

ARE WE ON THE SAME PAGE ABOUT SKIN-TO-SKIN CARE?

Are we on the same page about skin-to-skin care?

A descriptive correlational study exploring skin-to-skin care for postoperative NICU infants.

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in partial fulfillment of the requirements for the
Master of Science in Nursing

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Preface

Approvals Obtained to Conduct the Research

This study received Research Ethics Board approvals from both the University of Ottawa and the host institution where the research was conducted. See Chapter 3, Appendices P and Q.

Statement of Contributions and Co-authorship

Several authors contributed to this manuscript in partial fulfillment of the requirements for the Masters of Science in Nursing degree at the University of Ottawa. The authors' contributions are summarized below.

The thesis candidate, Catherine Larocque (CL), is the primary author of this thesis. CL conceived and conducted the literature review and concept analysis. CL then conceived the research question and drafted the proposal for the cross-sectional descriptive exploratory study. All data collection and analysis was completed by CL. CL drafted all chapters for the final version of this thesis. All steps of the process were conducted with feedback from the co-authors.

The thesis supervisor, Dr. Denise Harrison, RN, PhD (DH), was involved in the conception and design of all aspects of this project. DH guided and assisted CL with drafting the proposal, engaging staff at the host institution, completing ethics applications, and interpreting data and analyzing data. Throughout this study, DH had access to the research database to ensure data quality and protection. DH guided and approved all chapters of this thesis, as well as its final approval.

The thesis co-supervisor, Dr. Wendy Peterson, RN, PhD (WP), was also involved in the conception and design of all aspects of this study. In particular, WP guided CL with the literature review and concept analysis, refinement of the research question, the creation of survey items,

and the analysis of qualitative data. WP also reviewed and approved the proposal, the thesis chapters, and the manuscript.

Thesis committee member, Dr. Janet Squires, RN, PhD (JS) was involved with the design and methodology of this study. In particular, JS assisted with the study methodology and guided the development of data collection tools and the quantitative data analysis. JS also reviewed and approved the proposal, the thesis chapters, and the manuscript.

Thesis committee member, Ms. Martha Mason-Ward, RN, NNP (MMW) was involved with the design and conduct of this study. In particular, MMW reviewed the study design and data collection instruments to ensure their coherence with the reality of clinical practice. MMW also assisted CL in engaging unit staff, identifying potential participants, and providing valuable insights about unit routines and resources. MMW also reviewed and approved the proposal, the thesis chapters, and the manuscript.

Table 0.1

Summary of Contributions of Co-authors

	CL	DH	WP	JS	MMW
Design and conduct of literature review and concept analysis	✓	✓	✓		
Conception and design of research study	✓	✓	✓	✓	✓
Creation of data collection instruments	✓	✓	✓	✓	✓
Ethical approvals	✓	✓			
Data collection and recruitment	✓				✓
Quantitative data analysis	✓	✓		✓	
Qualitative data analysis	✓	✓	✓		
Final approval of thesis chapters	✓	✓	✓	✓	✓
Final approval of manuscript	✓	✓	✓	✓	✓
Responsibility for all content	✓				

Personal Impetus

As an undergraduate Bachelor of Science in Nursing student, I knew I wanted to make the most of education. I took a risk and, after only one year in the program, I reached out to Dr. Harrison inquiring about research opportunities. I had the privilege of working with her and the Be Sweet to Babies team and I developed a passion for research and advocating for those who cannot do so themselves: infants. While completing a placement in maternal newborn care, I was struck by the inconsistencies between our theoretical and research knowledge and the reality of clinical practice. In particular, babies were in their cot more often than skin-to-skin or being held and they were often taken away from their parents for *pokes* (heel lances and venipuncture). As a consolidation student in a surgical Neonatal Intensive Care Unit I once again noticed that the infants were rarely held and that parental presence and involvement was limited and, at times, discouraged. My subsequent clinical practice as a Registered Nurse in maternal-newborn care confirmed that this knowledge-to-practice gap was persistent.

This contradiction has been at the centre of my graduate research; my consolidation placement had a significant impact on me. The strength and simultaneous struggle of NICU families and their infants trying to become a family in such a unique set of circumstances deserved closer attention. While discussing my thoughts with Dr. Harrison, we discovered a significant gap in the literature with respect to family centered care for surgical NICU infants and their families. My research and clinical experiences coalesced and my thesis was conceived.

Abstract

Family-centered care (FCC) is considered the gold standard for care delivery in the Neonatal Intensive Care Unit (NICU). However, there are challenges with the implementation of FCC in practice and there is limited literature about how to tailor this approach for specialized NICU populations.

To explore FCC for surgical neonates in the NICU, the concept was explored using Roger's evolutionary concept analysis. Results illustrate that FCC in the NICU is a philosophy of care, rather than a set of interventions. The subsequent cross-sectional descriptive exploratory study showed that the surgical infants in our sample ($n=11$) received a limited amount of skin-to-skin care (median 0 mins/day) and parents reported challenges to being involved in their infant's care.

This thesis supports the challenges with the implementation of FCC in practice and both the need to consider multiple perspectives and the need for broader systemic change in order to support a FCC philosophy.

Dedication

This thesis is dedicated to my incredible grandmother who instilled in me a deep passion for learning that has carried me through my education. Without your encouragement, tutelage, and support none of this would be possible. I aspire to be the kind, thoughtful, and compassionate person you have molded me to be.

Acknowledgements

It is impossible to mention all the individuals who were integral to the conduct and completion of this thesis. First and foremost, I must acknowledge all of the families and infants who participated in this study. Without your contributions and dedication this research project would not have been possible. Thank you for trusting me with your experiences and collaborating with me on this important project. To the nurses in the NICU, thank you for your teamwork in supporting and facilitating the conduct of this study.

I must extend my most heartfelt gratitude to my supervisor and mentor Dr. Denise Harrison; I am forever indebted to you. As a first year undergraduate student, you took a chance and believed in me. Throughout my undergraduate degree, you invested countless hours of mentorship and support to ensure I had all the possible opportunities to learn about research and get involved in the conduct, presentation, and publication of research. You have made me the nurse and researcher I am today and I owe my passion for nursing research to you.

I would also like to thank my committee members Dr. Wendy Peterson, Dr. Janet Squires, and Ms. Martha Mason-Ward for your devoted support during the conduct of this thesis. Dr. Peterson, thank you for your kindness, feedback, and support during this process. Your warmth and smile have made this experience all the more meaningful. Dr. Squires, thank you for patience and expertise while guiding me through the methodology and analysis for this project. You are a wealth of knowledge and I truly appreciate the dedication you have shown to my success. Last but certainly not least, Ms. Mason-Ward- your involvement and assistance have been critical for the conduct of this study. Without your clinical expertise, facilitation, and positive attitude, I would have been lost.

To my dearest friends, I cannot name each of you that have touched me and supported me in this process. Kelli, Tara, and Shokoufeh you have been my number one cheerleaders and supporters throughout my MScN. Thank you for the countless conversations, crisis interventions, and support over the last three years. Rachael, I thank you for always being there for me, any time of day. Our conversations and reflections on practice, research, and philosophy have expanded my critical thinking and impassioned me to further my education. Jesse, Kelly, and Grace- you have stuck by me and believed in me for many years; for this, I am eternally grateful and humbled. Your friendships are all reflected in this thesis and in the work that I do.

To my pup, Freddy, I would not be here without you; we have seen each other through the toughest times. Your unconditional love is the impetus that keeps me moving forward. Mom and Dad, thank you for always supporting my academic success and pushing me to think critically. Although I may not have taken a straight path, I have found my passion. To my siblings Alex, Josh, and Cory- although each of our relationships is different, you have all been there for me when I needed you most.

Lastly, thank you to the University of Ottawa for the financial support which has allowed me to conduct and complete this thesis.

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List of Acronyms

BFI- Baby Friendly Initiative

COPE- Creating Opportunities for Parent Empowerment

FCC- Family-Centered Care

FiCare- Family-Integrated Care

HCP- Health Care Provider

IDC- Integrative Developmental Care

IBCLC- International Board Certified Lactation Consultant

KT- Knowledge Translation

LC- Lactation consultant

NICU- Neonatal Intensive Care Unit

NIDCAP- Newborn Individualized Developmental Care and Assessment Program

NTISS- Neonatal Therapeutic Intervention Scoring Scale

PCMCH- Provincial Council for Maternal and Child Health

PH- Parental Holding

PHAC- Public Health Agency of Canada

PIPC- Parent Involvement in Pain Care

PP- Parental Presence

RCT- Randomized Controlled Trial

REDCap- Research Electronic Data Capture

RN- Registered Nurse

SCENE- Separation and Closeness Experiences in the Neonatal Environment

SSC- Skin to Skin Care

Table 0.2 Definitions and Glossary of Terms and Concepts

Concepts	Definitions	Sources
Family-Centered Care (FCC)	An approach to care wherein each member of the family is considered integral to the care of the patient. In the NICU, this means that parents are also recipients of care in the form of teaching, support, and inclusion as equal partners in care. According to the Public Health Agency of Canada (PHAC), family-centered maternal newborn care “is a complex, multidimensional, dynamic process of providing safe, skilled and individualized care. It responds to the physical, emotional, psychosocial and spiritual needs of the woman, the newborn and the family” (p. 5). See Chapter 3, Appendix B (p. 124) for further details.	1. Institute for Patient and Family-Centered care, (2020) 2. Shields et al., (2006) 3. Public Health Agency of Canada, (2017)
Parental presence (PP)	Parents being in the Neonatal unit, within proximity of the infant’s cot or incubator (within the pod area). This includes meeting with the health care team, participating in rounds, etc. Any absence from the unit lasting >15 minutes will be considered a lapse in parental presence.	Raiskila et al., (2017)
Parental holding (PH)	The infant is in the parents’ arms without ventral skin contact; this includes breastfeeding, if both mother and infant are clothed (no ventral skin contact). Due to the nature of certain surgical procedures, holding will also include: i) hand swaddling (a gentle cradling/containment technique), colloquially known by parents as <i>hand hugs/hand hugging</i>, ii) facilitated tucking, and iii) modified kangaroo care (also known as encircle holding). See Chapter 3, Appendix O (p. 149) for illustrations.	Raiskila et al., (2017) Description of hand swaddling: Philbin & Ross, 2011, p.369 Hand hugs/hugging: http://cpbf-fbpc.org/families/kangaroo-care/ Modified kangaroo care/encircled holding: http://www.rqhealth.ca/rqhr-central/files/0095.pdf
Skin to Skin Care (SSC)	Infant is wearing only a diaper (and maybe a hat or other medically required equipment), and is lying on the parent bare-chested. This includes breastfeeding, if mother and infant are skin to skin (tummy to tummy). See Chapter 3, Appendix O (p. 149) for illustrations.	1. Raiskila et al., (2017) 2. Altimier & Phillips, (2016)

Painful procedures	Heel lance, percutaneous venous catheter insertion, percutaneous arterial catheter insertion, peripheral arterial or peripheral venous cutdown, central venous line placement, umbilical catheter insertion, peripherally inserted central catheter placement, lumbar puncture, urethral catheterization, intramuscular/subcutaneous injection, endotracheal intubation, endotracheal suction, nasogastric or orogastric tube insertion. Following input from parents, dressing changes was added to the list. See Chapter 3, Appendix O (p.149).	1. Anand, (2001) 2. Ottawa Neonatal Pain Interest Group, (2015)
Parental presence during painful procedures	Parents want to be involved in providing comfort to their infants during painful procedures. Simply being present during a procedure can be comforting for an infant, but parents can also take a more active role and perform comforting techniques such as skin-to-skin care or breastfeeding.	1. Franck et al., (2012) 2. Bellieni et al., (2003) 3. Harrison et al., (2017)
Parent infant closeness	Encompasses emotional bonding and physical proximity. For the purposes of this proposed study, closeness will encompass PP, PH, and SSC.	Raiskila, (2018)
Neonatal Therapeutic Intervention Scoring System (NTISS)	The NTISS is a measure of therapeutic intensity, resource utilization, and neonatal illness severity. This scoring system was chosen as it provides an indication of the infant's acuity independent of gestational age. See Chapter 3, Appendix N (p. 150).	Gray et al., (1992)
Surgery	All procedures where the following three conditions are met: 1) anesthesia and sedation are required, 2) the body is manipulated with instruments by a surgeon and 3) the body is incised. This includes: cardiovascular, thoracic, neurologic, orthopedic, otolaryngologic, general surgery, urology, plastics, and gynecology surgeries performed in the operating room, on the unit, or at the bedside. Will also include abdominal wall defect procedures, such as reduction in cases of gastroschisis.	Bucher et al., (2016)

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CHAPTER 1

Introduction

1.1 Background

The process of pregnancy, birth, and parenthood is largely regarded as a life transition, engendering the beginning of family processes such as attachment and bonding (Gardner, Voos, & Hills, 2016; Willinger et al., 2005). However, when a baby is born sick or premature, these processes can be disrupted or delayed. In these cases, attachment becomes an increasingly complex process that requires particular attention and care (Franklin, 2006). Parents of preterm or sick infants in the Neonatal Intensive Care Unit (NICU) experience high stress levels and often have difficulty interacting with their newborns in developmentally supportive ways (Melnik et al., 2006). Nevertheless, evidence shows that when parents are supported to participate in their infant's care, they report less stress and exhibit more positive interactions with them (Melnik et al., 2006; Shields et al., 2012; Voos et al., 2015). In addition, as sick and preterm infants require multiple procedures as part of their ongoing care and monitoring, supporting parents to comfort their infants during painful procedures is vital for the infants and their families (Franck et al., 2004). As health care providers (HCPs), this is a critically important consideration because a family's functioning and responses to stress influence both the family's relationship with the infant and the infant's long-term development (Gardner et al., p. 830, 2016). In particular, families of neonates requiring surgical interventions are at an increased risk of experiencing feelings of fear, guilt, trauma, and helplessness and thus these parents often require education and information, support, and even permission to participate in their infant's pain care about pain management (Govindaswamy et al., 2019a, 2019b, 2019c; McNair et al., 2020)

1.1.1 Family-Centered Care. Parental presence (PP) is essential for both parental and infant well-being (Jiange al., 2014) in the NICU. Family-centered care (FCC) is care that is

“planned around the whole family, not just the individual child/person, and in which all the members are recognized as care recipients” (Shields et al., 2006, p.1318). This model of care delivery is advocated as the standard of care for NICUs and pediatric centres worldwide (Abraham et al., 2012; Cooper et al., 2007; Coughlin et al., 2009; Coyne, 2015). Key aspects of FCC include information sharing, respect and honouring difference, partnership and collaboration, negotiation, and care in context of family and community (Kuo et al., 2012; Shields et al., 2012). Broadly, FCC has been associated with lower costs, fewer adverse effects subsequent to hospitalization such as anxiety, increased satisfaction, and enhanced parent-child bonding (Coyne, 2015).

Bonding, in this context, is related to positive interactions between parents and their infant(s) *after* the birth; early physical contact begins the processes of “being together” and “getting to know each other” (Mäkelä et al., 2018, p.183). Although bonding and attachment are often used interchangeably they are distinct concepts. Attachment is the *relationship* that develops between parents and their infant(s) and, if the pregnancy is wanted, this process begins with confirmation of the pregnancy (Franklin, 2006). This process can be interrupted when the mother’s idealization of their infant is inconsistent with the clinical reality (i.e. their infant is ill and/or requiring admission to an NICU) (Gonçalves et al., 2011). In the NICU, the related processes of attachment and bonding occur through interactions between the parents, the infant, and the nurse (Mäkelä et al., 2018); if parents have an attachment to their infant, but have not had an opportunity to bond through physical closeness and meaningful participation in their infant’s care, this can result in patterns of insecure attachment, stress, anxiety, and even post-traumatic stress disorder amongst parents (Kim et al., 2015; Roué et al., 2017). Although further empirical trials are needed, a recent review by Yu & Zhang, (2019) found that, for preterm

infants in the NICU, FCC had a positive impact on length of stay and some effect on overall morbidity, feeding and growth, and neurobehavioural performance. For parents, evidence supports that FCC reduces anxiety and stress, improves overall satisfaction with care, facilitates secure parent-infant attachment, and increases parental confidence (Broom et al., 2017; Coyne & Cowley, 2007). As a result of this evidence base, key stakeholders, such as Children's Healthcare Canada (formerly known as the Canadian Association of Pediatric Health Centres) (Canadian Association of Paediatric Health Centres [CAPHC] & Complex Care Community of Practice, 2018), and the Institute for Patient-and-Family-Centered Care (<https://www.ipfcc.org/>), provide guidelines and recommendations endorsing and supporting FCC.

Despite this, FCC is a difficult philosophy to implement in practice (Petersen et al., 2004; Skene et al., 2016). In a study conducted by Coyne (2015), parents and nurses cited poor communication, lack of role negotiation, and over-reliance on parents as barriers to the implementation of FCC. The literature suggests that this may be because it requires a shift in mentality away from paternalism (Axelin et al., 2014; Weis et al., 2015). Within the health care context paternalism has been widespread since the 20th century; paternalistic practices occur when HCPs determine the patient's and family's wishes or choices on their behalf (Cody, 2003). Family-centered care attempts to directly address this inequity in power differential between HCPs and parents (D'Agata & McGrath, 2016). These difficulties are echoed in the literature and researchers have identified that: FCC is being "defined by experts and then carried out to families" (MacKean, Thurston, & Scott, 2005, p.81), some parents are experiencing resentment at being expected to perform care (Coyne, 2008), and that many barriers such as nurse workload and communication hinder role clarity (Coyne, 2015).

1.1.2 Pain. Neonates hospitalized in the NICU undergo many painful procedures each day. As reported in a systematic review of 18 studies, neonates admitted to a NICU undergo an average of 7.5–17.3 procedures per day (Cruz et al., 2016), consisting primarily of heel lances and venipunctures for the purposes of medical monitoring (Carbajal et al., 2008; Johnston et al., 2011; Taddio et al., 2002). Despite evidence that neonates have nervous systems capable of feeling pain, many infants do not receive analgesia (Cruz et al., 2016). This is concerning as a systematic review of 13 studies concluded that, for preterm NICU infants, pain-related stress in the neonatal period is the strongest predictor of negative long-term developmental and functional sequelae when compared to full-term non-NICU infants at one year of age (Valeri et al., 2015). More recent research supports that the frequency of skin-breaking procedures in the early neonatal period is related to altered brain function and reduced cortical brain matter at 3 years corrected gestational age (Duerden et al., 2017). Evidence shows that when parents are present, infants are more likely to receive evidence-based pain treatment (Latimer et al., 2009). Additionally, pain treatment during acute painful procedures, such as venipuncture or heel lance, aligns with the goals of the Baby-Friendly Initiative (BFI) (Harrison & Dunn, 2016). The BFI is an international World Health Organization (WHO) initiative to promote, protect, and support breastfeeding (World Health Organization, n.d.). This initiative provides guidelines for hospitals and community centers and recently, in the Canadian context, the Public Health Agency of Canada (PHAC) committed \$1.3M to improve breastfeeding rates (Baby Friendly Initiative Ontario, 2019). Given this, it is imperative for hospitals and HCPs to consider pain treatment during painful procedures on neonates.

Parents express distress at watching their infants in pain and wish to be more involved in their care (Franck et al., 2005; Gale et al., 2004). In fact, in a study including 257 parents, 57%

reported that they would prefer to be present during painful procedures, and 87% stated that they would want greater involvement in their infant's pain care (Franck et al., 2004). Despite this, parents have reported that their involvement is passive and superficial, rather than a true partnership (Simons et al., 2001). In addition, parents have reported they require more information about, and opportunities for, their involvement in their neonate's pain care (Franck et al., 2012). Parental presence is important for effective pain management. Bellieni et al. (2003) reported that analgesia, such as small amounts of sugar water, are more effective when there is parental presence due to the affective experience of anxiety and stress that neonates experience alongside pain. In addition to parents' role in the management of pain, their presence not only increases the chances that their infant will receive adequate pain management, but their collaboration and feedback in pain assessment helps prevent untreated pain (Franck et al., 2011; Marfurt-Russenberger et al., 2016). Over time, parents become intuitively connected to their infants and may be better at recognizing their patterns, possibly perceiving their infant's pain before HCPs (Anand, 2007; Gooding et al., 2011).

Many studies have been published about the evaluation and treatment of pain in preterm and sick neonates (Harrison, 2012; Harrison et al., 2017), but few examine postoperative pain in the newborn population uniquely. This distinction is clinically important as contemporary animal and human studies show that the degree of tissue injury incurred during neonatal surgery results in more sustained long-term negative effects, such as hyperalgesia, when compared with infants admitted to a NICU who did not undergo surgery (Peters et al., 2005; Walker et al., 2009). While infants' acute pain immediately following surgery is typically well assessed and well managed, most postoperative infants do not receive appropriate pain assessments due to the lack of understanding of persistent *chronic* pain in this population that follows the initial period of acute

pain (Anand, 2017). In a review of consequences of neonatal surgical pain, Beggs (2015) concluded that, in order to improve long-term health, there is an urgent need to better understand neonatal pain in the context of surgical injury. In light of this, Anand (2017) suggests that nonpharmacological relationship-based methods, such as involving parents, may offer potential to address chronic surgical pain. With education, support, and encouragement parents can become the ideal partners in their infant's pain care and the primary providers of comfort measures (Franck et al., 2011; Franck et al., 2012; Marfurt-Russenberger et al., 2016).

1.1.3 Skin-to-Skin Care. A key role of the nurse is to act as their patients' advocate. In the NICU context, the nurse also needs to advocate for parents and assist the parents in caring for, and adjusting to, having a sick baby. Skin-to-skin contact/care (SSC) is a simple intervention that is a key component of newborn developmentally supportive care (Altimier & Phillips, 2016; Roué et al., 2017). Skin-to-Skin contact facilitates parental attachment and is critical for early stages of parenting and family formation, which are essential processes for the social and emotional well-being of the family (Flacking et al., 2012; Raiskila et al., 2017). Although the exact physiological mechanisms of SSC are not fully understood, it is posited that SSC encourages "neurobehavioural organization" in neonates (de Sousa Freire et al., 2008; Johnston et al., 2017). This in turn promotes self-regulation in infants and mediates infants' circadian rhythms and autonomic stability (de Sousa Freire et al., 2008). Further, SSC increases the level of oxytocin in the mother; this increases the temperature of the mothers' breasts, thereby contributing to the infant's thermoregulation (Cleveland et al., 2017). There are many measurable benefits of SSC for both parents and their infants; physiologically, SSC is linked to enhanced and earlier attainment of exclusive breastfeeding (Oras et al., 2016), a decreased need for pharmacological pain management in preterm neonates (Holmes et al., 2016; Johnston et al.,

2017), earlier discharge, long term improvements in weight gain and a multitude of physical, psychosocial, and cognitive developmental outcomes (Gardner et al., 2016, p. 289). For parents, SSC is linked to increased parental confidence, improved mood, more consistent parental responses, and overall improved family functioning and cohesiveness (Gardner et al., 2016, p. 289). Mothers, in particular, have reported that SSC increases their feelings of competence in comforting their infant, which in turn leads to relationship building and attachment (Johnson, 2007; Melnyk et al., 2006; Willinger et al., 2005). In fact, SSC is such an important part of newborn care that the WHO recommends that SSC be more systematically promoted and applied in practice in order to improve uptake and subsequent outcomes (Chan et al., 2016). However, SSC has been reported as difficult to implement in practice; Kymre and Bondas (2013) reported that nurses struggle with balancing what they perceive to be the neonates' needs and the parents' readiness.

There is a strong evidence base supporting SSC as beneficial and effective for healthy newborns and research shows that it is consequently practiced more often in obstetrical settings and special care nurseries where infants are less acutely ill than in NICUs (Engler et al., 2002; Franck et al., 2002). In keeping with this, guidelines exist for the implementation of SSC with preterm neonates including intubated preterm infants (Ludington-Hoe et al., 2003; Ludington-Hoe et al., 2007). These guidelines include readiness assessment criteria which include, but are not limited to, infant's vital signs, oxygen support, blood gases, as well as environmental support, and parental and nurse readiness (Ludington-Hoe et al., 2007). Further, there is a safe protocol for SSC with mechanically ventilated (MV) infants that provides concrete step-by-step instructions for nurses to transfer MV infants from the incubator, to the parent, and back to the incubator (Ludington-Hoe et al., 2003). Despite their seeming comprehensiveness, these

guidelines do not address all populations of sick infants and, in particular, do not make provisions for post-operative infants.

Although abundant literature exists to support the benefits, safety, and effectiveness of SSC, there is a paucity of SSC literature concerning post-operative neonates specifically (Harrison & Ludington-Hoe, 2015; Shields et al., 2012; Shields et al., 2006). There are existing guidelines for SSC with preterm ventilated infants (Ludington-Hoe et al., 2007), although these guidelines do not apply to surgical infants, ventilated or not. Notwithstanding, SSC is still recommended as a developmentally supportive intervention to promote maturation and parental bonding with more critically ill infants (Korja et al., 2008; Nyqvist et al., 2010). In a case study of a postoperative 18-day-old newborn with hypoplastic left heart syndrome, Harrison & Ludington-Hoe (2015) noted no adverse events and a decrease in heart rate and respiratory rate, and an increase in oxygen saturation during one SSC session lasting 135 minutes. This case study supports that SSC for neonates in the week following cardiac surgery may be safe. Further, a recent study by Ortmann & Dey, (2019) found that early ‘mobilization’, defined as a parent holding the infant outside the cot or incubator for a minimum of one hour, of intubated critically ill infants less than 6 months is safe and resulted in no additional adverse outcomes. The literature supports that parents and nursing staff require more education about SSC in general, and in particular for postoperative infants, and that there should be written protocols about SSC including criteria for initiation, positioning, transferring and monitoring (Cattaneo et al., 2018; Nyqvist et al., 2010).

In light of the benefits for both parents and infants (Lester et al., 2014; Marfurt-Russenberger et al., 2016), the ethical imperative to treat pain in neonates (Harrison, 2012; Harrison et al., 2017), and new evidence supporting the safety of holding and SSC for critically

ill infants (Ludington-Hoe et al., 2005; Ortmann & Dey, 2019), parent involvement in pain care (PIPC), in the form of SSC, is a reasonable and effective developmentally supportive intervention (Axelin et al., 2009; Ludington-Hoe et al., 2005; Warnock et al., 2010).

Furthermore, some of the frequently performed minor painful procedures, such as capillary or venous blood sampling and airway suctioning, can be performed while the neonate is skin-to-skin with a parent (Nyqvist et al., 2010). In terms of effectiveness for pain relief during minor painful procedures (such as heel lance or venipuncture), a systematic review of 19 studies showed that SSC reduced pain during the procedures compared to standard care (Johnston et al., 2017). Further, Johnston et al. (2017) found that SSC is more effective than sweet solutions at reducing pain as measured on the Premature Infant Pain Profile (PIPP). Although parental holding and facilitated tucking are also shown to reduce pain (Axelin et al., 2006), SSC is more effective than either of these interventions (Johnston et al., 2017). Despite this body of evidence, the simplicity of SSC for pain care, as well as local, national, and international guidelines supporting this strategy (Lee et al., 2014; Ottawa Neonatal Pain Interest Group, 2015), its uptake in practice remains poor and neonates continue to have poorly treated postoperative pain (Harrison et al., 2015; Johnston et al., 2011; Lagunas & Hall, 2016; Roofthoof et al., 2014). Therefore, there is a need to explore SSC for pain care in neonates within the context of family-centered and developmentally supportive care.

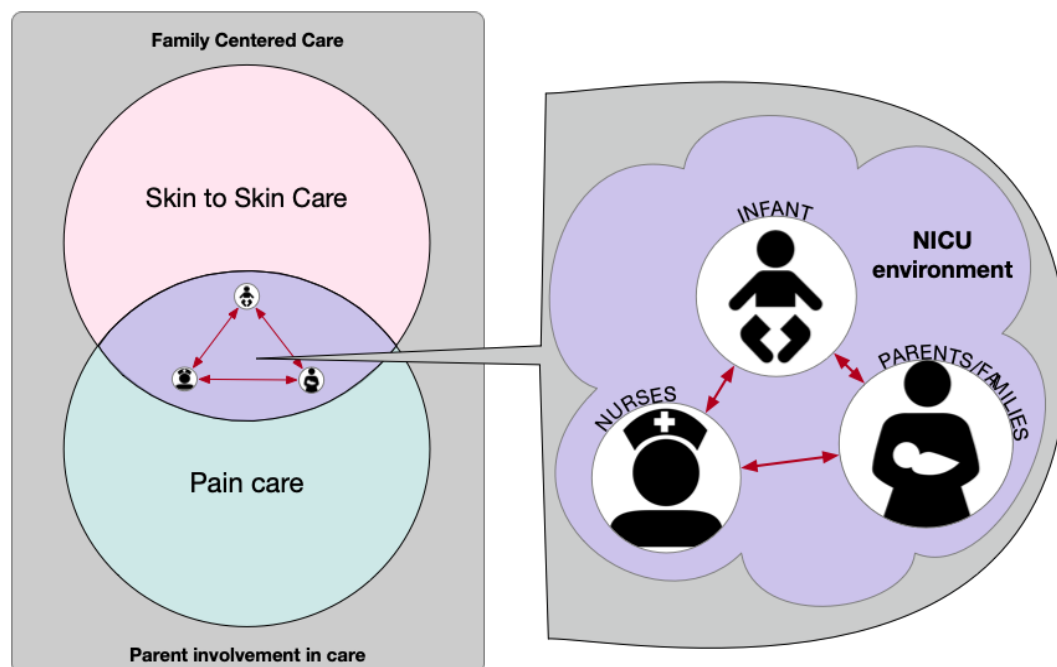
1.1.4 Relationship Between Key Concepts. Overall stress experienced by the mother and the family is compounded when infants require not only hospitalization, but also surgery (Gephart & McGrath, 2012). Family-centered care is considered a necessity for the provision of nursing care in the NICU due to the unique developmental needs of neonates, the attachment and bonding needs of the family, as well as the natural role of parents as advocates for pre-verbal

infants (Gooding et al., 2011). Within a FCC approach, SSC should be the norm; it is the optimal environment for NICU infants as it promotes physiological homeostasis, favours neurodevelopment, and supports attachment and bonding (Altimier & Phillips, 2016). The relationship between FCC, parent involvement in pain care, and SSC cannot be understated, particularly for the postoperative neonatal population (Roué et al., 2017). An overall atmosphere of FCC is required in order to facilitate SSC, parent involvement in pain care, and parent involvement in general. Reflexively, SSC and parent involvement in pain care are required for the provision of developmentally supportive FCC (Altimier & Phillips, 2016; Coughlin et al., 2009; Franck et al., 2012; Marfurt-Russenberger et al., 2016). In addition, the relationship between the nurses, parents, infants, and overall NICU context are essential considerations (Fegran & Helseth, 2009; Guillaume et al., 2013; Raiskila et al., 2017). This relationship is visually represented in a conceptual diagram created by the researcher (CL) in Figure 1.1. On the left, the diagram illustrates that SSC and pain care occur within the larger context of FCC. On the right, the diagram highlights the interrelationship between the NICU environment, infant factors, parent and family factors, and nursing factors. Taken as a whole, the diagram illustrates that no aspect of FCC, SSC, or parent involvement in pain care occurs in isolation, they affect one another and are affected by the environment and actors (e.g. parents, neonates, nurses) involved.

Despite the importance of these concepts for caring for infants and families in the NICU, the majority of the literature surrounding FCC, pain, and SSC in the NICU deals with preterm or very preterm infants and there is a paucity of literature looking at these factors for post-surgical infants and family experiences surrounding postoperative care in the NICU. Of note, a significant portion of the literature about SSC originates from Scandinavia and Europe (Baylis et

al., 2014; Blomqvist et al., 2011; Nyqvist et al., 2010), which is a context distinct from North American settings. In addition, regarding the current literature on FCC in the NICU, D'Agata & McGrath (2016) state that “none of these intervention studies have gone far enough to truly change the power differential and allow parents their rightful place at the bedside,” which suggests challenges engaging in true partnerships with parents (p.252). With respect to barriers to using SSC in the NICU, Benoit et al., (2016) identified the perception by NICU nurses that SSC during painful procedures increases nursing workload, and that parents are not sufficiently present on the unit. This highlights the complexities of providing FCC in the NICU and underscores the need for further research.

Figure 1.1- Conceptual Diagram



1.2 Research Problem.

In sum, the nurse-parent relationship, the context of care delivery, and various infant/parent/nurse factors underpin the core concepts of FCC, SSC, and parent involvement in pain care for neonates admitted to the NICU (Altimier & Phillips, 2016; Coughlin et al., 2009; Franck et al., 2012; Marfurt-Russenberger et al., 2016). In particular, these concepts remain almost completely unexplored among postoperative infants. Given this, there is a unique and important opportunity to explore SSC in the postoperative neonatal context to shed light on current practices and ultimately improve outcomes for parents and their infants.

1.3 Study Objective

The literature supports that parents want to be involved in their infant's care in the NICU and that parental presence (PP), parental holding (PH), and SSC are important for both infants and their families. However, given the aforementioned gaps in the literature, and the paucity of literature dealing with postoperative neonates specifically, we do not know if PP, PH, and SSC are promoted by HCPs nor if this is feasible and acceptable for parents. Therefore, this research study aimed to explore and contribute new insights about FCC, parent involvement in pain care (PIPC), and SSC for surgical neonates hospitalized in an NICU.

1.4 Study Aims

To these ends, the aims of this study were to assess and explore parental presence (PP), parental holding (PH), SSC, and parental involvement in pain care (PIPC) in a NICU that cares for infants requiring surgery. The specific goals of this study were fourfold:

- i) to describe the frequency and duration of PP, PH, and SSC in a surgical NICU,
- ii) to determine the frequency of PP, PH, and SSC during minor acute painful procedures (i.e. heel lance),

- iii) to assess the relationship between PP, PH, and SSC and illness severity, and
- iv) to identify parent, infant, and environmental factors that influence PP, PH, and SSC.

In light of the robust literature supporting and advocating for SSC, this study explored and discussed SSC in particular, recognizing that it is a key component of developmentally supportive FCC and PIPC.

1.5 Thesis Outline

This dissertation is presented in five chapters. This first chapter presents an overview of the thesis providing background on the content area, a conceptual diagram, and the study aims and specific goals. The second chapter is a manuscript entitled “Family-Centered Care and Neonatal Surgery: A concept analysis and literature review” formatted for publication in the *Journal of Neonatal Nursing*. Chapter three provides detailed information regarding the study’s theoretical underpinnings, design, methods, ethical considerations, and data analysis. Chapter four is a manuscript entitled “Family-Centered Care, Parental Presence, and Skin-to-Skin care for post-operative NICU infants: a descriptive correlational study” formatted for publication in the *The Lancet*’s special issue entitled *Nursing in 2020* (Lucas & Horton, 2020). Chapter five presents an integrated discussion of the results and delineates implications for practice and future research.

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CHAPTER 2

Family-Centered Care in the Neonatal Intensive Care Unit: A concept analysis and literature review

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ABSTRACT

Aim/Purpose. Family-centered care (FCC) is a necessary component of neonatal nursing. Due to challenges with its operationalization in practice, the aim of this paper is to clarify the meaning of FCC in the NICU in order to inform future research.

Methods/Approach. Rodger's evolutionary concept analysis. Three databases were searched, each representing a different discipline: CINAHL, Medline, and PsycINFO. A total of 188 full-text papers were included.

Results. The concept of FCC in the NICU was defined according to its surrogate terms and related, antecedents, attributes, and consequences.

Discussion. Although interdisciplinary in nature, the literature is still dominated by a biomedical perspective. Several important conceptual departures, namely developmental care and family-integrated care, are discussed.

Conclusion. Considering FCC as a model of care is too reductionist; it must be regarded as a philosophy. Further work should explore the delivery of FCC for increasingly specialized NICU populations, such as perioperative infants.

INTRODUCTION

Throughout the 19th and 20th century, paternalism in healthcare was widespread. In this modality of care, care and services were organized according to the physician's expertise without taking the patient and families' wishes into account (Cody, 2003). Within the pediatric context this paternalism limited parents' ability to participate in their infant's care. In fact, prior to the 1950s, parents were considered a "negative factor" and were not allowed to visit hospitalized children (Shields, 2010, p. 2630). Throughout the 1900s, this modality of care was questioned due to concerns about maternal-child separation (Shields, 2010). In the late 1950s, a collaborative committee was appointed by the British government to set out recommendations for parents to accompany their hospitalized infants (Irlam and Bruce, 2002; Shields, 2010). The resulting report, the Platt Report (Platt, 1959), was a landmark document that is still used to this day as a point of reference for Family-Centered Care (FCC) (Coyne, 2008).

Family-Centered Care is care that is "planned around the whole family, not just the individual child/person, and in which all the members are recognized as care recipients" (Shields et al., 2006). Within the context of the Neonatal Intensive Care Unit (NICU), parents are uniquely positioned to be partners in care due to their innate protectiveness and desire to care for their infant(s) and children (Cleveland, 2008; Gooding et al., 2011). In light of this, FCC is considered the gold standard model of care for NICUs worldwide (Abraham et al., 2012). Today, research evidence supports the positive impact of FCC on parental satisfaction, cost reduction, and reducing negative impacts after hospitalization for both infants and parents (Coyne, 2015). Within the NICU context, recent empirical evidence suggests that FCC reduces overall length of stay and may have a positive impact on feeding, growth, and neurodevelopment (Yu and Zhang, 2019). As a result, key stakeholders such as the Registered Nurses Association of Ontario

(RNAO) (2015), Accreditation Canada (2015), Children's Healthcare Canada (formerly the Canadian Association of Pediatric Health Centres) (Canadian Association of Paediatric Health Centres [CAPHC] & Complex Care Community of Practice, 2018) and the Public Health Agency of Canada (PHAC) (2017) all provide guidelines and recommendations endorsing and supporting FCC. Independent organizations, such as the Institute for Patient- and Family-Centered Care, also provide guidelines and advocate for the uptake of a FCC modality of care in clinical settings (Institute for Patient and Family-Centered care, 2020).

Family-Centered Care in the NICU directly impacts many aspects of Registered Nurses' (RN) practice. For example, FCC requires a shift in mentality away from paternalism (Axelin et al., 2014; Weis et al., 2015), it addresses inequities between health care providers (HCPs) and parents (Carrier, 2002; D'Agata and McGrath, 2016), and it directly influences patient/ parent satisfaction (Bruns and Klein, 2005; Butt et al., 2013; Dunn et al., 2006). Despite both the evolution of the concept of FCC since the mid 20th century and the multitude of guidelines and reviews recommending its use in practice, its uptake and implementation in clinical practice remains equivocal (Coyne, 2015; Smith, 2018). The literature suggests that implementing FCC as a model of care is challenging in light of the breadth and vagueness of the concept and the lack of empirical evidence evaluating its impact(s) (Coyne, 2015; Shields, 2017). Various researchers have identified that FCC is being "defined by experts and then carried out to families" (MacKean et al., 2005, p.81), that some parents are experiencing resentment at being expected to perform care (Coyne, 2008; O'Haire and Blackford, 2005), and that nurses continue to report lack of training and education to effectively deliver FCC (Coyne, 2015). This contradiction between the idea of FCC and its implementation necessitates further exploration in order to inform future research and clinical practice.

Amidst these conceptual tensions, HCPs must address the increasingly complex needs of neonatal patients and their families. Within the neonatal context, research and technological developments of in the last several decades have allowed for the resuscitation and care of infants at lower gestational ages and birth weights. Since the advent of medications such as lung surfactant and antenatal steroids, neonatal morbidity and mortality surrounding prematurity has decreased (Lee et al., 2020), but infants are at risk of succumbing to later-stage complications and infections (Simpson et al., 2010). In light of these trends, research pertaining to FCC in the NICU has dealt almost exclusively with preterm infants. However, there has also been an increase in infants born at later stages of gestation with complex surgical conditions that have gone largely unstudied (Govindaswamy et al., 2019a, 2019b; Murthy et al., 2014). Given the unique needs of this population, and trends suggesting that infants are requiring increasingly invasive and complex procedures, there is a need to explore the delivery of FCC for the postoperative NICU population. In light of the lack of pre-existing literature on this topic, this concept analysis and literature review will trace both the evolution of the concept of FCC in the NICU and the interdisciplinary contributions to its operationalization in research and practice. In order to advance our understanding of FCC with specialized NICU populations, we must first synthesize and clarify what is already known about FCC in the NICU population generally.

METHODS

The purpose of a concept analysis is to determine the current state of the science surrounding a concept of interest with the goal of *integrating* the literature rather than just a synthesizing (Hupcey and Penrod, 2005). In this approach, integration moves beyond synthesis (organization of findings) as it requires the researcher to examine and critically reflect on implicit and explicit assumptions as they vary over time and within different contexts, which

ultimately results in a more holistic understanding of the “state of the science” surrounding a particular concept (Hupcey and Penrod, 2005, p. 205; Tofthagen and Fagerstrøm, 2010). This is ideally suited to explore the concept of FCC in the NICU as there is an evident contradiction between the state of the evidence supporting its implementation and the state of clinical practice reporting challenges with its operationalization.

Rodger’s Evolutionary Concept Analysis.

This concept review was conducted using Rodger’s Evolutionary Concept Analysis as outlined in Tofthagen and Fagerstrøm, (2010). This method stresses the importance of context, the temporal nature of concepts, and the importance of cross-disciplinary sampling (Tofthagen and Fagerstrøm, 2010; Weaver and Mitcham, 2008). Using this method permits comparison within and across disciplines, cultures, and perspectives. This method is well-suited for exploring FCC in the NICU. Firstly, the concept of FCC has existed in the academic literature for over 50 years (Johnson, 2000; MacKean et al., 2005), and it is important to examine changes over time given advances in health sciences and resulting changes in clinical practice. Secondly, due to the high acuity level of the patients, interprofessional/interdisciplinary collaboration is paramount and any definition of FCC in the NICU should consider these perspectives (Trujillo et al., 2017). Thirdly, the context of the NICU is very unique and this tends to be an insular specialty; therefore, the importance of the context cannot be understated (Fegran and Helseth, 2009).

Concept of interest

In the initial phase of concept analysis, the researcher must select the concept(s) of interest and the context(s) of that concept (Tofthagen and Fagerstrøm, 2010). For this review, the concept of interest was FCC and the setting of interest was the NICU. As a preliminary step, a search for systematic reviews, meta-syntheses, best practice guidelines, and previous concept

analyses was conducted using Google Scholar. This search helped identify key terms, headings, related concepts, and provided an overview of the FCC in the NICU literature landscape. From this search, two existing concept analyses were found (Malusky, 2005; Ramezani et al., 2014), a Cochrane systematic review was identified (Shields et al., 2012), as well as a meta-synthesis of qualitative studies by the same authors (Shields et al., 2006). After reviewing this literature, the search terms detailed in Table 2.1 were developed.

Table 2.1

Search Terms and Strategy

P (population)	I (intervention)	C (context)	O (outcome)
Neonates (<28 days)	Family-Centered Care	ICU/NICU	N/A
Neonate OR neonatal OR premature OR preterm OR newborn OR infant OR pediatrics OR children	Family focused care OR family cent#red care OR family cent#red approach	Neonatal intensive care unit OR NICU OR special care baby unit OR SCBU OR tertiary care OR intensive care unit OR ICU OR critical care	

Note: Key terms in PICO format. The same terms were used in each database, and searched in the article title (TI), abstract (AB), major headings (MH), and subject (SU)).

Context of concept and data sources

In an evolutionary approach, the context of a concept refers to how it used within a discipline or profession (Toftagen and Fagerstrøm, 2010). Given the highly interdisciplinary nature of the NICU, examining divergences and convergences between various disciplines' conceptualizations of FCC in the NICU is crucial. Therefore, databases reflecting various health disciplines were selected. Namely, CINAHL, PsycINFO, and MEDLINE. All three databases were searched with the terms detailed in Table 2.1.

Titles and abstracts of results were reviewed and inclusion and exclusion criteria, as follows, were applied: English full-text must be available, FCC must be a central variable or concept under study, FCC must be mentioned in the article, the context of FCC must be in a NICU. Detailed information about the data search and selection can be found in Figure 2.1. Following Rodger's approach, various sources of data should be included (Toftagen and Fagerstrøm, 2010). Therefore, inclusion was not limited to research articles; any papers meeting the criteria above were included.

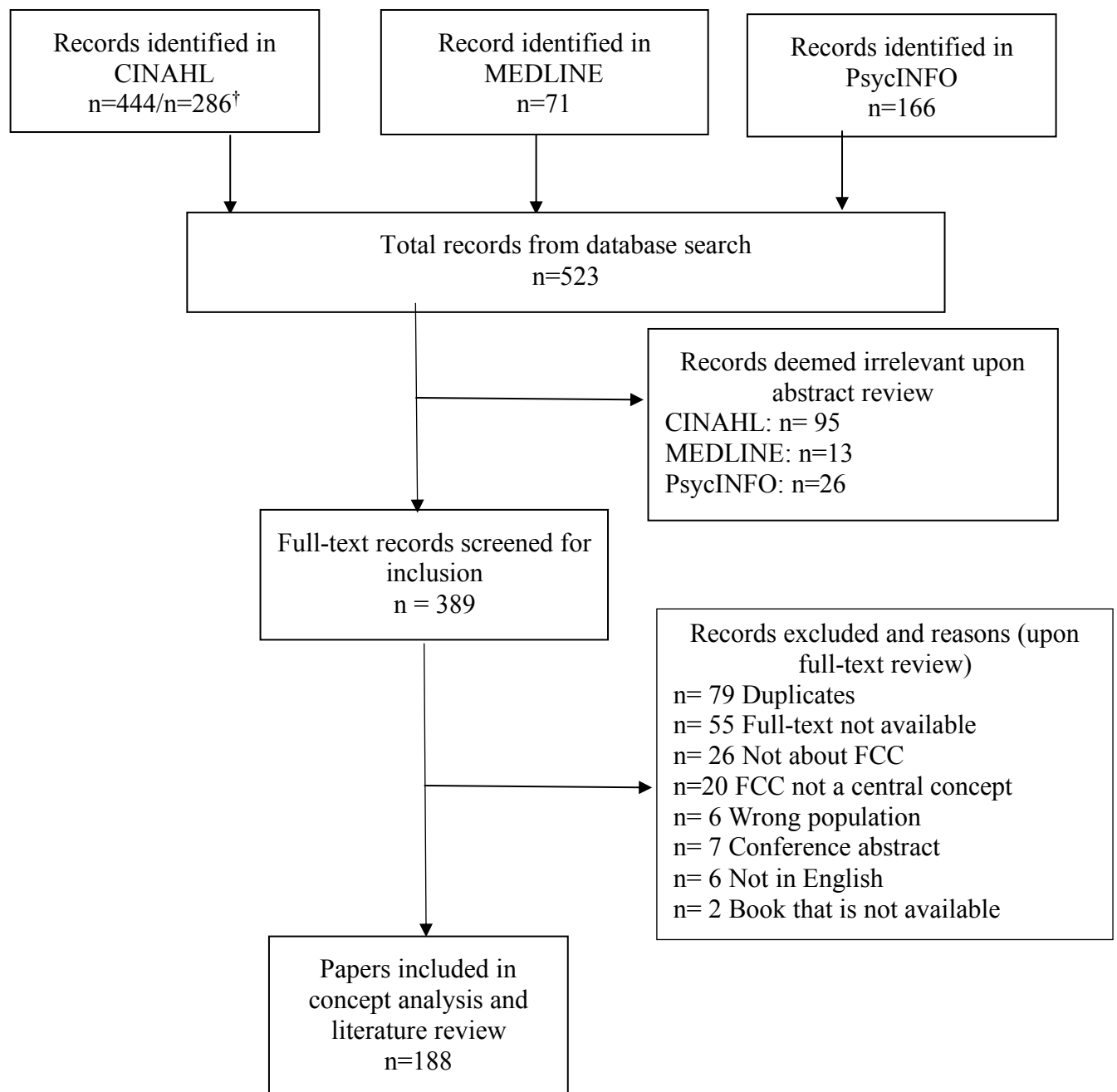
Data management and analysis

As shown in Figure 2.1, a total of 188 articles were included, read in full, and sorted according to: the year of publication, the discipline of the primary author, the country of origin, the type of article, and the term used. This information can be found in Supplementary File 1. Supplementary File 2 includes all 188 articles, organized by author, year, discipline, type of publication and methods, country, term used and related terms used.

In keeping with Rodger's method, during the Core Analysis phase, every article was read with particular attention paid to the concept's context, surrogate terms, antecedents, attributes, examples, and consequences (Toftagen and Fagerstrøm, 2010). During each reading, the questions in Table 2.2 were used to guide the identification of patterns, similarities, and dissimilarities between the texts. Following this, representative articles from various disciplines were read in-full once again to ensure an equitable representation. Specifically, the disciplines/professions of Occupational Therapy (e.g. Gibbs et al., 2010), Social Work (e.g. Levick et al., 2010), Psychology (e.g. Provenzi and Barelo, 2015), Nursing (e.g. Kjellsdotter et al., 2018), and Medicine (e.g. Dunn et al., 2006) were targeted. Various types of articles were

also sought, such as theory (e.g. Nyqvist and Karlsson, 1997), commentaries (e.g. Callister, 2015), and quality improvement (e.g. Maree et al., 2017).

Figure 2.1- PRISMA diagram detailing search and selection



[†]value after year restriction >2000 applied

Table 2.2*Questions used during the core analysis phase*

Surrogate terms	Do other words say the same thing as the chosen concept? Do other words have something in common with the concept?
Antecedents	Which events or phenomena have been associated with the concept in the past?
Attributes	What are the concept's characteristics?
Examples	Are concrete examples of the concept described in the data material?
Consequences	What happens after or as a result of the concept?

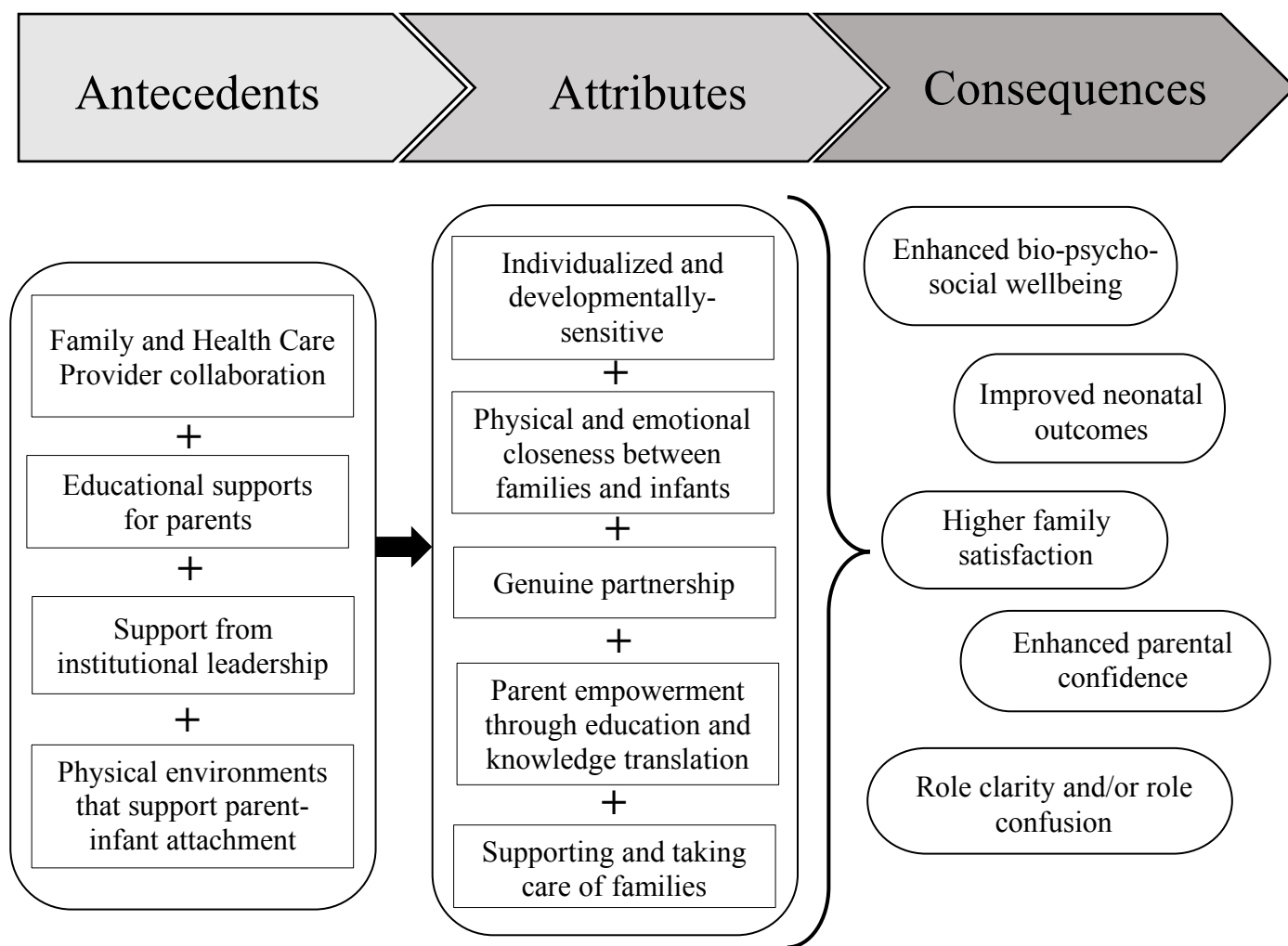
Note: Taken from Tofthagen, R., Fagerstrøm, L.M., 2010. Rodgers' evolutionary concept analysis - a valid method for developing knowledge in nursing science. *Scand. J. Caring Sci.* 24, 21–31. doi: 10.1111/j.1471-6712.2010.00845.x

RESULTS

The profession of Nursing supplied the most papers (n=106) followed by Medicine (n=37). Most authors were from the United States of America (n=96) followed by Canada (n=19); Scandinavian countries accounted for n=18 of the papers. Developing countries, such as Iran, Jordan, and Turkey contributed minimally (n=1 each) to the total of papers reviewed. Most articles were published between 2011 and 2018 (n=123), despite the longstanding history of the concept. Most papers were original research (n=92), followed by clinical papers (n=27), such as clinician reflections, opinions, narratives, and recommendations, non-systematic reviews (n=22), and quality improvement (n=12). Only four randomized controlled trials (RCTs) were identified. Further details can be found in Supplementary File 2.

In keeping with Rodger's method (Toftthagen and Fagerstrøm, 2010), the concept of FCC is defined in terms of its: surrogate and related terms, antecedents, attributes, and consequences (Figure 2.2).

Figure 2.2- Family-Centered Care in the NICU



Surrogate and Related Terms

Surrogate terms express the same concept with different words and related terms; they have something in common with the concept of interest but do not have the exact same characteristics (Toftthagen and Fagerstrøm, 2010). In this review, a few surrogate terms were

identified. These terms included Family-Centered Care Approach(es) (i.e. Shimizu and Mori, 2018), Holistic Family-Centered Care (i.e. Zimmerman and Bauersachs, 2012), and Family-Centered Care Practices (i.e. Lee et al., 2014). Of note, the discipline of social work used terms such as Culturally Competent or Holistic FCC (i.e. Nicholas et al., 2014; Trujillo et al., 2017) and used these interchangeably with FCC.

Many related terms were identified often reflecting various perspectives and developments of the central concept of FCC. In 1982, Als elaborated the Synactive Theory of Development which considers the interaction between an infant's environment and the neurobiological development inherent to the neonatal period. Care according to the Synactive Theory of Development aims to create stability in an infants' various subsystems, such as self-regulation, through interventions on infants' environment, such as clustering care (Byers et al., 2006; Lester et al., 2011). Subsequent to the development of the Synactive Theory of Development, Als et al. (1986) conducted a two-phase nonexperimental study and determined that reducing unnecessary stimuli and individualizing care to each infant improved their overall medical status; this study was foundational in the development of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) (<https://nidcap.org/en/>). In the 1990s, NIDCAP was further elaborated to specifically address *the neurobiological development needs* of infants requiring NICU hospitalizations. The NIDCAP model of care now includes provisions for pain care, reduction in overall stimuli, naturalistic observations of infants, and provisions for the physical layout of NICUs (Westrup, 2007). In contrast to the typical hospital environment, neonates require reduced noise and light levels, longer periods of uninterrupted sleep, and skin-to-skin care (SSC), to name a few (Coughlin et al., 2009).

In light of these developments, in the early 1990s, the concept of developmentally-sensitive care (care according to the Synactive Theory of Development) became regarded as an essential component of providing FCC in an NICU setting (Brown, Pearl, & Carasco, 1991; Dobbins, Bohlig, & Sutphen, 1994). Therefore, one of the earliest related terms to emerge was Developmental Care/Developmentally-Sensitive or Supportive FCC (Aita and Snider, 2003; Nyqvist and Karlsson, 1997). After the emergence of this concept in the literature, FCC in the NICU became synonymous with developmental care; the core concept of FCC was adapted specifically for the needs of NICU population and context. Although there are universal developmental requisites, each infant has unique developmental needs depending on their clinical picture; therefore, developmentally-sensitive care implies a shift from a task-based orientation to an individualized approach (Byers et al., 2006). This is unique from FCC as neurobiological development is not a core tenet or attribute of FCC in other settings.

In the 2000s, NIDCAP was further popularized by Westrup et al., (2000; 2007). Building on the NIDCAP principles, the term Family-Integrated Care (FiCare) has begun to appear in the literature (Jiang et al., 2014; O'Brien et al., 2015). This concept is unique from FCC, and developmentally-sensitive FCC, as it emphasizes *genuine integration of parents* as part of the care team; in this model of care, parents provide all the primary care for their infant, excluding only complex medically-necessary care such as ventilators and central lines (Bracht et al., 2013). In 2016, Altimier and Phillips elaborated seven “core measures” of Neuroprotective Family-centered Developmental Care and emphasized the importance of a healing environment for NICU infants; this healing environment centers on parent-infant closeness and bonding through SSC, which is the direct contact of parental skin with the infant’s skin. These seven measures also include adequate rest, pain care, optimized nutrition, and collaborative partnerships between

HCPs and parents (Altimier, 2015; Altimier and Phillips, 2016). Therefore, it is reasonable to delineate that the latest developments in FCC in the NICU emphasize not only the infant's environment (such the synactive theory of development), but also the importance of parental presence and parental participation in care in facilitating that environment.

All other identified related terms are presented in Supplementary File 2.

Antecedents

Defined by Weaver and Mitcham, antecedents are “conditions required for an instance of the concept to occur” (2008, p.188). Many potential antecedents for FCC in the NICU were identified in the literature. These can be grouped into four primary categories forming the foundation of the concept (Figure 2.2).

Family and HCP collaboration. The most strongly identified antecedent for FCC is collaboration. In the NICU, collaboration rests on trust and open and prompt communication (Cone, 2007; Wataker et al., 2012). Oft mentioned were the importance of interdisciplinary collaboration (Nightlinger, 2011; Ramezani et al., 2014), parent involvement in discharge planning (Purdy et al., 2015), parental presence at interdisciplinary rounds (Harris, 2014), and honouring personal beliefs and cultural practices (Hendson et al., 2015). However, this is not always easy; a Finnish study revealed that close collaboration with parents results in unclear work identity among nurses, and that some even oppose FCC (Axelin et al., 2014). Despite the challenges, a strength-based approach and helping to build and engage groups, such as appreciative inquiry, can be successful in bringing about positive change (Trajkovski et al., 2015). Additionally, the importance of individualized and evolving care plans that adjust to a family and infant's changing needs cannot be understated (Byers et al., 2006).

Education and support for parents. Supporting parents with the knowledge they require is essential for the well-being of NICU families; parent education reduces stress while enhancing overall comfort and confidence (Cooper et al., 2007; O'Brien et al., 2015). Individualized educational interventions, such as simulations, enhance respect and dignity through information sharing, participation in decision-making, and collaboration as equals (Arnold and Diaz, 2016). In particular, parents require education and support to facilitate SSC (Cleveland, 2008), parent involvement in pain care (Skene et al., 2012), and breastfeeding (Alves et al., 2013). Support is a critical component of the education pillar as it is necessary for both the transfer of information (e.g. skills) and emotional well-being (e.g. support groups) (Ballweg, 2001; Dunn et al., 2006). Also discussed were the importance of parent councils and advisors (Moore et al., 2003), peer-to-peer parent support (Levick et al., 2014), and sibling support groups (Levick et al., 2010; Morrison and Gullón-Rivera, 2017).

Institutional support. Support from the highest levels of leadership is required for any paradigmatic shift within an organization. Policies and procedures that are not family-centered can create conflict between nurses and parents (Jones et al., 2015). Policies such as open units that allow parents unrestricted access 24 hours a day (Voos and Park, 2014), 24/7 visiting hours (Griffin, 2013), and sibling visitation (Levick et al., 2010) support families' unrestricted access to their infant, which is essential for FCC (Montes Bueno et al., 2016). Also mentioned was easing financial burdens for families, such as compensation for parking (i.e. parking passes) (Hurst, 2004; O'Brien et al., 2015) and the provision of long-term follow-up (Beveridge et al., 2001). From an ideological standpoint, organizations must also support a shift in philosophy towards nurses as educators and parents as primary providers (Li et al., 2017; Trajkovski et al., 2012). Providing tools and training for educators and managers enables them to support their

staff (Asai, 2011). In particular, encouraging reflective practice among HCPs helps them integrate the principles of FCC (Carrier, 2002).

Physical environments that support parent-infant attachment. Although FCC can be enacted in any setting, without certain amenities and physical spaces parent infant closeness is difficult to achieve. In a study by Raiskila et al., (2017), the ability to stay overnight was ranked as the most important factor promoting parent-infant closeness. Accordingly, the move towards single-room unit style (Single-family Room [SFR]) was extensively explored in the included papers (i.e. Beck et al., 2009; Jones et al., 2016; Toivonen et al., 2017). Additionally, Baylis et al. (2014), found that early parent-infant closeness is most affected by unit routines and environments, which has profound implications for delivering FCC in the NICU. Also mentioned was the importance of family lounges (Flacking et al., 2012).

Attributes

Attributes are “clusters of characteristics” that allow something to be classified under the concept; they can be thought of as the definition of the concept (Tofthagen and Fagerstrøm, 2010, p. 27). In this review, five main categories of attributes emerged (see Figure 2.2).

Individualized and developmentally-sensitive. Due to a focus on the developmental needs of neonates, the concept of ‘individualized and developmentally sensitive care’ adapted FCC to the NICU population (Nygqvist and Karlsson, 1997). As a result, this attribute was foundational in the reviewed papers and was often used interchangeably with FCC in the NICU after its appearance in the literature (i.e. Byers et al., 2006; Obeidat et al., 2009; Westrup et al., 2000).

Physical and emotional closeness between families and infants. The evolution of the concept of FCC emphasizes the importance of parental presence (i.e. Ahlqvist-Björkroth et al., 2017; Ballweg, 2001; Byers et al., 2006; Goldstein, 2013). For example, parents report that SSC

is comforting and HCPs report that it is highly effective in promoting bonding (Cooper et al., 2007). Best stated by Jiang et al., (2014), “it is obvious that parental presence in the NICU is vital to both the infant's and the parents' well-being” (p. 782). In addition, the development of single-family rooms was spurred by the importance of this attribute as they favour FCC by allowing for more privacy, places to sleep, and physical closeness between infants and parents (Beck et al., 2009; Jones et al., 2016).

Genuine partnership and collaboration. Genuine partnership results in individualized care optimized to each family and tailored to their needs where the family's input bears equal weight to that of HCPs (Carrier, 2002). However, this attribute can be complex as it requires mutual trust and respect; trust is gained through continuous and nonbiased sharing of information (Gephart and McGrath, 2012; Weis et al., 2013). Communication was addressed in every reviewed paper as an essential component of this attribute, making it a necessary component of FCC in the NICU (i.e. Ahlqvist-Björkroth et al., 2017; Cone, 2007; Wataker et al., 2012). Of note, parental presence at interdisciplinary rounds has been recommended as standard practice by the American Academy of Pediatrics since 2003 (Grzyb et al., 2014), which furthers supports the importance of this attribute.

Parent empowerment through education and knowledge translation. This attribute involves education that is tailored to the needs of each individual parent (Arnold and Diaz, 2016; Axelin et al., 2014; Bracht et al., 2013). Once parents have the knowledge and the skills to care for their infant, they can be recognized as the primary caregivers and other HCPs, such as nurses, become mentors and educators (Jiang et al., 2014; O'Brien et al., 2015). This shift from nurse-led to parent-led care ensures that parents can truly be involved throughout their infant's

hospitalization, including participating in rounds and decision-making as equals (Lester et al., 2011; Purdy et al., 2015; Umberger et al., 2018).

Taking care of families. Family-centered care in the NICU necessitates taking care of the *whole* family (Nyqvist and Karlsson, 1997). Taking care of families broadly describes the need to adopt family-supportive policies and practices that support families emotionally and financially (Milford, 2016; O'Brien et al., 2015; Umberger et al., 2018). Assessing and providing for each families' unique needs ensures that they can equitably participate in the care of their infant (Altimier, 2015; Ramezani et al., 2014). This also includes the creation of parent councils and peer-to-peer parent networks (Hall et al., 2015).

Consequences

Consequences are the result of “the use of the concept in a practical situation” and they follow the occurrence of the concept (Toftthagen and Fagerstrøm, 2010, p. 27). Despite the connotation of the word, consequences of FCC in the NICU are mostly positive. As shown in Figure 2.2, consequences identified in this review were grouped into 5 categories.

The first consequence of FCC in the NICU is overall enhanced bio-psycho-social well-being (Axelin et al., 2014). For parents, FCC results in less stress, anxiety and depressive symptoms, and more positive parenting interactions in the NICU, among others (Melnik et al., 2006). For the infant, the presence and involvement of their parents is critical for their development and for their overall well-being (Jiang et al., 2014; Westrup et al., 2007). Studies report that the infants have shorter lengths of stay, demonstrate more secure attachments to their parents, and exhibit more organized behaviour (Johnston et al., 2006), in addition to improved feeding outcomes, decreased ventilator and oxygen requirements, and a shorter time to oral feeding (Byers et al., 2006). A recent systematic review of four studies by Yu & Zhang (2019)

found that, for preterm infants in the NICU, FCC had a positive impact on length of stay (LOS) and some effect on overall morbidity, feeding and growth, and neurobehavioural outcomes.

Thirdly, the literature supports that FCC results in enhanced family satisfaction (Coyne, 2015; Gooding et al., 2011; Jiang et al., 2014). When parents view their relationship with HCPs positively, they report higher satisfaction with the overall care (Cleveland, 2008). This positive relationship contributes to enhanced parental confidence and empowerment which reduces stress and enhances the overall parental role (Melnyk et al., 2006). Additionally, FCC in the NICU supports maternal confidence with lactation and promotes breastfeeding, which is critically important for ill neonates (Alves et al., 2013; Dunn et al., 2006). Parents also exhibit enhanced confidence at discharge (Griffin, 2006; Johnston et al., 2006; Nightlinger, 2011).

Lastly, as a result of parent empowerment and the shifting of tasks from nurses to parents, FCC in the NICU necessarily results in a change in power hierarchy (Axelin et al., 2014). This change may result in role confusion among HCPs (Hendricks-Muñoz et al., 2010) and parents alike (Arnold et al., 2013; Gibbs et al., 2015). Parents report a desire for nurses to adopt the role of facilitator, teacher, and guardian (Reis et al., 2010). However, this shift in the role of nurses requires further clarification as many nurses struggle with its implementation in their working contexts (Jones et al., 2015; O'Brien et al., 2015; Trajkovski et al., 2012). Studies describe power struggles between parents and nurses (Cleveland, 2008; Gibbs et al., 2015) and nurses struggling to understand their role in FCC (Mirlashari et al., 2019).

DISCUSSION

During the conduct of the core analysis phase in this paper, certain trends were identified. For example, there were notable differences in the content of articles from various disciplines. Articles from Occupational Therapists (n=8) focused on support groups, helping parents

understand their role in the NICU (Gibbs et al., 2016), and assisting parents with the occupations of parenting such as feeding and positioning (Gibbs et al., 2010; Holloway, 1994). Articles by Social Workers (n=7) focused on communication (Macdonell et al., 2015; Trujillo et al., 2017), visitation policies (Levick et al., 2010), and the availability of support programs and family lounges (Levick et al., 2014). Of note, articles by Child Life Specialists have begun to appear in the literature (n=2). These articles discussed the role of Child Life Specialists in the NICU with a particular emphasis on supporting siblings (Morrison and Gullón-Rivera, 2017). However, there is great potential to expand this role in areas such as supporting bereavement, education for parents, and facilitating developmentally sensitive interventions (Smith et al., 2014). The vast majority of the papers stemmed from the disciplines of nursing, medicine, and psychology (n=145 combined). These articles focused largely on interventions and elements relevant to direct care such as communication (i.e. Wataker et al., 2012), education and training for both parents and HCPs (i.e. Altimier et al., 2015; Arnold and Diaz, 2016), evaluations of interventions (i.e. Ahlqvist-Björkroth et al., 2017), and parent stress and satisfaction (i.e. Dall'Oglio et al., 2018). This diversity illustrates the importance of the interdisciplinary perspectives in the provision of FCC in the NICU, but also the complexity and breadth of expertise required to deliver truly interdisciplinary care.

Considering the papers as a whole, the majority can be characterized as research (n=92), clinical articles (n=27), and non-systematic reviews (n= 22). Many of the research articles used scales and questionnaires to quantitatively measure various aspects of FCC, such as the Empowerment of Parents in the Intensive Care–Neonatology (EMPATHIC-N) (Kjellsdotter et al., 2018), the Family Needs Inventory (Mundy, 2010), the Parental Stressor Scale (Weis et al., 2013), and the Family Nurse Caring Belief Scale (Magri, 2014). Qualitative studies ranged in

approaches and examined lived experiences (i.e. Maastrup et al., 2018; Valizadeh et al., 2018) and perceptions (i.e. Hendson et al., 2015; Hurst, 2001) of both parents and HCPs. Despite many research studies, there were only four RCTs and five systematic reviews identified in this review. This highlights the difficulties with quantitatively evaluating a concept as theoretical and broad as FCC in the NICU. Notwithstanding, other types of reviews and syntheses were prevalent (Bourque et al., 2018; Byrne and Garber, 2013). Clinical papers, which encompass expert clinician features (Hookway, 2013; Shaker, 2013), reflections and narratives (Carrier, 2002; Ward, 1999), opinions (Nichols, 2013), and practice guidelines (Cockcroft, 2012; Robison, 2003); these articles are important for practice disciplines as they may provide insights for future research (Gobel, 2018). Only five of the 188 articles included in this review were led by parents. These articles were narratives written by parents (Lightbody, 2009; Van Dell, 2011; Woodwell, 2002) and accounts of parent stories with suggestions for practice (Sweeney, 1997; Sydnor-Greenberg and Dokken, 2000). The plurality of perspectives and aims of reviewed papers contributes to the evolving nature of the concept of FCC in the NICU and helps to further clarify and refine the antecedents and attributes of the concept, as well as their implementation and impact.

From an evolutionary perspective, a clear pattern emerged. Family-centered care was adapted to NICU context soon after the appearance of the concept in the form of developmental care (i.e. Ballweg, 2001; Nyqvist and Karlsson, 1997). As discussed, following a synactive theory of development, developmental care emphasizes the neurobiological developmental needs inherent to the neonatal period based on evidence that it improves outcomes in infants requiring medically-invasive care (Als 1982, 1983, 1986; Byers et al., 2006). Following this development, FCC in the NICU became synonymous with developmentally-sensitive FCC. The literature

reflects that the term *individualized* also appeared synonymously with these terms as this is implied and subsumed within the concept of developmentally-sensitive care. This culminates in the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) which is based on the concept of newborn competence and neurobiological development, a further development of synactive theory (Als 1986; Westrup, 2007). The NIDCAP program was widely adopted both nationally and internationally and contributed to the development of Neonatal Integrative Developmental Care (IDC), which paved the way for the development of seven neuroprotective core measures for family-centered developmental care of neonates (Altimier and Phillips, 2016). These seven holistic measures categorize the ideal environment for NICU infants as: Healing Environment, Partnering with Families, Positioning and Handling, Safeguarding Sleep, Minimizing Stress and Pain, Protecting Skin, and Optimizing Nutrition (Altimier and Phillips, 2016). According to Altimier and Phillips (2016), the most important aspect is the overall healing environment, which reflects the importance of SSC, reducing unnecessary stimuli, and privacy for the family. These core measures build on decades of empirical research further tailoring FCC to the NICU population. Most recently, challenges with the implementation of FCC in the NICU have led to the development of the Family-Integrated Care model (FiCare). FiCare focuses on empowering and educating parents so that they may provide most (if not all) of their infant's care in NICU (O'Brien et al., 2015). This model attempts to address the role clarity/confusion that often results from implementing FCC in the NICU. The concept of family *integrated* care is fundamentally different from family *centered* care and may represent a significant shift in thinking surrounding care delivery in the NICU.

A final trend that emerged was with regard to the weight placed on particular aspects of FCC in the NICU, namely family presence at rounds (Nichols et al., 2015), SFRs (Erdeve et al.,

2008), SSC (Benoit and Semenic, 2014), and pain management (Harrison et al., 2015). These aspects broadly reflect the aforementioned seven core measures identified in Altimier & Phillips, 2016. This suggests that these are foundational aspects of FCC in the NICU, which is reflected in the attributes (Figure 2.2). The literature highlighted the prominence of the biomedical perspective on FCC; this naturally stems from the large representation of articles from the disciplines of nursing, medicine, and psychology. This focus on the readily quantifiable aspects of FCC has resulted in interventions to modify its antecedents and attributes. However, many non-modifiable aspects remain unexplored, such as the impact of families' socioeconomic status on FCC.

Considering the lack of comprehensive empirical evaluations of FCC (Coyne, 2015), the focus on particular quantifiable aspects of FCC (such as room design or pain care), and the persistent challenges with its operationalization, it is reasonable to delineate that treating FCC as a model that can be implemented without an institutional shift in philosophy of care is reductionist and unrealistic (Spence and Lau, 2006). In contrast to FCC, models such as FiCare, NIDCAP, and the IDC provide clear guidelines and stipulate that there must be a fundamental change in ontology at the organizational and practitioner levels in order to "shift the paradigm of NICU care" (Altimier and Phillips, 2016; Jiang et al., 2014, p. 782; Westrup, 2007). Therefore, these models provide guidelines to achieve particular ends (i.e. increase parental presence, increase rates of SSC) but are all underpinned by, and originate from, the core concept of FCC. This suggests that FCC in the NICU is a philosophy of care, rather than a model that can be readily implemented. This suggests that the persistent tensions are likely the result of a misunderstanding and oversimplification of FCC.

IMPLICATIONS

In the Further Analysis phase, Rodgers does not promote a final conclusion, but rather suggestions for further research (Toftthagen and Fagerstrøm, 2010). Given that this review supports that FCC is a philosophy of care rather than a model, it is necessary to adapt it to various settings in order to implement its tenets. However, in the process of doing so, FCC becomes a unique concept. Thus, FCC in the NICU and FCC in other settings are conceptually different and have unique antecedents and attributes. Given that well-defined concepts promote the further systematization of a concept (Toftthagen and Fagerstrøm, 2010), further research pertaining to FCC in the NICU should explore these potential conceptual departures. For example, the FiCare program emphasizes its difference through the use of the word integrated rather than centered; this is an important difference as, in order for parents to become their infant's primary caregiver, they must commit to being present for six to eight hours each day (Jiang et al., 2014). Naturally this engenders a new set of antecedents, attributes, and consequences, which should be the subject of future research and refinement.

This review confirmed a lack of articles pertaining to perioperative neonates; the articles focused almost exclusively on premature infants. Given the importance of pain treatment and stimuli reduction inherent to FCC in the NICU, further research should explore the individualized needs of this population of sick infants. This review also demonstrated that an emphasis on interdisciplinary perspectives is vital for the provision of FCC in the NICU. As such, future research initiatives should strive to involve *all* members of the interdisciplinary team as equal partners including, but not limited to, researchers and clinicians from various disciplines as well as families. It is important to probe broadly when exploring FCC in the NICU; a plurality of perspectives may help provide new understandings of the concepts.

CONCLUSION

Several limitations associated with this review must be acknowledged. Firstly, Rodger's method of concept analysis advocates for the inclusion of various data sources, including artistic works such as dance and visual art (Toftagen & Fagerstrøm, 2010); in this case, this was not done. Including more varied sources may have resulted in a deeper understanding of the concept. Secondly, the search terms were not modified in between the searches, they were kept consistent in all databases. This may have resulted in missed articles due to differences in indexation of the various database hosts.

Family-centered care in the NICU must be regarded as a philosophy; reducing it to an intervention is reductionist and unrealistic. Despite the longstanding history of this concept, foundational elements of this philosophy have remained in flux. This concept analysis and literature review attempts to provide both a synthesis of existing literature as well as an overview of the evolution of the concept of FCC in the NICU in order to arrive at a guiding framework (Figure 2.2). With the support of parents, organizations' leadership and buy-in from staff, interventions targeting aspects of FCC in the NICU are warranted. Ultimately, health care providers are not the architects of FCC, the families are. Therefore, FCC must be flexible, and easily adaptable to any context or family situation; it will not always look the same. When families feel respected they are more able to provide the care that they know their infant needs and ultimately contribute positively, in ways that HCPs cannot, to their own health, wellbeing, and development as well as that of their child.

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Supplementary File 1.

Summary of included studies by year, discipline, country, type of article, and term used

Year	n	Discipline	n	Country	n	Type	n
1991	2	Nursing	106	USA	96	Research	92
1992	0	Medicine	37	Canada	19	Clinical paper/article	27
1993	0	Psychology	12	Sweden	9	Review	22
1994	2	Occupational Therapy	8	UK	9	Quality Improvement	12
1995	2	Social Work	7	Australia	8	Theoretical Research	6
1996	2	Education	4	Denmark	8	Continuing Education	5
1997	2	Health Administration	3	Finland	7	Parent Perspective	5
1998	0	Epidemiology	2	Iran	6	Systematic Review	5
1999	1	Sociology	2	Italy	4	Dissertation	4
2000	3	Child Life Specialty	2	Japan	4	Protocol	4
2001	5	Engineering	1	Norway	3	Commentary	3
2002	2	Global Health	1	Portugal	3	Concept Analysis	2
2003	5	Physiotherapy	1	Brazil	2	Case Study	1
2004	3	Public Health	1	China	1	Total:	188
2005	2	Speech Pathology	1	Czech Republic	1		
2006	9	Total:	188	France	1		
2007	8			India	1		
2008	4			Israel	1		
2009	6			Jordan	1		
2010	6			Korea	1		
2011	12			South Africa	1		
2012	11			Spain	1		
2013	17			Turkey	1		
2014	18			Total:	188		
2015	21						
2016	19						
2017	14						
2018	11						
2019	1						
Total:	188						

Keyword (term) Used	n
Family-Centered Care (Family-Centred Care)	173
Family-Centered approaches	2
Family-Sensitive Care	2
Patient- and- Family-Centered Care (PFCC)	2
Compassionate Family Care Framework	1
Developmental and Family-Centered Care	1
Developmentally Supportive Family-Centered Care	1
Family-Centered Principles	1
Family-Centred Developmental Care	1
Family-Centered Neonatal Care	1
Individualized Family-Centered Developmentally Supportive Care	1
Partnered Relationship	1
Patient- and- Family-Centered Care Model	1
Total:	188

Supplementary File 2.

Table of all included studies.

Author(s)	Year	Discipline	Type	Methods (if applicable)	Country	Keyword (term) used
Ahlqvist-Björkroth, S. et al.	2017	Psychology	Protocol		Finland	Family-Centered Care
Ahn, Y.-M. & Nam-Hee, K.	2007	Nursing	Research	Quasi-Experimental	Korea	Family-Centered Care
Aita, M. & Snyder, L.	2003	Nursing	Concept Analysis		Canada	Family-Centered Care
Allison, B. A., & Burcin, E.	2011	Nursing	Clinical Article		USA	Family-Centred Care
Altimier, L.	2015	Nursing	Theoretical Research		USA	Compassionate Family Care Framework
Altimier, L., Kenner, C., et al.	2015	Nursing	Research	Survey-Correlational	USA	Family-Centred Developmental Care
Alves, E., et al.	2013	Epidemiology	Review	Literature Review	Portugal	Family-Centred Care
Alves, E., et al.	2016	Epidemiology	Research	Survey validation	Portugal	Family-Centered Care
Arnold, J., & Diaz, M. C. G.	2016	Medicine	Review		USA	Patient- and- Family-Centered Care
Arnold, L., et al.	2013	Psychology	Research	Thematic analysis	UK	Family-Centred Care
Asai, H.	2011	Nursing	Research	Cross-sectional survey	Japan	Family-Centered Care
Axelin, A., et al.	2014	Nursing	Research	Descriptive Qualitative	Finland	Family-Centered Care
Baía, I., et al.	2016	Medicine	Research	Cross-sectional survey, Observational	Portugal	Family-Centered Care
Bailey, S. M., et al.	2013	Medicine	Research	Survey	USA	Family-Centered Care
Balbino, F. S., et al.	2016	Nursing	Research	Quasi-Experimental	Brazil	Patient- and- Family-Centered Care Model

Ballweg, D. D.	2001	Nursing	Quality Improvement	Performance Improvement	USA	Developmentally Supportive Family-Centered Care
Bastani, F., et al.	2015	Nursing	Research	RCT	Iran	Family-Centered Care
Baylis, R., et al.	2014	Neonatology	Research	Longitudinal-Survey	Sweden	Family-Centred Care
Beal, J., & Heaman, M.	2006	Nursing	Commentary		USA	Partnered Relationship
Beck, S. A., et al.	2009	Nursing	Research	Grounded Theory	Denmark	Family-Centered Care
Benoit, B., & Semenic, S.	2014	Nursing	Research	Qualitative descriptive	Canada	Family-Centered Care
Berns, S. D., et al.	2007	Medicine	Research	Cross-sectional survey	USA	Family-Centered Care
Beveridge, J., et al.	2001	Nursing	Clinical Article		Canada	Family-Centered Care
Blackington, S. M., & McLauchlan, T.	1995	Nursing	Research	Survey	USA	Family-Centered Care
Blomqvist, Y. T., et al.	2011	Neonatology	Research	Quantitative Descriptive	Sweden	Family-Centred Care
Boardman IV, C. H.	1995	Occupational Therapy (OT)	Review		USA	Family-Centered Care
Boukydis, Z.	2011	Psychology	Commentary		Finland	Family-Centered Care
Bourque, C. J., et al.	2018	Sociology	Review		Canada	Family-Centered Care
Bracht, M., et al.	2013	Nursing	Research	Qualitative analysis	Canada	Family-Centered Care
Brødsgaard, A., et al.	2015	Nursing	Research	Longitudinal, Qualitative synthesis	Denmark	Family-Centred Care
Brødsgaard, A., et al.	2016	Nursing	Protocol		Denmark	Family-Centered Care
Brødsgaard, A., et al.	2017	Nursing	Research	Qualitative content analysis	Denmark	Family-Centered Care

Brown, W., et al.	1991	Neonatology	Review		USA	Family-Centered Care
Bruns, D. A.	2000	Education	Dissertation		USA	Family-Centered Principles
Bruns, D. A., & Klein, S	2005	Education	Research	Retrospective-Survey and Interview data	USA	Family-Centered Care
Byers, J. F., et al.	2006	Nursing	Research	Quasi-Experimental	USA	Family-Centered Care
Byrne, E., & Garber, J.	2013	Physiotherapy	Review		USA	Family-Centered Care
Callister, L. C.	2015	Nursing	Commentary		USA	Family-Centered Care
Carrier, C. T.	2002	Nursing	Clinical Article		USA	Individualized Family-Centered Developmentally Supportive Care (IFDC)
Chung, R. K., et al.	2018	Medicine	Research	Cross-sectional survey	USA	Family-Centered Neonatal Care
Cleveland, L. M.	2008	Nursing	Systematic Review		USA	Family-Centered Care
Cockcroft, S.	2012	Nursing	Clinical Article		UK	Family-Centered Care
Cone, S.	2007	Nursing	Clinical Article		USA	Family-Centered Care
Cooper, L. G., et al.	2007	Social Work	Research	Quasi-Experimental	USA	Family-Centered Care
Curtis, K., et al.	2016	Nursing	Review	Integrative review	Australia	Family-Centered Care
Dall'Oglio, I., Mascolo, R., et al.	2018	Nursing	Systematic Review		Italy	Family-Centred Care
Dall'Oglio, I., Fiori, M., et al.	2018	Nursing	Research	Survey validation	Italy	Family-Centered Care
De Bernardo, G., et al.	2017	Medicine	Research	Prospective Cohort-Survey	Italy	Family-Centered Care
Dobbins, N., et al.	1994	Education	Research	Survey	USA	Family-Centered Care

Dokken, D., & Ahmann, E.	2006	Health Administration	Clinical Article		USA	Family-Centered Care
Dokken, D., et al.	2007	Health Administration	Clinical Article		USA	Family-Centered Care
Dol, J., et al.	2017	Global Health	Review		Canada	Family-Centered Care
Domanico, R., et al.	2011	Medicine	Research	Prospective Cohort	USA	Family-Centered Care
Dudek-Shriber, L.	2004	OT	Research	Survey	USA	Family-Centered Care
Dunn, M. S., et al.	2006	Medicine	Quality Improvement		Canada	Family-Centered Care
D'Agata, A. L., et al.	2016	Nursing	Theoretical Research		USA	Family-Centered Care
Epstein, E. G., et al.	2013	Nursing	Research	Prospective Descriptive	USA	Family-Centered Care
Epstein, E. G., et al.	2017	Nursing	Review	Integrative Review	USA	Family-Centered Care
Erdeve, O., et al.	2008	Medicine	Research	Prospective Cohort	Turkey	Family-Centred Care
Faber, K.	2013	Nursing	Quality Improvement		USA	Family-Centred Care
Fegran, L., et al.	2008	Nursing	Research	Hermeneutic	Norway	Family-Centred Care
Fegran, L., & Helseth, S.	2009	Nursing	Research	Hermeneutic	Norway	Family-Centred Care
Fisheing, R., et al.	2016	Nursing	Research	Qualitative descriptive	USA	Family-Centered Care
Flacking, R., et al.	2012	Nursing	Review		Sweden	Family-Centred Care
France, D., et al.	2009	Medicine	Research	Survey	USA	Family-Centered Care
Frize, M., et al.	2013	Engineering	Research	Usability study	Canada	Family-Centered Care
Gephart, S. M., et al.	2012	Nursing	Clinical Article		USA	Family-Centered approaches

Gibbs, D., et al.	2010	OT	Review		UK	Family-Centred Care
Gibbs, D., et al.	2015	OT	Review	Meta-ethnographic synthesis	Canada	Family-Centred Care
Gibbs, D. P., et al.	2016	OT	Research	Qualitative-Paradigmatic analysis	Canada	Family-Centred Care
Globus, O., et al.	2016	Neonatology	Research	Survey	Israel	Family-Centered Care
Goldstein, L. A.	2013	OT	Review		USA	Family-Centered Care
Gooding, J. S., et al.	2011	Health Administration	Review		USA	Family-Centered Care
Griffin, T.	2013	Nursing	Continuing Education		USA	Family-Centered Care
Griffin, T., Abraham, M.	2006	Nursing	Review		USA	Family-Centered Care
Griffin, T.	2006	Nursing	Continuing Education		USA	Family-Centered Care
Grzyb, M. J., et al.	2014	Neonatology	Research	Cross-sectional survey	Canada	Family-Centered Care
Hadian Shirazi, Z., et al.	2015	Nursing	Research	Inductive Content Analysis	Iran	Family-Centered Care
Hadian Shirazi, Z., et al.	2016	Nursing	Research	Hermeneutic/Phenomenological	Iran	Family-Centered Care
Hall, S. L., et al.	2015	Neonatology	Review		USA	Family-Centered Care
Harris, G. M.	2014	Nursing	Clinical Article		USA	Family-Centered Care
Heffernan, J., et al.	2014	Nursing	Clinical Article		USA	Family-Centered Care
Hendricks-Muñoz, K., et al.	2010	Neonatology	Research	Survey	USA	Family-Centered Care
Hendson, L., et al.	2015	Nursing	Research	Grounded Theory	Canada	Family-Centered Care

Henry Bowie, B., et al.	2003	Nursing	Quality Improvement		USA	Family-Centered Care
Himuro, N., et al.	2015	Public Health	Research	Survey validation	Japan	Family-Centered Care
Holloway, E.	1994	OT	Clinical Article		USA	Family-Centered Care
Holmes, A. V., et al.	2016	Medicine	Quality Improvement		USA	Family-Centered Care
Hookway, L.	2013	Nursing	Clinical Article		UK	Family-Centred Care
Horikoshi, Y., et al.	2018	Medicine	Research	Retrospective	Japan	Family-Centered Care
Hurst, I.	2001	Nursing	Research	Ethnography	USA	Family-Centered Care
Hurst, I.	2004	Nursing	Research	Case study	USA	Family-Centered Care
Hurst, I.	2006	Nursing	Research	Survey	USA	Family-Centered Care
Jarrett, M. H.	1996	Nursing	Clinical Article		USA	Family-Centered Care
Jiang, S., et al.	2014	Medicine	Review		Canada	Family-Centered Care
Johnson, A. N.	2008	Nursing	Clinical Article		USA	Family-Centered Care
Johnston, A. M., et al.	2006	Medicine	Research	Case Studies	USA	Family-Centered Care
Jones, L., et al.	2015	Psychology	Research	Qualitative descriptive	Australia	Family-Centered Care
Jones, R., et al.	2016	Psychology	Research	Quasi-Experimental	Australia	Family-Centered Care
Joseph, R. A.	2016	Nursing	Clinical Article		USA	Family-Centered Care
Kallan, J. C.	2013	Sociology	Dissertation		USA	Family-Centered Care
Kjellsdotter, A., et al.	2018	Nursing	Research	Cross-sectional survey	Sweden	Family-Centered Care
Koh, G., et al.	2005	Medicine	Systematic Review		Australia	Family-Centered Care

Koh, T., et al.	2000	Medicine	Research	Survey	Australia	Family-Centered Care
Lee, L. A., et al.	2014	Nursing	Quality Improvement		USA	Family-Centered Care
Lester, B. M., et al.	2011	Psychology	Theoretical Research		USA	Family-Centered Care
Levick, J., et al.	2010	Social Work (SW)	Quality Improvement		USA	Family-Centered Care
Levick, J., et al.	2014	SW	Clinical Article		USA	Patient- and- Family-Centered Care
Li, X.-Y., et al.	2017	Medicine	Research	Retrospective	China	Family-Centered Care
Lightbody, T.	2009	SW	Parent Perspective		Canada	Family-Centred Care
Maastrup, R., et al.	2018	Nursing	Research	Qualitative-Thematic analysis	Denmark	Family-Centred Care
Macdonell, K., et al.	2015	SW	Research	Questionnaires	Canada	Family-Centered Care
Magri, E. P.	2014	Nursing	Dissertation		USA	Family-Centered Care
Manning, A. N.	2012	Nursing	Continuing Education		USA	Family-Centered Care
Maree, C., et al.	2017	Nursing	Quality Improvement		South Africa	Family-Centered Care
McGrath, J. M.	2001	Nursing	Theoretical Research		USA	Family-Centered Care
Meiers, S. J., et al.	2007	Nursing	Research	Survey validation	USA	Family-Sensitive Care
Meyer, E. C., et al.	1996	Psychology	Research	Pre-and-Post survey	USA	Family-Centered Care
Meyer, E. C., et al.	2011	Psychology	Research	Pre-and-Post survey	USA	Family-Centered Care
Milford, C. A.	2016	Psychology	Clinical Article		USA	Family-Centered Care
Mirlashari, J., et al.	2019	Nursing	Research	Interpretive Phenomenology	Iran	Family-Centered Care

Montes Bueno, M. T., et al.	2016	Nursing	Research	Cross-sectional survey	Spain	Family-Centred Care
Moore, K. A. C., et al.	2003	Nursing	Quality Improvement		USA	Family-Centered Care
Morrison, A., et al.	2017	Child Life Specialty	Clinical Article		USA	Family-Centered Care
Mullaney, D. M., et al.	2014	Nursing	Research	Survey	USA	Family-Centered Care
Mundy, C. A.	2010	Nursing	Research	Descriptive correlational	USA	Family-Centered Care
Nicholas, D. B., et al.	2014	SW	Research	Grounded Theory	Canada	Family-Centered Care
Nichols, A.	2013	Nursing	Clinical Article		UK	Family-Centred Care
Nichols, A.	2014	Nursing	Research	Thematic content analysis	UK	Family-Centred Care
Nichols, K., et al.	2015	Nursing	Continuing Education		USA	Family-Centered Care
Nightlinger, K.	2011	OT	Clinical Article		USA	Family-Centered Care
Nyqvist, K. H., et al.	1997	Nursing	Theoretical Research		Sweden	Family-Centered Care
O'Brien, K., et al.	2015	Medicine	Protocol		Canada	Family-Centered Care
Obeidat, H. M., et al.	2009	Nursing	Systematic Review		Jordan	Family-Centered Care
Ortenstrand, A., et al.	2010	Nursing	Research	RCT	Sweden	Family-Centered Care
Palazzi, A., et al.	2018	Psychology	Review	Literature Review	Brazil	Family-Centred Care
Palma, J. P., et al.	2012	Medicine	Research	Pre-and-Post survey	USA	Family-Centered Care
Parker, M. E., et al.	2012	Nursing	Case Study		USA	Family-Centered Care
Pasek, T. A., & Licata, J.	2016	Nursing	Research	Survey	USA	Family-Sensitive Care

Petersen, M. F., et al.	2004	Nursing	Research	Survey	USA	Family-Centered Care
Polizzi, J., et al.	2003	Nursing	Quality Improvement	Performance Improvement	USA	Developmental and Family-Centered Care (DFCC)
Provenzi, L., & Santoro, E.	2015	Psychology	Systematic Review		Italy	Family-Centred Care
Purdy, I. B., et al.	2015	Nursing	Review		USA	Family-Centred Care
Raiskila, S., et al.	2014	Medicine	Research	Retrospective Chart Reviews	Finland	Family-Centered Care
Raiskila, S., et al.	2016	Medicine	Research	Prospective Cohort	Finland	Family-Centred Care
Raiskila, S., et al.	2017	Medicine	Research	Correlational	Finland	Family-Centred Care
Ramezani, T., et al.	2014	Nursing	Concept Analysis		Iran	Family-Centered Care
Reis, M. D., et al.	2009	Nursing	Theoretical Research		Canada	Family-Centered Care
Reis, M. D., et al.	2010	Nursing	Research	Interpretive Description	Canada	Family-Centered Care
Robison, L. D.	2003	Nursing	Clinical Article		USA	Family-Centered Care
Roué, J.-M., et al.	2017	Medicine	Review		France	Family-Centred Care
Shaker, C. S.	2013	Speech Pathology	Clinical Article		USA	Family-Centered Care
Shimizu, A., & Mori, A.	2018	Nursing	Research	Cross-sectional survey	Japan	Family-Centred Care
Sikorova, L., & Kucova, J.	2012	Nursing	Research	Survey	Czech Republic	Family-Centered Care
Skene, C., et al.	2012	Nursing	Research	Focused ethnography	UK	Family-Centered Care
Skene, C., et al.	2016	Nursing	Protocol		UK	Family-Centred Care
Smith, J. G., et al.	2014	Child Life Specialty	Research	Survey	USA	Family-Centered Care

Spence, K., & Lau, C.	2006	Nursing	Research	Pre-and-Post survey	Australia	Family-Centred Care
Stacey, S., et al.	2015	Psychology	Research	Qualitative Thematic analysis	UK	Family-Centred Care
Stevens, D. C., et al.	2011	Medicine	Research	Prospective Cohort	USA	Family-Centered Care
Sudia-Robinson, T.	2011	Nursing	Continuing Education		USA	Family-Centered Care
Sundean, L. J., & McGrath, J. M.	2013	Nursing	Clinical Article		USA	Family-Centered Care
Sweeney, M. M.	1997	Nursing	Parent Perspective		USA	Family-Centered Care
Sydnor-Greenberg, N., & Dokken, D.	2000	Nursing	Parent Perspective		USA	Family-Centered Care
Thurman, S. K.	1991	Education	Clinical Article		USA	Family-Centered approaches
Toivonen, M., et al.	2017	Nursing	Research	Quantitative-Comparative, Observational	Finland	Family-Centered Care
Trajkovski, S., et al.	2012	Nursing	Research	Inductive Thematic Analysis	Australia	Family-Centred Care
Trajkovski, S., et al.	2015	Nursing	Research	Appreciative Inquiry	Australia	Family-Centred Care
Trujillo, J. A., et al.	2017	SW	Quality Improvement		USA	Family-Centered Care
Umberger, E., et al.	2018	Neonatology	Review		USA	Family-Centered Care
Valizadeh, S., et al.	2018	Nursing	Research	Qualitative-Hermeneutic/Phenomenological	Iran	Family-Centered Care
Van Dell, T.	2011	Nursing	Parent Perspective		USA	Family-Centered Care
van den Berg, J., et al.	2017	Nursing	Research	Longitudinal Cohort	Sweden	Family-Centered Care
Van Riper, M.	2001	Nursing	Research	Descriptive correlational	USA	Family-Centered Care

Verma, A., et al.	2017	Medicine	Research	RCT	India	Family-Centered Care
Voos, K. C., & Park, N.	2014	Medicine	Research	Pre/post survey	USA	Family-Centered Care
Voos, K. C., et al.	2015	Medicine	Quality Improvement		USA	Family-Centered Care
Walsh, J., & Goser, L.	2013	Nursing	Research	Case study	USA	Family-Centered Care
Ward, K. G.	1999	Nursing	Clinical Article		USA	Family-Centered Care
Wataker, H., et al.	2012	Nursing	Research	Pre-and-Post survey	Norway	Family-Centered Care
Weis, J., et al.	2013	Nursing	Research	RCT	Denmark	Family-Centered Care
Weis, J., et al.	2014	Nursing	Research	Quality improvement	Denmark	Family-Centered Care
Weis, J., et al.	2015	Nursing	Research	Qualitative Descriptive	Denmark	Family-Centered Care
Westrup, B.	2007	Medicine	Review		Sweden	Family-Centered Care
Westrup, B., et al.	2007	Medicine	Review		Sweden	Family-Centered Care
Whelihan, E.	2015	Nursing	Dissertation		USA	Family-Centered Care
Woodwell, W. H	2002	Nursing	Parent Perspective		USA	Family-Centered Care
Zimmerman, K., & Bauersachs, C.	2012	Nursing	Clinical Article		USA	Family-Centered Care

CHAPTER 3

Methods

3.1 Introduction

In this chapter, I will first describe my theoretical framework and positioning as it relates to this study. I will then discuss the study design and describe the pilot testing of the instruments. Following, I will discuss the participants and recruitment procedures, data storage and management, and data analysis. Lastly, I will discuss informed consent and ethical considerations.

To summarize this study's purpose, the literature supports that parents want to be involved in their infant's care in the NICU. In particular, PP, PH, SSC, and PIPC are important for both parents and their infant(s). However, given a paucity of research pertaining to post-operative infants, we do not know if these practices are encouraged by HCPs nor if they are acceptable and/or feasible for parents. Therefore, the aims of this study were: i) to describe the frequency and duration of PP, PH, and SSC in a surgical NICU, ii) to determine the frequency of PP, PH, and SSC during minor acute painful procedures (i.e. heel lance), iii) to assess the relationship between PP, PH, and SSC and illness severity, and iv) to assess parents' perceptions of parent, infant, and environmental factors that influence PP, PH, and SSC for post-operative neonates admitted to a surgical NICU.

3.2 Theoretical framework

3.2.1. Ontology and epistemology.

For nursing practice, the nature of human experience is a consideration necessary for the provision of care (Holtslander, 2008). Nursing knowledge is at its core eclectic, combining empirical data with aesthetic, ethical, personal, and emancipatory knowing (Carper, 1978; Chinn & Kramer, 2013). There is often an imposed dichotomy between post-positivism and constructivism, artificially making researchers choose if deduction or induction, a relativist or a

realist ontology, should govern their reality (Andrews, 2016; Holmes et al., 2006; Johnson & Onwuegbuzie, 2004). In the setting of the NICU, the culture and philosophy surrounding nursing care and its provision and the experiences/feelings of parents of infants are inseparable from the knowledge that can be generated. Therefore, it would be incommensurate with the reality of nursing practice to adopt a purely post-positive, or purely constructivist, worldview. In addition, with infant populations, there is always the limitation that neonates are pre-verbal and cannot communicate complex emotions or perspectives in perceptible ways. Infants cannot talk and therefore we must use quantitative approximates to paint a picture of their experiences and perceptions.

3.2.2 Pragmatism.

An overall pragmatist worldview, that rejects an inductive deductive dichotomy, is therefore warranted. Pragmatism is pluralistic and problem-centered, focusing on what works and the consequences of research findings for clinical practice, bringing methodology closer to how researchers work and apply findings in reality (Creswell & Plano Clark, 2017, p.38-40). This philosophical orientation recognizes the existence and importance of a natural world but places a high regard for the reality and influence of each person's inner world as a product of their experience. Through a rejection of reductionism, organisms are seen as constantly adapting and changing in an infinite loop; trying to make sense of past understandings in ways that fit with the present world in which we are operating (Johnson & Onwuegbuzie, 2004; Teddlie & Tashakkori, 2012). This theoretical orientation is well suited to this study's cross-sectional descriptive quantitative methods. Quantitative descriptive designs have a quality of realism which offers the potential for practical solutions to clinical problems (LoBiondo-Wood et al., 2010).

3.2.3 Framework.

The concept analysis and literature review of FCC in the NICU (Chapter 2) identified many frameworks and guidelines to implementing FCC; for instance, the Family-Integrated Care model (FiCare) (O'Brien et al., 2015), the Creating Opportunities for Parent Empowerment (COPE) program (Melnik et al., 2006) and the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) (Westrup et al., 2000). Despite this, no pre-existing frameworks or guidelines pertaining to FCC or SSC for postoperative infants specifically were identified. Given this, and given the exploratory nature of this inquiry, this study employed a certain level of theoretical eclecticism. In this case, the underlying philosophy or epistemology on which the research is based served as the principles to inform the study (Green, 2014). Therefore, content within five existing publications formed the theoretical basis for this study (see: Altimier & Phillips, 2016; Coughlin et al., 2012; Public Health Agency of Canada, 2017; Westrup, 2007). Referring to Figure 1 (Chapter 1, p. 12), FCC, SSC, and PIPC are the three foundational concepts underpinning this study. To define these concepts, various principles from existing sources (philosophies, guidelines, models, and frameworks) were extrapolated.

3.2.3.1 Family-Centred Care

For the purposes of this study, the concept of FCC in the NICU was informed by i) the NIDCAP (Als et al., 1986; Westrup, 2007), ii) Coughlin et al's (2009) core measures for developmentally supportive care (Appendix A), and iii) PHAC's guidelines on family-centered maternal newborn care, (2017) (Appendix B). Als et al., (1986) identified over 30 years ago that the involvement of parents and other family members is essential when caring for neonates in the NICU. This was foundational in developing NIDCAP, which is an evidence-based systematic approach to NICU care that emphasizes developmental support and individualized care for

newborns (<http://nidcap.org/en/about-us/faq/>). In particular, the goal of NIDCAP is to “empower the family by helping them develop appropriate care skills and techniques, thus including them as part of the health care team” (Westrup, 2007, p.445). In fact, family, and by extension FCC, is a core pillar of NIDCAP training. The NIDCAP training manual identifies that parents should be their infant’s primary caregivers from admission to discharge, and that the health care team should perform medical tasks in collaboration with parent facilitation of infant stability, relaxation, and comfort. The promotion of SSC, and to a lesser extent PP (without SSC, or PP with just PH), is paramount to the NIDCAP program; ideally, parents should hold their infants SSC as often and for as long as possible (Smith et al., 2015). In an attempt to extend the NIDCAP model, Coughlin et al (2009) developed a framework of core measures essential for developmentally supportive care of the newborn. One of these core measures is FCC (Appendix A). Of note, the family’s unrestricted 24-hour access to the infant, with opportunities to parent, is an essential attribute of FCC. More specifically, this means that parents should be offered the opportunity to be present, with support, during invasive procedures/resuscitative measures and that they should be supported in parenting activities such as SSC, PH, feeding, dressing, bathing, and diapering (Coughlin et al., 2009) (Appendix A). The primacy of FCC was affirmed in 2017 when PHAC released the 2nd edition of their national guidelines on family-centered maternal and newborn care. Among its underlying principles is the philosophy that “family-centred maternal and newborn care applies to all care environments,” including the NICU (Appendix B). In particular, the PHAC framework includes a discussion about the importance of SSC/kangaroo care and the NIDCAP program (Public Health Agency of Canada, 2017, pp.13-14). To the researcher’s knowledge, this would be one of the first studies to use this new philosophy and its guiding principles as core theoretical underpinnings.

3.2.3.2 Concept of skin-to-skin care

The concept of SSC was informed by the Neonatal Integrative Developmental Care Model (IDC) developed by Altimier & Phillips (2016), which places SSC at the centre of all care in the NICU (Appendix C). The centrality of SSC is affirmed as “the ultimate healing environment for newborn infants” (Altimier & Phillips, 2016, p. 232) and supports all seven neuroprotective core measures identified in the IDC. Evidence supports that SSC is the best environment for optimal brain development and overall healing and growth, in addition to protecting the infant from the negative effects of separation through the promotion of attachment and self-regulation (Altimier & Phillips, 2016; Baley, 2015). In addition, a systematic review of 19 studies and 1594 infants found that SSC effectively reduces procedural pain in neonates (Johnston et al., 2017). This furthers the connection between SSC, parent involvement in pain care, and FCC overall.

3.2.3.3 Concept of parent involvement in pain care

Lastly, the concept of parent involvement in pain care was informed by the model of parent involvement in infant pain management developed by Franck et al., (2012), (Appendix D). When developing their model, Franck et al. (2012) identified that most parents seek full involvement in their hospitalized infant’s pain care, but that they required more information, more opportunities for involvement, increased sensitivity, and increased overall use of pain-relieving strategies by NICU staff. In addition, some authors purport that parental presence during any distressing/painful procedure should be mandatory due to a neonates’ sensitivity to a reassuring presence (Bellieni et al., 2003). However, in a study by Harrison et al. (2015), many barriers to supporting parent involvement in pain care were identified. Among these barriers were healthcare provider attitudes, preference to perform blood sampling without the parents,

blood sampling technique, parent availability and parent stress, infant health status, and organizational factors such as unit culture, education, and staffing. These barriers resonate with the overall poorly acknowledged role of parents, which raises questions about the state of partnerships between HCPs and parents in the NICU, which are at odds with the values of FCC in the NICU. In the Franck et al. (2012) model the potential trajectory for parent involvement in pain care is illustrated with accompanying barriers and facilitators. In sum, this model considers the parents' desired level of involvement, the degree of opportunity for parental involvement, and barriers to parents achieving their desired outcomes. It acknowledges parental beliefs, available information and support for parents, and overall parent-infant proximity.

To say that the concepts of FCC, SSC, and parent involvement in pain care are linked is an understatement; they are inexorably interwoven. The literature used to inform these foundational concepts illustrates these undeniable linkages; SSC and parents' involvement in pain care are indicators of FCC, but are also required in order to deliver care in a family-centered developmentally supportive way. As per the core measures identified by Coughlin et al (2009), FCC, pain assessment and management, and a healing environment are all essential elements of care for newborns in the NICU. This is echoed by Altimier & Phillips (2016), who state that partnering with families, minimizing stress and pain, and the overall healing environment are all essential for providing care for neonates in the NICU. Skin-to-skin care is a common concept throughout as it is i) the centre of the lotus (Altimier & Phillips, 2016), ii) a core measure for developmentally supportive care (Coughlin et al., 2009), and also iii) as a comfort measure for both parents and infants during painful procedures (Franck et al., 2012). Of note, none of these models or frameworks include a discussion of postoperative infants specifically. Despite this, it is justifiable to use guiding principles from these many influences to constitute the general

theoretical underpinnings for this study. As such, the conceptual framework presented in Chapter 1 (Figure 1, p. 12) was delineated according to these theoretical underpinnings.

3.3 Methods and Study Procedures

Within the quantitative research tradition, this study employed a cross-sectional nonexperimental descriptive design to shed light on key infant and family factors impacting the frequency of parental holding and SSC (Johnson, 2001; Polit & Beck, 2017). In nonexperimental designs, variables are not manipulated and the researcher is seeking deeper insight into a phenomenon (Johnson, 2001; LoBiondo-Wood et al., 2010). Due to a scarceness of published studies examining SSC for postoperative infants specifically, the primary goal of this study was to determine the frequency and duration of PP, PH, and SSC in a surgical NICU and what factors appear to be related with the frequency and duration of PP, PH, and SSC (see study aims, Chapter 1).

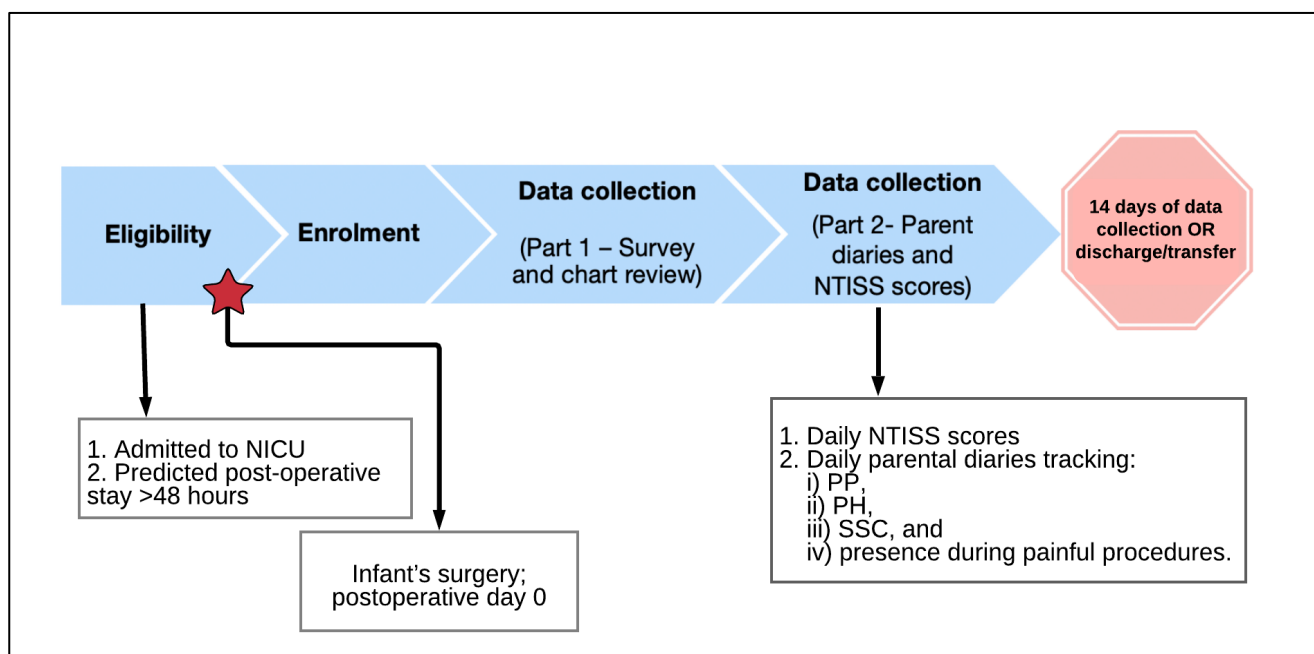
3.3.1 Study Design.

This study employed a cross-sectional nonexperimental descriptive design, as defined by Johnson, (2001) and LoBiondo-Wood, Haber, & Singh, (2010). There is precedent in the literature for the use of descriptive quantitative designs when attempting to explore phenomena in intensive care environments with potentially small sample sizes. For example, Bailey, Sabbagh, Loiselle, Boileau, & McVey, (2010) used a quantitative descriptive design to assess parent feedback on an educational resource with a limited sample size. Figure 3.1 illustrates the study flow.

3.3.1.1 Setting.

This study was conducted in a level 3b NICU in Canada. According to the Provincial Council for Maternal and Child Health (PCMCH), a level 3b neonatal unit is the highest level of care; these units house the sickest neonates and have surgical capabilities (Provincial Council for Maternal and Child Health, 2013, 2018). The host institution's NICU was ideal for this study because it cares for surgical neonates, at all ages of gestation. In addition, this 20-bed inpatient NICU has a room-in design which permits family members to stay overnight, which is essential for facilitating parent-infant closeness (Raiskila et al., 2017; Stevens et al., 2011). This unit receives approximately 400 admissions per year with about one-third of admitted neonates (~130) requiring surgical intervention.

Figure 3.1- Study Flow



3.3.1.2 Eligibility criteria and sample size

This study used a convenience sampling approach in order to maximize potential participants. All decisions about eligibility were made in partnership with the health care team for the infant; an exclusion criterion of *deemed inappropriate for inclusion by health care team* was included. This criterion included any situation when withdrawal of care was imminent or when the health care team deemed that infants that were too ill or unstable. Otherwise, all infants with a surgical condition, either pre or post operatively, admitted to the study NICU during the period of recruitment were considered potentially eligible for inclusion in the study. Any infants with an expected post-operative stay <48 hours were excluded as these were often minor procedures, such as inguinal hernia repairs, that were unlikely to reflect the reality and experiences of most surgical infants. In order to participate in the study, a parent or legal guardian was required for consent; if the parent or legal guardian was not available (in cases such as maternal complications or patients from distant geographic regions), the consent process could also be completed over the phone by CL and the parent (or legal guardian) could be sent an electronic copy of the consent form to complete and sign. In the cases where the parent(s) or legal guardian(s) were not physically present with the infant, they had the option of designating a primary caregiver who would be present with the infant who could complete the parent diaries and survey. For a summary of inclusion and exclusion criteria, see Table 3.1.

Given the exploratory nature of this inquiry and CL's timeline for study completion, enrolment was scheduled to last for six months. No a priori sample size was set given the limited number of potential participants and the timeline for study. In light of the international COVID-19 pandemic, recruitment was terminated after five months in accordance with the host institution and the University of Ottawa's guidelines.

Table 3.1*Inclusion and Exclusion Criteria*

	Criteria	Rationale/Limitation
Infant	- Currently admitted to host institution NICU - Has a surgical diagnosis or is expected to have surgery (as defined in the glossary) - Predicted post-operative stay longer than 48 hours * In consultation with each infant's health care team, infants may be deemed inappropriate for participation due to compassionate reasons.	- Addresses the population of interest, without restriction. - Ensures we are not applying pre-conceived restrictions about which infants should or shouldn't be eligible for holding/SSC - May erroneously enroll infants who do not end up having surgery or miss infants who have surgery unexpectedly.
Parents/ Families	• A parent or legal guardian must be available (in person or by phone) to consent • Must speak and read English or French *If parent(s) or legal guardian(s) will not be physically present with the infant, they may designate another primary caregiver to complete the parent diaries and survey.	• Broad and does not place a priori assumptions or considerations

3.3.1.3 Recruitment.

Information about the study was shared with nurses on the unit through communications from their nurse educator. Health-care provider targeted posters were posted in English and French on the unit, in the nursing station, and in the designated break room (Appendix E). A study summary was also prepared and circulated to staff and management via e-mail and placed on the designated research board in the unit (Appendix F). CL conducted one-on-one education with staff nurses for one week prior to the commencement of the study and throughout the study as needed to inform them about the study, its aims, and the data collection procedures. Parent-

targeted information posters were also posted throughout the unit in French and English (Appendix G).

All new admissions, transfers, and currently admitted patients (who may have been diagnosed since admission with a surgical condition or developed a surgical condition) were screened on a daily basis to assess for eligibility; screening was done in collaboration with committee member MMW, a Nurse Practitioner in the NICU where this study was conducted. Although it would be ideal to enroll all infants pre-operatively, given limitations with parent availability participants were enrolled at any time, pre and post-surgically. For all eligible infants, CL approached the patient and family's assigned Registered Nurse (RN) to discuss appropriateness for participation in the study. Once express consent was obtained from the family to introduce CL into the circle of care, the parent(s) or legal guardian(s) were approached. CL then explained the study, with particular attention paid to the demographic and study variables that would be collected during the survey, the daily NTISS scores, as well the parent diary. Once the study was explained the parents were given time to review the consent form and ask questions. Once the parents' willingness to complete the parent-infant closeness diary was determined, informed consent was obtained. At the time of informed consent, parent participants' e-mail addresses were collected.

For potential participants consenting over the phone, a member of the circle of care asked potential participants for their permission to have the researcher contact them by phone or e-mail. If permission to contact was obtained, CL arranged a time to discuss the consent form via telephone. Before the telephone call, potential participants were sent a unique link to a REDCap (Research Electronic Data Capture) electronic consent form (Appendix H). REDCap is a secure web-based application designed for research studies and offers 128-bit encryption (Harris et al.,

2009; Wright, 2016). The electronic consent form is an innate feature of REDCap, although the content was designed by the researcher. During the scheduled phone call, the potential participant was prompted to open the link in the e-mail and then to enter a password to verify their identity, and their preferred language (English or French). Following the correct entry of the password, the consent form appears. CL then reviewed the consent with the potential participants and gave them time to ask questions. At the end of the consent, the potential participants are asked to agree or disagree with eight statements to illustrate their understanding of the consent material (Appendix H). As stated above, the eConsents and eSignatures are stored in the REDcap database for seven years and then deleted; these databases will be checked periodically by CL for accessibility and correctness.

Recruitment of intensive care unit patients, in particular NICU patients, can be challenging (Chlan et al., 2009). In situations with potentially challenging recruitment and retention, researchers have used Social Exchange Theory to guide study recruitment and participant retention (McGregor et al., 2010). Social Exchange Theory posits that individuals exchange resources believing that each will benefit; this exchange can only continue if there is perceived reciprocity, that a resource will continue to flow as long as there is a valued return contingent upon it, in other words as long as the exchange is positively reinforced (Emerson, 1976). In this sense, potential participants will be weighing the potential benefit they may receive from participating in this study with the overall work required to complete it. As such, a five-dollar gift card to the host institution's cafeteria was offered to all parents who agree to participate as a small appreciative token for their time. From an ethical perspective, payments to potential participants could be seen as coercion. However, Largent et al. (2012) conducted a survey which revealed that most individuals are not concerned about small 'tokens' but rather

payments that are considered substantial. In addition, fewer than 20% of respondents felt that a ‘token’ would coerce someone into participating (Largent et al., 2012). Given this, in order to facilitate recruitment, a one-time five dollar gift card token to the host institution’s cafeteria was offered to the parents/families of infants at the time of enrolment.

Another important strategy that aligns with Social Exchange Theory is frequent enjoyable contacts between the researcher, the participants, and unit staff (McGregor et al., 2010). Bozzette, (2011) published recommendations for overcoming challenges in nurse-led research in the NICU and emphasized the importance of researcher presence on the unit. Among these recommendations are also the need for staff education, providing continuous and ongoing support/availability to participants, providing updates on study progress, and providing incentives (p. 156). In this study, as previously mentioned, staff were made aware of the overall study aims, design, and data collection methods through communications from their nurse educator and CL made presentations during rounds and huddles. In addition, posters were arranged around the unit to act a reminder to staff (Appendices E and F). Given this, in order to facilitate both the overall conduct of the study and participant retention, CL made daily visits to the NICU (Monday-Friday) and made herself available to participants and staff via e-mail and telephone at any time.

3.3.2 Data Collection.

There were four primary sources of data:

- i) *Parent-infant closeness diaries.* The parent-infant closeness diaries were developed and validated by Raiskila (2018) in collaboration with the Separation and Closeness Experiences in Neonatal Environment (SCENE) research group (www.utu.fi/scene). These diaries provided quantitative information regarding the frequency and duration

of PP, PH, and SSC (in minutes/day) as well the frequency of PP, PH, and SSC during painful procedures; see Appendix I. This diary was modified to suit individual families as required (i.e. changing mother and father to birth mother and mother to better represent participants' identities, translation to French);

- a. Enrolled parents were asked to keep a parent-infant closeness diary in which they recorded the time spent present (PP), time spent holding (PH), and time spent in SSC (all in minutes/day). Parents also recorded any painful procedures that occurred during presence, holding, or SSC. This diary was kept at the infant's bedside and was completed by the parents and designated family members during their visits using a pen provided by CL. Families completed the diaries for 14 days, or until discharge/transfer, whichever came first. This self-report data can likely be considered accurate as research supports that parent reports of SSC are more accurate than nurse documentation of SCC (Blomqvist & Nyqvist, 2011). See Appendix J for an example of a completed closeness diary.
- ii) *Parent-surveys*. The parent survey provided information regarding factors that may influence parental closeness; it was developed by CL and the thesis committee (DH, WP, JS, MMW) (see Appendix K). This survey was informed by the literature review and concept analysis presented in Chapter 2, as well as the following validated scales:
 - a) the Parents' and Nurses' Perspectives on FCC in the NICU scales (Al-Motlaq et al., 2017) and
 - b) The Parental Stressor Scale (Miles et al., 1993).For detailed information about the supporting literature for each survey item, see Appendix L.

- a. The survey, which was e-mailed to parents at the e-mail address collected at the time of enrolment, collected information about various concepts and principles that are foundational to FCC, SSC, and PIPC. Although many surveys exist to measure parent satisfaction and/or FCC (e.g. Raiskila, 2018, p. 25-27), none currently in existence measure SSC or parental involvement in pain care for postoperative infants specifically. Survey items were informed by the conceptual framework represented in Chapter 1 (Figure 1, p.12) and were consequently broken down in four categories, namely: parent, environment, nurse, and infant. See Appendix K for the parent survey and Appendix L for details regarding its construction.
- iii) A *chart review* provided demographic information on the infant (e.g. diagnosis, birthweight, and gestational age; see Appendix M), and
- iv) Daily *Neonatal Therapeutic Intervention Severity Scale* (NTISS) scores (Appendix N) provided information about neonatal illness severity.
 - a. The NTISS was developed by Gray et al. (1992) and is used as a measure of neonatal illness severity. Studies support the NTISS in determining illness severity, intensity of care, and in predicting mortality (Carvalho et al., 2012; Harrington et al., 2012; Wu et al., 2015). The literature also supports the importance of considering physiologic instability and overall neonatal illness severity and its impact on nurse workload within the context of FCC and parent involvement in pain care (Benoit et al., 2016). The NTISS consists of eight subscales with points allocated for various interventions within each of the subscales. For example, under the respiratory subscale an infant would be

given four points if they are receiving mechanical ventilation, but only two points for continuous positive airway pressure (CPAP). See Appendix N for a detailed NTISS scoring sheet.

Referring to Figure 1 (Chapter 1, p. 12) the conceptual diagram for this study, the parent diaries captured information related to SSC and pain care (pink and blue circles), the NTISS captured information related to nursing care/infant severity of illness (nurse and infant bubbles), and the survey captured data related to the parents, the NICU environment, and overall delivery of FCC (parent bubble, purple NICU cloud, and grey FCC rectangle).

At the time of enrolment, parents were e-mailed an electronic link to complete the survey at their convenience within 14 days. Each survey is linked to a particular study ID, determined at the time of enrolment ensuring only one survey per enrolled infant. In addition to this link, a binder was placed at the infant's bedside by CL. This binder contained: 14 parent diaries (for the 14-day study period; Appendix I), definitions and pictures of PP, PH (including hand swaddling, facilitated tucking, encircled holding, and clothed breastfeeding), and SSC (Appendix O), a pen, a study poster (Appendix G) with contact information for CL and DH, and a copy of the signed consent form. The binder, and all data collection tools, were thoroughly discussed with the parents at the time of enrolment.

3.3.2.1 Expected duration of subject participation.

The day of enrolment was considered the start of the study period. The study period continued for 14 days (or until discharge or transfer) and parents completed a parent diary for each of these days. They could complete the parent survey and revisit their answers at any point in this study period. For each day of the study period CL completed NTISS scores for each enrolled infant.

3.2.3 Potential Risks and Benefits.

There were no known risks to participating in this study. The infant's care was in no way affected by parents' participation, or not, in the study. Despite this, due to the limited literature about the safety of holding and SSC for infants needing surgery or after surgery, it was made clear to participants that when holding their baby, or doing SSC, they must always involve their infant's RN to ensure that SSC was appropriate and safe, the infant was transferred to SSC in a safe and timely matter, and to ensure that any and all equipment was properly cared for.

The primary benefit that participants could expect from participating in this study was the opportunity to contribute to the literature surrounding care for infants needing surgery or after surgery. CL discussed with parents the limited literature on this subject and that the results of this study have the potential to inform policies and educational strategies. Ultimately, it is hoped that their participation in this study will help us to improve the care for all NICU infants and their families.

3.3 Pilot testing

The parent-infant closeness diary, survey items, definitions, and informed consent form were pilot tested with two parents in the study NICU for clarity, readability, and acceptability. These parents were *not* part of the study sample. Following their feedback, the parent diary was modified to include other family members (Appendix I). The parent survey was also modified to include open text comment boxes. In addition, the list of painful procedures was modified to include procedures considered by parents to be distressing, such as dressing changes and suctioning. With explicit and informed consent, photos of these parents and their infant were taken in order to illustrate PH and SSC (Appendix O). These photos and associated descriptions were then also pilot tested for clarity and acceptability.

3.4 Data Analysis

As mentioned above, all data was stored on the host institution's instance of REDCap (<https://www.project-redcap.org/>). Quantitative data was imported into GraphPad Prism version 8.0 for mac OS (GraphPad Software, 2019) and the Statistical Package for the Social Sciences (SPSS; IBM Corp., 2017). Responses to open-ended questions were imported into QSR International's NVivo 12 for Mac software (QSR International Pty Ltd., 2014) for data management. These data were analyzed using qualitative content analysis following the methods established by Graneheim & Lundman, (2004). Descriptive statistics were used to describe participant demographics. Given the limited number of participants, medians and interquartile ranges are presented alongside means and standard deviations and nonparametric tests were used. See tables 3.2-3.6 below for the detailed quantitative data analysis plan for each outcome.

To restate, the specific outcomes of this study were:

- 1) What is the *frequency and duration* of PP, PH, and SSC for all enrolled infants over the study period?
- 2) What is the *frequency* of PP, PH, and SSC during painful procedures for all enrolled infants over the study period?
- 3) What is the *relationship* between illness severity (NTISS) and the frequency and duration of PP, PH, and SSC?
- 4) What are parents' *self-reported perceptions* of parent, environment, nurse, and infant factors that impact FCC, PP, PH, and SSC?

Table 3.2*First Primary Outcome*

Statistical research questions	1. What is the frequency and duration of PP, PH, and SSC? a. Mean (Standard Deviation), Median (range), and Median (IQR) for aggregate i. Graphical representations b. Friedman test for related groups to compare for significant differences 2. Is there a difference mothers and fathers? a. Mean (Standard Deviation), and Median (range), and Median (IQR) for mothers and fathers b. Wilcoxon signed-rank test to compare for significant differences in duration of PP/PH/SSC between mothers and fathers c. Chi-square to compare for significant differences in duration of PP/PH/SSC between mothers and fathers
Source of data	Parent diaries
Variables, level of measurement, and statistical tests	
<u>Variables of interest</u> <u>[Level of measurement]</u>	<u>Statistical tests</u>
<i>Parental Presence (PP)</i> • Measured in minutes/day → [ratio]	• Descriptive statistics for aggregate: ○ Duration of PP ▪ Mean (Standard Deviation), Median (range), and Median (IQR) ○ Frequency of PP ▪ Absolute frequency and percentage • Descriptive statistics for mothers and fathers separately: ○ Duration of PP ▪ Mean (Standard Deviation), Median (range), and Median (IQR) ○ Frequency of PP ▪ Absolute frequency and percentage
<i>Parental Holding (PH)</i> • Measured in minutes/day → [ratio]	• Descriptive statistics for aggregate: ○ Duration of PH ▪ Mean (Standard Deviation), Median (range), and Median (IQR) ○ Frequency of PH ▪ Absolute frequency and percentage • Descriptive statistics for mothers and fathers separately: ○ Duration of PH ▪ Mean (Standard Deviation), Median (range), and Median (IQR)

	○ Frequency of PH ▪ Absolute frequency and percentage
<i>Parental Skin to Skin Care (SSC)</i> • Measured in minutes/day → [ratio]	• Descriptive statistics for aggregate: ○ Duration of SSC ▪ Mean (Standard Deviation), Median (range), and Median (IQR) ○ Frequency of SSC ▪ Absolute frequency and percentage • Descriptive statistics for mothers and fathers separately: ○ Duration of PP ▪ Mean (Standard Deviation), Median (range), and Median (IQR) ○ Frequency of PP ▪ Absolute frequency and percentage

Table 3.3*Second Primary Outcome*

Statistical research questions	1. What is the frequency of PP, PH, and SSC during painful procedures? a. Absolute value for the total number of painful procedures recorded by parents b. Absolute value and percentage for the frequency of PP/PH/SSC during the recorded painful procedures 2. Is there a difference between mothers and fathers? a. Absolute value and percentage of PP/PH/SSC during painful procedures for mothers and fathers individually b. Fisher's exact test to evaluate for significant differences between PP/PH/SSC during painful procedures between mothers and fathers
Sources of data	Parent diaries for PP/PH/SSC during painful procedures
Variables, level of measurement, and statistical tests	
<u>Variables of interest</u> <u>[Level of measurement]</u>	<u>Statistical tests</u>
<i>Parental Presence (PP)</i> during painful procedures • Measured in frequency → [nominal]	For aggregate: • Frequency and percentage of PP during painful procedures over the entire study period For mothers and fathers individually: • Frequency and percentage of PP during painful procedures over the entire study period
<i>Parental Holding (PH)</i> during painful procedures • Measured in frequency → [nominal]	For aggregate: • Frequency and percentage of PH during painful procedures over the entire study period For mothers and fathers individually: • Frequency and percentage of PP during painful procedures over the entire study period
<i>Parental Skin to Skin Care (SSC)</i> during painful procedures • Measured in frequency → [nominal]	For aggregate: • Frequency and percentage of SSC during painful procedures over the entire study period For mothers and fathers individually: • Frequency and percentage of PP during painful procedures over the entire study period

Table 3.4*Third Primary Outcome*

Statistical research questions	1. Is the frequency of PP, PH, or SSC influenced by the neonates' illness severity? <i>In other words: What is the strength and direction of the association between NTISS and the frequency of PP, PH, and SSC?</i>	
Sources of data	• Parent diaries provided the frequency and duration of PP, PH, and SSC • Nurse documentation and patient charts provided the information for the NTISS scores	
Variables, level of measurement, and statistical tests		
<u>Dependent Variables</u> <u>[Level of measurement]</u>	<u>Independent variables</u> <u>[Level of measurement]</u>	<u>Statistical tests to use</u>
<i>Parental Presence (PP)</i> • Measured in minutes/day over the study period → [ratio] <i>Parental Holding (PH)</i> • Measured in minutes/day over the study period → [ratio] <i>Parental Skin to Skin Care (SSC)</i> • Measured in minutes/day over the study period → [ratio]	<i>Daily Neonatal Therapeutic Intervention Scale scores (NTISS)</i> (Collected daily over the study period) • Scale ranging from 0-47 → [Interval/continuous]	1. <i>Spearman's Rho (Spearman's rank-order correlation coefficient)</i> (will use aggregate participant data) • PP + NTISS (minutes/day and score/day over the study period) • PH +NTISS (minutes/day and score/day over the study period) • SSC + NTISS (minutes/day and score/day over the study period) 2. <i>Pearson's R (Pearson correlation coefficient)</i> • PP + NTISS (minutes/day and score/day over the study period) • PH +NTISS (minutes/day and score/day over the study period) • SSC + NTISS (minutes/day and score/day over the study period)

Table 3.5

Fourth Primary Outcome

Statistical research questions	1. What are parents' perceptions of family, environment, nurse, and infant factors as measured by the parent survey?	
Sources of data	• Parent surveys provided quantitative and qualitative information about parent, family, and environment factors • Chart review and parent surveys provided demographic information	
<u>Survey item</u> [Level of measurement]	<u>Response options</u>	<u>Statistical test</u>
Where are you staying while your baby is hospitalized? [Nominal]	• Home • Family member or friend's home • Rotel or another hotel • Ronald McDonald House • Other → Please specify	<u>Frequencies</u> • Absolute • Relative
Mother's highest educational achievement [Ordinal]	• Some high school • High School • Some university • Completed University degree • Prefer not to answer	<u>Frequencies</u> • Absolute • Relative
The staff encourages me to participate in my infant's care. [Interval]	Likert-style, 1-5 (strongly disagree- strongly agree)	<u>Frequencies</u> • Absolute • Relative <u>Descriptive statistics</u> • Mean and Standard Deviation

†For clarity and brevity, sample survey questions of each type are given here. For the full list of survey items please see Appendix K.

As mentioned above, open-ended questions that yielded qualitative data were analyzed using qualitative content analysis. Following the methods recommended by Graneheim & Lundman (2004), as individual comments were analyzed codes were aggregated into categories. These categories then informed broader themes that were subsequently compared across comments.

3.4 Rigour and Ethics

3.4.1 Rigour.

Rigour for non-experimental quantitative studies can be challenging, due to the increased likelihood of selection bias and the lack of validated tools to evaluate nonexperimental research (Claydon, 2015). For this study, the Cochrane collaboration's guidelines on assessing nonexperimental research provided a framework for considering validity and reliability. According to the Cochrane collaboration, nonexperimental studies should discuss: confounding bias, selection bias (including attrition bias and missing data), information bias (including detection bias), and reporting bias (Sterne et al., 2019). Table 3.6 describes how each of these types of bias was addressed in this study. It is important to note that both the NTISS and the parental closeness diary have both been validated and can, as such, be considered reliable instruments (see: Gray et al., 1992; Raiskila et al., 2017).

3.4.2 Ethics

Ethical approval was obtained from the host institution's site Research Ethics Board and CL's educational institution (see Appendices P and Q). The consent form clearly outlined the management and storage of data, potential harms and benefits, right to withdraw, etc. (see Appendix R). All documents were translated into French according to the host institution's policy.

Table 3.6*Rigour and Bias*

Type of Bias and brief description	How it was addressed
<i>Confounding bias</i> Confounding bias occurs when there are factors that influence the outcome(s) of interest which are not addressed nor controlled. This contributes to the study's generalizability and overall validity.	- Given this study's small sample size, the results may not be generalizable beyond this particular unit and/or these particular participants. - As this study was not blinded, it was difficult to ensure that participants in the study do not receive different care than those not currently enrolled in the study. However, there was no intervention in this study to promote PP, PH, SSC or PIPC; time spent in these activities were simply recorded by the parents.
<i>Selection and attrition bias</i> When some participants are excluded or lost in a way that impacts the outcome(s) of interest.	- A thorough description of the participants is provided through the use of descriptive statistics. - Consent rate is presented - No participants were lost in this study
<i>Information and detection bias</i> Information bias occurs when outcomes are misclassified or measured in error. Detection bias refers to systematic differences in outcome assessment, including misclassification of covariates.	- Standardized definitions of PP/PH/SSC were provided to each enrolled family (Appendix O). This helped to reduce any discrepancies in reporting and enhance overall fidelity and reduce the likelihood of information bias - The NTISS and parent-infant closeness diary are validated instruments, which helped to ensure a reduced likelihood of detection bias (see Gray et al., 1992; Raiskila, 2018).
<i>Reporting bias</i> Refers to publication biases as well as the reporting of only selected outcomes (ex. only reporting results that are significant)	The study protocol, with all variables and potential outcomes, will be made available in the form of a dissertation to ensure transparency and allow examination of reporting bias.

Note: Definitions according to Cochrane Collaboration Handbook for Systematic Reviews (Sterne et al., 2019).

3.4.3 Data Handling and Record Keeping.

3.4.3.1 Data Management Responsibilities.

Personal health information will not be released externally, nor kept on any mobile devices, and is stored securely at all times on the host institution's instance of REDCap (Wright, 2016) and on the host institution's encrypted and secured local network. Mobile devices (i.e. laptops and USB keys) that contain de-identified study information and electronic files are all password protected and encrypted.

At the time of screening for eligibility, the neonate's date of birth, date of admission, and admitting diagnosis were recorded and a screening number was assigned. This information was entered into an electronic password-protected screening log (Excel spreadsheet). After the informed consent process, participant e-mails and full names were collected and stored in an electronic master list. This master list is also an electronic password-protected excel file. All participants were assigned a unique alphanumeric study ID and this ID is only linked to their personal information in the master list. Only CL and DH have access to the screening log and master list. These password-protected files will be saved on the host institution's local network and kept for a period of seven years. Each participant was emailed a unique survey link; the survey results are stored in a password-protected database on the host institution's instance of REDCap. Chart review items are also entered into an eCRF on REDCap. As mentioned above, only CL and DH have access to the REDCap database. These databases will be kept accessible, accurate, and active for a period of seven years.

The thesis committee members, WP, JS, and MMW had access to de-identified data and aggregate data during on-site meetings at the host institution. This was required to facilitate data and statistical analyses.

3.4.3.2 Confidentiality & Privacy Protection.

Information about study participants is kept confidential. In accordance with regulations regarding the circle of care, CL always sought introduction into the circle by prospective participants' nurse. If the prospective participants (parents) agreed to speak with CL, the study was explained and parents were given ample time to review the consent form and ask questions. Once the parents were ready, CL completed the informed consent process. A study ID number was assigned at the time of enrolment. Personal information (participant name, participant's relationship to the infant, the infant's name and date of birth, and the participants' e-mail address) is only linked with the study ID in the encrypted electronic master list. In all other documents and in online databases only the participants' study ID was used. In any publications or reports, only aggregate data will be reported and no individual-level data will be identifiable.

3.4.3.3 Record Retention.

All paper documents, such as consent forms and parent diaries, are kept in a locked cabinet in a locked office at the host institution's Research Institute. These documents will be kept for a period of seven years and then destroyed. All electronic documents, such as parent surveys and chart reviews, were entered as electronic Case Report Forms on the host institutions' instance of REDCap. CL will periodically check these databases for accessibility and correctness. After seven years, these databases will be deleted.

3.5 Budget and Finance.

All expenses incurred in the conduct of this study (printing and appreciation tokens) was personally funded by CL as this study was completed in conjunction with fulfilling the requirements of the Master of Science in Nursing program (thesis stream) at the University of Ottawa.

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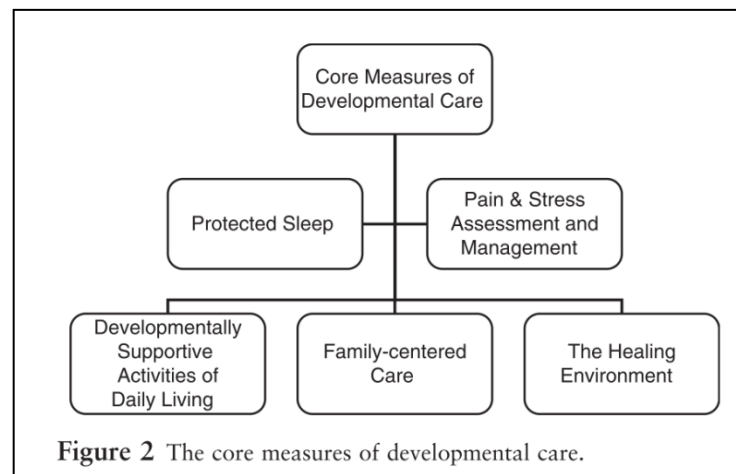
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Appendix A

Coughlin's 5 Core Measure for Developmentally-Supportive Care



Note: Taken from Coughlin et al., (2009), p. 2242. Illustrates the 5 core measures for developmentally supportive care of the newborn in the NICU.

Table 4 Family-centred care core measure

Attribute	Criteria
The family (defined by the infant's parents and/or guardians) has 24-hour unrestricted access to their infant and is provided the opportunity to parent; family definition and participation is documented (Johnson <i>et al.</i> 2004, Nibert & Ondrejka 2005)	1. Family is offered the opportunity to be present and/or participate in medical rounds and change of shift report 2. Family is offered the opportunity to be present during invasive procedures and/or resuscitative interventions 3. Family is supported in parenting activities to include skin-to-skin care, holding, feeding activities, dressing, bathing, diapering, singing and all infant care interactions
The family's level of emotional well-being and parental confidence and competence is assessed and documented weekly (Doucette & Pinelli 2004, Kaarsen <i>et al.</i> 2006)	1. Mental health professionals resource families weekly 2. Family observations and input regarding their infant are sought by the clinical care providers and documented in the patient's health records 3. Health care providers share unbiased infant information weekly with the family
The family has access to resources and supports that assist in short term and long term parenting, decision making and parental well-being (Doucette & Pinelli 2004)	1. Families are invited to participate in a neonatal intensive care unit family support group 2. Culturally sensitive family education on infant safety and infant care is available in various formats 3. Resources for the social, spiritual and financial needs of families are provided

Note: Taken from Coughlin et al., (2009), p. 2244. Attributes and criteria of FCC core measure.

Appendix B

Public Health Agency of Canada- Family-centred maternity and newborn care

Family-centred maternity and newborn care (FCMNC) is a complex, multidimensional, dynamic process of providing safe, skilled and individualized care. It responds to the physical, emotional, psychosocial and spiritual needs of the woman, the newborn and the family. FCMNC considers pregnancy and birth to be normal, healthy life events and recognizes the significance of family support, participation and informed choice. The Public Health Agency of Canada along with maternal and newborn health experts developed the following evidence based guiding principles for FCMNC in Canada:

1. A family-centred approach to maternal and newborn care is optimal
2. Pregnancy and birth are normal, healthy processes
3. Early parent-infant attachment is critical for newborn and child development and the growth of healthy families
4. Family-centred maternal and newborn care applies to all care environments
5. Family-centred maternal and newborn care is informed by research evidence
6. Family-centred maternal and newborn care requires a holistic approach
7. Family-centred maternal and newborn care involves collaboration among care providers
8. Culturally-appropriate care is important in a multicultural society
9. Indigenous peoples have distinctive needs during pregnancy and birth
10. Care as close to home as possible is ideal
11. Individualized maternal and newborn care is recommended
12. Women and their families require knowledge about their care
13. Women and their families play an integral role in decision making
14. The attitudes and language of health care providers have an impact on a family's experience of maternal and newborn care
15. Family-centred maternal and newborn care respects reproductive rights
16. Family-centred maternal and newborn care functions within a system that requires ongoing evaluation
17. Family-centred maternal and newborn care best practices from global settings may offer valuable options for Canadian consideration

For references consult **Chapter 1: Family-Centred Maternity and Newborn Care in Canada: Underlying Philosophy and Principles** in: Public Health Agency of Canada. Family-Centred Maternity and Newborn Care: National Guidelines. Ottawa (ON): PHAC; 2017.

Note: Taken from Public Health Agency of Canada, (2017) p. 5.

Appendix C
 Altimier's Integrative Developmental Care Model

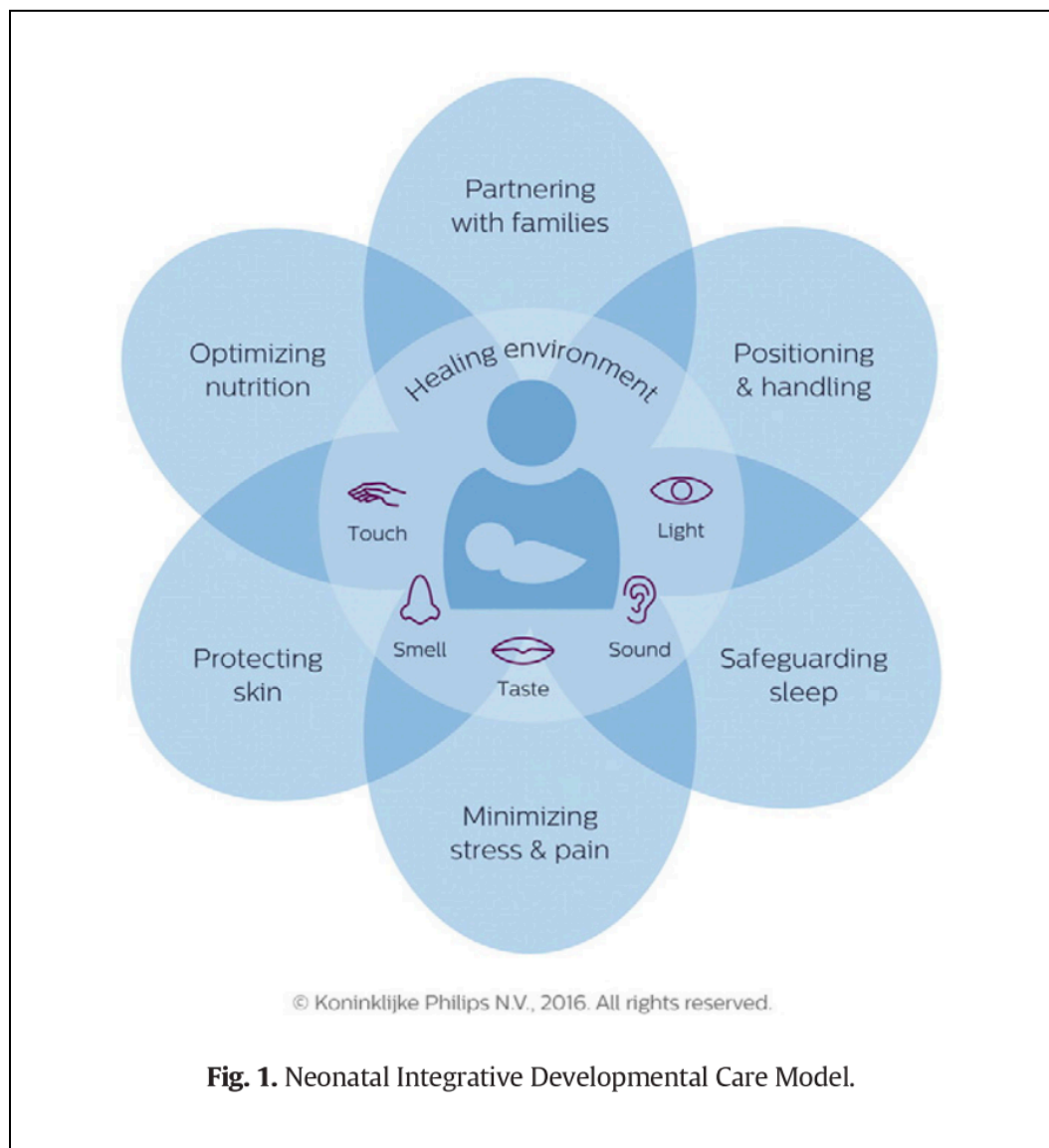
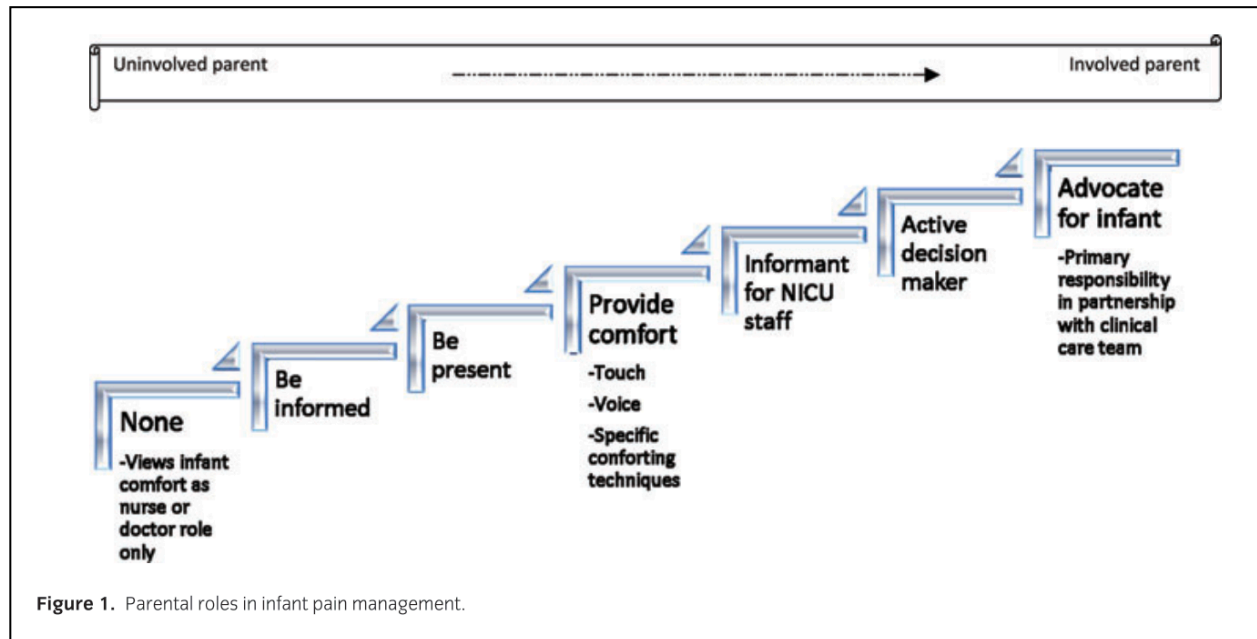


Fig. 1. Neonatal Integrative Developmental Care Model.

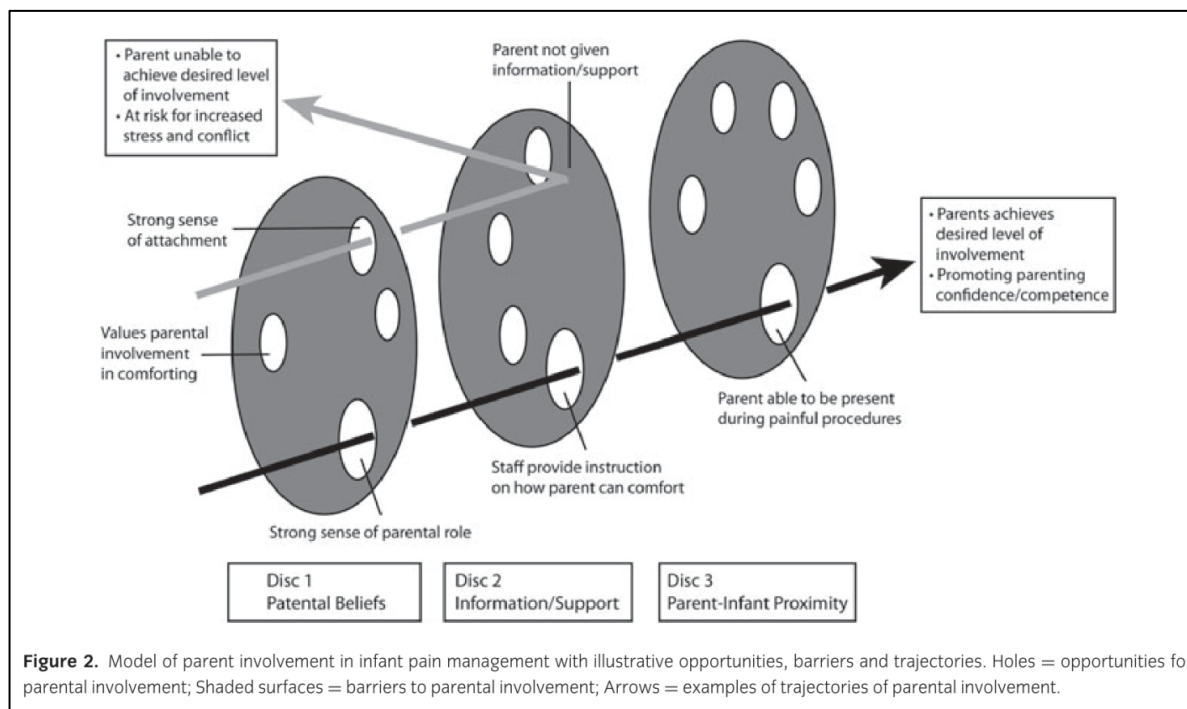
Note: Taken from Altimier & Phillips, (2016), p. 2. This model identifies seven distinct core measures that provide clinical guidance for NICU staff in delivering neuroprotective family-centered developmental care to infants and their families in the NICU. Of note, SSC forms the centre of the lotus flower, emphasizing its primacy as the optimal environment for newborns.

Appendix D

Franck's Model of parent involvement in infant pain management



Note: Taken from Franck et al., (2012), p. 48. Illustrates the range of roles parents want to play in their infant's pain care. The critical component to moving a parent from uninvolved to involved is communication, information, and education.



Note: Taken from Franck et al., (2012), p. 52. Illustrates the interaction between factors that allow or block desired level of parental involvement (discs), the opportunities for parent involvement (holes), and the barriers to parent involvement (shaded areas).

Appendix E

Health Care Provider targeted posters (also available in French)

Are we on the same page about skin to skin care?

A descriptive correlational study exploring skin to skin care for postoperative NICU infants

Principal Investigator:

Catherine Larocque, RN

Master of Science in
Nursing student at the
University of Ottawa



Co-Investigators:

Denise Harrison, RN, PhD

Chair in Nursing Care of
Children, Youth, and Families,

Martha Mason-Ward, RN, NNP
Neonatal Nurse Practitioner,

Purpose: to discover factors that influence parental presence (PP), parental holding (PH), and skin to skin care (SSC), and parent involvement in pain care for postoperative infants in the NICU.

As a nurse, how can you help?

During screening

All infants who have a surgical plan of care, and whose parents/guardians speak English or French, are potentially eligible to participate. In collaboration with eligible infants' nurse and care team, the researcher will identify potential participants.

Approaching parents

The researcher will ask to be introduced into the circle of care. Once the parents have agreed to speak with the researcher, the researcher will approach parents to obtain informed consent following a thorough explanation of the data collection instruments (survey, diaries). Data collection will start on post-op day 0.

During study

Parents will be asked to complete a one-time survey and daily diaries (for 14 days) tracking the time they spend: present in the unit, holding their infant, and skin to skin with their infant. The researcher will complete daily illness severity (NTISS) scores on all enrolled infants.



This study has been approved by the [redacted] and uOttawa Research Ethics Boards.

Appendix F

Study Summary

Are we on the same page about skin to skin care?

A descriptive correlational study exploring skin to skin care for postoperative NICU infants



STUDY SUMMARY



What is this study about?

- We know that parents want to be involved in their infant's care and that parental holding and SSC are important for families in the NICU.
- However, with neonates who require surgery or are recovering from surgery, we do not know if holding and SSC are promoted by the health care staff or if it is feasible and acceptable for parents.

Study Purpose:

1. To discover factors that influence parental presence (PP), parental holding (PH), and skin to skin care (SSC), and parent involvement in pain care for postoperative infants in the [REDACTED] NICU.
2. To discover how much infants in the [REDACTED] NICU are held or receive SSC and if parents are encouraged to do so during painful procedures.

Families that are eligible:

- Parent(s) or legal guardian(s) speak English or French
- Neonate has a surgical plan of care (awaiting surgery or recovering from surgery)



Study procedures:

- The NICU research team will screen new admissions and notify the PI if there are any eligible families/infants. In coordination with the infant's nurse, the PI will obtain informed consent.
- Parents will be asked to complete a one-time online questionnaire and daily parent diaries following their infant's surgery. This diary will last for 14 days or until discharge/transfer from the NICU
- The PI will complete daily Neonatal Therapeutic Intervention Severity scores (NTISS) on enrolled neonates using data available in EPIC for 14 days, or until discharge/transfer from the NICU

Principal Investigator:

Catherine Larocque, RN
Master of Science in Nursing
student at the University of
Ottawa [REDACTED]
[REDACTED]

Co-Investigators:

Denise Harrison, RN, PhD
Chair in Nursing Care of Children,
Youth, and Families, [REDACTED]
[REDACTED]

Martha Mason-Ward, RN, NNP
Neonatal Nurse Practitioner,
[REDACTED]

This study has been approved by [REDACTED] and uOttawa Research Ethics Boards | Protocol number: 19/39X



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Faculty of Health Sciences

Appendix G

Parent-targeted information poster (also available in French)

Are we on the same page about skin to skin care?

A descriptive correlational study exploring skin to skin care for postoperative NICU infants

For more information please contact:

Catherine Larocque, RN
Master of Science in
Nursing candidate at the
University of Ottawa



Catherine Larocque is supervised by Denise Harrison, RN, PhD, Chair in Nursing Care of Children, Youth, and Families at [REDACTED]

This study has been approved by [REDACTED] Research Ethics Board and the University of Ottawa Research Ethics Board.

Is your baby *having surgery*? Are you interested in *family-centred care*?

We are conducting a study about parent-infant closeness for babies who have had surgery.

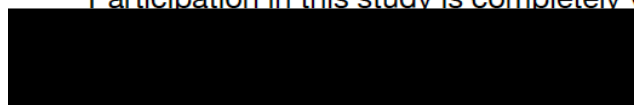
If you speak **English or French** and your **baby is admitted to the NICU** and **having surgery**, you may be eligible to participate!



As a participant, you will be asked to:

- * Complete a survey, and
- * Complete a parent diary for 14 days

Participation in this study is completely voluntary.



Appendix H
REDCap electronic informed consent (also available in French)

First page of eIC

- Tells potential participants how long it will take to complete the eIC
- Contains a password provided by the researcher over the phone to validate the potential participants' identity



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Resize font: 

[Returning?](#)

eConsent

Thank you for agreeing to discuss this study with the researcher. Please follow along as the researcher describes the study. If you have any questions, feel free to ask them at any time. You will be e-mailed a copy of the consent form once the process is complete. This consent will take about ten minutes to review together; if you need to stop at any point, you may exit and return at a later time.

Page 1 of 3

eConsent password/
Mot de passe pour le consentement électronique:
* must provide value

Consent language/
Sélection de langue:
* must provide value

Next Page >>

Save & Return Later

Appendix H (continued)
REDCap electronic informed consent

End of eIC

- Aids in understanding of consent form
- Potential participants must *Agree* to all statements in order to be prompted to sign the eSIG

After reading the consent form, I confirm that: Après avoir lu le formulaire de consentement, je confirme que:	
	Agree Disagree
I have read all of the information in this Parent Information and Consent Form, and I have had time to think about it. * must provide value	☐ ☐
All of the risks and benefits of participation have been explained to me * must provide value	☐ ☐
All of my questions have been answered to my satisfaction. * must provide value	☐ ☐
I voluntarily agree to participate in this study with my infant. * must provide value	☐ ☐
I understand that I may freely choose to stop my participation at any time and any data collected will not be used any further. * must provide value	☐ ☐
I allow access to my child's medical records and/or personal information as described in this consent form. * must provide value	☐ ☐
I have received or will receive a copy of this Parent Information and Consent Form to keep for myself * must provide value	☐ ☐
I do not give up my legal rights by signing this form * must provide value	☐ ☐
First name * must provide value	
Last name * must provide value	
Infant's name * must provide value	
Relationship of person giving consent to infant: * must provide value	 e.g. mother, father, foster parent

Participant must agree with all statements in order to enter information required for eSIG

Appendix H (continued)
REDCap electronic informed consent

eSignature

- Once participants complete the fields that appear after agreeing to all the statements above, they must certify that their information is correct and that they understand that they are giving their consent (see below)

Page 3 of 3

Displayed below is a read-only copy of your survey responses. Please review it and the options at the bottom.

copy of this Parent Information and Consent Form to keep for myself

I do not give up my legal rights by signing this form ⊗ ○

First name Catherine

Last name Larocque

Infant's name Baby Doe

Relationship of person giving consent to infant: Legal guardian
(e.g. mother, father, foster parent)

☐ I certify that all the information in the document above is correct, and I understand that signing this form electronically is the equivalent of signing a physical document.

If any information above is not correct, you may click the 'Previous Page' button to go back and correct it.

Displayed below is a read-only copy of your survey responses. Please review it and the options at the bottom.

copy of this Parent Information and Consent Form to keep for myself

I do not give up my legal rights by signing this form ⊗ ○

First name Catherine

Last name Larocque

Infant's name Baby Doe

Relationship of person giving consent to infant: Legal guardian
(e.g. mother, father, foster parent)

☒ I certify that all the information in the document above is correct, and I understand that signing this form electronically is the equivalent of signing a physical document.

If any information above is not correct, you may click the 'Previous Page' button to go back and correct it.

Appendix H (continued)
REDCap electronic informed consent

Copy of eIC

- Participants have the following options:

- Receive a confirmation email with a pdf copy of the paper consent
- Return to their eIC survey by following the link in the email and entering the code provided
- Downloading their 'survey responses' which is their completed version of the eIC.

 Enter your email to receive confirmation message?

A confirmation email is supposed to be sent to all respondents that have completed the survey, but because your email address is not on file, the confirmation email cannot be sent automatically. If you wish to receive it, enter your email address below.

[Send confirmation email](#)

* Your email address will not be stored



You may return to this survey in the future to modify your responses by navigating to the survey URL and entering the code below.

Return Code:

YY8YERNH

Download your survey response (PDF):



Download

Appendix I

Parent-infant closeness diary

ID: _____ DATE: _____

Mother present																																																
Mother holding																																																
Mother SSC																																																
	0:00 1:00 2:00 3:00 4:00 5:00 6:00 7:00 8:00																																															
Father present																																																
Father holding																																																
Father SSC																																																
	8:00 9:00 10:00 11:00 12:00 13:00 14:00 15:00 16:00																																															
Mother present																																																
Mother holding																																																
Mother SSC																																																
	16:00 17:00 18:00 19:00 20:00 21:00 22:00 23:00 24:00																																															
Father present																																																
Father holding																																																
Father SSC																																																

Reminder: Mark time arrived (or start of holding/start of skin to skin) with an X and time of departure (or end of holding/end of skin to skin) with X. Mark any painful procedures with an asterisk (*).

Protocol #: 19/39X_1 Version date: 2019-05-03

Parent-infant closeness diary

ID: _____ DATE: _____

Other family present																																																
Other family holding																																																
Other family SSC																																																
	0:00 1:00 2:00 3:00 4:00 5:00 6:00 7:00 8:00																																															
Other 2 present																																																
Other 2 holding																																																
Other 2 SSC																																																
	8:00 9:00 10:00 11:00 12:00 13:00 14:00 15:00 16:00																																															
Other family present																																																
Other family holding																																																
Other family SSC																																																
	16:00 17:00 18:00 19:00 20:00 21:00 22:00 23:00 24:00																																															
Other 2 present																																																
Other 2 holding																																																
Other 2 SSC																																																

Other family, please specify: _____ Other 2, please specify (if applicable): _____

Reminder: Mark time arrived (or start of holding/start of skin to skin) with an X and time of departure (or end of holding/end of skin to skin) with X. Mark any painful procedures with an asterisk (*).

Protocol #: 19/39X_1 Version date: 2019-05-03

Appendix J

Example of completed parent diary (also available in French)

Examples of completed parent diaries



This would be interpreted as the mother was present from 0900-12:00 (noon) and was holding her infant in SSC from 10:00 to 10:30.



This would be interpreted as the mother was present from 0900-12:00 (noon) and a painful procedure happened at 0915. The mother held her infant in SSC from 10:00 to 10:30.



This would be interpreted as: mother present from noon to 16:00 (4:00pm) and was holding baby from 14:15 (2:15pm) to 1445 (2:45pm). Dad was present from noon to 14:00 and again from 15:00 to 16:00.

Protocol #: 19/39 X | Version date: 2019-03-05

Note: This is fictitious data created by CL for illustrative purposes.

Appendix K

Parent Survey- Section 1

Confidential

Page 1 of 10

Are we on the same page about Skin to Skin Care? Parent Survey

Le contact peau-à-peau: sommes-nous sur la même longueur d'onde? Sondage auprès des parents.

Le français suit.

Please answer the following questions to the best of your ability.
You do not need to answer any question that you do not want to answer.
You may start the survey now and complete it at a later time, but you must complete the survey within 14 days.

If you have any questions, comments, or concerns please contact Catherine Larocque at [REDACTED]

Veillez s'il-vous-plaît répondre aux questions suivantes du mieux que vous le pouvez.
Vous pouvez refuser de répondre à n'importe quelle(s) question(s) que vous voulez.
Vous pouvez commencer le sondage maintenant et y revenir ultérieurement mais vous devez le compléter d'ici 14 jours.

Si vous avez des questions, commentaires, ou des inquiétudes quelconque, veuillez contacter Catherine Larocque à [REDACTED]

SECTION 1

What is your relationship to the infant?

- ☐ Mother/Mère
☐ Father/Père
☐ Other/Autre

Quelle est votre relation à l'enfant?

Please specify.

Veillez préciser.

Were you aware that your infant may need to be admitted to the NICU before delivery?

- ☐ Yes/Oui
☐ No/Non

Avant l'accouchement, étiez vous au courant que votre enfant aurait peut-être besoin d'être admis à l'UNSI?

Was your infant a singleton or multiple pregnancy?

- ☐ Singleton/Monofoetale
☐ Multiple (twins or more)/Multiple (jumeaux ou plus)

Es-ce-que votre enfant faisait partie d'une grossesse monofoetale ou multiple?

Appendix K (continued)
Parent survey- Section 2

SECTION 2

What is your highest level of educational completion?

Quel est votre plus haut niveau d'études complété?

- ☐ Some high school/Un peu de secondaire ou Lycée
☐ High school diploma/Diplôme du secondaire ou du Lycée
☐ Some university/ Un peu d'université
☐ Completed university degree/Diplôme universitaire
☐ Prefer not to answer/Je préfère ne pas répondre

How many other children live in your home?
(in numbers)

Il y a combien d'autres enfants qui habitent chez vous?
(en chiffres)

Where are you staying while your baby is hospitalized?

Où demeurez-vous pendant que votre enfant est hospitalisé?

- ☐ At home/À la maison
☐ At a family member or friend's home/Chez un membre de la famille ou chez un(e) ami(e)?
☐ Rotel or another hotel/ Au Rotel ou un autre hôtel
☐ Ronald McDonald House/À la maison Ronald McDonald
☐ Other/Autre

Please specify.

Veuillez préciser.

Approximately how long does it take you to get to [REDACTED] to visit your baby? (in Km, minutes, hours, etc.)

Approximativement, combien de temps prend-t-il pour vous rendre au [REDACTED] pour visiter votre enfant?
(en Km, minutes, heures, etc.)

Are you currently employed?

Travaillez-vous actuellement?

- ☐ Yes/Oui
☐ No/Non

If so, which of the following best describes your current working situation:

Si oui, lequel des options ci-dessous décrit le mieux votre situation de travail?

- ☐ Working full time/Travail à temps plein
☐ Working part time or casual/Travail à temps partiel ou occasionnel
☐ On parental leave/En congé parental
☐ Other/Autre

Please describe.

Veuillez décrire.

What is your approximate family household income per year?

Quel est approximativement le revenu total de votre famille par année?

- ☐ Less than or equal to \$40 000/moins de, ou approximativement, \$40,000
☐ Between \$40 000 and \$65 000/Entre \$40,000 et \$65,000
☐ Between \$65 000 and \$80 000/Entre \$65,000 et \$80,000
☐ Greater than \$80 000/Plus de \$80,000
☐ Prefer not to answer/Je préfère ne pas répondre

Appendix K (continued)

Parent Survey (Section 2 continued)

Where do you get most of your information about your baby (their diagnosis, their medical care, etc.)? Select all that apply. Où obtenez-vous la majorité de vos renseignements concernant votre enfant (leur diagnostique, leur plan de soins, etc.)? Cochez la ou les case appropriée(s).	☐ Social media/Les médias sociaux ☐ Online (e.g. Wikipedia, webMD)/En ligne (ex: Wikipédia, webMD) ☐ Books/Les livres ☐ Family/La famille ☐ Nurses/Les infirmières ☐ Doctors/Les médecins ☐ Other/Autre (Select all that apply)
Please describe Veuillez décrire.	

Where do you get most of your information about caring for your baby in the NICU? Où obtenez-vous la majorité de vos renseignements concernant comment vous occuper de votre enfant durant son admission à l'UNSI?	☐ Social media/Les médias sociaux ☐ Online (e.g. Wikipedia, webMD)/En ligne (ex: Wikipédia, webMD) ☐ Books/Les livres ☐ Family/La famille ☐ Nurses/Les infirmières ☐ Doctors/Les médecins ☐ Other/Autre (Select all that apply)
Please describe	

Thinking about your experience in the NICU, for the following questions, please rate your level of agreement from 1-5, with 1 being strongly disagree and 5 being strongly agree.

En pensant à votre expérience dans l'UNSI, pour les questions suivantes, veuillez évaluer votre niveau d'approbation de 1 à 5 avec 1 étant fortement en désaccord et 5 étant fortement d'accord.

	1. Strongly disagree/Fortement en désaccord	2. Disagree/ En désaccord	3. Neither agree nor disagree/Ni d'accord ni en désaccord	4. Agree/D'accord	5. Strongly agree/Fortement d'accord
I feel supported to care for my infant. Je me sens soutenu pour prendre soin de mon enfant.	☐	☐	☐	☐	☐
I am able to stay overnight with my infant. Je suis capable de rester du jour au lendemain avec mon enfant.	☐	☐	☐	☐	☐
I am encouraged to help feed my infant. (i.e. breastfeeding, pumping, bottle feeding) Je suis encouragé(e) d'aider avec la nutrition de mon enfant (l'allaitement, l'emploi d'un tire lait, la bouteille).	☐	☐	☐	☐	☐
I feel that the NICU staff are supportive of my cultural practices and traditions. J'ai l'impression que le personnel de l'UNSI respectent mes valeurs et pratiques culturelles.	☐	☐	☐	☐	☐

Appendix K (continued)

Parent Survey (Section 3)

SECTION 3

The room where my infant is being cared for has a window. ☐ Yes/Oui ☐ No/Non

La salle où mon enfant reçoit ses soins à une fenêtre.

The room where my infant is being cared for has a bed for me. ☐ Yes/Oui ☐ No/Non

La salle où mon enfant reçoit ses soins a un lit pour moi.

The room where my infant is being cared for has a reclining chair (or rocking chair). ☐ Yes/Oui ☐ No/Non

La salle où mon enfant reçoit ses soins à un fauteuil inclinable (ou une chaise berçante).

Thinking about your experience in the NICU, for the following questions, please rate your level of agreement from 1-5, with 1 being strongly disagree and 5 being strongly agree.

En pensant à votre expérience dans l'UNSI, pour les questions suivantes, veuillez évaluer votre niveau d'approbation de 1 à 5 avec 1 étant fortement en désaccord et 5 étant fortement d'accord.

	1. Strongly disagree/Fortement en désaccord	2. Disagree/ En désaccord	3. Neither agree nor disagree/Ni d'accord ni en désaccord	4. Agree/D'accord	5. Strongly agree/Fortement d'accord
Despite the nurse being busy, sufficient attention is paid to us. Malgré la charge de l'infirmière, nous recevons de l'attention suffisante.	☐	☐	☐	☐	☐
I/we have unrestricted access to my/our infant. Je/nous avons un accès illimité à mon/notre enfant.	☐	☐	☐	☐	☐
There is sufficient privacy for me and my family in the room where my infant is being cared for. Dans la salle où mon enfant reçoit ses soins, il y a suffisamment d'intimité pour moi et ma famille.	☐	☐	☐	☐	☐
Generally, I would say that the staff support parent infant closeness. En général, j'ai l'impression que le personnel soutiennent la proximité parent-enfant.	☐	☐	☐	☐	☐
I am aware of unit resources for parent support (e.g. parent support groups, social workers). Je suis au courant des ressources offertes par l'UNSI pour les parents (ex: groupes d'entraide pour les parents, travailleuse sociale).	☐	☐	☐	☐	☐
I am aware of hospital resources for parents (e.g. multi-faith room, cafeteria). Je suis au courant de ressources offertes par le CHEO pour les parents (ex: la pièce oecuménique, la cafétéria).	☐	☐	☐	☐	☐

Appendix K (continued)
Parent Survey (Section 4)

SECTION 4

Thinking about your experience in the NICU, for the following questions, please rate your level of agreement from 1-5, with 1 being strongly disagree and 5 being strongly agree.

En pensant à votre expérience dans l'UNSI, pour les questions suivantes, veuillez évaluer votre niveau d'approbation de 1 à 5 avec 1 étant fortement en désaccord et 5 étant fortement d'accord.

	1. Strongly disagree/Fortement en désaccord	2. Disagree/ En désaccord	3. Neither agree nor disagree/Ni d'accord ni en désaccord	4. Agree/D'accord	5. Strongly agree/Fortement d'accord
I am aware when my baby will undergo a procedure (such as bloodwork). Je suis au courant quand mon enfant doit subir une procédure (tel qu'un échantillon sanguin).	☐	☐	☐	☐	☐
I was oriented to the unit when my infant was admitted. J'ai reçu une orientation à l'UNSI quand mon enfant a été admis.	☐	☐	☐	☐	☐
I participate in parenting activities with my infant (such as changing diapers, bathing). Je participe aux activités parentales avec mon enfant (tel que le changement des couches, les bains, etc.).	☐	☐	☐	☐	☐
I have a clear understanding of the things I can do to be involved in my baby's care. J'ai une compréhension claire des activités que je peux faire pour m'impliquer dans les soins de mon enfant.	☐	☐	☐	☐	☐
The nurses encourage me to hold my baby. Les infirmières m'encouragent de prendre mon bébé.	☐	☐	☐	☐	☐
The nurses offer open and honest communication. Les infirmières communiquent honnêtement et clairement.	☐	☐	☐	☐	☐

Appendix K (continued)
Parent Survey (Section 4 continued)

The nurses provide consistent messages about my baby's care and my involvement. Les infirmières m'offrent des renseignements cohérents par rapport aux soins de mon enfant et comment je peux m'impliquer.	☐	☐	☐	☐	☐
The nurses give me information about pain and how to help my baby with pain during painful procedures (i.e. heel pokes, bloodwork). Les infirmières m'offrent de renseignements par rapport à la douleur de mon enfant et comment je peux l'aider durant les procédures douloureuses (tel que la ponction au talon ou veineuse).	☐	☐	☐	☐	☐
The nurses encourage me to participate in my infant's care. Les infirmières m'encouragent de participer aux soins de mon enfant.	☐	☐	☐	☐	☐
The nurses teach me about how to care for my baby. Les infirmières m'enseignent comment je peux prendre soin de mon enfant.	☐	☐	☐	☐	☐
The nurses help me cope with the stress of having a baby in the NICU. Les infirmières m'aident à gérer le stress qui accompagne avoir un enfant admis à l'UNSI.	☐	☐	☐	☐	☐
In general, I would say that I have enough information to participate equally in my infant's care. En général, je dirais que j'ai suffisamment d'information pour participer aux soins de mon enfant.	☐	☐	☐	☐	☐
In general, I feel that my input about my baby is valued (e.g. their condition, their care). En général, je me sens que mes commentaires par rapport à mon enfant sont appréciés (par exemple par rapport à leur état de santé ou leur soins).	☐	☐	☐	☐	☐
In general, I feel like I am an equal member of my baby's care team. En général, je me sens comme un membre égal de l'équipe des soins de mon enfant.	☐	☐	☐	☐	☐

Appendix K (continued)
Parent Survey (Section 5)

SECTION 5**Open answer questions/Questions à réponses ouvertes**

For this last section, please feel free to tell us anything that you think might be important for us to know. Your answers will be kept in strict confidence and will in no way impact you or your infant's care.

Pour cette dernière section, sentez-vous à l'aise de nous dire n'importe quoi que vous croyez serait important que l'on sache. Nous garderons vos réponses strictement confidentiels et elles n'auront aucun impact sur vous ou les soins de votre enfant.

Tell me about what helps you to take care of your baby while they are admitted to the NICU.

Décrivez-moi ce qui vous aide(nt) à prendre soins de votre enfant lorsqu'il/elle est admis à l'UNSI.

Tell me about what has made it more difficult for you to care for your baby while they are admitted to the NICU.

Décrivez-moi ce qui rend plus difficile pour vous de prendre soin de votre enfant lorsqu'il/elle est admis à l'UNSI.

Tell me about things that would encourage you, or have made it easier for you, to be with your baby while they are admitted to the NICU.

Dites-moi ce qui vous encourage ou pourrait vous encourager, ou à rendu plus facile ou pourrait rendre plus facile, pour vous d'être avec votre enfant durant leur admission à l'UNSI.

Is there anything else you would like to tell me?

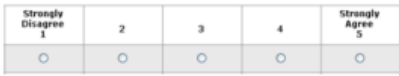
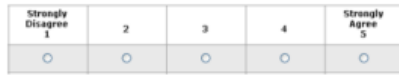
Y-a-t-il autres choses que vous aimeriez me dire?

Appendix L

Supporting literature for the construction of the parent survey items

SECTION 1 – Infant factors and demographics		
Survey item and level of measurement	Response options	Evidence/Rationale
What is your relationship to the infant? [Nominal]	• Mother • Father • Other → Please specify	Demographic information only
Were you aware that your infant may need to be admitted to the NICU before delivery? [Nominal]	• Yes • No	Demographic information only
Was your most recent pregnancy a singleton or multiple pregnancy? [Nominal]	• Singleton • Multiple (twins or more)	There is evidence to support that singletons receive more SSC (Raiskila et al., 2017).
SECTION 2– Parent and family factors		
Survey item and level of measurement	Response options	Evidence/Rationale
Mother's highest educational achievement [Ordinal]	• Some high school • High school • Some university • Completed university degree • Prefer not to answer	Raiskila et al. (2017) found a positive association between the mother's educational achievement and PP/SSC. Prefer not to answer was added after parent feedback during beta testing.
How many other children live in your home? [interval]	Open numerals	Parents have reported in the literature that caring for the infant's siblings hinders their ability to participate in care (Palomaa et al., 2016; Raiskila et al., 2017).
Where are you staying while your baby is hospitalized? [Nominal]	• Home • Family member or friend's home • Rotel or another hotel • Ronald McDonald House • Other → Please specify	Given the high acuity of the patients, some families travel large distances to be with their infant (Raiskila et al., 2017).
Approximately how long does it take you to get to [HOST]	Open (in minutes)	Travel time has been identified as a covariate to parental

INSTITUTION] to visit your baby? [Ratio]		presence in the literature (Palomaa et al., 2016; Raiskila et al., 2017; Aija et al., 2019).										
Are you currently employed? [Nominal]	• Yes • No Please describe.	Having to work is associated with lower parental presence. (Palomaa et al., 2016)										
What is your approximate family household income? [Ratio]	• Less than or equal to \$40 000/year • Between \$40 000 and \$65 000 • Between \$65 000 and \$80 000 • Greater than \$80 000 • Prefer not to answer	Part of the NICU Family Needs Inventory (Ward, 2001). Income is associated with parental stress (Palomaa et al., 2016; PHAC 2017). Criteria are based on Statistics Canada before tax Low-Income Cutoffs (LICOs). Prefer not to answer was added after parent feedback during beta testing.										
Where do you get most of your information about your baby's care? *select all that apply	• Social media • Online (e.g. Wikipedia, webMD) • Books • Family • Nurses • Doctors • Other → Please describe.	Identified as important by parents during beta testing.										
<i>For the following questions, please rate your level of agreement from 1-5, with 1 being strongly disagree and 5 being strongly agree.</i> [approximates interval level]												
I feel supported to care for my infant.	<table border="1"> <tr> <td>Strongly Disagree 1</td> <td>2</td> <td>3</td> <td>4</td> <td>Strongly Agree 5</td> </tr> <tr> <td>☐</td> <td>☐</td> <td>☐</td> <td>☐</td> <td>☐</td> </tr> </table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Part of the Parental Stressor Scale; lack of support is associated with higher levels of stress among parents (Miles et al., 1993).
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
I am able to stay overnight with my infant.	<table border="1"> <tr> <td>Strongly Disagree 1</td> <td>2</td> <td>3</td> <td>4</td> <td>Strongly Agree 5</td> </tr> <tr> <td>☐</td> <td>☐</td> <td>☐</td> <td>☐</td> <td>☐</td> </tr> </table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Ability to stay overnight is the most important factor in determining parental presence (Palomaa et al., 2016; Raiskila et al., 2017).
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								

I am encouraged to help feed my infant (i.e. breastfeeding, pumping, bottle feeding)		Part of the Nurse-Parent Support Scale. Associated with higher overall satisfaction among parents (Al-Motlaq et al., 2017). Breastmilk is very important for a sick baby's development and parents want to provide that support for them (Altimier & Phillips, 2016) .
I feel that the NICU staff are supportive of my cultural practices and traditions.		Identified as important by parents during beta testing.
SECTION 3 - NICU environment/context factors		
Survey item and level of measurement	Response options	Evidence/Rationale
The room where my infant is being cared for: i) has a window ii) has a bed for me iii) has a reclining chair (or rocking chair)	i) yes or no ii) yes or no iii) yes or no	i) Exposure to daily cycles facilitate circadian rhythm-good for babies and parents (Altimier & Phillips, 2016). ii) Facilitates PP overnight; ability to stay overnight is the most important aspect in PP (Raiskila et al., 2017). iii) These facilitate SSC as they are comfortable for parents to sit in for prolonged periods (Palomaa et al., 2016).
<i>For the following questions, please rate your level of agreement from 1-5, with 1 being strongly disagree and 5 being strongly agree.</i> [approximates interval level]		
Despite the nurse being busy, sufficient attention is paid to us.		Part of the EMPATHIC-N (EMpowerment of PArents in THE Intensive Care- Neonatal); important for parent participation in care (Latour, 2011).
I/we have unrestricted access to baby.		Parental participation depends on access to the baby (Cisneros Moore et al., 2003).

There is sufficient privacy for me and my family in the room where my infant is being cared for.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Privacy is necessary for creating the ideal environment for healing for neonates and for the comfort of parents in the NICU (Altimier & Phillips, 2016; Raiskila et al., 2017; Coughlin,et al., 2009). Identified as important by parents during beta testing.
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
Generally, I would say that the staff support parent infant closeness.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Essential for developmental care although distinct from PP, PH, and SSC (Raiskila, 2018).
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
I am aware of unit resources for parent support (e.g. parent support groups, social workers).	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Important for supporting parents’ mental health, stress, coping (Altimier & Phillips, 2016; Skene et al., 2016). Refined during beta testing.
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
I am aware of hospital resources for parents (e.g. multi-fait room, cafeteria).	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Identified as important by parents during beta testing.
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
SECTION 4- Nurse/family relationship factors												
Survey item and level of measurement	Response options	Evidence/Rationale										
For the following questions, please rate your level of agreement from 1-5, with 1 being strongly disagree and 5 being strongly agree. [approximates interval level]												
I am aware when my baby will undergo a procedure (such as bloodwork)	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	One of the key concepts of interest in this study; awareness is essential for parent involvement in pain care (Benoit et al., 2016; Harrison et al., 2015; Palomaa et al., 2016).
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
I was oriented to the unit when my infant was admitted.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Nurses in Al-Motlaq et al., (2017) felt this was very important for implementing FCC. In my own clinical practice, I noticed that this piece was lacking.
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
I participate in parenting activities with my infant (such as changing diapers, bathing)	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Parenting activities should be part of parenting (Altimier & Phillips, 2016); demonstrates
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								

		collaboration, which was identified in the concept analysis and literature review.										
I have a clear understanding of the things I can do to be involved in my baby’s care.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Identified as important by parents during beta testing.
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
The nurses encourage me to hold my baby.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	An aspect of FCC that is essential for parent-infant closeness (Al-Motlaq et al., 2017) and one of the key concepts of interest in the descriptive exploratory study (PH).
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
The nurses offer open and honest communication.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Essential aspect identified in concept analysis and literature review; facilitates trust (Al-Motlaq et al., 2017)
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
The nurses provide <i>consistent</i> messages about my involvement in my baby’s care.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Identified as important by parents during beta testing.
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
The nurses give me information about pain and how to help my baby with pain during painful procedures (i.e. heel pokes, bloodwork).	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	The basis for involving parents in pain care. An essential consideration in Franck et al., (2012)’s model of parent involvement in infant pain management and also essential for the IDC’s neuroprotective core measure #5 (Harrison et al., 2015).
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
The nurses encourage me to participate in my infant’s care.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	The literature supports that parents require encouragement to participate in care with their infant(s) (Flacking et al., 2016; Mäkelä et al., 2018).
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
The nurses teach me about how to care for my baby.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Education identified as key antecedent in concept analysis and literature review (Al-Motlaq et al., 2017; Altimier & Phillips, 2016; Palomaa et al., 2016).
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
The nurses help me cope with the stress of having a baby in the NICU.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	(Al-Motlaq et al., 2017; Miles et al., 1993)
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								

In general, I would say that I have enough information to participate equally in my infant’s care.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Genuine partnership is an attribute identified in the concept analysis and literature review. It is also important for information sharing and negotiation, which are important for communication (Ramezani et al., 2014; Raiskila, 2018).
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
In general, I feel that my input about my baby is valued. (e.g. their condition, their care)	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Identified as important by parents during beta testing.
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
In general, I feel like I am an equal member of my baby’s care team.	<table><tr><td>Strongly Disagree 1</td><td>2</td><td>3</td><td>4</td><td>Strongly Agree 5</td></tr><tr><td>☐</td><td>☐</td><td>☐</td><td>☐</td><td>☐</td></tr></table>	Strongly Disagree 1	2	3	4	Strongly Agree 5	☐	☐	☐	☐	☐	Identified as important by parents during beta testing.
Strongly Disagree 1	2	3	4	Strongly Agree 5								
☐	☐	☐	☐	☐								
SECTION 5- Open response questions												
Survey item and level of measurement	Response options	Evidence										
Tell me about what helps, or has made it more difficult for you care for your baby while they are admitted to the NICU.	Open text	Identified as important by parents during beta testing.										
Tell me about things that would encourage you, or have made it easier for you, to be with your baby while they are admitted to the NICU.	Open text	Identified as important by parents during beta testing.										
Is there anything else you would like to tell me?	Open text	Identified as important by parents during beta testing.										

Appendix M

Chart Review

Chart review		Page 1 of 1
Record ID		
Infant's date of birth		
Infant's assigned sex at birth	☐ Female ☐ Male ☐ Ambiguous	
Infant's birthweight (in grams)		
Infant's gestational age (GA) at birth		
Infant's date of admission to [REDACTED] NICU		
Infant's diagnosis/reason for admission		
Type of surgery		
Total number of surgeries during hospital stay		
Mother's age		
Distance from parent/legal guardians primary address to [REDACTED]		
Infant's date of discharge from [REDACTED] NICU		
Infant's total length of stay		
Infant's outcome	☐ Discharged home ☐ Transferred to another unit at [REDACTED] ☐ Transferred to another NICU or hospital ☐ Neonatal Demise	

Appendix N
Neonatal Therapeutic Intervention Severity Scale (NTISS)

Items	Sub-scores	Items	Sub-scores
Respiratory		Metabolic / Nutrition	
O2 Supplementary	1(a)	Gavage	1
CPAP	2(a)	Phototherapy	1
IMV	3(a)	Lipid EV	1
IMV + relaxing	4(a)	Amino acid EV	1
IMV high frequency	4(a)	Insulin	2
Surfactant	1	Potassium Infusion	3
Intubation	2	Transfusions	
Tracheostomy care	1(b)	Gammaglobulin EV	1
Tracheostomy placement	1(b)	Total Exsanguination	3
Extracorporeal oxygenation	4	Partial Exsanguination	2
Monitoring		Erythrocytes ≤ 15 ml / kg	2(g)
Vital signs	1	Erythrocytes > 15 ml / kg	3(g)
Phlebotomy (5/10)	1(c)	Platelets	3
Phlebotomy (> 10)	2(c)	Leukocytes	3
Cardio Respiratory Monitoring	1	Procedures	
"Thermo-regulated Environment O2 Noninvasive Monitoring"	1	Transportation	2
PA Monitoring	1	Dialysis	4
PA Invasive Monitoring	1	Simple Thoracic Drain	2(h)
Vesical catheter	1	Multiple Drain Thoracic	3(h)
Water Balance	1	Thoracentesis	3
Cardio-Vascular	1	Pericardial Drain	4(i)
indomethacin		Pericardiocentesis	4(i)
Expander ≤ 15 ml / kg	1	Small Surgery	2(j)
Expander > 15 ml / kg	1(d)	Major Surgery	4(j)
Vasopressor (1)	3(d)	Medicines	
Vasopressor (2)	2(e)	Antibiotics ≤ 2	1(k)
Resuscitation	3(e)	Antibiotics > 2	2(k)
Standby Pacemaker	4	Diuretic VO	1(l)
Pacemaker Use	3(f)	Diuretic EV	2(l)
Vascular access	4(f)	Anticonvulsant	1
Peripheral		Aminophylline	1
Arterial Catheter	1	Corticoid	1
Central Venous Catheter	2	K exchange resin	3
	2	NaHCO ₃	3
		Other drugs	1
		NTISS TOTAL = _____	

* The letters in parenthesis represent the variables among which only the highest scores were computed⁽⁷⁾.

Note: Taken from Ferreira Curan & Rossetto, (2014) and Gray et al., (1992).

Appendix O

Definitions and photos for parents (also available in French)

Important definitions for completing the parent diary

Remember that when holding your baby, or doing SSC, **always involve your infant's Nurse** to ensure that all equipment is properly attached and supported.

1. Parental presence (PP)	A parent or other family member is present if: • They are on the unit, within your infant's room or pod ○ This also includes participating in rounds and meetings with the health care team. • The infant is in their incubator/cot Any absence lasting >15 minutes should be reflected in the diary (mark the time you left and the time you came back, if applicable). You DO NOT need to record on the diary if you leave for less than 15 minutes, such as a washroom break.		
2. Parental holding (PH) No ventral skin contact (baby's tummy and your bare chest are NOT in contact)	A parent or other family member is holding if: • They are holding your infant in your arms and they are clothed and/or the baby is clothed or wrapped in a blanket • They are breastfeeding or bottle feeding and the infant is clothed • They are purposely cradling/containing the infant in the cot/incubator (also known as hand swaddling/hand hugging) • They are performing facilitated tucking with the infant in the cot/incubator • They are performing modified kangaroo care (or encircled holding) with the infant in the cot/incubator <i>See pictures on next page.</i>		
3. Skin to Skin Care (SSC) Ventral skin contact	A parent or other family member is skin to skin if: • Your infant is wearing only a diaper (and maybe a hat or other medically required equipment), and is lying on your bare chest. • This includes breastfeeding and/or bottle feeding, if you and your infant are skin to skin (tummy to tummy). <i>See pictures on next page.</i>		
4. Painful procedures	For the purposes of this study, please indicate (with an asterisk*) the following on your parent diary: <table border="1"> <tbody> <tr> <td data-bbox="516 1423 1008 1745"> 1. Heel poke (to obtain a blood sample) 2. IV insertion (in a vein) 3. Arterial line insertion (like an IV in an artery) 4. Cutdown to access a vein or artery 5. Central line placement (includes peripherally inserted central catheters or PICCs) 6. Insertion of a line into the umbilical cord 7. Lumbar puncture </td><td data-bbox="1008 1423 1403 1745"> 8. Injections (in the muscle or the fat tissue) 9. Intubation (inserting a breathing tube) 10. Suctioning 11. Inserting a feeding tube 12. Dressing change (such as PICC dressing, pressure dressings, etc.) 13. Urethral catheterization </td></tr> </tbody> </table>	1. Heel poke (to obtain a blood sample) 2. IV insertion (in a vein) 3. Arterial line insertion (like an IV in an artery) 4. Cutdown to access a vein or artery 5. Central line placement (includes peripherally inserted central catheters or PICCs) 6. Insertion of a line into the umbilical cord 7. Lumbar puncture	8. Injections (in the muscle or the fat tissue) 9. Intubation (inserting a breathing tube) 10. Suctioning 11. Inserting a feeding tube 12. Dressing change (such as PICC dressing, pressure dressings, etc.) 13. Urethral catheterization
1. Heel poke (to obtain a blood sample) 2. IV insertion (in a vein) 3. Arterial line insertion (like an IV in an artery) 4. Cutdown to access a vein or artery 5. Central line placement (includes peripherally inserted central catheters or PICCs) 6. Insertion of a line into the umbilical cord 7. Lumbar puncture	8. Injections (in the muscle or the fat tissue) 9. Intubation (inserting a breathing tube) 10. Suctioning 11. Inserting a feeding tube 12. Dressing change (such as PICC dressing, pressure dressings, etc.) 13. Urethral catheterization		

Appendix O (continued)
Definitions and photos for parents

HOLDING

(page 1 of 2)



In these pictures, we can see fully clothed parents *holding* their wrapped infants in their arms. There is no skin contact.

In these pictures, we can see parents doing what is called *hand hugging*. In the first picture, a mom places one hand firmly on her baby's head, and the other firmly cupping her baby's bottom.

In the second picture, parents are comforting their baby by holding his hands and arms.



Appendix O (continued)
Definitions and photos for parents

HOLDING

(page 2 of 2)

In these photos, a parent has one of their hands on their baby's head, and their other hand cupped around their baby's torso or lower limbs. With both hands, the parent helps their baby stay in a flexed contained position while on their side. This is called *facilitated tucking*.



(Axelin, Lehtonen, Pelander, & Salanterä, 2010)



(Helder & Latour, 2008)



In these photos, a parent leans over their baby in the crib and places their arms on either side of him, with hands cupped over the head. This is called *encircled holding*. If your arms are bare and touching baby's skin, it is called *modified kangaroo care*.

Appendix O (continued)
Definitions and photos for parents

SKIN TO SKIN CARE



In this picture, we can see the infant is naked, except for a diaper. Mom's bare chest is exposed and the baby's tummy is against mom's tummy.

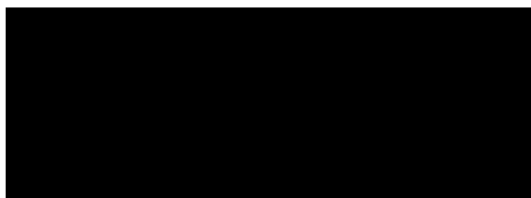
In these pictures, we can see the infant is snuggled on Mom's bare chest, skin to skin. They are covered by a hospital gown.



In this picture, we can see the infant naked, except for a diaper, and is breastfeeding while skin-to-skin. In addition, the nurse is doing bloodwork with the infant feeds.

Appendix P

Ethical Approval- Host institution



Research Ethics Board Approval - Delegated Review

Principal Investigator: Ms. Catherine Larocque

REB Protocol No: 19/39X

Romeo File No: 20190195

Project Title: REB# 19/39X - Are we on the same page about skin-to-skin care? A descriptive correlational study exploring skin to skin care for postoperative NICU infants

Primary Affiliation: Clinical Research\Nursing

Protocol Status: Active

Approval Date*: May 23, 2019

Approval Expiry Date:** May 15, 2020

Documents Reviewed & Approved:

Document Name	Comments	Version Date
Protocol	Protocol_clean	2019/05/15
Investigator Response	Investigator response letter	2019/05/15
Consent Form	Consent form_clean	2019/05/15
Investigator Response	Itemized response letter (signed by PI CCL)	2019/05/03
Other Document	Master list	2019/05/03
Other Document	Screening log	2019/05/03
Other Document	Definitions and photos for parents	2019/05/03
Other Document	Examples of completed diaries for parents	2019/05/03
Recruitment Materials	Recruitment poster for parents	2019/03/15
Case Report Form	Parent diary data collection	2019/05/03
Case Report Form	Parent diaries_eCRF	2019/03/18
Case Report Form	NTISS_eCRF	2019/03/18
Recruitment Materials	Poster for nurses	2019/05/03
Case Report Form	eCRF for chart review	2019/05/03
Questionnaire/Survey	Study questionnaire_EN	2019/03/15

Appendix P (continued)

Ethical Approval- Host Institution

Case Report Form	Enrolment_eCRF	2019/03/18
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This is to notify you that the [REDACTED] Research Ethics Board has granted approval to the above named research study on the date noted above. Your project was reviewed within the delegated stream, which is reserved for projects that involve no more than minimal risk to human participants.

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

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

Should you have any questions or concerns, please do not hesitate to contact the Research Ethics Board Office at [REDACTED]

Regards,

[REDACTED]

Chair, Research Ethics Board
Président, Comité d'éthique de la recherche

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

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

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

• If the date of review and approval was **after** the 15th of the month, the expiry date will be the 15th of the month in which the date of review and approval by the REB *in the following year*.

Appendix Q

University of Ottawa Ethical Approval

14/06/2019

Université d'Ottawa

Bureau d'éthique et d'intégrité de la recherche

University of Ottawa

Office of Research Ethics and Integrity

Lettre d'approbation administrative | Letter of administrative approval

Numéro de dossier / Ethics File Number

H-06-19-4652

Titre du projet / Project Title

Are we on the same page about skin-to-skin care? A descriptive correlational study exploring skin to skin care for postoperative NICU infants.

Type de projet / Project Type

Thèse de maîtrise / Master's thesis

CÉR primaire / Primary REB

Statut du projet / Project Status

Approuvé / Approved

Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)

14/06/2019

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

15/05/2020

Équipe de recherche / Research Team

Chercheur / Researcher Affiliation

Role

Catherine LAROCQUE

École des sciences infirmières / School of Nursing

Chercheur Principal / Principal Investigator

Denise HARRISON

École des sciences infirmières / School of Nursing

Superviseur / Supervisor

Janet Elaine SQUIRES

École des sciences infirmières / School of Nursing

Co-chercheur / Co-investigator

Wendy PETERSON

École des sciences infirmières / School of Nursing

Co-chercheur / Co-investigator

Conditions spéciales ou commentaires / Special conditions or comments:

REB # 19/39X

Appendix R

Informed Consent Form (also available in French)



Family Information and Consent Form

Are we on the same page about skin to skin care? A descriptive correlational study exploring skin to skin care for postoperative NICU infants.

Co-principal
Investigators:

Denise Harrison, RN, PhD
Chair in Nursing Care of Children, Youth and Families

Professor
School of Nursing, *University of Ottawa*
613-737-7600 x 4140

Catherine Larocque, BScN, RN
Master's student
University of Ottawa

Co-investigators:

Janet Squires, RN, PhD
Senior Scientist
Clinical Epidemiology Program, *The Ottawa Hospital Research Institute*
Associate Professor
School of Nursing, *University of Ottawa*

Wendy Peterson, RN, PhD
Associate Professor,
School of Nursing, *University of Ottawa*

Martha Mason-Ward, RN, NNP
Neonatal Nurse Practitioner

*For simplicity, "your infant" will be used throughout this consent form to mean your child or legal ward.

Conflict of Interest

This research project is being undertaken by Catherine Larocque to meet the requirements of the Master of Science of Nursing program at the University of Ottawa.
The research team members are not benefiting personally, financially or in some other way from this study.

Introduction

You are being invited to participate in a research project about parental presence, parental holding, skin-to-skin care (SSC), and parent involvement in pain care in the Neonatal Intensive Care Unit (NICU). You are being invited because your infant is currently admitted to the

Appendix R (continued)

Informed Consent Form



■■■■■■■■■■ NICU and they are either awaiting surgery or recovering from surgery. Please read this Information Sheet and Consent Form carefully and ask as many questions as you like before deciding whether to participate in this research study.

Why is this study being done?

Family-centered care is the gold standard for many NICUs and pediatric hospitals. Family-centered care (FCC) is when parents and professionals work together to plan, provide, and evaluate the care your child receives while at ■■■■■■■■■■ this approach places an emphasis on collaboration, mutual respect, and communication. For more information about the FCC approach at ■■■■■■■■■■ please visit the following link:

- ■■■■■■■■■■

We know that parents want to be involved in their infant's care and, in particular, parental holding and SSC are especially important for families in the NICU. However, with neonates who require surgery or are recovering from surgery, we do not know if holding and SSC are promoted by the health care staff or if it is feasible and acceptable for parents. Therefore, the aim of this study is to collect information about which infant and family factors influence parental presence, parental holding, and SSC. In addition to this, we hope to discover how much infants in the ■■■■■■■■■■ NICU are held or receive SSC and if parents are encouraged to do so during painful procedures. There are no additional procedures or interventions that will be conducted as part of this study.

Why am I being asked to be in this research project?

We are asking you to participate in this research project because:

- Your infant is admitted to the ■■■■■■■■■■ NICU and is either awaiting surgery or recovering from surgery, and
- You were identified by your infant's nurse as being the parent or legal guardian.

What would my participation consist of?

If you agree to participate in this study, your participation will continue for two weeks. During this time, you will be asked to:

1. Complete a one-time questionnaire consisting of 40 short multiple choice and likert style questions (strongly disagree to strongly agree) and 3 short answer questions, and
2. Maintain a parent-infant closeness diary which will be kept at your infant's bedside. This diary consists of one page per day that corresponds to 24 hours with six timelines: parent present, parent holding, parent SSC; other family present, other family holding, other family SSC. We will also ask you to record any painful/distressing procedures that occur (such as heel poke or blood sample from a vein) while you are with your infant. An example of the diary can be found on the next page.

In addition to the questionnaire diary, the researcher will collect the following information about your infant from their medical chart: their sex, their birthweight, their diagnosis and/or reason for admission, their gestational age (GA) at birth, their total length of stay in the NICU, and their type of surgery. For the duration of the two-week period, the researcher will also do daily Neonatal Therapeutic Intervention Severity Scores (NTISS) to assess your infant's health and medical status. The NTISS scoring will be completed by the researcher based on treatments that your infant is already receiving. The data for completing the NTISS score will be obtained from your infant's health team and medical record. The scoring involves an evaluation of your infant's current treatment and therapies. Examples of items captured by the NTISS include (but are not limited to): if your infant has an intravenous or PICC line, how your infant is being fed (e.g. nasogastric tube), if your infant is on oxygen (e.g. ventilator, CPAP), and any procedures

Appendix R (continued)

Informed Consent Form



(e.g. surgery). This information will be used in conjunction with the parent-infant closeness diary and the survey.



Example of parent diary for baby with study ID 016 on May 3rd, 2019
The mother was present from 9:00 until noon and was holding her baby from 10:00-10:50am.

What are the alternatives to participation?

Your participation in this study is entirely voluntarily and you are in no way obliged to participate. Your decision to participate or not in this study will not affect the care you presently receive at [REDACTED] not any care in the future that you are entitled to. If you prefer not to participate in this study simply advise the researcher.

How many people will be a part of this study?

We will be recruiting new participants for a period of 6-8 months, but you and your infant's participation will only last 14 days, or until discharge, as described above. We hope to have between 50 and 100 families participate.

What are the risks of the study?

There are no known risks to participating in this study. The care your infant is receiving will not be affected by your participation, or not, in this study. Despite this, due to the limited literature about

Appendix R (continued)

Informed Consent Form



the safety of holding and SSC for infants needing surgery or after surgery, there may be side effects or harms that are not anticipated. When holding your baby, or doing SSC, always involve your infant's Registered Nurse to ensure that any and all equipment is properly attached and cared for.

What if I (or my infant) is injured?

In the event that you or your child suffers injury as a direct result of participating in this study, normal legal rules on compensation will apply. Medical care will be provided to you or your child, as needed. By signing this consent form you are in no way waiving your legal rights or releasing the investigator from their legal and professional responsibilities.

Are there benefits to taking part in the study?

If you decide to participate, you may or may not benefit from participating in this study; however, we think that this study will help us to improve the care for all children and their families at [REDACTED]

Will I be paid for my participation or will there be any additional costs to me?

This study will not incur you any additional costs in and of itself. However, as a token for your time and participation in this study, as well as a recognition of the transportation costs incurred (such as parking), you will receive a \$5 gift card to [REDACTED] cafeteria.

Participation in the study

Your participation in this study is entirely voluntarily. You may decline to participate in the study. You may also stop your participation at any time, without any change to your infant's care. If your infant is admitted for less than 48 hours after surgery, your data will not be used in the final analysis.

You will be informed in writing and asked to sign a new informed consent if new information becomes available that would affect your willingness to continue your participation in the study.

If I so choose, how would I withdraw from the study?

You are free to withdraw at any time and there will be no penalty to you or your infant. You may opt to withdraw at any time during the two-week period, or after its completion. If you would like to withdraw, please contact Catherine Larocque (contact information listed on the first page of this form). At the time of your withdrawal, you will be given the option to have your data excluded from any analysis or publication.

What about confidentiality and privacy?

Your personal information will be kept strictly confidential except as required or permitted by law, such as in cases of reported or suspected child abuse.

For this study, we will be collecting personal identifiers and personal health information from your infant. The identifiers include things like gestational age (GA) at birth, diagnosis, length of hospital stay, and parents' distance to the hospital. In addition, in order to complete the NTISSs, the researcher will also collect information about your infant's medical status each day. This information could include but is not limited to medications, transfusions, interventions and procedures, and monitoring (vital signs).

You and your infant's personal identifiers (name, contact information) will be kept in a document that links this information with a study ID, called a master list. Only the master list will contain the link between the participant (you and your infant) and the study ID. The study ID will be used in all of the research documents instead of your personal information to protect your privacy.

Appendix R (continued)

Informed Consent Form



You and your infant will not be identified in any conference proceedings or publications. The master list will be stored separately from the research data. It will be stored on the secure [REDACTED] network in a password protected document, with access restricted to the research team, mentioned on page 1. The de-identified research data (your survey responses, the NTISS scores, demographic information listed above) will be stored on the [REDACTED] instance of the Research Electronic Data Capture system (REDCap). REDCap is a secure online survey platform for [REDACTED] researchers [REDACTED]

In accordance with [REDACTED] and uOttawa policy, the research data produced from this study will be stored on the secure [REDACTED] network (including the instance of REDCap) and in the locked office of the supervisor (DH). Only the individuals mentioned on the first page of this form will have access to the data. Following completion of the study the research data (parent-infant closeness diaries, database with all health information, survey responses), and master list will be kept for 7 years after the last publication of this study. They will then be destroyed.

Representatives from the [REDACTED] Quality Assurance and Risk program, and the [REDACTED] Research Ethics Board, may review your child's medical records under the supervision of the Investigator and staff to ensure that all research standards and regulations are met

A copy of the signed consent form will be provided to you.

Will I be provided with results of the study?

You will be offered a summary of the study results which can be mailed to you by post or emailed to you. This summary will include all infants and their families, so will not be about your child specifically, as no individual infant will be identifiable.

What are the roles and responsibilities of the [REDACTED] and uOttawa REB?

The [REDACTED] Research Ethics Board (REB), and the University of Ottawa's REB, have reviewed and approved this research project. The REB is a committee of individuals from different professional backgrounds. The Board reviews all research that takes place at the hospital. Its goal is to ensure the protection of the rights and welfare of people participating in research. The Board's work is not intended to replace a parent or child's judgment about what decisions and choices are best for them. You may contact the Chair of the Research Ethics Board, for information regarding patient's rights in research studies at [REDACTED] although this person cannot provide any health-related information about the study.

You may also contact the University of Ottawa's REB If you have any questions regarding the ethical conduct of this study. You may contact the:

Protocol Officer for Ethics in Research,
University of Ottawa, Tabaret Hall,
550 Cumberland Street, Room 154,
Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

If you have any questions concerning your participation in this study, or if at any time you feel that you are experiencing harm as a result of your participation in the study, or if you would like more information, please contact the Principal Investigator, Catherine Larocque, at [REDACTED]

Appendix R (continued)

Informed Consent Form



Parent Information and Consent Form Signatures

(One signed copy required per participant)

To become a part of this study, please sign this page.

By signing this page, you are confirming the following:

- You have read all of the information in this Parent Information and Consent Form, and you have had time to think about it.
- All of the risks and benefits of participation have been explained to you.
- All of your questions have been answered to your satisfaction.
- You voluntarily agree to participate in this study with your infant.
- You may freely choose to stop your participation at any time and any data collected will not be used any further.
- You allow access to your child's medical records and/or personal information as described in this consent form.
- You have received a copy of this Parent Information and Consent Form to keep for yourself.
- You do not give up your legal rights by signing this form.

Name of infant

Name of participant

Relationship to infant

Participant's signature

Date

Name of person obtaining consent

Signature

Date

Study Results

I wish to receive a summary of the findings to review once the data collection and analysis are complete:

Yes ☐ No ☐

Please provide your email address and the researcher Catherine Larocque
[REDACTED] will contact you with your unique survey link.

CHAPTER 4

Family-Centered Care, Parental Presence, and Skin-to-Skin care for post-operative NICU infants: a cross-sectional nonexperimental descriptive study

This chapter is an unpublished manuscript formatted for publication in The Lancet, Special Issue Nursing in 2020

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Denise Harrison, PhD, RN

Professor, School of Health Sciences, Faculty of Medicine, Dentistry and Health Sciences,

University of Melbourne

Abstract

Background.

Family centered care (FCC) is considered the gold standard in Neonatal Intensive Care Units (NICU). Despite this, challenges with adopting FCC in clinical practice are reported, and there is a paucity of research pertaining to postoperative neonates.

Study aims: 1) describe the frequency and duration of parental presence (PP), parental holding (PH), and Skin-to-Skin care (SSC); 2) determine PP, PH, and SSC during minor acute painful procedures (i.e. heel lance); 3) assess relationships between PP, PH, SSC and illness severity; and 4) identify parent, infant, and environmental factors that influence PP, PH, and SSC for postoperative neonates in an NICU.

Methods.

Cross-sectional nonexperimental descriptive design conducted in a level 3b NICU in Canada. There were four primary sources of data, namely: parent-infant closeness diaries, patient chart reviews, Neonatal Therapeutic Intervention Severity Scale, and a parent questionnaire.

Descriptive statistics and nonparametric tests were used to summarise and evaluate quantitative data. Qualitative data was analyzed using content analysis.

Findings.

Eleven infants were enrolled (141 days of data). PP occurred for a median of 440 minutes (7.3 hours) and PH for a median of 100 minutes. SSC rarely occurred (median 0 hours). The parent questionnaire showed that most parents agreed that parent-infant closeness was supported, however, lower scores were reported for having a clear understanding of how to be involved in their baby's care and knowing how to help their infant during painful procedures. Key facilitators for PP included available resources, shift in nurses' role to that of an educator for parents, and parents' roles as equal partners in care. Barriers included a lack of holistic care for the family and not welcoming parents as partners.

Interpretation.

Further research exploring FCC, PP, PH, SSC, and parent involvement in pain care for postoperative neonates is warranted.

Funding.

University of Ottawa Graduate Admission Scholarship and Anne Whitaker Memorial Scholarship (University of Ottawa)

Introduction

Nurses and healthcare providers (HCPs) in the Neonatal Intensive Care Unit (NICU) face the unique challenge of providing biomedically complex care to infants while also caring for the infants' families. Family-Centered Care (FCC) is considered the gold standard for care delivery in NICUs worldwide (1) due to the unique developmental needs of neonates and the attachment and bonding needs of the family (2,3). In this context, attachment refers to the relationship that develops between parents and their infant, and bonding refers to positive interactions between them. Given that FCC is care that is "planned around the whole family, not just the individual child/person, and in which all the members are recognized as care recipients" (4 p1318), the family and parents' needs are considered synergistically with those of the infant. Research evidence supports the positive impact of FCC on parental satisfaction, cost reduction, and reducing negative impacts after hospitalization for both infants and parents (5), as well as a reduction in overall length of stay and a positive impact on infant feeding, growth, and neurodevelopment (6).

Despite the evidence base and longstanding history of FCC, results of a literature review and concept analysis showed that regarding FCC as a model that can be readily implemented is too reductionist and that the existing literature deals almost exclusively with extremely preterm and preterm infants (7). Considering advancements in perinatology over the last two decades, such as the administration of surfactant and antenatal steroids, neonatal morbidity and mortality surrounding prematurity has decreased (8,9). Accordingly, the rates of infants with complex surgical needs born at later stages of gestation have increased and gone largely unstudied (9–11). Given that families of neonates requiring surgical interventions are at a high risk of experiencing feelings of fear, guilt, trauma, and helplessness there is a need to explore FCC and its delivery for this population (11–13).

Due to the lack of pre-existing frameworks or guidelines pertaining to FCC for perioperative neonates specifically, this study employed a certain level of theoretical eclecticism in order to capture key aspects of this complex philosophy of care. This study was primarily informed by Coughlin's 5 Core Measures for developmentally-sensitive care (14), Altimier's Integrative Developmental Care Framework (15), and Franck's model for parent involvement in pain care (16). Parental presence (PP), Skin-to-Skin Care (SSC), parent involvement in pain care (PIPC), and the NICU environment are central in each of these existing evidence-based approaches to FCC delivery in the NICU. Therefore, in order to provide a broad explanatory cross-sectional view of FCC for postoperative neonates, these were the central variables of interest in this study.

Objectives

In light of the aforementioned gaps identified in the literature, and the paucity of literature addressing FCC for postoperative neonates specifically, this research study aimed to assess and explore PP, parental holding (PH), SSC, and PIPC in a population of postoperative NICU patients. The specific goals of this study were fourfold: 1) to describe the frequency and duration of PP, PH, and SSC; 2) to determine the frequency of PP, PH, and SSC during minor acute painful procedures (i.e. heel lance); 3) to assess the relationship between PP, PH, and SSC and illness severity; and 4) to identify parent, infant, and environmental factors that influence PP,

PH, and SSC.

Methods

Design and setting

In light of the exploratory nature of this inquiry we employed a cross-sectional nonexperimental descriptive design as defined by Johnson (17) and LoBiondo-Wood, Haber, & Singh (18). This study was conducted in a level 3b (19) NICU within a pediatric hospital in Canada. In the province where this study was conducted, level 3b NICUs provide the highest level of care; they house the sickest neonates and are the only NICUs with surgical capabilities (19,20). The host institution's NICU was ideal for this study because it cares for both preterm and term surgical neonates. In addition, each of the 20 inpatient beds in this NICU have a room-in design which permits family members to stay overnight, which is essential for facilitating FCC (21–23).

Participants and data collection instruments

This study used a convenience sampling approach in order to maximize the potential sample size. All decisions about eligibility were made in partnership with the health care team for the infants. All infants with a surgical plan of care, either pre or post operatively, currently admitted to the study NICU were considered potentially eligible for inclusion in the study. Any infants with an expected or actual post-operative stay <48 hours were excluded. In order to participate in the study, a parent or legal guardian was required for consent; if the parent or legal guardian was not present, the consent process could also be completed over the phone by the researcher and the parent (or legal guardian) could be sent an electronic copy of the consent form to complete and sign. At the time of enrolment, parents were provided a study binder which contained definitions and pictures of PP, PH (including hand swaddling (24), facilitated tucking (25,26), encircled holding, and clothed breastfeeding), SSC, and a standardized list of painful procedures. A copy of this document is provided in Chapter 3, Appendix O (p. 149-152).

There were four sources of data in this study. Namely:

1. Parent-infant closeness diaries

Parents were asked to keep a parent-infant closeness diary which was created for, and tested in, a series of trials by Raisikla et al. (21). The diaries were created based on the parental Cry and Fuss diary (27) and adapted by the SCENE research group (28) for parents to record the time spent present (PP), time spent holding (PH), and time spent in SSC (all in minutes/day). In order to ensure the validity of this instrument, the aforementioned researchers conducted two pilot studies wherein they i) compared the parents' documentation on the diaries with the nurses' documentation, and ii) compared the parents' documentation on the diaries with simultaneous data collection through a daily text-message survey sent to parents who were completing the diaries (29). They found an overall Kappa correlation of 0.63, with raw agreement of 77% between the nurses' documentation and the parents', and used Kaplan-Meier curves to illustrate parents' adherence to the diaries and their accuracy within and between the two pilot groups (29).

For this study, the diary was used and modified with explicit permission from its authors (see Raisikla et al. 2017). It was modified so that i) parents could also record any painful procedures that occurred during presence, holding, or SSC, ii) translated to French per the host institutions' policy, and iii) to better reflect parents' gender identity(ies). This diary was kept at the infant's bedside and was completed by the parents and designated family members. Families completed the diaries for 14 days, or until discharge/transfer, whichever came first. See Chapter 3, Appendix I (p. 134) for an example of the parent diary.

2. *Chart review*

A chart review provided demographic information on the infant. Items included: infant's date of birth, assigned sex at birth, birthweight, gestational age, date of admission, diagnosis, surgical procedure(s), total length of stay, and outcome, mother's age, and the distance from the parents' primary address to the host institution.

3. *Neonatal Therapeutic Intervention Severity Scale (NTISS) scores*

The NTISS was developed by Gray et al. in 1992 (30) and modified by Ferreira, Curran, and Rosetta in 2014 (31) and is used as a measure of neonatal illness severity. Studies support the NTISS in determining illness severity, intensity of care, and in predicting mortality (32–34). The NTISS consists of eight subscales with points allocated for various interventions and physiologic indicators within each of the subscales. Scores range from zero to 47, with zero indicating no interventions or monitoring. A copy of the NTISS scoring system is provided in Chapter 3, Appendix N (p. 150).

4. *Parent Questionnaires*

An electronic questionnaire was e-mailed to parents and collected information about the key variables PP, PIPC, and the NICU environment (15,35–39). Although many questionnaires exist to measure either parent satisfaction and/or FCC (29,37), none currently in existence measure FCC, SSC, or PIPC for postoperative infants specifically. The questionnaire was completed electronically by parents through the host institution's instance of the Research Electronic Data Capture (REDCap) web-based application (40). A list of the questionnaire's full items is provided in Chapter 3, Appendix K (p. 136-142).

The definitions and photos for parents, as well as all the data collection instruments, were pilot tested for acceptability, readability, and clarity with a subset of parents in the host institution's NICU. Subsequently, the parent questionnaire was modified to include an open comment section and the list of painful procedures was modified to include procedures considered by parents to be distressing, namely suctioning and dressing changes.

Statistical and qualitative analysis

Demographic, dichotomous, and categorical variables are presented as frequencies and percentages. Likert scale results are presented as Mean (SD). Due to a small sample size (n=11),

Median (IQR), Median (range), and nonparametric tests (i.e. Friedman, Wilcoxon signed-rank, Chi-Square, and Fisher's Exact test), were used to analyze the remaining data. All statistical analyses were performed on GraphPad Prism version 8.0 for mac OS (41) and SPSS for MacIntosh version 25 (42).

Qualitative data from the parent questionnaire, accounting for four of 42 questions, were imported into QSR International's NVivo 12 for Mac software (43) for data management. These data were analyzed using qualitative content analysis. Following the methods established by Graneheim and Lundman (44), as individual responses were analyzed, a coding scheme was created. As the coding scheme evolved, earlier responses were re-coded using the final scheme. The codes were then aggregated into representative categories, with them informed broader themes.

Ethics & Role of Funding

Ethical approval was obtained from both the host institution and the University of Ottawa's Research Ethics Boards. Funders had no role in the design, conduct, analysis, or interpretation of the result. The authors had full access to all the de-identified data and the corresponding author had final responsibility for the decision to submit this paper for publication.

Results

Between October 16th 2019 and March 16th 2020, N=11 infants were recruited (Figure 4.1) and a total of 141 days of data collection were recorded. For ten of the infants, both mothers and fathers reported PP, PH, and/or SCC (21 parents recording data on 11 infants) but all except one of the questionnaire respondents were mothers (one survey per infant). Infants' demographic characteristics are presented in Table 4.1. Ten of the infants were assigned male sex at birth, and one was assigned female. Five of the infants underwent a gastrointestinal surgery and three infants underwent a repair of neural tube defects. The mean birthweight was 2282g and mean gestational age was 33 weeks and 6 days. Over half the parents had a university degree (n=7; 64%) and just under half (n=5; 45%) reported a combined family income over \$80,000. Six parents (55%) reported currently being unemployed. The majority of respondents lived at least 30 minutes away from the host institution and had at least one other child at home (n=7; 64%).

Frequency and duration of PP/PH/SSC

Data from the parent-infant diaries for the amount of time mother and/or father were present, holding, and SSC are presented in tables 4.2 and 4.3. As shown, parents were present for a median (IQR) of 440 (256-780) minutes, but only holding for a median (IQR) of 100 (0-178) minutes in total and SSC for a median of 0 minutes over the 14-day period post-operatively; significant differences were found between each of the conditions (PP, PH, and SSC) ($p < 0.001$). Figures 4.2 and 4.3 presents these findings visually. Significant differences were also found between the duration of PP, PH, and SSC between mothers and fathers ($p < 0.001$) (Table 4.3); fathers were present, holding, and doing SSC for significantly less time than mothers. Accordingly, significant differences were also found between the absolute frequency (occurrences) of PP, PH, and SSC between mothers and fathers ($p < 0.001$) (Table 4.4). Not only

did fathers spend less *time* present, holding, and SSC than mothers, they also had fewer *occurrences* of presence, holding, and SSC with their infant

Figure 4.1- Participant Flow

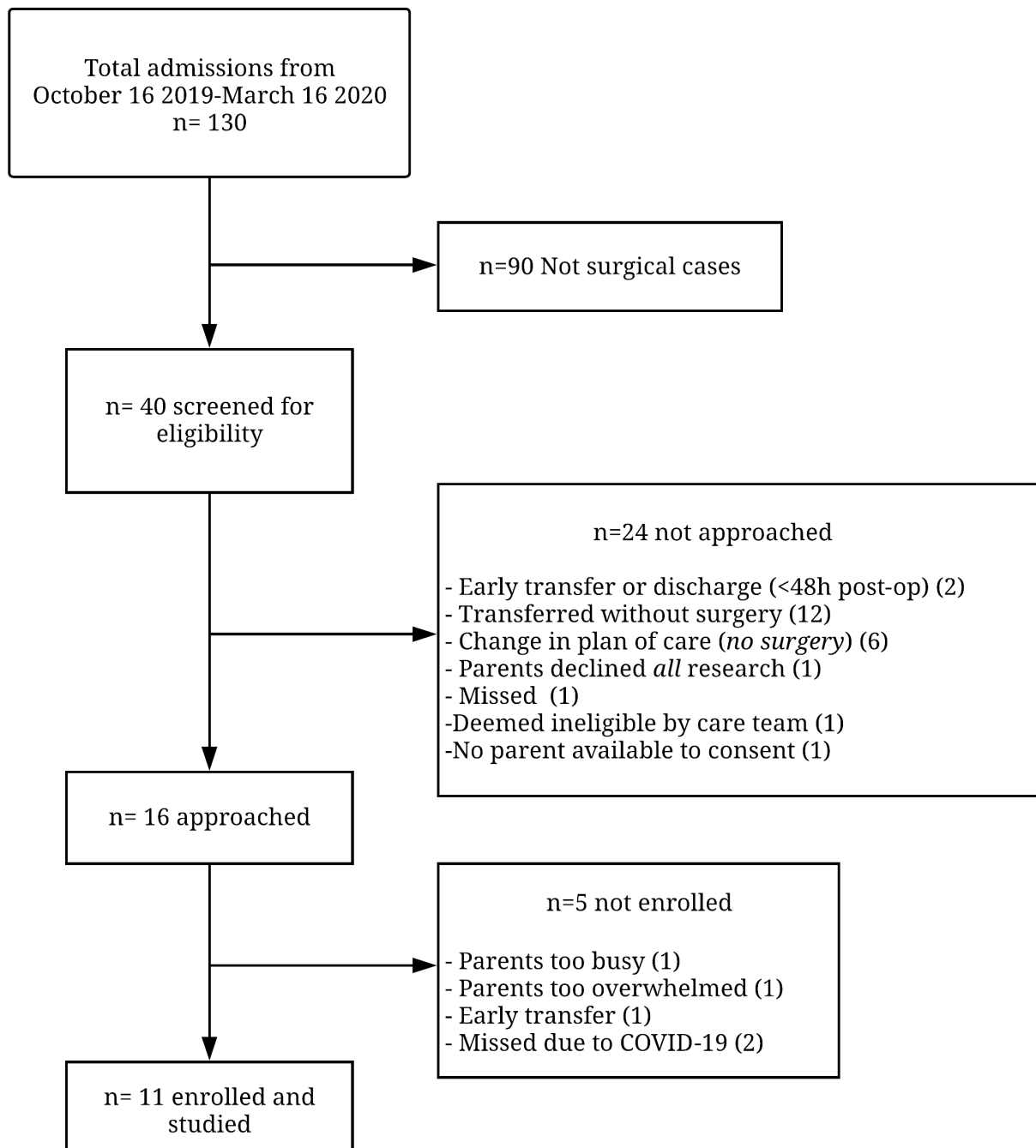
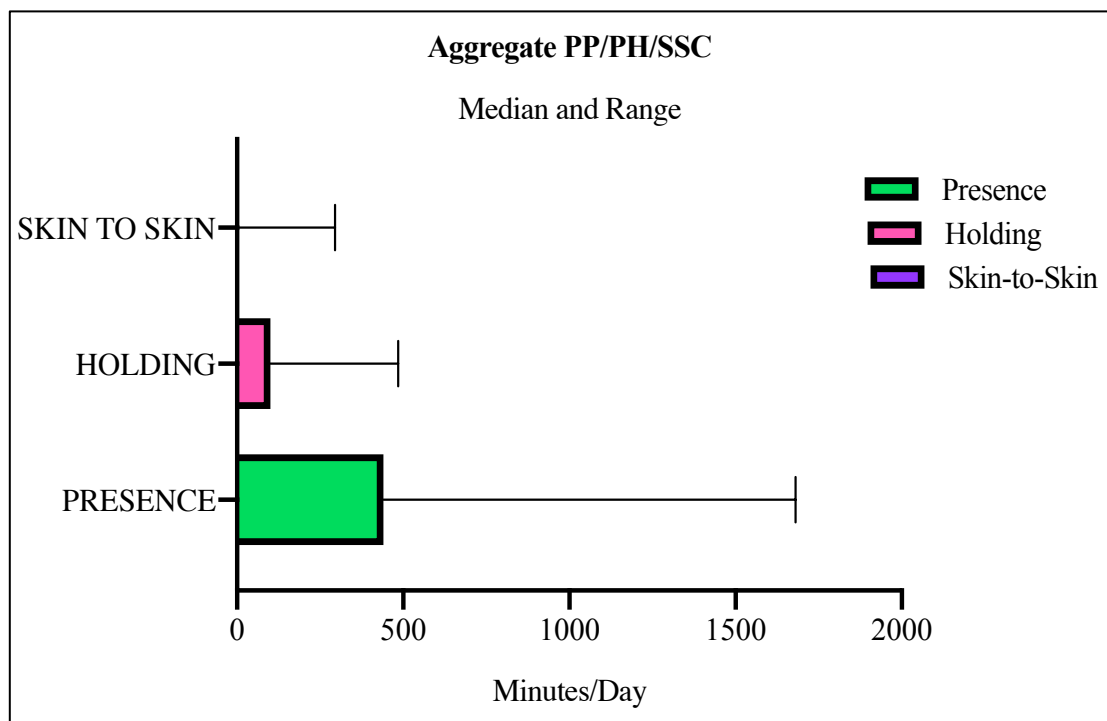


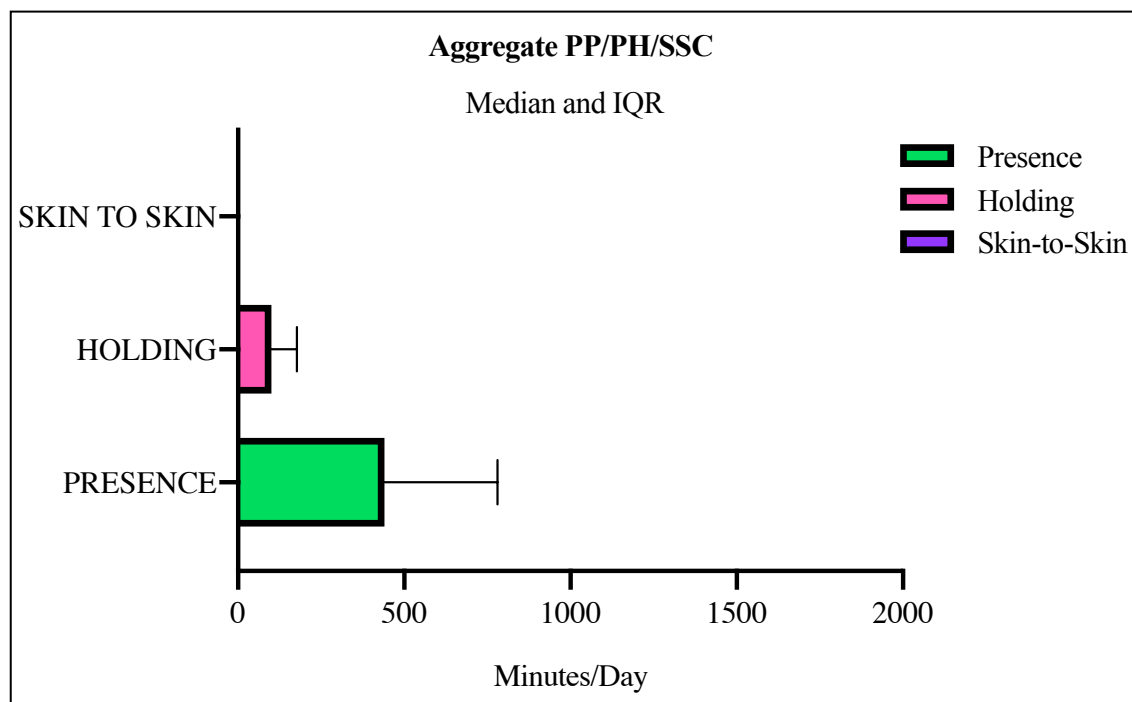
Table 4.1*Infant and family demographics (N=11)*

	n	%
Assigned sex at birth		
Male	10	91%
Female	1	9%
Reason for admission		
Tracheoesophageal Fistula (TEF)	3	27%
Neural tube defect	3	27%
Necrotizing Enterocolitis (NEC)	2	18%
Congenital bowel obstruction	1	9%
Hernia	1	9%
Hydrocephalus	1	9%
Infant's total length of stay (in days)		
0-14	1	9%
15-30	4	36%
31-60	2	18%
61-120	0	0%
>121	4	36%
Type of surgery during study period		
TEF repair- transesophageal	1	9%
Colostomy/Ileostomy	3	27%
Inguinal Hernia repair	1	9%
Omphalocele closure	2	18%
Myelomeningocele closure	1	9%
G-tube insertion	2	18%
Ventricular shunt	1	9%
Number of surgeries during admission		
1	4	36%
2	2	18%
3	1	9%
4 or more†	4	36%
Infant's outcome		
Discharged home	3	27%
Transferred to another unit	5	45%
Still admitted at time of study close†	3	27%
	Mean (Range)	Median (IQR)
Birthweight (in grams)	2282 (620-3400)	2560 (1320-3131)
Gestational age at birth (in weeks ^{+days})	33 ⁺⁶ (25 ⁺² – 38 ⁺⁵)	35 ⁺¹ (30 ⁺³ – 37 ⁺⁵)
Mother's age (in years)	27.82 (16-35)	30 (25-32)
Distance from primary residence to CHEO host institution (in Km)	253.25 (10-2445)	38 (20-52)
	n	%
Relationship of person completing questionnaire to infant		
Mother	10	91%
Father	1	9%

Language used to complete the study		
English	9	73%
French	2	18%
Gestation		
Singleton	9	82%
Multiple	2	18%
Highest level of education completed		
Some High School	3	27%
High School Diploma	0	0%
Some university	1	9%
Completed university degree	7	64%
How many other children live in the home		
0	4	36%
1	5	45%
2	1	9%
3	1	9%
Where are you staying while your baby is hospitalized?		
At home	10	91%
At a family member's	0	0%
Hotel	0	0%
Ronald McDonald House	0	0%
In the NICU	1	9%
How long does it take you to get to CHEO to come visit your baby? (in minutes)		
1-15	1	9%
16-30	3	27%
31-45	3	27%
46-60	4	36%
Are you currently employed?		
Yes	5	45%
No	6	55%
If yes, which of the following best describes your current working situation?		
Working full-time	2	18%
Working part-time	0	0%
On parental leave	3	27%
What is your approximate family household income per year?		
≤ \$40,000	2	18%
\$40,000-\$65,000	2	18%
\$65,000-\$80,000	2	18%
≥\$80,000	5	45%
Prefer not to answer	0	0%

Figure 4.2 - Cumulative PP/PH/SSC during study period presented as median and range

Note: Cumulative time reflects the sum of time that mothers and fathers spent present.

Figure 4.3 - Cumulative PP/PH/SSC during study period presented as median and IQR

Note: Cumulative time reflects the sum of time that mothers and fathers spent present.

Frequency of PP/PH/SSC during painful procedures

Parents recorded a total of 27 painful procedures. Despite being present for over half of these procedures (n=17; 62%), they were infrequently holding (n=5, 19%) and rarely SSC (n=2, 7%). On three instances (11%), parents (mother and father were both present in all three instances) were asked to leave the unit during the procedure. With respect to mothers and fathers, no significant differences were found between PP and PH during painful procedures (p value set at 0.05). Skin-to-Skin was excluded from the analysis due to a cell value of zero for fathers doing SSC during painful procedures. These data are presented in Table 4.5.

Relationship between NTISS and PP/PH/SSC

The median NTISS score was 12 (IQR: 8-18; range: 4-36), which corresponds to the infant being “mildly ill, still at small risk” (30). Spearman’s Rho was used to calculate the correlation coefficient between the NTISS score and PP, PH, and SSC due to a non-normal distribution and a small sample size. Using Cohen’s criteria (45), a moderate negative correlation was identified between NTISS score, PP ($r = -0.36$) and PH ($r = -0.4$). A small negative correlation was identified between NTISS score and SSC (-0.3). All were significant at $p < 0.001$. These correlations are interpreted to mean that as the NTISS score (illness severity) increases, parents were less likely to be present. Among parents who were present, as the NTISS score increased, they were less likely to hold and even less likely to do SSC. The strongest association was found between PH and NTISS which suggests as the infant becomes more ill and requires more interventions, parents are less involved in the care, despite their presence at the bedside.

Parent questionnaire

Tables 4.6-4.8 present the full questionnaire items with means and standard deviations (SD) for each of the Likert scale questions and proportions for dichotomous items.

Referring to tables 4.6-4.8, in terms of knowledge and education, all 11 parents reported getting most of their information about *caring* for their baby from the nurses, and the information about their baby’s diagnosis and plan of care from the physicians. Despite this, parents responded variably with respect to receiving education from nurses about how to care for their infant (3.64 (1.29)) and feeling like an equal member of the team (3.63(1.03)). Parents reported feeling generally supported to care for their infant (4.18(0.87)) and agree that the staff supported parent-infant closeness (4.27(1)). However, there was significant variation in regards to having a clear understanding of how to be involved in their baby’s care (3.54 (1.29)), feeling supported in coping with stress (3.81(1.17)), and feeling that their cultural practices are respected (3.81(1.08)). Parents also had lower mean responses with respect to being aware of procedures (3.54 (0.96)) and knowing how to help care for their infant during painful procedures (3.54(0.93)).

With respect to the NICU room design, four parents (36%) reported that there was no bed for them to stay overnight with their infant, which is in contrast to the host institutions’ information regarding beds and places for parents to sleep (23). There was also significant variation in parents’ responses in regards to having enough privacy (3.9(1.14)) and having unrestricted

access to their infant (4 (1.41)). Additionally, there was significant variation on all items related to being oriented to the units' routines and resources.

Parents' written responses to the open-ended questions were coded, sorted into categories and summarized in three broad themes: i) barriers and ii) facilitators to FCC and iii) suggestions for improvement. Facilitators include resources available to/for parents, shifting from nurse as provider to nurse as supportive educator, and parents as equal partners in care. Barriers include a lack of holistic care for the family, challenges with the NICU design and environment, and not welcoming parents as partners. Suggestions included a thorough orientation for all parents including unit routines, resources, and salient practices (such as when parents are allowed to hold). Although unprompted, most parents mentioned breastfeeding and/or the importance of being able to supply their milk for their infant. They suggested more consistent reminders about pumping and the assistance of a lactation consultant.

A summary of codes, categories, and themes with illustrative quotes is presented in Supplementary File 3.

Table 4.2

Comparison of cumulative duration of PP/PH/SSC

	Minutes/day			
	Mean (SD)	Median (IQR)	Median (range)	p-value [†]
Parental Presence (PP)	527 (351)	440 (256-780)	440 (0-1680)	<0.001
Parental Holding (PH)	119 (114)	100 (0-178)	100 (0-485)	<0.001
Skin-to-Skin (SSC)	14 (41)	0 (0-0)	0 (0-295)	<0.001

[†] Friedman's test indicated a significant difference between all groups (Dunn procedure).

Table 4.3*Comparison of duration of maternal/paternal PP/PH/SSC in minutes/day*

	Minutes/day		
	Mother	Father	p-value [‡]
Parental Presence (PP)			
Mean (SD)	320 (261)	177 (177)	<0.001
Median (IQR)	300 (150-430)	150 (0-300)	
Median (range)	300 (0-1440)	150 (0-840)	
Parental Holding (PH)			
Mean (SD)	78 (93)	34 (49)	<0.001
Median (IQR)	60 (0-110)	0 (0-60)	
Median (range)	60 (0-485)	0 (0-215)	
Skin to Skin (SSC)			
Mean (SD)	14 (41)	0 (1.3)	<0.001
Median (IQR)	0 (0-0)	0 (0-0)	
Median (range)	0 (0-295)	0 (0-15)	

[‡]Wilcoxon signed-rank test used to evaluate difference between Mothers and Fathers PP/PH/SSC**Table 4.4***Comparison of occurrences of PP/PH/SSC between mothers and fathers (N=141 days)*

	Not present	Present	Holding	Skin to Skin
Mother	14 (10%)	127 (90%)	94 (66%)	23 (16%)
Father	46 (33%)	95 (67%)	64 (45%)	1 (0.7%)

[‡]Chi-Square P value <0.001**Table 4.5***Total painful procedures recorded by parents and instances of PP/PH/SSC by parent*

	Presence	Holding	Skin-to-skin
Mother	17 (55%)	4 (13%)	2 (6%)
Father	6 (19%)	2 (6%)	0
Total	23 [†]	6*	2

[†]Parents recorded n=4 procedures for which both mother and father were present

*Parents recorded n=1 procedure for which mother and father took turns holding

[‡]Fisher's exact test showed no significant differences between groups (SSC excluded from analysis due to a cell value of zero for fathers doing SSC during a painful procedure)

Table 4.6

Parent Survey (N=11): Likert items to evaluate parents' perceptions of the NICU environment, communication, education, and nurse-family relationship.

Likert items were: 1- Strongly disagree, 2- disagree, 3-Neither agree not disagree, 4-Agree, 5-Strongly

Survey item	Mean (SD)	Survey item	Mean (SD)
I feel supported to care for my infant	4.18 (0.87)	I participate in parenting activities with my infant (such as changing diapers, bathing).	4.27 (0.9)
I am able to stay overnight with my infant	3.9 (0.83)	I have a clear understanding of the things I can do to be involved in my baby's care.	3.54 (1.29)
I am encouraged to help feed my infant	4.27 (0.9)	The nurses encourage me to hold my baby.	4.09 (0.7)
I feel that the NICU staff are supportive of my cultural practices	3.81 (1.08)	The nurses offer open and honest communication.	4.09 (0.83)
Despite the nurse being busy, sufficient attention is paid to us	4 (0.89)	The nurses provide consistent messages about my baby's care and my involvement.	4 (1)
I/we have unrestricted access to my/our infant	4 (1.41)	The nurses give me information about pain and how to help my baby with pain during painful procedures (i.e. heel pokes, bloodwork).	3.54 (0.93)
There is sufficient privacy for me and my family in the room where my infant is being cared for.	3.9 (1.14)	The nurses encourage me to participate in my infant's care.	4 (0.89)
Generally, I would say that the staff support parent infant closeness.	4.27(1)	The nurses teach me about how to care for my baby.	3.64 (1.29)
I am aware of unit resources for parent support (e.g. parent support groups, social workers).	3.54(1.21)	The nurses help me cope with the stress of having a baby in the NICU.	3.81 (1.17)
I am aware of hospital resources for parents (e.g. multi-faith room, cafeteria).	3.36 (1.69)	In general, I would say that I have enough information to participate equally in my infant's care.	4 (0.77)
I am aware when my baby will undergo a procedure (such as bloodwork).	3.81 (0.98)	In general, I feel that my input about my baby is valued (e.g. their condition, their care)	4.09 (0.83)
I was oriented to the unit when my infant was admitted.	3.4 (1.35)	In general, I feel like I am an equal member of my baby's care team.	3.63 (1.03)

Table 4.7*Parent survey: Source of education/knowledge (N=11)*

Survey item	n	%
Where do you get most of your information about your baby? (e.g. diagnosis, medical care, etc.) [Select all that apply]		
Social media	2	18%
Online (Wikipedia, Web MD)	5	45%
Books	0	0%
Family	2	18%
Nurses	7	64%
Doctors	11	100%
Where do you get most of your information about caring for your baby in the NICU? [Select all that apply]		
Social media	0	0%
Online (Wikipedia, web MD)	1	9%
Books	1	9%
Family	2	18%
Nurses	11	100%
Doctors	7	64%

Table 4.8*Parent survey: Dichotomous items to assess parents' perceptions of the NICU room design. (N=11)*

Survey item	n	%
The room where my infant is being cared for has a window:		
Yes	6	55%
No	5	45%
The room where my infant is being cared for has a bed for me:		
Yes	7	64%
No	4	36%
The room where my infant is being cared for has a reclining chair for me:		
Yes	11	100%
No	0	0%

Discussion

This was the first study to explore PP, PH, SSC, and PIPC for post-surgical infants in a NICU. Our findings provide new insights into the needs of this understudied population that have important implications for further research.

Safety of parental holding and skin-to-skin care

Five of the infants underwent a gastrointestinal surgery and three infants underwent a repair of neural tube defects; these surgeries carry unique implications for positioning (i.e. supine positioning and limiting movement, and prone positioning respectively) and therefore impacting parents' ability to hold or do SSC. Harrison and Ludington-Hoe (46) presented a case study of an 18-day-old infant recovering from critical congenital cardiac surgery who was safely held SSC for 65 minutes. The infant's heart rate was significantly lower while being held SSC and their oxygen saturation was significantly higher. In a trial of 24 intubated infants under the age of six months, Ortmann and Dey (47) concluded that parental holding is safe and does not result in an increase in adverse events. Although these findings are promising, neither study was conducted in an NICU. Our findings showed a significant negative correlation between the infant's severity of illness and the time spent holding or SSC, which suggests that despite the safety of the interventions, challenges remain with respect to balancing the complex medico-surgical needs of these infants with their developmental and attachment needs. Additionally, parents reported that surgical devices such as gastric tubes and infant positioning (i.e. prone for neural tube defects) impeded their ability to hold or touch their infant. This is consistent with prior research (11,13,48) and further supports the relationship between the infant's severity of illness and the opportunities allowed for parents to be involved in their baby's care.

Skin-to-skin care

In the unit where this study was conducted, it is standard practice for images and education about SSC (or kangaroo care) to be posted in each room and on the wall near the nursing station. Nurses are prompted to enter the time infants spend SSC by both their worksheet and the electronic documentation system. In addition, parent orientation booklets included information on the importance of SSC. Despite this, our study showed that most of the post-operative infants in this sample received no SSC and those that do only received short durations. According to existing FCC recommendations for NICU infants, it is strongly recommended that they should be held SSC "for prolonged periods" (24) and a minimum of "6 hours a week for 8 weeks" to achieve improved neurodevelopmental outcomes (15). Therefore, our results suggest that there may be a knowledge-to-practice gap with respect to SSC for surgical infants.

A recent development in FCC for NICUs is the FiCare (family integrated care) model (49). In the FiCare model, parents are considered the infant's primary caregiver and must accordingly agree to be present for a minimum of 6 hours (360 minutes) per day with their infant (50). In our sample, the median daily parental presence for mothers was 300 minutes (5 hours) and for the 10 fathers, a median of 150 minutes (2 hours and 30 minutes). These all fall below the required 360 minutes (6 hours) in the FiCare model, which is clinically significant given the aforementioned guidelines. However, our study supports that it is important to consider that not all parents are

able to, or desire this level of involvement (51), nor do they all have the resources to make such a commitment without financial or child-care support. For example, in our parent questionnaire, parents identified child care and the cost of parking as barriers to their presence at the bedside (see Supplementary File 3). The differences between mothers and fathers is consistent with existing literature (39,52–54). Despite this, Blomqvist et al. reported that when fathers are involved in SSC, the infant receives more SSC overall during their hospital stay (55), which supports the need to further explore factors that contribute to, or influence, paternal presence and involvement in the NICU.

Parent involvement in pain care

It is well documented in the literature that hospitalized infants undergo many medically-necessary acute painful procedures (such as a heel lance or venipuncture) during their hospitalization (56). In our sample, three infants had no painful procedures recorded in their parent diaries and, for the remaining 8 infants, parents only recorded 27 such procedures. Therefore, it is reasonable to assume that most painful procedures occurred when parents were not present. Govindaswamy et al (13) identified that the greatest stressors for parents of infants requiring surgery is parental role alteration and their infant's pain. She advocates for the need to involve parents in their infant's pain management and to support parents with individualized FCC to assist parents in caring for, and bonding with, their baby. This is supported by prior work which identified similar concerns for parents of non-surgical infants (57–60). A recent meta-synthesis of seven studies by McNair et al. (61) strongly supports our finding that parents still experience challenges with respect to being involved in their infant's pain management. McNair et al. (61) identified that parents require knowledge and education, and that the physical environment of the NICU impeded their ability to participate in care (61). Additionally, McNair et al. (61) identified stress and anxiety for *both* parents and HCPs; this can result in HCPs "gatekeeping" parents' participation and further limiting their participation (61). In our sample, parents recorded three occasions on which they were asked to leave the room, which, in conjunction with the likely underreporting of painful procedures on the parent diaries, suggests that gatekeeping may be increasingly present in complex environment such as a surgical NICU.

It is acknowledged in the literature that there is a need for the development of tools to properly assess and treat *chronic prolonged* pain in neonates- such as that experienced after surgery (62). Given that parents of surgical infants experience increased stress compared to parents of non-surgical infants (11), and given the robust evidence base supporting SSC, it is reasonable to state that this should be further explored as a modality of managing and minimizing the unique pain experience of surgical infants. Despite this, parents only reported 2 instances (7% of total 27 reported painful procedures) of SSC during a painful procedure. This further supports knowledge-to-practice gaps with respect to both SSC and overall PIPC for parents of postoperative neonates.

Parental satisfaction with family-centered-care

Our parent questionnaire identified that parents were satisfied overall by the care their infant received, but there was significant variation on many of the questionnaire items suggesting that each family has a unique and different experience during their infant's NICU hospitalization. In

particular, parents disagreed about respect for cultural practices, receiving support and education to help care for their infant, and the NICU environment. Many parents also reported that they did not have enough privacy, and four parents reported that there was no bed for them to stay overnight. The parents' perceptions of the unit and room design are especially interesting because the NICU where this study was conducted was designed following single-family room recommendations (63); the fact that the parents' *perception* conflicts with the institution's information should be further investigated in order to tailor the NICU environment to meet family and infant developmental needs. Parents largely agreed that they were unaware of unit and hospital resources and recommended the implementation of a unit orientation upon admission. Once again, this perception differs from the purported unit practice of orienting each family on admission and providing them with an information package. Our parent questionnaire results reflect the findings of Butt et al. (64); although parents are satisfied overall, there were particular aspects of FCC that were lacking and did not meet the parents' needs. This supports the importance of the parent perspective as it offers insights not considered by institutions and HCPs.

Implications for future research

Our results support many of the challenges with FCC that have been reported in the literature. For example, Benzies et al. (65) found that the healthcare system was making "too much noise" to allow for FCC. This means that unit routines, workload, lack of training for nurses, and the changing medical needs of the infants all hinder the implementation of FCC practices. There is a growing perspective that FCC is too idealistic and impractical to implement (5,66,67). This suggests that there is an impasse between endorsing FCC principles and embracing FCC as a philosophy that underpins all care (65). In light of these challenges, certain developments have sought to replace PP and SSC by technological interventions, such as robots, that are meant to "mimic" contact with parents (68). Interventions such as these have the potential to further undermine the importance of the parental role in an increasingly technological healthcare context (69). Therefore, rather than seeking technological solutions, it is imperative to explore factors influencing PP in order to allow parents their rightful place at the bedside (70).

Limitations

Several important limitations must be discussed. Chiefly, recruitment was challenging in light of the small potential sample size. From October 2019 to March 2020 only 16 families were approached. To compound this issue, although data collection was planned to continue until April 16th 2020 with the plan to recruit a larger sample, recruitment was stopped due to COVID-19 and instructions from the institution's ethics committee to cease all non-essential clinical research. Additionally, the unit where this study was conducted does not perform invasive cardiac surgeries, which further limits the potential sample size. Lastly, due to limitations surrounding the availability of beds, some infants were transferred to other hospital wards before their surgeries or immediately following.

Conclusion

In our study sample, mothers and fathers spent on average less than six hours present in the NICU, and very little time holding their infants. There was a negative correlation between the infant's severity of illness (NTISS) and the time parents spent present, holding, or SSC. Given that post-operative neonates are an understudied population, these findings highlight that there is a need to explore parent participation in the care of medically fragile post-operative infants (11,13). Our findings also suggest that parent perspectives may help in the identification of salient barriers and facilitators of PP, PH, SCC, PIPC, and FCC in this population. Further research should work towards the development of guidelines for safe holding and SSC in the population of post-operative neonates.

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Supplementary File 3.

Data dictionary: Open answer questions from the parent surveys

Table 4.9*Facilitators to Family-Centered Care*

Theme	Facilitators to Family-Centered Care				
Category	<i>Resources available for/to parents</i>		<i>Shifting from nurse as provider to nurse as supportive educator</i>		<i>Parents as equal partners</i>
Sub-category	Resources for parents	Families' resources	Nurse-family relationship	Education for parents	
Codes	-Family Room/Ronald McDonald room -Pastoral care, cafeteria, café, education sessions	- Care for other children	- Support and encouragement from nurses - Lactation support	- Knowledge translation - Modeling/role modeling - Education from nurses	- Working together - Parent participation in rounds - Open communication - Access card

Table 4.10*Barriers to Family-Centered Care*

Theme	Barriers to Family-Centered Care						
Category	Taking care of families/Holistic care of family				NICU Environment	Not welcoming parents as partners	
Sub-category	Resources for parents	Family factors	Unit factors			Nurse-family relationship	Challenges with communication
Codes	- No food for parents - Lack of accommodations - Unaware of hospital resources (parent room, pastoral services)	- Cost of parking - Travel time - Other children at home	- No orientation to unit - Unaware of unit routine - Only one access card - Limitations on visitors	- No care for Postpartum mothers - No Lactation Consultant-issues with milk supply	- Bright lights/loud noises - Lack of privacy - Not enough space/chairs - Heavy workload of nurses and physicians	- Feelings of helplessness - Lack of education - Lack of support/encouragement - Feelings of exclusion	- Inconsistent communication - Lack of communication

Table 4.11*Illustrative quotes*

Facilitators	Resources available to/for parents	Resources for parents	“The Ronald McDonald room was a nice place to have a snack and take a shower. The fact that it was so close to the NICU was great.” (P006)
		Parents’ resources	“Being able to have care for my other children.” (P010)
	Shifting from nurse as provider to nurse as supportive educator	Nurse-family relationship	“Getting an update about the baby when we come in everyday.” (P008) “The nurses always stressed that we could call anytime to check in on baby.” (P001) “I also really appreciated the breastfeeding support and pumping equipment provided, as this allowed me to provide breast milk for baby when she was unable to nurse, and then provided me the best opportunity to establish breastfeeding once she was allowed to feed orally” (P001)
		Education for parents	“Support and guidance from the nurses helped us to care for baby. They showed us what we could do to help throughout the stages of baby’s recovery from surgery (ex. When it was safe for us to participate in skin to skin, or when we could not pick baby up they showed us how we could lay our hands on her to help comfort, etc).” (P001)
	Parents as equal partners		“Being able to hold the baby, change the baby, being taught how to care for the baby, support for pumping breast milk and establishing milk supply.” (P008) “It helps me when I know the plan for my baby’s care the following day and how he was during the time I was gone. I get information from the doctors about his care, I ask questions and ask them to explain things to me so I understand.” (P005)
Barriers	Taking care of families	Resources for parents	“To have nutritious meals provided to the breastfeeding moms would be helpful. With everything happening, it is easy to forget to eat, which is bad for the milk supply.” (P006) “Didn’t even know about the family room until another patient told me about it” (P007)
		Family factors	“Having a completely private room we’re all family could come and go freely, cheaper parking and closer commute to the hospital!” (P009) “Having another child at home creates challenges as we would like to always be present to care for baby in the NICU, but also must ensure our child at home is cared for as well.” (P001)
		Unit factors	“More guidance initially when first visiting NICU, perhaps a pamphlet/booklet on how NICU works (e.g. When are rounds, shift changes, pumping/feeding and milk supply, bath times, visiting hours, with a notes section to record relevant baby specific info).” (P008) “We only get one pass in and out of NICU makes it difficult to coordinate [...]. Would be nice if both parents had passes.” (P008) “It took a while to find help on establishing milk supply (no lactation consultant on staff).” (P008) “The difficulty to apply proper postpartum personal care while staying at the hospital (e.g. not having the possibility to take seat baths). I have lost my peri bottle after just two days; I asked if I could have another one, but the NICU does not carry this. So, even though, I felt great when I was discharged from the hospital after giving birth, I had a setback in the NICU.” (P006)
	NICU environment		“The lack of space for the parents in the room. The uncomfortable chair/bed. Over night, the constant alarms going off, the chatting of the nurses, the bright lights” (P006)

	Not welcoming parents as partners	Nurse-family relationship	“Aucune information mes transmit on me montre pas grand chose et ont m'encourage pas non plus” (P011) “Not clear direction on how to care for infant, or what we are allowed to do and touch.” (P007) “Although we understand that the breathing tube and chest tube were essential for baby's recovery, these made it difficult for us to participate in baby's care.” (P001) “We had one nurse that really wasn't happy, and didn't like that we wanted to continue our son's life on because she thought he would be better off passing.” (P002)
		Communication challenges	“Sometime support and advice is inconsistent between nurses. Sometimes it's lack of knowledge about how to help. Sometimes medical terms are used that we don't understand (had to learn overtime).” (P008)
Suggestions	“The following items were also helpful/would be helpful if they happened more often: when we got early and specific prompts from the nurses doctors asking about milk supply/pumping, nurses automatically giving updates when we visit, nurses suggesting good times to hold him when they give updates on the baby.” (P008) “More guidance and orientation to unit practices. What can I do? (touch, hold, put clothes on baby), what are the unit protocols? (rounds, shift changes, visiting hours, role of volunteers).” (P007)		

CHAPTER 5

Integrated Discussion

5.1 Introduction

Despite the longstanding history of FCC in pediatric health care, and extensive academic literature supporting its use, there remain challenges with its implementation in practice (Coyne, 2015; MacKean et al., 2005; Petersen et al., 2004; Skene et al., 2016). In addition, most of the existing literature pertains to premature and extremely premature infants (Govindaswamy et al., 2019b, 2019a; Shields et al., 2012). Given this, the purpose of this thesis was to clarify the meaning of FCC in the NICU and explore its operationalization with an understudied population, namely post-surgical infants. In this chapter, I will briefly discuss the main findings from both the literature review and concept analysis (Chapter 2), and the descriptive exploratory study (Chapter 4). In order to situate these results and this thesis within the existing literature, I will then provide an integrated discussion falling broadly under the headings of i) knowledge-to-practice gaps, ii) taking care of families and iii) philosophical and conceptual tensions. Thereafter I will discuss implications for nursing practice, education, future research, and leadership and policy development. Finally, I will discuss strengths and limitations of this thesis and provide concluding remarks.

5.2 Summary of Findings

5.2.1 First Manuscript: Literature review and concept analysis

In order to explore the contradiction between the evidence supporting FCC and the challenges with its implementation in practice, I first conducted a literature review and concept to clarify the concept of FCC in the NICU setting in particular. Following Rodger's Evolutionary concept analysis, as detailed by Toftthagen & Fagerstrøm (2010), the concept of FCC in the NICU was defined in terms of its antecedents, attributes, and consequences.

Three databases representing different disciplines were searched, namely CINAHL, MEDLINE, and PsychINFO. A total of 188 articles were included covering a broad range of disciplines (e.g. medicine, nursing, psychology, social work, etc.), article types (e.g. reviews, quality improvement projects, research projects, commentaries, etc.), and year and country of publication. The first related terms to emerge were individualized and developmental care/developmentally-sensitive FCC (Aita & Snider, 2003; Nyqvist & Karlsson, 1997). In this approach to FCC, care is tailored to the neurobehavioral needs of each infant and parental stress/role alteration (Lester et al., 2011; Obeidat et al., 2009). After its appearance in the literature, the concept of developmentally-sensitive FCC became synonymous with the concept of FCC in the NICU context. Recently, the Family-Integrated Care model (FiCare), which emphasizes parental presence and shifts most, if not all, aspects of caring for the infant to the parents (Jiang et al., 2014; O'Brien et al., 2015), has become prominent in the literature. This represents a significant conceptual departure from the concept of FCC in the NICU or developmentally-sensitive FCC due to its enhanced focus on parental presence. In addition to the antecedents, attributes, and consequences presented in Chapter 2, Figure 2.2. (p. 39), four aspects of FCC in the NICU were extensively discussed in the reviewed literature, namely i) family presence at rounds (e.g. Nichols et al., 2015), ii) single-family rooms (e.g. Erdevi et al., 2008), iii) SSC (e.g. Benoit & Semenic, 2014), and iv) pain management (e.g. Harrison et al., 2015).

This review supports that FCC is a philosophy of care rather than a model; therefore, it is necessary to adapt it to various settings in order to implement its tenets. Thus, FCC in the NICU and FCC in other settings are conceptually different and have unique antecedents and attributes. For the population of sick infants and their families in the NICU, individualized and

developmentally-sensitive care, and the reciprocal need for physical and emotional closeness, are particularly important and unique considerations.

5.2.2 Second Manuscript: Descriptive exploratory study

Due to the aforementioned paucity of research pertaining to surgical infants in the NICU, the cross-sectional descriptive exploratory study of this thesis (Chapter 4) sought to explore and describe the current state of FCC in a surgical NICU. Accordingly, based on the results from the literature review and concept analysis, I delineated the conceptual model in Chapter 1 (Figure 1.1, p. 12) to guide identification of key variables.

There were four primary outcomes in this study, namely: i) to describe the frequency and duration of PP, PH, and SSC in a surgical NICU, ii) to determine the frequency of PP, PH, and SSC during minor acute painful procedures (i.e. heel lance), iii) to assess the relationship between PP, PH, and SSC and illness severity, and iv) to identify parent, infant, and environmental factors that influence PP, PH, and SSC for post-operative neonates admitted to a surgical NICU. Data were collected from parent diaries, a parent survey, a chart review, and daily NTISS scores. Quantitative data were analyzed using descriptive statistics and nonparametric tests, and qualitative data were analyzed using content analysis (Graneheim & Lundman, 2004).

A total of 11 parents participated in the study. The results showed significant differences between the amount of time (duration) parents spent present, holding, or SSC. In addition, fathers spent significantly less time present, holding, and SCC than mothers. Parents rarely held or did SSC during painful procedures and, at times, were asked to leave the room or unit completely. Of note, parents spent a median of zero minutes SSC with their infant. We identified moderate correlations between the infant's illness severity (as measured by the NTISS) and the

amount of time parents spent present, holding, or SSC. We found that the sicker the infant, the less time parents spent present, holding, or SSC. The parent survey identified mean scores of less than 4.0 and significant variability ($SD > 0.9$) with respect to perceptions on the provision of education on how to care for their infant, respect for their cultural practices, feeling like an equal member of the team, and being aware of how they can help during painful procedures. Parents also identified not feeling supported holistically, challenges with the NICU's physical environment, and not feeling welcomed as partners. They suggested the implementation of a thorough orientation for all parents and families on admission.

In sum, the findings of this study support many of the challenges with FCC identified in the literature. Given the unique challenges of caring for medically fragile post-operative infants, these findings also highlight the need to further explore PP, PH, SSC, and PIPC for post-surgical infants hospitalized in a NICU.

5.3 Integrated Discussion

Considering these findings and this thesis in their entirety, key considerations will be discussed under the following headings: i) knowledge-to-practice gaps, ii) taking care of families, and iii) philosophical and conceptual tensions.

5.3.1 Knowledge-to-Practice Gaps

As discussed throughout this thesis, the existing literature highlights various challenges with the implementation of FCC in NICUs. While the principles and elements of FCC are extensively discussed and ubiquitously upheld by institutions and stakeholders, their incorporation in practice remains equivocal (Coyne, 2015; Shields, 2017; Smith, 2018; Watts et al., 2014). Through the conduct of this thesis, several key knowledge-to-practice gaps relevant to the provision of FCC in the NICU were identified. These gaps will be discussed according to the

diagram presented in Chapter 1 (Figure 1, p.12), namely in terms of SSC, PIPC, and the NICU environment.

5.3.1.1 Skin-to-Skin Care.

As discussed in Chapter 2, the provision of FCC in the NICU must be developmentally-sensitive. The concept of developmentally-sensitive care stems from Als's (1982) Synactive Theory of Development wherein the infant's environment is modified in order to create stability, or competence, in their various subsystems, such as self-regulation and autonomic functioning (Byers et al., 2006; Macho, 2017; Westrup, 2007). Several important and influential models of NICU care have further emphasized the importance of developmentally-sensitive care for the neurocognitive development of the infant. The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) was developed by Als et al. (1986) and highlights the need to individualize care to each infants' needs. This early intervention program focuses on naturalistic observations of infants in order to gauge their reaction to various stimuli and make appropriate adjustments (Westrup, 2007). The emphasis on neuroprotection and individualized care is further refined in the Neonatal Integrative Developmental Care model (IDC) which outlines seven core measures for the provision of neuroprotective and developmentally-sensitive FCC for neonates (Altimier & Phillips, 2016). In the IDC, SSC is considered the most important aspect for providing developmentally-sensitive FCC in the NICU as it supports all seven core measures (Altimier & Phillips, 2016). There is a robust evidence base supporting not only the multitude of benefits of SSC for both infants and their mothers/families (Holmes et al., 2016; Oras et al., 2016), but also its critical importance for bonding, attachment, and family formation (Flacking et al., 2012; Johnson, 2007; Raiskila et al., 2017). In light of this, the World Health Organization (WHO) has endorsed and encourages kangaroo mother care (KMC), which is the practice of

early and prolonged periods of SSC between mother and infant, ranging from a few hours a day to 24 hours a day (Cattaneo et al., 2018; Chan et al., 2016; Blomqvist & Nyqvist, 2011). The NIDCAP program recommends that infants be held SSC for “prolonged periods” (Smith et al., 2015, p.11) and the IDC recommends a minimum of “6 hours a week for 8 weeks” to achieve improved neurodevelopmental outcomes (Altimier & Phillips, 2016, p.232).

The aforementioned recommendations are in contrast to the findings of our descriptive exploratory study. As presented in Chapter 4 (tables 4.2-4.4, p. 173-174), the infants in our study received a median of zero minutes of SSC per day (mean of 14 minutes/day). We also found that despite being present, parents spent significantly less time holding and, despite holding, they spent significantly less time SSC. There was only reported instance of a father holding their infant SSC and this was for 15 minutes. As mentioned, this self-report data can likely be considered accurate as research supports that parent reports of SSC are more accurate than nurse documentation of SCC (Blomqvist & Nyqvist, 2011). Of note, in the unit where this study was conducted, images and information about the importance and practice of SSC were posted in each room and in various locations around the unit. In addition, nurses are prompted by their electronic documentation system to enter the amount of time spent SSC each shift for each of their patients. This illustrates that despite a robust evidence base, HCP and parent-targeted education, and reminders there remains a knowledge-to-practice gap. This gap is also reflected in the literature; barriers such as staff workload (Benoit & Semenic, 2014), challenges with mediating the infant’s physiologic instability with the need for SSC (Benoit et al., 2016; Kymre & Bondas, 2013), and lack of staff education (Benoit et al., 2016), still exist and impact the effective implementation and uptake of SSC in practice.

5.3.1.2 Parent involvement in pain care.

Given that infants hospitalized in NICUs undergo many painful procedures per day (Cruz et al., 2016), another key aspect of developmentally-sensitive FCC in the NICU is pain management. In fact, pain-related stress in the neonatal period is the strongest predictor of adverse long-term developmental outcomes in preterm infants (Valeri et al., 2015). Accordingly, with its focus on neurodevelopment, the NIDCAP program stresses the importance of pain assessments and pain care (Westrup et al., 2007) and minimizing stress and pain is a core measure identified in the IDC (Altimier & Phillips, 2016; Harrison et al., 2015). In light of this, appropriate pain management during painful procedures is consistent with the goals of the Baby-Friendly Hospital Initiative (Harrison & Dunn, 2016), which is a WHO initiative to increase breastfeeding rates worldwide (World Health Organization, n.d.). Despite this, many infants do not receive evidence-based pain care (Cruz et al., 2016). However, parental presence during painful procedures increases the chances that infants will receive adequate pain management (Franck et al., 2011). Although parents express distress at seeing their infant in pain, the literature supports that they nonetheless still wish to be involved their infant's care and provide comfort (Franck et al., 2005; Gale et al., 2004). Franck et al. (2012) developed a model of parent involvement in infant pain management that emphasizes parental beliefs, information and support, and parent-infant proximity. In all the models discussed, SSC is recommended as an effective and safe method of managing the infant's pain and involving parents; for infants experiencing chronic or surgical pain, PIPC and SSC may be particularly effective (Anand, 2017).

In our descriptive exploratory study, parents reported 27 painful procedures and on three reported instances they were asked to leave the room. Only two instances of SSC during a

painful procedure were reported. In addition, given the evidence supporting the frequency of painful procedures in this population, it is likely that parents only reported a small fraction of the total painful procedures that occurred during the study period. On the survey, there was significant intra-group disagreement ($SD > 0.9$) and there were lower mean scores (< 4.0) on the Likert scale items related to being aware of, and involved in, painful procedures. This supports the findings of a metasynthesis of seven articles by McNair et al. (2020) which identified that HCPs control whether or not parents can be present or participate in painful procedures. Similarly, Harrison et al. (2015) found that some HCPs reported preferring to perform painful procedures without the parents present. Parents reported feeling as though the staff viewed SSC during painful procedures as an “inconvenience” (Harrison et al., 2015, p.120). Franck et al. (2012) found that parents felt “in the way” (p. 48), that parents lacked the appropriate information, and that staff attitudes and behaviours often hindered their participation in their infant’s pain care.

5.1.3.3 NICU environment.

The NICU environment, both the physical spaces and the routine practices, are also essential aspects of FCC in the NICU that have been extensively explored in the literature. In a pan-European trial, Raiskila et al. (2017) identified the ability for parents to stay overnight with their infant as the most important factor supporting parent-infant closeness, which is essential for the provision of developmentally-sensitive FCC (Jiang et al., 2014). In addition, unit routines and the physical layout of the NICU are the most important aspects influencing parents’ first-time contact with their infant and the initial stages of bonding and family formation (Baylis et al., 2014). This aligns with the focus on single family rooms (SFRs) that was identified in the concept analysis and literature review. Single-family rooms, in contrast with a traditional open-

bay design, increase overall parental satisfaction with care (Stevens et al., 2011), ensure that parents have the privacy to initiate and maintain a close relationship with their infant (Umberger et al., 2018), and facilitate unrestricted access to their infant (Altimier, 2015). Jones, Jones, & Feary (2016) evaluated the SFR design and found that mothers of infants in SFRs spent markedly more time with their infant and were more likely to initiate and maintain breastfeeding. Therefore, it is recommended that all NICUs advocate for a SFR design (Altimier & Phillips, 2016).

In the literature review and concept analysis, we also identified a focus on collaboration. In order to foster collaboration, parents require open communication and clear explanations of their infant's health status (Guillaume et al., 2013). Cone (2007) argues that given the increasing complexity of the NICU environment, a focus on communication is essential in order to collaborate with parents as partners. In the IDC, the second core measure is partnerships with families; it describes the importance of "around-the-clock" information, parents' unrestricted access to their infant, and encourages parental presence at interdisciplinary rounds (Altimier & Phillips, 2016, p. 237-238). The practice of parental presence at rounds further facilitates collaboration by providing an opportunity for meaningful shared decision making between parents and the interdisciplinary team (Grzyb et al., 2014; Harris, 2014).

The results of our descriptive exploratory study suggest that many of these goals may be difficult to achieve. On the survey, four of 11 parents reported that they had no bed to stay overnight with their infant. In addition, there was marked intra-group variability on survey items related to privacy and unrestricted access to their infant ($SD > 0.1$). In the open comment boxes, parents discussed inconsistent messaging between different members of the interdisciplinary team. They recommended providing parents with further information about unit routines, such as

the timing of rounds, and policies to provide clarity about how they can be involved in their infant's care. Similar to the other knowledge-to-practice gaps I have discussed, these findings highlight important differences between the ideals of FCC and their feasibility in practice. In a series of two articles, Fegran et al., (2008; 2009) describe the complex relationship that develops between parents and nurses as a result of close collaboration in the context of FCC in the NICU. The resulting physical and emotional closeness is challenging for both parents and nurses; breakdowns in this relationship can result in communication problems wherein parents do not receive adequate information to collaborate as partners in care (Axelin et al., 2014).

5.3.3.4 Summary and refinement of conceptual diagram

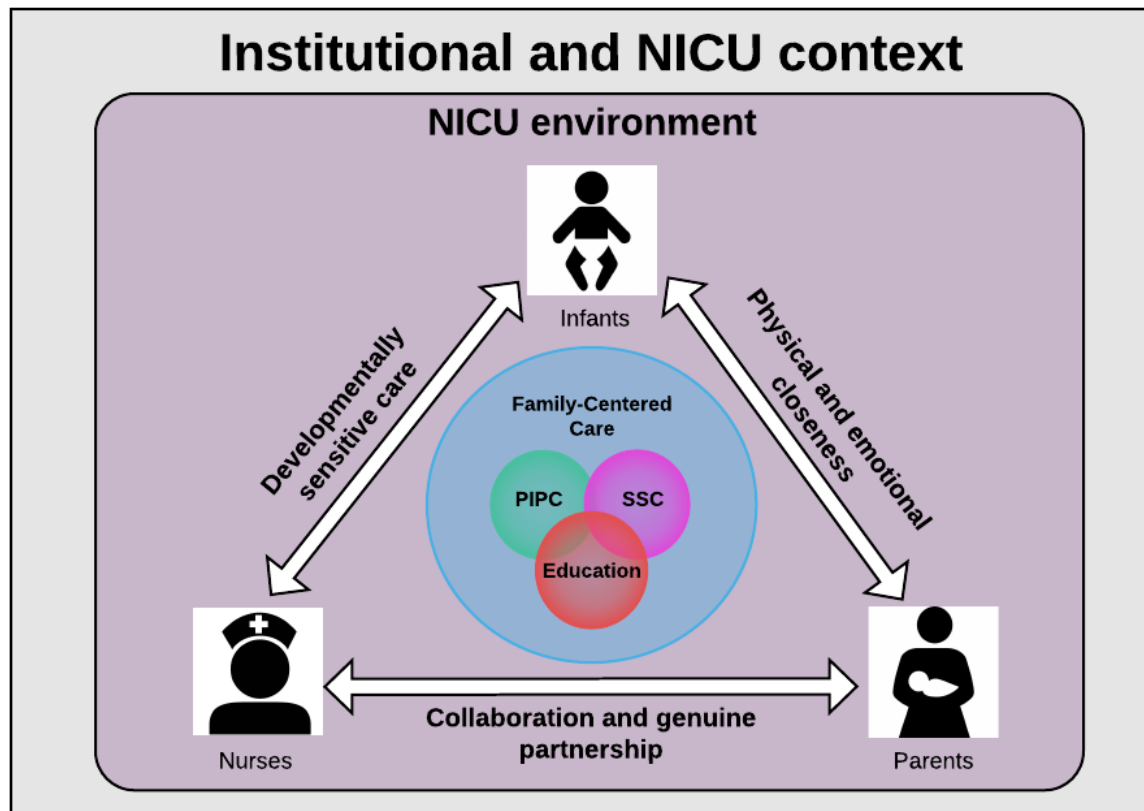
Comparing the findings of our concept analysis and literature review with those of the descriptive exploratory study raises important questions. The literature review and concept analysis revealed many existing models, frameworks, and research projects; it contained largely the perspectives of health professionals and researchers. The results of our descriptive exploratory study largely support the challenges with implementing FCC in the NICU reported in the literature; this study focused largely on parent reports and perspectives. This suggests an important difference in how researchers, HCPs, and parents conceptualize, perceive, and approach various FCC practices. Despite robust evidence, conceptual models, practice guidelines, and HCP education, these knowledge-to-practice gap persists. In light of these findings, the conceptual diagram for this study (Figure 1.1, p.12) requires refinement to inform future research. Foremost, the original diagram does address the antecedents and attributes of FCC in the NICU identified in the concept analysis and literature review (Figure 2.2, p. 39). In order to further explore the barriers to FCC in for postoperative infants the NICU, an emphasis on context, environment, education, and collaboration is required. In addition, there must be

equal weight placed to the nurses', parents', and infants' perspectives. The persistent knowledge to practice gaps suggest that integrating these various perspectives may provide more clarity regarding the challenges with implementing FCC in the NICU.

As illustrated in Figure 5.1, the revised conceptual diagram, the provision of FCC depends foremost on the institutional and unit context. Within that larger context, support from institutional and unit leadership is required in order to take care of families (as described above) and respond to the learning needs of nurses. The NICU environment, understood as both the physical layout and the practice environment, impacts the nurses, parents, and the infants. Referring to Figure 2.2 (p. 39), other attributes of FCC are represented in the new conceptual diagram by the bidirectional arrows. In order for care to be family centered, it must be developmentally sensitive and individualized to each infant; this means that the nurse must continually respond to each infants' unique needs and modify care where appropriate. Part of this developmentally sensitive care is physical and emotional closeness between parents and their infants. This closeness meets both parents' attachment and bonding needs, as well as the infant's developmental needs. Family-centered care also depends on collaboration between nurses and parents and the development of a genuine relationship. Subsequently, FCC occurs at the intersection of these factors, namely: the NICU environment, individualized and developmentally-sensitive care, physical and emotional closeness between parents and infants, and collaboration/genuine partnership between parents and nurses. Key aspects of FCC in the context of postoperative infants, namely PIPC, SSC, and education are represented within the delivery of FCC. This revised diagram more accurately represents both the antecedents and

attributes of FCC in the NICU and emphasizes the importance of considering various perspectives.

Figure 5.1- Revised model of FCC in the NICU



5.3.2 Taking Care of Families

Defined by Ramezani et al. (2014), taking care of families consists of comprehensive and individualized assessments of each family in order to provide for their unique needs. For Altimier (2015), this results in comprehensive care plans that make provisions for the entire family, not just the neonate. In the concept analysis and literature review, we identified supporting and taking care of families as an attribute of FCC in the NICU. We defined taking care of families as the policies and practices that support families' bio-psycho-socially in order to facilitate greater parental presence and thus parent-infant closeness (Milford, 2016; O'Brien et

al., 2015; Umberger et al., 2018; Zimmerman & Bauersachs, 2012). Supporting parents and families underpins all the attributes presented in Chapter 2, Figure 2 (p. 40); FCC in the NICU cannot occur if parents are not able to be present with their infant. I will discuss the concept of taking care of families in terms of its importance and implications for ensuring individualized and supportive care, developmentally sensitive care, and interdisciplinary collaboration.

5.3.2.1 Individualized and Supportive Care.

As discussed, given the biomedical complexity of caring for infants in the NICU, tailoring care to their individual needs is essential (Macho, 2017). In the descriptive correlational study, parents described challenges with participating in care due their infant's medical equipment, surgical wounds, and positioning. This is also reflected by our findings of a moderate negative correlation between the infant's severity of illness and the time parents spent present, holding, or SSC. This means that, as the infant requires increasingly complex interventions to maintain homeostasis, the opportunities for parental involvement decrease. Consequently, Govindaswamy et al. (2019b) describe that parents of infants in surgical NICUs have fundamentally different needs from parents of preterm NICU infants. In particular, they require enhanced communication about pain management, continued reassurance, and collaboration (Govindaswamy et al., 2019b). Given the particular importance of positioning and the prevalence of medical equipment (such as breathing tubes and central lines) in this population, taking care of families must include education, coaching, and mentoring to support them in caring for their infant and, ultimately, reduce their stress and minimize parental role alteration (Altimier & Phillips, 2016; Govindaswamy et al., 2019b; Govindaswamy et al., 2019c). In our sample, parents spoke about the facilitating impact of individualized education from nurses, such as how and when to hold the baby, on their ability to participate in care. Conversely, parents also

discussed how inconsistent messaging, lack of encouragement, and unclear expectations were barriers to their participation in care. These findings further highlight the complexity of forming close, collaborative, and individualized relationships between parents and nurses in the NICU (Fegran et al., 2008; Fegran & Helseth, 2009). The contrasting views of parents in our sample may indicate that the quality of these relationships ultimately contributes to their opportunities for involvement.

Some parents in our descriptive exploratory study also reported being unable to be present with their infant due to a loss of income, lack of childcare, and challenges with transportation. In the existing literature, the aspect of socioeconomic support is often overlooked as a part of providing FCC in the NICU, despite the reality that many parents incur significant costs during their infant's hospitalization (Hurst, 2004; Lasiuk et al., 2013). In a systematic review of 11 qualitative studies, Shields et al. (2006) identified both the financial and emotional cost of parenting an infant in the NICU; they mentioned lack or loss of income, cost of providing for other children, and cost of food and/or accommodations. Milford (2016) argues that a genuine individualized assessment and interest in each families' need must also include financial and social aspects. In the FiCare model, parents are provided with "as much physical, psychological and financial support as possible" such as complementary parking or a transit pass (O'Brien et al., 2015, p.7). Although the FiCare model acknowledges the financial burdens on parents, there must be buy-in from all institutions' leadership in order to allocate funds accordingly. However, given the precarious nature of funding in the healthcare system, it is unlikely that individual institutions could feasibly provide economic support to parents and families in need. To implement or improve financial supports for families of infants in the NICU, institutions, nurses, and nursing leaders can lobby government bodies to address nursing staff

shortages and financial needs (Duncan, 2014; Hart & Warren, 2015; Registered Nurses Association of Ontario, 2017). In addition, gaining the support of professional bodies may further strengthen lobbying efforts (Registered Nurses Association of Ontario, 2012). Particularly for NICU infants in Canada, organizations such as the Canadian Association of Neonatal Nurses, the Canadian Nurses Association, and the Canadian Association of Perinatal and Women's Health Nursing would be key stakeholders in efforts to improve FCC in the NICU. To these ends, the Registered Nurses Association of Ontario (2012) suggests emphasizing the evidence-based nature of the proposed changes and developing a detailed plan that clearly defines the benefits of such practices.

A final consideration is each parents' desired level of involvement. As mentioned previously, authors in the existing literature describe HCPs' gatekeeping behaviours. Although present in all areas of nursing (Gastaldo & Holmes, 1999), gatekeeping in the NICU often takes the form of nurses deciding the level and frequency of parents' involvement in their infant's care (McNair et al., 2020). In the literature, nurses discuss a desire to protect parents from seeing their infant in pain (McNair et al., 2020), a need to be in control of the situation (Axelin et al., 2015), and a lack of role-clarity (Axelin et al., 2014). In order to mediate this, Franck et al. (2012) acknowledge that assessing the parents' desired level of involvement is the first step in determining how best to involve them in care. This approach allows parents to make meaningful choices about their infant's care and the extent of their involvement (Franck et al., 2012). Genuine interest in the individuality of each family facilitates the process of taking care. Assessing parents' needs on a regular case-by-case basis ensures they receive the support and education they need to make informed choices about their infant's care and their involvement. However, we must be careful to ensure this collaboration and negotiation between HCPs and

parents does not result in a simple division of tasks where the parents perform the manual work and the nurses perform the intellectual work; this hinders the development of a genuine partnership as the nurse is still in control of care planning and co-ordination (Shields, 2010).

5.3.2.2 Developmentally Sensitive Care.

Parental presence and involvement in care in the NICU is foundational to the developmental needs of neonates and the psychological well-being of parents (Ahlqvist-Björkroth et al., 2017; Jiang et al., 2014). In the newborn period, parent-infant closeness is required to facilitate the initial stages of bonding and family formation (Ahlqvist-Björkroth et al., 2017). Beyond physical proximity, there is also an emotional closeness (or connection) that forms between parents and their infants (Flacking et al., 2012). The practice of SCC is important for facilitating both physical and emotional closeness between parents and their infants (Raiskila, 2018). As discussed, the IDC asserts the primacy of SSC as the “optimal environment” (p. 232) for newborns and thusly the most fundamental aspect of providing developmentally-sensitive care in the NICU (Altimier & Phillips, 2016). For parents, SSC also promotes feelings of confidence (Anderzén-Carlsson et al., 2014), and develops and affirms the parental role through bonding (Maastrup et al., 2018).

In contrast, isolation or separation can lead to parents feeling alienated, out of control, and incompetent in their parenting role (Flacking et al., 2012; Umberger et al., 2018). The stress and anxiety of the NICU experience is associated with higher levels of postpartum depression, anxiety, and post-traumatic stress disorder amongst parents (Flacking et al., 2012; Goldstein, 2013; Jiang et al., 2014). Goldstein (2013) explains that stress is one of the most common barriers to effective parenting, yet one of the most strongly associated with the infant’s

development. This is supported by Jiang et al. (2014) who state that providing parents with means to reduce their stress and enhance their confidence is essential for the infant's outcome. On the parent survey in our descriptive exploratory study, parents reported agreeing that the staff supported parent-infant closeness, but disagreed about feeling supported in coping with stress. They also discussed not having a clear understanding of how to be involved in their infant's care and feeling disempowered by the lack of education. Our results also highlight the limited amount of PP for both parents. The parent diaries showed that mothers were present in the NICU on most of the study days (127 days; 90%) but performed SSC on only 23 (16%) of the study days for an average of only 14 minutes. In comparison, fathers were present on 95 (67%) of the study days and performed SSC on only one occasion (0.7%) for 15 minutes. Parents in our sample rarely stayed overnight with their infant. This is also reflected in the parent survey where four of the 11 parents reported there was no bed for them to stay overnight. These results are consistent with barriers previously identified in the literature. In an evaluation of PP in six different European NICUs, Raiskila et al. (2017) found that units where at least one parent could stay overnight had significantly higher parental presence. In addition, they found that SSC was more likely to occur in units with a SFR design (Raiskila et al., 2017). The differences between mothers and fathers is also reflected in the literature (Provenzi & Santoro, 2015; Valizadeh et al., 2018). However, Blomqvist et al. (2013) found that when fathers are involved in SSC, the infant receives more SSC overall.

In order to take care of the entire family's developmental needs, parent-infant closeness must be promoted and protected. For parents of infants in a surgical NICU, role alteration is one of the most significant stressors (Govindaswamy et al., 2019c, 2019b). In the FiCare model, psychological support is provided to parents in a peer-to-peer format with "veteran parents"

(Jiang et al., 2014, p.783), an approach which is also supported by Bourque et al. (2018) and Levick et al. (2014). However, some evidence suggests that parent support programs should offer more than one format (Hurst, 2006). Due to the challenges with providing an environment ideally suited for parent-infant closeness identified in our study, efforts should be made to enhance the quantity and quality of psychosocial support.

5.3.2.3 Interdisciplinary Collaboration.

The concept analysis and literature review of this thesis included contributions by various health care providers and identified the importance of interdisciplinary collaboration (Nightlinger, 2011; Ramezani et al., 2014). Similarly, Macho (2017) identified collaborative as an attribute of Individualized Developmental Care in the NICU. They stated that an interdisciplinary approach is essential to the success of FCC in the NICU (Macho, 2017). Members of an interdisciplinary team in a North American NICU can include but are not limited to doctors, nurses, respiratory therapists, social workers, dieticians, and physiotherapists. The plurality of perspectives results in more holistic assessments of infants and their families, ultimately allowing for individualized supports that facilitate parent-infant closeness (Westrup, 2007). Comparing the results of the literature review and concept analysis with those of our cross-sectional descriptive exploratory study, important considerations for interdisciplinary care in taking care of families will be discussed under the following three headings: biomedical, psychosocial and occupational, and lactation and breastfeeding.

5.3.2.3.1 Biomedical.

Given the intensity of interventions required for NICU patients, the biomedical aspects of care are often at the forefront. With the highly technical nature of this care, parents are at an increased risk of feeling helpless and disconnected from their infant (Joseph, 2016; Obeidat et

al., 2009; Sikorova & Kucova, 2012). These feelings ultimately increase their risk for stress, depression, and role alteration (Enke et al., 2017). Therefore, nurses must encourage and support parents to participate in care and touch and hold their infant in order to facilitate parent-infant closeness (Joseph, 2016). This support is multifactorial; it includes reassurance (Govindaswamy et al., 2019b), education (Melnik et al., 2006), and compassionate communication (Altimier, 2015). In complex cases, such as postsurgical infants, supporting the parents in these caring activities must also include caring for the equipment (such as ventilators, cardiac monitoring, surgical devices, etc.). This requires multiple HCPs in order to simultaneously care for the infant, care for the infant's equipment, and to monitor safety throughout (Joseph, 2016). These intricacies place strain on bedside nurses who must mediate the competing demands of ensuring the infant's safety and also facilitating parent-infant closeness with limited resources.

In our descriptive exploratory study, all 11 parents reported getting most of their information about their baby's diagnosis and medical plan of care from the physicians, and most of their information about caring for their infant from the nurses. In conjunction, as mentioned above, they also discussed inconsistent messaging, an unclear understanding of ways they can be involved, and a lack of encouragement. In light of similar challenges reported in the literature, Kjellsdotter et al. (2018) recommend that both nurses and physicians receive education and training in order to learn how to best tailor their communication and education in order to support parental participation.

In order to best take care of families' needs, D'Agata & McGrath (2016) describe a need to refocus nursing care and support nurses in adopting a primarily supportive/educative role for parents, rather than a wholly compensatory one. Individualized and interdisciplinary educational interventions for parents, such as simulations, increase parental confidence and promote

collaborative decision making (Arnold & Diaz, 2016). Likewise, evidence supports that education for parents is most effective when it is available in multiple formats, such as at the bedside, online, on paper, and through peer-to-peer support (Bracht, O’Leary, Lee, & O’Brien, 2013; O’Brien et al., 2015). However, as noted above, HCPs are ultimately constrained by resources, which presents a significant limitation for facilitating and promoting FCC in the NICU.

5.3.2.3.2 Psychosocial and Occupational.

In addition to doctors and nurses, other disciplines in a North American NICU can include social workers, physiotherapists, and occupational therapists. As discussed above, supporting parents psychosocially is essential for the overall well-being of the infant and the family. The concept analysis and literature review discussed how interdisciplinary professionals define and approach FCC from varied perspectives. Notably, the discipline of Social Work uses terms such as holistic FCC or culturally-competent FCC (i.e. Nicholas et al., 2014; Trujillo et al., 2017) in the literature. This reflects the biopsychosocial nature of social work assessments which often include in-depth explorations of the family’s context, both current and historical, and their coping strengths and weaknesses (Drisko & Grady, 2019). In order to provide parents with individualized and comprehensive support, the expertise of a social worker is required (Bracht et al., 2013; Goldstein, 2013; O’Brien et al., 2015).

However, to fully deliver family-centered care in the NICU, we must consider more than just the parents. Parents in our cross-sectional descriptive exploratory study reported challenges with child care and visitation policies. In the NICU where this study was conducted, siblings under 12 years old are not allowed to visit; parents must arrange care for their other children in order to be present at their infant’s bedside. Concerns with sibling visitation lie primarily with the

potential transmission of pathogens to the fragile infants. However, Horikoshi et al. (2018) conducted a retrospective study and found that sibling visitation did not result in an increase in nosocomial infections. Therefore, it may be possible for institutions to adopt family-friendly (or sibling-friendly) visitation policies. Such policies may have the potential to increase overall PP at the bedside by removing the barrier of having to find care for their other children. Accordingly, there is the possibility of expanding the role of child life specialists (Levick et al., 2010); in some countries, child life specialists are educated and trained in the principles of child development, family systems, stress, coping, and play (Smith et al., 2014). The addition of a child life specialists' perspective to the interdisciplinary team may further facilitate a more comprehensive approach to FCC in the NICU. In sum, considerations for visitation policies are to individualize them to the needs of each family; parents should be allowed to decide whose support they deem necessary (Cockcroft, 2012).

In the literature review and concept analysis we included one article by physiotherapists (Byrne & Garber, 2013). In this article Byrne and Garber (2013) discuss the role and contribution of physical therapy in the NICU. Using an infant-driven, family-centered approach, physiotherapists can support parents with infant handling and positioning (i.e. flexed or prone), appropriate developmental interactions (i.e. reaching, grabbing), and recognizing cues and behaviours (Byrne & Garber, 2013). With the surgical population of infants, this role may have an additional importance due to the challenges with infant positioning and appropriate interactions reported by parents in our study. In collaboration with parents, all members of the interdisciplinary team contribute to the development of the parental role (Nightlinger, 2011). However, given that one of the most significant stressors for parents of infants in the NICU is parental role alteration, an occupational therapists' perspective of parenting in the NICU can be

an invaluable contribution for taking care of families (Dudek-Shriber, 2004). An occupation-based approach may help parents with the process of occupational adaptation, which occurs when their expectations of parenting do not align with the reality (Gibbs et al., 2016). By refocusing parents' expectations of their parental role and helping them discover new ways to engage in parenting occupations, Occupational Therapists may support parents in being meaningfully involved in their infant's NICU admission (Gibbs et al., 2015).

5.3.2.3.3 Lactation and Breastfeeding.

The role of lactation and breastfeeding in the neonatal period is multifaceted; it supports the infant's physical and developmental growth while simultaneously facilitating bonding and feelings of control amongst mothers (Oras et al., 2016). Therefore, it is essential for taking care of families. Parents report both breastfeeding and feeding their infant expressed human milk as significant first-time events in their parenting journey in the NICU (Baylis et al., 2014). Research supports that the presence of an International Board Certified Lactation Consultant (IBCLC) in the NICU increases the number of infants receiving human milk during admission and at discharge (Dweck et al., 2008; Mercado et al., 2019). In addition, in light of their focus on breastfeeding, lactation consultants also promote SSC, which, as discussed, is essential for the developmentally-sensitive care of neonates (Gharib et al., 2018; Maastrup et al., 2012). Considering the postsurgical NICU population that may not be able to breastfeed directly, lactation support to initiate pumping and maintain milk supply is essential for optimal nutrition of the neonate (Briere et al., 2015; Froh et al., 2017). Despite this, many NICUs do not employ lactation consultants and their role is only cursorily discussed in the existing literature (Froh et al., 2017). Barriers to employing lactation consultants are often fiscal and the added burden of breastfeeding support often falls on already strained nurses (Mercado et al., 2019).

In the cross-sectional descriptive exploratory study, most parents discussed the importance of breastfeeding and providing milk for their infant. Parents mentioned the facilitating effect of support from their bedside nurses, but also discussed challenges such as a lack of meals hindering milk supply, inability to commit to pumping schedule due to competing priorities, and lack of support. They recommended the addition of lactation consultant to the interdisciplinary team to address their challenges. This is reflected in the existing literature. In a study by Benoit & Semenik (2014), parents identified lactation consultants as key members of the interdisciplinary team due to their role in facilitating breastfeeding, pumping, and SSC. Benoit & Semenik (2014) also discuss how lactation consultants are ideally positioned to advocate for and support the Baby Friendly Hospital Initiative (World Health Organization, n.d.), which is a stated goal of many hospitals and organizations worldwide. Given that lactation consultants support and facilitate many key aspects of developmentally-sensitive FCC, it is reasonable to suggest that their addition to interdisciplinary NICU teams may enhance taking care of families.

5.3.2.4 Summary.

Considering the concept of taking care of families in the context of this thesis, there is an evident impasse between attending to the infant's biomedical needs and providing holistic care for the family. These considerations are increasingly important in the population of postoperative infants due to their, and their families', unique needs (Govindaswamy et al., 2019a). Govindaswamy et al. (2019a) delineated guidelines for supporting parents of infants in surgical NICUs specifically. They recommend open and honest communication, supporting parents in their parental role, education for HCPs, and family-centered policies at the institutional level (Govindaswamy et al., 2019a). However, due to the increasingly complex and technological

nature of healthcare, and the precarity of financial resources, the ability for HCPs and institutions to focus on holistic psychosocial family care is limited. This results in challenges at the bedside mediating the medico-surgical needs of the infant with the psychosocial needs of the family.

5.3.3 Philosophical and Conceptual Tensions

Thus far, I have discussed knowledge-to-practice gaps and challenges with taking care of families. In both these instances, comparing the results of our concept analysis and literature with those of our descriptive exploratory study sheds light on conflicting points of view and competing priorities. Despite the ubiquitous nature of FCC being touted as practiced in pediatric and neonatal settings, there are persistent challenges with its implementation. Given that FCC is an approach rather than a prescription for care, there are differences in its implementation in various contexts (Benzies et al., 2018). However, given the lack of empirical evidence actually supporting FCC (Kuo et al., 2012; Shields, 2017), these differences result in a lack of clarity in fundamental concepts and what is identified as “ad hoc operationalization” (Coyne 2015, p. 797). For the purpose of this thesis, I will discuss the implications of these philosophical and conceptual tensions under two broad headings, namely: “too much noise” (Benzies et al., 2018, p.1) and power hierarchies.

5.3.3.1 Too much noise.

In a study of NICU practitioners and administrators, Benzies et al. (2018) identified that the health care system is making “too much noise” for the delivery of FCC in the NICU. They discuss how many of the barriers to implementing FCC in the NICU are related to systems level issues and thus, without addressing these issues, educational interventions alone are likely to be ineffective (Benzies et al., 2018). However, systems level issues require complex assessments and are typically not directly modifiable (D’Agata & McGrath, 2016). Often fiscal in nature,

these issues have largely been overlooked in the literature. Given the precarious nature of health funding and a resulting inability to enact financial changes, research and interventions have focused on more readily modifiable aspects of care delivery. In our concept analysis and literature review, we identified that these aspects can include parent and nurse education, behavioural modification interventions, and targeted interventions to improve measurable aspects of FCC such as SSC or parental presence. However, this thesis suggests that these approaches may not be holistic. Further, these approaches may be antithetical to the foundational notion that FCC should recognize parents as equal partners, rather than FCC being “defined by experts and then carried out to families” (MacKean et al., 2005, p.81). From this perspective, FCC can be an opportunity to shift care from HCPs to parents in order to save money for health care institutions (MacKean et al., 2005). Considering both these factors, namely fiscal barriers and the resulting emphasis on modifiable factors, the psychosocial aspects of FCC, which are key considerations for its effective implementation, have been overlooked or ignored. This is worsened by the business discourse of hospital administration and research funding allocation, which emphasize deliverables and cost-savings measures (Coyne, 2015; D’Agata & McGrath, 2016; MacKean et al., 2005).

Given the current practice reality, FCC in the NICU may be too idealistic. In our concept analysis and literature review, we argue that FCC must be regarded as an overall philosophy of care rather than as a set of interventions or principles. Consequently, this requires an institutional shift, which is likely not fiscally possible. However, Benzies et al. (2018) make certain recommendations for improving the health care system that include refining staffing models, enhancing professional development, and supporting parents to be with their infants (Benzies et al., 2018). This financial support should include, but is not limited to, travel, accommodations,

parking passes, and childcare for older children (Benzies et al., 2018). With this evident contradiction between parents' needs and health care institutions' capacity to provide holistic FCC in the NICU, there continues to be impasse between the idealized version of FCC in the literature and the experience of parents and HCPs in practice settings.

Despite the challenges, the lack of evidence, and critiques, new models of FCC in the NICU, such as FiCare, continue to emerge. For example, the FiCare model emphasizes parental presence and requires parents to commit to being present in the NICU with their infant for a minimum of six to eight hours per day (Broom et al., 2017; O'Brien et al., 2015). Although literature supports that FiCare improves outcomes for both parents and infants (Bracht et al., 2013; Broom et al., 2017; Jiang et al., 2014), results from our descriptive exploratory study demonstrate that this commitment is likely not possible for many parents. Feeley et al. (2016) highlight that, despite the potential of the FiCare model, parents' desired and feasible level of involvement should be considered, rather than prescribing what they should do. This model attempts to target the modifiable factors of parental presence and education; however, as I have discussed, parental presence is impacted by a complex array of factors that necessitate an institutional commitment to taking care of families. Likewise, as mentioned, educational interventions alone are likely to be ineffective without addressing the complex systems issues that underpin challenges with FCC in the NICU (Benzies et al., 2018). Recently, the term Newborn Intensive Parenting Unit (NIPU) has been adopted to further delineate the shifting of tasks and roles towards parents as providers (Hall et al., 2017). The NIPU model situates the provision of FiCare within a larger institutional shift that supports the practices inherent within it to ensure that "intensive parenting begin[s] as soon as possible" (Hall et al., 2017, p.1). While Hall et al. (2017) do state that support from leadership is required, they emphasize that this

support should largely focus on staff education and emotional support; they fall short of addressing the higher-level systems issues, such as financial barriers, that I have discussed.

A central consideration is whether these newer models, such as FiCare, represent a significant conceptual departure from FCC in the NICU or whether they represent a continued disconnect between institutional, HCP, and parent perspectives. Considering the complex and individualized needs of surgical infants, there is a particularly urgent need to clarify the meaning and operationalization of key FCC concepts for this population specifically (Govindaswamy et al., 2019a). Our cross-sectional descriptive exploratory study brings to light the additional challenge of mediating biomedical needs (such as equipment, pharmaceuticals, interventions) with FCC needs of the family in these populations. Bridging the perceptual divide between these two priorities, namely the infant's health status and the family's needs, is necessary to ensure appropriate delivery of care in surgical NICUs (Govindaswamy et al., 2019b). However, in these highly-technological environments, new dichotomies between endorsing FCC in name but not in substance exist. Consider the case of a "substitute parent device" for simulating parental presence during painful procedures (Ullsten et al., 2019) developed by researchers for the NICU setting. This device mimics a parents' heart rate and respiratory rate and is meant to replace SSC during painful procedures (Ullsten et al., 2019). While these devices are well-intentioned and potentially cost-effective (Standley et al., 2010), they fundamentally undermine the importance of parent-infant closeness and are therefore not family-friendly (Ullsten et al., 2019). Rather than focusing on the fact that not all parents can be present at the bedside, we should focus on the psychosocial factors impacting or impeding their desired level of involvement. Similarly, researchers have begun to explore the role of text messaging (Globus et al., 2016), video monitoring (Epstein et al., 2017), remote electronic chart access (Chung et al., 2018) and

electronic learning (Monaghan et al., 2020) as new methods of communicating with parents. While these adaptations may enhance the amount of information parents have, they serve to further undermine the parental role by relegating parental presence as no longer necessary (D'Agata & McGrath, 2016). This is in stark contrast to the ubiquitous endorsement of FCC in the NICU, which is underpinned by parent-infant closeness, and illustrates the focus on readily influenceable factors rather than taking a holistic approach to systematically removing barriers for parental presence.

With the system making too much noise, is a philosophy such as FCC truly plausible? The literature supports persistent challenges with addressing systemic barriers to FCC, resulting in inconsistent operationalization of concepts and the dominance of the biomedical perspective of FCC. This engenders significant problems individualizing and aligning the delivery of care to best suit the needs of parents and families. In order to operationalize FCC in this setting, we must first define it. In order to define it, we must first resolve the philosophical and conceptual tensions created by the competing priorities and perspectives. Without the resources to embody the family-centered philosophy, institutions and practitioners are limited in what they can provide.

5.3.3.2 Power hierarchies.

Some authors posit that challenges with the operationalization of FCC result from the fact that the family-centered philosophy challenges traditional power hierarchies within healthcare (Axelin et al., 2014; Weis et al., 2015). D'Agata & McGrath (2016) go as far as stating that “none of these intervention studies have gone far enough to truly change the power differential and allow parents their rightful place at the bedside” (p. 252). This supports that although parent perspectives are discussed in the existing literature, they may not be considered holistically or

given equal importance as HCPs or researchers' perspectives. It follows that without considering all perspectives, it is challenging to define nurses' and parents' roles within the provision of FCC in the NICU. These power hierarchies have implications for the nurse-patient relationship and role confusion.

5.3.3.2.1 Nurse-parent relationship.

The concept of FCC emerged as a response to traditional paternalism, which limited parents' ability to participate in the child's care (Cody, 2003; Shields, 2010). This paternalism stems from the medical model and the notion of professionalism; professionalism confers a body of knowledge upon certain individuals which places them in a position of authority as an expert (MacKean et al., 2005). Despite the longstanding history of the concept of FCC described in our concept analysis and literature review, HCPs continue to define the ways in which parents can be involved (MacKean et al., 2005). This privileged knowledge allows nurses to act as gatekeepers to FCC, which becomes "described by experts and then carried out to parents" (MacKean et al., 2005, p.81). Therefore, they have the power of defining what parents can and should do, and reflexively what they can't and shouldn't do (D'Agata & McGrath, 2016; McNair et al., 2020). If a parent does something the nurse does not agree with, they can become subject to punishment and social exclusionary tactics (Campbell-Yeo et al., 2017; Coyne, 2008; Shields, 2017). In a qualitative study with 60 parents, Guillaume et al. (2013) identified that parents felt subject to the authority of the nurses due to their reliance on them to care for their infant. In addition, parents described that the conduct of nurses fundamentally impacted their ability to have contact with, and participate in care for, their infants (Guillaume et al., 2013). Although parents want to participate in care, they require the guidance, support, and an invitation to do so (McNair et al., 2020). Rather than empowering parents, this results in "guarded alliance[s]" where parents must

trust that nurses know best (McGrath, 2001). Consequently, partnerships and collaboration, which underpin the concept FCC in the NICU, are difficult to achieve.

In acute neonatal settings, such as the NICU where this study was conducted, nurses determine when infants are “stable enough” for the parents to be “allowed” to participate in their care (D’Agata & McGrath, 2016, p.250) based on their expert knowledge. The parents in our descriptive exploratory discussed tensions related to what the nurses thought, or didn’t think, they should do. For example, one parent discussed how a nurse “really wasn’t happy with us because she didn’t like that we wanted to continue our son’s life because she thought he would be better off passing” (P002). On the survey, parents were ambivalent as to whether they felt that they were equal members of their infant’s care team. As aforementioned, they also reported ambivalence about understanding and being aware of the things they can do to participate in their infant’s care. For example, parents had the lowest mean response to the survey item “The nurses give me information about pain and how to help my baby with pain during painful procedures.” Given that loss of the parental role and their infant’s pain management are the two largest stressors for parents in a surgical NICU (Govindaswamy et al., 2019c), and despite the importance of appropriate pain management in the population of postsurgical infants for both their development (Anand, 2017) and the parents’ wellbeing (Govindaswamy et al., 2019a), our study supports that nurses can act as obstacles that obstruct parents from participating in their infant’s pain care (McNair et al., 2020).

5.3.3.3.2 Role confusion.

MacKean et al. (2005) argue that this lack of collaboration results in a dissolution of tasks from nurses to parents. While parents perform the manual tasks, nurses are responsible for the intellectual work, which reflects a Marxist division of labour (de Lima et al., 2001; Shields et al.,

2006). Although parents want to participate in care, this shift in responsibilities can be burdensome; they must worry about finances and other children, among other things, in order to care for their infant in the NICU (MacKean et al., 2005). In the FiCare model, and in the NIPU, parents are expected to provide as much care as possible, providing most if not all caregiving (Hall et al., 2017; Jiang et al., 2014). In both these models, there is little to no financial compensation or social support for parents. Rather than being an extra pair of hands, parents want informed choice about their level of involvement, reflecting the need for FCC in the NICU to be individualized to each families' needs (Coyne & Cowley, 2007; MacKean et al., 2005). In a qualitative study of 18 nurses and 18 parents, Coyne (2015) reports that nurses relied on parents to provide care due to their busy workloads. In doing so, this "downloading" of responsibility to parents saves money for institutions (Coyne, 2008; MacKean et al., 2005). In order for parents to assume these tasks, the delivery of FCC in the NICU has focused largely on education and training for parents (Fegran et al., 2008; MacKean et al., 2005, p. 82), which is a core attribute of FCC in the NICU identified in our concept analysis and literature review. This shift from nurse as caregiver to nurse as educator results in a change in power, which can lead to a loss of empowerment and role confusion among nurses (Axelin et al., 2014). In this new role, the nurse-parent relationship is described as "befriending," which further blurs professional boundaries and identity (Fegran & Helseth, 2009, p. 672). The additional emotional labour required to maintain these relationships and gain parents' trust can result in emotional exhaustion among nurses (Fegran & Helseth, 2009). While some models, such as the IDC, advocate for mental health support and training focused on interpersonal relationships for nurses working in the NICU (Altimier & Phillips, 2016), this is often not the clinical reality.

Although we did not include nurses in our descriptive exploratory study, our results suggest a certain level of role negotiation between nurses and parents. As discussed, all parents reported unclear expectations regarding what they could and could not do, as well as what they were expected to do. In the highly technological environment of a surgical NICU, nurses may have additional barriers in negotiating their role as educator and coach for parents due to the emphasis on biomedical knowledge (Altimier & Phillips, 2016). In order to mediate both their caregiving responsibilities to infants and their supportive-educative responsibilities to parents, nursing workloads should be adjusted (Benzies et al., 2018). In addition, nurses should receive education about how to be effective coaches and educators, as well as how to develop close relationships while maintaining professional distance (Altimier & Phillips, 2016).

5.3.4 Conclusion

Through an exploration of knowledge-to-practice gaps, the concept of taking care of families, and philosophical and conceptual tensions surrounding FCC, I have situated my findings within the existing literature and discussed their consequences. In doing so, I have explored the causes and impact of the misalignment between family/parent needs and perspective, and those of HCPs and researchers. Despite new developments such as FiCare, recent literature supports that parent and nurses still experience role confusion, challenges with communication, and inadequate education (Monaghan et al., 2020). The persistence of this dichotomy suggests that traditional approaches to research and KT may be incommensurate with the reality of adopting and implementing a philosophy such as FCC in the NICU. Therefore, FCC concepts and interventions in the NICU remain persistently and fundamentally misunderstood (Benzies et al., 2018; McGrath, Samra, & Kenner, 2011).

5.4 Nursing Implications

The implications of this thesis will be discussed under the following headings: implications for nursing practice, nursing education, nursing research and theory development, and nursing leadership and policy development.

5.4.1 Implications for Nursing Practice

The practice of FCC in the NICU is shrouded by the impasse between the theoretical perspective of FCC and the reality in practice. This results in increased burden amongst nurses who are often held accountable for delivering FCC in the NICU; as a result, they are often targeted when there are implementation challenges (Fegran & Helseth, 2009). In particular, I will discuss the practical implication of persistent knowledge-to-practice gaps, shifting the role of nurse from caregiver to supportive educator, and interdisciplinary collaboration.

5.4.1.1 Persistent knowledge-to-practice gaps.

While much research has focused on translating knowledge and evaluating barriers and facilitators to FCC in the NICU (Benoit & Semenic, 2014; Brødsgaard et al., 2016; Hogan & Logan, 2004), there has been little reported change in mediating the complex perspectival tensions that have arisen. As discussed, there are significant knowledge-to-practice gaps pertaining to the use of SSC, PIPC, and optimizing the NICU environment to facilitate PP. In the literature, nurses have described their perceptions and challenges with these practices. For example, in a study by Benoit et al. (2016), nurses cited the infant's physiologic instability and the highly technological equipment required to maintain and sustain life as barriers to using SSC for pain management. These interventions require time, emotional investment, and expertise on the part of the nurse; heavy workloads and competing priorities have also been cited as barriers to SSC and PIPC (Fegran & Helseth, 2009; MacPhee et al., 2017). Although most nurses agree

with the tenets of FCC in the NICU, as well as many practices such as SSC and pain management (Petersen et al., 2004; Pölkki et al., 2018), continuing to target nurses with educational interventions to modify their behaviour have been limited in efficacy. Rather than focusing on nurse ‘non-compliance,’ these persistent gaps imply that structural and systems level factors have a significant impact on nurses’ practice realities (McMillan & Perron, 2013). These systems-level factors include but are not limited to understaffing, unit design, restrictive visitation policies, and a lack of role clarity; these broader factors must be addressed in order to align the philosophy and practice of FCC with the practice reality in the NICU (Renolen et al., 2018).

With respect to the implementation and uptake of EBPs, the concept of change fatigue is important to consider. Traditional evaluations have labelled nurses as “obstructive” and “resistant” to change, and thusly have viewed this attitude as a problem to fix, rather than examining the broad factors behind these perceptions and attitudes (McMillan & Perron, 2013, p. 30). This is sometimes referred to as change resistance, which is distinct from change fatigue (Brown et al., 2018). In practice, nurses experience change fatigue as a result of the culture of constant change and pressure to continuously adapt their practice in the healthcare system (McMillan & Perron, 2013). In particular, practice changes resulting from advancements in health sciences and technology can result in feelings of stress, exhaustion, and burnout amongst nurses (Camilleri et al., 2019). In order to address change fatigue, organizational leaders can adopt a participatory approach (McMillan & Perron, 2013). Participatory approaches involve nurses in the planning and implementation of EBPs and subsequently increase staff participation and accountability (McMillan & Perron, 2013). In addition, staffing reforms may address some

of the competing priorities nurses face when providing FCC in the NICU by allowing for more time to learn, practice, and implement EBPs such as SSC and PIPC.

5.4.1.2 Shift from nurse as caregiver to nurse as supportive educator.

As discussed above, the role of the nurse changes when providing FCC in the NICU changes. In models such as FiCare and the IDC, nursing tasks shift from lead to a loss of empowerment amongst nurses (Axelin et al., 2014). In practice, this results in role confusion and emotional burdening (Axelin et al., 2014). As previously discussed, change fatigue is also an important consideration in the current healthcare context (McMillan & Perron, 2013). When nurses are continually required to adapt their practices, such as is required when their role shifts from caregiver to supportive educator, they experience increased stress and may become apathetic (Camilleri et al., 2019). These factors, namely: disempowerment, role confusion, emotional burdening, and change fatigue, not only compound the competing priorities faced by NICU nurses, but also impact the quality of the nurse-patient relationship (Wiechula et al., 2016). Given that the nurse-family relationship is one of the most important factors for parents' overall satisfaction with their NICU experience, (Dall'Oglio et al., 2018; Reis et al., 2010), supporting nurses in understanding and developing this new role is essential.

One recommendation to support nurses practically in this role is the incorporation of a trauma-informed approach to facilitate the individualization required for each family (Marcellus, 2014). In a trauma-informed approach, HCPs approach each family as unique, understanding the importance of creating a safe environment that acknowledges the prevalence of trauma and its longstanding impacts (Stokes et al., 2017). Given the increased prevalence of postpartum depression and post-traumatic stress disorder among NICU parents (Lefkowitz et al., 2010), trauma-informed care may support nurses in fostering FCC in the NICU despite potentially

limited time and resources (Coughlin, 2016). In the IDC, Altimier & Phillips (2016) describe the importance of supporting nurses and parents both from an educational and psychosocial perspective, which further supports the potential beneficial impact of a trauma-informed approach with this population.

Given the availability of parent and HCP targeted educational interventions, and given the continued difficulties with applying FCC in the NICU, it is reasonable to delineate that adequately supporting parents and nurses' roles in practice requires more than education. In a systematic review of 24 studies, Thompson & Stapley (2011) found that educational interventions were limited in their efficacy at improving nurses' judgement and clinical decision making. They recommend balancing a pedagogical approach with a behavioural approach; accounting for the context of practice behaviours requires clinically-focused education, such as modeling, role-modeling, and mentorship (Abdullah, 2015; Thompson & Stapley, 2011). Considering the changing role of nurses in NICUs, future efforts to improve clinical practice should aim to better describe the expectations, competencies, and training required for a supportive-educative nurse role in the NICU (Maher, 2017).

5.4.1.3 Interdisciplinary collaboration.

In the concept analysis and literature review we identified the importance of interdisciplinary perspectives for providing developmentally-sensitive and holistic care of NICU infants and their families (Nightlinger, 2011; Ramezani et al., 2014; Spellman, 2019). The expertise from a broad range of specialties optimizes the care of both infants and their families (Hynan & Hall, 2015). In our descriptive exploratory study, this was evidenced by parent's expressed need for the expertise of a lactation consultant. Particularly for the population of surgical infants, and NICU infants in general, achieving and maintaining a milk supply is

important for both infants and their mothers (Gharib et al., 2018). In practice, Mercado et al. (2019) state that the ideal staffing for IBCLCs is 1 full-time equivalent (FTE) for each 235 NICU admissions. Therefore, in the NICU where this study was conducted, guidelines are that there should be 1.5 FTE IBCLCs.

Although the importance of interdisciplinary collaboration is not contested, exploration of barriers and facilitators to interdisciplinary collaboration in the NICU has been limited. However, Miller & Freeman (2004) describe that in practice, interdisciplinary collaboration is undermined by power hierarchies. Therefore, the process of interdisciplinary collaboration involves complex, multi-layered processes such as defining role expectations and boundaries, and negotiating a shared philosophy of care (Miller & Freeman, 2004). Research supports that HCPs view interdisciplinary collaboration differently, and thusly challenging inherent power differentials and negotiating equality is essential for the practice of interdisciplinary collaboration (Dunn, 2011). Although there is limited literature on addressing power differentials in clinical practice, existing interprofessional competency tools and/or frameworks may provide a starting point. In particular, the Canadian Interprofessional Health Collaborative (CIHC) developed a national interprofessional competency framework that stresses the importance of team functioning, role clarification, conflict resolution, and collaborative leadership to ensure effective interprofessional collaboration and ultimately improved patient outcomes (Canadian Interprofessional Health Collaborative, 2010). With this framework, institutions and researchers can begin exploring various interventions to buffer power differentials, such as persuasive knowledge exchange (Dunn, 2011) and interprofessional education such as simulations and role-playing.

5.4.1.4 Summary.

When considering nursing practice in general, we must consider the implications of constantly targeting nurses as the potential modifiable factor in our interventions. Given the business discourse prominent in the health care system (D'Agata & McGrath, 2016), the ongoing devolution of responsibilities to nurses, or the responsabilization of nurses as the end agents in the chain of hospital management and cost-savings measures, leaves them in an increasingly precarious position (Brown, 2015). As a result, McMillan & Perron (2013) discuss the concept of change fatigue, which results in feelings of disempowerment, apathy, and disillusionment amongst nurses. They argue that the interventional outcomes-based approach in health sciences, and therefore nursing, creates strain on nurses and results in a complex interaction with the notions of organizational change (McMillan & Perron, 2013). To summarize, I would like to put forth that, when it comes to changing practices, 'you can't get blood from a stone'- meaning that the existing pressures on nurses in the contemporary system act as significant barriers on their ability to respond to, and provide, EBPs and FCC in practice. Realigning our approaches to explore nurses' perspectives on change is essential to provide a more comprehensive understanding of the practical barriers of providing FCC in the NICU (McMillan & Perron, 2013).

5.4.2 Implications for Nursing Education

In the concept analysis and literature review, we identified parent empowerment through education and KT as a key attribute of FCC in the NICU. However, the results of the descriptive correlational study, and supporting literature, demonstrate that parents still experience knowledge gaps that impact their ability to be involved in their infant's care. Accordingly, in

order to effectively and confidently deliver FCC in the NICU, nurses, nursing students, and other HCPs also require additional education, training, and professional development.

5.4.2.1 Parents.

Individualized parent education is essential for their well-being and the well-being of their infant(s). Existing literature has explored various parent-targeted educational interventions such as videos (Lavin Venegas et al., 2019), audiotaped educational-behavioural sessions (Melnyk et al., 2006), in person group education (Cooper et al., 2014), and peer-to-peer education (Bourque et al., 2018). Although there is evidence to support that these interventions are acceptable to parents and improve their overall satisfaction, these approaches all implicitly acknowledge the strain of providing one-on-one individualized education; nurses simply do not have the time or capacity to conduct in-depth individualized educational assessments and to deliver the appropriate educational interventions. Education in the context of the NICU is relational and the quality of communication and the nurse-patient relationship impacts parents' overall satisfaction with, and understanding of, the education provided (Meyer et al., 2011). Therefore, nurses require training and support to solidify, model, and individualize knowledge transfer and education with parents.

The results of the descriptive exploratory study support that parents experienced a lack of clarity and understanding about the things they can do to be involved in their infant's care. These concerns are accentuated for parents in surgical NICUs when compared to parents in traditional NICUs (Govindaswamy et al., 2019b). In the surgical context, these difficulties also include positioning, surgical equipment, and involvement in pain care. For example, the implications for parent involvement following a cardiac surgery may be significantly different from the implications after the repair of a neural tube defect. Given the relational nature of knowledge

transfer in the NICU, methods such as written information or standardized care pathways may not be sufficient to account for these unique considerations. It follows that the type and amount of both information and support given to parents must be tailored and individualized for each parent and infant's unique needs. In order to provide more opportunities for parent involvement,

5.4.2.2 Nurses.

Multiple models of FCC in the NICU indicate the need for enhanced training and professional development in order for nurses to confidently and effectively deliver FCC. In the literature, nurses report the need for increased training regarding a variety of aspects related to FCC in the NICU, for example: performing painful procedures while infants are held SSC (Harrison et al., 2015), establishing and maintaining close relationships with parents (Fegran et al., 2008; Fegran & Helseth, 2009), communication (Weis et al., 2013), and collaboration (Ahlqvist-Björkroth et al., 2017). In addition, given the fact that working in the NICU is stressful, the addition of FCC principles and the complex relationships that form as a result place additional strain on nurses (Altimier & Phillips, 2016; Rochefort & Clarke, 2010). As a result, it is recommended that training about FCC in the NICU also include information and education about mental wellness for staff (Altimier & Phillips, 2016; Jiang et al., 2014). Addressing these educational gaps is essential for ensuring that nurses feel empowered and capable of delivering FCC in the NICU (Chaghari et al., 2017). Thus, if institutions and nursing leaders wish to adopt a FCC philosophy and ensure its principles are applied in practice, they must commit to an ongoing professional development program for their NICU nurses (Altimier et al., 2015; Benzies et al., 2018). They must also engage in continuous quality improvement in collaboration with nurses to address their needs as they arise in the course of clinical practice (Purdy et al., 2017).

In the Canadian context, patient-and-FCC is a core competency and ethical obligation for Registered Nurses (Canadian Nurses Association, 2017; Public Health Agency of Canada, 2017). Given the challenges in practice, I recommended re-orienting the competencies of pre-graduate nursing education at both the theoretical and practical levels to better reflect these essential skills in nursing curricula (Jiang et al., 2014; John & Flowers, 2009). At the theoretical level, literature supports that employing parents and families as faculty to teach and explore FCC offers valuable lessons and fosters reflection among students in health professions (Johnson et al., 2006). From a clinical practice perspective, I recommend a three-pronged approach involving clinical instructors, students, and parents themselves. Although it is a poorly researched role, clinical instructors require enhanced support to meet the demands of working in both the clinical and academic contexts simultaneously (Dahlke et al., 2012). Engaging with clinical instructors and providing professional development to support them in mentoring and role-modelling a FCC approach is the first step in communicating to students that FCC is about *how* care is delivered rather than *what* care is given. To prepare students for a clinical environment that embraces a FCC philosophy, the use of standard actors in laboratory simulations has been shown to increase nursing students' insight about the importance of caring for the entire family and empathic communication (Fitzgerald & Ward, 2019). Despite these recommendations, in a study with 24 pediatric medical residents, Mann et al. (2013) found that a family-centered care curriculum did not impact the residents' perceived level of competence with FCC. However, evidence supports that parents have the knowledge and desire to be involved in the assessment of nursing students' clinical practice (Balasa, 2019). In the pediatric or neonatal setting, the parents' unique perspective may help to bridge the gap between curriculum and competence. Ultimately, better

preparing nurses at the baccalaureate level could reduce the eventual burden on institutions and ultimately better prepare nurses for the intricacies of FCC in practice.

5.4.3 Implications for Nursing Research and Theory Development

This thesis carries important implications for future research and theory development. In particular, further research should explore: the particular implications of operationalizing FCC with surgical infants, the institutional and systemic barriers impacting the delivery and implementation of FCC, and how to increase the amount of parent perspectives in the literature. From a theoretical perspective, supporting nurses in a supportive-educative role requires exploring Patterns of Knowing (Carper, 1978) other than empiric, such as aesthetic.

5.4.3.1 Surgical infants.

As evidenced in this thesis, there is a significant gap in the literature regarding appropriate FCC for surgical infants in NICUs. In a prospective cohort study with 111 parents, Govindaswamy et al. (2019b) showed that parents of infants in surgical NICUs have needs and stressors that are distinct from parents of preterm infants. They conclude that parents' needs in these settings is best met by individualizing the delivery of FCC (Govindaswamy et al., 2019b). Therefore, based on a systematic review of 20 articles, Govindaswamy et al. (2019a) established key recommendations for supporting parents of surgical, term, and near-term NICU infants. The recommendations include: open and honest information, effective communication, training for HCPs regarding parental needs and stressors, continued professional development for HCPs, and organizational family-friendly policies (Govindaswamy et al., 2019a). In the descriptive exploratory study, we identified significant challenges and knowledge-to-practice gaps in a surgical NICU. For example, despite the importance of SCC and PIPC in this population, infants in our study received little of either. Therefore, it is reasonable to state that there is an urgent

need to explore FCC in the context of neonatal surgery to tailor its delivery to the unique needs of this population.

Further, the concept of FCC in the NICU has evolved significantly since its first appearance in the literature. The concept analysis and literature review identified the need to explore whether concepts such as family integrated care represent an evolution of FCC in the NICU or a conceptual departure. Given that the majority of the literature informing the concept of FCC in NICU deals almost exclusively with preterm infants, we must also consider the possibility that FCC in a surgical NICU is conceptually different from FCC in other NICUs. Although the philosophy of FCC may underpin its delivery in many contexts, it must be conceptually adapted to each unique setting; to do otherwise would be to violate the fundamental stipulation that FCC must be individualized based on each family's needs. Although we developed a basic framework for exploring FCC in surgical NICUs in this thesis, further research should be conducted to deepen our understanding about the implications of operationalizing FCC for this population specifically.

5.4.3.2 Evaluating barriers holistically.

Holistic barrier assessments conducted in collaboration with nurses and HCPs may provide avenues for institutions and researchers to begin exploring these gaps knowledge-to-practice gaps. Models such as the Theoretical Domains Framework (TDF) (Cane et al., 2012; Michie et al., 2005) are used to identify salient factors that impact knowledge utilization and uptake in clinical practice. While KT includes a multilevel organizational perspective (Estabrooks et al., 2007; Estabrooks et al., 2006), Implementation Science focuses primarily on behaviour change (Atkins et al., 2017). Both these approaches have been used to evaluate barriers to EBPs that contribute to FCC. For example, Stevens et al. (2014) used a KT approach

to increase the uptake of evidence-based pain management for hospitalized children. As part of this approach, they identified barriers that influenced the use of evidence-based pain management such as competing priorities, not enough time, and a decrease in staff engagement over time (Stevens et al., 2014). The influence of context, a central consideration in KT, on the use of research evidence in pediatric settings is well-documented (Squires et al., 2013). In a qualitative interview study with 11 nurses, Benoit & Semenic (2014) found that most participants describe numerous contextual barriers to implementing the Baby Friendly Hospital Initiative, an evidence-based WHO program to increase breastfeeding rates (World Health Organization, n.d.). Therefore, using these approaches with an emphasis on the specialized context of NICUs may help researchers and HCPs probe broadly when identifying barriers to certain practices such as SSC and PIPC.

Given that the majority of studies about barriers to FCC in the NICU have used a scientific approach, the use of theoretical eclecticism may also allow for a more in-depth and holistic assessment of barriers to FCC in the literature. For example, Kymre & Bondas (2013) used a phenomenological approach to explore the phenomenon of initiating SSC for nurses; their findings provide insight into the complex interplay of having to balance the infant's needs with those of the parents. Hermeneutic approaches explore the lived experience and meanings associated with various phenomena (Van Manen, 2016). To better understand parents' experiences, Fegran & Helseth (2009) used a hermeneutic approach to understanding the meanings that both nurses and parents ascribe to their relationship with one another in the NICU. These findings shed light on factors that are associated with the perceived quality of the nurse-patient relationship, which is essential for parents' overall satisfaction with the NICU experience (Fegran & Helseth, 2009). Lastly, a critical approach may also provide clarity regarding systemic

barriers in light of its historical and social science perspective and orientation towards social justice (Foth et al., 2017; Gastaldo & Holmes, 1999). Given the plurality of perspectives required to provide FCC in the NICU, it would follow that research and knowledge generation pertaining to this concept should also include a plurality of perspectives and approaches.

5.4.3.3. Considering new methods to increase parent perspectives.

In the concept analysis and literature review we identified a paucity of publications by parents or with parents as co-authors and a prominence of the biomedical perspective. Although many studies explore parent perspectives of FCC in the NICU, it is unclear if member-checking or including parent advisors in the development of the studies was done. Skene et al. (2016) describe a participatory action approach to explore the implementation of FCC in the NICU. In this approach, parents, nurses, and other members of the interdisciplinary team are all fully integrated in the development of the study, the design on the intervention, implementing the change, and evaluating the change (Skene et al., 2016). This approach can potentially bridge the knowledge-to-practice gap regarding FCC in the NICU as it identifies what is feasible and acceptable at the outset (Skene et al., 2016). This approach also has the potential to challenge the power hierarchies between researchers, HCPs, and parents by respecting everyone's contributions equally and not defining a priori (from the researcher's perspective) the research questions and/or the intervention design. Another participatory approach described by Trajkovski et al. (2015) is appreciative inquiry. An appreciative inquiry approach acknowledges and emphasizes the importance of discourse in enhancing or impeding change and growth; appreciative inquiry facilitates crossing boundaries, engaging groups, and constructing a shared vision of FCC in the NICU (Trajkovski et al., 2015). Trajkovski et al., (2015) used an appreciative inquiry approach in their study with nine nurses and six parents. The discussions

engendered a strength-based approach that bridged disagreements and the varied perspectives of participants (Trajkovski et al., 2015). These approaches challenge the notion that the privileged knowledge of professionals, such as nurse, allows them to best interpret and direct care (MacKean et al., 2005).

5.4.3.4 Redefining the role of nurses?

From a theoretical perspective, the shift from nurse as caregiver to nurse as coach, mentor, and educator requires further exploration. Nursing has changed significantly since its recognition as a distinct calling in the works of Florence Nightingale (Nightingale, 1860). As a result, defining the role of nurses and nursing has been a central goal of the nursing profession. In 1978, Carper delineated four patterns of knowing in nursing, namely: empirics, aesthetics, personal knowing, and ethics, to provide a guideline for generating nursing knowledge. While nurses must balance and integrate all these patterns of knowing in their professional practice, empirical knowing is the most well-developed (Chinn & Kramer, 2013). Accordingly, this focus on the biomedical and task-based aspects of nursing has become the contemporary clinical reality of nursing in many contexts. Despite this, in order to deliver FCC in NICU nurses must shift from a caregiving role to a supportive-educative role which ultimately results in role confusion and loss of empowerment (Axelin et al., 2014). To support this role change, research should explore how best to incorporate these patterns of knowing in a primarily supportive-educative role, rather than the wholly compensatory approach typically required in acute settings such as the NICU.

In particular, Carper (1978) described the aesthetic way of knowing as the art of nursing which involves empathy and gaining new perspectives and awareness. The process of aesthetic knowing involves engaging, interpreting, and envisioning; the expression of this knowledge is

borne out in the actions of the nurse towards their patients (Bournaki & Germain, 1993). Like FCC, aesthetic knowing in nursing is not about actions *concretely* but rather *how and why* those actions were undertaken. In a family-centered supportive-educative role the nurse must engage with families and respond to their unique needs; developing nurses' aesthetic knowing would support them in integrating a family-centered philosophy into their own practice.

5.4.3.5 Summary

Given that the cross-sectional descriptive exploratory study primarily explored parents' perspectives, immediate future research should begin by exploring nurses' perspectives on delivering FCC with surgical infants in particular. Given the unique needs of this population, nurses' perspectives are essential in order to gain insight into the practice realities and the institutional context. In addition, in order to gain new insights on systems level barriers to FCC, future research should also explore the perspectives of nursing managers and hospital leaders, which is largely absent from the current literature.

5.4.4 Implications for Nursing Leadership and Policy Development

An overarching theme of this thesis is that support from institutional leaders and policy makers is essential for delivering FCC in the NICU. As stated by Dykes et al. (2016), there needs to be "political motivation, appropriate policy planning, legislation and resource allocation" (p. 1039) in order to facilitate parent-infant closeness and FCC in the NICU. In order to delineate the implications of this thesis for nursing leadership and policy development I will discuss: family friendly policies, fiscal reform, and advocacy.

5.4.4.1 Family-friendly policies.

As discussed, parent-infant closeness is essential for FCC in the NICU. Best practice for FCC in the NICU is that parents should have unrestricted access to their infant (Coughlin et al.,

2009; Moore et al., 2003). Shifting from parents as visitors to parents as caregivers requires revisiting standard visitation policies (Altimier & Phillips, 2016). Traditional visitation policies in the NICU reflect concerns about the potential for nosocomial infections, ensuring the safety of such vulnerable patients, and ensuring a developmentally-supportive environment that is free of excessive stimuli (Griffin, 2013; Lee et al., 2014). In the NICU where the descriptive exploratory study was conducted, traditional visitation policies included: limit of two individuals at the infant's bedside at any given time, no children under the age of 12 in the unit at any time, and only one unit access card is given to parents. Given that parents in the literature and in our study reported challenges with traditional visitation policies, we must leverage our concerns with the fact that individualizing visitation policies to each family empowers them to decide who is, and isn't, integral to their support system during their infant's hospitalization, which is essential for FCC in the NICU (Altimier, 2015). Griffin (2013) describes the need to shift traditional visitation policies to "family-centered visitation policies" (p.160). In order to facilitate these FVPs, facilities must revisit the language used when approaching visitation and center policies around collaborative communication with parents to come to individualized and mutually agreeable visitation 'policy' for each family (Griffin, 2013).

Although most NICUs support a FCC approach, claims of unrestricted access typically only reflect the infant's parents, which becomes increasingly the case during viral season winter months (Tan, Clarkson, & Sharkey, 2018). Policies should also reflect the importance of the entire family's involvement which includes siblings, grandparents, and any other individual that the parents deem necessary for their support (Mirlashari et al., 2019). Given that care for other children is a significant concern for parents both in this thesis and in the existing literature, efforts to include siblings may improve parental presence overall. Evidence supports that when

siblings are encouraged to be present at the bedside the overall parent-nurse relationship improves and siblings demonstrate greater attachment to the infant (Milford, 2016; Morrison & Gullón-Rivera, 2017). In order for institutions to enact and support FVPs, they must first change their discourse and terminology. Parents should not be “visitors” but rather integral members of the team (Altimier & Phillips, 2016); rather than visitation policies, these should be “family participation guidelines” (Levick et al., 2010, p. 920). Addressing discourse also facilitates the holistic embodiment of FCC as a philosophy from an organizational perspective.

5.4.4.2 Fiscal reform.

To deliver FCC in the NICU in substance and not just in name, challenging the cost-efficient business discourse of health institutions is required (Coyne, 2015; D’Agata & McGrath, 2016; MacKean et al., 2005). As discussed in our concept analysis and literature review, FCC in the NICU must be regarded as a philosophy, rather than a prescription for care. Therefore, for institutions to fully embrace this philosophy, they must reorient their priorities. This includes: financial support for parents, staffing, and unit redesigns.

5.4.4.2.1 Financial support for parents.

The financial impact of NICU hospitalizations on parents and families was mentioned in the discussion above. This finding is not unique to this thesis; previous studies have identified the financial burdens of NICU hospitalizations on parents (Milford, 2016; Shields, 2010). As discussed above, taking care of families must also involve the social, and thusly the economic, impacts of a NICU hospitalization on the family. Despite the identification of this barrier in the literature, models and interventions such as FiCare and the IDC are limited in the financial support they can offer (Altimier & Phillips, 2016; Jiang et al., 2014). In the existing literature, certain approaches have provided some financial relief to parents by offering transit passes,

subsidized parking, and a kitchen for food preparation (Jiang et al., 2014; O'Brien et al., 2015). Although this falls short of being holistic, I argue that this gap is due to lack of institutional buy-in and the resulting impossibility of allocating additional funds to such initiatives. A possible explanation is that the impact of such efforts is difficult to measure quantitatively; therefore, the immense effort required to shift the austere fiscal approaches in healthcare is not justifiable. It is clear that PP at the bedside is the most important factor in facilitating FCC in the NICU; therefore, organizational change approaches should also consider the radical financial and economic changes necessary to facilitate this practice when implementing a FCC approach.

5.4.4.2.2 Staffing.

Several studies describe nursing workloads as a barrier to providing FCC in the NICU (Benzies et al., 2018; Marfurt-Russenberger et al., 2016). In order for nurses to practice their supportive-educative roles, they require sufficient time to develop the complex trusting relationships with parents that allow them to individualize care (Axelin et al., 2014; Heinemann et al., 2013; Kjellsdotter et al., 2018). For the population of surgical infants, pain management is a key stressor for parents (Govindaswamy et al., 2019c). Therefore, it is particularly important in this context to consider that inadequate staffing results in lower rates of SSC during painful procedures (Benoit et al., 2016), and lower rates of pain management in general during similar procedures (Anand et al., 2005). Despite this, staffing ratios remain static. One possible explanation is that nursing ratios are almost solely decided based on infant acuity (Rogowski et al., 2015). For example, the Winnipeg Assessment of Neonatal Nurse Needs Tool (WANNNT) is an assessment tool designed to assess “how much of a nurse” is required to provide patient care (Winnipeg Regional Health Authority, 2013a, p.1). According to this tool, infant needs are ranked in terms of the pre-determined time-intensity required to care for them (Sawatzky-

Dickson & Bodnaryk, 2009). For example, an infant in active opioid withdrawal would require 0.5 nurses and a convalescing infant with parents requiring education would require 0.3 nurses (Winnipeg Regional Health Authority, 2013b). Recently, the WANNNT has been adapted for surgical neonates (WANNNT-SC) and includes provisions for aspects such as diagnostic imaging and post-operative care (Hart et al., 2019). While this tool may more accurately reflect the biomedical needs of surgical infants, Hart et al. (2019) concede that “neurodevelopmental care, such as transfers for skin-to-skin care, and certain subjective aspects of workload such as interacting with parents were not explicitly addressed [in the WANNNT-SC]” (p. 295). Given this, and the particular importance of SSC in the population surgical infants, it is reasonable to question whether the time required to provide FCC in the NICU can be truly captured within these existing staffing models.

When considering staffing reform to facilitate FCC in the NICU, Coyne (2015) recommends that staffing ratios be adjusting to reflect the fact that providing FCC in the NICU requires caring for infants and families. In our descriptive exploratory study, the mean NTISS score was 12, corresponding to the infant being “mildly ill, still at small risk” (Gray et al., 1992). However, the parents in our sample still reported challenges with key aspects of FCC, such as PIPC. Therefore, it is reasonable to suggest that fiscal reforms for surgical NICUs in particular requires a revaluation of appropriate workloads given these infant’s unique needs, such as positioning and incision care, that are not necessarily reflected in the infant’s acuity.

Staffing reforms should also reflect the interdisciplinary nature of providing care in the NICU. As mentioned, providing holistic FCC in the NICU requires a variety of perspectives and approaches. In keeping with the idea of considering aspects other than the infant’s acuity when determining appropriate staffing levels, activities such as lactation support and psychosocial

assessments (for example) are both necessary and time-consuming in the postsurgical NICU context. As discussed, lactation consultants facilitate the practice of SSC (Benoit & Semenic, 2014), which further helps mothers achieve and maintain milk supply, and increases maternal empowerment and satisfaction with care (Mercado et al., 2019). Despite the presence of international and national guidelines and recommendations about the importance of breastfeeding and IBCLCs, namely the WHO's Baby Friendly Hospital Initiative (Baby Friendly Initiative Ontario, 2019; World Health Organization, n.d.) and the Public Health Agency of Canada's national guidelines on family-centered maternity and newborn care, many NICUs do not employ, or under-employ, lactation consultants (Mercado et al., 2019). This is due in part to the perception that nurses can provide the same care, and thusly allocating funds to hire lactation consultants is seen as superfluous (Froh, Dahlmeier, et al., 2017). However, this does not consider that existing workload burden on nurses in the context of the NICU may prevent the delivery of comprehensive and appropriate lactation support. In order to alleviate burden on the nurses, institutions must acknowledge the importance of interdisciplinary expertise and the appropriate staffing levels for these professionals and providers (Froh, Dahlmeier, et al., 2017; Froh, Deatricks, et al., 2017; Mercado et al., 2019). As discussed above, this requires institutions to fully embrace the FCC philosophy and actively work against the dominant biomedical-outcomes based fiscal discourse (D'Agata & McGrath, 2016).

5.4.4.2.3 Unit redesign.

In the concept analysis and literature review we identified physical environments that support parent-infant closeness as an antecedent to providing FCC in the NICU. Certain unit designs facilitate parental presence, while others present barriers to parents' ability to be present. The typical NICU layout, or open ward (OW), consists of rooms (or bays) that can house

anywhere from four to 20 infants (Stevens et al., 2011). This design has been criticized due to its lack of privacy, inability for parents to stay overnight, and excessive auditory and visual stimuli (Raiskila, 2018; Shahheidari & Homer, 2012). An alternative family-centred approach, single-family rooms (SFRs), allows for more privacy, space, and stimuli reduction to encourage developmentally-sensitive care (Palomaa et al., 2016; Toivonen et al., 2017). In the context of surgical NICUs, SFRs facilitate greater parent involvement in pain care (Benzies et al., 2018; McNair et al., 2020). In the NICU where the descriptive exploratory study was conducted, the unit was designed as a hybrid between OW and SFR. The unit consisted of three major bays housing four to six neonates, one isolation room, and two SFRs. Accordingly, four parents in our study reported that there was nowhere for them to sleep and many discussed challenges with lack of privacy, space, excessive stimuli, and involvement in pain care. As mentioned, the ability for parents to stay overnight is the most important factor in determining their ability to be present at the bedside and perform SSC (Raiskila et al., 2017). While SFRs may not be feasible in every NICU, institutions with surgical NICUs should consider their particular importance for this population.

Infrastructure changes within a tertiary hospital are complex and resource-intensive; therefore, these changes are not feasible for many institutions. Despite the degree of commitment of each institution to the philosophy of FCC, legislative change is required to ensure sufficient funding is allocated to such an initiative (Altimier, 2015; Sundean & McGrath, 2013). Therefore, whether institutions have an open ward design, a hybrid design, or a SFR design these are factors that they must consider to maximize outcomes for infants and their families (Vohr, 2019).

5.4.4.2.4 Summary.

Despite the fact that compensation for parents, staffing reform, and unit design are identified and discussed in the literature, there has been little work to actually address these barriers. Acknowledging that this is likely due to a lack of financial resources, future organizational change initiatives should consider the importance of the broader systemic changes required to embrace FCC in the NICU as a philosophy. In light of the persistent challenges with the operationalization of FCC in practice, and the pervasive yet unaddressed impact of economics and finances, it is reasonable to suggest that fiscal reform may have a significant impact on the feasibility of providing FCC in the NICU.

5.4.4.3 Advocacy.

To reflect the ever-changing role of nurses, Chinn & Kramer (2013) added emancipatory knowing to the patterns of knowing in nursing mentioned above. In the Canadian Nurses Association (2017) code of ethics for Registered Nurses, promoting justice and advocating for equity are ethical obligations of Registered Nurses. Acting as a patient and family advocate is an intrinsic and key part of nursing practice (Fahlberg & Dickmann, 2015). In the context of the NICU, nurses struggle with finding a balance between the needs of the family and the needs of the infant (Feeley et al., 2016; Kymre & Bondas, 2013). While it may appear clear the patient in this context is in fact the entire family, it is less clear what this looks like in practice. This confusion is also related to the lack of role clarity surrounding the NICU nurse's new supportive-educative role. Therefore, clarifying priorities and expectations at both institutional and professional levels is necessary to ensure nursing's equal voice in the interdisciplinary team.

Social justice requires activism and political involvement, therefore making the act of nursing fundamentally political, whether this is explicitly acknowledged or not (Perron, 2013).

Lunardi, Peter, & Gastaldo (2002) discuss the notion of power anorexia; they describe how nurses who challenge the status quo are often putting their professional careers at risk in order to do so. Therefore, their moral agency to advocate for change is limited (Lunardi et al., 2002). The perceived (or actual) inability to affect systems-level changes partially explains why a large proportion of KT and implementation science studies in the NICU address modifiable factors, such as parent and nurse education, nurse attitudes, and nurse behaviours. While this is an important aspect of impacting the uptake of FCC and related EBPs, it is likely to be ineffective on its own (Benzies et al., 2018). This scenario is somewhat paradoxical; nurses are healthcare agents that experience significant pressures and scrutiny, yet they are unable to speak out against the conditions within which they work (McMillan & Perron, 2013). As a result, “nursing leaders have a professional obligation to advocate within their communities and at the national level for the patients and families they serve, the institutions they represent, and the nursing profession” (Groenwald & Eldridge, 2020, p. 28). In the context of this thesis, nursing leaders must be actively involved in advocacy to influence public policies that have implications for the health of NICU families (Spenceley et al., 2006).

5.4.4.4 Summary.

Nurses and nursing leaders are ideally positioned to participate in public policy advocacy and development due to their knowledge of health and the social determinants of health, the trust they hold with the public, and their acknowledged role as advocates for health equity (Spenceley et al., 2006). Nurses must actively challenge the dominant financial discourses of cost savings pervasive in health policy to promote a FCC philosophy at institutional, national, and international levels. To this end, engaging with regional, national, and international stakeholders (such as the Better Outcomes Registry and Network [BORN], PCMCH, and PHAC) is essential

in order to shift the discourse around FCC and garner political will to make FCC in the NICU a priority. As Lunardi, Peter, & Gastaldo (2002) ask, are submissive nurses ethical?

5.5 Strengths and Limitations

Several strengths and limitations pertaining to this thesis require mention. To our knowledge, this was the first study to explore FCC, and in particular PP, PH, SSC, and PIPC, for post-surgical infants in a NICU. The results from this thesis provide important insights into the clinical reality of operationalizing FCC with specialized NICU populations. In particular, it highlights significant knowledge-to-practice gaps and offers important avenues for further exploring and adapting FCC for surgical NICUs.

From the perspective of limitations, the cross-sectional descriptive exploratory study was constrained by a small sample size, which was compounded by the early cessation of participant recruitment in light of the COVID-19 pandemic. Second, although the search strategy and inclusion criteria were broad, only five included articles were led by parents. This was likely compounded by the fact that only peer-reviewed sources were included and other forms of expression, such as visual art, were not included. Similarly, the descriptive exploratory study was limited due to the lack of health care provider perspectives. Due to the timeline for thesis completion, it was not possible to explore both parents and HCP perspectives. Therefore, in keeping with the philosophy of FCC, I chose to focus on parents. Further work should strive to integrate these perspectives in literature reviews, quality improvement projects, and research, in order to give an equitable voice to families and HCPs.

From a theoretical perspective, this study was limited by the lack of a pre-existing framework for exploring FCC with surgical NICU infant. Therefore, I relied on theoretical

eclecticism and the literature review and concept analysis to inform the conduct of the descriptive correlational study.

5.6 Conclusion

This thesis sought to clarify and define the concept of FCC in the NICU and subsequently explore its operationalization in a surgical NICU. Emphasizing the key aspects of parental presence and skin-to-skin care, the integration of findings from the concept analysis and literature review and the descriptive exploratory study helped to illustrate the divide between the theoretical concept of FCC and its implementation in practice. The results of the cross-sectional descriptive exploratory illustrate that despite a strong evidence base supporting FCC practices in the NICU, many complex barriers require further assessment in tailoring this approach to surgical NICUs. Holistically, this thesis also raises particular implications for resource allocation and brings into question traditional discourses based on efficiency and cost-savings. The importance and value of FCC in the NICU is incontestable, but the realities of clinical practice appear to be increasingly incommensurate with its provision. In closing, the remarks of Linda Shields (2017) ring particularly true- “all is not well with family-centred care” (p. 14).

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