at any time during or after the study about research in general you may contact the Research Office of the IWK Health Center at (902) 470-8765, Monday to Friday between 9:00am-5:00pm.

**Conflict of Interest:**

The PI and her thesis supervisor do not have any commercial or financial interest in this study.

**Consent:**

By signing this form, I agree that:

- 1) You have explained this study to me. You have answered all my questions.
- 2) You have explained the possible harms and benefits (if any) of this study.
- 3) I know that it is my right to choose to participate or not participate in this research study. I understand that I have the right to withdraw at any time. My decision about taking part in the study will not affect my employment status at the IWK Health Centre.
- 4) I am free now, and in the future, to ask questions about the study.
- 5) I understand that no information about who I am will be given to anyone or be published without first asking my permission.
- 7) I agree, or consent, to take part in this study.

\_\_\_\_\_

Printed Name of Subject

\_\_\_\_\_

Subject's signature & date

\_\_\_\_\_

Printed Name of person who explained consent

\_\_\_\_\_

Signature of person who explained consent & date

\_\_\_\_\_

Printed Name of Witness

\_\_\_\_\_

Witness' signature & date

If you have any questions about this study, please call Shelley Lowther (Principal Investigator) at (902) 470-7705/shelley.lowther@iwk.nshealth.ca or Margot Latimer (Thesis Supervisor) at (902) 494-2391/mlatimer@dal.ca

If you have questions about your rights as a subject in a study, please call the IWK Research Ethics Coordinator at (902) 470-8520.

If you would like to be informed of the study results, please check the Yes box below and include your name and email address.

Yes \_\_\_\_\_ No \_\_\_\_\_

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

Email: \_\_\_\_\_

*AI Interview Protocol (AIIP)*

<b>Phase</b>	<b>Questions</b>	<b>Field notes</b>
<p><b><i>Discover</i></b>  <i>(The best of what is or has been)</i></p> <p>Interviewer needs to:</p> <ul style="list-style-type: none"> <li>• Inquire</li> <li>• Explore</li> <li>• Appreciate</li> </ul>	<p><i>Opening Questions</i></p> <p><i>Let's begin by talking about your background as a nurse and your work.</i></p> <p><i>How many years have you been working as a nurse?</i></p> <p><i>How many years have you worked in your present unit (PMU, 6Link, MSNU, or NICU)?</i></p> <p><i>Tell me a little about your background in nursing (units worked on, roles in nursing, nursing education).</i></p> <p><i>What attracted you to nursing and working with the pediatric population?</i></p>	

	<p><i>What do you find the most meaningful about your work with children and families?</i></p> <p><i>What stories can you share that were the most memorable, challenging, or exciting to you?</i></p> <p><i>What are some of the things that you value the most about yourself and your position as a nurse?</i></p> <p><i>... the unit and the team that you work with?</i></p> <p><i>... and the organization as a whole?</i></p>	
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	<p><i>Talk about your best shining moment in (PMU, MSNU, NICU, or 6Link). This could be an event, an achievement, a moment of recognition, or a key experience that you have had while working on your present unit.</i></p> <p><i>What do you value and recognize as your role in engaging or involving parents in pain management during painful procedures with their child?</i></p> <p><i>If you were orientating a new nurse to the unit, what would you tell him or her if they asked you to describe the most effective non-pharmacological pain management strategies for children?</i></p> <p><i>What would you tell them about which strategies were the most effective with parental involvement?</i></p>	
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	<p><i>Can you describe a positive experience when you were involved in engaging a parent or parents in procedural pain management strategies with their hospitalized child?</i></p>	
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<p><b>Dream</b> <i>(What might be)</i></p> <p>Interviewer needs to work with nurses to:</p> <ul style="list-style-type: none"> <li>• co-construct a vision</li> <li>• a reason for achieving that vision</li> <li>• a strategic statement about how this might be achieved</li> </ul>	<p><i>Based on this particular experience of involving parents, what do you think happened to make it so positive and what sorts of things happened on your unit to make this experience possible?</i></p> <p><i>What would the unit look like, if you were able to always be able to involve parents in pain management strategies for procedural pain all the time?</i></p> <p><i>If all the nurses...and the unit had... and the hospital did...we could support parent involvement in pain management strategies.</i></p>	
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<p><b>Design</b> (What should be)</p> <p>Interviewer needs to focus on creating an ideal way of involving parents in N-PPMSs (this needs to be related to their own context and should be based on grounded experiences)</p>	<p><i>Now I want you to think about how you think that procedural pain care and parent involvement should look like in the future...</i></p> <p><i>Based on your experiences, what do you see as the key strategies and processes needed to achieve optimal pain care with children and their parents during painful procedures?</i></p> <p><i>If you had three wishes related to improving the delivery of pain care, specifically engaging parents in non-pharmacological pain management strategies, what would they be? These can be related to your own professional development or the organization of the unit)</i></p>	
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<p><b><i>Destiny</i></b> <i>(What will be)</i></p> <p>The interviewer needs to focus the participant to create ideal ways of providing pain care through strengths and capabilities</p> <p>The participant should create networks and structures that can improve pain care in that area</p>	<p><i>What are the innovative, sustainable changes that you would describe to enhance the delivery of services related to pediatric procedural pain care? ...related to nursing development</i></p> <p><i>...related to interprofessional roles and relationships</i></p> <p><i>...related to your work culture and environment</i></p> <p><i>...related to the organization of services</i></p> <p><i>These last few questions are just to highlight and review your thoughts...Can you summarize how you think parents could be involved in an ideal, but realistic way, in procedural pain management?</i></p> <p><i>What networks and structures would be in place in order to achieve this?</i></p>	
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	<p><i>How would you monitor and evaluate parental involvement in pain management strategies?</i></p> <p><i>Any further thoughts or comments?</i></p>	
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Cooperrider & Whitney (2005)

## Appendix F

### *Focus Group Guide*

After analyzing all the interview data, I have identified some common themes, some variations, and some patterns. These groupings represent my interpretation of the main ideas or main factors that you have identified as significant to engaging parents in non-pharmacological procedural pain management strategies (N-PPMSs).

I will provide you with some anonymous quotes from the individual interviews and ask you to group them according to some identified themes and patterns. After we will determine if the themes and patterns that I have identified hold similar meanings to those that you have assigned.

I would like you to look at the themes and patterns that you have arranged and would ask you to discuss consistencies and discrepancies between the factors (i.e., facilitators) that have been identified and your practice area.

I would also like you to look at the factors and help to identify practical strategies that might be used in your practice area or in the organization as a whole to facilitate parent engagement in N-PPMSs to reduce procedural pain in their hospitalized child.

Appendix G

*Transcriptionist Confidentiality Agreement*

**Study title:** *Examining the Conditions that Facilitate Parents' Active Engagement in Non-Pharmacological Pain Management Strategies with Their Hospitalized Child*

I \_\_\_\_\_ have been employed to transcript verbatim the audio file interviews from the study *Examining the Conditions that Facilitate Parents' Active Engagement in Non-Pharmacological Pain Management Strategies with Their Hospitalized Child*.

In transcribing these audio files I will substitute pseudonyms for the names of the participants and their friends. I will delete the copies of the transcriptions and audio files from my computer once I have given the transcriptions to Shelley Lowther, the Principal Investigator (PI) for this study. I will not make or keep any copies of the audio files or transcriptions.

I realize that the information I learn through transcribing these audio recordings are of a confidential nature and I will not share any information that I have learned from transcribing these audio files to anyone.

Name of Transcriptionist (Print): \_\_\_\_\_

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

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

Time: \_\_\_\_\_

**STATEMENT BY PERSON OBTAINING CONSENT**

I have explained the nature of the consent form to the transcriptionist and judge that they understand the nature of confidentiality.

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

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

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

## Appendix H

### *Additional Quotes that Support the Themes and Sub-Themes*

<i>Discovery theme – Establishment of meaningful interpersonal relationships</i>
<p>Well there is this one little girl, I think she was four years old, and I think I try to separate a lot of my emotions, so I don't usually cry at work. It's not my point to fall in love with the kids, but this kid, I was off work and I had been her nurse throughout the day, and we had a few laughs and jokes and stuff, and then I got on the elevator and she got in with her dad. She came over and held my hand during the elevator ride and at the end of the ride, she let go of my hand and did her thing with her dad, and I went my way. But you know, just that little thing that said, you know, you're pretty good. I like you and I'll hold your hand. That was really special for me, just a little connection there.</p>
<p>We were playing in the playroom...and the game was the game of life...and they were her rules...there was no reading the instructions (laughs). And she insisted...there was like a 3 foot by 3 foot pup tent set up in the playroom and she insisted that we play this game of life in this pup tent...And while myself and her did not fit in there well at all, we (laughs) definitely got in there and were playing this game (laughs). ...And that was definitely memorable...You would never have these experiences anywhere else, and you go home and compare your day with others...they're different days...you have really different experiences.</p>
<p>I remember a little boy we had over on 5 South, whose parents had to go talk to the doctor that day, so I went in and we were playing a board game. And the parents were getting bad news, and I knew what they were getting. He was diagnosed with cancer, and they were going to talk about all his treatments and that. So I got to know the parents and that too that day, and I only had them for one day. And they came back to the unit a couple of times looking for me, and coming back to say hi to me and come to see me, so that was nice.</p>
<p>So a difficult, sick, very difficult, new diagnosis, you see them through teaching, caring for them, pain management and a very hard go, and had this patient a lot, so a lot of time is spent caring for this patient, and then their care finishes. So you're a part of their life for six months to a year, and it's quite a lot, and then you know, it was eight years later this patient, he comes back specifically with names for a few nurses that he had spent a lot of time with throughout the years, coming back saying that he just graduated from high school and was going to university, and he wanted to say hi, and wanted to give us graduation pictures.</p>
<p>I don't know if it is so much age group as it is for an individual child. For example you could have a 3 year old that copes better blowing bubbles than...what I'm trying to say is there are many techniques, non-pharmacological techniques for the whole population and it all comes down to the individual.</p>
<p>I think, my wish for parents would be, that we could all have more cultural and diversity training, and just really bring about more individualized care...bringing a lot more of those aspects into the baby's care if we could...help with the babies, and hopefully helps with the families too...really assessing what their coping skills are because sometimes it's too little information or too much information, or depending on their role.</p>

<p>The patient in this particular situation, was getting a PICC line inserted, so it was really important that she had to hold still until after the dressing was done and everything was in place...and this girl, she wasn't really interested in her focus being moved from what was happening. Her mom did a great job...I think she really made a big difference. She was using an iPad...I think they were baking cupcakes or something like that, so there was constant interaction, like what color are we going to make the batter, and what kind of ingredients are we going to put in. So there were always questions and things to pull her back into the cupcake, into the distraction. I spent some time talking with mom about that...just about staying focused on the task.</p>
<p>I think they learn as they go and I think they get better at helping their child as they go. They see...and whether they learn it through us as example...some are very good at advocating and saying this is what we need, this is when it needs to happen. ...And I think it's our responsibility to kind of help a parent...guide them to be the best support that they can be for their child because sometimes they might not be supportive enough when they don't know that they can be.</p>
<p>Knowledge. It's knowledge...the more they know and the more they see, they can adapt how they are there and care and participate in these procedures or events. You know, they hear from other families. They witness, they see, they know...so do we. We see Child Life or whoever, do something that works, we're going to repeat that.</p>
<p>I just think it's important because for the most part, I mean these parents know their children best and even though they may not be familiar with sort of the medical aspects of things, they're still the child's parents. I think they're their best advocates, and I think it's all education, because you're sort of giving them the tools to use. For a lot of parents, it's their first introduction to the health care system, having a baby and having a sick baby, and so I think it enables them and facilitates them through the rest of their, you know, life with their child...</p>
<p>I think that parents can be educated so that they know the extent to which they can improve their child's experience. I think that we can educate them in potential ways to help support their child more than they might know themselves. While they know their child best they might not know how to utilize their knowledge and all the forms of distraction that they might be able to provide and knowing the disciplinary team and knowing who can be there to help and those kinds of things.</p>
<p>I'm comfortable enough starting IVs and doing venipunctures and heel pokes, and other procedures that we may do. I'm comfortable with myself from doing them...so I'm never uncomfortable when parents are with me, so I think that makes a difference. If you're uncomfortable doing it to begin with, then you're uncomfortable with someone watching you do it, and that's one of the things I've learned through the years as well.</p>
<p>To be honest, I kind of feel like in the last three or four years, my nursing practice has changed in that I think of everything more. I want to say, if all the nurses had experience, because experience kind of, I feel like the first few years, five years of your career, you're kind of just focused on doing technical, getting stuff done...and then as you mature...you can see more, like the whole family, the whole patient. Whereas at the start you're just like...I have to do this and I have to do it right now.</p>
<p style="text-align: center;"><i>Dream theme – Fostering a culture of collaboration</i></p>
<p>I think collaboration, like between the staff, and, you know, the RTs and the whole team that's caring for the child...for them to talk about, because we all sort of have our</p>

<p>specialties too...so is one contributing to the other...just talking about are they seeing pain, when maybe, you know, we're not.</p>
<p>It's nice to know the docs ask our opinions as well. They involve us in discussions; it's inter-professional...it's very goal-oriented. We're all working towards one goal, I feel like everybody respects each other and trust that we're going to help.</p>
<p>I've never been belittled for asking a questions or made to feel stupid about not knowing something, or if I need help with a procedure, I'm totally comfortable going to pretty much everybody, and we've had a lot of personnel changes and it is something about the culture of (particular unit) that makes that really, positive...people are just very supportive, great team and teamwork's really important to people. I don't think it's really articulated in that way, but it's manifested in that way; people just do it, they work together, they help each other out, little things like putting charts together on nights when you get an admission, to big things like, you know, helping you do something that you haven't done in a long time, or going over with you to help you do it again. I think that's what I value most about (particular unit).</p>
<p>We work as a team. If somebody needs something, no one is going to say no to you. And it's automatic, without question. If you have a lot of stuff going on, it's very rare that you would have to ask somebody for help. Usually somebody just jumps in there. It's nice knowing each other so closely that they know what you're going to do, and you know what they're going to do for you. So it's kind of a great relationship because everybody works together.</p>
<p>Parents would have to be present more than not, so we'd have to have facilities to be present with their babies, the majority of the time...and an environment where blood work doesn't always have to be done and received the report at a certain time prior to rounds and things like that...but I do certainly respect the fact that there has to be some order to the operation of you know, so it isn't centered completely just on the patient and just on the family, as it is also on the operational parts of the unit. So the ideal situation...for parents to be able to be with their babies all the time and for there to be 24 hour care of the baby based on what's best for the baby and the family.</p>
<p>It would have to be completely individualized, holistic, family-centered care. With the focus with them being in the centre and that we were just on periphery versus setting our own agenda. I think that that's probably a main starting point, would be that if they didn't stay directly with baby, that we had enough parent rooms for families that want to be present and want to participate in the pain, present for painful procedures with their baby, could actually be present...and then I think also that you know it would helpful to be really a 24 hours care operation versus the bulk of care being done kind of in the...8-12 hours and then the rest of it being kind of just supplemental care, but if it was truly 24 hours care, by all departments.</p>
<p>I certainly think that I would really love see the unit when it's single room care, I would look forward to that...I think it will have huge benefits in our unit. I know that there's a lot of sceptical feelings but these babies belong to their parents, they don't belong to us and I certainly see parents that are uncomfortable and feel like they're in a fish bowl, they feel like other people are checking up on them, what they're doing...they certainly don't need to see other issues going on in the unit. Single rooms are more private and the noise level certainly should be much better...I can see parents being far more</p>

comfortable in the unit. There's a lot of stress now with parents wanting to be near their baby and there's not enough room for people to stay over night.

I just think it's important because for the most part, I mean these parents know their children best and even though they may not be familiar with sort of the medical aspects of things, they're still the child's parents and I think they're their best advocate. I think it's all education, because you're giving them the tools to use. For a lot of parents, it's their first introduction to the health care system, having a baby and having a sick baby, and so I think it enables them and facilitates them through the rest of their life with their child...it's our job to educate them, and teach them and really listen to them too, because for a large part, that's how you learn about the babies and their specific needs...not every baby with the same diagnosis is going to have the exactly same course so it's important to take the parent's leads...

I think they can be involved by...first, us involving them. So letting them know that they can be involved. Because a lot of times, a parent doesn't know what they should or shouldn't do, what they can do, so I think that us letting them know that they can be involved.

In an ideal world, the parents would be involved in every procedure. Unfortunately they're not all comfortable with every procedure, but involving them either right up to or as close to after their procedure is important for comforting the child. So if they can't be involved during the procedure, then very soon after, involved in comforting...because I think it makes a big difference when the parent comforts the child.

I think my role is to encourage parents to do what they're comfortable with, suggesting strategies that can be helpful. Like in infants, if moms are breastfeeding, skin-to-skin while breastfeeding, as more evidence and research comes out, that's something I do much more often...then I know that distraction works well with older age groups and trying to get parents involved in that, just playing with toys or playing with their children while we try to do other things. Sometimes these painful procedures it's not appropriate, they can't be playing but always trying to have parents involved, but sometimes also if it's something really traumatic, maybe it's better for parents not to be there, so the child doesn't associate the parent with that painful procedure. I mean sometimes that's a tricky one, cause sometimes the child may feel that the parents' abandoning them in this time of trauma. My role is I guess a discussion with the parents about what their comfort level is.

I'll bring all the supplies in and I'll be like, why don't you do it this time and I'll stay and help you, and just get them feeling more comfortable. I would explain everything to the parents and say, this is what we're going to do when we're in there. Make sure to focus on what you're doing and not on what's happening around. So I would just have that conversation with parents about how we're going to help the patient get through the procedure. And so I think that's the most helpful information. Because we're not going to be there when they get home, so I think it's important that they feel comfortable, to have that environment where it's okay to ask.

<p>I don't know if families sometimes know how much they can be involved...more so, probably new patients because the ones who have been here for a while kind of know how much they can definitely help with the procedure but if they are new they are hesitant to speak up and help out. They might expect that that's our job so maybe a clarification of roles and what it can be like.</p>
<p>I think if we had a general philosophy of how we provide care relative to this subject of comfort by parents during painful procedures, I think that could be offered upon either prior to admission if it's a planned admission or on admission...or even at a suitable time you know early after admission. This is how we...if we had a plan of care...then we could present that as our general philosophy. However, with that...we appreciate that you may have feelings one way or another about that and have an open discussion. It's time...it's being able to take the time for these things to happen...to fully explain and give options and facts of what can be offered and what is a benefit to your baby</p>
<p><i>Design theme – Pain as a priority (from a philosophy to a standard of care)</i></p>
<p>Child Life would be in...doing activities with these kids, baking cookies, painting, or, it's this distraction piece, but also the play piece. It doesn't have to be around painful procedures, it's just something else to do to distract from being in hospital and I think for children that's really important. Like the playroom it's an amazing place, like it's a pain free zone, and you don't do anything painful in there...in my ideal world we'd have Child Life worker for every child that was in the hospital and available all the time for those kinds of things...and the playroom would be open all day long, the kids could go there whenever they want.</p>
<p>Even the playroom itself, being able to have that open as much as possible so that the kids can, like before a procedure maybe, help with their distraction. And then after a procedure, maybe that could be part of the reward you know, yay, when we're done we can go to the playroom and we can do this and that and the next thing. So that would be great.</p>
<p>Having someone available that just strictly works on the pain team, that works just on the floor and assesses each patient or keeps up-to-date with each patient...even going in and speaking with the parents...like what works best for this child...and that's strictly their job is just to go in and like talk to the parents. Because that would be something that would make parents feel better too...give them options...like they have one nurse who their job is actually to go in and talk to them about painful procedures and what the options are...make them part of the plan...</p>
<p>There are some families that are only able to come at night say, or only on weekends, and a lot of those extra support people aren't around at those times.</p>
<p>I think the commitment, and I think the vision, and how they want to move forward...they want to be the best hospital that we can be...they want to do that not only within the four walls but through community support and outreach programs, and constantly trying to change and advance our practice.</p>
<p>It needs to be an evolving, changing plan of pain management. You'll see something on a care plan that is weeks or months old and it no longer pertains to that patient so it's important to be current. That child that has been here for 6 months...what they require to get through a procedure may change...Their developmental level might change...So it's important to go back and reassess constantly...re-evaluate...and revise.</p>

<p>We have a lot of problems when one family comes from one unit to another, because everybody follows different rules. So then it becomes an argument and it breaks that relationship.</p>
<p><i>Destiny theme</i> – Sustainability through advanced knowledge and skills</p>
<p>Certainly with our pain management team, I don't believe that we utilize them enough, in many situations, and the fact that it's frowned upon if nursing takes it upon themselves to do a consultation. I think that anybody should have the right to make consultations and be able to bring the right person to the right baby at the right time, it doesn't matter who they are as far as I'm concerned.</p>
<p>You don't really see them that closely involved with patients, and I understand that they are not necessarily kids who are here (inpatients), perhaps that clinic deals more with chronic pain kids who undergo pain daily in their lives, but it would be helpful I think that if they were even a team that could be called, and I guess they are, we do consult the pain team often, but just more accessible I guess. I don't know if that's fair to them, maybe it's the culture of PMU that has to change to use our resources that exist more. We do have a pain clinic here and you know maybe they could be enlisted to do education with us, or just bring someone in to talk about specific topics on the staff education days.</p>
<p>I think that there is a pain team at the IWK...I see it used on a very minimal basis...I mean I'm sure they're busy too, but if we used them more for our education days, our workshops days, if they could come in and give us the latest information...maybe a more active pain team presence in our unit, or even with posters, or even a physician, even our own neonatologist, or nurse practitioners, or if a nurse really took on that role of a pain nurse...it actually, might even be helpful to bring a lot of these things forward, and you know keep them on the forefront.</p>
<p>I think most parents would be shocked if we had someone to go in, if we had the money to do it, and everything else, like in a perfect world. But it would be pretty cool to have someone go in and say...I'm the pain nurse, so if there is something that comes up that your child is going to have a painful procedure, we can sit down and discuss some options of what we can do for them to make that less painful...</p>
<p>The NP would definitely have a role when she goes in to assess a patient or interact with what's going on. So yes, she may have a role talking about pain procedures, and what's going to happen, and how they could deal with it. So yes, the NP could have somewhat of a role, but usually it's the bedside nurse that's going to be doing the procedure with them, so it often ends up with the frontline nursing and the bedside nursing.</p>
<p>Whether it's clinical clerks or nursing students or new nurses who are coming in...if the first part of their experience always includes something about pain and pain management strategies for pain management...I think that's what makes something sustainable if everybody coming through is getting a consistent message and can carry that one because then they have students that will be passing on the same messages. I think it starts right at orientation, right at clinical placements and students doing that.</p>
<p>I'm comfortable enough starting IVs and doing venipunctures and heel pokes, and other procedures that we may do. I'm comfortable with myself from doing them...so I'm never uncomfortable when parents are with me, so I think that makes a difference. If</p>

<p>you're uncomfortable doing it to begin with, then you're uncomfortable with someone watching you do it, and that's one of the things I've learned through the years as well.</p>
<p>I think continued education, regular updates on "this is new", "this is the best", and "this is shown to be effective to do it this way".</p>
<p>I think education or supporting not just nurses. Nurses I think are going to have the primary role in supporting a family with pain for their child, so I'll focus on nursing. So I think education and support for nurses would be huge...just supporting, having some type of resources to support pain management, and pain management support ideas for us to offer to families and patients because sometimes we may just not know what to offer, so I think those kinds of resources would be great.</p>
<p>I do think if all the nurses had education or support around what pain means to families and different strategies on how pain is managed differently for everyone, and different options...again, probably supports in place for nurses, but we need to have a supportive physician team as well. And that's always a challenge.</p>
<p>So I think if we started to involve parents more, and we see the benefit from it, if parents give us feedback on how well it worked for them, then I think it would be utilized more.</p>
<p>So I would always ask the parents, 'how do you feel that went?'...'Did you feel like that was enough?', 'do you feel like we could have done something differently?'...Just kind of going in and talking about what happened, and seeing how they felt about it. If it worked for them...if it didn't work...if they feel like there was something else we should do...if they were comfortable with the whole thing or if they weren't...just kind of getting their feel on the situation.</p>
<p>I think in longer term, you could always go back and look at...do a research study on what was your patient stay, what was your infection rate, you know, how good was your growth...those sorts of things.</p>

## Appendix I

### *Most Effective N-PPMSs*

Most effective N-PPMS with...	Children	Infants	Parental involvement
<b>Participant 1</b>		<ul style="list-style-type: none"> <li>• Skin-to-skin positioning</li> <li>• Non-nutritive sucking</li> </ul>	<ul style="list-style-type: none"> <li>• Skin-to-skin positioning</li> <li>• If unable to come out of incubator, facilitated tucking and non-nutritive sucking</li> </ul>
<b>Participant 2</b>	<ul style="list-style-type: none"> <li>• Timing of procedures</li> </ul>	<ul style="list-style-type: none"> <li>• Timing of procedures</li> <li>• Swaddling and sucrose</li> </ul>	<ul style="list-style-type: none"> <li>• Containment</li> <li>• Skin-to-skin positioning</li> <li>• Breastfeeding Distraction</li> </ul>
<b>Participant 3</b>		<ul style="list-style-type: none"> <li>• Soother and bundling with sucrose</li> </ul>	<ul style="list-style-type: none"> <li>• Explanations about the procedure and pain management strategies</li> </ul>
<b>Participant 4</b>	<ul style="list-style-type: none"> <li>• Distraction (could be different for every child (iPad, conversation, bubble blowing))</li> </ul>		<ul style="list-style-type: none"> <li>• Parent presence for comfort or participation</li> </ul>
<b>Participant 5</b>	<ul style="list-style-type: none"> <li>• Distraction (xbox, Wii, TV, DVD, computer)</li> <li>• Hot/cold compresses</li> <li>• Trying different strategies (very individualized)</li> </ul>	<ul style="list-style-type: none"> <li>• Skin-to-skin</li> <li>• Breastfeeding</li> </ul>	<ul style="list-style-type: none"> <li>• Encourage parents to be present, supportive and provide physical contact</li> </ul>
<b>Participant 6</b>	<ul style="list-style-type: none"> <li>• Buddy the clown, distraction with toys, movies, music, asking them questions (about life, school, sports)</li> </ul>	<ul style="list-style-type: none"> <li>• Distraction with rattle/toys</li> </ul>	<ul style="list-style-type: none"> <li>• Distraction. Important to provide role modeling and demos so parent learn by seeing you do it and it works</li> </ul>
<b>Participant 7</b>	<ul style="list-style-type: none"> <li>• Distraction (TV)</li> </ul>	<ul style="list-style-type: none"> <li>• Soother, blanket, comfort measures with sucrose, parental presence</li> </ul>	<ul style="list-style-type: none"> <li>• Comfort measures, presence, holding, squeezing their hand</li> </ul>

Most effective N-PPMS with...	Children	Infants	Parental involvement
<b>Participant 8</b>	<ul style="list-style-type: none"> <li>• Different for different age groups</li> <li>• Distraction (questions, technology, music, movies, iPods)</li> <li>• Comfort/touching</li> <li>• Information, but this is individualized as to how much they want to know about the procedure</li> </ul>		<ul style="list-style-type: none"> <li>• Parents are often worried and cannot focus on distraction. Nurse may need to step in and help.</li> <li>• Parental presence, comfort, and support are beneficial</li> </ul>
<b>Participant 9</b>	<ul style="list-style-type: none"> <li>• Most effective strategies are individualized to the child</li> </ul>		<ul style="list-style-type: none"> <li>• Distraction (parent talking to the child)</li> <li>• Parents providing comfort/warm approach/warm vibe</li> </ul>
<b>Participant 10</b>	<ul style="list-style-type: none"> <li>• Distraction (TV), and asks them questions during the show (i.e., about the characters) or asks them general questions (i.e., do you have a dog at home? What is your doll's name?)</li> </ul>		<ul style="list-style-type: none"> <li>• Infants – holding</li> <li>• Children – distraction</li> <li>• Thinks that for parents, some of the skills for distraction are innate and some is learned through role modeling</li> </ul>
<b>Participant 11</b>	<ul style="list-style-type: none"> <li>• Parental presence</li> <li>• Parent holding and talking to their child</li> <li>• Child Life using distraction items like iPad, playing games</li> </ul>		<ul style="list-style-type: none"> <li>• Telling parents that it is OK to do what you do at home. Tells us what works (expert knowledge of parents)</li> </ul>
<b>Participant 12</b>	<ul style="list-style-type: none"> <li>• Repositioning</li> <li>• Cold/warm therapy</li> <li>• Distraction (books, toys, Child Life, iPad)</li> </ul>		<ul style="list-style-type: none"> <li>• Distraction (when parents keep focused on the distraction and not the procedure).</li> <li>• Need to provide anticipatory guidance</li> </ul>

Appendix J

*PARIHS Framework*

Promoting Action on Research Implementation in  
Health Services (PARIHS)



(Rycroft-Malone, 2004)

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