

EXAMINING THE RELATIONSHIP BETWEEN NICU-PARENT ANXIETIES, THEIR
PERCEPTIONS OF NEONATAL PAIN AND DESIRE FOR PARTICIPATION IN PAIN
CARE

by

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Abstract

Background: Neonatal Intensive Care Unit (NICU) patients undergo painful procedures that if undertreated impact their recovery and development. Evidence based practice, calls for parental participation in their neonate's NICU care. This participation may improve neonatal non-pharmacological pain management; however, anxiety is a common emotion for NICU-parents, which may affect their involvement. Research demonstrates that one's intrapersonal characteristics may impact the assessment and response to another's pain.

Methods: A descriptive correlational study with a convenience sample of NICU- parents ($N = 102$) was used to examine the degree and type of anxiety (i.e., state, trait, NICU and pain anxiety) parents experienced; the relationship of these anxieties to perceptions of procedural pain intensity, and desire for participation pain management.

Results: Parental anxieties were related to their ratings of expected and observed neonatal procedural pain intensity. Specifically, parents with higher levels of NICU-anxiety tended to expect/observe greater neonatal procedural pain intensity. Parental desire to participate in pain management was high and anxieties were not related to this desire or their actual participation.

Conclusion: Anxiety may be related to NICU-parent's expectations and observations of neonatal procedural pain intensity but does not prevent them from wanting to participate in procedural pain management. Parental participation in pain care should be encouraged.

List of Abbreviations and Symbols Used

Abbreviations (in alphabetical order):

ASD – Acute Stress Disorder

CI – Confidence Interval

CPPR – Centre for Paediatric Pain Research

df – Degree of Freedom

EBM – Expressed Breast Milk

F – F Statistic

FCC – Family Centered Care

FIC – Family Integrated Care

FT – Facilitated Tucking

GA – Gestational Age

IM – Intramuscular

IV – Intravenous

IVH – Intraventricular Haemorrhage

KC – Kangaroo Care

M – Mean

MANOVA – Multivariate Analysis of Variance

N – Number of Participants in Total Population

n – Number of Participants in Subset of the Population

NAS – Neonatal Abstinence Syndrome

NICU – Neonatal Intensive Care Unit

NNS – Non-nutritive Sucking

p – Significance

PAIN – Parental Assessment of Infant Nociception

PCS – Pain Catastrophizing Scale

PI – Principal Investigator

PSS: NICU – Parental Stress Scale: Neonatal Intensive Care Unit

PTSD – Post Traumatic Stress Disorder

r – Pearson’s Correlation

RCT – Randomized Controlled Trial

REB – Research Ethics Board

SD – Standard Deviation

SCMP – Social Communication Model of Pain

SDT – Self-determination Theory

SPSS – Statistical Package for Social Sciences

STAI – State Trait Anxiety Inventory

t – t-test Statistic

Symbols:

α – Alpha

β – Beta

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Chapter One: Introduction

Background of the Problem

Many new parents experience anxiety (Steen, Jones & Woodworth, 2013), the occurrence of which is especially prevalent in parents of preterm or ill neonates (Edell-Gustafsson, Angelhoff, Johnsson, Karlsson & Mörelius, 2014). The nature of the NICU environment is often stressful for parents as they cope with parental role alteration, uncertainty, and a sense of powerlessness as their neonate undergoes medical procedures (Edéll-Gustafsson et al, 2014). Unfortunately, due to the prematurity of their birth, nature of their illness, and necessity of treatment, patients in the NICU regularly experience procedural pain. Regrettably, research has shown that this pain often goes untreated (Carbajal et al., 2008; Cruz, Fernandes & Oliveira, 2016; Latimer, Jackson, Johnston & Vine, 2011, Pillai Riddell et al., 2015; Simons et al., 2003, Stevens, Yamada, Ohlsson, Haliburton, & Shorkey, 2016; Walter-Nicolet, Calvel, Gazzo, Poisbeau, & Kuhn, 2017) despite numerous non-pharmacological pain control options (e.g., sucrose, kangaroo care, non-nutritive sucking, breastfeeding, swaddling, etc; Carbajal, 2017; Johnston et al., 2017; Stevens et al., 2016; Shah, Herbozo, Aliwalas & Shah, 2012; Shu, Lee, Hayter & Wang, 2014). The Family Centered Care (FCC) philosophy, a standard of care adapted by many health care facilities as a method for health care delivery to hospitalized children, has called for the involvement of parents in their child's care (Shields et al., 2012). More recently there has been a movement towards family integrated care (FIC) in neonatal units, which builds upon FCC, and encourages parents to be their neonate's primary caregiver in collaboration with their neonate's health care team (Patel, Ballantyne, Bowker, Weightman, & Weightman, 2017; O'Brian et al., 2013; Warre, O'Brian & Lee, 2014).

Research has shown that most parents (as many as 94%; Orr et al., 2017) desire to be present during painful procedures to help reduce the discomfort felt by their neonate (Jones, Quazi & Young, 2005). Despite these findings and the implementation of FCC and/or FIC in many NICUs, parents often remain absent from the bedside during painful procedures (Franck, Oulton & Bruce, 2012; Skene, Franck, Curtis & Gerrish, 2012). The reasons for this absence most often cited in the literature are environmental, contextual or systems issues (i.e., not able to be at the hospital, other family/parental commitments, feeling unwanted or uninvited, being unsure how to help; Chertok, McCrone, Parker & Leslie, 2015; Heinemann, Hellstrom-Westas & Nyqvist, 2013; Palomaa, Korhonen & Pölkki, 2016; Marfurt-Russenberger, Axelin, Kesselring, Franck, & Cignacco, 2016). Although these factors are reported most often, it is possible that a small number of parents would prefer to be absent during painful procedures performed on their neonate, regardless of these barriers. Indeed, research has suggested that parental desire to participate in their neonate's care does not extend to all procedures (Gallagher & Franck, 2012; Palomaa et al., 2016). One poorly examined factor that may be contributing to this decreased desire in a minority of participants is parental emotions. Although research related to adult dyads has shown that individuals' emotional states impact their assessment (i.e., estimates of pain intensity) and response (i.e., pain care) to persons in pain (Craig, 2015; Hadjistavropoulos et al., 2011), this research has not been well described in parent-neonate relationships. This would seem to be an important yet overlooked area of study as pain researchers have shown that, due to the neonate's stage of development, unmanaged pain in the neonatal period can have lasting effects (Anand, 2001; Grunau, Holst & Peters, 2006; Hatfield, Meyers & Messing, 2013; Johnston, Barrington, Taddio, Carbajal, & Filion, 2011; Kopenhaver Doheny, 2017). Thus, the aim of this study was to improve understanding of the parental experience of anxiety and its

relation to their perception of pain intensity and desire to participate in pain management to improve pain care delivery in the neonatal setting.

It has been well-established that anxiety is closely associated with a person's motivation or desire to participate in a wide variety of activities (e.g., public speaking, meeting new people, taking a test; Munz, Costello, & Korabik, 1974). Due to the nature of the NICU environment and the stress of becoming a new parent, it is not surprising that NICU-parents experience increased levels of anxiety (Edéll-Gustafsson et al., 2014; Holditch-Davis et al., 2015). Since anxiety has been shown to impact perceptions and behaviours, it was proposed that parental anxiety could be related to parental expected and observed intensity of their neonate's pain (i.e., perceptions) as well as to their desire to participate in pain care (i.e., behaviours). Furthermore, given that anxiety may stem from various internal and external factors (e.g., personal temperaments, environmental stressors), the cause or type of anxiety most related to parental desire to participate in pain care was of interest. Specific constructs of anxiety deemed to be of relevance to the procedural pain experience in the NICU included general anxiety (i.e., one's tendency to experience anxiety in a variety of situations), NICU anxiety (i.e., anxiety related to the NICU environment) and pain anxiety (i.e., the tendency to catastrophize or worry about one's own pain). In short, the proposition that the 'parent is anxious' does not adequately capture the full understanding and complexity of the circumstance of having one's neonate in the NICU, nor indicate how these anxieties are related to parental perceptions of neonatal pain or their desire to participate in pain care.

In general, anxiety has often been conceptualized along two dimensions (i.e., trait anxiety and state anxiety; Spielberger, Gorsuch, Lushene, Vagg & Jacobs, 1983). Trait anxiety refers to a person's innate tendency to experience greater levels of anxiety than others, whereas state

anxiety refers to an individual's experience of higher levels of anxiety in the moment during a stressful situation (Spielberger et al., 1983). Research has shown that anxiety can impact behaviour positively and negatively (Munz et al., 1974; Wu & Cheng, 2006); the impact being largely dependent on the level of anxiety experienced. Briefly, the Yerkes-Dodson law suggests that moderate levels of anxiety lead to positive behaviours, such as preparation and improved performance and coping; while, high anxiety often leads to feeling overwhelmed, decreased mental faculties, and an urge towards avoidance (Andreano & Cahill, 2006; Mendl, 1999; Mogg & Bradley, 1998; Yerkes-Dodson, 1908).

Research has shown that the NICU environment itself can be inherently anxiety-provoking for parents (Flocking et al., 2012; Woodward et al., 2014); and it is possible that the nature of the surroundings may influence parental perception of pain and desire to participate in pain care. Although past research has spoken to high levels of parental anxiety related to the NICU environment, research has also illustrated a high parental desire to participate in their neonate's care. Taken together, these findings have suggested that, in the absence of logistical barriers, anxiety may be adaptive for many parents. That is, anxiety may motivate parents, allowing them to actively learn to comfort their neonate and ultimately participate in their neonate's pain care. However, for some parents, the level of anxiety may be maladaptive and lead to the avoidance of opportunities to learn and participate in pain care to reduce their own anxiety or avoid their neonate's distress.

With regard to pain anxiety, a breadth of research (particularly with adults) has shown that one's tendency to be anxious about their own pain (i.e., pain catastrophizing) affects their reactions and provision of support to another person in pain (Bailey, McWilliams & Dick, 2012; Kim & Carver, 2007; Millings, Walsh, Hepper & O'Brian, 2012; Simpson, Rholes, Orina &

Grich, 2002); thus, it is possible that a parent's tendency to catastrophize about their own pain would be associated with their thoughts about their neonate's pain, and in turn be related to their desire for participation in their neonate's pain management.

Statement of the Problem

Neonates cared for in the NICU are exposed to painful procedures that are often undertreated despite evidence of effective non-pharmacologic pain control measures. It was of interest to explore how characteristics of the parent (i.e., parental anxieties) were related to parental expectations and observations of neonatal pain intensity as well as their level of desire for participation in their neonates' pain care. There have been no known studies that have investigated the way specific types of parental anxiety are associated with parental perceptions of neonatal pain or their desire to participate in pain management in the NICU.

Purpose of the Study

The purpose of this study was to examine how four types of parent anxieties were related to their expectations/observations of neonatal pain intensity and their desire for participation in their neonate's pain management using the Social Communication Model of Pain as a conceptual framework to guide the study (SCMP; Craig, 2015).

Research Questions

1. To what degree do parents with a neonate admitted to the NICU experience different types of anxiety (i.e., state anxiety, trait anxiety, NICU anxiety, and pain anxiety)?
2. To what degree are the various types of parental anxiety (i.e., state anxiety, trait anxiety, NICU anxiety and pain anxiety), related to the parent's anticipation of the painfulness/intensity of the procedure?

3. Is there a relationship between parental anxieties (i.e., state anxiety, trait anxiety, NICU anxiety, and pain anxiety) and the *parent's desire* to be *present* during their neonate's painful procedure?
4. Do parents who *are present and participate* in neonatal procedural pain care differ across levels of general anxiety (i.e., state and trait anxiety), environmental anxiety (i.e., NICU anxiety) or pain anxiety (i.e., pain catastrophizing)?

Chapter Two: Literature Review

In this chapter, the evidence related to neonatal procedural pain and its management are presented. The literature surrounding FCC, FIC and parental participation during painful procedures, along with associated facilitators and barriers to participation, are reviewed. The concepts of anxiety are discussed as they relate to parent's experience related to their neonate's procedural pain in the NICU. Finally, the existing literature surrounding these anxiety constructs, with respect to their potential influence on parent's pain perceptions and their participation in neonatal procedural pain care are explored in detail.

Neonatal Pain

Neonates who are born preterm (i.e., less than 37 weeks gestation), or are considered at risk (e.g., those with low birth weight, birth trauma, or significant pathophysiology), often require admission to the NICU (Akuma & Jordan, 2012; Chertok et al, 2014). Although these neonates vary in their intensive care needs, most experience a host of painful interventions and procedures to preserve their health and wellbeing (Chertok et al., 2014; Johnston et al., 2014; Latimer et al., 2011). Historically, it was believed that neonates particularly those born preterm, did not experience pain due to their immature nervous systems and inability to remember painful experiences (Eland & Anderson in Akuma & Jordan, 2011). However, based on landmark research conducted by Anand and Hickey in 1987, there has been longstanding sound evidence that neonates, born as early as 23 weeks gestation, experience pain. Not only has research demonstrated that neonates feel pain, it has also highlighted the negative risks associated with repeated exposure to painful stimuli in the neonatal period (Anand, Coskun, Thirivikraman, Nemeroff & Plotsky, 1999; Elserafy et al., 2009; Hatfield et al., 2013; Kopenhaver Doheny, 2017; Ohlsson & Shah, 2016; Valeri, Holsti, & Linhares, 2015). Undermanaged neonatal pain

can have both short and long-term effects. Short term consequences of undermanaged pain include decreased oxygenation, hemodynamic instability, and increased intracranial pressure that increases the risk of intraventricular haemorrhage (IVH; Anand & Scaizo, 2000; Elserafy, Alsaedi, Louwrens, Sadiq, & Mersal, 2009; Valeri et al., 2015). Long term consequences of frequent exposure to untreated pain during this critical time of neurodevelopment can include changes in nervous system structure (Bouza, 2009; Hatfield et al., 2013), altered future pain response (Anand, 2001; Grunau et al., 2006) and increased likelihood for the development of chronic pain (Mitchell & Boss, 2002; Kopenhaver Doheny, 2017). Undertreated pain during this stage of development may also increase the likelihood of anxiety disorders, attention deficit, and developmental delay (Anand et al., 1999; Kopenhaver Doheny, 2017; Valeri et al., 2015). Unfortunately, routine care in the NICU involves numerous noxious procedures making pain a common experience for neonates (Ohlsson & Shah, 2016) and raises the concern for their short and long-term wellbeing.

Neonatal procedural pain. Pain inflicted during routine procedures or tests (i.e., procedural pain) is the most common type of pain experienced by this patient population (Cruz et al., 2016; Johnston, Collinge, Henderson & Anand, 1997; Johnston et al., 2017; Stevens et al., 2016). Tissue-breaking procedures such as intravenous (IV) insertion, intramuscular (IM) injection, veinipuncture and heel lance are among the most common types of procedural pain inflicted on neonates in the NICU (Johnston et al., 2014). In fact, due to standard policies, even well newborns are subjected to procedural pain during routine care (i.e. IM vitamin K administration, routine blood work requiring heel lance, and immunization; Bellieni et al., 2016; Ohlsson & Shah, 2016). In their 2014 research, Roofthoof, Simns, Anand, Tibboel and van Dijk discovered that neonates receiving care in Canadian NICUs can undergo an average of 11 painful

procedures per day. The extensive research in this area has resulted in improvements in the treatment of neonatal pain with two thirds of Canadian NICUs having policies or guidelines in place to guide neonatal procedural pain management (Taddio et al., 2009). Unfortunately, research has shown that the quality and utilization of these guidelines is often inconsistent (Lee, Carter, Stevenson & Harrison, 2014). Furthermore, procedural pain has remained undermanaged despite the implementation of guidelines, health care professionals' possession of knowledge about a neonate's ability to experience pain, the potential detrimental effects of under treatment, and readily available treatment options (Campbell-Yeo et al., 2013; Cruz et al., 2016; Walter-Nicolet et al., 2017). Studies have shown that nearly 50% of painful procedures performed on neonates occur without analgesia (Carbijal et al., 2008; Johnston, Barrington, Taddio, Carbajal & Filion, 2011; Simions et al., 2003) despite the availability of pain control options (Cruz et al., 2016; Stevens et al., 2016).

Neonatal procedural pain management. Procedural pain can be alleviated by pharmacological and/or non-pharmacological methods. Pharmacological methods of pain control include topical anaesthetic, opioid analgesic (e.g., fentanyl and morphine) and non-opioid analgesic (e.g., acetaminophen) medications (Ohlsson & Shah, 2016). Non-pharmacological methods of pain control include oral sucrose, non-nutritive sucking (NNS), facilitated tucking (FT), swaddling, kangaroo care (KC) and breastfeeding or expressed breast milk (EBM; Axelin Lehtonen, Pelander & Salanterä, 2010; Campbell-Yeo, Fernandes & Johnston, 2011; Johnston et al., 2017; Liu, Huang Luo, & Peng, 2017; Shu et al., 2014; Stevens et al., 2016). Although both pharmacological and non-pharmacological analgesia are valid pain control options in the neonatal population, there are some situations that require one form over the other.

Pharmacological analgesia for procedural pain. Pharmacological pain management is most often utilized to alleviate surgical or post-operative pain (Johnston et al., 2008). These analgesic options are not as often used to provide relief from procedural pain and some studies have suggested they are not always effective (Carbijal et al., 2008; Johnston et al., 2007; Latimer, Johnston, Ritchie, Clarke & Gilin, 2009; Ohlsson & Shah, 2016). Topical anaesthetic may appear to be an optimal choice for heel lance or veinipuncture; however systematic reviews point to a lack of evidence indicating that topical anesthetic alleviates this type of pain (Foster, Taylor & Spence, 2017). Furthermore, even if topical anaesthetic was proven to be effective in the future, its use requires approximately 30 minutes of application prior to a procedure (American Academy of Pediatrics, 2016; American Academy of Paediatrics & Canadian Pediatric Society, 2007); a period of time which may not be feasible in emergent situations. Fentanyl and morphine are the most common opioid analgesics used in the neonatal population, most often for sedation and analgesia in ventilated neonates or post-operative pain management (Axelin, Salanterä, Kirjavainen & Lehtonen, 2009). The use of opioids for minor procedural pain remains controversial with inconsistent evidence of pain relief and some suggestion that their use in neonates carries some risk (e.g., neurological morbidity, prolonged ventilation and delayed passage of meconium; Anand et al., 2010; Axelin et al., 2009; Bellu, de Waal & Zanini, 2008; Carbajal et al., 2008; Carbajal et al., 2015; Rana et al., 2017). Acetaminophen has also been found to be an ineffective pain control option for procedural pain, with trials finding it comparable to a placebo during a heel lance procedure (Lingen, Deinum, Quak, Okken, & Tibboel, 1999; Ohlsson & Shah, 2016; Shah, Taddio, & Ohlsson, 1998). Given that pharmacological pain care options are not overly effective, require a physician's order, and time

to ensure effectiveness, they may not be the optimal strategy for procedural pain (Campbell-Yeo et al., 2013).

Non-Pharmacological analgesia for procedural pain. Non-pharmacological pain control measures have been the most widely examined methods of neonatal procedural pain management (Carbajal, 2017). These methods are desirable as they are readily available, cost effective, simple, and generally well-tolerated by neonates (Campbell-Yeo et al., 2011; Fernandes, Campbell-Yeo & Johnson, 2011; Liaw et al., 2011; Pillai Riddell et al., 2015). Decisions regarding the application and method of non-pharmacological pain management strategies are often nurse driven (Fernandes et al., 2011). With the exception of KC and breastfeeding, the majority of these strategies do not necessitate parent participation; that said, due to their simplicity, one could envision parental participation in many, if not all, of the strategies outlined below.

Sucrose and non-nutritive sucking. The most widely examined procedural pain control measure is sucrose (i.e., a mixture of glucose and fructose, which is a naturally occurring sweetener; Liu, Lin, Chou, & Lee, 2010; Liu et al., 2017; Stevens et al., 2016; Taddio, et al., 2008). Sucrose has been found to have a rapid onset, peaking two minutes after administration, and a short duration of action, lasting three to five minutes and fading after five to eight minutes (Stevens et al., 2016). After reviewing 74 studies, Stevens and colleagues (2016) concluded that sucrose reduces procedural pain in neonates with minimal to no side effects. Non-nutritive sucking (i.e., pacifier use or sucking on a gloved finger), has also been found to be effective for procedural pain relief and can potentiate the effect of sucrose when the two are used in combination (Curtis, Jou, Ali, Vandermeer, & Klassen, 2007; Elserafy, Alsaedi, Louwrens, Bin Sadiq, & Mersal, 2009; Liu et al., 2010; Stevens et al., 2016).

Facilitated tucking, containment or swaddling. Facilitated tucking (FT) or containment, when an neonate is held in a side lying, flexed fetal position to restrict movement while offering support, has also been found to decrease the neonate's pain response (Axelin et al., 2009; Fernandes et al., 2011). Swaddling, wrapping an neonate tightly in a blanket, has also been found to decrease pain response and improve recovery time from painful stimuli (Fernandes et al., 2011; Huang, Tung, Kuo & Chang, 2004; Shu et al., 2014). Although this intervention has typically been performed by nurses, FT by a parent has been shown to effectively relieve procedural pain in two studies (Axelin, Salantera, & Lehtonen, 2006; Axelin et al., 2010). In these two studies, parents who participated in FT reported an improved ability to cope with their own stress and believed their participation decreased their neonate's pain.

Breastfeeding and expressed breast milk. In full term neonates and infants up to age one, it has been found that breastfeeding is an effective method of pain relief during painful procedures, as it has been shown to decrease crying time and pain scores (Harrison et al., 2016; Shah et al., 2012). Research has found that EBM given by syringe was far less effective than the act of breastfeeding in full-term newborns and EBM alone, may not provide sufficient analgesia (Benoit, Martin-Meisner, Latimer & Campbell-Yeo, 2017; Shah et al., 2012). However, due to a paucity of research with the neonatal population, Shah and Colleagues (2012) encouraged further research on both breastfeeding and EBM use for pain management in neonates. Breastfeeding and EBM may not be viable options for neonates who are too ill or premature to orally feed or suckle at the breast.

Kangaroo care. Kangaroo care (KC), also known as kangaroo mother care or skin-to-skin, is performed by holding the neonate wearing only a diaper in an upright position against the mother's bare chest; and has been shown to decrease the pain response in neonates as young as

28 weeks gestation and is useful when breastfeeding is not appropriate (Campbell-Yeo et al., 2011; Castral, Warnock, Leite, Haas & Scochi, 2008; Johnston et al., 2017). Although the majority of studies have assessed KC for pain management using only mothers (Johnston et al., 2014), KC has been shown to be effective and have physiological benefits (e.g., thermoregulation, decreased mortality, improved vital signs and growth) for the neonate when provided by fathers and other family members as well (Campbell-Yeo, Disher, Benoit & Johnston, 2015; Boundy et al., 2016; Johnston et al., 2008).

Benefits of KC extend to parents as well. In their study of mothers providing KC during heel lance in a NICU, Campbell-Yeo and colleagues (2010) found that the majority of mothers who participated reported positive feelings and nearly all said they would participate again (80% and 99%, respectively). More recently, research has found KC to be associated with improvements in parental confidence, breastfeeding rates, and parental anxiety (Sweeney, Rothstein, Visintainer, Rothstein, & Singh, 2017).

Undermanaged procedural pain. As previously discussed, repeated exposure to painful stimuli in the neonatal period has short- and long-term consequences. Neonates have a right to pain management just as any other hospitalized patient would (Baulch, 2010; Carbajal, 2017; Maccagno, 2009; Twycross, Forgeron, Chorney, Backman & Finley, 2016), yet they continue to undergo painful procedures without analgesia of any kind. The potential reasons for inadequate treatment of procedural pain have been poorly understood. In line with the SCMP, the literature has suggested that social or organizational factors (i.e., nursing assignments, time constraints and resources), intrapersonal nursing factors (i.e., critical thinking, aptitude, knowledge, values, beliefs, attitudes, and empathy) and neonatal factors (i.e., pain response, gestational age, and perceived illness severity) may play a role in a nurse's assessment and treatment of pain (Benoit

et al., 2016; Campbell-Yeo et al., 2007; Cruz et al., 2016; He et al., 2005, Latimer, Ritchie & Johnston, 2010). Many of the factors examined in the literature to explain under treatment of procedural pain have involved nurses since they traditionally have been the health care provider primarily responsible for the assessment and alleviation of pain; indeed, pain management has been widely recognized as a fundamental aspect of the nursing role (Gibbons et al., 2015; Wood, 2002). It has been found that even neonatal nurses who possessed the required theoretical knowledge, as it relates to evidence-based procedural pain management, have sometimes failed to properly treat procedural pain (Latimer, Johnston, Ritchie, Clarke, & Gilin, 2009; Latimer et al., 2010). These findings may suggest that, at times, systems issues (e.g., limited nursing time to prepare and administer pain management) may take precedence over nurses' critical thinking, knowledge, and empathy. Thus, one could also envision improved treatment of neonatal procedural pain if nurses were to encourage parents to implement non-pharmacological strategies; especially given that paediatric literature has shown an association between increased parental involvement and better implementation of non-pharmacological pain management strategies (Pölkki et al., 2003).

Parental perception of pain. Studies have demonstrated that parents and health care providers tend to provide differing assessments regarding the presence and severity of an infant's pain (Balda & Guinsburg, 2007; Elias, Guinsburg, Peres, Balada & Dos Santos, 2008; Elias, Dos Santos & Guinsburg, 2014). Compared to health care professionals (who tend to underestimate pain severity; Rajasagaram, Taylor, Braitberg, Pearsell & Capp, 2009), parents have tended to be more precise when estimating their older child's level of pain (i.e., they rated their child's pain closer to their child's own rating of their pain intensity; Craig, Lilley & Gilbert, 1996; Jylli & Olsson 1995; Manne, Jacobson & Redd, 1992; Miller, 1996). In a study of infant pain, it was

found that parents' ratings of pain intensity were higher than ratings assigned by health care professionals (Pillai Riddell, Horton, Hillgrove & Craig, 2008). Along with this, parents have been shown to rate observed pain experienced by an infant twice as high as that experienced by an adult undergoing the same procedure (Taddio et al., 2014). Despite these higher ratings of pain intensity, parents were more likely than health care professionals to believe that infants only began to experience pain similar to an adult after they were older than one month of age (Pillai Riddell, Horton, Hillgrove & Craig, 2008). This finding may suggest that parental expectations of pain may differ in the neonatal period compared with their older infant or child, illustrating the need to further explore parental perceptions of neonatal procedural pain in the NICU. Regarding parental ideas concerning pain treatment, research has illustrated that parents may be more hesitant than health professionals to utilize pharmacological methods of pain control (Dorkham, Chalkiadis, von Ungern Sternberg & Davidson, 2013; Pillai Riddell et al., 2008; Rony, Fortier, Chorney, Perret & Kain, 2010). These findings, along with research in which parents expressed a desire to learn comfort measures to employ during their neonate's painful procedures (Franck et al, 2015; Orr et al., 2017; Parvez et al., 2010; Taddio et al., 2009), suggested that parents may prefer to focus on non-pharmacological pain alleviation strategies and leave pharmacological analgesic decisions to health care professionals.

The varied findings noted previously raised a couple of valuable points. First, it suggested parents are quite vigilant to their child's pain and good judges of their pain levels. Thus, it was speculated that parents would serve as good advocates for their neonate's pain care. Second, and as stated above, given that parents were hesitant to recommend pharmacological pain-management strategies, it was posited that they may be most open to exploring non-pharmacological approaches. Finally, as illustrated in the paediatric literature, parental

participation has been shown to have the capacity to improve the implementation of non-pharmacological pain management strategies (Guedj et al., 2014; Johnston et al., 2011; Pölkki et al., 2003) which, in turn, may empower parents and reduce parental anxiety. This notion that increased parental participation in neonatal pain care may be advantageous for both the neonate and the parent is in line with FCC.

Family Centered Care

Efforts put forth to include family in patient care and encourage parent-neonate bonding are cornerstones of FCC (i.e., a care philosophy that assures the health and wellbeing of children and families by treating parents as experts and allowing them to participate in their child's health care delivery and decisions; American Academy of Paediatrics, 2012; Gooding et al., 2011). This FCC philosophy has been widely adopted as a standard of care by neonatal and paediatric units (Lee et al., 2014; Voos, Miller, Park & Olsen, 2015). Research has shown that benefits of implementing FCC extend to both patients and their families and include: improved health outcomes, decreased length of hospital stay, improved parent involvement, coping, role attainment and competence (Lee et al., 2014; Shahheidari & Homer, 2012; Sweeney et al., 2017; Voos et al., 2015).

Family integrated care. There is growing evidence that family integrated care (FIC), which builds upon the foundation set by FCC, is an even more efficient way of providing high quality care to hospitalized neonates and their families (Banerjee, Aloysius, Platonos, & Deierl, 2017). Although similar to FCC, FIC advocates a more integral and active role for the parents as their neonate's primary caregiver. Within FIC, health care providers rescind their traditional role as primary caregiver and take on a teaching and mentorship role (O'Brian et al., 2013; Patel et al, 2017). Furthermore, FIC uses technological advancements to improve parental involvement by

educating parents through mobile applications and using cameras, videos and webcams to keep parents involved when they are absent from the hospital (Banerjee et al., 2017). Like FCC, studies have demonstrated that the FIC model is beneficial to the neonate and parent (O'Brian et al., 2013). Studies have also found that implementing FIC, in which parents provide much of the neonate's care, is feasible and safe (O'Brian et al., 2013).

Family centered care in the NICU. Despite its wide adaption as a standard of care in pediatrics, FCC has traditionally been difficult to implement in the NICU due to the constraints of the physical environment and many of the necessary interventions for the neonate's care and recovery (e.g., seclusion in incubators, assisted ventilation; Shahheidari & Homer, 2012; Voos et al., 2015). Research has suggested that a NICU with single patient rooms or individual pods allows for better incorporation of FCC; and thus, allows neonates and families to reap more benefits of FCC (Palomaa et al., 2016; Shahheidari & Homer, 2012). Despite research recommending single patient rooms, many NICUs have continued to operate with an open bay concept in which parents are unable to "room-in" and be in continuous contact with their neonate; instead parents are often separated from their neonates and spend time travelling to and from the hospital each day (Engler et al., 2002; Raiskila et al., 2016). Many of these open bay NICUs boast a "24/7" visiting policy for parents; yet in some hospitals, these policies include exceptions (i.e., during nursing shift change, physician rounds, resuscitation), which limit parental involvement and input with the health care team (Griffin, 2013). Since the nature and layout of this intensive care environment hinders parent-neonate interaction, nurses and health care professionals promote FCC by encouraging parents to visit, interact, and participate in their neonate's care (Fenwick, Barcaly & Schmied, 2008; Franck, Allen, Cox & Winter, 2005; Skene et al., 2012). However, these efforts have often been unsuccessful to overcome the physical

layout and perceived unwelcoming nature of the NICU environment, and ultimately may fail to improve parental participation (Burns & Klein, 2005; Franck, Cox et al., 2005; Griffin, 2013). Although FIC may be seen as an improvement upon FCC this care model also faces these implementation challenges (Jiang, Warre, Qui, O'Brian & Lee, 2014; O'Brian et al., 2013; Patel et al., 2017). Along with these barriers to implementation, it could be argued that FIC requires greater changes in NICU culture (Jiang et al., 2014; O'Brian et al., 2013). With FIC both staff and parents are faced with adapting to a new role (O'Brain et al., 2013). These adaptations can be challenging for both parties as staff facilitate parents' transition into the role as primary caregiver and parents deepen their knowledge, skill and confidence in caring for a preterm or ill neonate (O'Brian et al., 2013; Patel et al., 2017; Seidman et al., 2015; Vazquez & Cong, 2014). Although any level of parental involvement can be difficult to implement, both FCC and FIC models have resulted in improved parental participation with many aspects of neonatal care; however, parental absence during painful procedures often remains commonplace (Feeley, Waitzer, Sherrard, Boisvert, & Zelkowitz, 2013; Franck et al., 2012; Johnston et al., 2011).

Family involvement in neonatal pain management. The literature has shown that both neonates and parents benefit from FCC and FIC (Lee et al., 2014; O'Brian et al., 2013); more specifically, parental participation in pain care, though often lacking, has also been shown to benefit both parties (Axelin et al., 2015). For the neonate, parental involvement during painful procedures has been linked with improved nursing pain assessment and documentation (Franck et al., 2011), improved non-pharmacological pain management (Guedj et al., 2014; Johnston et al., 2011), and decreased pain exposure and severity (Lester et al., 2014). Parental benefits to participation in pain management include improved parental role attainment and coping (Axelin, Lehtonen, Pelander & Santera, 2010; Franck et al., 2011; O'Brian et al., 2013; Sweeney et al.,

2017). Along with the benefits of parental involvement, studies have shown that many parents worry about their neonate's pain and want to help alleviate their neonate's pain (Franck, Scurr & Couture, 2001, Franck et al., 2007; Orr et al., 2017).

Parental desire to participate in pain management in the NICU has been measured several times within the literature. A review of these studies has suggested that, over time, parental desire to participate seems to have grown quite substantially. Whereas in separate studies conducted in 2001 and 2004, 53% ($N = 95$) and 57% ($N = 257$) of surveyed parents wished to remain with their neonate during painful procedures (Franck et al., 2001; Franck, Cox, Allen & Winter, 2004), while in 2011 and 2017, 90% ($N = 85$) and 94% ($N = 72$) of surveyed parents expressed a desire to remain at the bedside, respectively (Franck et al., 2011; Orr et al., 2017).

It has also been well-established in the literature that parents want information about neonatal pain and pain control (Franck et al., 2001; Franck et al., 2004; Franck et al., 2011; Orr et al., 2017). For example, in their 2017 study, Orr and colleagues found that 96% of surveyed parents wanted more information on how to comfort their neonate during procedures. Furthermore, findings have indicated that increased information about neonatal pain may increase parental desire to be present for painful procedures (Campbell-Yeo et al., 2010; Franck et al. 2011). In 2011, an RCT was conducted by Franck and colleagues in which, the intervention group was provided with an information booklet about pain and comfort in the NICU along with demonstrations of specific comfort techniques that they could employ with their neonate. Meanwhile, the control group received only a generic NICU information booklet and an attention placebo. Their findings suggested that the more specific pain/comfort information significantly affected parental desire for participation ($p < .01$), with 75% of the control group ($n = 84$) and 90% of the intervention group ($n = 85$) wanting to be present at the

bedside during painful procedures (Franck et al., 2011). Similarly, research on KC during heel lance in the NICU found that 99% of mothers (N= 69) who participated in the study indicated a desire to provide KC for painful procedures again in the future (Campbell-Yeo et al., 2010).

Unfortunately, research has shown that parental desire to be present was not necessarily correlated with actual parental presence during pain care (i.e., in studies conducted in 2001, 2004, and 2011 by Franck, most parents chose a response option indicating that they were sometimes present versus the options often present or always present). Furthermore, in their RCT, Franck and colleagues (2011) found that, although information about neonatal pain care increased parental desire to be present at the bedside, this did not translate to an increase in actual parental presence (i.e., there was no statistical difference between intervention and control group in parental presence during painful procedures). The intervention's failure to improve parental presence during painful procedures further illustrated a gap between evidence and practice, suggesting there may be other factors (beyond education) interfering with parental presence.

To date, research into parent involvement in neonatal pain has firmly established a few points. First, parent participation can be advantageous for both the neonatal patient and the parent (Axelin et al., 2015; Franck et al., 2012; Lester et al., 2014; Johnston et al., 2011). Second, parents want to receive neonatal pain information and to participate in their neonate's pain management (Franck et al., 2001; Franck et al., 2004; Franck et al., 2011; Orr et al., 2017). Third, parents report an increased desire and can take part in their neonate's pain management when they receive appropriate support, encouragement, guidance, and teaching (Axelin et al., 2010; Blount, Piira, Cohen & Cheng, 2006; Bettel, Latimer, Fernandez & Hughes, 2017; Franck et al., 2011; Simons et al., 2001; Wood, 2002). Finally, parental desire does not always translate

into action, and contextual factors (i.e., nature of the procedure, NICU structure, NICU policies, nursing approach and time constraints) or external commitments (i.e., caring for other children, being away from the hospital, being in poor health themselves), can be major factors impacting parental presence and participation during painful procedures (Benoit et al., 2016; Lester et al., 2014; Marfurt-Russenberger et al., 2016; Palomaa et al., 2016; Raiskila et al., 2016).

Regarding the points summarized above, it is important to highlight that a small contingent of parents continue to report little desire to participate in their neonate's pain care, despite interventions (i.e., education), and that reported desire to participate does not always translate into action. Along these lines, it is also important to note that, although contextual factors have been well-studied, the association between parental intrapersonal factors (i.e., anxieties) and their desire to participate in their neonate's pain care have not been explored. Thus, it was speculated that parental anxieties may be contributing to: (a) the decreased desire to participate amongst some parents; and/or (b) the tendency for some parents who do indicate a desire to be present but are absent or leave during painful procedures. The findings of Franck and colleagues (2012) may provide support for this speculation. In a follow-up to their 2011 study, Franck and colleagues analyzed the written comments of the 10% of participants who indicated a preference to be absent during their neonate's procedures. Their findings revealed that emotional difficulties related to witnessing their neonate's pain was cited as a parental barrier to participation. Although the authors did not follow-up with those parents who reported a desire to participate but were not present during painful procedures, it could be theorized that emotional difficulties contributed to this phenomenon as well. Indeed, intrapersonal characteristics of the parent (i.e., anxieties) may be related to their desire for and participation in pain management as indicated by the authors of the SCMP (Craig, 2015), which is helpful in

understanding why parents may want to be present but are not able to participate in the direct management of their neonate's pain care.

Social Communication Model of Pain

The SCMP (Craig, 2015), which is further delineated in chapter three, redirects attention from the individual in pain to the social context in which the pain is experienced. It posits that both characteristics of the pain sender (i.e., the person experiencing pain) and the pain observer (i.e., the person observing the individual in pain) influence one's interpretation of the pain experience (Craig, 2015). The SCMP has provided a foundation for research into the characteristics of both the pain sender and, to lesser extent, the pain observer. The model has allowed for the investigation of interpersonal and intrapersonal characteristics of both the sender and observer, along with ways these factors affect an observer's appraisal of the sender's pain, and thus how these appraisals influence the care provided to those in pain (Bailey et al., 2012).

In regard to characteristics of the pain sender, research has shown that pain senders' pain expressiveness, age, gender, and attractiveness are all related to observers' assessment of their pain (Craig, 2015). In the past decade, characteristics of pain observers have gained increasing attention within the SCMP (Hadjistavropoulos et al., 2011). For example, research has shown that observers' assessment and treatment of a person in pain is affected by their gender and attachment style. More relevant to the current study, research has also shown that certain personality traits (e.g., neuroticism or anxiety) are related to perceptions of pain (Courbalay, Deroche, Prigent, Chalabaev & Amorim, 2015; Rash, Prkachin & Campbell, 2015). Similarly, a growing body of research has shown that the tendency of an observer to catastrophize about his/her own pain (i.e., to maintain an exaggerated negative cognitive-affective reaction toward anticipated or actual pain; Quartana, Campbell & Edwards, 2009) has an impact on the

perception of the pain sender's distress and their need for support (Sullivan, Martel, Tripp, Savard, & Crombez, 2006). Finally, it is important to note that the SCMP recognizes the role of the interpersonal context in which the observer and sender interact.

Although the vast majority of research into observers' characteristics within the context of the SCMP has been conducted within the adult pain literature, it was proposed that the SCMP could provide a framework to study neonatal pain situations as well. Due to the age and maturity of neonates, their ability to express pain is limited to crying and pain behaviour which, with repeated exposure to pain, can become heightened or dampened over time (Carbajal et al., 2008; Grunau, 2013; Valeri, Holsti & Linhares, 2015); therefore, it was thought that using the SCMP to examine the characteristics of the observer (i.e., parent) would be particularly important within this population. Furthermore, examination of the association between parental characteristics and their participation in pain management was considered important because pain responses can impact the sender's (i.e., the neonate) future experiences of pain (Craig, 2015). Since the SCMP also recognizes the role of the interpersonal context in which the parent and neonate interact, it allowed for the proposition that the environment in which potential caregiving can take place (i.e., the physical context of the NICU and parent's associated anxiety) may also play a role. Due to its prevalence in the neonatal parent population (Edéll-Gustafsson et al., 2014) anxieties were of value to examine in the SCMP context of observer characteristics. One's general anxiety, the anxiety created by the NICU environment and anxiety about pain were thought to possibly be related to parental perceptions of pain intensity, along with their desire to participate in pain management.

Anxiety

Becoming a parent is a life event filled with many mixed emotions including anxiety. Anxiety is an emotion associated with changes in thoughts, behaviours, and physiology and occurs in anticipation of a threatening event or situation or in the face of uncertainty (Grupe & Nitschke, 2013). The level of anxiety one experiences is often dependent on their disposition (i.e., tendency to be anxious) and the situation at hand; these two components of anxiety have often been described as trait and state anxiety (which will be used to operationalize the experience of general anxiety for the purposes of this research; Spielberger et al., 1983).

State and trait anxiety. As noted previously, anxiety has often been discussed in terms of trait anxiety and state anxiety (Spielberger et al., 1983). In general, trait anxiety is a measure of one's general disposition (i.e., one's innate tendency to experience anxiety), while state anxiety, on the other hand, measures the temporary emotion experienced at any given moment. Compared to trait anxiety, state anxiety is much more responsive to the situation (i.e., a person with low trait anxiety but has an intense fear of snakes may score low on a measure of trait anxiety and high on a measure of state anxiety if they completed the measure while sitting in a room with a snake). A high level of state anxiety, related to any specific trigger, often elicits a strong urge to avoid the anxiety trigger and, as a result, serves to maintain the anxiety over time (Clark & Beck, 2009). Such avoidance results in an immediate decrease in anxiety but does little to change one's thoughts about the anxiety topic. Thus, it was speculated that a parent who experiences greater levels of general anxiety may expect higher levels of pain experienced by their neonate and thus avoid their neonate's painful procedures. For this research, generalized parent anxiety was operationalized by measuring their state and trait anxiety.

Impact of anxiety on behaviour. The experience of anxiety has been shown to be either adaptive or maladaptive depending on the level of anxiety and how it motivates one's behaviour (Munz, et al., 1974). The experience of anxiety is an adaptive emotion when it allows one to prepare to cope with some future dilemma or problem; it becomes maladaptive when it interferes with functioning and wellbeing (e.g., fatigue, loss of appetite, sleep deprivation, irritability and panic, Wu & Cheng, 2006). The Yerkes-Dodson Law provides a well-established and helpful framework for understanding the relationship with anxiety and performance, and argues that anxiety can sometimes serve as a source of motivation (Yerkes & Dodson, 1908). It states that individuals who experience very little anxiety often underperform in situations as their lack of anxiety prevents them from making appropriate preparations. Those with excessive anxiety, on the other hand, perform negatively as they often freeze, escape, or avoid the situation. This law argues that optimal performance occurs with moderate levels of anxiety, as it motivates individuals to be attentive and make appropriate preparations. Applied within the interpersonal context of a neonate's pain, it was posited that those with moderate levels of anxiety could be those who provide the best care (i.e., sufficient anxiety to attend to neonate's needs but not so intense that the parent freezes or feels compelled to avoid the situation).

Anxiety and perceptions of pain. Research has also shown that an individual's anxiety may be associated with their observation of pain intensity in others; specifically, that those who are more anxious are more likely to perceive heightened levels of pain in others (Crombez, Van Damme & Eccleston, 2005; Rash et al., 2016). For example, in their study of parents of children with cancer, Link and Fortier (2016) found that, regardless of education, parents with higher trait anxiety perceived their children as having more frequent episodes of pain than did parents with lower trait anxiety. Franck et al. (2004) found that parents were concerned about neonatal pain

and that parental anxiety was associated with greater expectations of pain and greater ratings of neonatal pain.

It appears anxious parents, as opposed to non-anxious parents, were most vigilant to their neonate's pain behaviour, raising the possibility that anxious parents may serve as the best advocates. However, since anxious parents may also be the most likely to avoid their neonate's painful procedures (Franck et al., 2004), their opportunity for advocacy could be lost. Given that their involvement may minimize adverse outcomes of pain and improve early bonding, it was considered advantageous to understand if anxiety was negatively related to parental behaviour to develop ways to decrease avoidance and increase participation.

NICU related anxiety. The terms anxiety and stress have been used interchangeably throughout the neonatal literature to explain the parental experience of having one's neonate cared for in the NICU. Levels of parental anxiety or stress related to the NICU setting and experience have been measured using various instruments; regardless of instrumentation, a NICU admission is inherently anxiety provoking for parents and, not unexpectedly, it has been found that parents of preterm neonates experience more anxiety than those of healthy full-term neonates (Busse et al., 2013; Erdem, 2010; Gustafson et al., 2016; Franck et al., 2005; Franck et al., 2011; Holditch-Davis et al., 2015; Miles et al, 1993; Woodward et al., 2014). The NICU environment increases parental anxiety due to parental role alteration, uncertainty, helplessness, neonates' appearance, and parent neonate separation (Bouet, Claudio, Ramirez & Garcia-Fragoso, 2012; Busse et al., 2013; Miles et al., 1993; Schappin, Wijnroks, Uniken Venema & Jongmans, 2013). Some of the consequences of anxiety, such as fatigue, sleep deprivation, and irritability may alter parental behaviour and perception of parental competence, and may ultimately lead to inadequate attendance to neonates (Edell-Gustafsson et al., 2014; Feldman &

Elderman, 2007; Melnyk et al., 2006; Olshtain-Mann & Auslander, 2008). Though these are considered common manifestations of anxiety, there has been some research to suggest that anxiety disorders such as Acute Stress Disorder (ASD) and Post Traumatic Stress Disorder (PTSD) can occur in NICU parents (Holditch-Davis, Bartlett, Blickman & Miles, 2003; Lefkowitz, Baxt & Evens, 2010; Shaw, Bernard, Storfer-Isser, Rhine & Horowitz, 2013; Shaw et al., 2006). Though these anxiety disorders are rare and extreme manifestations of anxiety, their occurrence in the NICU parent population has illustrated the impact that this environment may have on parents' mental health.

There have been several studies examining factors affecting the incidence of anxiety in parents of hospitalized neonates. In their study, Cao, Gao, Zheng and Fan, (2007) found that more than half of mothers experienced post-partum anxiety when separated from their neonates, a common occurrence when an neonate is admitted to the NICU (Nystrom & Axelsson, 2002). Within the context of NICU hospitalization, researchers have pointed to numerous variables that further impact parent anxiety. Specifically, male gender, length of hospital stays (Erdem, 2010), parental education, lack of social support (Kong et al., 2013) and concern about neonatal pain (Franck et al., 2004) have been associated with higher anxiety levels in NICU parents. The nature of their neonate's illness and treatment requirements often results in limited opportunities for parents to provide care, shared caregiving responsibilities with staff and an inability to parent in a traditional way (Gibbs, Boshoff, & Stanley, 2016; Miles, Funk & Carlson, 1993; Rossman et al., 2015, Franck et al., 2004); this parental role alteration has often been cited as a significant source of anxiety for NICU parents (Busse et al., 2013; Gustafson, Labrecque, Graham, Tella & Curley, 2016; Miles et al. 1993).

Although the experience of anxiety elicited by the NICU setting and experience may be encompassed by measuring state anxiety, other transient factors occurring in one's life may also impact state anxiety. It was of interest to distinguish the anxiety experienced in this particular NICU circumstance and examine this construct more specifically; thus, for the purposes of this study, NICU anxiety has been operationalized using a measure of NICU stress. This measure (i.e., the parental stressor scale: NICU) was chosen to operationalize NICU anxiety due to its specificity around the NICU experience. Furthermore, the PSS: NICU scale defines a stressful experience as one that has elicited anxiety or tension illustrating its ability to measure parental anxiety. Regardless of the method of measurement or terminology used, separation, long hospital stays, uncertainty, and misinterpretation of medical information are all unfortunate consequences of the NICU environment that may cause anxiety. Despite efforts of health care providers, many of these factors cannot be altered; therefore, NICU anxiety can never be eliminated, illustrating the value of examining the relationship between parental NICU anxiety and neonatal pain care.

NICU anxiety and responses to neonatal pain. Parental concern and lack of understanding about neonatal pain may increase parental NICU anxiety. Along these lines, studies have found parental distress to be positively related to concerns about their neonate's pain (Franck et al., 2012; Franck et al., 2005, Franck et al., 2004). After controlling for neonatal illness severity and parental state anxiety, Franck et al. (2004) found that 18.2% of the variance in parental NICU anxiety was positively related to their concerns about neonatal pain (i.e., estimation of worst pain, number of worries about pain/pain management, and degree of dissatisfaction with information). Furthermore, parent's estimates of their neonate's worst pain (i.e., parents were asked to rate the worst pain their neonate had felt since admission, on a ten-

point scale) was positively associated with the number of reported concerns about pain. Finally, Franck and colleagues (2004) found that parents with high levels of NICU anxiety rated their neonate's current pain higher than those parents with low levels of NICU anxiety.

Anxiety related to the NICU environment may have a negative relationship with parental behaviour (i.e., inadequate attendance of their neonate) by altering their perception of parental competence (Feldman & Elderman, 2007; Melnyk et al., 2006; Olshtain-Mann & Auslander, 2008). Parents often feel unprepared about neonatal pain management and unable to comfort their neonate; this feeling of helplessness commonly expressed by NICU parents, is a significant source of anxiety (Chertok et al., 2014; Franck, 2007). Franck (2007) posited that parents may actively pursue information or involvement as a means of coping with this feeling of helplessness. On the other hand, it has been found that anxious NICU parents have a difficult time absorbing and retaining information provided by health care professionals; in turn, this may make it more difficult to maintain involvement in their neonate's care. Similarly, Franck (2007) suggests that NICU parents may evade painful procedures performed on their neonate due to feeling overwhelmed or fearing they will interfere with the neonate's care. These varied findings may appear as inconsistencies in research; however, the possible ramifications of NICU anxiety outlined above seem to be consistent with the Yerkes-Dodson Law of anxiety and performance (Yerkes & Dodson, 1908). Based on this principle, one could speculate that parents with little anxiety may be indifferent regarding their presence and do little to seek information or participation, while parents with excessive levels of anxiety may be those likely to avoid information and participation in an effort to decrease their own distress. The principle posits that optimal performance occurs with moderate levels of anxiety; and therefore, these parents are

most likely to make necessary preparations to assist with their neonate's comfort by seeking information and participation.

Pain Anxiety

The concept of pain anxiety has been thoroughly reviewed in the literature as a construct with intra- and inter-personal consequences. Most often, and for the purpose of this study, this pain-related anxiety has been conceptualized as pain catastrophizing (Sullivan et al., 2001). Broadly, catastrophizing has been defined as an irrational and pessimistic speculation of future events that was first introduced by Albert Ellis and later modified by Aaron Beck to describe a negative thought process employed by individuals afflicted with anxiety or depressive disorders (in Quartana et al., 2009). Building on this conceptualization, pain catastrophizing was initially conceived as a maladaptive coping strategy employed in anticipation of, during, or following a painful experience. Pain catastrophizing is characterized by the tendency to have fixated, exaggerated, and helpless thoughts of pain (Chaves & Brown, 1987; Rosenstiel & Keefe, 1983; Spanos, Radtke-Bodorik, Ferguson & Jones, 1979). Research has demonstrated that pain catastrophizing is an overwhelming predictor of negative pain-related outcomes (Quartana et al., 2009).

Pain anxiety and responses to pain. Initially, pain catastrophizing was explored as a predictor of one's emotional and behavioural responses to their own pain (Quartana et al., 2009). Indeed, research has found it to be a powerful contributing factor to numerous pain-related outcomes such as greater ratings of one's own pain, (Keefe, Brown, Wallston, & Caldwell, 1989; Sullivan, Adams & Sullivan, 2004; Sullivan, Bishop, & Pivik, 1995), increased stress, depression disability and social functioning (Block & Brock, 2008; Petrie, Moss-Morris, & Weinman, 1995; Severeijns, van den Hout, Vlaeyn, & Picavet, 2002; Quartania et al., 2009). Building on the

suggestion put forth by Craig's (2009) SCMP that observer characteristics influence one's assessment and response toward those in pain, researchers have more recently begun to evaluate the effect of observer pain anxiety on pain related judgments of others (Bailey et al., 2012; Sullivan et al., 2006). To date, there have been several studies that have suggested that a parent's tendency to catastrophize about their child's pain is related to the parent's perceptions and reactions toward their child's pain (Birnie, Chambers, Chorney, Fernandez, & McGrath, 2015; Caes, Vervoort, Eccleston & Goubert, 2012; Caes, Vervoort, Eccleston, Vandenhende & Goubert, 2011; Goubert, Eccleston, Vervoort, Jordan & Crombez, 2006).

Similar to findings in spousal relationships (See Cano et al., 2003), studies have found that parents with increased anxiety about their child's pain were more likely to participate in solicitous behaviour toward their child particularly during acute episodes of pain (Caes et al., 2012; Goubert et al., 2012). Solicitous pain behaviours are actions by parents that draw attention to their child's pain and serve to reinforce their child's pain (e.g., taking over tasks for the child, encouraging the avoidance of usual activities, and providing extra care and attention to the child; Bailey, Holmberg, McWilliams & Hobson, 2017; Langer et al., 2017; Peterson & Palermo, 2004). Researchers have proposed that solicitous behaviours are consequences of anxiety and are motivated by a desire to avoid the distressing situation (i.e., child's pain; Link & Fortier, 2016). In line with the SCMP (Craig, 2015) parental solicitous behaviour has been found to increase their child's pain related disability and has been associated with an increased risk for altered future pain responses (Langer et al., 2017; Link & Fortier, 2016; Peterson & Palermo, 2004).

In 2011, Caes and colleagues conducted a study in which parents witnessed their child completing an experimental pain task (i.e., school age children undergoing a cold-pressor task)

and evaluated the relationship between parental catastrophizing and parental tendency to stop their child's pain-inducing activity. It was found that parents who catastrophized about their child's pain reported more feelings of distress and exhibited higher stop tendency than those who did not catastrophize about their child's pain. They posited that, amongst those scoring high on measures of pain catastrophizing, the tendency towards stopping the child's pain-induction was a form of escape behaviour driven by a desire to decrease their own feelings of distress and anxiety. Since parents in the NICU are unable to decrease their distress by stopping the painful procedure, it was suspected that they may avoid being present thereby decreasing their anxiety.

The suspicion that avoidance activity could be more common in NICU-parents with high pain anxiety was further supported by paediatric research (Goubert, Vervoot, Sullivan, Verhoeven & Crombez 2008). In 2008 Goubert et al. evaluated the impact of parental catastrophizing about their child's pain, catastrophizing about their own pain, and dispositional empathy (i.e., when observing someone in distress, empathy manifests in one of two responses: self-oriented, feelings of personal discomfort, anxiety and unease or other-oriented responses, sympathy and compassion; Davis in Goubert et al., 2008) on the emotional responses of parents to their child's pain. They found that self-oriented emotions (i.e., personal distress and discomfort) were most strongly influenced by the tendency to catastrophize about their child's pain; thus, they suggested that parents who experience high catastrophic thought about their child's pain may employ behaviours to decrease their own personal anxiety rather than the distress of their child. Also of interest to the current study was Goubert and colleagues' (2008) finding that parental catastrophizing about their child's pain was positively correlated with their own tendency to catastrophize pain. In other words, it seems to support the proposition that similar cognitive mechanisms involving orientation towards threat are activated when responding

to one's own pain as when responding to another's pain. Thus, it was proposed that an individual's tendency to catastrophize about their own pain would likely serve as a useful predictor of the tendency to catastrophize about the pain of significant others (e.g., children).

Although most research examining the impact of pain anxiety has not been conducted with a neonatal pain population, the studies reviewed demonstrated the potential impact of pain anxiety on parents' pain behaviour. In fact, solicitous pain behaviour was also found to be more prevalent in former NICU parents; and Jaing and colleagues (2008) posited that neonatal pain exposure and hospitalization may cultivate this type pain behaviour in NICU-parents. Richter and Reck's (2013) found that a parent's pain behaviour can moderate the risk of prematurity and developmental outcomes; this finding is congruent with Craig's (2015) SCMP which would suggest that parental responses to pain may impact the neonate's future experience of pain. Given that premature neonates are already at risk for altered pain responses due to their stage of development, these studies along with those outlined above, further demonstrated the importance of examining parental pain anxiety as a factor that may contribute to the development of negative pain behaviours or avoiding involvement in their neonate's pain care.

Summary

The literature reviewed demonstrated that procedural pain is a common occurrence in the NICU and, despite several safe pain control options, this pain remains under managed (American Paediatric Society & Canadian Paediatric Society, 2007). Inclusion of parents, as outlined in FIC and FCC, in the use of non-pharmacological pain management techniques is one method that may improve neonatal procedural pain management. Furthermore, the literature highlighted the high incidence of parental desire for participation in pain management within the NICU. However, a gap was identified between these expressed desires, the ideal scenario put forth by

FIC, and actual parental presence during painful procedures (i.e., a small minority of parents' report being consistently present at the bedside for painful procedures in the NICU; Franck et al., 2011).

Although, it has been shown that inconsistent parental presence during painful procedures is often due to systems or organizational factors (e.g., visiting hours and inability to room in), it was postulated that intrapersonal parental characteristics, such as anxieties may also play a role. The research reviewed illustrated the possibility that several anxiety dimensions are experienced by NICU parents and may be associated with parental pain assessments and behaviour; in particular, three potential constructs were identified. First, general and subjective feelings of anxiety arising from dispositional (i.e., trait anxiety) and situational (i.e., state anxiety) were posited as being of relevance. Second, contextual factors related to the NICU (i.e., NICU anxiety) were identified. Finally, pain-related anxiety (i.e., pain catastrophizing) was deemed relevant in related research.

Despite its limited use in the parent-neonate relationship, the SCMP (Craig, 2015) was utilized to help frame the chosen concepts in this study as it has been successfully used to illustrate an association between intrapersonal characteristics (e.g., parental anxieties) and one's assessment of pain and offerings of support in other pain contexts.

Chapter Three: Theoretical Framework

Social Communication Model of Pain (SCMP)

The SCMP (Figure 1) was used to guide the proposed study due to its renowned ability to move away from using the biomedical approach to pain (i.e., a concrete examination of pain focusing on neurological and physiological processes of pain; Bendelow, 2013) and allowance for the evaluation of pain within an interpersonal context (Craig, 2015). The SCMP has suggested that all pain occurs within a social environment involving at least two individuals; the person who is experiencing pain (i.e., the pain sender) and those interacting with or caring for the individual in pain (i.e., the pain observer; Craig, 2015). The SCMP authors delineate a four-stage model, involving both the pain sender and observer. The first stage is referred to as *Pain Experience*; this stage involves the internal pain experience, which includes the individuals' thoughts, feelings and sensations associated with the pain. In the second stage, *Pain Expression*, the sender expresses the pain. Given that neonates lack language abilities, at this stage of development pain expression can take the form of vigorous crying, facial grimacing, or withdrawal from the pain stimulus. This pain expression allows for the third stage which is labelled *Pain Assessment*. In this third stage, the observer (i.e., parent) becomes aware of the neonate's experience of pain and interprets the presence and severity of pain based on this expression. In the final stage, *Pain Reaction*, the pain observer reacts to the sender in any number of ways. Depending on the caregivers' assessment of pain severity, different pain relieving behaviours may be enacted. For example, in the case of a neonate, a sender may utilize strategies including but not limited to cuddling, distraction, breastfeeding, KC, and pain medication. The model posits that the caregiver's response may impact the neonate's future pain experience. It is important to note that within the SCMP, intrapersonal characteristics (i.e., what

each individual brings to the interaction) and interpersonal variables (e.g., immediacy and type of response as mediated by the relationship and context in which the pain experience occurs) of both the sender and observer can impact each stage of the model (Craig, 2015; Hadjistavropoulos & Craig, 2002).

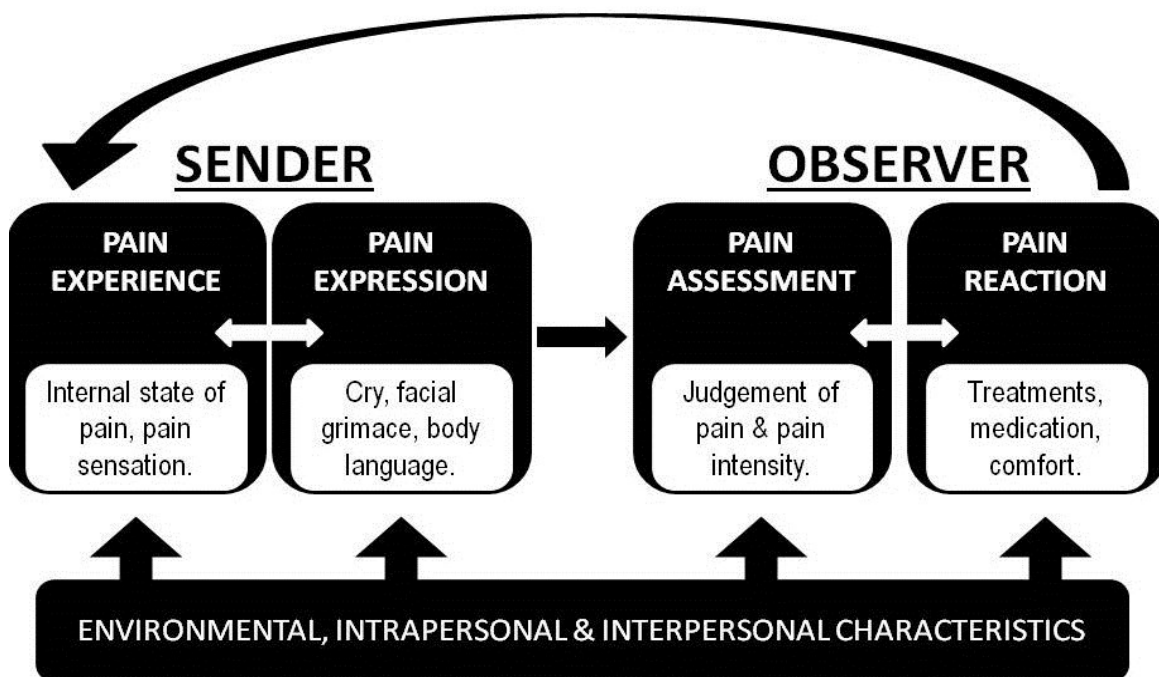


Figure 1. Social Communication Model of Pain (Adapted from Craig, 2015, Fig 1, p. 24).

The review of the literature had demonstrated that the experience of anxiety may influence one’s assessments and behavioural reactions to pain which is in keeping with Craig’s (2015) SCMP. Since the SCMP has been successfully used to guide pain research in other populations this model was chosen to anchor the study concepts selected as relevant within the neonatal pain population as well. Of interest to this research were the intrapersonal characteristics of parents (i.e., the pain observers), namely anxiety, on the third and fourth stages of this model. Thus, parental anxiety (i.e., intrapersonal observer characteristic); its relationship to parental observations and expectations of neonatal pain (i.e., SCMP, stage three; assessment of pain) and its relationship parental desire to be present and participatory in pain care (i.e.,

SCMP, stage four; pain management) was examined. The methods used to examine these constructs are outlined in the following chapter.

Chapter Four: Methods

Neonates cared for in the NICU undergo treatments that inflict pain. The SCMP (Craig, 2015) illustrates that observer, or in this instance parent characteristics, can be related to their assessments of pain and their responses toward those in pain. There is currently a paucity of SCMP research involving the neonatal population in relation to pain experiences. Furthermore, there is a gap between what is suggested by the FCC and FIC literature and the practice of parents actively participating during procedural pain management. Therefore, the current study explored the parental characteristic of anxiety, specifically different types of anxiety, and how these anxieties related to parental preferences and perceptions surrounding neonatal procedural pain. In this chapter the research setting, sample selection, instrumentation, data collection procedures will be explained. Preliminary analysis procedures and the planned analysis to address each research question will also be outlined.

Research Setting

Participants were recruited from the IWK Health Centre's NICU, a tertiary referral center in Halifax, Nova Scotia. The IWK NICU is a level three nursing unit that provides care to neonates from throughout Atlantic Canada with approximately 1000 admissions per annum. Patients are admitted to the NICU for numerous reasons including: gestation less than 35 weeks, respiratory distress, medication administration, resuscitation, surgical needs and birth trauma. In this setting, nurses are the designated care providers that perform many of the painful procedures (e.g., IV initiation, IM injection, etc.). This NICU has an open visiting policy, meaning 24 hours a day, encouraging parents to spend as much time with their neonate as they wish and to participate in their neonate's care as much as possible.

Sample

A convenience sample of NICU parents was obtained to complete this study. Recruitment took place from September 2016 through March 2017 to achieve an appropriate sample. According to Polit (2010, pg. 242), a sample of 85 participants was required for regression analyses based on four predictors (i.e., state anxiety, trait anxiety, NICU anxiety and pain catastrophizing), to achieve a moderate effect size ($R^2 = .13$), power of .80 and an alpha of .05. However, a sample size goal of 100 was set to account for attrition and incomplete questionnaires.

Inclusion/Exclusion Criteria

All parents (i.e., both mothers and fathers) over the age of 19, whose neonate had been admitted to the NICU, with the ability to read in English, were eligible for inclusion. Parents of neonates experiencing Neonatal Abstinence Syndrome (NAS; neonates experiencing withdrawal symptoms due to maternal drug use during pregnancy; Maguire, Cline, Parnell & Tai, 2013) were excluded due to the possibility that NAS may cause these neonates to display exaggerated pain responses (Finnegan, Hagan, & Kaltenbach, 1991).

Recruitment

Participants were recruited during their neonate's admission to the IWK NICU. Following the approval of the IWK research ethics board (REB) and the NICU nurse manager, parents were invited to participate via poster (Appendix F) placed in the NICU, in person by the principal investigator (PI) or via postcard (Appendix G) left at the bedside. In collaboration with the NICU team leader the PI identified parents who met inclusion criteria and were appropriate to approach. The PI then approached those parents at their neonate's bedside and briefly explained the study and what was requested of participants (i.e., completion and return of

a 20-minute questionnaire). Interested parents were provided with a questionnaire package which included a demographic questionnaire (Appendix C) and four self-report measures to be completed and returned in a sealed envelope. If parents were absent from the NICU but deemed eligible for the study, a post-card (Appendix G) was left at their neonate's bedside directing parents to the questionnaire location in the NICU. Posters were also placed throughout the NICU in parent areas inviting parents to select a questionnaire package and participate, following routine study process for this unit. Inside each questionnaire package, along with questionnaires, was an introduction letter (Appendix A) which provided the PI's contact information, an explanation of the study (including potential benefits and risks) and participation requirements. The introduction letter also provided a link to an online version of the questionnaires which enabled parents to complete the study electronically if they preferred.

Ethical Considerations

Prior to participant recruitment IWK REB approval was obtained. As described above, all parental participants who met criteria were provided with written information, along with the student PI's (and supervisor's) contact information, by way of an introduction letter (Appendix A) to ensure parents were fully informed about the study prior to participation. The intro letter outlined that participation was voluntary and would not affect care delivery to their neonate. Potential participants were encouraged to contact the PI with any questions or clarification needs after reviewing written information. Completion and return of the research questionnaire was considered implied consent for participation. Thus, the introduction letter also clearly outlined the purpose of the study, the data collection methods and any known risks to participation. Furthermore, the letter explained that participants had the right to withdraw from the study at any given time, and that confidentiality and anonymity of participant responses would be maintained

throughout data collection, analysis and publication. Confidentiality and anonymity was maintained by assigning participant codes to data measures rather than personal identifiers. No personal identifying information was gathered (i.e., name, neonatal unit number, etc.). All raw data was immediately separated from participants' responses. Online questionnaire data (i.e., data collected using Opinio survey software hosted by Dalhousie University Information Technology department) was encrypted, de-identified and stored on a secure server. Participants were offered an incentive for completing the questionnaire package in the form of a five-dollar Tim Hortons' gift card and the chance to win one of four fifty-dollar Babies R' Us gift certificates. For the first round of questionnaires left in the NICU, a coffee gift card was in the questionnaire packet but due to a high degree of questionnaire removal and low rate of completion the process to provide gift cards changed. To receive these incentives parents voluntarily submitted their name and mailing address in a locked box in the NICU, which was separate from their returned questionnaire package. Parents were also provided with the opportunity to request the results, in summary format, by submitting contact information separate from their responses.

Instrumentation

The following is a review of the variables and how each was operationalized in a measure in the current study. Table 1, presented at the end of this section provides a summary of the relevant variables and their conceptualization in this study.

Demographic profile. A brief questionnaire (Appendix C) was used to obtain information from study participants regarding their age, sex, marital status, ethical/racial background, and location of residence in relation to the hospital, as well as their neonate's gestational age (GA) and birth order.

State Trait Anxiety Inventory. The State Trait Anxiety Inventory (STAI; Spielberger et al., 1983) is a commonly used self-report scale to measure both participants' current anxiety and general propensity to be anxious. The STAI has 40-items divided into two subscales. The State Anxiety Scale (Form Y-1) evaluates the current/more transient experience of anxiety; asking participants to respond to statements that measure how they feel "right now, that is, at this moment" on a 4-point Likert scale ranging from 1 (not at all) to 4 (very much so). The Trait Anxiety Scale (Form Y-2) assesses ones' predisposition to be anxious; asking participants to respond to statements indicating how they "generally" feel using a 4-point Likert scale ranging from 1 (almost never) to 4 (almost always). Possible scores for each subscale range from 20 to 80 with higher scores indicating higher levels of anxiety. Internal consistency was demonstrated by strong alphas ranging from 0.86 to 0.95 (Spielberger et al., 1983). The STAI has been one of the most frequently used measures of general anxiety (Julian, 2011) which speaks to its construct validity (Polit & Beck, 2012).

Parental Stressor Scale: NICU. The Parental Stressor Scale: NICU (PSS: NICU; Miles et al., 1993) was used to assess anxiety related to the NICU. It is a 34-item self-report questionnaire which consists of three subscales, in which parents rate a range of experiences on a Likert scale from 1 (*not at all stressful*) to 5 (*extremely stressful*). A *not applicable* option is provided for parents who did not have the experience to which the item referred. The scale explains stressful as "an experience that has caused you to feel anxious, upset or tense" making it an appropriate measure of NICU related anxiety for this research. Items have been grouped into three subscales: (i) a 6- item Sights and Sounds subscale related to the physical environment and equipment (e.g., noises of monitor alarms); (ii) a 17-item Infant Behaviour and Appearance subscale related to their neonate's physical appearance, behaviour and treatments (e.g., color,

crying, tubes or wires attached to the neonate); and (iii) an 11-item Parental Role Alteration subscale related to parental feelings about their parental role and relationship with the neonate (e.g., being separated from the neonate). Internal consistency has been demonstrated with Cronbach's alphas ranging from 0.73 to 0.92 for the subscales and 0.89 to 0.94 for the total scale (Miles et al., 1993). The PSS: NICU scale's construct validity was initially demonstrated by finding significant Pearson correlation coefficients between PSS: NICU scores and State anxiety scores measured via the STAI and is maintained by its continued, successful use throughout neonatal literature (Franck, Cox et al., 2005, Franck et al., 2011, Miles et al., 1993). The scale has also been shown to demonstrate good test-retest reliability at 0.87 (Miles et al., 1993, Miles & Brunssen, 2003).

Two different scoring techniques can be used with this scale (i.e., Metric 1, stress occurrence level and Metric 2, overall stress level). According to the scale's developer, Metric 1 is recommended when examining parental responses to stressors to which they *were actually exposed* in the NICU environment (i.e., stress experienced in relation to a specific situation). Metric 2 is recommended to examine the overall stress level of the parents as it relates to stressors to which they *could be exposed* to in the NICU environment (Miles et al., 1993). As previously indicated, to allow parents to indicate they did not experience a particular element of the NICU, a '*not applicable*' option was included; this option is what facilitates this scale's two scoring options. Metric 1 scores parents on only those items they have experienced. Metric 2 scores all items giving '*not applicable*' a score of 1 (*not at all stressful*); this score indicates a parent experienced no distress or anxiety related to this aspect of the NICU setting or experience. Given this study's focus on the parent's overall anxiety related to the NICU environment and experience, as well as recognition that some parents may experience more varied stressors,

Metric 2 was used; in short, the use of Metric 2 ensured that all participants' responses were scored using the same possible range.

Pain Catastrophizing Scale. Interpersonal consequences of pain catastrophizing have been studied in two ways; first, by measuring one's tendency to *catastrophize about one's own pain* (i.e., participants were asked to reflect on their thoughts and feelings when they have experienced pain on the Pain Catastrophizing Scale [PCS]; Sullivan et al., 1995); and second, by measuring one's tendency to *catastrophize about another person's pain* (e.g., using the Pain Catastrophizing Scale – Parent Version [PCS-P], parents are asked to reflect on their thoughts and feelings when they have witnessed their child in pain; Crombez, Eccleston, Van Damme, Vlaeyen & Karoly, 2012). In this study, pain catastrophizing was operationalized and measured as one's tendency to catastrophize and be anxious about their pain. This was deemed optimal because the tendency to catastrophize about one's own pain is strongly correlated with the tendency to catastrophize about another's. It was also considered that parents of neonates may lack prior experience in which they observed their neonate's pain; thus, the option to have them consider another's pain PCS-P was deemed less reliable as a measure.

The PCS (Sullivan et al., 1995) was used to assess parental tendency to catastrophize one's own pain. It is a 13-item self-report questionnaire designed to assess catastrophic thoughts and feelings associated with the experience of pain. Participants were asked to reflect on past painful experiences and indicate the degree to which each of the 13 items represents their thoughts or feelings when experiencing pain. This measure also uses a 5-point Likert scale ranging from 0 (*not at all*) to 4 (*all the time*). Internal consistency is demonstrated with an alpha of 0.95 (Osman et al., 2000), while the test-retest reliability has been measured to have a high degree of stability at 0.75 (Sullivan et al., 1995).

Outcome measure. The outcome measure (Appendix D) collected information on parental views, expectations and preferences for neonatal procedural pain care. This measure consisted of items adapted from the PAIN Questionnaire (Franck et al., 2004). The original PAIN Questionnaire is comprised of 48 items including dichotomous, forced choice, scale, checklists and open-ended questions and has good internal consistency for measuring parental expectation of pain ($\alpha = 0.71$) and parental satisfaction ($\alpha = 0.84$) and has been used successfully in quantitative and qualitative research (Franck, Cox et al., 2005, Franck et al., 2011). Despite its use in previous studies this scale did not completely capture the dependent variables as required for the analyses proposed for this research; therefore, the most relevant items from the PAIN questionnaire (Franck et al., 2004) were selected and adapted, with the authors' permission, and the outcome measure utilized consisted of 12 questions. This outcome measure was developed to more accurately measure the dependent variables of interest. Of the original 48 items, six items had the wording modified and were used in five of the items in the outcome measure utilized (See Appendix E). Along with these five adapted items, seven new items were added to better capture parental preferences, comfort level and stress with painful procedures performed on their neonate.

Table 1

Summary of Variables

Variable	Conceptual Definition	Operationalization	Items
General Anxiety	Trait Anxiety: one's innate tendency to experience greater levels of anxiety than others.	STAI	20
	State Anxiety: one's temporary experience of anxiety brought on by a specific event or situation.		20
NICU Anxiety	One's experience of anxiety resulting from having one's neonate cared for in the NICU.	PSS: NICU	40
Pain Anxiety	One's tendency to be anxious about their own pain.	PCS	13
Outcome Measure	One's observations, expectations and views of procedural pain intensity experienced by their neonate. Also, one's desire to be present, and participate; along with estimated stress and comfort level during painful procedures performed on their neonate.	New/Adapted items from PAIN (Appendix D).	12

Note. STAI = State Trait Anxiety Inventory (Spielberger et al., 1983), PSS: NICU = Parental Stressor Scale: NICU (Miles et al., 1993), PCS = Pain Catastrophizing Scale (Sullivan et al., 1995), PAIN = Parent Assessment of Infant Nociception Questionnaire (Franck et al., 2004).

Analyses

The software program IBM SPSS 23 was used to analyze all data. Consistent with the recommendations of Polit and Beck (2010), the database was screened for missing data, outliers and normality prior to examination the research questions. Missing values at the item level were identified as random in nature and item values were imputed using the respondent's average score from the scale associated with the missing value provided the scale was missing less than 10% of responses to its items. Scales missing greater than 10% of items were not included in the analysis. Preliminary analyses are described below along with an outline of the analysis plan for each specific research question.

Preliminary analyses. Following the raw data examination, univariate outliers were examined by computing z-scores for each dependent and predictor variable. As noted by

Tabachnick and Fidell (2007) z-scores that are discontinuous from the rest of the distribution, that is, are greater than 3.29 (or less than -3.29), may be considered outliers. Two data points with z-scores outside these parameters of -3.29 – 3.29 were identified; both scores occurred on the parental rating of desire to be present. These two data points were found to be extreme outliers. Initially, to correct for this deviation, the outlying scores were changed to one unit lower than the next lowest non-outlying data point. The impact of these adjustments on the item's distribution was further examined; the results of these examinations are further outlined below.

To detect multivariate outliers, Mahalanobis Distance scores were computed for each set of planned analyses. These scores were then compared to critical values derived from a Chi-Square table at the .001 significance level. For the regression analyses, Mahalanobis Distance scores were computed using the full database and relevant variables; multivariate outliers were identified (Tabachnick & Fidell, 2007). Only one multivariate outlier was detected; given that only one outlier was detected, and it was not particularly disconnected from the other cases, it was left in the data file for analyses (Pallant, 2013).

To assess normality, skewness and kurtosis values were examined for the dependent and predictor variables. Skewness and kurtosis values were converted to z-scores and scores greater than an absolute value of 3.29 ($p < .001$) were significantly different from normal. As Table 2 illustrates, two variables were found to be significantly different from normal (i.e., one variable had significant skewness and kurtosis and one variable had significant skewness only). To reduce the impact of skewness and kurtosis, transformations were computed and examined for each variable. The variable with a significant moderate positive skewness (i.e., PCS) underwent a square root transformation whereas the variable with a significant severe negative skewness

(i.e., Parental rating of Desire) underwent reflect and inverse transformation (Polit, 2010). The results of these transformations are also presented in Table 3. As shown, skewness values were significantly improved in the PCS variable. Although the skewness index of Parental rating of Desire was improved significantly enough to classify the distribution as normal (i.e., z-scores within +/- 3.29), with the majority (79.2%) of scores falling between 8 and 10, visually the distribution remains negatively skewed.

Given that, as noted previously, extreme univariate outliers were identified in the Parental Rating of Desire variable, the distribution for this variable was also examined for normality with extreme outliers adjusted (i.e., scored one point below the next lowest non-outlying score). Despite correction of these outliers, the distribution was found to be significantly negatively skewed. Thus, a reflect and inverse transformation was also performed on this adjusted distribution. The original and transformed skewness and kurtosis values differed only mildly from those of the original distribution; therefore, in the final analyses, outliers were not corrected, and original values were used.

Given that the transformation produced an improvement to normality of distribution for the PCS and Parental rating of Desire variables, they were considered for inclusion in relevant analyses. Since transformed variables can increase the difficulty of interpretation (Tabachnick & Fidell, 2007), the relevant analyses were computed twice: once without the transformations and once with the transformations to determine whether the results were affected by the variables' departure from the normality. Comparison of the findings revealed no differences between the two sets of results. That is, the transformed variables returned the same set of significant and/or non-significant findings as the untransformed variables. Given this, results from analyses using the untransformed variables have been reported.

Table 2

Skewness and Kurtosis Values Before and After Transformation for the Relevant Variables.

Variables	Original		Transformed	
	Skewness	Kurtosis	Skewness	Kurtosis
PCS	0.820*	-0.056	-0.129	-0.923
Parental Rating of Desire	-2.028*	3.683*	-0.555*	-1.492

Note. Values with asterisks are those that are statistically different than normal. PCS = Pain Catastrophizing Scale, Parental Rating of Desire = Parental rating of desire to be present during a painful procedure performed on their neonate.

Upon examination of parental responses on the outcome measure it was found that several parents indicated either that their neonate did not have a painful procedure or that they were not present during a painful procedure while still providing a response to the question “If you were with your baby during a procedure, did you help keep your baby comfortable?” In developing this question, the response of “not applicable” option had not been included. Thus, prior to any analyses, responses to the question “If you were present with your baby during a procedure, did you help keep your baby comfortable?” were recoded to exclude participants who had previously indicated they were not present for a painful procedure.

Reliability analyses for each scale, presented in table 3, are within acceptable range and similar to those found in previous studies. Additionally, correlations between analyzed variables are presented in table 3. Similar to past research, anxieties were positively associated with each other (Franck et al., 2005; Miles et al., 1993; Rash, et al., 2015).

Table 3

Descriptive Statistics, Cronbach's Alphas and Correlations between Analyzed Variables.

Measure	α	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7
1. State	0.95	45.3	13.5	-	.680 **	.595 **	.445 **	.259 *	.298 **	-.278 **
2. Trait	0.93	39.9	11.0		-	.495 **	.501 **	.170	.191	-.116
3. PSS:NICU	0.93	2.6	0.8			-	.570 **	.353 **	.384 **	-.192
4. PCS	0.95	13.8	12.4				-	.136	.242 *	-.152
5. Expected	-	5.08	2.0					-	.529 **	-.080
6. Observed	-	4.29	2.3						-	-.120
7. Desire	-	8.60	2.4							-

Note. PSS: NICU = Parental Stressor Scale, Neonatal Intensive Care Unit; PCS = Pain Catastrophizing Scale; Expected = Parental rating of expected pain; Observed = Parental rating of actual observed pain; Desire = Parental rating of desire to be present during their neonate's painful procedure; *M* = Mean; *SD* = Standard Deviation; α = Cronbach's alpha
* $p \leq .05$; ** $p \leq .01$

Descriptive statistics. Descriptive statistics, including a measure of frequency, central tendency, variance and shape were calculated to describe the sample. Additionally, after calculating parental scores for each anxiety measure, descriptive statistics were used to examine research question number one: *To what degree do parents who have a neonate in the NICU environment experience different types of anxiety?*

Inferential statistics. Standard multiple regression and logistical regressions were used to analyze the remaining research questions. These analyses will be further described below.

Multiple regression. Standard multiple regression was used to answer research question two, research question three, and for post-hoc exploratory analyses. For every multiple regression analyses the predictor variables were entered into the regression analysis simultaneously. For each analysis, a two-tailed test with an alpha of .05 was used. Multiple

regression can be used to examine the amount of variance in a single outcome variable that can be attributed to a set of predictor variables and each separate predictor variable (Polit, 2010); making it an appropriate choice to address these two research questions.

Examination of research question two: *To what degree are the various types of parental anxiety related to the parents' anticipation of the painfulness/intensity of the procedure?*

required two regression analyses, one to examine relationship of the predictor variables (i.e., State Anxiety, Trait Anxiety, NICU Anxiety and Pain Catastrophizing) on the outcome variable, parental rating of *expected* of pain (i.e., anticipation of painfulness) and another to examine the relationship of these predictor variables to the outcome variable, parental rating of *observed* procedural pain. Examination of research question three; *Is there a relationship between parental anxieties and the parents desire to be present during their neonates' painful procedure*, one regression analysis was conducted to examine the relationship of the same predictor variables on the outcome variable parental *desire* to be present (i.e., parental ratings of how much they want to be present during a painful procedure; 0 = not at all, I do not want to be there, 10 = very strongly, I really want to be there).

After reviewing the significant results of the regression analyses to address research question two, further post-hoc exploratory regression analyses were conducted using a different set of predictor variables. For these two regression analyses the PSS: NICU subscales (i.e., Sights and Sounds, Parental Role Alteration and Infant Looks and Behaviour) were used as predictor variables. The outcome variable in the first regression was parental expectation of pain and parental rating of observed procedural pain in the second. These additional unplanned analyses were conducted to explore which aspect of NICU anxiety was most related to parental expectations and observations of procedural pain for their neonate.

Logistic regression. Logistic regression analysis was used to address research question number four (*Do parents who are present and participatory in neonatal procedural pain care differ across levels of general anxiety, environmental anxiety or pain anxiety?*). According to Polit (2010), logistic regression is useful to examine the ability of a set of predictor variables (i.e., anxieties) to correctly classify cases on a dichotomous predictor variable (i.e., participation vs. non-participation) and recommends 10 – 20 cases per predictor. This recommendation was met for four predictor variables (i.e., state anxiety, trait anxiety, NICU anxiety and pain anxiety; $n = 82$). Polit (2010) further advises that analysis take place with a similar proportion of cases in each group to improve classification accuracy of the logistic regression. To meet this recommendation and improve accuracy of the analysis, variables were coded as outlined in table 4. By grouping parents who indicated they sometimes or never participated into one group (26.8%, $n = 22$), and parents who often or always participated into another group (73.2%, $n = 60$), proportion of cases in each group was improved but still uneven. Ideally, groups would have been divided more specifically to truly represent those who had never participated (6.1%, $n = 5$) and those who had been present and participated (93.9%, $n = 77$), but division in this manner was far too uneven. This statistical test was two tailed with a conventional alpha of .05 (Polit, 2010).

Table 4

Variable Codes for Logistic Regression

Variable	Questionnaire Item	Response Options	LR Dummy Codes
Participation	If you were with your baby during a procedure, did you help keep your baby comfortable?	<ul style="list-style-type: none"> • Never • Sometimes • Often • Always 	Never/Sometimes = 0; Often/Always = 1

Note. LR = Logistic Regression

Chapter Five: Results

The aim of this study was to examine the relationship between different types of anxieties and parental preferences to participate in procedural pain management in the NICU; as well as to explore how anxieties relate to parental observations and expectations of procedural pain intensity in this setting. Throughout this chapter data from the research questionnaires will be presented along with the results of the analyses previously outlined. To organize results, each research question will be stated followed by the results of the analyses conducted to address that research question.

Descriptive and Demographic Results

A total of 102 NICU parents participated in this study by completing a questionnaire package, with a response rate 43%. A slight majority of the sample was comprised of mothers (60.8% of the sample; $n = 62$). Parents had an average age of 31.3 years ($SD = 6.24$, Range: 19 - 46 years) and were predominantly Caucasian (81.4%; $n = 83$), married or in a common-law relationship (58.8%; $n = 60$ and 28.4%; $n = 29$, respectively). The neonate admitted to the NICU was the first child for most parental participants (62.4%; $n = 63$). Gestational age of neonates ranged from 24 to 41 weeks at birth with an average age of 32.9 weeks ($SD = 4.77$). Most parents resided within one hour driving distance to the hospital (54.9%; $n = 56$) while the remainder (45.1%; $n = 46$) lived a greater distance away. A summary of the demographic variables is presented in Table 5.

Table 5
Descriptive Statistics for Participant Sample (N = 102)

Variable	N	%	M (SD)	Standardized	
				Skewness	Kurtosis
Participant Age (yrs)	100		31.3 (6.24)	-0.046	-0.586
Fathers	40	39.2%	32.3 (6.58)	0.045	-0.557
Mothers	60	60.8%	30.6 (5.97)	-0.201	-0.762
Neonate's GA (wks)	102		32.9 (4.77)	-0.089	-0.985
Participant Race					
Caucasian	83	81.4%			
Asian	3	2.9%			
Aboriginal	5	4.9%			
Black	6	5.9%			
Other	5	4.9%			
Participant Marital Status					
Married	60	58.8%			
Common Law	29	28.4%			
Dating	9	8.8%			
Single	4	3.9%			

Note. % = Valid percent, GA = Gestational Age

Parents answered questions about their expectations and preferences with regard to procedural pain in the NICU. Most parents expected that their neonate would experience pain in the NICU (70.3%, $n = 71$) and identified that their neonate had experienced a painful procedure (87.1%; $n = 88$). The amount of procedural pain intensity that parent's expected was moderate 5.08 ($SD = 2.05$; $n = 79$) on a ten-point scale and slightly higher than what they rated the pain that they observed 4.29 ($SD = 2.34$; $n = 91$), meaning they anticipated the pain to be higher than what they observed.

Most parents reported being asked by staff to stay for procedures (76.3%; $n = 71$) at least *some of the time* and a few indicated they were *never* asked (23.7%; $n = 22$). Most parents indicated they were present (82.0%; $n = 82$) during a painful procedure, at least *some of the time*; while very few (18.0%; $n = 18$) indicated, they had *never* been present. Of parents who reported being present during a painful procedure, 47.6% ($n = 39$) reported *always* providing comfort to their neonate and 25.6% ($n = 21$) reported *often* providing comfort. The remainder of parents

who were present for a procedure reported providing comfort to their neonate *sometimes* (20.7%; $n = 17$); while a small minority of parents reported *never* (6.1%; $n = 5$) providing comfort.

Most parents reported a preference to stay and help provide comfort (68.3%; $n = 69$) and the remainder of parents reported preferring to stay without providing pain care (16.8%; $n = 17$) or to leave the room during the procedure (7.9%; $n = 8$). It should also be noted that a small minority reported they would prefer not to know that their neonate was having a painful procedure (6.9%; $n = 7$). On a ten-point scale, parents provided a relatively strong rating of desire to be with their neonate during a painful procedure [$M (SD) = 8.60 (2.36)$]. Participants indicated they anticipated feeling somewhat comfortable with the situation of being present for a painful procedure performed on their neonate [$M (SD) = 6.99 (3.04)$]; in addition, they expected the situation to be moderately stressful for themselves [$M (SD) = 7.12 (2.72)$].

The outcome measure asked parents to indicate the reason they were most often absent during their neonate's procedures. Many participants selected more than one reason for being absent from the following choices: (a) not applicable (32.7%; $n = 33$), (b) I was away from the hospital (40.6%; $n = 41$), (c) staff asked me to step out (11.9%; $n = 12$), (d) it was too stressful to be there (13.9%; $n = 14$), (e) I was sick (4.9%; $n = 5$) or (f) other (9.9%; $n = 10$). To better understand reasons parents were absent and to obtain the frequencies presented above, each of these responses were dichotomized into two possible options (i.e., yes/no; see table 6). Some of the other reasons written in by parents included "I was not asked or notified", "sterile procedure", "caring for another child", "did not want to watch", "I was at work", "I felt he was in good hands", and "not enough time between feedings to pump, eat and rest."

Table 6

Percentage of parents who endorsed reason for being absent during painful procedures.

Variable	<i>N</i>	%
I was away from the hospital		
Yes	41	40.6
No	60	59.4
Staff asked me to step out		
Yes	12	11.9
No	89	88.1
It was too stressful to be there		
Yes	14	13.9
No	87	86.1
I was sick		
Yes	5	4.9
No	96	95.0
Other		
Yes	10	9.9
No	91	90.1
Not Applicable		
Yes	33	32.4
No	68	66.7

Note. % = Valid percent.

Research Question One

To what degree do parents who have a neonate admitted to a NICU environment experience different types of anxiety? Parental anxiety scores were calculated for each type of anxiety and are displayed in Table 7. Regarding general anxiety, with possible scores ranging from 20 to 80, parents ($n = 102$) reported experiencing moderate levels of general anxiety and, on average, reported higher state anxiety ($M [SD] = 45.29 [13.45]$) than trait anxiety ($M [SD] = 39.86 [11.02]$). Participant scores ranged from 20 to 78 on the state anxiety scale and from 21 to 71 on the trait anxiety scale. Participants ($n = 100$) reported a modest level of NICU related anxiety with an average PSS: NICU score of 2.58 ($SD = 0.81$; $n = 100$); with possible scores ranging from one to five. The subscale with the highest average score was Parental Role Alteration with a mean score of 2.79 ($SD = 0.97$; $n = 102$), followed by Infant Looks and

Behaviour [$M (SD) = 2.57 (0.93)$; $n = 101$] and lastly by Sights and Sounds [$M (SD) = 2.25 (0.81)$; $n = 101$]. Although parental scores of pain catastrophizing ranged from 0 (the lowest possible score) to 52 (the highest possible score); on average parental levels of pain catastrophizing were low with a mean PCS score of 13.79 ($SD = 12.36$; $n = 102$) and a mode of zero.

Table 7

Parents experience of anxiety in NICU.

Variable	<i>N</i>	<i>M (SD)</i>	Standardized Skewness	Kurtosis
General Anxiety				
State	102	45.29 (13.45)	0.294	-0.480
Trait	102	39.86 (11.02)	0.233	0.637
PSS: NICU	100	2.58 (0.81)	0.301	-0.646
Sight/Sound	101	2.25 (0.81)	0.882	1.180
Looks	101	2.57 (0.93)	0.423	-0.597
Parent Role	102	2.79 (0.97)	0.038	-0.750
Pain Anxiety				
PCS	102	13.79 (12.36)	0.820	-0.056

Note. State = State Anxiety, Trait = Trait Anxiety, PSS: NICU = Parental Stressor Scale: NICU, Sight/Sound = PSS: NICU subscale Sights and Sounds; Parent Role = PSS: NICU subscale Parental Role Alteration; Looks = PSS: NICU subscale Infant Looks and Behavior, PCS = Pain Catastrophizing Scale.

Research Question Two

To what degree are the various types of parental anxiety, related to the parents' anticipation of the painfulness/intensity of the procedure? This research question contains two parts therefore two separate multiple linear regression analyses were performed with parental anxieties (i.e., state anxiety, trait anxiety, NICU anxiety and pain anxiety) as the predictor variables. The first multiple linear regression analysis examined the relationship of these anxieties to parents' rating of expected neonatal pain as the outcome variable. The results of the regression analysis are presented in Table 8. While this model, with all predictor variables, explains a statistically significant amount of the variance (8.9%, $n = 79$) in parents'

report of expected neonatal procedural pain ($F_{[4, 72]} 2.87, p = .029$), only one of the four predictor variables made a statistically significant contribution to explaining this variance. Anxiety related to the NICU (i.e., PSS: NICU scores) made a significant contribution to the predictive capability of the model. An increase in NICU anxiety ($\beta = .36$) made a moderately positive contribution to explaining the variation in parental expectation of neonatal procedural pain in the NICU.

Table 8

Results of Standard Multiple Regression of Anxiety Type Affecting Parental Expectation of Neonatal Pain (n = 79)

	B-weight	95% CI	β	t-value (p-value)	R ²	Test Statistics
Predictors						
State	.017	-0.032 to 0.067	.11	0.69 (.490)		$F = 2.87$
Trait	-.006	-0.065 to 0.052	-.04	-0.22 (.825)	.089	$df 4,72$
PSS: NICU	.919	0.157 to 1.674	.36	2.41 (.019)		$p = .029$
PCS	.017	-0.063 to 0.029	-.10	-0.74 (.463)		
Constant	2.431					

Note. 95% CI = 95% Confidence Interval of the B-weights. β = Beta; R² = Adjusted R squared. State = State Anxiety, Trait = Trait Anxiety, PSS: NICU = Parental Stressor Scale NICU, PCS = Pain Catastrophizing Scale.

A second multiple linear regression was completed to examine the relationship of this same set of anxieties (i.e., state anxiety, trait anxiety, NICU anxiety and pain anxiety) with parents' rating of procedural pain intensity as the outcome variable and results are presented in Table 8. This model explains a statistically significant amount of the variance (11.9%; $n = 91$) in parents' report of their neonates' procedural pain intensity ($F_{[4, 84]} 3.97, p = .005$). In this model only one of the four predictor variables made a statistically significant contribution to explaining the variance in parents' rating of their neonates' procedural pain. Once more, NICU anxiety (i.e., PSS: NICU scores) made a significant contribution to the predictive capability of the model. An increase in anxiety related to the NICU ($\beta = .31$) made a mild positive contribution to explaining the variation in parental rating of procedural pain intensity.

Table 9

Results of Standard Multiple Regression of Anxiety Type Affecting Parental Rating of Procedural Pain Intensity (n = 91)

	B-weight	95% CI	β	t-value (p-value)	R ²	Test Statistics
Predictors						
State	.027	-0.025 to 0.078	.15	1.03 (.306)		$F = 3.97$
Trait	-.019	-0.079 to 0.042	-.09	-0.61 (.541)	.119	$df 4,84$
PSS: NICU	.906	0.117 to 1.696	.31	2.28 (.025)		$p = .005$
PCS	.007	-0.041 to 0.056	-.04	-0.30 (.762)		
Constant	1.385					

Note. 95% CI = 95% Confidence Interval of the B-weights. β = Beta; R² = Adjusted R squared. State = State Anxiety, Trait = Trait Anxiety, PSS: NICU = Parental Stressor Scale NICU, PCS = Pain Catastrophizing Scale.

Research Question Three

Is there a relationship between the different types of parent anxiety and parents' desire to be present during their neonate's painful procedure? A multiple linear regression was performed with parental anxieties (i.e., state anxiety, trait anxiety, NICU anxiety and pain anxiety) as the predictor variables and parents' rating of how strongly they wanted to be present during a painful procedure entered as the outcome variable. Although this model approached significance ($F_{[4, 94]} 2.38, p = .057$), it did not explain a statistically significant amount of the variance in parents' desire to be present.

Research Question Four

Do parents who are present and participatory in neonatal procedural pain care differ across levels of general anxiety (i.e., state and trait anxiety), environmental anxiety (i.e., NICU anxiety) or pain anxiety (i.e., pain catastrophizing)? As outlined above, parental participation was dichotomized into participate or not (see table 4). A logistic regression was completed to assess the relationship between parental anxieties and their participation during a painful procedure performed on their neonate in the NICU. The model contained each type of parental anxiety (i.e., state anxiety, trait anxiety, NICU anxiety and pain catastrophizing). The

full model containing all the predictors was not statistically significant, [$\chi^2 (4, n = 80) = 3.39, p = .495$], indicating that the model was unable to distinguish between respondents who participated and those who did not participate.

Post-Hoc Exploratory Analyses

Regression analyses found that PSS: NICU scores made a significant unique contribution to the variance in parental ratings of observed pain and expected pain. Given these findings, post-hoc exploratory analyses were conducted to uncover if any aspect of NICU anxiety was most related to the variance in parental ratings of pain and expected pain.

To explore the relationship between specific types of NICU stress and parental rating of observed pain intensity, a multiple regression analysis was conducted in which the three PSS: NICU subscales (i.e., Sights and Sounds, Parental Role Alteration and Infant Looks and Behaviour) were entered as a predictors of observed pain intensity. Results of the multiple linear regression analysis are presented in Table 10. This model explained a statistically significant amount of variance in parental ratings of procedural pain intensity ($F_{[3, 86]} 6.57, p < .001$). This group of predictor variables explained approximately 15.8% of the variance in parental ratings of observed procedural pain. No one predictor variable made a significant unique contribution to explaining the variance in parental rating of procedural pain intensity. However, the subscale measuring stress caused by the neonate's looks and behaviour approached significance ($p = 0.057$).

Table 10

Results of Standard Multiple Regression of PSS: NICU Subscales Affecting Parental Rating of Procedural Pain Intensity (n = 91)

	B-weight	95% CI	B	t-value (p-value)	R ²	Test Statistics
Predictors						
Sight/Sound	.592	-0.118 to 1.302	.207	1.66 (.101)		<i>F</i> = 6.57
Parent Role	.748	-0.730 to 0.549	-.037	-0.28 (.780)	.158	<i>df</i> 3,86
Looks	-.090	-0.002 to 1.497	.297	1.98 (.051)		<i>p</i> < .001
Constant	2.591					

Note. 95% CI = 95% Confidence Interval of the B-weights; β = Beta; R² = Adjusted R squared. Sight/Sound = PSS: NICU subscale Sights and Sounds; Parent Role = PSS: NICU subscale Parental Role Alteration; Looks = PSS: NICU subscale Infant Looks and Behaviour.

Another multiple regression analysis was performed with the PSS: NICU subscales as the predictor variables (i.e., Sights and Sounds, Parental Role Alteration and Infant Looks and Behavior), with parental expectations of pain as the outcome. The results of this multiple linear regression are displayed in Table 11. This model explained a statistically significant amount of the variance observed in the parental ratings of expected pain ($F_{[3, 74]} 4.26, p = .008$). The total variance explained by this group of predictor variables was approximately 11.3%. Again no one subscale made a statistically significant unique contribution to explaining the variance in parental expected pain ratings.

Table 11

Results of Standard Multiple Regression of PSS: NICU Subscales Affecting Parental Rating of Expected Procedural Pain Intensity (n = 91)

	B-weight	95% CI	B	t-value (p-value)	R ²	Test Statistics
Predictors						
Sight/Sound	.515	-0.173 to 1.203	.206	1.49 (.101)		<i>F</i> = 4.261
Parent Role	.106	-0.513 to 0.726	.050	0.34 (.780)	.113	<i>df</i> 3,74
Looks	.402	-0.324 to 1.129	.182	1.10 (.051)		<i>p</i> = .008
Constant	2.591					

Note. CI = 95% Confidence Interval of the B-weights; R² = Adjusted R squared. 95%; Sight/Sound = PSS: NICU subscale Sights and Sounds; Parent Role = PSS: NICU subscale Parental Role Alteration; Looks = PSS: NICU subscale Infant Looks and Behaviour.

Mothers versus fathers. Upon determining a large number of participants were fathers, further post-hoc analyses were conducted to explore the presence of differences between mothers and fathers across relevant variables. Independent samples t-tests were conducted to compare mothers' and fathers' ratings of expected pain (mothers, [$M = 4.9, SD = 2.25$]; fathers, [$M = 5.3, SD = 1.70$]), actual observed pain (mothers, [$M = 4.3, SD = 2.34$]; fathers, [$M = 4.3, SD = 2.37$]) and desire for participation (mothers, [$M = 8.6, SD = 2.24$]; fathers, [$M = 8.7, SD = 2.56$]). T-tests revealed there was no significant difference in parents' ratings of expected pain ($t [77] = .858, p = .39$, two-tailed), actual observed pain ($t [89] = .039, p = .97$, two-tailed) and desire for participation ($t [99] = 211, p = .83$, two-tailed) based on their sex. A one way between-groups multivariate analysis of variance (MANOVA) was also performed to investigate parental sex differences on measures of anxiety. Four dependent variables were used: trait anxiety, state anxiety, NICU-anxiety and pain anxiety. The independent variable was parent sex (male or female). There was no significant difference between mothers and fathers on the combined dependent anxiety variables, $F (4, 94) = 1.38, p = .247$; Pillai's Trace = .95, partial eta squared = .06. Examination of results from the MANOVA revealed a Levene's test of equality of error variances was significant for state anxiety, indicating the assumption of equal variance had been violated; thus, significance for each set of analyses was determined based on Pillai's criterion, which is less susceptible to this violation (Pallant, 2013; Tabachnick & Fidell, 2007). In conclusion, these analyses reveal no significant differences between mothers and fathers across the relevant variables examined in this study.

Summary

In summary, parent participants on average, self-reported low levels of pain anxiety, moderate levels of NICU anxiety and moderate levels of general anxiety. Regarding general

anxiety, state anxiety scores were overall greater than trait anxiety levels. In reference to NICU anxiety, parental role alteration contributed to the greatest anxiety response among parents with the highest average score of the measures' subscales. Furthermore, multiple regression results indicated that parental anxieties were significantly related to the variance in parental ratings of expected neonatal pain and rating of actual procedural pain intensity; but not significantly related to parental rating of desire (want) to be present. Parents with higher levels of NICU related anxiety reported higher ratings of both expected and observed neonatal procedural pain intensity than parents with lower levels of NICU anxiety. Given these findings (i.e., NICU anxiety was the only predictor variable that made statistically significant unique contribution to parental ratings of expected and observed pain intensity), further post-hoc exploratory regression analyses were completed to examine if any relationship existed between specific types of NICU anxiety and parental ratings of expected and observed pain intensity. These analyses revealed that although the group of predictor variables contributed to the variance in parental ratings of expected and observed pain intensity, no one aspect of NICU anxiety (i.e., NICU Sights and Sounds, Infant Looks and Behaviour or Parental Role Alteration) made a significant unique contribution. However, the subscale measuring the anxiety caused by the neonate's looks and behaviour was approaching significance when explaining the variance in parental rating of observed procedural pain intensity. Finally, logistic regression analysis revealed, in this sample of parents, there were no statistically significant differences in anxiety levels of parents who participated in comfort measures during painful procedures compared to those who did not participate.

Chapter Six: Discussion

There is a growing body of neonatal and FIC literature suggesting that NICU-parents should be involved as the primary caregivers in many aspects of their neonate's care, including pain care. Developments in pain-related literature suggest that multiple variables affect our assessment of and response to an individual in pain, many of which are unrelated to the pain condition itself (Hadjistavropoulos et al., 2011). In the current study, the SCMP (Craig, 2015) was used as a guiding intrapersonal framework within which the PI explored the parental (i.e., observer) intrapersonal characteristic of anxiety in relation to pain assessments and management in the neonatal intensive care setting. The following chapter offers a critical elucidation of the study findings within the context of the SCMP and neonatal pain literature. A review of the study's strengths and limitations will follow, and the chapter will conclude by highlighting the implications for clinical practice and future research.

Parent Demographics

The study sample consisted of 102 parents and while many fathers participated, most participants were mothers (60.8%). These demographics are consistent with other neonatal pain studies that involve both mothers and fathers (Franck et al., 2011, Pillai-Riddell et al, 2004; Polkki et al, 2016). The average age of parents was 31.3 years and consistent with other research of this nature (Franck et al., 2011; Gustafson, LaBrecque, Graham, Tella, & Curley, 2016). The average age of maternal participants was close to the national and provincial average age of women at childbirth (29.9 years and 29.0 respectively; Statistics Canada, 2013), with this study's average maternal age being 30.6 years (paternal 32.3 years). Many studies examine a population of parents of *preterm* neonates when examining parental experiences of the NICU; whereas, in the current study, all parents with a neonate admitted to the NICU were eligible to participate.

Participants were parents of neonates ranging from 24 to 41 weeks' gestation ($M = 32.9$ weeks), which is consistent with the sample of Franck and colleagues (2004; 2005) and slightly younger than the average age of Paloma et al.'s (2016) sample of 35.3 weeks gestation. These findings support that this study's sample could be comparable and representative of other research conducted in the population of interest.

Parent Anxiety

Past research has demonstrated that parents whose neonate is admitted to the NICU experience higher levels of anxiety compared to parents of healthy full-term newborns (Busse et al., 2013; Edell-Gustafsson et al., 2014; Holditch-Davis et al., 2015; Schappin, 2013; Yin et al., 2010). Thus, this study sought to extend this knowledge by determining the degree to which NICU parents experience different types of anxiety and how that may relate to their participation in pain management.

State/trait anxiety. On average parents experienced a higher level of state anxiety than trait anxiety, which is similar to previous studies of NICU parents (Erdem, 2010; Franck et al., 2011; Holditch-Davis et al., 2015). The average parental state anxiety score ($M = 45.3$) in the current study fell within range of what has been suggested in some research (scores greater than 39-40) as a clinically significant level of anxiety; (Addolorato et al., 1999; Knight, Waal-Manning & Spears, 1983; Julian, 2011). Since state anxiety is the temporary experience of anxiety brought on by a specific situation or event (i.e., having a neonate in the NICU; Spielberger et. al., 1983), elevated state anxiety was an expected finding.

As noted previously, the construct of state anxiety is meant to capture one's transient levels of anxiety as they are impacted by situational factors; thus, it would stand to reason that the experience of having one's neonate admitted to the NICU, and exposure to their neonate's

painful procedure, would elevate one's level of state anxiety. However, it's important to note that state anxiety would also encompass broader stressors of an individuals' situation (e.g., family resources, social support, current health, etc.); therefore, it was of interest to examine parents' anxiety specific to the NICU experience and setting. Thus, the concept of anxiety in this circumstance was examined in more detail and theoretically specific to caring for a neonate undergoing a painful procedure in the NICU.

NICU anxiety. Given the parent's higher state anxiety, it is not surprising that on average parents also reported moderate levels of NICU anxiety; indeed, a strong correlation was identified between these two dimensions ($r = .60, p \leq .01$). These findings are in line with other studies of NICU parent anxiety using the same measure (Franck et al., 2005; Franck et al., 2011; Gustafson et al., 2016; Miles et al. 1993). In this study, parents reported moderate levels of anxiety related to all three aspects of the NICU as examined by the three subscales encompassed within the PSS: NICU (Sights and Sounds, Infant Looks and Behaviour, and Parental Role Alteration; Miles et al., 1993); that is, as a group, parents scored in the moderate range on each of these subscales. However, parents scored relatively higher on the Parental Role Alteration subscale, followed by Infant Looks and Behaviour. The finding of greater levels of anxiety related to this element of the NICU experience (i.e., parental role alteration) is a consistent finding with previous studies of NICU parents (Busse et al., 2013; Gustafson et al., 2016; Franck et al., 2005; Miles et al, 1993; Woodward et al., 2014).

There are several possibilities that could explain the relatively higher levels of parental NICU anxiety related to their role alteration (as opposed to the physical environment of the NICU). First, qualitative studies have shown that NICU-parents express distress related to their perception of having a restricted and secondary role (following nursing staff) in parenting their

neonate (Lupton & Fenwick, 2001; Obeidat, Bond & Callister, 2009; Palomaa, Korhonen & Polkki, 2016; Provenzi et al., 2016). Thus, it is likely that parental anxiety related to role alteration stems from having to adjust to the loss of independence in parenting their neonate as they might have expected when imagining themselves as parents of a newborn (Black, Holditch-Davis & Miles, 2009). Second, along with the loss of the independence, it is also possible that adopting a parental role earlier than expected and in such a public environment (i.e., learning to parent one's neonate under the view of medical professionals) may be anxiety-provoking for parents. Indeed, previous research demonstrates that mothers wish to be seen as a 'good mother' when parenting in a nursery setting (Lupton & Fenwick, 2001), and this may add additional expectations and anxiety to parents adjusting to a new role. Given that the current study did not utilize narrative discussion or follow-up questioning regarding responses, it is difficult to conclude the reasons for parental role alteration to elicit a greater level of anxiety than other NICU elements in this study.

Pain anxiety. Another anxiety construct which may also contribute to the elevated levels of state anxiety in the current study's parents may have been pain anxiety; with a strong correlation found between these two variables ($r = .45, p = \leq .01$). A well-established body of research has shown that an individual's tendency to catastrophize about their own pain experience has a significant impact on their tendency to catastrophize about the pain experience of others. Although the vast majority of this research has been conducted within the context of adult dyads (Bailey et al., 2012; Sullivan et al., 2006), researchers have begun to demonstrate that parental catastrophizing about their own pain predicts their tendency to catastrophize about their child's pain (Kraljevic et al., 2012; Langer, Romano, Levy, Walker, & Whitehead, 2009). While no known study has looked at parental pain anxiety (i.e., pain catastrophizing) in relation

to their response to their neonate's pain, the findings reported above suggest it may be a construct of interest. In the current study the average level of pain anxiety (i.e., PCS scores, Sullivan et al., 2009) was relatively low ($M = 13.8$). Sullivan and colleagues (2009) suggest an expected mean PCS score of 20 amongst adults with chronic pain, with scores greater than 30 considered a clinically relevant level of pain anxiety. However, Sullivan and colleagues (2009) also caution against using these limits with asymptomatic samples, or individuals experiencing acute pain. Given that this parent sample was not considered the primary patients and likely asymptomatic, it is not surprising that participant pain anxiety scores fell below the average of those with chronic pain and well below the level of suggested clinical significance. The average PCS score in this sample is consistent with other asymptomatic adult samples (Goubert et al., 2008; Osman et al., 2000; Van Damme, Crombez, Bijttebier, Goubert & Van Houdenhove, 2002). The following sections are an elaboration on these findings and provide insight into the relationship between these anxieties and parental expectations/observations of their neonate's pain during painful procedures.

Parental Perceptions of Neonatal Pain

Overall, parental reports of moderate levels of intensity regarding expectations and observations of neonatal pain are consistent with previous studies by Franck and colleagues. In 2001 Franck and colleagues also found consistency across the expected and actual observed levels of neonatal pain. While Franck and colleagues (2004) found that parents actually observed greater levels of pain than expected, this finding may be explained by a distinction between the questions posed by each study: that is, Franck and colleagues measured the *worst* level of pain observed whereas the current study measured the *average* level of pain observed.

Parental anxieties and their perceptions of neonatal pain. When examining the relationship between parental anxieties and their ratings of expected and observed neonatal pain intensity in the NICU, it was found that approximately 8.9% and 11.9% of the of the variance in parental ratings, respectively, may be explained by participants' anxieties (i.e., state anxiety, trait anxiety, NICU anxiety and pain anxiety). However, only one of the four types of anxiety made a statistically significant and unique contribution to explaining the variance in parents expected and observed pain. In both analyses, an increase in the level of NICU anxiety (i.e., PSS: NICU scores) made a moderately positive contribution to explaining the variation in both parents' expectations and observations of neonatal procedural pain intensity. To facilitate the discussion of these analyses, a review of the findings within the context of the four dimensions of anxiety (i.e., NICU anxiety, state and trait anxiety, pain anxiety) follows.

NICU anxiety and perceptions of pain. Parents were asked, if they were present for a painful procedure, to rate the average amount of pain felt by their neonate (i.e., observed pain). This study's finding, that parental NICU anxiety was a significant predictor of ratings of observed pain, is in line with those of previous research conducted by Franck and colleagues (2004); who found that parents with high NICU anxiety rated their neonate's current pain higher than those with low NICU anxiety. Given these findings, post-hoc exploratory analyses were conducted to determine whether any single aspect of NICU anxiety was uniquely contributing to this finding. When entered together, all aspects of NICU anxiety (i.e., three PSS: NICU subscales; Sights and Sounds, Infant Looks and Behaviour, and Parental Role Alteration) accounted for 15.8% of variance, however no single subscale was found to be a significant predictor of parental ratings of observed pain intensity.

The finding that parents with higher levels of NICU anxiety expect more procedural pain, compared to parents with lower levels of NICU anxiety, appears to be the first of its kind. Although, Franck and colleagues (2004) measured both parental expectations of neonatal pain and NICU anxiety, they did not publish any analyses regarding the relationship between these two variables. Again, post-hoc exploratory analyses were conducted to determine which, if any, aspect of NICU anxiety was uniquely contributing to this finding. Not surprisingly, as with observations of pain, all aspects of NICU anxiety accounted for 11.3% of the variance in parental expectations of pain intensity, when entered simultaneously. This exploratory analysis suggests that parents experiencing higher levels of NICU setting anxiety may also be more likely to expect higher levels of pain for their neonate. However, no single aspect of the NICU experience was found to contribute uniquely or significantly to the variance in parental ratings of expected pain. Although results could not be found for comparison, it is possible, given the positive relationship found between parental NICU anxiety and higher ratings of expected and observed procedural pain, that parents who expect higher levels of pain are also likely to rate observed pain higher.

A brief consideration of the nature of anxiety, including its current conceptualization as an interactive system of cognitive, physiological, and behavioural components may provide a good explanation for these heightened expectations and observations of pain. In particular, it has been well established that subjective anxiety as evoked under conditions of uncertainty and uncontrollability, is associated with greater estimations of anticipated threat and danger (Grupe & Nitschke, 2013). Furthermore, it is also well established that anxiety, via activation of the sympathetic nervous system, is associated with hypervigilance and orientation towards threat detection (Bar-Haim, Lamy, Pergamin, Bakermans-Kranenburg & Ijzendoorn, 2007). In turn,

such hypervigilance is associated with increased perceptions of danger and risk (Bar-Haim et al., 2007). Thus, a parent's tendency to anticipate and observe greater risk (i.e., pain for their child) when feeling anxious within the unpredictable and uncontrollable NICU environment, is not a surprising finding.

State/trait anxiety and perceptions of pain. This study did not find a significant relationship between either parental state or trait anxiety and observations or expectations of pain. There are few studies that examine the effect of parental state and trait anxiety on their assessments of neonatal pain. In a study of parents of children, Link and Fortier (2015) found that, parents with higher trait anxiety perceived their children as having more frequent episodes of pain than did parents with lower trait anxiety. With neonates, Franck et al. (2004) reports that state anxiety was associated with greater expectations of pain and greater ratings observed pain. The lack of findings regarding an association between state anxiety and parental perceptions of pain intensity was unexpected. A relationship seemed likely given the clinically elevated average state anxiety scores, as well as the significant correlations between state anxiety, and both observed and expected ratings of pain. However, strong correlations were also found between the measure of state anxiety and the measure of NICU anxiety; thus, it is quite likely any predictive power of the state anxiety variable may overlap significantly with the NICU anxiety item.

Pain anxiety and perceptions of pain. There is a growing body of literature suggesting that the tendency to catastrophize about pain influences one's emotional and behavioural responses to pain (Quartana et al., 2009); yet, in this study, no significant relationship between pain anxiety (i.e., pain catastrophizing) and parental pain assessments (observed) was evident. Furthermore, pain anxiety has been found to impact parental behaviours and reactions to their

child's pain (Caes et al., 2012; Caes et al., 2011; Goubert et al., 2006). Research with adult and paediatric pain, demonstrates that those who experience anxiety about pain tend to perceive greater levels of pain in others (Sullivan et al., 2006, Bailey et al., 2012). The lack of relationship between parental pain anxiety and their perceptions of pain is contradictory to what has been found in the paediatric and adult pain populations. It is possible that the lack of significant findings in the current study is due to several factors; first, most studies to date include individuals experiencing chronic pain, whereas the current study includes relatively young adults of child-bearing age who may be less likely to suffer from such chronic pain. Although this information was not captured in the demographics of this study, the average age of parents in the current study (31.3 years) is much lower than commonly reported average age in chronic pain samples (e.g., 49.9 years; Brevik, Collett, Ventafridda, Cohen & Gallacher, 2006; Caes et al., 2012; Goubert et al., 2006). Furthermore, the national prevalence of chronic pain for this age group (i.e., 26-35 years of age) is relatively low for both women and men (i.e., 17.4% and 15.3%, respectively; Schopflocher, Taenzer, & Jovey, 2011). Secondly, and in line with the prior comment, the mean level of pain anxiety found in the current study was quite low, limiting the variance available for analyses. Thirdly, similar to state anxiety, a strong correlation was found between the measure of pain anxiety and the measure of NICU anxiety; thus, it is again possible that any independent predictive power of the pain anxiety variable may overlap significantly with the NICU anxiety item.

Parent Participation in Pain Care

Previous research indicates that NICU parents want more involvement in their neonate's procedural pain management (Franck et al., 2011; Franck et al., 2012; Orr et al., 2017). Results of this study provide further support for this; on a multiple-choice scale (i.e., stay at the bedside,

stay and help by providing comfort, leave the room, not know it was happening), the majority of parents indicated, during a painful procedure, they would prefer to either be present and provide comfort to their neonate, or to simply be present with their neonate. Furthermore, parents' scores indicate a strong desire to be present (average of 8.6/10); despite the finding that parents expect to experience a substantial amount of personal stress, and being only moderately comfortable if present while their neonate was undergoing a painful procedure. The anticipation of stress and discomfort are noteworthy given how strongly parents rate their desire to be with their neonate during a painful procedure. These findings of desire level are not novel or unexpected, further demonstrating that overall, parents want to participate in their neonate's pain care. Despite this desire to participate, there are several factors that influence parents' actual participation.

Factors affecting participation. Given the literature on the topic of FIC and parental participation, it is known that NICU parents are not always present at their neonate's bedside (Griffen, 2013). Although this study's aim was to explore how intrapersonal parental characteristics relate to their perceptions of, and participation in, neonatal pain care, it is well known that interpersonal and systemic factors can impact parental participation (i.e., parental absences, lack of invitation by hospital professionals, and poor parental pain education; Benoit et al., 2016; Chertok, et al., 2014; Franck et al., 2011; Heinemann et al., 2013). Most studies exploring parental participation in neonatal pain management have focused on these factors.

Nurses and health care professionals. Health care professionals' attitudes and behaviour are often cited as a factor with the potential to influence parental participation in the NICU; negative or ambivalent attitudes may lead to parents feeling unwelcome at the bedside or being asked to step out during procedures (Franck et al., 2012; Heinemann et al., 2013; Russenberger et al., 2016). In fact, Franck's 2011 results indicate that less than 25% of parents

were asked about their preferences for participation in pain management. Of note, the findings of the current study contradict these 2011 findings of Franck and colleagues; with most parents (76.3%) reporting that, staff did invite them to be present during a painful procedure at least some of the time. In this NICU study setting only 23.7% of parent's report 'never being asked' to stay and even fewer (11.9%) report that they had 'been asked to leave.' It is impossible to determine the context in which parents were asked to step out (i.e., how it was presented to them and how this request made them feel) in the current study. Evidence indicates that nurses are the most highly valued source of information for NICU parents (Orr et al., 2017) and although not part of this study, that presenting information to parents about the procedure, their role, and the significance of their presence, may increase their participation in pain care (Palomaa et al., 2016).

Given that NICU nurses have traditionally been responsible for the implementation of non-pharmacological pain management with neonatal patients, it stands to reason that they would serve a significant role in enabling parents to fulfill this role. The contradictory reports in the literature indicate that nurses can serve as either a barrier, or facilitator, to parental participation; this seems to further suggest that nursing's approach to parents is integral to a parent's involvement in pain care (Heinemann et al., 2013; Marfurt-Russenberger et al., 2016; Palomaa et al., 2016). That is, affording parents an opportunity to stay and participate may encourage and facilitate their participation; in contrast, asking them to step out may be discouraging and thus, hinder their participation. The findings of this study, which show an improvement in the number of parents being invited to participate, are encouraging. Although the difference in the current findings may be a result of numerous factors (e.g., a difference in sample, NICU setting or NICU culture), it may also indicate a change in nursing practice,

effective implementation of FCC or FIC, and translation of evidence into practice. It is of note, given the role of systemic issues that six years have passed between the Franck et al.'s RCT, and the current study. This time frame seems to have coincided with an increase in neonatal research. Indeed, a recent comprehensive review has shown a significant increase in research focusing on the neonatal pain population, over time (Caes et al., 2016).

NICU environment and policies. Research has demonstrated that the type of NICU (i.e., open bay versus private rooms) can impact parental involvement with their neonate's care (Palomaa et al., 2016; Shahheidari & Homer, 2012). Also, units with policies outlining pain management and parental involvement are liable to have increased participation and lower levels of neonatal pain (Akuma & Jordan, 2011; Reavey et al., 2014). With the current study site being an international center of excellence around neonatal pain research and management, the speculation that this study's findings are a result of changes in nursing practice and uptake of neonatal pain and FCC/FIC evidence may be likely. The hospital pain policy encourages the use of patient support systems and this NICU's policy for providing KC recognises its use as a non-pharmacological method of pain control and states that parents should be encouraged to provide KC during any procedures that are safe to perform in this position.

Furthermore, this particular NICU is located in the IWK Health Centre, hospital documents state that the IWK is committed to providing safe, high-quality patient and family centered care. The IWK is also home to the Centre for Pediatric Pain Research (CPPR). The CPPR is an international leader in interdisciplinary paediatric pain research. This NICU frequently participates in research and has been the research site of many published studies with a focus on neonatal procedural pain (e.g., Campbell-Yeo et al., 2013; Johnston et al., 2011; Orr et al., 2017; Latimer et al., 2011). The IWK NICU's public website gives a brief overview of the

NICU and encourages parents to “spend as much time with your baby as you wish and to help in the care of your baby as much as possible.” Additionally, this unit has several parent rooms for parents to room-in near or with their neonates, and is about to undergo renovations that will facilitate the implementation of FIC. These renovations include 44 private rooms; allowing neonates and their families to remain together and webcams that allow parents to be involved when they cannot be physically present. These NICU changes aimed at improving family involvement and moving from FCC to FIC further illustrates the efforts put forth by this facility to provide evidence based care to its patients and their families. Taken together, these factors may indicate this NICU has a very supportive parent culture; which, may assist in explaining why parents were more welcome to participate and did so at higher rates than other research.

Reasons for parental absences found in this study. Given the incidence of painful procedures in the NICU and evidence suggesting numerous potential impediments to familial presence at the bedside, this study took the opportunity to inquire as to the primary reason parents were most absent during their neonates’ painful procedures (on a multiple-choice scale). Many parents’ chose more than one response option, while a few, in writing, gave additional reasons that were not included in the list. The fact that parents felt the need to select multiple options could be an indication of the myriad of conflicting demands on a parent’s life. Despite the presence of the option ‘I was away from the hospital,’ which was the most frequently endorsed reason for parental absence (40.6%), some parents wrote “caring for other children,” “at work” and “in my hospital room” as reasons for their absence. These multiple replies and written additions may suggest that some parents feel the need to justify their absence from the NICU.

Parents in this study also said, ‘it was too stressful’ (13.9%), or they did not want to be there during a procedure (7.9%). Few indicated they would prefer not to know their neonate was having a procedure (6.9%). These findings may indicate that even in the absence of barriers (e.g., family commitments, staff support, accommodations to stay, etc.), a small number of parents may prefer or opt to leave during a painful procedure. This finding, of a very small percentage of parents preferring to be absent for procedures is in keeping with other studies of parent participation in pain care (Franck et al., 2011; Campbell-Yeo et al., 2010). Other notations made by parental participants to potentially explain their absences were “would not want to be there,” “did not want to watch,” and “felt he was in good hands.” These statements may indicate that parents were not disappointed if they were absent and that they trusted staff to comfort and care for their neonate.

Anxiety and parental participation. Guided by the SCMP (Craig, 2015), it was of interest to explore how intrapersonal parental characteristics (i.e., anxieties) relate to their participation during their neonate’s painful procedures. Logistical regression analyses did not find parental anxiety to be predictive of participation. That is, parents who participate in pain care did not differ in anxiety from those who did not participate. Although no other studies have examined anxiety’s impact on parental participation in this manner, previous research into paediatric and adult pain populations has demonstrated that anxieties are associated with responses toward and management of another’s pain (Caes et al., 2012; Caes et al., 2011, Cano et al., 2003; Goubert et al., 2006). Franck and colleagues’ (2011) RCT, previously discussed in chapter two, may provide some further insight. In this RCT, they attempted to explore the impact of a pain education program on parents’ NICU anxiety as well as their desire to participate in their neonate’s pain management. They found no significant difference in parent

participation in pain care between the intervention and control group. Franck and colleague's pain education intervention was also unsuccessful in its attempt to decrease NICU-related parental anxiety. Despite these shortcomings, parents who received education regarding pain management expressed a stronger desire to participate in their neonate's pain care (90% versus 75% for the control group). Based on the findings of the current study and those of the RCT (Franck et al., 2011), it appears neither lack of parental education nor parental anxieties are associated with parental provision of pain care in the NICU, yet the intervention may be a factor as well. Furthermore, these studies suggest that anxiety may not significantly impact parental desire for participation.

Anxiety and Desire for Participation

Given the conflicting demands faced by many new parents and the myriad of reasons for parental absence during neonatal painful procedures, this research sought to explore parental desire to be present. It was hoped that this would allow for examination of how strongly parents wanted to participate in the absence of other barriers and how parental anxieties were related to their desire level; thus, the question posed to parents was '*In an ideal world without any barriers, how strongly do you **want** to be with your baby when they are having a procedure?*' Although regression analysis findings were approaching significance, ultimately the analysis did not explain a statistically significant relationship between anxieties and desire for participation. Given that this is the first known study to examine this relationship, comparison to other research is difficult. Due to the potential of anxiety to induce avoidance, coupled with the significant level of anxiety found in these participants, the absence of a relationship between anxiety and desire for participation in pain care was unexpected.

The lack of a significant relationship may indicate that parental desire to be present is not influenced by their anxieties or that desire to participate may overpower their feelings of anxiety toward the situation. In short, even though parents were anxious in the NICU setting, they still want to participate in pain care. Taken together, one could propose that parents are aware that they themselves will experience anxiety or distress during their neonate's painful procedure but are willing to place the comfort of their neonate ahead of their own.

Parental pain response within the SCMP. Within the SCMP (Craig, 2015), this study examines only one intrapersonal observer characteristic (i.e., parental anxieties), on two stages of this model (i.e., pain assessment and pain response) and found support for a positive relationship between anxieties and the assessment stage (i.e., observations of pain). The finding that parental anxieties are not related to participation or desire for participation could initially appear to be contrary to the model; which posits that observer characteristics impact their pain response or provision of pain care. However, that would be a disservice to this model, because its purpose is to consider the broader context in which the pain is being experienced. This model argues that the pain experience is not limited to the traditional biomedical model of pain (Bendelow, 2013); and that multiple factors are interacting to influence the experience, expression, assessment and response to pain. Other factors put forth by the SCMP (Craig, 2015) could be moderating the impact of anxieties on parental provision of pain care. For example, aside from the intrapersonal characteristics of the parent (i.e., the observer), this model calls into consideration the context in which the pain takes place, the interpersonal characteristics of those involved, and the intrapersonal characteristics of the pain sender. In the scenario whereby a neonate is undergoing a procedure in the NICU other elements that may factor into a parent's desire for participation according to the SCMP include: (i) the context and setting of the procedure including elements

like the number of health care professionals present, type of procedure, privacy from other patients and parents, (ii) the interpersonal relationship, in this case the parent-neonate relationship, (iii) intrapersonal characteristics of the pain sender, including but not limited to, the neonate's size, age, sex, expressiveness and perceived vulnerability. Certainly, other research has demonstrated these elements can significantly impact each of the four stages of this model (Hadjistavropoulos, Craig, Grunau & Whitfield, 1997; Pillai Riddell & Racine, 2009).

It is highly possible that these other elements, particularly the interpersonal parent-neonate relationship, are enough to overpower the experience of parental anxieties; thus, lessening their impact on desire for participation. Indeed, in the development of the SCMP, Craig (2015) expected that relationships between the observer and pain sufferer would have a major impact on one's desire to provide pain care. One could speculate that if these same parent participants were asked about the pain of a neonate who was not their own child, anxieties' impact on their assessment and desire for participation may be very different. Understanding why other elements may win-out over parental anxiety when examining responses to their neonates' pain within the SCMP, may be better understood by examining literature that attempts to explain parenting motivation, values and goal prioritization.

The urge to avoid an anxiety-provoking situation, like the experience of pain (Craig, 2015), does not occur in isolation; there are often multiple competing emotions, factors or goals occurring simultaneously (Crombez, Eccleston, Van Damme, Vlaeyen & Karoly, 2012, Rasmussen, Wrosch, Scheier & Carver, 2006). When faced with pain inflicted on their neonate, along with anxiety, parents may experience a myriad of competing emotions and desires (e.g., empathy, desire to protect their neonate, desire to be a good parent, etc.) and may be required to make a judgement of which desires and emotions to act upon. It is possible that parents may

place a higher value on these other emotions than on the avoidance of anxiety, explaining their desire for participation in the face of anxiety. This idea is in line with goal pursuit theories.

Goal pursuit. Goal pursuit theories suggest that individuals can shift their priorities between goals depending upon the outcome value (Karsdorp & Vlaeyen, 2011; Winch, Moberly, & Dickson, 2015). Goal pursuit is most often examined within the context of chronic pain populations and useful when considering the anxiety literature (Schrooten, Wiech & Vlaeyen, 2014; Winch et al., 2015). It has been found that individuals may be willing to prioritize long term achievement goals over short term hedonic goals (i.e., mood/pain management goals; Karsdorp & Vlaeyen, 2011). That is, they may be willing forgo avoidance of upsetting sensations (e.g., pain, anxiety) to pursue an achievement goal that holds higher importance to that individual. Given this, it is possible that, amongst participants who place a higher value or importance on achievement of positive parenting, the pursuit of this goal may diminish the avoidance tendency of decreasing anxiety.

Motivation. Along with goal pursuit theories, self-determination theory (SDT; Deci & Ryan, 2000) and parent motivational research may offer some explanation of parent behaviour in this circumstance. Briefly, SDT (Deci & Ryan, 2000) suggests two classes of variables that impact one's motivation to behave: intrinsic (i.e., autonomous) and extrinsic (i.e., controlled). Autonomous motivation captures the tendency to carry out a task because it is interesting and meaningful, and is derived from internal values (Deci & Ryan, 2000; Jungert et al., 2014). Controlled motivation refers to the tendency to carry out a task based on expectations or pressures; this motivation derives from societal pressures (Deci & Ryan, 2000; Jungert et al., 2014). When examining parenting motivation, Jungert et al., (2014) found autonomous motivation for parenting was higher when parenting younger children as opposed to older

children. Although they did not include a neonatal population, one could postulate that this finding might extend to parenting motivations of NICU-parents as well. As suggested by Desi and Ryan (2000), parents may derive meaning, competence and autonomy from providing comfort care to their neonate and thus explain their high desire for participation. Given the complex interplay of emotions and competing goals parents are experiencing in this environment, it is also plausible that controlled motivations may be at play in the NICU as well. That is, parents may feel an obligation to attend to their neonates' pain; especially if parents perceive that participation is an expectation of NICU staff or as a means to be viewed as a good parent. Although not related to pain, it has been found that mothers' choice to breast feed can be motivated by autonomous and/or controlled factors (Kestler-Peleg, Shamir-Dardikman, Hermoni & Ginzburg, 2015), raising the possibility that parenting motivations in the neonatal period may be derived from either of these sources. Yet, these concepts were not under study in this research.

Furthermore, previous findings indicate that anxiety has a complicated relationship with behaviour (Mendl, 1999; Wu & Cheng, 2006). Varying levels of anxiety have a different impact on one's actions; with higher levels of anxiety leading to poor performance or avoidance and moderate levels of anxiety being associated with problem solving and preparation (Andreano & Cahill, 2006; Mogg & Bradley, 1998; Yerkes-Dodson, 1908). In the absence of physical barriers, parental choice to participate in neonatal pain care likely depends on a myriad of contextual factors (e.g., type of painful procedure, their role in pain management, level of pain intensity, etc.), along with parental intrapersonal and interpersonal characteristics (e.g., values, personality traits; propensity to be anxious, attachment to their neonate, etc.; Austin & Vancouver, 1996; Caes et al., 2012; Eccleston & Crombez, 1999; Goubert et al., 2008). This

complex interplay is in keeping with the SCMP (Craig, 2015); however, it is possible that the linear examination of anxiety's impact on parental provision of pain care was not enough to capture the complex nature of this phenomenon. That is, focusing on one element of this model (i.e., observer anxiety in this study or parental pain knowledge; Franck et al., 2011) in isolation of other factors might be too narrow a focus to fully understand what impacts parental participation.

In conclusion, although the examination of goal pursuit theory and SDT may enrich our understanding of parental behaviour, the SCMP (Craig, 2015) does suggest a complex, comprehensive examination of the many factors that may impact the experience, expression, assessment and treatment of pain. In fact, a parent's values and source of motivation could also be interpreted as intrapersonal characteristics of the pain observer. Thus, it is likely that there are other intrapersonal characteristics of parents impacting their responses to their neonate's pain that were not specifically under study or evident in the current study.

Limitations

Although a strength of the current study is that it is the first known study to examine parental observer characteristics about neonatal pain assessments and responses, it is not without its limitations. Firstly, correlational descriptive designs are generally regarded as weaker in comparison to experimental or quasi-experimental designs (Polit & Beck, 2012) due to the inability to make inferences of causality. That said, this design was practical and appropriate (sample size, etc) to address the research questions put forth and added information to begin filling the gap in current neonatal pain literature. Attempts were made to critically examine these research findings within the existing literature to increase the value of these findings. Taken at face value, these findings will provide valuable descriptive information and provide a foundation

for further investigation into the intrapersonal characteristics of parents and how they impact their provision of pain management to their neonates in NICU. However, it is recognized that this is one of the first studies to apply some of these propositions to parents of neonates; thus, further research is necessary to generalize findings.

Secondly, convenience sampling from only one NICU was employed from September 2016 through March 2017. Although all eligible participants were recruited, not all eligible participants opted to participate and complete the study questionnaire. This type of sampling makes generalizability difficult as it is impossible to know if the parents who chose to participate were typical of the NICU-parent population (Polit & Beck, 2012). Another limitation is that it is not possible to calculate an accurate response rate for this study, due to the method of questionnaire distribution. That is, initially questionnaire packages and a five-dollar honorarium were distributed passively (i.e., questionnaires were located in the NICU for parents to ‘take one’ for completion and return to a drop-box). During this time of passive distribution questionnaire distribution was high; however, return was quite low and there was some concern that questionnaire packages were taken to obtain the gift cards rather than for participation in research. With the approval of the REB, this concern led to the revision of distribution method and the removal of gift cards from the questionnaire packages. Parent participants were actively recruited (i.e., approached by the PI in person) as well as passively and only received honoraria upon return of their questionnaires. The questionnaire return rate improved with these changes. Exact response rates were not calculated before and after this change in recruitment and distribution to truly determine the effect of distribution method on overall response rate. Forty three percent of all questionnaires were returned; however, it is unknown what percentage of the population was truly sampled and participated. Furthermore, it is not possible to collect

information from those who declined participation. It is possible that parents who are anxious about their neonate's admission to the NICU may feel too overwhelmed to participate in research. Sampling from only one NICU and a response rate of 43% reduces the ability to generalize this study's findings to other NICU-parent populations.

Thirdly, the use of self-report questionnaires to collect data is a limitation of this study. Questionnaires may be subject to social desirability bias (i.e., participants may choose responses that are more socially desirable versus their actual experience; Polit & Beck, 2012). Another limitation of self-report measures is increased likelihood of blank responses, missed items and the inability to assess participant understanding (Polit & Beck, 2012). To reduce these effects, questionnaire packages were submitted anonymously in sealed envelopes. Furthermore, questionnaires may oversimplify the topic of interest and not allow for a full evaluation of participants' rich and complex experiences. It should also be noted here that most items included in the outcome measure had not been pre-validated prior to its implementation, which is a further limitation of this study. Particularly the self-report item that sought to measure parent desire for participation may have presented a limitation to this study. Although it was deemed to meet criteria for normality most scores falling at the upper end of the rating scale (79.2% fell between 8 and 10) which could suggest a ceiling effect (Polit & Beck, 2012). Polit and Beck (2012) warn that ceiling effects of parent desire for participation may reduce the correlations between parent desire and other parent characteristics.

Studies involving NICU parents traditionally focus on mothers, whereas this study opted to include both mothers and fathers. Since each parent was thought to have an individual and unique view of neonatal pain mothers and fathers were treated as independent in the analysis. To protect anonymity, if both parents chose to participate their responses were not linked to each

other. Though this may be a limitation, this method was supported by findings of previous research conducted with both mothers and fathers (Franck et al., 2004; 2011). In a study evaluating both maternal and paternal views of neonatal pain, it was found that responses of the couples did not differ significantly from the total group or from the respective subgroups of mothers and fathers, and their responses were not more correlated than for the total group (Franck et al., 2004; 2011). It is difficult to determine representativeness of a sample as the characteristics of those who opt not to participate are unknown. However, the large number of fathers who participated helps make this study more representative of NICU-parents; whereas in past research fathers have often been under represented.

Sample size calculations were conducted prior to initiating data collection and the recommended sample size was reached. However, a larger sample would likely yield more accurate results and be more representative of the NICU-parent population and may have provided further insight into analyses approaching significance (Polit & Beck, 2012). Also, a larger sample size would have been advantageous for examining the relationship between parental anxieties and their actual participation in pain management during a painful procedure. Sample size recommendations for logistic regressions were met; however, a similar proportion of cases in each group of the dichotomous outcome variable is also recommended (Polit, 2010). Despite attempts to improve the similarity between the two groups via dummy coding, outlined in Chapter 4 (table 4), the proportion of cases in each group remained far too uneven. Ultimately, the inability to divide the groups as desired (i.e., participatory versus non-participatory) is a limitation of this study, which may have been improved upon with a larger sample size.

Implications

Despite the limitations of this research, this study is the first to evaluate the parental assessments of pain and provision of pain care through the SCMP lens within the context of neonatal procedural pain. Although the preliminary nature limits the number of studies for comparison, it was successful in its goal of exploring parental anxieties and their relationship to parent expectations/observations of pain and desire for participation. Furthermore, this research can serve as inspiration for further examination of parental perceptions of neonatal pain and their desired level of participation and may include measures of motivation and goal pursuit theory. It also provides valuable information to NICU staff on the parental experience of neonatal pain and participation in pain care and that even though parents experience a high degree of NICU anxiety they want to participate in their neonate's pain care.

Implications for future research. Anxiety and stress are complex emotions that motivate behaviour differently depending on the level experienced; their impact on parental behaviour within the context of neonatal pain management needs further examination. Different methodology might provide additional information into parental participation and their experiences within this aspect of NICU-parenting. Observational studies, qualitative interviews, RCTs, interventional, longitudinal and/or mixed methods studies along with the incorporation of other theories, would deepen the understanding of pain management/participation preferences of NICU parents.

Although most parents expressed a strong desire to be present with their neonate and/or participate in keeping them comfortable, there are still a small number of parents who express a preference to step out or not know the procedure was happening. Given that these parents are the minority, further research into this population of parents may provide improved understanding of

parents who opt out of participation. The use of qualitative methodology would allow further narrative understanding surrounding this phenomenon. Furthermore, given that sample size requirements for qualitative research are generally smaller, this methodology may be more appropriate to study this subgroup of parents. Additionally, previous research has suggested parental participation in their neonate's care may increase overtime (Skene et al., 2012). Thus, longitudinal research would allow for the examination of anxiety and participation in pain care over the duration of the admission.

Observing parent interactions with their neonate and NICU-staff may illustrate facilitators and barriers to parental participation. Furthermore, the incidence of study participants adding narrative information to a forced choice questionnaire item asking about parental absence during painful procedures, may point to parents wanting to provide additional details that this type of questionnaire does not allow. It was speculated that parents may feel the need to justify why they were absent from the bedside, this speculation could use further exploration; and may be better examined though a qualitative lens.

Given the paucity of studies examining neonatal pain within the context of the SCMP, further research into any aspect of this pain model with this pain population would add to the neonatal pain and SCMP literature base. The findings of this research support previous research indicating parents want to participate; it appears this desire persists despite an expected level of discomfort and anxiety. The absence of a significant relationship between parental anxieties and level of desire to participate may be just as important as if a relationship was found. Further studies are needed to support and expand on the interplay between parental anxieties and motivation to participate is of interest and warrants further investigation. Thus, the examination of this phenomenon more fully within the SCMP (Craig, 2015) and/or within the context of other

theories (e.g., SDT; Deci & Ryan, 2000) may deepen our understanding of parental pain responses.

Nursing practice implications. While parents want to participate, nurses be gatekeepers to the neonatal patients in the NICU and they are perfectly positioned to facilitate participation and empower parents to be actively involved in their neonate's care. Attempts to integrate parents into this environment and involve them in their neonate's care may improve their assessments of pain and in turn reduce parental anxiety, as well as result in positive outcomes for their neonate.

This study results indicate that parental anxieties are related to parental assessments of pain but not to their desire to participate in pain care. Thus, nurses could be more aware that even if a parent appears anxious or hesitant to be present or participate in pain management they may still desire to support and comfort their neonate. Nurses could afford all parents the opportunity to participate and be supportive of parental presence at the bedside during painful procedures.

These findings contribute to the body of literature that guides FCC, FIC and pain management practices in the NICU. Future research is needed to better understand parental motivation to participate in their neonate's pain care despite the experience of anxiety; in the meantime, the findings of this study serve to raise consciousness and discourse surrounding parental participation in NICU pain management. Going forward, if nurses acknowledge parental anxiety, explore their preferences for participation and support them through this process it may ultimately improve health services to neonates and their parents.

Conclusion

In summary, this research has successfully met its goal of exploring the relationship of parental anxiety to perceptions and participation in management of neonatal pain while in the NICU setting. It is the first step in filling some of the existing gaps in the literature, in that it is the first study to examine parental observer anxieties in relation to neonatal pain assessments and responses within the framework of the SCMP. It is evident that motivation of parent behaviour about participation in pain management in the NICU is complex. The interplay of parental emotions, goals and values, along with external and systemic factors requires further examination to more fully understand the drive behind parent participation.

In the meantime, nurses can attempt to allay parental anxiety surrounding their neonate's NICU admission. By involving parents in their neonate's care, they can restore some of the parental role that is lost when one's neonate requires intensive care. Additionally, gaining perspective from all stakeholders about possible interventions to improve the NICU experience and reducing anxiety for parents and improving outcomes for their neonates is necessary. Although, further research is needed to continue to improve the implementation of pain management and FIC evidence into practice; results of this study further demonstrate a relationship between parental neonatal pain assessments the level NICU related anxiety. Furthermore, it appears this is the first study to document a relationship between parental expectations of pain intensity and anxiety caused by the NICU setting and experience.

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APPENDIX A - Introduction Letter

Short Title: Parents Feelings of Anxiety while their Baby is the Neonatal Intensive Care Unit

Research Title: Examining the Relationship between Parental Anxieties and Parental Observations of Neonatal Pain and their Preferences to Participate in their Neonates' Pain Care

Researchers: Kathleen Bailey RN (Dalhousie University, Master of Nursing Student)
Margot Latimer, PhD, RN (Thesis Supervisor)
Marsha Campbell-Yeo, PhD, NNP-BC, RN (Thesis Committee Member)
Jill Chorney PhD, RPsych (Thesis Committee Member)

Dear NICU Parent:

I am a Dalhousie University Master of Nursing student and a nurse. I want to learn about how having a baby in the neonatal intensive care unit is related to feelings of anxiety and comfort in participating in your baby's care.

You are being invited to take part in a research study looking at this question. This letter gives information about the study. Before you decide to take part, it is important that you understand the reason for the study, how it may affect you, the risks and benefits of taking part and what you will be asked to do. You do not have to take part in this study. Taking part is voluntary. A staff member of the research team will be available to answer any questions you have. **Filling out the survey is considered implied consent to take part so please read this letter carefully before proceeding to the survey.**

Why is the researcher doing this study?

It is important for nurses to understand the parent point of view when caring for their children. This study will gather information about how parents' nervous feelings or anxiety are related to their experiences and thoughts about their baby having a painful test in the NICU.

How will the researcher do the study?

The researcher would like to collect information from parents about their experiences with their baby's pain in the NICU. A survey was created to gather this information, and information about parents' levels of anxiety.

Who can take part in this study?

If you have a baby in the NICU, are 19 years of age or older and can read and understand English you are invited to take part.

Who should not take part in this study?

Any parent who has a baby experiencing withdrawal from drugs taken during pregnancy is not eligible to take part.

What will I be asked to do?

You are being asked to complete a few short surveys on anxiety and your NICU experiences. You may complete the paper surveys included in this package **or** go online to the link provided below. You may fill out the surveys at any time that is best for you.

What other options do I have?

You do not have to take part in this research study. Taking part is optional and will in no way affect your baby's hospital care. You may choose to skip over any questions you do not feel comfortable answering.

Can I withdraw from the study?

You may decide to stop filling out the survey at any time. However, once you have turned in your paper survey or submitted your online survey it will be impossible to separate it from other surveys because there will be no names or identifying information linked with the survey.

What are the burdens, harms and potential harms?

The completion of this survey will take a small amount of your time, about 20 minutes. There are no suspected harms as a result of taking part; however, some questions may cause you to think back on a painful procedure performed on your baby. This may be upsetting for some people. You may choose to skip any questions you do not wish to answer. If you continue to feel upset or distressed as a result of filling out this survey, you are asked to contact the principal investigator (Kathleen Bailey at (902)xxx-xxxx or her supervisor (Dr. Margot Latimer (902)xxx-xxxx) for support.

What are the potential benefits?

There are likely no direct benefits to you for taking part in this study; however, it is hoped that the results of this study may be used to improve the care provided to NICU babies and their families in the future. You may feel good in knowing that you helped with this type of research. As a "Thank You" for your participation you will receive a \$5 Tim Horton's gift card and can enter your name into a draw for a chance to win one of four \$50 gift cards to Babies R Us.

Will the study cost me anything?

No, there will be no cost in money to take part.

How will I be informed of the study results?

If you wish to know the study results please print your name, e-mail or postal address on the bottom of this form, detach it, and place it in the collection box separately from your survey so that we may send you a summary of the results.

How will my privacy be protected?

We are not collecting your name or any personal identification so there will be no link to who you are and your responses. There are several questions on the survey asking about demographic information such as, gender, or ethnicity but these will not be used to identify you in any way.

Completed paper surveys will not have any identifying information such as your name, phone number or email address attached. Paper surveys will be stored in a locked cabinet in Dr. Latimer's office in the Centre for Pediatric Pain Research South at the IWK. After filling out the paper survey you may choose to print your name and contact information on the bottom of this form, detach it, and place it in the collection box separately from your survey so that we can enter your name into the prize draw.

If you choose to complete the survey online your responses will be encrypted and stored on a secure server at Dalhousie University, available only to research staff. Again, no identifying information such as name or e-mail address will be linked to your answers. After submitting online, you will be given the option to email your name and phone number separately to the CPPR research coordinator Tara Hatfield entry into the prize draw.

After each prize draw all names and contact information will be destroyed.

Are there any conflicts of interest?

This research study is needed for the researcher to complete the Master of Nursing program at Dalhousie University. The researcher does not stand to make any money by conducting this research. The researcher does not work at the IWK and will not be known to those who take part.

What if I have study questions or problems?

If you have any questions or problems please feel free to contact the principal investigator, Kathleen Bailey any time, at (902)xxx-xxxx, or at kt951811@dal.ca; or Dr. Margot Latimer (study supervisor) at (902)xxx-xxxx, or at mlatimer@dal.ca. If you have questions about this, or any research at the IWK, you may contact IWK Research Services at (902) 470-8520, Monday to Friday between 8 a.m. and 4 p.m.

If you would like to be entered into the draw for one of four \$50 gift certificates to Babies R Us, please fill out the form below, detach it and place it in the collection box. To keep your answers private please make sure your ballot it is not attached to your survey.

If you would like to take part in this research study, please continue and fill out the surveys included in this package or enter https://surveys.dal.ca/opinio/s?s=NICU_Parent_Survey into your computer or mobile device to fill out the on-line version.

I would like to receive a summary of the study results

By E-Mail: _____

Or

By Mail: _____

Prize Draw Entry

Name: _____

E-Mail: _____

Phone: _____

APPENDIX C - Demographic Profile

Study Title: Examining the Relationship between Parental Anxieties and Parental Observations of Neonatal Pain and their Preferences to Participate in their Neonates' Pain Care

Can you give some additional information about yourself and your baby? If there are any questions that you prefer not to answer just leave them blank. This information will be grouped together and used in the research, but you will not be identified in an individual way.

1. How old are you, in years? _____

2. What is your sex? Male Female

3. What is your racial background?
 - Caucasian Asian
 - Aboriginal Black
 - Other (Please Specify) _____

4. What is your marital status?
 - Single Married
 - Divorced Dating
 - Common Law

5. What is your baby's date of birth? _____
 - a. What was their gestation at birth? _____ weeks

6. Is this your first child?
 - Yes No
 - a. If no, how many children do you have? _____

7. Do you live more than 1 hour driving distance away?
 - Yes No

7. If you were with your baby during a procedure, did you help keep your baby comfortable?
- Never
 - Sometimes
 - Often
 - Always
8. When a painful procedure is being done on my baby I would most often prefer to:
(CHOOSE ONE)
- Stay at the bedside
 - Stay and help by providing comfort
 - Leave the room
 - Not know it was happening
9. In an ideal world without any barriers, how strongly do you **want** to be with your baby when they are having a procedure?
0 = not at all (I don't want to be there), 10 = Very strongly (I really want to be there)
(CHOOSE ONE)

0 1 2 3 4 5 6 7 8 9 10
Not at all **Very Strongly**

10. How **comfortable** would you be staying with your baby during a painful procedure?
0 = very uncomfortable, 10 = very comfortable (CHOOSE ONE)

0 1 2 3 4 5 6 7 8 9 10
Very Uncomfortable **Very Comfortable**

11. How **stressful** would it be for you to be with your baby during a painful procedure?
0 = Not at all stressful, 10 = Very stressful (CHOOSE ONE)

0 1 2 3 4 5 6 7 8 9 10
Not Stressful **Very Stressful**

12. Below are some of many reasons parents cannot be with their baby during a painful procedure. Which reason was most common for you not to be with your baby during a procedure?
- Not applicable
 - I was away from the hospital
 - Staff asked me to step out
 - It was too stressful to be there
 - I was sick
 - Other _____

APPENDIX E – Outcome Measure Adaptation Table

Table Outlining Outcome Measure Item Adaptations Made of PAIN Questionnaire Items

Outcome Measure Item	PAIN Item
<p>2. If yes, have you ever been asked if you wanted to be present during a procedure?</p> <ul style="list-style-type: none"> • Never • Sometimes • Often • Always 	<p>30. Have you been asked if you wanted to be present during painful procedures?</p> <ul style="list-style-type: none"> • Never • Sometimes • Often • Always • Don't Know
<p>3. Have you been present with your baby for any procedures that may cause pain?</p> <ul style="list-style-type: none"> • Never • Sometimes • Often • Always 	<p>29. Have you been present with your baby while they were undergoing a painful procedure?</p> <ul style="list-style-type: none"> • Never • Sometimes • Often • Always
<p>4. If you were present for a procedure, what was the average amount of pain your baby felt during a procedure? (CHOOSE ONE)</p>	<p>4. Please circle the worst pain you think your baby has felt since admission to the neonatal unit? (CHOOSE ONE)</p> <p>5. Please circle the least pain you think your baby has felt since admission to the neonatal unit? (CHOOSE ONE)</p>
<p>6. If yes, how much pain did you expect your baby would feel while being cared for in the neonatal unit? (CHOOSE ONE)</p>	<p>6. Please circle how much pain you expected your baby would have while in the neonatal unit. (CHOOSE ONE)</p>
<p>8. When a painful procedure is being done on my baby I would most often prefer to: (CHOOSE ONE)</p> <ul style="list-style-type: none"> • Stay at the bedside • Stay and help by providing comfort • Leave the room • Not know it was happening 	<p>31. When a painful procedure is being done on my baby I would most often prefer to: (CHOOSE ONE)</p> <ul style="list-style-type: none"> • Stay at the bedside • Stay and help by providing comfort • Leave the room • Other (please describe)

Note: PAIN = Parent Assessment of Infant Nociception Questionnaire (Franck et al., 2004).

Attention NICU Parents!!!



You are invited to complete a 20 minute survey about parent participation in pain care in the NICU.

(You may fill out a paper survey located in NICU 1 or go to https://surveys.dal.ca/opinio/s?s=NICU_Parent_Survey for the online version.)

For your participation you will receive a \$5 Tim Horton's gift card and have a chance to WIN one of four \$50 Gift Cards to Babies R Us

For more information contact Kathleen Bailey RN, MN (student) at kt951811@dal.ca

APPENDIX G – Parent Recruitment Post Card Invitation

Dear NICU Parent,

You are INVITED to take part in a research project,

We want to learn how you feel about being involved during procedures (such as blood work) happening with your baby in the NICU.



To Thank You,

You will receive a \$5 Tim Horton's gift card and will have the chance to win one of four \$50 gift cards to Babies R Us

If you are:

1. Over the age of 19
2. Your baby is NOT being treated for withdrawal from drug exposure during pregnancy

Then you can take part in our survey!

Please take 20 minutes to share your experience with us in one of two ways:

1. Go to:
https://surveys.dal.ca/opinio/s?s=NICU_Parent_Survey
or
2. Choose a survey package located near
*If you choose to fill out the paper survey please drop our completed package in the Dropbox in NICU 1.



IWK Health Centre



For more information check out our survey package either online or on paper or contact

Kathleen Bailey by E-mail: kt951811@dal.ca