PAIN CARE FOR CHILDREN WITH COGNITIVE IMPAIRMENTS: A PARENT-NURSE PARTNERSHIP

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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 acute care hospital where the research was conducted (Appendix A).

Statement of Contributions and Co-authorship

This thesis was co-authored by several individuals, in partial fulfillment of the requirements for the Master of Science in Nursing degree at the University of Ottawa. A summary of the authors' contributions is stated below.

1. Juliana Choueiry, RN, BScN

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The Master's student, Juliana Choueiry (JC), is the primary author of this thesis. JC conducted a review of the literature to determine knowledge gaps related to the research topic. Then, JC developed the research questions and drafted the thesis proposal as well as the study protocol. All data were collected and analyzed by JC. All chapters for the final version of this thesis were drafted by JC, with consideration of the feedback provided by the co-authors.

2. Julie Chartrand, RN, PhD

   Associate Professor, School of Nursing, Faculty of Health Sciences, University of Ottawa

The thesis supervisor, Dr. Julie Chartrand (JCh), provided guidance and feedback on all project elements including the conception and design of this study. JCh supported the development of the thesis proposal by drafting, reviewing, and approving the proposal. JCh also helped to complete ethics applications and was involved in data analysis. JCh independently coded interview transcripts, discussed research findings and assisted in developing the study's

codebook. The development of this thesis and each of its chapters was guided, reviewed, and approved by JCh.

3. Denise Harrison, RN, PhD

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Thesis committee member, Dr. Denise Harrison (DH), was involved in the design and methodology of this study, particularly assisting in refining the research question. DH assisted in data analysis by independently coding interview transcripts and discussing research findings. DH also reviewed and approved all study documents including the thesis proposal, the thesis chapters, and the monograph.

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Thesis committee member, Dr. Anna Don (AD), was involved with the design and methodology of this study. AD reviewed and approved the thesis proposal. AD also assisted with data analysis by independently coding interview transcripts and discussing research findings. AD reviewed and approved the thesis chapters and this manuscript.

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Thesis committee member, Dr. Wendy Peterson (WP), was also involved with the design and methodology of this study. WP reviewed and approved all study documents including the thesis proposal, the thesis chapters, and the manuscript.

6. Alice Domtinet

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Undergraduate nursing student, Alice Domtinet (AlD), was involved in interview transcription and data analysis. Alice was enrolled in the Undergraduate Research Opportunity Program (UROP) at the University of Ottawa, under the supervision of the thesis supervisor (JCh) and gained research experience while working on this study.

Abstract

Parent-nurse partnerships are essential for pain care of children with cognitive impairments (CI), who experience a high prevalence and intensity of pain. However, researchers have not published findings about how parents and nurses partner for pain care of this population and the guiding partnership philosophy has been reported to be ambiguous. Thus, this qualitative interpretive descriptive study aimed to explore nurses' experiences of establishing partnerships with parents for pain care of hospitalized children with CI. Videoconferencing interviews were conducted with eleven nurses. Verbatim transcripts were analyzed using an inductive, data-driven thematic analysis approach, resulting in eight main themes. Overall, nurses expressed uncertainty about providing pain care for this population and consequently, stressed the need to rely on parents. This study provides new knowledge relating to the realities of partnership practices. The findings have implications for nursing practice, education and research that may help to optimize pain care for children with CI.

Keywords: Pediatric Pain, Partnership, Children with Disabilities, Nursing, Cognitive Impairment

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Chapter 1: Introduction

According to the International Association for the Study of Pain (IASP), pain is defined as an "unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (2020). Unfortunately, hospitalized children frequently experience pain. In fact, a study by Harrison et al. (2014) revealed that a significant number of children (82%, *n* =62) experienced moderate to severe pain during hospitalization. While pain commonly affects all hospitalized children, it is a particularly prevalent issue in hospitalized children with cognitive impairments (CI) due to their neurological impairments, associated physical co-morbidities and limited ability to clearly express, or self-report pain (Hauer, 2010; Freund & Bolick, 2019). While there is no clear definition for CI, it has been used to describe "the condition of a child whose intellectual functioning level and adaptive skills are significantly below the average for a child of their chronological age" (Siskin Children's Institute, n.d.). Other studies have also used the terms intellectual disabilities, developmental disability, learning disability or cognitive disability to describe this population (Cascella et al., 2019; McKay & Clarke, 2012; Oulton et al., 2015).

According to the American Psychiatric Association, the diagnosis criteria for intellectual disabilities include deficits in general mental abilities that result in impairments of adaptive functioning and are determined by an intelligence quotient (IQ) of 70 or less (American Psychiatric Association, 2013). However, no diagnostic tools are available to precisely assess a child's IQ level (Cerebral Palsy Foundation, 2021). Instead, minimal speech ability has been used to assess a child's language development and CI. For example, a child who can make sounds but cannot express words would be considered to have profound cognitive impairment (PCI) (Terstegen et al., 2003). In previous reports, children with CI were diagnosed with a

spectrum of medical conditions including encephalopathy, epilepsy, hydrocephalus, neurodegenerative conditions, cerebral palsy (CP), and/or autism (Dubois et al., 2010; Garg et al., 2017; Oulton et al., 2015; Solodiuk, 2013).

For over a decade, researchers have reported that children with CI experience more frequent and more intense pain than children without CI (Breau et al., 2003; Carter et al., 2017; Stratton & Hartshorne, 2019). In fact, multiple studies over the years have reported high prevalence, high intensity, and long duration of pain in children with CI (Breau et al., 2003; Carter et al., 2017; Stratton & Hartshorne, 2019). For instance, in 2003, researchers in Nova Scotia conducted a prospective cohort study to document the frequency, duration and intensity of pain experienced by children with CI over a period of one year. Physicians working at a tertiary-care pediatric centre recruited parents for this study, who completed telephone pain surveys about their children. This study found that more than one-third of the 94 children included in the study experienced intense pain at least once a week, lasting longer than 9 hours (Breau et al., 2003). Similarly, in 2017, a mixed methods study, conducted in the United Kingdom, used parent-targeted pain surveys to determine the intensity, duration and timing of pain experienced by children with profound cognitive impairment. Parent surveys were administered weekly, for a total collection period of eight weeks (Carter et al., 2017). Eight parents participated in this study. All parents perceived their children with PCI to have high pain burden and endured intense pain daily, nightly or on most days (Carter et al., 2017). More recently, researchers in the United States of America (USA) conducted a study to identify the frequency and intensity of pain experienced by children with CI. Parents measured their children's pain using two pain scales (i.e., Paediatric Pain Profile [PPP] and the Non-Communicating Children's Pain Checklist-Revised) and completed a pain questionnaire. On a "good" day, parents felt that their

children with CI experienced mild or moderate pain (Stratton & Hartshorne, 2019). Similar findings were reported in all studies, concluding that children with CI experience a high prevalence and intensity of pain regularly.

Multiple studies have also reported that children with CI experience more hospitalizations than children without CI (Bebbington et al., 2013). Although these studies are dated, they remain relevant to the topic. For example, a 2004 study, conducted in the USA, revealed that children with CI had over 4 times the number of hospitalizations and spent 8 times as many days in hospitals as other children (Newacheck et al., 2004). Additionally, an Australian study found similar results, reporting that children with CI had a significantly higher risk of hospitalization than children without CI (RR = 1.64, 95% CI 1.6-1.7, $p < 0.0001$) (Williams et al., 2005). Williams et al. found that almost 80% of children with CI were admitted to the hospital four times within their first five years of life. Comparatively, 48% of children without CI were admitted once in the same time frame (Williams et al., 2005). Similar findings were reported in a 2010 Canadian study, which concluded that individuals of all ages with CI were hospitalized at a higher rate than individuals without CI (Balogh et al., 2010). Thus, healthcare professionals (HCPs) working in hospitals frequently take care of children with CI.

Considering the high incidence of pain in this population, it is important for HCPs to help effectively treat their pain during hospitalization. It is well known that, if left untreated, pain can lead to adverse effects, inhibiting the development of essential adaptive functioning skills (i.e., communication, daily living, socialization and motor skills) and reducing one's quality of life (Breau et al., 2007; Ellzey et al., 2015). Moreover, an Australian study aiming to examine the impacts of comorbidities on the quality of life of children with CI found that recurrent pain experiences had a significant negative impact on the child's quality of life (Reddihough et al.,

2021). Thus, pain needs to be prioritized and measures need to be implemented to ensure high-quality, safe pain management in this group of vulnerable children (Reddihough et al., 2021).

Timely and reliable pain assessment is an essential component of effective pain treatment (Young, 2017). A hierarchy of pain assessment methods has been developed to guide clinicians in this process (Herr & Mccaffery, 2011). Self-report is considered to be the "gold standard" of pain assessment (Batalha & Sousa, 2018; Crellin et al., 2015). However, young children cannot reliably self-report pain, and children of all ages with CI may have limited ability to verbally communicate their pain (Dubois et al., 2010; Garg et al., 2017; Oulton et al., 2015; Solodiuk, 2013). Therefore, clinicians need to rely on observational pain scales to quantify children's pain behaviours (Crellin et al., 2015; Herr & Mccaffery, 2011). For example, one of the most used observational behavioural pain scales is the Face, Legs, Activity, Cry, and Consolability (FLACC) scale, which includes five pain behaviours to observe (Crellin et al., 2018). Each behaviour is measured on a 0-2 scale and compounded to obtain a total score. An increase in FLACC score is indicative of an increase in pain, prompting HCPs to further treat the child's pain (Crellin et al., 2018). While observational pain assessment tools are helpful, HCPs still struggle to reliably assess pain in children with CI. Researchers have identified several challenges that HCPs face when assessing pain in this patient population, including the presence of idiosyncratic behaviours (Doody & Bailey, 2019). In fact, children with CI may exhibit atypical, unique pain behaviours such as lack of expressivity in facial expressions, lack of, or excess motor activity and poor vocalization (Dubois et al., 2010). Children with CI may also have motor coordination or tonus disorders that can inhibit their ability to experience standard pronounced, coordinated pain behaviours (Dubois et al., 2010).

Studies report that HCPs find it challenging to provide effective pain care for children with CI and perceive pain assessment to be particularly ambiguous (Brudvik et al., 2017; Cascella et al., 2019; Crosta, 2014; Ely et al., 2012; Quinn & Smolinski, 2018; Terstegen et al., 2003; Young, 2017). Healthcare professionals' uncertainty related to assessing pain in children with CI is concerning. Multiple studies have reported that HCPs' uncertainty may lead to inaccurate assessments of pain in children with CI thereby increasing the risk of inadequate pain treatment (Brudvik et al., 2017; Carter et al., 2017; Dubois et al., 2010; Ely et al., 2012; Herr & Mccaffery, 2011). In fact, a questionnaire was developed in a USA study to gather clinicians' (i.e., nurses, anesthesiologists, and non-anesthesiologist physicians) perspectives on several pain constructs in children with CI. This study reported that 152 (71%) clinicians reported under-prescribing analgesics for children with CI and 176 (82%) clinicians believed that children who do not complain are less likely to be treated appropriately for their pain (Malviya et al., 2005). Considering these data, it is important for HCPs to understand how to optimize pain care for this population.

Children with CI may communicate their pain with individualized patterns of behavioural cues such as facial expressions, vocalizations, changes in posture, changes in eating, sleeping patterns and mood, feeding intolerance, irritability, or changes in their baseline behaviour (Freund & Bolick, 2019). These unique patterns of pain behaviour are usually best interpreted by children's primary caregivers (Chen-Lim et al., 2012). Thus, it is crucial for HCPs to partner with the primary caregivers (i.e. parents) of children with CI in order to provide optimal pain care (Brudvik et al., 2017; Douglas et al., 2015; Freund & Bolick, 2019; Hauer, 2010; Herr & Mccaffery, 2011; Quinn et al., 2015; Quinn & Smolinski, 2018; Solodiuk, 2013). In the context of pediatric care, partnerships are guided by the philosophy of Family-Centred Care (FCC),

which will be further explained in the following chapters (Kuo et al., 2012; Shields, 2010). Partnership is central to pediatric care and is defined as the integral relationship that exists between parents and HCPs (Barratt et al., 2021). In general, parents have been reported to be better than HCPs at assessing their children's pain (Batalha & Souda, 2018; Brudvik et al., 2017). Parents have a long-term familiarity with their child and can sense a deviation from their child's baseline behaviours (Carter et al., 2002; Cascella et al., 2019; Solodiuk, 2013; Stratton & Hartshorne, 2019), highlighting that parent-HCPs partnerships are vital for pain care of children with CI (Carter et al., 2002; Cascella et al., 2019; Ely et al., 2012; Ryan & Quinlan, 2017; Solodiuk, 2013). It is a principle of nursing practice for nurses to involve parents in the pain assessment of their children and nurses should consider parents as partners in care (Freund & Bolick, 2019). Accordingly, the Royal College of Nursing recommends involving parents as partners in pain care by providing them with training in the use of pain assessment tools such as the FLACC scale (Freund & Bolick, 2019). Similarly, the Registered Nurses' Association of Ontario (RNAO) suggests that pain assessment tools should be explained to patients and their families and pain should be assessed using input from children and their parents (Registered Nurses Association of Ontario [RNAO], 2013). The RNAO also suggests obtaining pain care-related information from children's caregivers, defined as any person providing direct care to the child (Merriam-Webster, n.d.; RNAO, 2013). A quality improvement study conducted in the USA found that the revised-FLACC (r-FLACC) scale is the most appropriate pain assessment scale for children with CI. This finding was based on the study's evidence, literature review and feedback from a Family Advisory Council. The r-FLACC scale takes into consideration the importance of parent proxy assessments by making it necessary to involve parents in order to appropriately use the scale for pain assessment (Chen-Lim et al., 2012).

It is important to note that partnerships with parents can also potentially facilitate the participation of the individual with CI in care (Pfister et al., 2020). No research has been conducted to assess how clinicians partner with the child with CI for care. However, a study using grounded theory methodology about the participation of adults with CI was conducted (Pfister et al., 2020). This study, which included 23 individuals, found that families (i.e., parents, siblings, grandparents) of individuals with CI were an important reference and support for individuals with CI. Thus, findings may be extrapolated to families of children with CI and their need to be supported by HCPs early on to enhance participation in pain care for children with CI (Pfister et al., 2020).

Nurses play a crucial role in assessing and managing pain (Batalha & Sousa, 2018). Nurses have an ethical obligation to provide effective pain management and comfort to all individuals (Herr & Mccaffery, 2011; Canadian Nurses Association [CNA], 2017). Appropriate pain management is a fundamental human right and institutions are required to ensure that this health standard is respected (RNAO, 2013; United Nations Human Rights Office of the High Commissioner [UN Human Rights], 1990). In fact, according to the Declaration of Montreal, HCPs would breach patients' human rights if they failed to ensure appropriate pain assessment and management (IASP, 2018). Children have the right to enjoy the highest attainable standard of health and to appropriate treatment of their illness and pain (UN Human Rights, 1990). It has been recognized that partnering with parents is crucial for effective pain care of children with CI and that nurses play an important role in pain care (Batalha & Sousa, 2018; Ryan & Quinlan, 2017). However, little is known about nurses' experiences establishing partnerships with parents during pain care of hospitalized children with CI. This study aimed to address this knowledge gap and to contribute to the literature in this understudied group of children.

Research Purpose and Questions

The purpose of this qualitative study was to explore nurses' experiences of establishing partnerships with parents for pain care of hospitalized children with CI. More specifically, this study aimed to understand how nurses partner with parents during pain care of hospitalized children with CI and identify related facilitators and barriers for this process by addressing the following research questions:

(1) What are pediatric nurses' experiences when establishing partnerships with parents for pain care of hospitalized children with cognitive impairments?

(2) What factors do pediatric nurses believe facilitate partnerships with parents for pain care of hospitalized children with cognitive impairments?

(3) What factors do pediatric nurses believe impede partnerships with parents for pain care of hospitalized children with cognitive impairments?

Researcher's Positionality

As for any qualitative study, it is important for the researcher to clarify their positionality in relation to the phenomenon of interest, including assumptions, values and beliefs about the study topic. Thus, this study was inspired by my own previous experiences. I am a female, pediatric registered nurse and research nurse in a pediatric quaternary care hospital, with experience working as a research assistant (RA) for studies relating to pediatric pain. In my role as an RA, I led a project that was focused on developing a training tool to help nurses and nursing students better understand how to appropriately use the FLACC scale. While conducting that study, I reviewed the literature repeatedly and gained extensive knowledge related to pediatric pain assessment scales and to the prevalence of pediatric pain. Notably, I came across many research articles reporting a high prevalence of pain in children with CI and that parent

involvement in their pain care was important. However, in my practice as a registered nurse, it was unclear if and how parents were being involved in the pain care of their children with CI. There were no guidelines to instruct nurses on how to partner with parents in pain care of their children with CI. As each nurse practices differently, partnership practices are also subject to tremendous variation. With no indications to guide nurses in this practice, I wanted to know more about how nurses were currently partnering with parents to provide pain care for children with CI. With this considered, I knew that it was necessary to capture nurses' experiences with providing pain care to children with CI, in partnership with parents. Thus, I made this the focus of my thesis as part of my Master of Science in Nursing.

Researcher's Philosophical Stance

I hold a relativist ontological view, acknowledging that every nurse's reality is subjective and variable. I acknowledge that the nurses' realities are influenced by their contexts, time and by my subjective interpretation and preconceptions (Bradshaw et al., 2017; Thorne et al, 2004; Thorne, 2016). Considering the subjective nature of reality, I hold a subjectivist epistemology. In other words, the knowledge gained from this study is influenced by the research questions that I have constructed, based on my values and on the gaps that I found in the literature (Bradshaw et al., 2017; Guba and Lincoln, 1982). It is also gained through the perspectives of the nurses experiencing the phenomenon and is only known through my subjective awareness of it (Bradshaw et al., 2017; Guba and Lincoln, 1982). Moreover, the findings are influenced by my values as well as the research team's values because we were subjectively interpreting the data, supported by verbatim quotations of participants (Bradshaw et al., 2017; Guba and Lincoln, 1982). My ontological and epistemological views influenced the methodology of this study, which will be explained in the upcoming chapters of this manuscript.

Thesis Outline

The format of this thesis follows the traditional format recommended by the University of Ottawa and contains six chapters. In this first chapter, I introduce the research topic, state the research problem, provide background information related to the topic, and explain my philosophical stance. In chapter 2, I present a review of the existing literature pertaining to parent-nurse partnerships in the context of pediatric pain care and its current guiding philosophy. In the third chapter, I explain the theoretical framework of this study, including the Collaborative Partnership Approach to Care and the Pillars of Partnership in Pain Care Conceptual Model. In chapter 4, I describe the design and methodology of this study, providing details regarding the methods used for participant recruitment, data collection, and data analysis. In the fifth chapter, I present the findings of this study, supported by verbatim quotations from participants. In chapter 6, I provide a discussion and conclusion of the study findings, pointing out future implications of this study.

Chapter 2: Literature Review

In this chapter, I summarize the literature relevant to the phenomenon of interest. I conducted a non-systematic literature review to understand the existing knowledge related to this topic and the limitations of the current literature. In collaboration with the University of Ottawa librarian, who is a specialist in health sciences databases, I developed a detailed search strategy for the Cumulative Index to Nursing and Allied Health Literature (CINAHL) database. As there is limited research related to parent-nurse partnerships for pain care of children with CI, I used the following broad concepts (and similar terms) for the search: (1) pain, (2) parent, (3) collaboration, (4) nursing, and (5) cognitive impairments. I also included articles deriving from the reference lists, if relevant. I limited the search to English and French literature. Additionally, I only included peer-reviewed articles published from 2010–2022 to ensure the inclusion of the most recent high-quality research (Poland, 2013).

Overall, there is very little research produced on pain care for children with CI. In fact, only 0.03% of published pain research has focused on children with disabilities (Belew et al., 2014; as cited in Garg et al., 2017). The previously published research has predominantly focused on parents' and/or HCPs' perceptions of partnerships in care of children with disabilities. However, most studies did not specifically focus on pain care. In the following sections, I describe the guiding philosophy of partnership practices and summarize the existing research examining this philosophy. Then, I present a summary of previous evidence describing HCPs' and parents' perceptions of partnerships in the care of children with disabilities.

Guiding Philosophy of Partnership in Pediatric Care

Partnerships between parents and nurses in the context of pediatric care are established when (1) shared roles and decision-making, (2) parental participation, (3) mutual trust and

respect, (4) communication, and (5) negotiation are established (Barratt et al., 2021). Establishing this relationship is essential for care and the best interest of the child (Barratt et al., 2021). Studies have highlighted that the Family-Centred Care (FCC) approach is a guiding philosophy of care for establishing partnerships with parents during pediatric pain care (Kuo et al., 2012; Shields, 2010). FCC is defined as a mutually beneficial partnership approach between HCPs, patients and families during healthcare decision-making, to attain optimal healthcare (Kuo et al., 2012; Shields, 2010). Similar to the elements of partnership, FCC is based on principles to follow including (1) information sharing, (2) respect and honouring differences, (3) partnership and collaboration, (4) negotiation, and (5) care in the context of family and community (Kuo et al., 2012). In the context of pediatric care, the child is at the core of this approach (Shields, 2010). Therefore, if the child is affected by something, then all family members are affected as well. In turn, the care provided to the child must also be integral to the family members (Shields, 2010).

In general, FCC is well-accepted as a philosophy for partnership practices (Coyne, 2015; Terp et al., 2021). Researchers conducted a qualitative descriptive study including 18 children (7-16 years), their parents and 18 pediatric nurses in Ireland. In this study, parents and nurses believed that FCC was essential for the provision of quality care because they perceived it to reduce stress and integrate parent knowledge in care (Coyne, 2015). Furthermore, families and children perceived that FCC was beneficial by reducing adverse effects during hospitalization, reducing the family's anxiety, and improving their satisfaction with care (Coyne, 2015). Furthermore, a Swedish qualitative descriptive study was conducted to describe parents' perceptions of FCC at a pediatric intensive care unit (PICU) (Terp et al., 2021). In this study, 70 parents of hospitalized children were given the Empathic-30 questionnaire, containing five open-

ended questions. The purpose of this instrument was to measure parental satisfaction with their child's care, and it included questions relating to the five principles of FCC. Researchers found that parents had positive FCC experiences when they were treated with empathy, respect and when the treating team supported them as a family unit. However, parents of children with disabilities expressed that they needed more support and felt that their parental expertise was ignored. Parents perceived the staff to be very competent and felt comfortable having some relief from their role as caregivers. Overall, parents had a positive FCC experience but identified some areas of improvement including participation in decision-making and person-centred communication (Terp et al., 2021).

While FCC has been positively perceived, several studies report barriers to implementing it in practice. The reported barriers to implementation include a lack of negotiation with parents, organizational issues, and a lack of nurse training in FCC (Coyne, 2015; Lotze et al., 2010; Bezdek et al., 2010). Moreover, a mixed method study was conducted to examine HCPs' self-reported family-centred behaviours and HCPs' perceptions of barriers to FCC with children with complex healthcare needs and their families (Lotze et al., 2010). Researchers used the Measure of Processes of Care for Service Providers (MPOC-SP) questionnaire to collect data. In this study, 12 (50%) HCPs reported institutional culture and 8 (33%) HCPs reported care coordination as challenges with implementing FCC in practice (Lotze et al., 2010). In this study, institutional culture was perceived as a barrier because technical skills were thought to be prioritized over time with families (Lotze et al., 2010). Lack of training was also identified as a barrier to FCC, which contributes to inconsistent application of FCC in practice (Lotze et al., 2010). Participants perceived that the lack of training significantly affected the effective implementation of FCC and consequently, the quality of care (Lotze et al., 2010).

Inconsistent application of FCC has been reported in multiple studies and is not only thought to be due to a lack of training for HCPs but several other factors (Bezdek et al., 2010; Coyne, 2015; Kuo et al., 2012; Lotze et al., 2010; Shields et al., 2007; Shields, 2010). For instance, Coyne (2015) found that nurses expressed dependence on parents to provide care. This resulted in FCC practice that was more focused on nurses' workload management rather than parent-patient empowerment. In this study, there was a clear contradiction between how FCC was practiced and how the philosophy was intended to be practiced (Coyne, 2015). Additionally, South American researchers published a commentary regarding the state of FCC in child health (Kuo et al., 2012). These authors state that there is a lack of clarity on how FCC is implemented in practice as there is no blueprint for practical FCC actions for providers (Kuo et al., 2012). The umbrella term of FCC may also have led HCPs to interpret it in many ways. As a result, FCC actions are perceived to be ambiguous by HCPs and expectations of FCC differ between parents and HCPs (Kuo et al., 2012). Similar findings were reported by researchers in the USA, using a grounded theory methodology study conducted to understand allied health perceptions on parent-HCPs partnerships (Bezdek et al., 2010). Twenty participants were given a pilot partnership scale and completed an open-ended interview (Bezdek et al., 2010). The family-professional partnership scale was piloted with a group of professionals as part of a larger study that was not specified (Bezdek et al., 2010). In this study, researchers found that there was a gap between family-centred language and actions expressed by HCPs (Bezdek et al., 2010). HCPs did not express true partnership when discussing their experiences. In fact, this study found that 18 (90%) respondents used family-centred language but had difficulty characterizing family-centred actions (Bezdek et al., 2010).

An Australian discursive article also found that there was scant evidence of FCC being effective for practice, due to the lack of a consistent definition of FCC (Shields, 2010). This researcher identified that there was no level 1 or 2 evidence to evaluate if FCC is beneficial and makes a difference for the families that are cared for (Shields, 2010). To clarify, level 1 evidence refers to experimental studies, randomized controlled trials (RCTs) and systematic reviews of RCTs, with or without meta-analysis (Oregon Health and Science University, 2022). Level 2 evidence includes quasi-experimental studies as well as systematic reviews of RCTs and/or quasi-experimental studies, with or without meta-analysis (Oregon Health and Science University, 2022). There is minimal supporting evidence indicating that FCC is a philosophy of care that can be realistically implemented as a model for partnership practices (Larocque et al., 2021). In fact, researchers conducted a Cochrane systematic review to assess the effects of FCC for hospitalized children on child, family, and health service outcomes (Shields et al., 2007). Researchers found that all studies about FCC lacked rigour in the following domains: (1) blinding of outcome assessment, (2) prevention of contamination between experimental and control groups and (3) allocation concealment (Shields et al., 2007). Researchers have concluded that FCC is an ideal that would be beneficial for practice but is difficult to implement (Shields, 2010).

The above-mentioned studies are related specifically to the perceived application of FCC in pediatric care. Overall, it is a well-perceived philosophy but there are many challenges with implementing it in practice. The following sections describe parents' and nurses' experiences with partnerships in the specific context of care and pain care for children with CI.

Parent Experiences with Partnerships in Care

While many researchers have reported that parents of children with CI highly valued and sought partnerships with HCPs to provide care for their children with CI, they also found that parents' partnership experiences were not ideal (Fereday et al., 2010; Iversen et al., 2013; Hagvall et al., 2016). For instance, several researchers found that parents felt like they were taking on too much responsibility in care during their child's hospitalization, which negatively affected their perceptions of partnership with HCPs (Fereday et al., 2010; Iversen et al., 2013; Hagvall et al., 2016). A 2010 qualitative interpretive study was conducted in Australia to understand parents' experiences of interacting with health professionals (i.e., physicians, nurses, dentists) throughout the care of their children with disabilities (Fereday et al., 2010). Researchers conducted semi-structured focus groups and individual interviews with parents. Parents identified that it was important for HCPs to respect their expertise about their child and that partnership was influenced by HCPs' knowledge about their child's disability (Fereday et al., 2010). Fereday et al. (2010) also reported that partnership was negatively affected because parents felt that HCPs did not have an understanding of their child's disabilities. As a result, parents felt the need to continuously advocate for their child's needs and rights, which placed too much responsibility on them, and left them feeling stressed and overwhelmed (Fereday et al., 2010). Similar findings were found in a Norwegian qualitative exploratory study conducted in 2013 (Iversen et al., 2013). Researchers used a hermeneutic phenomenological approach and conducted in-depth interviews with parents to explore their experiences related to their children with cerebral palsy undergoing surgery (Iversen et al., 2013). Of the nine parents included in this study, five parents had a child with CI that had difficulties verbally communicating. This study found that parents of hospitalized children with CP felt vulnerable and depended very much on

HCP's competencies (Iversen et al., 2013). However, like the previous study (Fereday et al., 2010), the evidence suggests that parents doubted the ability of HCPs to take care of their children with complex needs (Iversen et al., 2013). Parents reported wanting to teach HCPs about their children's pain needs and interpretation of their unique behaviours to reduce the burden of responsibility for their children's well-being. However, parents felt that nurses did not take the time to get to know their children and had difficulty interpreting their children's gestures. As a result, parents felt that nurses were not administering adequate pain relief for their children with CP. Thus, they experienced a lack of trust in nurses and felt that they were given too much responsibility for the care of their children (Iversen et al., 2013). Ultimately, this affected parents' experiences with partnership, and they felt let down by HCPs (Iversen et al., 2013). The feeling of having too much responsibility in care was also reported by parents in a 2016 study conducted in Sweden (Hagvall et al., 2016). This qualitative descriptive study aimed to describe parents' experiences of caring for their hospitalized children with medical complexities (i.e., extensive physical and developmental disabilities, visual or hearing impairments, autism, epilepsy) (Hagvall et al., 2016). Researchers reported an overarching theme of "a balancing act between acting as a caregiver and being in need of care" (Hagvall et al., 2016, pg. 70-71). Like the findings of the previous studies, parents shared that they had to provide most of the care because they perceived staff to lack knowledge regarding various disabilities and did not trust them to provide appropriate care (Hagvall et al., 2016). Because of this, parents felt that they could not leave children's bedsides. While too much responsibility was placed on the parent, parents still wanted to be involved in every care decision related to their children because they understood their child's condition the best and they were their children's representatives (Hagvall et al., 2016). However, parental expertise was not used consistently by

clinical staff (Hagvall et al., 2016). A systematic review published in 2021 reported findings related to the importance of acknowledging parental expertise in partnership with HCPs. Parents perceived partnership to be a collaborative effort, combining expertise from both parties, and partnership was perceived to be crucial for their children's care (Barratt et al., 2021).

Other studies also reported that parental expertise was not used consistently, which had a negative impact on parent partnership experiences (Hayles et al., 2015; Mcneilly & Kelly, 2017). For example, an Australian qualitative grounded theory study found that parents of children with CP and CI reported that their expertise was being disregarded by HCPs (Hayles et al., 2015). Parents reported that they wanted to be listened to as a parent who knows their children best. While they wanted mutual respect in partnerships with HCPs, parents felt that there was a lack of partnership and that this had a direct impact on their emotional well-being (Hayles et al., 2015). Additionally, a mixed-methods study conducted in the United Kingdom reported similar results (Mcneilly & Kelly, 2017). This study used parent surveys and semi-structured interviews with parents of children with disabilities to explore parents' experiences of participating in their children's care. Seventy-seven parents completed the surveys and of this sample, 30 parents participated in the interviews. Researchers reported that parents felt frustrated and felt that there was a power struggle in care when HCPs did not take into account parental expertise. In this study, almost all of the 77 participating (91%) parents felt that their participation in care was extremely important. HCPs who actively listened to parents and viewed them as experts were highly respected and this fostered positive partnerships. Parents also valued HCPs who took the time to get to know their children and this gave them reassurance when care decisions were being made (Mcneilly & Kelly, 2017). When HCPs took the time to get to know the child,

parents felt like the nurse had enough knowledge and trusted the nurse to care for their children, allowing them to feel comfortable in taking a break (Barratt et al., 2021).

Moreover, parents also valued formal negotiation in partnership to discuss how they could be involved in their children's care, and valued mutual trust and respect (Barratt et al., 2021). However, an exploratory qualitative study conducted in the United Kingdom found that parents and HCPs had different expectations about collaboration in care (Smith et al., 2018). While HCPs perceived themselves to be facilitators in collaboration, parents perceived that true collaboration was difficult to achieve. Smith and colleagues (2018) described that when parents and HCPs did not have a shared understanding of collaboration, this ultimately affected partnership in care, and parents expressed that working with HCPs was unrelenting and exhausting. Parents did not feel like they were equal care partners and felt that their contribution was not valued. They expressed needing to be resilient, assertive, and persistent when working with professionals. Researchers found that HCPs provided service-led care rather than family-centred care, which ultimately affected partnerships (Smith et al., 2018). It is also essential for parents to have a shared understanding of collaboration with HCPs (Smith et al., 2018).

While all of the above-mentioned studies relate to this topic, none of them are specific to parent-nurse partnership experiences in the context of pediatric pain care of children with CI. In fact, only one study was published about parents' experiences partnering with nurses for pediatric pain care (Vasey et al., 2019), however, this was not focused on children with CI. . Vasey et al (2019) conducted an ethnographic study to explore parental involvement in children's acute pain care in the setting of a pediatric hospital ward. Non-participant observation and follow-up semi-structured interviews with 44 parents/caregivers were used to collect data, over four weeks. Findings highlighted that parents expressed a range of satisfaction with their

involvement in their children's pain care. However, parents that wanted to be more involved attempted to manage their children's pain without the nurse and expressed dissatisfaction with care. No standard of partnership practices was reported. They identified variability in how nurses involved parents in pain care (Vasey et al., 2019).

Overall, the evidence suggests that parents' partnership experiences vary tremendously. Parents seek and highly value partnerships with HCPs for the care of their children with CI. Parents want to be involved in care, listened to as experts and valued as active partners in care. However, some researchers reported that parents perceived partnerships were negatively affected because too much responsibility was placed on them for care. On the other hand, other researchers have found that parents perceived their expertise was not used and they were not valued as an equal partners in care, which also affected their perceptions of partnerships with HCPs. For successful parent-nurse partnerships to be established, researchers found that parents seek formal negotiation to discuss parents' involvement in their children's care.

Healthcare Professionals' Experiences with Partnerships in Care

Like parents, HCPs highly value their partnerships with parents for the care of children with CI (Aston et al., 2014; Smith et al., 2018; Lewis et al., 2019). However, the realities of partnerships as perceived by HCPs are also far from ideal (Smith et al., 2018). For instance, a study conducted in the USA with 20 HCPs, using grounded theory, found that HCPs did not express true partnership when discussing their experiences (Bezdek et al., 2010). Instead, HCPs expressed that there is an amount of parent participation in care that is "just right", characterized by the parent assisting the professional. When parents were perceived to be too involved, HCPs felt frustrated and felt that parents did not trust them to do their jobs. However, HCPs also expressed frustration when parents were perceived to have too little involvement, which

ultimately led to ineffective partnerships (Bezdek et al., 2010). Little evidence of collaboration was also found in a pilot study conducted in the United Kingdom in 2011 (Hunt & Franck, 2011). The researchers aimed to evaluate the implementation of a pain assessment tool for children with CI from the perspectives of parents and nurses in a pediatric tertiary referral hospital. Researchers collected data via semi-structured interviews and questionnaires regarding the key topics, including collaborative working between parents and nurses. Hunt and Franck (2011) reported that HCPs expressed that partnership was represented by openly negotiating expectations, roles, and responsibilities. While over half of the nurses reported negotiating and discussing pain scores with parents, there was minimal evidence of collaboration between nurses and parents (Hunt & Franck, 2011). Similar findings were reported in a study conducted in Ireland, aiming to explore parents' and HCPs' (including nurses) perceptions of collaboration in managing care for children with long-term conditions (including autism and multiple disabilities) (Smith et al., 2018). While HCPs expressed that they actively promoted working collaboratively with parents in care, the realities of partnership practices were reported to be different from the desired HCPs' expectations (Smith et al., 2018).

Moreover, another qualitative study conducted in Australia, including 8 nurses, found that nurses perceived parents as experts in care for children with intellectual disabilities and perceived parental knowledge to be essential for a higher quality of care (Lewis et al., 2019). Nurses expressed that care was more effective when the child's familiar care routine was implemented. Parent knowledge was perceived to be crucial to learn about the child's usual routine, which led to a higher quality of care. Nurses also perceived that familiarity with the patient and family contributed to more effective parent-nurse relationships and increased nurses' confidence in providing care (Lewis et al., 2019). However, some studies report that nurses had

difficulty incorporating parent knowledge in clinical decisions and demonstrated little evidence of supporting parents as advocates (Aston et al., 2014; Smith et al., 2018). In a study aiming to understand the personal, social and institutional experiences of hospitalized children with intellectual disabilities (e.g., autism, developmental delay, CP), their parents and their nurses, nurses reported several barriers to partnerships (Aston et al., 2014). Nurses reported that a lack of time, energy, resources, and knowledge hindered the development of relationships with parents. Some nurses expressed fear when taking care of children with CI due to their lack of knowledge, experience, or both. Thus, instead of partnering with parents, nurses relied on parents for their assessments and care (Aston et al., 2014).

Overall, parent-nurse partnerships for care of children with CI are highly valued by both parents and HCPs (Aston et al., 2014; Downs et al., 2016; Fereday et al., 2010). However, the literature suggests that the practical application of parent-HCP partnerships has not been optimal (Hayles et al., 2015). The guiding philosophy of partnership practices (i.e., FCC) has been reported to be ambiguous, misunderstood, and difficult to implement in practice (Shields, 2010). Research has reported that FCC has no blueprint to guide practical actions by providers (Kuo et al., 2012). For effective collaboration with parents, nurses need to identify practical strategies for parental involvement (Vasey et al., 2019). However, it is not clear how the driving philosophy of collaboration has been implemented and research reports an overall lack of understanding of FCC (Shields, 2010). Considering this data, there is a clear gap between actual practices and the wish for effective collaboration (Ryan & Quinlan, 2017). It is unknown how parent-nurse partnerships are established for pain care of children with CI. Thus, there is a need for a clear and coherent framework to guide parental partnership during pain care in practice (Vasey et al., 2019). The aim of this study, therefore, was to provide new knowledge relating to nurses'

experiences establishing partnerships with parents for pain care of children with CI. Based on Thorne's interpretive description (ID) (2016), the findings are expected to lead to a better understanding of what to expect in future clinical encounters related to this topic as well as enable clinicians to have meaningful sensitivity around establishing parent partnerships for pain care of children with CI.

Chapter 3: Study Framework

For this study, I used the Collaborative Partnership Approach to Care and the Pillars of Partnership in Pain Care Model as well as my experiential knowledge to refine the research objectives, study questions, and inform the methodology. In this chapter, I describe the approach as well as the conceptual model and explain how these were used to frame the study.

Collaborative Partnership Approach to Care

At its core, the nursing process is collaborative, valuing the person and the family as partners in care (Gottlieb et al., 2006). When collaborative partnerships are established, people experience better health and well-being as well as increased satisfaction with care (Gottlieb et al., 2006). In a collaborative partnership, nurses perceive themselves as having expert knowledge while recognizing that parents also have unique knowledge that is critical to the care process. Thus, it is crucial for assessments and care decisions to be made by both professionals and parents, while considering the parents' and patients' perceptions, needs and goals (Gottlieb et al., 2006). However, establishing partnerships is a complex process requiring advanced interpersonal and communication skills. Thus, the collaborative approach to care was developed to help nurses understand how to work collaboratively with their patients (Gottlieb et al., 2006).

Despite being published a decade ago, I considered this approach to be the most relevant to frame this study because it is specific to collaborative work in care between nurses and the person. In the context of this study, I wanted to better understand the reality of partnership practices between nurses and parents (including stepparents and/or guardians and caregivers). Therefore, I used the Collaborative Partnership Approach to Care as part of the guiding framework and used it to help me interpret the findings of this study.

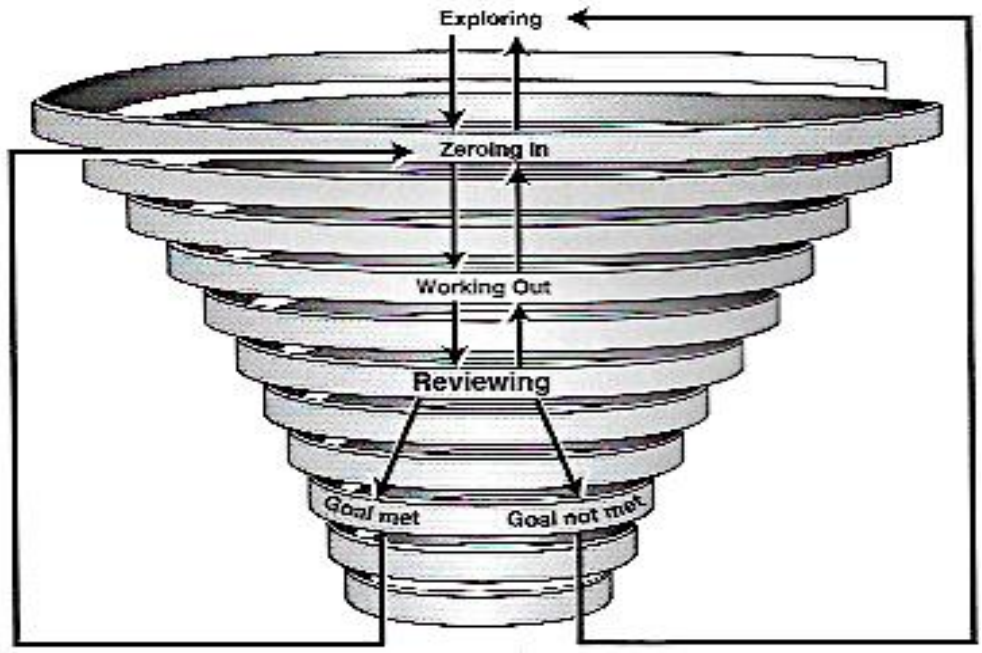
For a collaborative partnership to be successful, pediatric nurses need to identify the knowledge they have or do not have about their patients and acknowledge the expertise of the parents (Gottlieb et al., 2006). The combined knowledge of the nurse and the parents will result in the best care (Gottlieb et al., 2006). Additionally, nurses need to be curious and interested in the parents' understanding of their situation and willing to develop a relationship with the parents. A collaborative partnership can be fulfilled when nurses demonstrate respect to the parents, by viewing them as competent, capable partners who can participate in the partnership (Gottlieb et al., 2006). Respecting parents' beliefs, values, behaviours, and perspectives are also essential for a collaborative partnership (Gottlieb et al., 2006). In addition, nurses need to spend time with the parents to define the individualized issues, set the direction of the work and determine what needs to be accomplished (Gottlieb et al., 2006). Finally, a collaborative partnership can only be established when nurses are self-aware and reflective (Gottlieb et al., 2006). It is important to note that while nurses also collaborate with children that have CI, I limited this study to parent-nurse partnerships because of the timeline and scope of this Master's thesis project.

Spiralling Model of Collaborative Partnership

Gottlieb et al. view the phases and processes involved in a collaborative approach to care as a Spiralling Model of Collaborative Partnership (Figure 1). In this model, the nurse and the parents can spiral in and out of each phase. The model is composed of four phases including (1) exploring and getting to know each other, (2) zeroing in, (3) working out, and (4) reviewing (Gottlieb et al., 2006). Each phase will briefly be described below.

Figure 1

Spiralling Model of Collaborative Partnership



The first phase, exploring and getting to know each other, is characterized by exchanging information, revealing concerns, and establishing trust. In exchanging information and revealing concerns, parents share concrete information about their concerns. On the other hand, the nurse shares information about their role and what they have to offer for pain care while also allowing the parents to share their concerns. Both partners' expertise is brought forward in this phase. To establish a collaborative partnership, nurses need to listen to the parents' concerns to understand the situation from their perspective. This requires nurses to be open, responsive, and responsible for gathering as much information as the parents are willing to share. To do so, nurses engage in open-ended questioning, active listening and observing non-verbal behaviour (Gottlieb et al., 2006). In establishing trust, nurses seek and value parents' opinions to convey to parents that

they can freely share their input. When nurses are interested in parents' input and available to them, parents can start to develop trust in the nurse (Gottlieb et al., 2006).

The second phase, zeroing in, requires the nurse to open a discussion, leading to an understanding of what the parents want to achieve. Nurses need to use strategies to help parents clarify their care goals such as observing, active listening, posing purposeful questions, validating, rephrasing, and interpreting. Nurses can also share their input or impressions regarding the care goals. If nurses and parents have different goals, negotiation should take place and both partners should be involved in the negotiation for a collaborative partnership. To negotiate, nurses need to listen carefully, communicate clearly, and explain their input in a way parents can understand. Once parents and nurses have reached a consensus, they can move on to the next phase (Gottlieb et al., 2006).

The third phase, working out, involves the consideration of alternatives and trying out a plan. Nurses and parents need to brainstorm to identify ways to achieve the care goal. Nurses need to be open to ideas and willing to consider new approaches. Nurses should ask what has been tried in the past and what has worked and ask other questions that can help identify options. Once a goal has been identified, the nurse and parents can work together and identify a plan to attain this goal (Gottlieb et al., 2006).

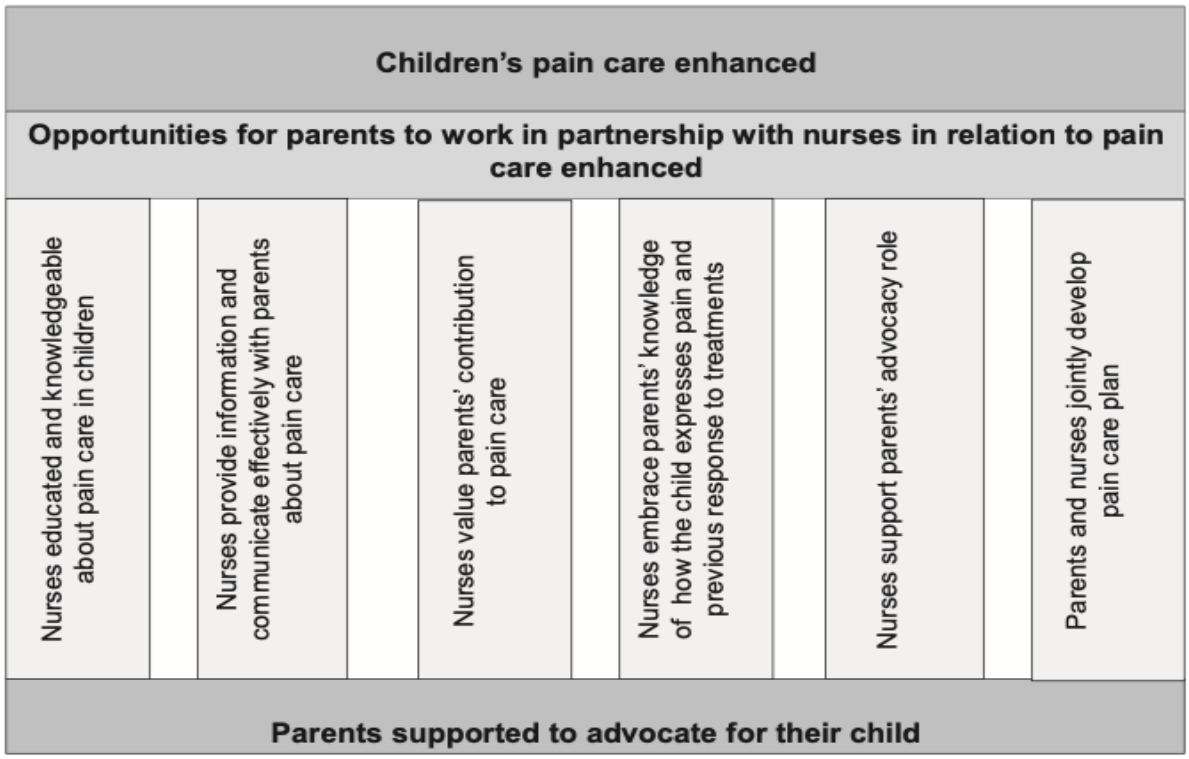
Finally, parents and nurses review how well the plan is working. Nurses need to examine the alternatives that were used, if the plan was successful and effective (Gottlieb et al., 2006). This process helps parents learn from the experience and gain greater insight into how things have happened, increasing the likelihood of applying this knowledge to future situations (Gottlieb et al., 2006).

Pillars of Partnership in Pain Care Conceptual Model

As this study focused specifically on establishing partnerships between parents and nurses for pain care of children with CI, I also used the Pillars of Partnership in Pain Care Model (Figure 2) (Vasey et al., 2019) to frame the study. This evidence-based model proposes six practical strategies to support nurses in partnering with parents as advocates for their children's pain and has the potential to optimize pediatric pain care (Vasey et al., 2019). It was developed as an alternative approach to FCC in order to overcome barriers to parental involvement in pediatric pain care (Vasey et al., 2019).

Figure 2

Pillars of Partnership in Pain Care Model



Three concepts underpin the Pillars of Partnership in Pain Care Model. The first concept is that parents are advocates for their children by ensuring that their children's pain care needs

are met, that pain care is initiated and that it is informed by knowledge of their children. The second concept is that nurses promote parental involvement and partnership by listening to parents and valuing their contribution. Finally, the third concept suggests that nurses prevent parental involvement by omitting to actively encourage parental participation in care decisions (Vasey et al., 2019). Based on these concepts, recommendations have been made for nurses to enhance pediatric pain care. The six recommended opportunities are identified in Figure 2. For this model, the assumption is made that, if nurses use these strategies, parents will feel supported in their role as advocates for their children's pain thereby optimizing pediatric pain care. The model is also based on the premise that parental involvement will enhance the overall pain experience for children, parents and nurses involved. In other words, parents would feel valued, and nurses would be able to understand parental perspectives of pain care and learn from their experience (Vasey et al., 2019).

The framework for this study included both the Collaborative Partnership Approach and the Pillars of Partnership in Pain Care model. Together, the approach and the conceptual model informed the conceptualization of this study, the development of the interview guide, and the data analysis. This framework also helped in understanding and interpreting the findings of this study.

Chapter 4: Research Design and Methodology

In this chapter, I will present the research design and methodology that I chose to conduct this study. First, I will explain the qualitative research approach that I adopted, including details regarding its theoretical underpinnings. Then, I will describe the specific methods I applied for this research. Finally, I will explain the strategies that I used to promote rigour and respect ethics for qualitative research.

Qualitative Research Approach: Interpretive Description

Since there is very little research published about establishing parent-nurse partnerships during pain care of children with CI, an exploratory qualitative study was conducted, using an interpretive description (ID) approach (Fortin & Gagnon, 2016, p. 190; Thorne, 2016, p. 41). This approach aims to answer the who, what, where and why of experiences (Bradshaw et al., 2017). Interpretive description is intended to be used in qualitative studies to investigate a clinical phenomenon to capture patterns based on subjective perceptions (Bradshaw et al., 2017). Thus, it is an appropriate design for the purpose of this study.

Inspired by Guba and Lincoln's axioms of naturalistic inquiry (1985), ID considers reality to be socially constructed, influenced by time, context, and senses (Bradshaw et al., 2017; Thorne et al., 2004; Thorne, 2016). In other words, ID assumes that every individual has an interpretation and meaning related to a phenomenon that can be shared or contradictory (Bradshaw et al., 2017; Thorne et al., 2004; Thorne, 2016). Interpretive description has a qualitative descriptive component that strives for an in-depth understanding and literal description of a phenomenon. It also has an interpretive component, which focuses on understanding human phenomena through analysis and interpretation of individuals' meaning of that phenomenon (Bradshaw et al., 2017). In this way, ID recognizes that there is an inseparable

interaction between the researcher and the object of study. Therefore, the researcher has an influence on the research outcome (Thorne et al., 2004; Thorne, 2016).

In the context of this specific research problem, ID is the most fitting study design for several reasons. First, traditional qualitative approaches such as phenomenology and ethnography are not entirely compatible with nursing's practical demands (Thorne, 2016; Burdine et al., 2020). On the other hand, ID is grounded within nursing science and aims to generate a coherent interpretive description that is useful for informing clinical understanding and applying the insight to practice (Bradshaw et al., 2017; Burdine et al., 2020; Thorne, 2016). As the topic of this thesis is related to nursing practice, I believed ID would result in findings that could answer the research questions in a way that could benefit practice. Second, this methodology is aligned with my interpretive naturalistic orientation and emphasizes the need to understand subjective knowledge of lived experiences to advance applied practice. To uncover the realities of partnership practices in the context of this study, the use of an ID approach was appropriate because it considers that multiple socially constructed realities exist relating to a phenomenon (Thorne, 2016). Additionally, this approach considers the researcher as the instrument of data collection and recognizes that the findings are influenced by my personal biases, assumptions, and background (Thorne, 2016). Finally, research findings produced thematic patterns and describe commonalities that characterize a phenomenon (Thorne et al., 2004). Studies using an ID approach result in findings that are beneficial to inform clinical reasoning, expand the insight for practice decisions and make sense of variations in healthcare applications (Burdine et al., 2020; Thorne et al., 2004). In this way, the findings can be useful for clinicians and policymakers (Bradshaw et al., 2017). Ultimately, the results of this study are anticipated to enable an understanding of how nurses establish partnerships with parents of

hospitalized children with CI to optimize patient pain care. As there is little knowledge about this topic, it would provide a useful base for clinicians to determine if practice interventions need to be improved.

Study Setting

This study was set in a pediatric academic quaternary hospital in Eastern Ontario. With a mission to create the best life for every child and youth, this institution prioritizes partnership with children, youth and families in health and states that it is their commitment to care (Children's Hospital of Eastern Ontario [CHEO], 2020). The hospital has grouped 25 parents, caregivers and former patients to form the Family Advisory Council (FAC) (CHEO, 2021). The FAC works directly in partnership with hospital staff by advising on hospital programs, participating in committees and sharing their experiences. In their key messages, the FAC states that parents and caregivers seek trust from healthcare workers, reinforcing that they know their children and want to be involved in decision-making at all levels of care (CHEO, n.d.).

The literature states that children with CI are hospitalized more frequently than children without CI (Bebbington et al., 2013). Therefore, it is likely that nurses would take care of a child with CI at this institution. In fact, of the 4285 patients admitted at this study's site between January 2020 to January 2021, 296 (6.9%) were children with CI (J. Guo, personal communication, June 10, 2021). These data were pulled by the study site's data analyst, who reviewed the hospital's online patient database and identified all admitted patients with nursing documentation of being "non-verbal" in the flowsheets. This strategy was recommended by the data analyst as it was the only way to estimate the number of patients with CI admitted over a period of time. Of these children, most were admitted to inpatient medicine units (n=195; 36%), the surgical unit (n = 67; 23%) and the oncology unit (n = 18; 6%) (J. Guo, personal

communication, June 10, 2021). Therefore, for the scope of this study, the setting was focused on the medical, surgical and oncology units of this hospital.

Study Sample

A homogenous purposive sampling strategy was used to reach the appropriate individuals with particular characteristics that could be able to best address the research questions (Bradshaw et al., 2017; Fortin & Gagnon, 2016). This strategy seeks participants who are well-informed about the phenomenon and willing to provide information based on their experiences (Etikan et al., 2016). With this considered, it is a useful sampling procedure for qualitative research as it allows efficient utilization of available resources (Etikan et al., 2016). For this study, participants were acute care pediatric registered nurses and registered practical nurses. Pediatric nurses were eligible for inclusion if they: (1) had experience taking care of a hospitalized child with CI within the last six months, and (2) worked in the following inpatient units: medicine, surgery and oncology at the time of the study. These eligibility criteria enabled the recruitment of participants with relevant experience related to the phenomenon of interest.

Sample size in qualitative research has been a subject of debate (Van Rijnsoever, 2017). Previous studies using an interpretive description approach have commonly reported sample sizes of between 5 and 30 participants (Thorne, 2016). While recognizing that qualitative data collection related to a phenomenon could be endless, the decision was made to stop collection for this study when I perceived to have gathered data that provided a meaningful clinical description of the phenomenon (Thorne, 2016). As such, a total of 11 nurses were recruited for this study, which allowed for a significant amount of rich qualitative data to be collected and was appropriate in the context of a master’s research project.

Participant Recruitment

Prior to recruiting participants, I (MScN student, JC) obtained approval from the study site's Research Ethics Board (REB) as well as from the University of Ottawa's REB to conduct this study (Appendix A). For the recruitment of eligible participants, I informed the clinical unit managers about the study and obtained their approval to send recruitment emails to their nursing staff. Once approved, I sent one recruitment email to inform nurses about the study (see Appendix B). I did not send email reminders as they were not required. Additionally, the study information was included on recruitment posters that were posted in the staff rooms, staff washrooms, around the nursing stations and near the elevators of eligible units (see Appendix C). After gaining approval from the unit managers and ensuring COVID-19 restrictions were followed, I also presented the study to nursing staff in person once on each unit, during their team huddles. If a nurse expressed interest in participating in the study, I shared the study information with them and gave them a consent form for their review. Once I answered all their questions related to the study and if the nurse shared their interest in participating, I obtained the nurse's informed consent. Participants then signed the information and consent form (see Appendix D). Finally, an interview time, date, and method (i.e., videoconferencing or telephone) were determined based on participant preference. To acknowledge the nurses' time, I offered them a 10$ Starbucks gift card and thanked them for their time and generosity.

Data Collection

I conducted individual semi-structured interviews consisting of open-ended questions to gather first-hand in-depth knowledge from individuals who have experienced the phenomenon and to obtain an understanding of what to expect in future similar clinical encounters (Thorne, 2016).

I conducted all interviews via a videoconferencing platform (i.e., Zoom). All interviews were held during the nurses' personal time. Interview dates and times were set with the participants when it was most convenient for them. I structured interviews with an interview guide (see Appendix E) that I developed based on the recommended parent-nurse partnership strategies from "Pillars of Partnership in Pain Care Model". I used the interview guide to explore topics focused on: (1) previous pain care experiences, (2) partnership practices with parents of children with CI, and (3) perceived barriers and facilitators to establishing partnerships with parents of children with CI in the context of pain care. I included follow-up questions to help guide the conversation. I also asked questions to collect demographic data relating to the work experience and work unit of participants. This information was useful to further specify the characteristics of the study sample and their contexts. I discussed all aspects of the interview guide (i.e., the content of questions, and the order of questions) with my thesis supervisor (JCh), who is an experienced researcher. To practice interviewing and test out the videoconferencing platform, I piloted the interview guide via individual pilot interviews with two pediatric nurses, who volunteered to help with this research. These nurses were not part of the study sample. Rather, this was an opportunity to test out the Zoom platform that was used. Minor modifications were made according to the feedback received from the pilot interviews. Aligned with the ID methodology, I collected data and conducted data analysis concurrently. Therefore, I also asked questions to participants about topics that were previously discussed in prior interviews to explore these further and understand different perspectives.

I held the interviews between October 2021 and January 2022. I audio-recorded the interviews using Zoom's local recording feature. I uploaded recordings to a password-protected laptop, always ensuring that a secure server was being used. I transcribed verbatim seven out of

the 11 interview recordings, and the remainder by a research team member (AlD), with consent from participants to do so (Thorne, 2016). Prior to and throughout data collection, I spent time considering my positionality (i.e., personal, or ideational influences and preconceptions about the phenomenon) to practice reflexivity (Thorne, 2016). I documented these in a personal reflective journal.

Data Analysis

The research team (JCh, AD, DH, AlD) and I synchronously analyzed data while data was being collected. I chose to use reflexive thematic analysis (TA) as the approach to guide data analysis, specifically choosing to apply a data-driven, inductive approach as described by Braun and Clarke (2022). This approach is useful to aid researchers in inductively analyzing qualitative interview data stemming from an individual participant and requires researchers to interpret data and generate ideas (Clarke & Braun, 2017; Thorne, 2016). Aligned with my relativist worldview, reflexive thematic analysis considers the active role of researchers in analysis and emphasizes that findings are influenced by their subjective assumptions and biases (Braun and Clarke, 2022). With this considered, each analysis step for this study was interpretive and dependent on the judgments, previous biases, and commitments of the research team members (AlD, JC, AD, DH) and I (Braun & Clarke, 2006). We analyzed data following the six recursive phases outlined by Braun and Clarke (Braun & Clarke, 2006; Braun & Clarke, 2022), keeping in mind the Collaborative Partnership Approach to Care and the research questions.

In the first phase of analysis, a research team member (AlD) and I transcribed the audio-recorded interview data. This initiated the interpretation of data as transcription is a key interpretive act in qualitative data analysis (Braun & Clarke, 2006). Once the data was transcribed, the team members (AlD, DH, AD, JCh) and I repeatedly and actively read the data

to become familiar with it (Braun & Clarke, 2006; Thorne, 2016). With repeated readings of data, we were able to uncover new elements and explore the rich diversity of meaning (Braun & Clarke, 2022). To practice active reading, we kept a critical mind and questioned the data being read. For example, while reading, we thought about the different meanings associated with the data and what we relied on to interpret data. This process was useful in attempting to make sense of the data and develop potential themes (Braun & Clarke, 2022).

In the second phase, my thesis supervisor (JCh) and I independently coded an interview to develop an initial code list. This step was essential as codes are the smallest units of analysis that consist of the foundation for theme development (Clarke & Braun, 2017). Coding was done electronically, using the comment feature of Microsoft Word. Based on these initial codes, we created a preliminary codebook and visually mapped out the codes. The codebook served as a tool to chart and collate similarly coded data. Analysis was, however, not limited to the codes included in the codebook. Subsequent interview data were always analyzed by one or more research team members and I. Multiple coders were useful because everyone noticed different aspects of the data, which led to findings that were rich and complex (Braun & Clarke, 2022). We read through the data set and coded data items that were perceived to be relevant to the study. We used semantic coding to capture meaning at the surface of the data and used codes that stayed close to the participants' language. We also used latent coding to capture a more conceptual level of meaning of the data. Using a combination of these coding strategies was appropriate for reflexive TA and we were able to capture a diversity of meaning within the data. We took part in collaborative coding by meeting virtually to discuss coded data, reflecting on our interpretations of the data and our assumptions. After each meeting, I reviewed the codes and refined them as well as the codebook to capture the meaning of the data. Throughout the coding

process, I read through the data set multiple times, going back and forth between interviews to further refine codes and ensure analytical rigour (Braun & Clarke, 2022). Throughout the coding process, the team and I met virtually several times to review codes. Once all research members agreed that the codes were consistent, thorough, and portrayed the various meanings in the data set, coding was determined to be complete.

In phase three, my thesis supervisor (JCh) and I sorted through the collated data and codes and reorganized them into candidate themes. The process of sorting and reorganizing was repeated several times, with input from the other research team members. The goal of this reorganization was to cluster codes that were coherent and contributed to the same central concept, always considering the research question (Braun & Clarke, 2022). During this phase, the mapped-out codes evolved into an in-progress thematic map, which included a visualization of potential themes and sub-themes.

Moreover, in phase four, I continuously revised and questioned the data, which resulted in revisions of the thematic map. The research team, consisting of experienced researchers, and I met virtually to review the validity and richness of provisional themes. The refinement of themes was determined to be completed when themes; (1) were consistent with the associated data and the research question, (2) had a central concept, (3) contained clear boundaries, (4) had enough evidence to support the theme and, (5) were coherent. Finally, phases five and six are presented in chapter 6 of this thesis and include a title and definition for each theme as well as the overall analysis report (Braun & Clarke, 2006).

Rigour and Trustworthiness of Data

The trustworthiness of qualitative research can be verified by considering Guba and Lincoln’s four major criteria of credibility, confirmability, transferability, and dependability

(1985). Credibility refers to the truth of the participant's view, as interpreted and represented by the researcher (Cope, 2014). To promote credible research, I made sure to promote a trusting environment during interviews to make participants feel comfortable and increase their likelihood of providing more rich or detailed responses (Cope, 2014). For example, I practiced the use of silence to allow participants time to think and provide their responses. Additionally, I practiced reflexivity by considering previous experiences and inherent values that influenced the research process and writing this down in a reflexive journal (Guba & Lincoln, 1982; Thorne, 2016). An audit trail was also used to promote this study's credibility. I kept track of the meetings held throughout the study as well as the decisions made related to the research process. Furthermore, I enhanced credibility by meeting with the research team to review several aspects of the research process. Finally, verbatim quotes are presented in this monograph as evidence of the research findings (Cope, 2014; Guba and Lincoln, 1982). While member checking is a strategy that I could have used to further promote credibility, I also wanted to respect participants' time. I acknowledged that member checking would require an additional time commitment from nurses that are already very busy, particularly during this unprecedented time of pandemic. To promote the confirmability of findings, I represented data by the participants' responses and included rich participant quotes to back up findings (Cope, 2014). I also practiced reflexive journaling throughout the study process to enhance the study's confirmability (Guba & Lincoln, 1982). Moreover, transferability relates to the applicability of findings in other settings or groups (Cope, 2014). I promoted transferability by using purposive sampling and provided sufficient information about the participants and their contexts (Cope, 2014; Guba & Lincoln, 1982). Finally, dependability refers to the constancy of data over similar conditions (Cope,

2014). I used an audit trail and kept track of how the interpretation was produced to promote the dependability of the study (Guba & Lincoln, 1982).

Ethical Considerations

To ensure that participants' consent was informed, I explained the risks and benefits and answered participants' questions relating to the study prior to obtaining consent. I provided potential participants with additional information to ensure their informed consent including the nature and conditions of participating, the protection and privacy of data, access to research findings as well as the research team's responsibilities (Fortin & Gagnon, 2016). I also emphasized the voluntary nature of participation in this study (Fortin & Gagnon, 2016). I provided the nurses (if interested) with the study information and a consent form and gave them time to review this information. Once the nurses understood the information provided, I obtained consent if the participants were interested in participating. The participants were aware that they could retract their consent at any point in time (Fortin & Gagnon, 2016). I provided all information in the participant's preferred language (in all cases, it was the English language) (Fortin & Gagnon, 2016).

To consider the privacy and confidentiality of participants, I stored the data from this research securely, on my encrypted and password-protected personal laptop. Only my thesis supervisor (JCh), the research team members and I had access to this data. To protect participants' privacy, a separate document contained any potential personal participant identifiers, and I assigned a study identification code to each participant. I stored this document securely and separately from other research files on a password-protected secured computer drive. No personal identifiers will be included in any publication or presentation of this study. All ethical considerations were made following the Tri-Council Policy Statement: Ethical

Considerations for Research Involving Humans (TCPS 2) (Fortin & Gagnon, 2016). Electronic data will be deleted from the laptop and the paper document will be shredded after a period of 7 years.

Chapter 5: Findings

In this study, I explored pediatric nurses' experiences of establishing partnerships with parents for pain care of hospitalized children with CI. In this chapter, I describe the realities of partnership practices and will highlight the barriers and facilitators to establishing parent-nurse partnerships. I support analytical claims with participant data extracts, allowing a better understanding of my interpretations of the data (Braun & Clarke, 2022). Overall, my thematic analysis revealed an overarching theme, seven main themes and eight sub-themes. The theme that encompasses all themes is (1) Assessing Pain as an Outsider: "A Complete Guessing Game". The main themes and sub-themes consisted of: (2) Relying on Parent Expertise for Pain Assessment, (3) Brainstorming with Parents for Pain Treatment, (4) Supporting Parents as Advocates for Pain Care, (5) Individualizing Pain Care with Parents, (6) Involving the Child in Pain Care: A Spectrum, (7) Barriers to Partnership in Pain Care, including (7.1) Lack of Time and (7.2) Multiple Parent Stressors, (8) Facilitators to Partnership in Pain Care, including (8.1) Taking the Time to Listen and Check-In, (8.2) Offering Supporting Services and (8.3) Continuing their Home Routine. In Figure 3, a visual relating the themes and sub-themes to one another is presented (see Figure 3). First, I present a description of the participant sample characteristics and details about the context of the study. Then, I describe the themes and subthemes.

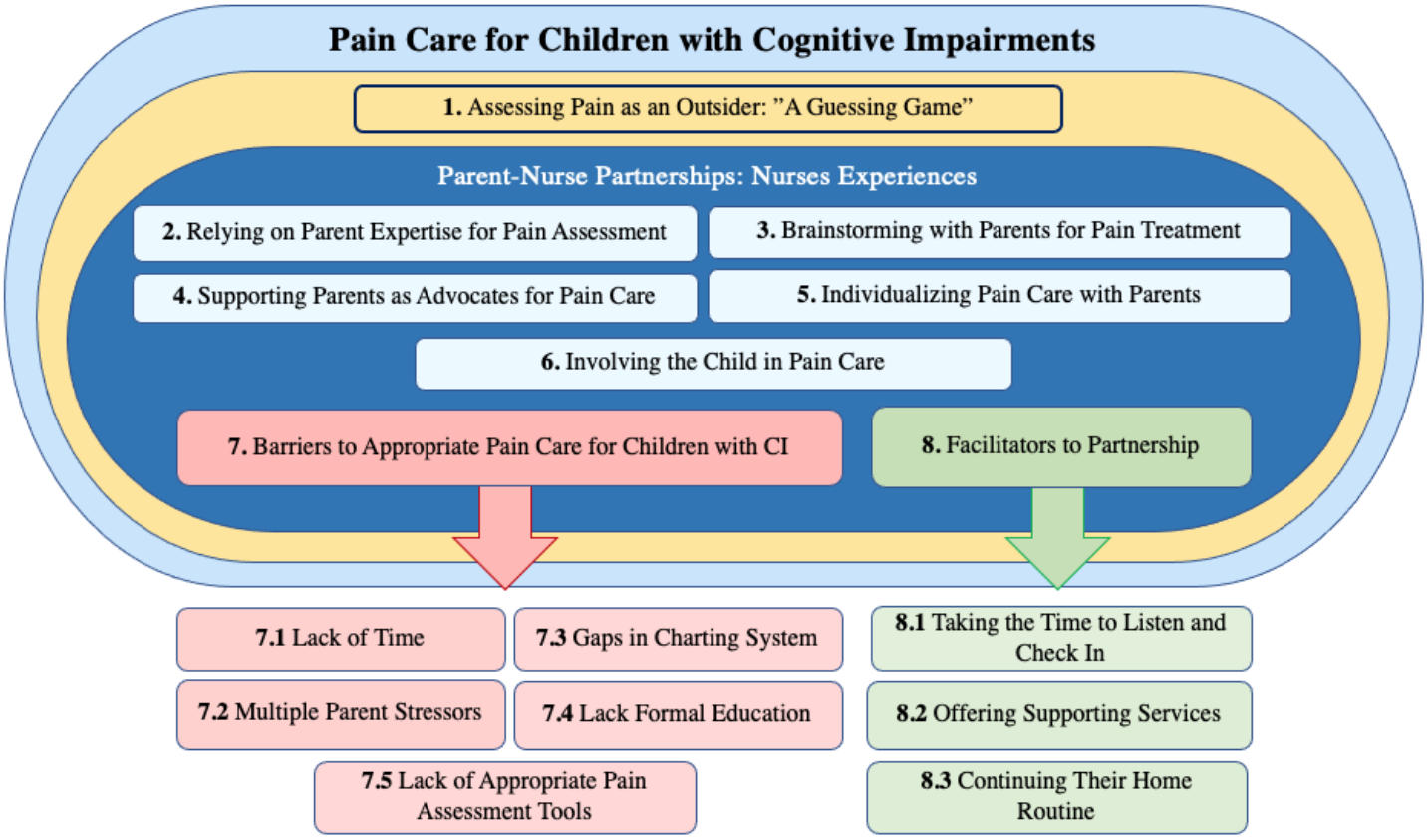
Participant Sample Characteristics and Context

Ten female nurses and one male nurse participated in this study. Of those, ten were registered nurses and one was a registered practical nurse. All interviews were conducted in English via the Zoom videoconferencing platform. The duration of the interviews was approximately one hour. Out of the eleven participants, five nurses worked in inpatient medicine,

three worked in inpatient surgery, and three on the inpatient oncology unit. The participants had varying years of nursing experience, ranging from one year to 40 years. All participants had experience providing pain care for hospitalized children with CI diagnosed with a spectrum of conditions. Participants expressed taking care of children with CI diagnosed with autism, congenital abnormalities, medulloblastoma, and neuroblastoma. Participants also used terms such as “complex care kids” (P04), “non-verbal” (P03), and “child with disabilities” (P02) to describe this population of children.

Figure 3

Parent-Nurse Partnerships in Pain Care for Children with CI: Themes and Sub-themes



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Assessing Pain as an Outsider: "A Complete Guessing Game"

Nurses in this study expressed strong feelings of uncertainty attributed to providing pain care to children with CI, regardless of their years of nursing experience. The feeling of uncertainty was exemplified by such statements as "we want to control your kids' pain, but we don't know how to" (P06) and "we can just assume or guess what we find based on vitals" (P08). One nurse also stated, "it is really quite difficult to tell as an outsider, like as their […] nurse instead of their main caregiver, what they're experiencing" (P04). In this quote, pain assessment was perceived to be more ambiguous due to the nurse's unfamiliarity with the child. Other nurses expressed similar statements, linking the feelings of uncertainty in pain care to being unfamiliar with the child. For example, "you have no way of figuring it out until you're given more time with that child" (P02) and "if someone doesn't see this specific child every day or know them over time, it's hard to tell [if they're in pain]" (P04).

Nurses recognized that children with CI experience unique pain behaviours with whom they require time to become familiar. One nurse identified a wide range of pain behaviours and stated "every child is different. So, their signs and symptoms will vary. It can range from crying, banging their head, sometimes just fidgeting, and appearing uncomfortable" (P01). Without knowing a child's unique pain behaviours, nurses stated that they experienced uncertainty with pain assessment and did not know what to assess. One participant shared,

> It's hard to tell whether their vocalizations are them crying out in pain or them just chatting and babbling as like a baby might do. If I have a child without a parent at the bedside and I hear them doing that, it's kind of up to me to figure out if it's a pain cry or if they are vocalizing and having fun…making happy noises. (P04)

In the above quote, the nurse perceived that it was difficult to differentiate between the child's pain cues and their baseline vocalizations. This nurse's uncertainty in pain assessment was expressed as "figuring out if it's pain" (P04). Another nurse made a similar statement and expressed, "I think we were always trying to figure out if her pain was coming from a pain perspective or if it was more anxiety, stress response, kind of distress. And it was sometimes hard to differentiate them" (P03). Without knowing what to assess, nurses expressed having to rely on vital signs or physiological signs. One nurse stated, "outside of those [physiological] signs, I really don't know how else to pick up on what's going on" (P01). Nurses perceived that their feelings of uncertainty changed the way they provided pain care. For example, this nurse shared,

> I have sometimes seen where nurses are hesitant to provide the same care when they have a child with a disability because I think there is an area of uncertainty. […] it is more complex. You know, the patient isn't able to sometimes verbalize. […] it is a completely different feeling. You walk into a child who doesn't have a disability, into their room, and it's "hey, how are you today?! Okay, yeah, like are we going to watch something …"[…]. Sometimes, you walk into the room and if you didn't realize or if you didn't read in the chart that they had a disability, sometimes you're thinking "oh, like, okay, my approach is going to be a little different". This can sometimes put the nurse back a bit and they never really feel comfortable during their shift. (P02)

In the above quote, the nurse compared nurses' perceptions of care for a child who can verbalize versus a child with a CI who cannot. When describing the care of a child who can verbalize, this nurse describes conversing with the child and asking questions to get to know them. However, when describing the care of children who cannot verbalize, this nurse described

it as “a completely different feeling” (P02). The inability of the child to verbalize was perceived to contribute to the nurse's uncertainty and "put the nurse back a bit" (P02), leading them to feel a level of discomfort and hesitancy with their approach to care. Similarly, another nurse expressed, “it is kind of difficult to numerically rate a child’s pain when they are not able to tell us” (P04).

Due to nurses' unfamiliarity with the child’s pain behaviours and perceived communication barriers, pain care for children with CI was characterized as “a complete guessing game” (P05). To navigate their uncertainty, nurses expressed that they provided patients with pain medications to assess if it made a difference thereby identifying that the behaviours were indicative of pain. One nurse stated, "sometimes, we'll give Tylenol for no reason, but it seems to help, we'll just try it" (P08). Another nurse stated, “we can just try [Tylenol] once and see if it helps” (P03). This process was described as trial-and-error, attempting different medications to try and relieve the children’s symptoms. In the example below, one participant shared their thought process when attempting to provide pain care to children with CI. This participant stated,

> Guess! Like, are you nauseous? Let’s try this. Are you in pain? Let’s try this! It literally comes down to a guessing game. Let’s give it a try and see if it helps. Then it’s like okay, so whenever they are showing these kinds of things, it’s nausea. Whenever they are showing these kinds of things, it’s pain. (P05)

The trial-and-error process was perceived to potentially delay the provision of appropriate pain care. For example, P03 stated, “I think we eventually… it can sometimes take a while to figure out what works and what helps” (P03). This was also expressed by P02, who stated, “you can start […] offering one thing at a time. It’s hard to offer ten different ways of

treating pain because you don't know which one worked. So, it takes a long time". Additionally, nurses' uncertainty was perceived to potentially lead to inadequate pain care. One nurse stated, "when parents are not there, I go by my intuition but then we don't know if our intervention is as effective and as good" (P08). Another nurse mentioned,

> I think they suffer a lot more than a neurotypical child because it is so much easier for nurses and parents to [treat their pain] as opposed to some of these kids who are just really uncomfortable, and we can't figure out why. (P03)

In summary, nurses shared strong feelings of uncertainty related to pain care for children with CI and felt like "outsiders" in their care (P04). Their unfamiliarity with the child's pain and baseline behaviours as well as perceived communication barriers were identified by nurses as contributing factors to their uncertainty. When parents were not at the bedside, nurses felt the need to use their intuition and a trial-and-error process to "figure out" if the child was in pain (P03). Ultimately, this was perceived to potentially delay appropriate pain care. The subsequent themes describe nurses' experiences of partnering with parents to alleviate their uncertainty and optimize pain care for children with CI.

Relying on Parent Expertise for Pain Assessment

Nurses shared how they partner with parents to provide appropriate pain care for children with CI. When describing their experiences, all participants expressed relying on parents to appropriately assess pain in children with CI. This was expressed in statements including "parents are the ones that are going to guide me and lead me" (P01), "a lot of it depends on the parents" (P02), and "I definitely would say I rely a lot on the parent" (P11). Nurses discussed that they rely on parents because they were the only ones who had expertise about the child, stemming from their long-term familiarity with their child. One nurse reported, "every single one

of these kids has their particular needs and wants that none of us are privy to except for the people that are there 24/7 caring for them" (P01). Another nurse stated,

> I usually just rely on the parent because in many cases the parents know their kid best and they can usually tell, kind of, over time if it's a pain thing or if it is something else bothering them. But it is quite tricky when the parents don't know because then we kind of have to try to figure it out together. (P04)

Nurses expressed that they needed to rely on parents because their expertise was not only useful but necessary for pain assessment in children with CI. One nurse stated, "I think the most important assessor is often the parents' opinion on how their child is doing" (P02). Another nurse mentioned, "[parents] are basically priceless in it. Like you need them because it's almost impossible to figure out a kid" (P05). Nurses stated that parents, as experts on their children, could offer information relating to their child's baseline status. This included data about their child's baseline behaviours as well as their baseline vital signs. Understanding a child's baseline behaviours was perceived by nurses to be crucial for pain assessment in children with CI as they present with unique pain behaviours. Thus, knowing what the child was typically like meant that the nurse could better identify when something was wrong. One participant expressed,

> It's hard with kids with cognitive impairment because I think, as nurses, we are so used to algorithms and like, being able to predict or anticipate things. But, with these kids, you really have to get a good baseline from a parent, and you have to be able to know alright, so, what does their face look like at baseline? Do they have contractures at baseline? So, I can't really use them tensing up as a score… it's a really, really different thing to do but, I find that the parents play a really, really, really big role in that. You have to get to know the kids on an individual basis. (P06)

Almost all nurses expressed similar statements and included “I rely a lot on the parents to tell me what the child’s baseline is and what the pain signs are” (P11), “having those conversations right away [about the child’s baseline] is super helpful” (P07) and “it was a huge deal to ask baselines from parents” (P06). Not only do parents provide expertise regarding their child's baseline but also about their child's pain behaviours. Participants stated, “they know their kid best and they know their [pain] tells so, usually it’s pretty accurate” (P02) and “anything they can tell us about their child can give us indications into their pain” (P04). Not only did nurses benefit from parent expertise but parents’ physical presence also facilitated pain care and lead to more accurate assessments. One nurse shared her experience and stated,

> I find it easier when parents are there for the assessment, you know. […] I find it's so crucial to do the assessment piece with the parent in the room […]. It’s just easier to kind of just have that discussion with the family instead of just trying to guess […]. It’s like no, no, stay, please do. Even if both parents are there, sometimes having both mom and dad is nice because then they can both offer their input. […] I can't really assess unless I have that verbal backup to confirm. (P02)

In this example, the nurse highlighted the importance of including parent expertise in pain assessment for children with CI. The participant explained that this information could help relieve nurses’ uncertainty in care and can be useful for pain assessment “instead of just trying to guess”. Without parental expertise, this nurse expressed “I can’t really assess” (P02). This showcases the degree of reliance on parent expertise for pain assessment. The nurse perceived that the care task could not be completed without parents. In this way, parents’ knowledge was used similarly to a pain assessment tool, relying on their input to provide appropriate pain care for their patients. One nurse stated, "also using parents a lot as a tool because parents can often

know their baseline and what pain is for them and what they look like, what they sound like" (P03). Not only did nurses express using parental feedback to validate their assessments but they shared that they trusted parents' instincts so much so, that pain assessment was led by parents. For example, one nurse stated,

> So, parents are the ones that are going to guide me and lead me into understanding what their child's needs are and what their child's norms are. So, if a parent is saying it's not normal for them to behave this way or a particular vital sign is not normal for them, that this is really my only source of truth. (P01)

Other participants also expressed trusting parental expertise for pain assessment and stated, "I trust [parents'] judgment most of the time" (P08) and "if you have a child with impairments, you have been through the medical system quite a bit, so I'm sure you've learned a lot, but I just trust that they know their child" (P11). Nurses trust parents as experts in the care of their children and value their contribution as care team members. One nurse expressed, "I think [parent contribution] is important, if not more important than our contribution as nurses" (P06). Overall, nurses expressed that they rely on parents for pain assessment because of their expertise in their child. They trust them to lead care and depend on them for appropriate pain care.

Brainstorming with Parents to Provide Pain Treatment

When nurses described working in partnership with parents for pain treatment, all nurses described a process of brainstorming with parents to try and identify strategies to appropriately treat the children's pain. Through descriptions of their experiences, nurses demonstrated being open to parents' ideas by incorporating their feedback into the pain care plan. This was expressed by multiple participants, who stated, "how their pain is managed is based a lot on parents and their suggestions on how to manage it" (P02), "as a nurse there is a bit of giving up control and

saying […], this parent will tell me when their kid needs something" (P07), "most of the time, I will listen and comply to the parents" (P08) and "I come up with a plan based on what [parents] are telling me" (P11). Nurses recognized that this population of children had specific pain regimens that were already previously established by parents at home. Thus, nurses reported that they took the time to ask what worked in the past to implement the home pain care routine in the hospital. For instance, P02 stated, "we follow their therapeutic approach based on what [parents] have originally come up with". Listening to parents' suggestions about pain treatment was perceived to enhance the quality of care provided to the child. One nurse mentioned "when [parents] give feedback, it's definitely important to put it in action to take the best possible care for the child" (P10). Another nurse stated, "I very much go off of what they give me because if you approach every situation the same, then you can get very different results" (P11). Conversely, without parents at the bedside, pain management was perceived by nurses to be sub-optimal. One participant explained,

> I mean, it is extremely hard to give these kids good pain control when the parents are not there. So, they are essential parts of the team. We can't give them optimal pain control without a caregiver there. (P07)

Nurses highly valued parental input about pain treatment and perceived them to be "essential parts of the team" (P07). Thus, nurses recognized that it is important for them to foster "positive relationships" (P03) with parents to collaborate with them for pain treatment. One nurse stated,

> It's hard because you need that positive relationship; that open, understanding, kind, mutually respectful relationship to exist to have like a really beneficial experience and conversation regarding pain management for these children but, I think there are a lot of

> things that complicate it [...]. But I would say that something that helps in managing pain is if both the nurse and the parent are open and understand to one another and have respectful conversations, and respect one another to come together to support the patient if that makes any sense. (P03)

Other participants also expressed similar statements, highlighting the importance of establishing partnerships for appropriate pain treatment. For example, "just building that trusting relationship is the biggest protecting factor and facilitating factor to talking about pain management" (P04), "you really have to have a really good relationship with parents, it is not a time to guess [about pain management]" (P06) and "I make my own assessment […] but I cooperate a lot with parents and it's a team effort" (P11). Collaborating with them as partners in care was important because parent contributions to pain treatment were perceived by nurses to be "irreplaceable" (P10). One nurse expressed the importance of parents guiding pain treatment and stated,

> I think parents should always feel comfortable initiating pain control for their kids. They should feel empowered to do so. They should feel empowered to steer the boat if it's not been steered in the right direction. I think it's of utmost importance for a parent to be involved. (P06)

To brainstorm a pain treatment plan with parents, nurses expressed that they also share their expertise in pain interventions. Nurses shared information about pain medications with parents to generate other pain treatment options and for parents to consider other alternatives. One nurse expressed, "if it's something that is really out of their realm, then […] I will teach them as they kind of come behind me, work with me." (P09). Another nurse stated,

> I give them education on the side effects of them, maybe we need to give PEG, watch out if your kid starts scratching or itching because it could be a side effect of the morphine. I do similar teaching for epidurals, and I talk to them about how it should be frozen […]. It is so different depending on what infusion and medications they have but, I usually do a lot of teaching to give parents more control over what their options are. (P07)

In this quote, the participant shared their nursing expertise with parents to empower parents and provide quality care. Sharing nursing expertise was perceived to help parents better understand the implications of different pain regimens, leading to a more informed decision for their child. For example, one nurse explained that parents wanted to give hydromorphone to their child experiencing GI-related pain. This nurse clarified the contraindications of this medication and stated, "just kind of work with them and be like oh that's actually contraindicated for them because of their constipation or GI issues" (P04). Additionally, when nurses shared their expertise and were transparent about available pain treatments, they perceived parents to be more open and accepting of new pain regimens. One participant stated,

> "If it's something that myself or another member of the team think is really important and [parents] are able to listen to the rationale of why we want to do it, they are generally pretty open to it, and wanting to try [pain medications] afterward. It's more like they are just lacking the education as to why it is safe and how it is not going to harm their child". (P05)

Another nurse explained,

> You just got to keep the parents involved and do as much as you can. Like I said, try to maintain a partnership and explain to them, you know, if you're doing something that's unpleasant, you know. But we've, I've told people sometimes because they say they don't

> want to be repositioned, for instance, you know, and I tried to explain to them that I will not be doing very good nursing care if I don't do the things that I know from my practice are beneficial to their child and in fact, will likely delay and prolong their recovery period. So, I think if you explain things, you know, people are on board. (P09)

Overall, nurses highly valued parent input for pain treatments and encouraged them to "steer the boat" (P06) with pain care. In partnership with parents, nurses brainstormed pain treatment options and provided their expertise about pain medications. Nursing expertise was perceived by participants to give parents more control over what pain treatment options would work best for their child.

Individualizing Pain Care with Parents

Nurses recognized that each child with CI is unique and has particular pain needs. Nurses expressed that they collaborate with parents to establish an individualized pain care plan, which takes into consideration the child and the family. One nurse stated, "it all comes back to family-centred care, which is taking care of not just our patients but taking care of our families as well and they're all one" (P10). To individualize care, nurses stated that they had conversations with parents to assess "how the family is and how involved [parents] want to be" (P02). Another nurse mentioned,

> I go in, introduce myself and ask them sort of a few questions about themselves like "do you have any other kids, how have things been going, what's brought you in" to get a baseline for myself, not necessarily about the kid but like "how are you", that kind of thing, initiating that therapeutic intake. I kind of suss out [identify] what's most important for you, do you want me to feed the kid? I honestly just ask them as many questions as I

> can about sussing out what they are comfortable with me doing with kid's care if they are there and what they feel is most important. (P06)

Not only did nurses express that they assess parents' desired level of care involvement, but they also discuss the family's unique care goals. They stated, "having those conversations to express goals and values to kind of, know more" (P03), "establishing those goals because each family will have different goals" (P02), and "depending on the child, I list the goals" (P08). By understanding the individualized goals of each family, nurses perceived that they were able to establish partnerships with parents and help them reach their care goals. For instance, one participant stated, "It's just being equal and being like we're both [HCP and parents] in it for the same goals" (P02). In this way, nurses adapted the goals in care to suit the family's particular needs.

Once nurses had established a pain care plan, they stated that this plan was shared with the parents. The pain care plan included information about the timing of the medication administration and of assessments as well as a list of the pain medications that were available to give as needed. Examples of this included, "listing the PRNs and letting them know how often they can have them" (P06), "I am planning on giving these oral medications through the night and there are breakthrough meds if needed" (P07), and "I just tell them what the nurse's plan is and I also ask for their opinion. Are you okay with this Tylenol being given all the time or if you want you can skip one and see what happens?" (P08). By sharing this information, nurses were being transparent about the proposed plan of care and perceived that this allowed parents to feel more prepared for the day. One nurse stated, "I try and kind of make up a plan for the day and kind of talk to them about what's going to happen today so that they're a little more prepared" (P10). Another nurse expressed,

> Even at night time, especially on the night shift, I will work it out with them and I will be like "if I do an assessment and I think that he is in pain, do you want me to wake you up and figure it out together and give him something and do you want me to treat it with whatever drug I think is appropriate for it and if it doesn't work then I'll wake you up?" (P05)

When creating a pain care plan, nurses expressed that they also involve other disciplines to meet the children's pain needs. One nurse stated, "involving [Pain and Symptom Management Team] and palliative care team and oncology […]. I definitely feel like in these situations it needs physio and [Occupational Therapy] a lot too. So, just bringing like the interdisciplinary team together to best support the patient and family" (P03). Another nurse expressed, "a lot of kids will need interventions in different ways, it could be physio…it doesn't have to be having to give them Tylenol" (P06). Involving different disciplines to meet the child's pain needs was perceived to better support the parents and help control the child's pain. One participant shared,

> Just creating a plan with multiple disciplinary teams to aid in that approach like it shouldn't just be nursing, it shouldn't just be the doctors because they're the ones that prescribe the medication or it shouldn't just be Child Life because they are the ones that offer, you know, the play and learn. So, it should just be, everybody is able to offer their tool and they come together to make the family happy about the care that they're receiving. (P02)

While nurses expressed spending time collaborating with parents to establish a plan, they shared that the pain care plans were mainly verbal because there is no dedicated pain care plan section in the online charting system in their setting. Another nurse shared her experience,

> […] sometimes you just get a sheet of paper and write down notes and taping over the head of a bed so it's not an official care plan and yet, it is a plan of care. So yeah, and you just take into account what the parents have to say […]. I've seen people, they'll write, "if I'm crying, please try this", you know "get me my teddy bear" or "turn on the cartoons" or "turn on my little music". (P09)

In this example, the nurse shared a creative way that was used to disseminate information to colleagues instead of the online charting system. Other nurses stated, "I'll just put it in my note; […]. Then, I will tell the oncoming nurse, please like if the child shows signs of pain, this is what we need to do. So, it's very much from nurse to nurse" (P11), "I would say it's verbal, I think I never really write it down" (P10) and "honestly, I don't really know if we've developed a formal plan" (P03). In these examples, nursing practices varied; some nurses took the time to disseminate the plan of care to their colleagues via various means, while others did not share the plan of care.

Overall, nurses shared how they create pain care plans in collaboration with parents. When creating a plan, nurses take into account the level of involvement that is preferred by the parents and their children. In accordance with parents' feedback, nurses also initiated the involvement of multiple disciplines to individualize the pain care plan and meet the pain needs of the children and their families. This plan was shared with the parents to help them know what to expect during the day. However, nurses expressed that there was no standard method of sharing the pain care plans with their colleagues.

Supporting Parents as Advocates for Pain Care

Nurses reported that the collaboration with parents as partners in pain care is crucial for many reasons. Almost all participants expressed the importance of involving parents in pain care

because they are their child's "biggest advocate" (P03). Similar statements were made by other participants, who expressed, "[parents] are their child's advocates. So, they're the ones, identifying, secondly, speaking out for their child" (P01) and "they're their child's advocates, they're the ones who know their child" (P11). Parent advocacy role was perceived to be essential for pain care in children with CI because parents could "speak out" for their child who could not verbally communicate with the nurse. One nurse stated,

> I don't think a lot of nurses really use the parents as a gauge and I think they forget that with cognitive disabilities, parents are a huge third arm. Do you know what I mean? They are a huge part, they are their advocate, they are their voice. I think a lot of nurses forget that because we get so task-oriented like we have to check all the boxes. (P06)

In the above quote, this nurse shared their perception of the importance of parent advocacy in pain care, comparing it to the child's "*third arm*". When parents acted as advocates, nurses valued their input as if it was voiced by the child. One nurse stated, "I don't know how else to communicate with [the child] other than with the caregiver" (P01). Nurses perceived that this was crucial because they could better understand if pain treatment was inadequate and if more needed to be done for appropriate pain care. For instance, one participant stated, "they're going to be more likely to be like hey, I do think he's in pain, can we give him something a little bit stronger"(P05). Other nurses stated, "if we are treating it with just Tylenol and Advil and it's not sufficient, it's really the parents that are going to be asking for more meds" (P01), and "they are very good at asking for something and saying something is up and that their kid needs something" (P07). Nurses perceived that this optimized pain care for the child and highly valued parent advocacy. For example, another nurse expressed,

> So, kind of going back to parents being a big advocate and so, having a lot of just like, those conversations with parents and hopefully the parent being on the kid's side to be an advocate. To allow us to get better information, to better support the patient and family but then also, parents are very much like, have a big role, have a presence at the bedside. (P03)

In the context of pain care for children with CI who cannot speak for themselves, nurses related parents' advocacy role to them being "active partners in care" (P07) and perceived that the "relationship with parents does look different because you work more closely with the parents" (P10). Recognizing parents as advocates and as "active partners" in pain care, nurses expressed supporting them as advocates. One nurse offered "verbal support and encouragement" (P05) to parents to encourage them in continuing to advocate for their child with CI. Other nurses explained that they offer support by acting as a liaison with the medical team and sharing parent concerns with the appropriate people. Participants stated, "ensuring that [parent] voices are being heard when it comes to their communication with the medical team as well" (P01), "it's maybe me going to the team and having a conversation with the team about like […] this is what the parent is saying and therefore I think there is a need for a higher level of pain management" (P03), "making sure [parents'] voices are heard and then, being an advocate for the exact same thing that they are trying to get" (P05) and "if parents find that their child is not doing great, then advocating for [Acute Pain Services] consult because they are better equipped to handle pain control" (P07). Another nurse expressed,

> So, I definitely would say that for me, with advocacy with parents, it's that I will absolutely back up the parents and make sure the team is hearing that okay, parents know the best way for us to take care of them. We need to make sure we're listening to this and

> that we're applying it because otherwise, we would not be giving the kid the same care that we would provide to another kid who […] is not cognitively impaired. So, I definitely would like to say I definitely push more with physicians and the team to make sure that parents are heard with these children because they advocate for their child all the time. (P10)

By doing so, nurses perceived that they are not only supporting parents as advocates but are also advocating for appropriate pain care for their patients. Nurses reported that they were in an ideal position to advocate for the children as they are frequently at the bedside and were "the eyes and the ears for the doctors" (P02). The same participant explained,

> So, unless the doctor is in and actually sees the patient during a pain episode, they are often relying on the nurse to provide them with updates. Okay, “the patient was in pain for a few hours overnight” or “it was managed with this or wasn’t managed. So, I feel like we need to have some changes”. So, I feel that the best thing is just to like to be super aware of all the things going on and then you’re able to kind of, bring it up to the appropriate people. (P02)

While nurses perceived that advocating is essential for appropriate pain care, they also reported that this can be an uncomfortable experience, stating "the nurse has to feel comfortable advocating" (P02). Nurses viewed advocating as an annoyance to their colleagues and compared it to "pestering the team" (P07) and stated, "I am annoying. I am the one that stands in the doorway of the rounds room, and I am like, so you guys are going to come and see this person yet? […] and don't walk away" (P05), "I find a lot of times that when it comes to pain medications, you have to push with the physicians to be like no, listen, especially with these children” (P11). While nurses viewed advocating as a difficult experience, they also recognized

the value of advocating and its positive impact on the quality of pain care and expressed "I think the nurse plays a huge role in being able to help manage the pain by, you know, having a bit of a backbone and saying, "I agree with the parents, the patient has been in pain for too long" (P04). Another nurse mentioned,

> […] if you have nurses who maybe aren't advocates for pain and who are maybe not as much, maybe it's not in their values. Potentially, for 12 hours, they could be in no pain and then the next nurse comes on and they're in pain the whole shift. (P03)

Overall, nurses highly valued when parents were advocates for their child's pain care as they perceived this to optimize the quality of pain care. Recognizing the importance of parent advocacy, nurses shared that they support parents in their role and encourage them to continue advocating. They also support parent advocacy by acting as advocates for pain care as well as ensuring that the children with CI are properly cared for.

Involving the Child with CI in Pain Care: A Spectrum

Nurses expressed various ways that they have involved a child with CI in their pain care. The level of involvement was perceived to be dependent on the child's communication abilities and degree of CI. When nurses discussed involving children with CI in their care, they stated, "[their level of communication] by itself is very complex on a patient-to-patient individualistic basis" (P03), "it depends on how cognitively impaired they are" (P07) and "depending on the severity of cognitive impairment" (P11). In this way, involving children with CI in their care is on a spectrum and depends on the individual. Many nurses expressed that their capacity to involve a non-verbal child in their pain care was limited and stated, "I don't think I can involve them more than that. I just inform them, but I don't necessarily expect feedback" (P08) and "It is hard to kind of tell if they are, like what they are going to be able to respond with and if they are

non-verbal […], it is hard to ask them about their pain" (P04). In these cases, nurses work with parents to facilitate communication with the children to involve them in care. One nurse shared,

> If they are completely non-verbal, I don't usually have the capacity to involve them but sometimes, parents can because they will say "they understand me and they are able to communicate in some way and maybe they have a way of saying yes/no". So, parents will sometimes be able to ask their kid "is it hurting?" or they would be able to move a limb and see if their kid reacts to that type of thing. […]. So, we can involve them a bit, but it depends on the kid. (P07)

In this example, the nurse had to understand the child's degree of cognitive impairment and adapted pain assessment accordingly. To facilitate child involvement, nurses expressed that they have used strategies like "asking yes or no questions to make it easier to respond" (P04) or "maybe they are able to nod. […] If I just even palpate a little bit harder, do they have that reflex where they pull away or make a facial grimace? (P04). Another participant shared,

> Actually, one thing is for the non-verbal or the ones who can't even shake their heads or anything, is getting them on board with eye blinking or thumbs up or down or a twitch because I know that that was a way that I communicated with one patient and the dad was all for it and the mom thought he was just blinking and that he wasn't trying. And I asked a bunch of questions, and he was only blinking for the ones that were true […]. (P05)

In the above quote, the nurse had previous experience working with children with CI and recalled different communication strategies that were used. This nurse trialed various strategies to assess if the child would respond to any of them. Additionally, nurses expressed that they have included other disciplines and tools to facilitate communication with a child that has a CI. They shared, "using those OT, different tools that we're able to get. We've had iPads where physio

would like, they'd be able to draw with a finger but wouldn't be able to talk to us" (P03) and "some kids will have communication iPads" (P04).

Overall, involving the children with CI in their pain care was perceived by nurses to depend on the child's severity of impairment. To facilitate the child's involvement in care, nurses expressed working with parents and involving other disciplines as well as using a range of communication tools.

Barriers to Appropriate Pain Care for Children with CI in Partnership with Parents

Nurses shared their experiences establishing partnerships with parents for pain care of children with CI. Notably, participants identified multiple barriers that were perceived to negatively impact the provision of pain care for children with CI, in partnership with parents. These will be described below and include (1) lack of time, (2) multiple parent stressors, (3) gaps in the charting system, (4) lack of formal education and (5) lack of appropriate pain assessment tools.

Lack of time

Almost all participants identified not having enough time during their shifts to establish partnerships with parents of children with CI for pain care. Participants shared, "everyone is working at their fullest capacity and so, there really is not a window of opportunity for you to step back and focus your attention on these cases" (P01), "you don't really have the time to sit down and either offer a therapeutic conversation or get down to, like, the basics of their needs" (P02) and "I don't know, especially with the pandemic, that we would ever get to the point of having those therapeutic, beautiful conversations […] because of how strapped we are in the hospital" (P02). Nurses perceived that they did not have enough time to establish therapeutic conversations for pain care because these conversations were lengthy. One nurse shared,

> Time is a big thing. It just takes a lot longer to have these discussions with parents of CI children. Partially because I sometimes get the feeling that parents are like "finally, someone that I can talk to about my experiences!" so they will just offload everything, which is great but also, we sometimes don't have time for that. It is also just more complex. Pain control in these kids is just more complex and it takes more time than other kids and if you are short-staffed on the floor and you don't have a whole lot of time, it is, unfortunately … I think these kids get missed the most because it takes so much more time to determine what they look like when they are in pain and everything. We can assume a lot more about the kids that are neurotypical. (P07)

In this example, the nurse perceived that it took a long time to initiate a partnership with parents to individualize care for children with CI. Additionally, this nurse expressed that parents of children with CI take time during these conversations to vent about other concerns. Due to the perceived lack of time, nurses felt that they were not able to engage in these discussions for establishing partnerships that are essential for the pain management of children with CI. Instead, nurses felt forced to “get to the nitty gritty” (P06), "just doing the bare minimum to get through your shift" (P02), and that “people are dealing with what they can with the time that they have” (P09).

Multiple Parent Stressors

Nurses identified that parents of children with CI handled a lot of stress which can impact the establishment and maintenance of partnerships. They expressed, “I find the parents of children with disabilities are already burnt out. They need that respite, and they don’t have it” (P02), “parents are really tired and have only so much patience to kind of go through an assessment with you” (P03) and “I find that [parents of children with CI] exhaust faster” (P05).

Participants perceived that parental stress stemmed from multiple different factors. For instance, nurses perceived that this population of children was admitted more frequently to the hospital and that previous negative hospital experiences may affect parents' willingness to partner with nurses during subsequent hospitalizations. One nurse stated,

> […] sometimes there's hesitancy with the parents because they've had negative experiences in the past. I would say we probably see that in this group more than any other group and obviously because they are overly medicalized. So, when dealing with parents that have had negative experiences, so there's a portion of bitterness and anger that's just underlying, it's difficult to obviously, establish that, you know, care provider relationship. (P01)

In this example, the nurse explained that previous negative hospital experiences resulted in parents being more hesitant and had underlying "bitterness and anger", which made it harder for nurses to establish partnerships. For instance, P09 explained that parents were upset because of an accumulation of unfortunate events such as "a meal from the kitchen didn't come", "they got an admission room, and somebody made a noise that woke their baby". Nurses expressed that the parents "swept it under the rug […] and maybe only the big things are discussed" (P02). These examples are events that were outside of the nurses' control but perceived to negatively impact the parent-nurse partnership and increase parent stress. For instance, one participant explained,

> I think even just little things are important too, just because it adds up. Like if you have ten little things that just keep getting swept under the rug then sometimes it's harder to gain trust with that family and then, that causes a little bit of a conflict situation, which then, it's hard to have a good rapport with that family because now, the trust is broken,

> something didn't go right more than one time and they're not really listening to you anymore. (P02)

While there are multiple factors leading to parental stress and burnout, almost all participants stated the same contributing stressor. Most nurses mentioned that the parents of children with CI constantly need to repeat themselves, explaining the same stories about their child multiple times to different health professionals. Nurses stated, "it must be quite tiring to repeat the same tells [pain behaviours] of the child and the same medication plan and going over it several times" (P04), "I think a lot of it comes down to stress, fatigue. I think parents get sick of just telling their stories over and over again" (P03), "I am sure they get sick of it and it kind of looks bad on our part too. It's like if this parent has been telling every nurse…" (P06) and "I am sure it's frustrating for parents probably constantly being asked this and constantly having to advocate for the same things when it should just be a standard" (P10). Nurses felt like they played a part in contributing to parental stress because they relied on parent expertise for pain care. One nurse stated,

> But, in situations where they're stressed, I'm sure they wish there was just a better way for nurses and physicians and healthcare providers to just know. You know, sometimes you're just done and you're like "I don't know, you're the professional here, I came here to you seeking help and I feel like I basically have to tell you how to do your job because you know, like, had I not told you that, would you have really known? Would you ever know?". […]. So, it's hard because we totally rely on them to do our job sometimes and you know, that can be discomforting to some families because they're not there to have that role anymore. (P02)

In this example, the nurse explained that the parents were likely already exhausted and stressed due to being in the hospital. However, rather than having nurses supporting parents in pain care, parents were the ones providing pain care support to nurses. Other nurses expressed similar statements, “I have a certain amount of reliance with the parents which is kind of unfortunate because then the parents feel a little more obligated to have to stay which will increase their caregiver burnout” (P10) and “I find in some situations, we rely on them. We definitely, sometimes, put a lot on parents’ shoulders”. (P11)

Gaps in the Charting System

Nurses stated that there were many issues with the health record system that made pain care for children with CI more challenging. In turn, nurses perceived this affected the establishment of their partnerships with parents. For example, nurses shared that the online system does not have a designated area to chart individualized pain care information. These nurses stated, “unfortunately, there are multiple places in which you can document multiple things […] it is very difficult to get a clear picture of what’s going on with my patient” (P01), “it’s accessible, just a matter of if people know where to find it. […] yeah, so, it wouldn’t be like on click, easy find” (P10), and “[…] well you chart it everywhere in EPIC, in different places” (P03). This made it harder for nurses to gather information about the child’s pain in preparation for their oncoming shift. While there are many places to chart pain information, nurses expressed that there are no designated sections to chart the child's baseline behaviours or unique pain cues. This was perceived by nurses to make it more challenging for them to know what to assess, feeling the need to rely on parental input. One nurse shared,

> There’s nowhere [to put the parent information about the child’s baseline in EPIC]. The only thing is passing it on from nurse to nurse and then those things get lost in translation

> and you play telephone in a way. Unless someone writes something super detailed in their note that somebody could go back to then, yeah then there's nowhere to find it. (P06)

Other nurses made similar comments, "with the way the system is set up, it's very difficult to get a clear idea of what my patient looks like or what's been happening" (P01), "I realize that other nurses tell me something about the kid and that's it or they tell me that's just him, but like, it's nowhere to be found" (P08) and "as you go through their chart, you'll find bits and pieces but I find there is no place to add in those little extra things. […]. There isn't anywhere that tells their daily routine or how they like things" (P09). To make up for the lack of a designated charting area for this information, nurses shared that they would include this data in the summary page section at the top of the patient's chart, in their end-of-shift notes, and/or give a verbal report about the patient's baseline to the oncoming nurse. However, these practices were perceived by nurses to be inconsistent and resulted in this information getting "lost in translation". One participant shared,

> […]. At 12 hours, sometimes you're like, you know, a little bit at the end, you're tired and you do your best to hand off, but I guess maybe sometimes if it's not clear or you didn't pass off […] so it's definitely, they can be lost in translation and there can be some miscommunication. (P11)

All nurses in this study expressed a need to improve the charting system and that this would be beneficial for the overall pain care in children with CI and for maintaining partnerships with parents. Nurses shared, "I think that it would be very beneficial for parents, nursing and medical staff […] they're going to be able to better identify quickly if they're in pain because we know their baseline" (P10), "It would help because I wouldn't have to spend five minutes at shift

change trying to explain what [the pain care plan] is to the nurse that's never had him before" (P05) and "maybe better education or a better flow of where to document things would give you a clear picture […]. I think those two things would probably make a difference in the daily care we provide" (P01). Nurses shared their concerns about the charting system and identified areas to improve the charting of individualized pain care. Overall, participants perceived that making such charting improvements would make a difference in pain care for this population of children.

Lack of Formal Education

All nurses reported that there is a need for formal education about pain care for children with CI as none of the participants received any education about this topic. Statements about the lack of education were made by nurses and included, "it doesn't exist. I honestly don't remember covering it in school. […]. We covered pain and pain scales briefly, at work, but nothing specific to the kids with CI" (P01), "I definitely would've appreciated more education from nursing school and even as a new nurse to [workplace]" (P03), "I feel like we didn't receive much education regarding it like either in school or at the job. A lot of it is like, figure out as you go" (P04), "There was no education. There was more so just here's a new situation, figure it out" (P05), and "We have no education on treating pain in kids that can't tell us they are in pain" (P06). As a result, nurses expressed that they had to compensate for the lack of education by "figuring it out" (P05) in practice and relying on parents. One participant shared,

> See, we don't learn much about that, specifically that population. We just got pain scales and a lot of drilling that pain controls are important and then from now on…, we personalize our approach with the kiddos. I don't have formal teaching; I go by intuition and whatever the parents tell me about their child. (P08)

Other nurses also shared that they have had to teach themselves and stated, “I think it’s been very much ‘on the job’ learning […] and learning from your co-workers” (P09), “Everything I have learned, I have learned on the job and from experience” (P07), “So, all of my knowledge has come from personal experience because there was no other way to get that information to learn how to do it until I was just forced to do it one day” (P02). Nurses expressed that there is a need for education about pain care for children with CI, especially because “it’s such a large population” and “it’s a pretty good chunk of people that you don’t know how to take care of” (P05). Nurses perceived that a lack of education in this area had a negative impact on pain care for children with CI. One nurse shared,

> I feel like there hasn't been any education, to be honest with you. I feel like it was very much self-taught, self-practicing, and there was no education. Definitely had no education when I first started as a nurse and very little, I think, in nursing school. [...] I feel like it’s reducing services to all of the children that we take care of. I feel like it puts them at a disadvantage and there’s going to be, yeah, higher risk for pain because we’re not able to identify the same way you will assess a kid who, hum, has a normal cognitive function. So, I feel like it's unfair for both children and nurses. (P10)

Thus, nurses expressed that implementing formal education was necessary to be better equipped to manage pain in children with CI. Nurses stated, “[…] it would be great to have education on pain crisis in those that are cognitively impaired. It’s an area that is not tackled at all” (P01) and “I think even having parents or palliative care do an in-house session or education day on pain management would be really helpful” (P06). Another nurse suggested,

> […]. There's a lot of people, let's say at [workplace] for example that work with children who have a cognitive impairment, and they would see and know a lot more of behaviours

> that new nurses wouldn't so I feel like bringing in a specialist who sees these children a lot and who knows like cues and behaviours would be very helpful. And then maybe somebody as simple as the pain management team, somebody like them to come in also to provide some education, that would be helpful. (P10)

Overall, nurses stated that they have not received any formal education regarding pain care for children with CI. They perceived that the lack of education negatively affected care and expressed a need for formal education to be better equipped at managing pain in this population of children.

Lack of Appropriate Pain Assessment Tools

Participants identified that there was a lack of appropriate pain scales for pain assessment of children with CI. All participants shared that they used the FLACC scale to assess pain in this population but perceived this scale to be inaccurate for children with such unique pain behaviours. Nurses expressed, "some of these kids are stuck in a position and I'm like no, well their limbs are flaccid. They're not rigid […]. So, it's not great for these kids where it's like the body is just not working" (P05), "we are left to the devices of an inaccessible pain rating scale. It doesn't work. It's not fair for the child to be held up against standards that don't make their ratings accessible" (P06) and "our go-to scale when a kid is non-verbal is FLACC, which, honestly, I don't think does a great job at capturing pain for these kids" (P07). In these examples, the participants shared the same perception about the FLACC scale, stating that it is not representative of the pain in children with CI. One participant shared,

> […] the FLACC score is highly based on how, like, how tense their arms or how tense their legs are, if they are kicking, things like that and for people, for kids who are cognitively impaired and also physically impaired… oftentimes, they will have

> contractures or an abnormal muscle tone, to begin with. So, I don't always find it the most accurate because some kids always have tense arms and legs, and some kids are always kicking around at baseline. And then, I mean, their facial muscles can be different in a lot of cases than, like, a typical child's face. (P04)

The lack of an appropriate pain scale for this population of children made nurses feel "frustrated" and "not able to do my job" (P06). Without a tool that could appropriately assess pain in children with CI, participants perceived pain assessment to be more difficult and felt forced to rely on parents for assessment instead. One nurse stated,

> I would say that's difficult, honestly, because the scales that we have right now aren't specific. Like the pain scale that we use at [hospital], I don't find it's very specific for these children and usually, it's the parents that know the children best. I usually end up, if they're around, trying to ask them. If the parents aren't around, that's kind of a process of elimination to see what might be causing their pain, which is not ideal. (P10)

Other nurses expressed similar statements, "I can't really use the FLACC or NIPS because it's not appropriate then you just go off of like, what you see and what you hear the parents say" (P06) and "If I find the rating is not doing much for me in general […] to tell me about their pain at all, I will write a comment saying caregiver states does not appear to be in pain" (P04). Nurses shared their perceptions of the pain scales and expressed concerns about their appropriateness for this population of children. To mitigate this, nurses stated that they rely on parents' assessments.

Overall, nurses perceived that they sometimes did not have enough time during their shifts to have therapeutic conversations with parents about pain care for their children with CI. This affected the nurses' ability to establish and maintain partnerships with parents for pain care.

Moreover, nurses felt like parents of children with CI had multiple stressors that affected their ability to be open to partnerships. While nurses seek partnerships with parents, they expressed that they contribute to their stress by repeatedly asking the same questions and relying on them for pain care.

Strategies to Establish Partnerships in Pain Care

Nurses shared their experiences with establishing partnerships with parents for pain care of children with CI and identified strategies for this process. These include: (1) taking the time to listen and check-in, (2) offering support services, and (3) continuing their home routine.

Taking the Time to Listen and Check-In

Participants expressed that active listening and checking in with parents facilitated partnership establishment. Nurses stated, “they’re [families] not being heard or listened to as much” (P05), “being able to just discuss things with someone and work through their emotions and everything is a really good thing for [parents]" (P07), "that’s the biggest thing you can do, is listen to them and let them be involved in their child’s care” (P09) and “they just need to talk […], just getting them to let a lot of things off their chest, it helps” (P11). Thus, recognizing the need for parents to discuss their concerns, nurses expressed that they take the time to listen to them when they can. One participant stated,

> I like to sit down, when people, when I’m meeting people with complex kids, and yeah, with impairments and stuff. I like to sit down so that the child, maybe, he can become aware of me, in their surroundings. […] I mean all of this is if you have time and depending on what the situation is when you walk in the room. [...] But yeah, initially, I like to sit, and I think that just kind of give everybody a chance to breathe and you know,

> parents, I think, are a little more comfortable and can tell me what's happening, and, and I think they feel […] they're not going to be pushed aside […]. (P09)

This nurse shared that listening also involved non-verbal body language that reflected openness and allowed parents to feel more comfortable in sharing their concerns. For example, this participant mentioned that sitting down and having a conversation with parents demonstrated to them that the nurse was available to listen. Along with listening to concerns, nurses shared that it was important for them to validate parent concerns and that this helped establish positive partnerships. P02 shared, "I think it's important to validate how they are feeling and let them know it's okay to be overwhelmed and […] that we're here to support them". Another nurse expressed,

> I mean, showing that you believe them. So, just validating their feelings I find is very important because if they feel that their feelings are brushed off in the slightest way, I feel like they tend to close up and not be as trusting at all. So, just validating them every step of the way. (P04)

In this example, the nurse expressed that invalidation made parents feel like they were being "brushed off" and led them "to close up" (P04), thus affecting partnership establishment. Nurses perceived that it was more likely for parents to be unwilling to partner in care if their concerns were not being taken seriously. One nurse shared, "[The father] wasn't listened to from the beginning, and everything keeps building up and now, we are this point, and it is way harder to get the parent cooperation" (P05). To prevent this, nurses expressed that they "check-in" (P07) with parents to see how they are doing. One nurse expressed, "throughout the day, I make sure to check with the parents and ask, 'Have you had any sleep today, have you had breakfast […]?" (P10). Another nurse stated, "it's really just continuing to communicate to see if the care that

we're continuing to provide is up to par with what it is that the parents want and that it's actually meeting the needs of the child" (P01). One participant shared,

> It's just constantly checking in so, again most of these children, you're already frequently in their room because they have lots of procedures, lots of medications so you're in the room quite frequently, but every time you're in, it's not just, oh I got to do my thing and then I have to leave. It's, ok, I'm going to see how they're doing and how mom's doing or dad's doing. "Is there anything I could do for you, guys? […] Instead of waiting for something to happen if you're the one who are proactive and oh, how is it going in here, is there anything I could do that helps? (P11)

In this example, the nurse perceived that being "proactive" (P11) and checking in on parents relieved some of their need to advocate when there's something wrong with the child. As a result, parents can share their concerns with the nurses promptly "instead of waiting for something to happen" (P11). Overall, nurses expressed that taking the time to check-in and listen to parents facilitated partnership establishment as it helped to relieve some parental stress.

Offering Supportive Services

As nurses perceived parent stress to be a barrier to partnership establishment, they expressed that offering supportive services helped to relieve some parenting stress thereby facilitating partnerships. Nurses expressed, "we need to be holistic in the way that we support parents and families by offering support from social work and massage therapy programs" (P03) and "offering a volunteer […], telling the parents that we have a volunteer that can come, I'm here as well, please go take that five-minute walk for coffee" (P10). A "holistic" approach to supporting parents was perceived to positively impact partnerships and care. When more services

were involved, one nurse perceived this to be "a strong team" (P11) that could offer better support to parents and facilitate partnerships. For example, this same nurse shared,

> When they have a strong team, it makes it so much better, because you are there to support them for a short period of time, but they have this child for life and if they have somebody who's going through that with them, then that really helps. […]. If he has other people who are involved for helping, like the social worker if ever they get involved, that helps, you know, because even if they can't afford to pay for a meal in the hospital, the social worker can get them a free meal pass, that helps. Just because again, in order for them to take care of their child, they need to be taken care of, so when they've been properly taken care of, that helps the partnership, yeah. (P11)

Involving other services to support parents was perceived to be beneficial because they could help nurses with "checking in" on parents to help relieve some of their stress. One nurse mentioned, "[…] we should get social work involved. This parent is close to burnout, and we need to provide some services for them because taking care of this child is a lot and they're overwhelmed" (P11). Another nurse shared,

> Our Child Life are absolutely fantastic, and they do a really good job in checking in with parents to see how they are coping and seeing "how have you been taking care of yourself, do you need to take a shower and do laundry and stuff like that?". So, they are really really helpful. Having people like [Health Care Aids] maybe go sit with the patient while the parent goes to take a break is really fantastic. […] Parents really appreciate that. (P07)

Overall, nurses shared that offering services to help support the parents facilitates partnership establishment. With more support, nurses expressed that the parents could take a

break and take care of themselves. In turn, nurses expressed that when parents are “properly taken care of” (P11), they feel more apt to partner with nurses in taking care of their child.

Continuing their Home Routine

Nurses expressed that the children with CI had a particular care routine that was previously established at home. By continuing their home care routine in the hospital, nurses perceived that this facilitated partnership establishment with parents. For instance, nurses stated, “[parents] expect things to be done a certain way and they get very upset if it’s not done that way” (P11) and “[parents] are very particular, rightfully so, about how things are done. So, any time that there’s a break in the routine, that tends to create friction” (P01). Being in the hospital was perceived by nurses to be stressful for parents. Nurses stated that continuing a familiar care routine for the child empowered parents, making them feel comfortable and facilitating partnership establishment. One nurse shared,

> Just giving them a sense of control. […]. The parents want to have some sort of control so, letting them set that schedule like “yeah, they can eat when they want, I am going to keep the curtains closed and you tell me if you need anything. […]. It’s not just about providing comfort or pain control for the kid but it’s also, helping the parent feel comfortable because that will help the child as well. (P06)

Not only did continuing the home routine provide parents with a "sense of control" (P06) but it also helped to build trust between nurses and parents for care. In turn, parents are less tense thereby being in a better state to establish partnerships in care. One participant shared,

> Well, because their kids can be… especially complex care kids can be… very specific and I think parents are just protective of their children and, which is very understandable […]. So, kind of, when we show that you’re competent in a way, the parent tends to have

> a more trusting relationship with you because I feel like they don't have to be tense and standing over their child to make sure everything is being done correctly. (P04)

Overall, nurses shared that children with CI have a particular home care routine that should be implemented in the hospital to facilitate partnerships with parents. Nurses perceived parents to feel more in control, trusting and less tense when the home care routine was provided in the hospital. Therefore, nurses perceived this facilitated partnership establishments with parents.

Summary of the findings

The findings of this study describe nurses' experiences with establishing partnerships with parents for pain care of children with CI. Nurses expressed feeling uncertain when providing pain care for children with CI, especially when parents are not at the bedside. In this study, nurses shared how they work in partnership with parents for pain care. Nurses expressed relying on parents for pain assessment and shared their expertise to support parents in guiding pain treatment. Nurses shared that they work in partnership with parents by establishing an individualized pain care plan together and working together to advocate for appropriate pain care. Finally, nurses identified that partnerships with parents can be hindered by nurses' lack of time and by parents' multiple stressors. On the other hand, partnerships can be facilitated when nurses take the time to listen, check-in, offer supportive services, and continue their home care routine. Nurses also identified areas to be improved to optimize pain care including (1) a charting system, (2) formal education, and (3) pain assessment tools. In the following chapter, I discuss these findings in relation to previous literature and will provide points for future implications.

Chapter 6: Discussion

In this chapter, I examine noteworthy findings presented in Chapter 5 and place these findings within the context of what is already known in the literature. Then, I identify the implications and recommendations for nursing practice, education, policy, and research. Lastly, I discuss the strengths and limitations of this study.

Introduction to Discussion of Findings

In this interpretive descriptive study, I explored nurses' perceptions of establishing partnerships with parents for pain care of hospitalized children with CI. The findings of this study indicate that while nurses use several strategies to promote collaborative partnerships with parents for pain care, they are faced with many challenges that make it difficult to establish partnerships. Consequently, nurses expressed that they felt the need to rely on parents for the provision of pain care for children with CI. The major findings that will be discussed in this section relate to nurses' reliance on parents for pain care of children with CI. More specifically, I will describe how (1) nurses' uncertainty, and (2) nurses' heavy workloads potentially contribute to nurses' reliance on parents for the provision of appropriate pain care of children with CI. I will also describe strategies that nurses used to facilitate partnerships with parents for pain care.

Nurses' Uncertainty in Pain Care Contributing to Reliance on Parents

As presented in chapter 5, the nurses in this study expressed feeling uncertain when providing pain care to children with CI, regardless of their nursing experience. The nurses perceived their uncertainty to impact the quality of pain care, comparing it to "a guessing game" (P05) and described pain care as a trial-and-error process. Consequently, nurses felt the need to rely on parents to appropriately assess pain in this patient population. Thus, their uncertainty was perceived to not only impact the quality of pain care but their partnerships with parents as well.

The perceived impact of nurses' uncertainty illustrates the need to discuss this challenge further. This study's findings will be discussed alongside previous literature to compare what has been established and locate the findings within a larger context.

As mentioned, pain research related to children with CI is sparse in the literature and even more so about parent-nurse partnerships in this context (Belew et al., 2014; as cited in Garg et al., 2017). On the other hand, research related to the general hospital care of this patient population is abundant in the literature. Many of the published studies relate to nurses' or parents' perceptions of hospital care of children with CI. Similar to our study's findings, previous research has found that nurses experience uncertainty in the care of children with CI in pediatric hospital settings (Aston et al., 2014; Carter et al., 2016; Hagvall et al., 2016; Oulton et al., 2015). For example, researchers in England published an ethnographic study in 2015 that explored parents', patients', and healthcare staff's perceptions about the needs of children with CI and their families during hospitalization (Oulton et al., 2015). Researchers observed participants in a hospital ward, had informal conversations with healthcare staff on wards and discussions with children and their parents, reviewed the staff's documentation, and conducted structured interviews with staff hospital-wide (Oulton et al., 2015). A total of 27 HCPs participated, ten were nurses who had previously worked with this population of children. Hospital staff from various professional backgrounds perceived that there was a lack of knowledge related to interacting with children with CI and perceived staff to be uncertain when interacting with this population of children and their families (Oulton et al., 2015). Another study was conducted in Canada to understand the hospital experiences of children with CI, their parents, and the nurses who cared for them (Aston et al., 2014). Researchers conducted semi-structured interviews with 17 mothers of children with CI, 12 nurses, and eight children with CI (Aston et al., 2014).

Similar to the findings of our study, nurses expressed that it was challenging to communicate with children with CI and perceived that this affected their ability to provide effective care (Aston et al., 2014). Nurses expressed fear and discomfort because they felt like they did not know how to communicate differently with children with CI (Aston et al., 2014). Participants in this study identified that the source of their uncertainty related to pain care of children with CI derived from being accustomed to working with the mainstream population and feeling unsure of how to proceed with care in this population (Aston et al., 2014). Moreover, a study conducted in Sweden in 2016 reported similar findings (Hagvall et al., 2016). Researchers conducted semi-structured interviews with 18 parents of children with CI to describe parents' experiences of caring for their child with CI in hospital (Hagvall et al., 2016). In this study, parents perceived HCPs to lack knowledge of their children's diagnoses and disabilities (Hagvall et al., 2016). Consequently, parents perceived staff to be uncertain and to have difficulty in caring for their children with CI (Hagvall et al., 2016). Only one previously published study was found to focus on nurses' experiences with pain care for children with CI (Carter et al., 2016). This study was conducted in the United Kingdom to explore how HCPs develop knowledge and skills related to pain management in children with CI (Carter et al., 2016). The researchers interviewed 19 HCPs to explore this topic, eight of whom were nurses. Similar to our findings, most HCPs expressed feeling uncertain about their pain care decisions when taking care of children with CI and found that their uncertainty affected the quality of pain care (Carter et al., 2016). Moreover, HCPs also perceived that the children's behavioural idiosyncrasies contributed to their uncertainty in pain care (Carter et al., 2016). While many of the studies described in this section are not specific to pain care, the findings of each study have been the same; nurses feel uncertain about providing appropriate care for children with CI in pediatric hospital care settings.

The concept of practice uncertainty has been well documented in the literature (French, 2006; Vaid et al., 2013; Vaismoradi et al., 2011). Uncertainty is defined as "a cognitive state of being unable to anticipate the meaning and/or outcome of an experience" and has been described with terms such as unfamiliarity, confusion, ambiguity, and anxiety (Vaid et al., 2013; Scott et al., 2008, p. 350). In clinical practice, uncertainty is an unavoidable characteristic that results from being faced with unfamiliar or challenging patient care situations (Vaid et al., 2013; Vaismoradi et al., 2011). When faced with uncertainty, it is common for nurses to feel frustrated, angry, agitated, and fearful, regardless of their years of nursing experience (Vaismoradi et al., 2011). These emotions were expressed by some participants in our study when sharing their experiences providing pain care to children with CI. When nurses encounter practice uncertainty, it has been documented that nurses seek expert opinions (specialists or parents) and, at times, have even given up their autonomy in care to avoid having to make decisions (Vaid et al., 2013).

In the context of our study, nurses expressed that they mitigated their uncertainty by seeking expertise from parents of children with CI. However, seeking parent expertise was described by our participants as reliance on their expertise to the degree that some nurses felt they could not provide pain care without parents. This has also been previously reported by several researchers (Aston et al., 2014; Carter et al., 2016; Malviya et al., 2005; Oulton et al., 2015). Malviya et al. (2005) found that 74% of nurses (n = 112) in their study reported they were likely to rely on parental input for pain assessment of children with CI, but these researchers did not explain the rationale for nurses' reliance. On the other hand, Carter et al. (2016) reported similar findings and attempted to explain the need for nurses to rely on parents. Researchers stated that nurses felt the need to manage their uncertainty in pain care of children with CI by seeking guidance from individuals they perceived as more knowledgeable because they felt like

they could not rely on their intuition (Carter et al., 2016). In the study by Carter et al., parents were also perceived to be experts, and parents' intuition was believed to be necessary for pain care (Carter et al., 2016). Moreover, Aston et al. (2014) reported the same findings and shared that nurses relied on parents due to their uncertainty and believed that the parents were experts on their children with CI's assessment and care. Similarly, the nurses who participated in the study conducted by Oulton et al. (2015) also perceived that they overly relied on parents, which potentially prevented parents from taking a break. Similar to the previous studies, nurses felt the need to rely on parents because they perceived them to be translators of expert knowledge, which was central to the nurses' abilities to individualize their care of children with CI (Oulton et al., 2015).

With this considered, nurses' uncertainty may have contributed to the change in the dynamic of the parent-nurse partnership as perceived by participants in this current study's context. It also may have made it more challenging for nurses to establish collaborative partnerships with parents for pain care. According to the Collaborative Partnership Approach to Care, all participants in a collaborative partnership bring knowledge, experience, and expertise (Gottlieb et al., 2006). Additionally, in a collaborative partnership, not only do nurses view themselves as having expert knowledge but also recognize that the parents hold unique knowledge that is critical for care (Gottlieb et al., 2006). In the context of our study, all nurses stated that they acknowledged parents' knowledge and highly valued their input in care. While nurses in our study do have expertise in pediatric pain care, they shared a different perception regarding their expertise in pain care for children with CI. Rather, all participants considered parents to be the experts in pain care for this population of children. When nurses recognize the parents' expertise, it serves as leverage for the parents' power in the partnership. In this way,

knowledge and information are important determinants of power (Gottlieb et al., 2006). The partner who is perceived to hold more knowledge tends to hold more of the power in the relationship (Gottlieb et al., 2006). Many functional aspects of HCP-parent relationships can reflect how power is shared in a partnership (Gottlieb et al., 2006). For instance, it is reflected by how decisions of care are made and whose opinion carries more weight (Gottlieb et al., 2006). For an effective collaborative partnership to be established, both the parents and the nurses need to share power because a combination of the parents' and nurses' expertise and experiences is essential for effective care (Gottlieb et al., 2006). Based on the Collaborative Partnership Approach to Care, nurses need to possess both clinical and experiential knowledge to work collaboratively in care (Gottlieb et al., 2006). This refers to theoretical knowledge of the situation as well as knowledge derived from getting to know the children with CI and their families (Gottlieb et al., 2006). The ability to collaborate can be affected based on the amount of knowledge that either the parent or the nurse has in the partnership (Gottlieb et al., 2006). In the context of this study, nurses needed to rely on parent expertise because they felt like they were lacking knowledge about pain care in children with CI and felt uncertain about their provision of care. In our study, nurses felt like they could not assess pain without parental expertise. A collaborative partnership cannot be achieved when power remains in the hands of one of the partners (Gottlieb et al., 2006). For successful power-sharing to be achieved, each partner must feel comfortable in assuming some power by sharing decision-making and taking on responsibility in care (Gottlieb et al., 2006). In our study and previous research, nurses have reported discomfort in providing pain care due to their uncertainty in the pain care of children with CI. As a result, parents are relied upon for assessment and decision-making, taking on more responsibility in care.

While our study did not explore parents' perceptions of partnership in pain care, parents' experiences have been explored in previous research. More specifically, the impact of nurses' uncertainty and reliance on parents has been documented in previous research. For instance, a phenomenological study conducted in 2013 by researchers in Norway explored the experiences of parents of children with cerebral palsy going through surgery (Iversen et al., 2013). Nine parents participated in this study. Most of the children (n=5) had difficulties communicating and had CI (Iversen et al., 2013). In this study, parents felt vulnerable and doubted HCPs' abilities to take care of their children's specific needs and perceived them to have difficulties in interpreting their child's body signs and pain behaviours (Iversen et al., 2013). Parents wanted to share their expertise about their child's needs and unique pain reactions but at the same time, they did not want to carry the weight of ensuring appropriate pain care for their child. Parents felt helpless. They felt like they were given too much responsibility and expressed being in a dilemma because they were not professionals but felt like they were responsible for determining when to give their children pain medication (Iversen et al., 2013). Similarly, Hagvall et al. (2016) reported that the parents felt like they had great responsibility in the care and felt like they were on their own due to HCPs' uncertainty in providing care to children with CI. Parents in this study also wanted their expertise to be used in care but wanted a balance of sharing their knowledge and not taking over HCPs' medical responsibilities in care (Hagvall et al., 2016). Another study reported similar findings. This mixed-methods study was conducted by researchers in the United Kingdom, who explored how parents acquired knowledge to assess and manage pain in their children with CI (Carter et al., 2017). Researchers used surveys and semi-structured interviews with eight mothers of children with CI to collect data (Carter et al., 2017). Mothers in this study perceived HCPs to be uncertain about providing pain care for their children and felt like HCPs could not guide pain

care as their children were exceptional (Carter et al., 2017). Some participants in this study felt overwhelmed by the expertise they had to develop for pain care (Carter et al., 2017).

To reduce the negative impacts of uncertainty, it is important to understand contributing factors of practice uncertainty. Some of these have been identified to be: (1) a lack of available evidence or access to information, (2) perceived self-deficit of knowledge, and (3) research-practice gaps (French, 2006; Vaid et al., 2013; Vaismoradi et al., 2011). In our study, nurses perceived that there was a lack of formal education related to this pain care for children with CI and a lack of appropriate pain assessment tools for this patient population. Thus, considering the contributing factors to nurses' practice uncertainty, it is important to further explore these findings in relation to previous research.

Nurses' Uncertainty Related to a Lack of Formal Education

In our study, nurses identified a need for formal education related to this topic. These findings have also been documented in previous literature. For example, North American researchers identified factors hindering appropriate pain treatment for children with CI (Malviya et al., 2005). A 67-item questionnaire was developed by researchers, based on previous literature, to ask participants about their perceptions and beliefs related to several constructs including pain assessment and documentation, knowledge regarding pain practices, and pain perception in this population (Malviya et al., 2005). Out of the 103 physicians and 112 nurses who completed the survey, 88% (n = 189) reported a lack of education about this topic, which was perceived to hinder their ability to effectively provide pain care (Malviya et al., 2005). While this study was conducted almost two decades ago, more recent studies have reported the same findings regarding a lack of education about pain care for children with CI (Aston et al., 2014; Carter et al., 2016; Fereday & Darbyshire, 2010; Oulton et al., 2015). For instance, Carter et al. (2016)

reported that nurses had very little formal training in pain assessment and management in children with CI. Nurses in this study reported that the only training received was an in-house session about a pain tool and felt that more clinical education was needed about this topic (Carter et al., 2016). Similarly, Oulton et al. (2015) reported that nurses identified a need for further training in how to communicate with children with CI and that the lack of training limited their abilities to engage with these children. Another study conducted in 2010 by researchers in the United Kingdom found similar findings (Fereday & Darbyshire, 2010). This qualitative study aimed to understand the experiences of parents of children with disabilities when interacting with HCPs. Researchers conducted five focus groups and seven individual interviews, with a total sample of 34 parents (Fereday & Darbyshire, 2010). In this study, parents perceived it to be a priority for HCPs to receive educational opportunities about disabilities, to have direct experience with children with disabilities, and to hear stories from families of children with disabilities for them to understand how to better care for this population and their families (Fereday & Darbyshire, 2010). Moreover, Aston et al. (2014) also reported similar findings; nurses suggested that there was a need for education, training, and knowledge about children with CI to mitigate their uncertainty with care and facilitate the development of partnerships in care.

Nurses' Uncertainty Related to a Lack of Reliable Pain Assessment Tools

While nurses in our study identified that there is a need for formal education, they also expressed a need to implement more appropriate pain assessment tools and felt the FLACC scale was not a useful tool for this patient population. These findings are supported by previous research. Pain care practice guidelines in Ireland and Ontario (Canada) both suggest that the FLACC pain scale is only reliable for assessing pain in pre-verbal children without CI

(Association of Paediatric Anesthetists of Great Britain and Ireland, 2012; RNAO, 2013). Additionally, a mixed-methods study was published in 2013 in the USA to examine the words that the parents of children with CI use to describe their child's pain to improve pain assessment (Solodiuk, 2013). In this study, an important finding was the variability and the range of pain responses (Solodiuk, 2013). This had important clinical implications because the researchers determined that it was necessary to individualize pain assessment tools for children with CI to capture the pain responses of a particular child (Solodiuk, 2013). With this considered, the researcher concluded that the FLACC scale limits pain assessments for this population as it is constricted by the 5 items (Solodiuk, 2013). Another North American prospective cohort study conducted in 2010 reported similar findings (Solodiuk et al., 2010). Researchers aimed to investigate the feasibility and describe the psychometric properties of the Individualized Numeric Rating Scale (INRS), which is an individualized tool for assessing pain in children that are non-verbal with CI (Solodiuk et al., 2010). Fifty children with CI and their parents participated in this study by completing the INRS with a nurse, who informally used the FLACC pain scale to help parents recall their child's pain indicators (Solodiuk et al., 2010). Researchers found that parents filled out the INRS using an average of 8.4 different pain descriptors, with a total of 421 descriptors. Of these 421 descriptors, 17.1% (n = 72) did not fit into the FLACC pain scale categories and included descriptors such as heavy breathing, breath holding, increased sleep, sweats, turning red, and making fists (Solodiuk et al., 2010). With this data, researchers concluded that the use of the FLACC scale limits the ability of the parent or nurse to appropriately assess the child's pain (Solodiuk et al., 2010).

Overall, nurses in our study experienced uncertainty when providing pain care for children with CI. In turn, they felt the need to rely on parents for pain care. These results are

consistent with what has previously been established in the literature. However, none of the previous research has reported nurses' perspectives on parent-nurse partnerships in the context of pain care of children with CI in a quaternary pediatric hospital care setting. When considering the principle of power-sharing in collaborative partnerships, nurses' uncertainty may have an impact on the dynamic of parent-nurse partnerships as they may feel powerless in the relationship. Nurses have been set back by the lack of education provided about this topic and the lack of appropriate pain assessment tools to assess pain in children with CI. Thus, improvements need to be made to mitigate nurses' uncertainty in this care context and facilitate the establishment of collaborative parent-nurse for pain care of children with CI.

Heavy Nursing Workloads Contributing to Reliance on Parents

Nurses in our study and previous literature shared that individualizing pain care was necessary to meet the child's unique pain needs and provide appropriate pain care (Oulton et al., 2015). In our study, nurses individualized pain care by collaborating with parents and used partnership strategies such as (1) initiating discussions about pain care, (2) asking open-ended questions, (3) asking purposeful questions to clarify pain care goals with parents, (4) providing suggestions for a pain care plan based on nursing expertise, and (5) asking parents for feedback on a suggested pain care plan. With consideration of the Spiralling Model of Collaborative Partnership, these strategies demonstrate that nurses in our study attempted to be open and respectful toward parents (Gottlieb et al., 2006). These elements are key in developing an individualized care plan that best suits the patient and the family's needs and are essential to establishing collaborative partnerships (Gottlieb et al., 2006).

While nurses value taking the time to gain parental input for care individualization, they also reported a lack of time as a barrier to having these discussions and establishing partnerships.

They also perceived discussions with parents of children with CI to take more time than with children without CI because it was an opportunity for parents to offload their concerns. Similar perceptions were reported by nurses in a study conducted in Australia (Lewis et al., 2019). Researchers conducted interviews with eight pediatric nurses to examine their experiences of caring for children with CI in an acute pediatric inpatient hospital ward setting (Lewis et al., 2019). Participants in this study also perceived it was important to have discussions with parents to learn about their care routines and individualize their child's care in hospital but felt that their care was time-consuming (Lewis et al., 2019). In this study, nurses needed to prioritize attending to the acute medical needs of their patients and relied on parents to help with the delivery of nursing care (Lewis et al., 2019). In our study, nurses also expressed that they rely on parents to "do our job" (P02) and that they did not have time to have therapeutic conversations with parents. Thus, our findings about nurses' perceived lack of time may also contribute to nurses' reliance on parents for pain care of children with CI. Nurses' experiences in our study shed light on the potential impact of organizational and situational factors on parent-nurse partnerships for pain care of children with CI. These findings will be compared to previous literature and placed within a larger context.

The social climate (or organizational culture) where care is provided affects the establishment of collaborative partnerships between nurses and parents (Gottlieb et al., 2006). In our study, nurses shared the desire to partner with parents for pain care but their ability to collaborate with parents seemed to be affected by the busy inpatient unit environments. Comparable to our findings, Gottlieb et al. (2006) noted that nurses' workloads were a factor that could shape collaborative partnerships and act as a barrier to establishing them. These findings have also been documented in previous literature. For instance, a 2015 descriptive qualitative

study was conducted in Ireland to investigate how FCC was enacted from families' and nurses' perspectives (Coyne, 2015). It is important to note that this study did not focus particularly on parent-nurse partnerships in the care of children with CI. However, the researcher reported similar findings related to the impact of nurses' workloads on parent-nurse partnerships in a pediatric inpatient care setting. The researcher collected data through interviews with 18 parent-child dyads and 18 pediatric nurses (Coyne, 2015). In this study, both nurses and parents perceived that nurses' busy workloads resulted in reliance on parents' contribution to care and was a barrier to effective FCC (Coyne, 2015). Nurses shared that they depended on parents' help with care because of their busy workloads and perceived parental contributions to be critical for the proper functioning of the wards (Coyne, 2015). Nurses expressed that relying on parents could make parents feel neglected, stressed, or unsupported and could lead to conflict with parents (Coyne, 2015). Similarly, another study was conducted in 2007 by researchers in Ireland to explore children's, parents', and nurses' perceptions of participation in care in inpatient pediatric wards (Coyne & Cowley, 2007). This study is dated but relevant as it also pertains to parent-nurse partnerships in a pediatric inpatient care setting. Researchers used a grounded theory approach and collected data through in-depth interviews and observation of 11 children, 10 parents, and 12 nurses (Coyne & Cowley, 2007). Parents reported feeling the need to constantly be at the bedside because the nurses were too busy and relied on parents to help with care (Coyne & Cowley, 2007). This was particularly concerning for parents who did not have much support outside of the hospital (Coyne & Cowley, 2007). These parents felt that they neglected their personal needs, felt burdened while in hospital, and had trouble coping with hospitalization (Coyne & Cowley, 2007). They perceived nurses to prioritize clinical duties (i.e., vital signs, giving medication) instead of taking the time to establish therapeutic relationships

with them (Coyne & Cowley, 2007). Our study reflects similar findings as nurses expressed feeling strapped to focus on the "nitty gritty" (P06) and had little time to have therapeutic conversations with parents of children with CI. In Coyne and Cowley's (2007) study, most nurses shared that they had trouble applying the partnership philosophy in practice and that the ideology of partnership did not reflect actual practice. While this study was conducted almost two decades ago, the reported findings are similar to those of our study. The organizational context impacted nurses' abilities to establish partnerships with parents for care (Coyne & Cowley, 2007). Another North American study conducted in 2001 reported similar findings about nursing workload and reliance on parents. While this study is also dated, it is relevant as the context is similar and focuses on care for hospitalized children with chronic illnesses, such as children with CI (Balling & McCubbin, 2001). Researchers conducted a cross-sectional, descriptive correlational study to examine the desired level of parent participation in the care of children with chronic illness (Balling & McCubbin, 2001). Researchers provided three questionnaires to 50 parents of children with chronic illnesses (including cerebral palsy and neurological dysfunction) (Balling & McCubbin, 2001). These questionnaires were composed of (1) demographic questionnaires, (2) a modified Parental Control Preference Scale (PCPS), and (3) Valuing of Parental Expertise Scale (VOPE) (Balling & McCubbin, 2001). The PCPS contained one open-ended question, which researchers analyzed using content analysis (Balling & McCubbin, 2001). When analyzing the data of the open-ended question, researchers found that 13 parents (33%) expressed that nurses were perceived to be too busy to be available to help with their child's care (Balling & McCubbin, 2001). In this study, parents wanted to participate in their child's care but felt the need to constantly attend at the bedside due to nurses' lack of time, which may add to parents' stress (Balling & McCubbin, 2001). In our study, nurses also

perceived that their need to rely on parents may have contributed to parents' stress while in hospital. Overall, the findings from our study are consistent with previously reported literature and highlight the potential impact of nurses' workload on parent-nurse partnerships.

Heavy Nursing Workloads Related to a Poorly Designed Pain Charting System

Nurses in our study perceived a poorly designed charting system that lacked a designated charting area for individualized pain care communication and shared that this contributed to their demanding workloads. To individualize pain care, nurses shared that they need to take the time to ask parents multiple questions to get to know the child and understand their usual home care routine. However, nurses shared that this useful data often gets "lost in translation" (P06) due to a lack of a designated charting area for it. Thus, nurses felt like they were forced to take the time to ask parents the same questions as the previous nurses to get to know the child and create a pain care plan. In this way, the lack of documentation for individualized pain care was perceived to potentially contribute to nurses' workloads and parents' stress. These findings were also reported in previous literature. For example, in the study conducted by Oulton et al. (2015), nurses shared that detailed information about the child was passed on verbally between staff and in written documentation. However, this practice was not consistent (Oulton et al., 2015). Nurses shared that they did not have enough time to pass along this information and perceived it was more important to pass along medical information (Oulton et al., 2015). Similar to our study's findings, the documentation system also did not have a dedicated section for this information (Oulton et al., 2015). Thus, HCPs reported having difficulty finding information to gain a better understanding of the children's abilities and their needs (Oulton et al., 2015). Nurses perceived that without detailed information about the child, staff could misinterpret data and make the wrong assumptions related to care (Oulton et al., 2015). As a result, HCPs relied on parental

input to provide information about their child and hindered their abilities to form partnerships with parents (Oulton et al., 2015). In another study conducted by Coyne (2015), parents also shared they had to constantly repeat the same information about their child's care to different nurses, which made parents feel like they always had to be at the bedside. In this study, the lack of a formal documentation system to chart parents' input about their child and parents' contribution to care also was perceived to increase nursing workloads (Coyne, 2015). Nurses in this study similarly identified a need for improvements in the charting system to optimize parent-nurse partnerships (Coyne, 2015).

The data reported in previous literature and our study about nursing workloads and parent-nurse partnerships are consistent. Heavy nursing workloads have been reported to be nurses' realities for over 20 years (Balling & McCubbin, 2001; Coyne, 2015; Lewis et al., 2019; Oulton et al., 2015). The impact of heavy nursing workloads on parent-nurse partnerships in pediatric care settings has been well documented (Balling & McCubbin, 2001; Coyne, 2015; Lewis et al., 2019; Oulton et al., 2015). This study adds to the literature and showcases that this remains a reality; nurses are still forced to prioritize medical or administrative tasks and do not have the time to focus on building collaborative partnerships with parents in pediatric care settings. This study adds to the body of knowledge related to the potential impact of nursing workloads on partnerships in the context of pain care for children with CI.

Partnership Promoting Strategies

In our study, nurses identified strategies that facilitate the establishment of collaborative partnerships with parents for pain care of hospitalized children with CI including (1) taking the time to listen and check-in, as well as (2) continuing the child's home care routine. When reviewing the literature, many authors have also previously identified these two strategies

intended to facilitate partnerships with parents for the care of children with CI. Thus, this section of the discussion will focus on describing these strategies in relation to previous research.

Active Listening to Promote Partnership

When asked what strategies facilitated a partnership with parents, almost all nurses in our study identified that active listening was key to collaborating with parents. One nurse stated that actively listening to parents is "the biggest thing you can do" (P09) for successful parent-nurse partnerships in pain care. Nurses in our study perceived listening to be essential for partnerships as it demonstrates the nurses' openness, allowing parents to feel more comfortable in sharing their concerns. This finding has also been discussed in previous research. For instance, a study was conducted in the United Kingdom to explore parental involvement in children's acute pain care and establish ways for nurses to identify, facilitate and enhance parental involvement in their child's care (Vasey et al., 2019). Researchers used an ethnographic approach with nonparticipant observation and follow-up semi-structured interviews over four weeks (Vasey et al., 2019). A total of 30 parent-child dyads and 14 nurses participated in the study (Vasey et al., 2019). It is unclear if parents of children with CI were included in the study as it was not listed in the demographic information of this paper (Vasey et al., 2019). The researchers observed interactions in pain care between the nurses, children, and parents, and interviews were held with nurses and parents, separately (Vasey et al., 2019). Vasey et al. (2019) found that nurses facilitated parental involvement in pain care by listening to parents and valuing their contributions. The authors identified this to be one of the opportunities for parents to work in partnership with nurses in relation to pediatric pain care, as per the Pillars of Partnership in Pain Care Model (Vasey et al., 2019). Similar to our study, nurses recognized the importance of listening to parents about their child's pain care (Vasey et al., 2019).

According to the Collaborative Partnership Approach to Care, well-developed communication and interpersonal skills are critical in a collaborative partnership (Gottlieb et al., 2006). Active listening is one of the fundamental communication skills that should be part of every nurse's skill set (Gottlieb et al., 2006). Active listening is necessary for the nurse to engage with the parents and their children to establish a partnership (Gottlieb et al., 2006). When nurses take the time to listen to parents and understand their perspectives, parents are more likely to feel understood and more likely to work in partnership with the nurses (Gottlieb et al., 2006). Active listening conveys to parents that their knowledge and opinions are critical within the collaborative partnership (Gottlieb et al., 2006). Active listening is also an important strategy for conveying openness and respect toward parents, which are essential ingredients to a collaborative partnership (Gottlieb et al., 2006).

Previous researchers have also found that parents also highly value when HCPs are actively listening to them and believe this is essential for partnerships in the care of their children with CI. For instance, a study conducted by Iversen et al. in 2013 explored the experiences of parents of children with cerebral palsy going through surgery (Iversen et al., 2013). In this study, the researchers stressed the need for HCPs to listen to parents when they are sharing information about their children (Iversen et al., 2013). Parents also perceived that it was important for HCPs to listen to them so that HCP can appropriately care for their children (Iversen et al., 2013). Thus, when parents shared that when they feel like they are not being heard, they are not as trusting of the HCPs in the care of their children with CI and feel helpless (Iversen et al., 2013). Similarly, a 2015 study conducted by Australian researchers to explore parents' experiences of healthcare for their children with CP concluded similar findings (Hayles et al., 2015). Using a grounded theory methodology, researchers conducted two focus groups and eight individual

interviews to collect data (Hayles et al., 2015). A total of 13 parents of children with CP participated in the study (Hayles et al., 2015). Parents shared that establishing partnerships with HCPs was key to ensuring that their children's needs were met (Hayles et al., 2015). Parents identified HCPs' attitudes that contributed to partnership (Hayles et al., 2015). In this study, parents wanted HCPs to listen to them as parents who know their children best and they wanted to have a voice in the care of their children (Hayles et al., 2015). When parents felt like HCPs did not take the time to listen to them, they were frustrated and perceived their children's needs to be disregarded (Hayles et al., 2015). The authors of this study concluded that when HCPs do not listen to parents, this indicates a lack of partnership and has a direct impact on how parents experience healthcare for their child with CP (Hayles et al., 2015). Carter et al. (2017) also concluded similar results (Carter et al., 2017). Mothers who participated in their study expressed that they valued HCPs that would take the time to listen to their concerns about their child's pain (Carter et al., 2017). When the mothers felt like they were not listened to, this was a diminishing and frustrating experience for them (Carter et al., 2017). Considering these data, our study's findings reflect what has been previously published and reinforce the importance for HCPs to take the time to actively listen to parents to establish collaborative partnerships with them for the pain care of their children with CI.

Continuing the Child's Home Routine to Promote Partnership

In our study, nurses shared the importance of continuing the child's usual home care routine while the child was admitted to hospital. Nurses in our study perceived that by doing so, parents would feel empowered, more comfortable, less stressed, and more likely to collaborate with nurses. This finding was also published by researchers in previous studies. For example, the 2019 study by Lewis et al. found that nurses perceived it was essential for them to identify, learn

and adhere (where possible) to the usual routines of children with CI and their families while in hospital. Nurses in this study believed that familiar routines promoted the organization of care and more effective care for the child (Lewis et al., 2019). Similar to our study, the nurses also perceived that adhering to the usual care routine while in the hospital would be more familiar for parents and thus, would make them feel more comfortable with care (Lewis et al., 2019). Additionally, Oulton et al. (2015) reported similar findings and found that it was distressing for children with CI and their families when their usual care routines were disrupted. Nurses in this study shared that they collaborated with parents to gain information about their children's usual care routine (Oulton et al., 2015). This included information about the child's preferences for eating, taking medication, playing, communicating, and interacting with others (Oulton et al., 2015). By gaining this information, nurses expressed they were able to individualize care for children, enhance the patients' experiences and deliver their care appropriately (Oulton et al., 2015). Nurses perceived that adhering to their routines made a big difference for patients and their families (Oulton et al., 2015).

In a traditional hierarchical relationship, the nurse will set the agenda for care (Gottlieb et al., 2006). However, nurses promote collaborative partnerships when they work with parents to establish a home care routine to implement in hospital together (Gottlieb et al., 2006). This requires nurses to be open to ideas, flexible in their nursing approach, and willing to consider alternatives (Gottlieb et al., 2006). In this case, both partners are sharing responsibility for achieving care goals (Gottlieb et al., 2006). Nurses in our study and previous research have expressed similar findings, thereby reinforcing the importance of continuing the child's home care routine as a strategy to promote parent-nurse partnerships in care.

Implications and Recommendations

Nursing Practice

Our findings highlight the need for nurses to continue using strategies such as active listening and continuing the child's home care routine to promote collaborative partnerships with parents for pain care of children with CI. As evidenced by our study and by previous research, these strategies are beneficial to collaborative partnerships with parents. This study also identified several barriers to establishing partnerships such as (1) lack of time, (2) multiple parent stressors, (3) gaps in the charting system, (4) lack of formal education, and (5) lack of appropriate pain assessment tools. Influenced by my pragmatic lens and dedication to create change via practical strategies, I chose to focus the following section on barriers 3-5 that are more tangible. While the barriers of lack of time and multiple parent stressors are still relevant, these barriers are more abstract and longstanding issues (Balling & McCubbin, 2001; Coyne & Cowley, 2007). I believe additional in-depth research focused specifically on these barriers would allow me to recommend changes for nursing practice that are more meaningful and productive.

Our findings also showcase the need for nurses to use more valid and reliable pain assessment tools in practice. Our findings as well as the previously reported literature also highlight the need to implement an appropriate pain scale for children with CI. Participants in our study expressed that the pain scales available to them in practice are not useful for assessing pain in children with CI. Notably, they stated the only available tool to use is the FLACC scale and that they could not rely on this tool for assessment. As presented above, previous literature has also reported similar findings (Association of Paediatric Anesthetists of Great Britain and Ireland, 2012; RNAO, 2013; Solodiuk et al., 2010). Nurses perceived the lack of appropriate

pain tools to not only affect the quality of pain care but hindered their parent-nurse partnerships as they were forced to rely on parents for pain assessment. Compared to children without CI, pain assessment in children with CI has been overlooked as pain scales for these children with CI have only been validated since the year 2000 and there is minimal evidence of the use of these tools in practice (Carter & Simons, 2014). This reflects the nurses' experiences in our study as there is no tool available for use that is appropriate to assess pain in children with CI in their clinical setting.

HCPs need to use tools that are validated for this population and could improve the quality of pain care and the child's life (Carter & Simons, 2014). A few studies have identified validated pain assessment tools for children with CI. A meta-analysis was conducted by Italian researchers to assess the reliability of different pain scales for the assessment of postoperative pain in children with CI (Pizzinato et al., 2022). Researchers found that the (Revised) r-FLACC scale was one of the most reliable and valid pain scales for assessing postoperative pain in children with CI (Pizzinato et al., 2022). Compared to the original FLACC scale, the r-FLACC version includes several additional pain behaviours and showed improved reliability for all categories when assessing pain in children with CI (Pizzinato et al., 2022). The r-FLACC scale can also be individualized with the addition of parental input (Pizzinato et al., 2022). Researchers found that the inclusion of parent descriptors also improved the scale's reliability and validity for pain assessment in children with CI (Pizzinato et al., 2022). Individualizing pain tools also increase the comprehensiveness of pain assessment and allows the incorporation of a variety of unique pain behaviours (Solodiuk, 2012). Therefore, working in partnership with parents to individualize pain tools is fundamental to pain care for this patient population (Carter & Simons, 2014). Other studies also support the use of the r-FLACC for pain assessment in this patient

population (Cascella et al., 2019; Chen-Lim et al., 2012). For instance, a comprehensive review of pain assessment tools was conducted in 2019 by Italian researchers to review tools commonly used for children with CI (Cascella et al., 2019). The researchers provided brief descriptions of the advantages and disadvantages of each pain assessment tool, including the original FLACC, FLACC-r, Paediatric Pain Profile (PPP), the Pain Behaviour Checklist (PBC) and the Non-communicating Children's Pain Checklist (NCCPC) (Cascella et al., 2019). The PPP is a tool designed to assess and monitor behavioural pain in children with severe CI (Hunt et al., 2007). While parents found this tool to be more accurate than the r-FLACC, they also found it more difficult to use (Cascella et al., 2019). The PPP has also been found not to be helpful in acute hospital settings, such as the setting of our study (Cascella et al., 2019). The PBC was designed to assess four pain dimensions (i.e., distorted ambulation, affective distress, facial/audible expressions, and help-seeking) (Kerns et al., 1991). While this scale has 23 items, only 10 were found to be valid for children with CI. Researchers report that this scale requires a long observation time and that the 10-item version may be less accurate than the original (Cascella et al., 2019). Moreover, the NCCPC is a pain checklist designed for children that are non-verbal with CI (Breau et al., 2000). Researchers found that this scale is advantageous because no training is required for use, and it can be used by nursing staff that are unfamiliar with the child. However, they also reported that its application in practice is lengthy and can be difficult for routine pain assessment in acute clinical settings (Cascella et al., 2019). Compared to the above-mentioned pain assessment tools, the researchers reported that the r-FLACC was nurses' preferred tool to use for pain assessment during the hospitalization of children with CI (Cascella et al., 2019). Moreover, the researchers stated that the r-FLACC was an appropriate tool for acute pain assessment in children with CI because it is easy to perform and allows for

individualization of pain assessments (Cascella et al., 2019). Similarly, an American literature review was conducted by researchers in 2011 to examine pain tools for hospitalized children that are non-verbal with CI and reported similar findings (Crosta et al., 2011). Researchers searched electronic databases and included studies that examined the psychometric properties and/or clinical utilities of pain assessment tools for this population of children (Crosta et al., 2011). In this literature review, researchers compared the Non-communicating Children's Pain Checklist Postoperative Version (NCCPC- PV), the PPP, the Individualized Numeric Rating Scale and the r-FLACC (Crosta et al., 2011). The NCCPC-PV was adapted from the original version and validated in a post-operative inpatient setting (Crosta et al., 2011). Compared to the r-FLACC, nurses found the NCCPC-PV to be less desirable to use in practice due to its complexity, length, ease of use and incorporation into practice (Crosta et al., 2011). The Individualized Numeric Rating Scale (INRS) is a scale that measures pain based on parents' reports of their children's unique pain behaviours (Solodiuk et al., 2010). Limited research is available regarding the scale's clinical utility, but available findings recommend this scale for chronic care or residential settings (Crosta et al., 2011). Researchers in this study also reported that the r-FLACC was perceived by clinicians and nurses to be more clinically useful and more helpful in an acute care environment than other pain assessment scales (Crosta et al., 2011). Clinical benefits of the r-FLACC identified were flexibility in acute care settings, brief completion time and ease of use (Crosta et al., 2011). Recommendations to use the r-FLACC for pain assessment in children with CI have gone as far back as a decade ago. For example, North American researchers conducted a quality improvement project to implement a pain assessment tool for children with CI (Chen-Lim et al., 2012). The project team consisted of nurses, and nurse researchers, and the process included (1) a literature review, (2) a discussion with the Family Advisory Council, and (3)

implementation of the project in inpatient pediatric units (Chen-Lim et al., 2012). An end-of-shift questionnaire was given to 126 staff nurses who participated in this project and assessed the pain of children with CI on the units to assess their use of pain tools (Chen-Lim et al., 2012). Out of the 126 nurses, 74% (n = 93) preferred the use of the r-FLACC pain assessment tool because of its clinical practicality and 76.7% (n = 96) found this tool to be useful (Chen-Lim et al., 2012). Moreover, 72.5% of nurses (n = 91) perceived the r-FLACC to be a more accurate pain assessment tool for children with CI compared to another pain tool (Chen-Lim et al., 2012).

Considering the importance of appropriate pain assessment and management, it is crucial for validated and reliable pain assessment tools to be implemented and used in practice. The above data suggest that the r-FLACC is the most useful and reliable pain assessment tool for children with CI. The inclusion of the r-FLACC in the recommended pain tool list at acute care hospitals and its implementation in practice would be beneficial to improving nursing practices related to pain care for hospitalized children with CI. In turn, this would also potentially be beneficial for parent-nurse partnerships in the context of pain care for this patient population as the r-FLACC incorporates parent-reported descriptors. Thus, nurses would have access to a tool that already incorporates parental input and would be less likely to rely on parents.

Nursing Education

Nurses in our study identified that there is no formal education available about pain care for children with CI or about partnering with parents for their care. As mentioned above, the previous literature reflects our findings. Therefore, there is a need to offer education regarding this topic to optimize pain care for hospitalized children with CI. With increased knowledge, nurses would potentially feel less uncertain in care and therefore, less likely to rely on parents. Thus, offering education to nurses and nursing students would potentially be beneficial for

parent-nurse partnerships in the context of pain care for hospitalized children with CI. Some researchers have already made suggestions regarding education for the care of children with CI. For example, Fereday et al. (2010) reported that families of children with CI expressed that it is a priority for HCPs to receive education about HCPs' values and attitudes toward disabilities. Researchers suggested (1) developing online resources such as webcasts and podcasts to share experiences of children with CI and their parents to provide a narrative example of their lives, (2) developing communication skills guidelines to demonstrate how to interact with children with CI and, (3) incorporate a disability champion in the organization to teach others with evidence-based up-to-date knowledge regarding children with CI (Fereday et al., 2010). The RNAO states that the curricula in Canadian nursing schools should offer opportunities to enhance nursing students' pain competencies (RNAO, 2013). However, nurses in this current study reported that their nursing curriculum did not include any formal education about pain care for children with CI and therefore needs to be updated. To successfully implement educational programs on this topic, the RNAO suggests including (1) an interprofessional team of content experts, (2) education materials, and (3) and delivering the education using a standardized approach (RNAO, 2013).

While the nursing curricula should be updated, the nurses in our study also identified that there is a lack of pain education for this patient population in their organization as well. Therefore, the pain education offered to clinical staff needs to be reviewed and updated to include information about pain care for children with CI and strategies to partner with parents/caregivers for this process. The RNAO suggests that new staff should receive pain education that includes the organization's pain care policies, practices, and procedures (RNAO, 2013). Furthermore, the RNAO recommends that HCPs should participate in continuing

education courses to receive training in pain assessment and management, supported by their healthcare organizations (RNAO, 2013). However, the RNAO does not specify pain training programs to implement in healthcare organizations (RNAO, 2013).

To respond to the need for pain education specific to the needs of children with CI, a group of Canadian researchers conducted a two-phased study to develop and pilot an evidence-based training program about pain in children with CI for Respite Workers (RWs) (Genik et al., 2018). The goal of phase 1 was to explore RWs' pain care experiences and training preferences (Genik et al., 2018). In this phase, 22 RWs participated in either focus groups or individual interviews and completed pain-related questionnaires (Genik et al., 2018). Most, (15 of the 22 RWs) preferred in-person pain training and preferred, on average, a training length of about 5 hours (Genik et al., 2018). Additionally, 15 out of the 22 participants preferred the inclusion of interactive activities and all 22 participants wanted to receive a certificate of completion at the end of the training (Genik et al., 2018). Phase 2 of this study was designed to create a pain training program for RWs and then evaluate its efficacy (Genik et al., 2018). Fifty RWs participated in this phase of the study and completed two pain knowledge questionnaires (Genik et al., 2018). The pain knowledge questionnaires consisted of an adapted version of the Pediatric Pain Knowledge and Attitudes Questionnaire-Revised (PPKAQ-R) and the Questionnaire for Understanding Pain in Children with ID – Caregiver Report (QUPID=C) (Genik et al., 2018). After completing the questionnaires, participants participated in a 3.5-hour in-person pain training program, titled *Let's Talk About Pain,* which included group tasks and discussions (Genik et al., 2018). The pain training program format and content are derived from data from phase 1 of this study, data from the IASP Core Curriculum Pain, and the researcher's own experiences (Genik et al., 2018). Training content included information on (1) what pain is, (2)

pain expression, (3) pain assessment, and (4) pain management strategies (Genik et al., 2018). After training, participants completed the same pain knowledge questionnaires and a pain training evaluation questionnaire (Genik et al., 2018). Overall, the pain training significantly increased participants' knowledge, self-reported confidence, and pain care skills (Genik et al., 2018). Participants also perceived the pain training program to be highly acceptable (Genik et al., 2018). While the focus was on training for RWs, this pain education program may also be beneficial for nurses and nursing students.

Nursing Policy

Several acute care hospitals have been designated as Best Practice Spotlight Organizations (BPSO), which is an initiative launched by the RNAO to promote knowledge translation of best practice guidelines (RNAO, 2022). To facilitate this, the RNAO has developed a Toolkit for implementing best practices to be used by implementation teams in their organization (RNAO, 2013). Policymakers need to establish pain assessment and management as a priority of care (RNAO, 2013). In the setting where this current study took place, the r-FLACC has not yet been implemented in practice. Therefore, it is recommended that policy changes are made to update them and include the use of r-FLACC for the assessment of pain in children with CI (RNAO, 2013). As per the RNAO implementation toolkit, policymakers should (1) assess the organization's readiness for change and barriers, (2) involve all members in implementation, (3) reinforce best practices through education, and (4) appoint qualified individuals to support the implementation process (RNAO, 2013). Moreover, a potentially useful strategy would be for RNAO pain champions of acute care hospitals to help with knowledge translation and enhance the uptake of this best practice (RNAO, 2013). Pain champions are individuals that received specialized training in implementing evidence-based practices as well as strategies to help with

implementation in specific clinical practice areas (RNAO, n.d.). Moreover, the RNAO states that organizations should ensure that there are standardized tools for documenting and communicating pain assessment and management strategies to ensure safe and effective care outcomes (RNAO, 2013). However, the nurses in this study and previous research suggest that there is a need to improve the charting system for pain care in healthcare organizations. The charting systems need to be re-designed to include dedicated charting areas for individualized pain assessments. This will enable nurses to refer to this information in the future. For instance, adding a section in the charting system dedicated to developing an individualized pain care plan for children with CI would be useful. In this way, nurses could refer to this information and would be less likely repeatedly ask parents the same questions for this data. Therefore, this would potentially decrease the burden associated with needing to rely on parents. It would also be beneficial to help relieve nurses' workloads as they would not be forced to spend as much time figuring out the care plan with the parents. The literature suggests that appropriate documentation has promoted the successful implementation of partnership practices (i.e., FCC) (Coyne, 2015). Researchers recommend including a charting area where parents, children, and staff could record their discussions about care and roles, which would be beneficial for parent-nurse partnerships (Coyne, 2015).

Nursing Research

The findings of our study shed light on areas for future research. First, this study is one of few studies focusing on parent-nurse partnerships in the context of pain care for hospitalized children with CI. Thus, there is very limited knowledge regarding this topic and therefore many opportunities for future nursing research. This study's findings showcase the potential contributing factors that affect parent-nurse partnerships for pain care of children with CI. For

instance, nurses expressed uncertainty related to pain care for this patient population and felt the need to rely on parents for care. While uncertainty has been reported in previous literature, the findings of this study add to that knowledge and highlight the need for formal education as well as appropriate pain tools that nurses can use in practice. Therefore, it would be useful to conduct studies to explore nurses' perceptions of education programs and gain a better understanding of what education format and content are required and preferred by nurses for this topic. With this knowledge, education programs could be developed, and future research can be conducted related to the assessment of these education programs. As mentioned above, future research is needed to conduct an in-depth exploration of lack of time and parental stressors as barriers to establishing nurse-parent partnerships in pain care. This study also shines a light and extends the critique of how FCC is operationalized in practice. Future critical analysis research could support an in-depth critique of FCC. A secondary analysis of FCC with a feminist lens could also be beneficial in understanding the role of women and their exploitation in care. Furthermore, this study solely focused on nurses' experiences of parent-nurse partnerships in the context of pain care for children with CI in inpatient units at a quaternary pediatric healthcare centre. There is a need for future research to explore parents'/caregivers' as well as children's experiences with partnerships in pain care of children with CI to gain a better understanding of the phenomenon. Future research in other settings (e.g., emergency departments, primary care, rehabilitation centres) would also be beneficial to contribute to a deeper understanding of the conditions that impact nurses' experiences in establishing partnerships with parents of children with CI for their pain care.

Study Strengths and Limitations

One strength of this study was understanding the experiences of nurses with a variety of perspectives stemming from different inpatient units and a wide range of nursing experiences. Additionally, to evaluate the quality of interpretive descriptive studies, several criteria have been established including epistemological integrity, moral defensibility, disciplinary relevance, and contextual awareness (Thorne, 2016). First, this study demonstrates epistemological integrity in its consistency between the research question, the ontology, and the methodology of the study (Thorne, 2016). Second, the rationale of this study was also morally defensible as the aim was to understand nurses' parent-partnership experiences with the ultimate aim to optimize pain care for children with CI, knowing that parent-nurse partnerships are vital to this process. As this study pertains directly to nurses, the findings are relevant to the nursing discipline and the knowledge gained will help to advance the profession. Finally, findings in the context of inpatient units in a quaternary pediatric healthcare centre are well articulated and therefore, this study demonstrates contextual awareness.

This study also had some limitations. For instance, the findings are limited to the perceptions and experiences of nurses working in this specific clinical context. This study took place in one quaternary pediatric healthcare and research centre. While the purpose of this qualitative study is not to generalize the findings, the specific context of the study sample may limit the transferability of the findings. With this considered, a detailed description of the study setting was provided. Another limitation of the study was not being able to include the perspectives of parents/caregivers and children with CI due to time constraints. In addition, the purposive sampling strategy used to recruit nurses may have also limited our findings due to volunteer bias (Spencer et al., 2017). Considering the nature of purposive sampling, the

participants may have been individuals that were more interested in the topic compared to their colleagues. Also, as participants were sharing past experiences, this study may have been limited by recall bias. This bias may have influenced the participants' accuracy of their shared experiences (Spencer et al., 2017). Finally, my position as a registered nurse working at this healthcare centre may have limited the findings as participants may have perceived those certain answers might be judged as more appropriate than others. To mitigate this potential impact, I made sure to foster a comfortable interview environment by reminding participants that this study's findings would remain confidential.

Conclusion

The purpose of this study was to explore nurses' experiences in establishing parent-nurse partnerships for pain care of children with CI. Participants shared that parent-nurse partnerships are essential for the provision of appropriate pain care. Nurses also provided strategies they use to establish partnerships such as active listening and continuing their home routine. However, when nurses described their partnership experiences, they expressed a strong need to rely on parents and felt that they could not provide pain care without them, mainly due to their feelings of uncertainty in care. In this study, every single nurse expressed feeling uncertain in providing appropriate pain care for children with CI. Notably, this study's findings shed a light on the fact that nurses are set back in being able to feel competent as partners in pain care for children with CI due to several factors. Our findings highlight the gaps that need to be addressed in order to potentially improve this process such as (1) a lack of appropriate pain assessment tools, (2) a lack of formal education and training and (3) a poorly designed pain charting system. While heavy workloads were also identified as a challenge for establishing partnerships, it is not as tangible of a factor that can be addressed. Moreover, children with CI and their pain care have

been overlooked in pain research. While there has been evidence published for over two decades about this topic and the need for change, the nurses' experiences in this study are very similar to what has been experienced in the last 20 years. Thus, this study adds to the body of knowledge and reinforces the need to make a change in practice to improve parent-nurse partnerships and optimize pain care for children with CI in the context of acute inpatient pediatric care settings.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5 (Fifth edition.)* Arlington, VA: American Psychiatric Association

Association of Paediatric Anaesthetists of Great Britain and Ireland. (2012). Good practice in postoperative and procedural pain management (2nd edition). *Pediatric Anesthesia, 22*(Suppl. 1). 1-78. DOI: 10.1111/j.1460-9592.2012.3838.x

Aston, M., Breau, L., & MacLeod, E. (2014). Understanding the importance of relationships: Perspective of children with intellectual disabilities, their parents, and nurses in Canada. *Journal of Intellectual Disabilities*, *18*(3), 221–237. https://doi.org/10.1177/1744629514538877

Balling, & McCubbin, M. (2001). Hospitalized children with chronic illness: Parental caregiving needs and valuing parental expertise. *Journal of Pediatric Nursing, 16*(2), 110–119. https://doi.org/10.1053/jpdn.2001.23157

Balogh, R., Brownell, M., Ouellette-Kuntz, H., & Colantonio, A. (2010). Hospitalisation rates for ambulatory care sensitive conditions for persons with and without an intellectual disability-a population perspective. *Journal of Intellectual Disability Research, 54*(9), 820–832. https://doi.org/10.1111/j.1365-2788.2010.01311.x

Barratt. (2021). Children living with long-term conditions: A meta-aggregation of parental experiences of partnership nursing. *Journal of Clinical Nursing, 30*(17/18), 2611–2633. https://doi.org/10.1111/jocn.15770

Batalha, L. & Sousa, A. (2018). Self-report of pain intensity: correlation between children, parents, and nurses. *Revista de Enfermagem Referência, IV Série* (17), 15–22. https://doi.org/10.12707/RIV18002

Bebbington, A., Glasson, E., Bourke, J., de Klerk, N., & Leonard, H. (2013). Hospitalisation rates for children with intellectual disability or autism born in Western Australia 1983–1999: a population-based cohort study. *BMJ Open, 3*(2), e002356–. https://doi.org/10.1136/bmjopen-2012-002356

Bezdek, J., Summers, J. A., & Turnbull, A. (2010). Professionals' Attitudes on Partnering with Families of Children and Youth with Disabilities. *Education and Training in Autism and Developmental Disabilities, 45*(3), 356-365. http://www.jstor.org/stable/23880110

Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a Qualitative Description Approach in Health Care Research. *Global Qualitative Nursing Research, 4,* 2333393617742282–2333393617742282. https://doi.org/10.1177/2333393617742282

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE Publications.

Breau, L. M., McGrath, P. J., Camfield, C., Rosmus, C., & Finley, G. A. (2000). Preliminary validation of an observational checklist for persons with cognitive impairments and inability to communicate verbally. *Developmental medicine and child neurology, 42*(9), 609-616. https://doi.org/10.1017/S0012162200001146

Breau, L. M., Camfield, C. S., McGrath, P. J., & Finley, G. A. (2007). Pain's impact on adaptive functioning. *Journal of Intellectual Disability Research, 51*(2), 125–134. https://doi.org/10.1111/j.1365-2788.2006.00851.x

Breau, L. M., Camfield, C. S., McGrath, P. J., & Finley, G. A. (2003). The Incidence of Pain in Children with Severe Cognitive Impairments. *Archives of Pediatrics and Adolescent Medicine, 157*(12), 1219–1226. https://doi.org/10.1001/archpedi.157.12.1219

Brudvik, C., Moutte, S. D., Baste, V., & Morken, T. (2017). A comparison of pain assessment by physicians, parents, and children in an outpatient setting. *Emergency Medicine Journal, 34*(3), 138–144. https://doi.org/10.1136/emermed-2016-205825

Canadian Nurses Association. (2017). *Code of Ethics for Registered* Nurses. https://www.nscn.ca/sites/default/files/documents/resources/code-of-ethics-for-registered-nurses.pdf

Carter, McArthur, E., & Cunliffe, M. (2002). Dealing with uncertainty: parental assessment of pain in their children with profound special needs. *Journal of Advanced Nursing, 38*(5), 449–457. https://doi.org/10.1046/j.1365-2648.2002.02206.x

Carter, B. & Simons, J. (2014). Assessing and Managing Pain in a Child who is Cognitively Impaired Grace's Story. *In Stories of Children's Pain: Linking Evidence to Practice* (p. 111–). SAGE Publications Ltd. https://doi.org/10.4135/9781446288245.n9

Carter, B., Arnott, J., Simons, J., & Bray, L. (2017). Developing a Sense of Knowing and Acquiring the Skills to Manage Pain in Children with Profound Cognitive Impairments: Mothers' Perspectives. *Pain Research and Management*, 2017, 1-11. https://doi.org/10.1155/2017/2514920

Cascella, M., Bimonte, S., Saettini, F., & Muzio, M. R. (2019). The challenge of pain assessment in children with cognitive disabilities: Features and clinical applicability of different observational tools. *Journal of Pediatrics and Child Health, 55*, 129–135. https://doi.org/10.1111/jpc.14230

Cerebral Palsy Foundation. (2021). *Cognitive Impairment.* https://www.cerebralpalsy.org/information/cognition

Chen-Lim, M., Zarnowsky, C., Green, R., Shaffer, S., Holtzer, B., & Ely, E. (2012). Optimizing the Assessment of Pain in Children Who Are Cognitively Impaired Through the Quality Improvement Process. *Journal of Pediatric Nursing, 27*(6), 750–759. https://doi.org/10.1016/j.pedn.2012.03.023

Children's Hospital of Eastern Ontario Family Advisory Council. (n.d). Family Advisory Council (FAC): Partners in Health. [PowerPoint slides]. PowerPoint.

Children's Hospital of Eastern Ontario. (2020). *Commitment to Care.* https://www.cheo.on.ca/en/about-us/commitment-to-care.aspx

Children's Hospital of Eastern Ontario. (2021). *Family Advisory Council.* https://www.cheo.on.ca/en/get-involved/family-advisory-council.aspx

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal of Positive Psychology, 12*(3), 297–298. https://doi.org/10.1080/17439760.2016.1262613

Cope, D. G. (2014). Methods and meanings: credibility and trustworthiness of qualitative research. *Oncology Nursing Forum, 41*(1), 89-91. https://doi.org/10.1188/14.ONF.89-91

Coyne, & Cowley, S. (2007). Challenging the philosophy of partnership with parents: A grounded theory study. *International Journal of Nursing Studies, 44*(6), 893–904. https://doi.org/10.1016/j.ijnurstu.2006.03.002

Coyne, I. (2015). Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles. *Health expectations, 18*(5), 796–808. https://doi.org/10.1111/hex.12104

Crellin, D. J., Harrison, D., Santamaria, N., & Babl, F. E. (2015). Systematic review of the Face, Legs, Activity, Cry and Consolability scale for assessing pain in infants and

children: Is it reliable, valid, and feasible for use? *Pain, 156*(11), 2132–2151. https://doi.org/10.1097/j.pain.0000000000000305

Crellin, Harrison, D., Santamaria, N., Huque, H., & Babl, F. E. (2018). The Psychometric Properties of the FLACC Scale Used to Assess Procedural Pain. *The Journal of Pain, 19*(8), 862–872. https://doi.org/10.1016/j.jpain.2018.02.013

Crosta, Q. R., Ward, T. M., Walker, A. J., & Peters, L. M. (2014). A review of pain measures for hospitalized children with cognitive impairment. *Journal for specialists in pediatric nursing: JSPN, 19*(2), 109–118. https://doi.org/10.1111/jspn.12069

Doody, O., & Bailey, M. E. (2019). Understanding pain physiology and its application to person with intellectual disability. *Journal of Intellectual Disabilities, 23*(1), 5–18. https://doi.org/10.1177/1744629517708680

Douglas, C., Windsor, C., & Lewis, P. (2015). Too much knowledge for a nurse? Use of physical assessment by final-semester nursing students. *Nursing & Health Sciences, 17*(4), 492–499. https://doi.org/10.1111/nhs.12223

Downs, J., Torode, I., Ellaway, C., Jacoby, P., Bunting, C., Wong, K., … Leonard, H. (2016). Family satisfaction following spinal fusion in Rett syndrome, *Developmental Neurorehabilitation, 19*(1), 31–37. https://doi.org/10.3109/17518423.2014.898107

Dubois, A., Capdevila, X., Bringuier, S., & Pry, R. (2010). Pain expression in children with an intellectual disability. *European Journal of Pain, 14*(6), 654–660. https://doi.org/10.1016/j.ejpain.2009.10.013

Ellzey, A., Valentine, K. J., Hagedorn, C., Murphy, N. A., Specialty, P., Program, C., … City, S.L. (2015). Parent perceptions of quality of life and health care satisfaction for

children with medical complexity, *Journal of Pediatric Rehabilitation Medicine, 8*(2), 97–104. https://doi.org/10.3233/PRM-150323

Ely, E., Chen-Lim, M. L., Zarnowsky, C., Green, R., Shaffer, S., & Holtzer, B. (2012). Finding the Evidence to Change Practice for Assessing Pain in Children Who Are Cognitively Impaired. *Journal of Pediatric Nursing, 27*(4), 402–410. https://doi.org/10.1016/j.pedn.2011.05.009

Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American journal of theoretical and applied statistics, 5(*1), 1-4. doi: 10.11648/j.ajtas.20160501.11

Fereday, J., Rm, R. N., App, D., Nursing, S., Med, B. N., & Oster, C. (2010). Partnership in practice: what parents of a disabled child want from a generic health professional in Australia. *Health & Social Care in the Community, 18*(6), 624–632. https://doi.org/10.1111/j.1365-2524.2010.00935.x

Fortin, F., & Gagnon, J. (2016). *Fondements et étapes du processus de recherche: méthodes quantitatives et qualitatives (3e édition.).* Montréal (Québec): Chenelière Éducation

French. (2006). Uncertainty and information need in nursing. *Nurse Education Today, 26*(3), 245–252. https://doi.org/10.1016/j.nedt.2005.10.005

Freund, D., & Bolick, B. N. (2019). CE: Assessing a Child's Pain. *AJN American Journal of Nursing, 119*(5), 34–41. https://doi.org/10.1097/01.NAJ.0000557888.65961.c6

Garg, P., Haynes, N., Lima, J. De, & Collins, J. J. (2017). Profile of children with developmental disabilities attending a complex pain clinic of a children's hospital in Australia. *Journal of Paediatrics and Child Health, 53*(12), 1186–1191. https://doi.org/10.1111/jpc.13633

Genik, McMurtry, C. M., Breau, L. M., Lewis, S. P., & Freedman-Kalchman, T. (2018). Pain in Children with Developmental Disabilities: Development and Preliminary Effectiveness of a Pain Training Workshop for Respite Workers. *The Clinical Journal of Pain, 34*(5), 428–437. https://doi.org/10.1097/AJP.0000000000000554

Gottlieb, L. N., Feeley, N., & Dalton, C. (2006). *The Collaborative Partnership Approach to Care-A Delicate Balance: Revised Reprint.* Elsevier Health Sciences.

Guba, & Lincoln, Y. S. (1982). Epistemological and Methodological Bases of Naturalistic Inquiry. *Educational Communication and Technology, 30*(4), 233–252. https://doi.org/10.1007/BF02765185

Hagvall, Ehnfors, M., & Anderzén-Carlsson, A. (2016). Experiences of parenting a child with medical complexity in need of acute hospital care. *Journal of Child Health Care, 20*(1), 68–76. https://doi.org/10.1177/1367493514551308

Harrison, D., Joly, C., Chretien, C., Cochrane, S., Ellis, J., & Lamontagne, C. (2014). Pain prevalence in a pediatric hospital: Raising awareness during Pain Awareness Week. *Pain Research & Management, 19*(1), 24–31. https://doi.org/10.1155/2014/737692

Hauer. (2010). Identifying and managing sources of pain and distress in children with neurological impairment. *Pediatric Annals, 39*(4), 198–205. https://doi.org/10.3928/00904481-20100318-04

Hayles, Harvey, D., Plummer, D., & Jones, A. (2015). Parents' Experiences of Health Care for Their Children with Cerebral Palsy. *Qualitative Health Research, 25*(8), 1139–1154. https://doi.org/10.1177/1049732315570122

Herr, K., & Mccaffery, M. (2011). Position Statement Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations. *Pain Management Nursing, 12*(4), 230–250. https://doi.org/10.1016/j.pmn.2011.10.002

Hunt, A., Wisbeach, A., Seers, K., Goldman, A., Crichton, N., Perry, L., & Mastroyannopoulou, K. (2007). Development of the paediatric pain profile: role of video analysis and saliva cortisol in validating a tool to assess pain in children with severe neurological disability. *Journal of Pain and Symptom Management, 33*(3), 276-289. https://doi.org/10.1016/j.jpainsymman.2006.08.011

Hunt, K. A., & Franck, L. S. (2011). Special needs require special attention: A pilot project implementing the paediatric pain profile for children with profound neurological impairment in an inpatient setting following surgery. *Journal of Child Health Care. 15*(3), 210–220. https://doi.org/10.1177/1367493511407942

International Association for the Study of Pain. (2018). *Declaration of Montréal.* https://www.iasp-pain.org/DeclarationofMontreal

International Association for the Study of Pain (2020, July 16th). *IASP Announces Revised Definition of Pain.* https://www.iasp-pain.org/PublicationsNews/NewsDetail.aspx?ItemNumber=10475

Iversen, A. S., Graue, M., & Raheim, M. (2013). At the edge of vulnerability—lived experience of parents of children with cerebral palsy going through surgery. *International Journal of Qualitative Studies on Health and Well-Being, 8*(1), 1-10. https://doi.org/10.3402/qhw.v8i0.20007

Kerns, R. D., Haythornthwaite, J., Rosenberg, R., Southwick, S., Giller, E. L., & Jacob, M. C. (1991). The Pain Behavior Check List (PBCL): factor structure and psychometric

properties. *Journal of Behavioral Medicine, 14*(2), 155-167. https://doi.org/10.1007/BF00846177

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal, 16*(2), 297–305. https://doi.org/10.1007/s10995-011- 0751-7

Larocque, C., Peterson, W. E., Squires, J. E., Mason-Ward, M., Mayhew, K., & Harrison, D. (2021). Family-centred care in the Neonatal Intensive Care Unit: A concept analysis and literature review. *Journal of Neonatal Nursing: JNN, 27*(6), 402–411. https://doi.org/10.1016/j.jnn.2021.06.014

Lewis, P., Wilson, N. J., Jaques, H., Reilly, K. O., & Wiese, M. (2019). A qualitative study of nurses' perspectives of caring for children with intellectual disability and their families in a paediatric acute care setting. *Journal of Child Health Care, 23*(4), 639–651. https://doi.org/10.1177/1367493519867234

Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage.

Lotze, G. M., Bellin, M. H., & Oswald, D. P. (2010). Family-Centered Care for Children with Special Health Care Needs: Are We Moving Forward? *Journal of Family Social Work, 13(*2), 100–113. https://doi.org/10.1080/10522150903487099

Malviya, S., Voepel-Lewis, T., Merkel, S., & Tait, A. (2005). Difficult pain assessment and lack of clinician knowledge are ongoing barriers to effective pain management in children with cognitive impairment. *Acute Pain: International Journal of Acute Pain Management, 7*(1), 27–32. https://doi.org/10.1016/j.acpain.2005.01.002

McKay, M., & Clarke, S. (2012). Pain assessment tools for the child with severe learning disability: Mary McKay and Sonya Clarke assess three validated tools to help nurses identify pain behaviors in this client group. *Nursing Children and Young People, 24*(2), 14–19. https://doi.org/10.7748/ncyp.24.2.14.s22

Mcneilly, P., & Kelly, B. (2017). The participation of parents of disabled children and young people in health and social care decisions. *Child: care, health, and development, 43*(6), 839–846. https://doi.org/10.1111/cch.12487

Merriam-Webster. (n.d.). Caregiver. In *Merriam-Webster.com dictionary*. Retrieved June 15, 2022, from https://www.merriam-webster.com/dictionary/caregiver.

Newacheck, P., Inkelas, M., & Kim, S. (2004). Health Services Use and Health Care Expenditures for Children with Disabilities. *Pediatrics (Evanston), 114*(1), 79–85. https://doi.org/10.1542/peds.114.1.79

Oregon Health and Science University. (n.d.). *Evidence-Based Practice Toolkit for Nursing*. https://libguides.ohsu.edu/ebptoolkit/levelsofevidence

Oulton, K., Hons, B. A., Sell, D., Kerry, S., & Gibson, F. (2015). Individualizing Hospital Care for Children and Young People with Learning Disabilities: It's the Little Things that Make the Difference. Journal of Pediatric Nursing, 30(1), 78–86. https://doi.org/10.1016/j.pedn.2014.10.006

Pfister, A., Georgi-Tscherry, P., Berger, F., & Studer, M. (2020). Participation of adults with cognitive, physical, or psychiatric impairments in family of origin and intimate relationships: a grounded theory study. *BMC Public Health, 20*(1), 642–642. https://doi.org/10.1186/s12889-020-08770-x

Pizzinato, Liguoro, I., Pusiol, A., Cogo, P., Palese, A., & Vidal, E. (2022). Detection and assessment of postoperative pain in children with cognitive impairment: A systematic literature review and meta-analysis. *European Journal of Pain, 26*(5), 965–979. https://doi.org/10.1002/ejp.1936

Poland, G. (2013). The Importance of Peer Review. *Vaccine, 31*(4), 567–583. https://doi.org/10.1016/j.vaccine.2012.11.101

Quinn, B. L., & Smolinski, M. (2018). Improving School Nurse Pain Assessment Practices for Students with Intellectual Disability. *Journal of School Nursing, 34*(6), 480–488. https://doi.org/10.1177/1059840517722591

Quinn, B. L., Seibold, E., & Hayman, L. (2015). Pain assessment in children with special needs: A review of the literature. *Exceptional Children, 82*(1), 44–57. https://doi.org/10.1177/0014402915585480

Reddihough. (2021). Comorbidities and quality of life in children with intellectual disability. Child: Care, *Health, and Development., 47*(5), 654–666. https://doi.org/10.1111/cch.12873

Registered Nurses Association of Ontario. (n.d.) *About the Best Practice Champion Network.* https://rnao.ca/bpg/get-involved/champions

Registered Nurses Association of Ontario. (2022). *Best Practice Spotlight Organizations (BPSO).* https://rnao.ca/bpg/bpso

Registered Nurses Association of Ontario. (2013). Clinical Best Practice Guidelines; Assessment and Management of Pain, Third Edition. https://rnao.ca/sites/rnao-ca/files/AssessAndManagementOfPain2014.pdf

Ryan, C., & Quinlan, E. (2017). Whoever shouts the loudest: Listening to parents of children with disabilities. *Journal of Applied Research in Intellectual Disabilities, 31*(Suppl. 2), 203–215. https://doi.org/10.1111/jar.12354

Siskin Children's Institute. (n.d.). *The Facts About Intellectual Disability.* https://www.siskin.org/196.445/intellectual-disabilities

Shields, Pratt, J., Davis, L. M., & Hunter, J. (2007). Family-centred care for children in hospital. Cochrane Database of Systematic Reviews, 1, CD004811–CD004811. DOI: 10.1002/14651858.CD004811.pub2.

Shields, L. (2010). Questioning family-centred care. *Journal of Clinical Nursing, 19*(17- 18), 2629– 2638. https://doi.org/10.1111/j.1365-2702.2010.03214.x

Smith, J., Child, A., & Kendal, S. (2018). Parents' and Health Professionals' Views of Collaboration in the Management of Childhood Long-term Conditions. *Journal of Pediatric Nursing, 43*, 36–44. https://doi.org/10.1016/j.pedn.2018.08.011

Solodiuk, Scott-Sutherland, J., Meyers, M., Myette, B., Shusterman, C., Karian, V. E., Harris, S. K., & Curley, M. A. (2010). Validation of the Individualized Numeric Rating Scale (INRS): A pain assessment tool for nonverbal children with intellectual disability. *Pain (Amsterdam), 150*(2), 231–236. https://doi.org/10.1016/j.pain.2010.03.016

Solodiuk, J. C. (2013). International Journal of Nursing Studies Parent described pain responses in non-verbal children with intellectual disability. *International Journal of Nursing Studies, 50*(8), 1033–1044. https://doi.org/10.1016/j.ijnurstu.2012.11.015

Spencer, E.A., Brassey, J., & Mahtani, K. (2017). *Recall bias.* Catalogue of Bias Collaboration. https://www.catalogueofbiases.org/biases/recall-bias

Stratton, K. K., & Hartshorne, T. (2019). Identifying pain in children with CHARGE syndrome. *Scandinavian Journal of Pain, 19*(1), 157–166. https://doi.org/10.1515/sjpain-2018-0080

Terp, Weis, J., & Lundqvist, P. (2021). Parents' Views of Family-Centered Care at a Pediatric Intensive Care Unit—A Qualitative Study. *Frontiers in Pediatrics, 9*, 725040–725040. https://doi.org/10.3389/fped.2021.725040

Terstegen, C., Koot, H. ., de Boer, J. ., & Tibboel, D. (2003). Measuring pain in children with cognitive impairment: Pain response to surgical procedures. *Pain (Amsterdam), 103*(1-2), 187–198. https://doi.org/10.1016/S0304-3959(02)00453-0

Thompson Burdine, Thorne, S., & Sandhu, G. (2021). Interpretive description: A flexible qualitative methodology for medical education research. *Medical Education, 55*(3), 336–343. https://doi.org/10.1111/medu.14380

Thorne, S., Kirkham, S., & O'Flynn-Magee, K. (2004). The Analytic Challenge in Interpretive Description. *International Journal of Qualitative Methods, 3*(1), 1–11. https://doi.org/10.1177/160940690400300101

Thorne, S. (2016). *Interpretive description: qualitative research for applied practice (Second edition.).* Routledge. https://doi.org/10.4324/9781315545196

United Nations Human Rights Office of The High Commissioner General Assembly. (1990, September 2nd). *Convention on the Rights of the Child.* https://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf

Vaid, Ewashen, C., & Green, T. (2013). Practice Uncertainty: Changing Perceptions. The *Journal of Continuing Education in Nursing, 44*(10), 439–444. https://doi.org/10.3928/00220124-20130716-33

Vaismoradi, Salsali, M., & Ahmadi, F. (2011). Nurses' experiences of uncertainty in clinical practice: a descriptive study. *Journal of Advanced Nursing, 67*(5), 991–999. https://doi.org/10.1111/j.1365-2648.2010.05547.x

Van Rijnsoever, F. J. (2017). (I Can't Get No) Saturation: A simulation and guidelines for sample sizes in qualitative research. *PLoS ONE, 12*(7), e0181689. https://link.gale.com/apps/doc/A499323043/AONE?u=otta77973&sid=bookmark-AONE&xid=af42cda6

Vasey, J., Smith, J., Kirshbaum, M. N., & Chirema, K. (2019). Tokenism or true partnership: Parental involvement in a child's acute pain care. *Journal of Clinical Nursing, 28*(9–10), 1491–1505. https://doi.org/10.1111/jocn.1474

Williams, K., Leonard, H., Tursan d'Espaignet, E., Colvin, L., Slack-Smith, L., & Stanley, F. (2005). Hospitalisations from birth to 5 years in a population cohort of Western Australian children with intellectual disability. *Archives of Disease in Childhood, 90*(12), 1243–1248. https://doi.org/10.1136/adc.2004.062422

Young, K. D. (2017). Assessment of Acute Pain in Children. *Clinical Pediatric Emergency Medicine, 18*(4), 235–241. https://doi.org/10.1016/j.cpem.2017

Appendix A: Research Ethics Boards (REB) Approval

Approval Letter from the Study Hospital's Research Ethics Board

Study Hospital Logo

Approval of Annual Renewal

REB Protocol No: 21/113X

Principal Investigator: Ms. Juliana Choueiry

Protocol Title: - Pain Care for Children with Cognitive Impairment: A Parent-Nurse Partnership

Protocol Status: Active

Approval Date: July 18, 2022

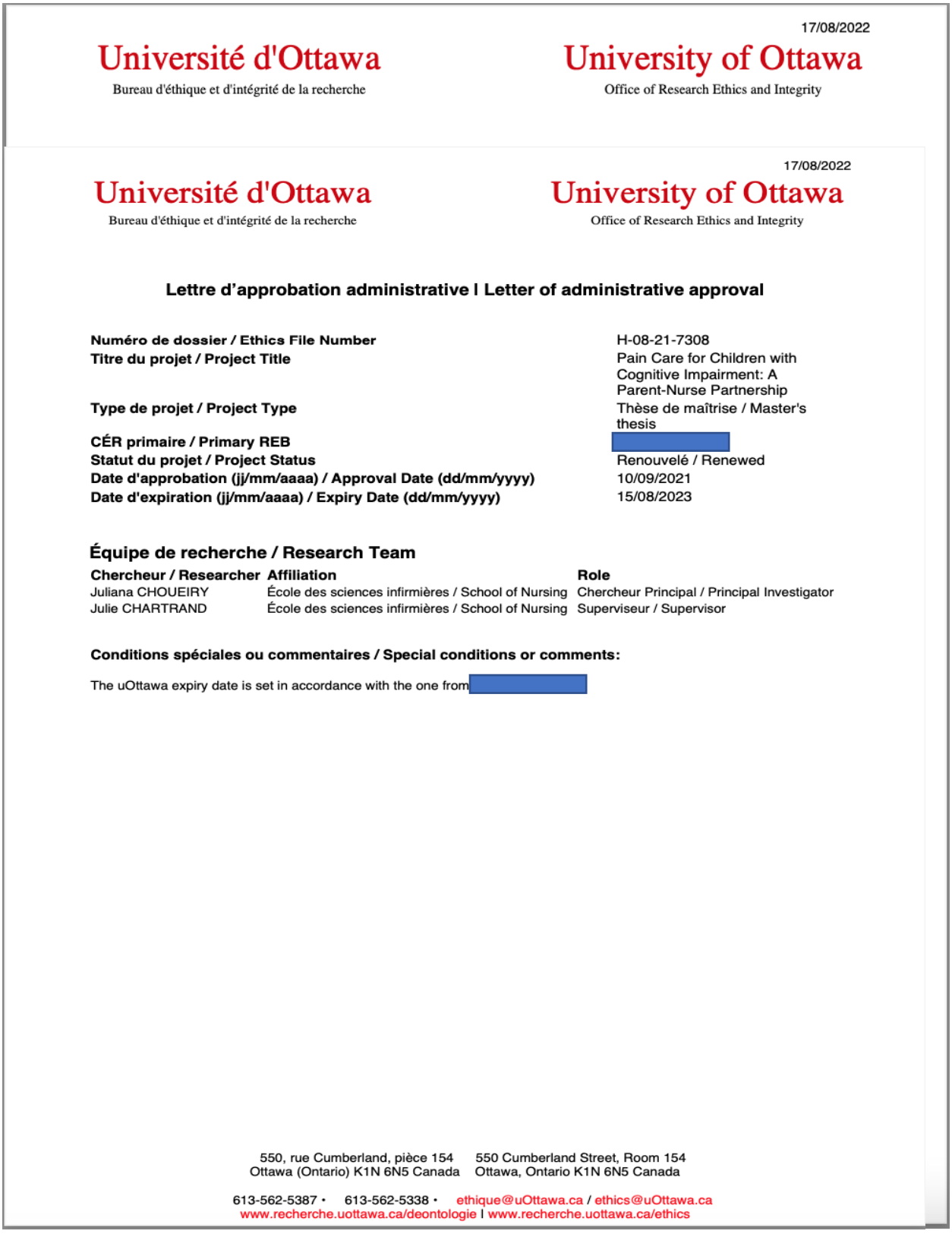
Approval Expiry Date: August 15, 2023

has conducted a delegated review and approved the renewal of the above-named study. Approval is valid for the period indicated above. Future annual renewals or study closures must be completed before the expiry date noted above.

The decision was ratified by the Full Board. REB members involved in the study do not participate in the review, deliberations, or decision.

Any modifications made to the study must be reviewed and approved by the REB prior to implementation, except when necessary to eliminate immediate danger or hazard(s) to study participants or when the change(s) involves administrative aspects of the study. Investigators must promptly alert the REB of any changes that increase the risk to participants or affect the safety of participants, all unanticipated and harmful events that occur, and new information that significantly impact the conduct of the study.

operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans (TCPS 2); the International Conference on Harmonization Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; and Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. is registered with the U.S. Department of Health and Human Services (DHHS) Office for Human Research Protection (OHRP).



17/08/2022

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

17/08/2022

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Lettre d'approbation administrative | Letter of administrative approval

Numéro de dossier / Ethics File Number	H-08-21-7308
Titre du projet / Project Title	Pain Care for Children with Cognitive Impairment: A Parent-Nurse Partnership
Type de projet / Project Type	Thèse de maîtrise / Master's thesis
CÉR primaire / Primary REB	[redacted]
Statut du projet / Project Status	Renouvelé / Renewed
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	10/09/2021
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	15/08/2023

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Juliana CHOUEIRY	École des sciences infirmières / School of Nursing	Chercheur Principal / Principal Investigator
Julie CHARTRAND	École des sciences infirmières / School of Nursing	Superviseur / Supervisor

Conditions spéciales ou commentaires / Special conditions or comments:

The uOttawa expiry date is set in accordance with the one from [redacted]

550, rue Cumberland, pièce 154
Ottawa (Ontario) K1N 6N5 Canada

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Appendix B: Sample Recruitment Emails

Recruitment emails

Dear Nursing staff,

You are being invited to participate in a study titled "Pain Care for Children with Cognitive Impairment: A Parent-Nurse Partnership". This study is related to parent-nurse partnerships during pain care of hospitalized children with cognitive impairments (CI) (impairments (i.e., the child can make sound but not express oneself through words).

This study is being led by Juliana Choueiry (Principal Investigator [PI], Registered Nurse at [redacted] and Master of Nursing student at the University of Ottawa) and Julie Chartrand (Assistant Professor, University of Ottawa) and has been approved by the [acute care hospital] Research Ethics Board.

Why I am being asked to participate in this study?
You are being invited to participate in this study because you are a registered nurse or registered practical nurse working on an inpatient unit (4W, 4E/5E or 4N) at [redacted] and have provided pain care for children with CI. We are inviting all nurses currently working on these inpatient units at [redacted] to participate. Your participation in this study is entirely voluntary.

What is the study about?
Parent-nurse partnerships are vital for effective pain assessment and management of hospitalised children with cognitive impairment (CI). Currently, Family-Centered Care (FCC) is the guiding approach to parent-nurse partnerships. However, FCC has been reported to be ambiguous and difficult to apply in practice. Therefore, little is known about how nurses partner with parents during pain care of children with CI. This study aims to gain an understanding of how parents and nurses partner together during pain care of children with CI in order to apply this insight to practice.

What does this study involve?
You will be asked to participate in one interview. During this interview, you will meet with a member of the research team. Each interview will be about 30–60 minutes in length and will take place either in-person, via video conference or telephone at a time that is most convenient for you. You will be asked to provide information about your experiences of partnering with nurses for your child's pain care.

You will receive a $10 Starbucks gift card to thank you for your participation.

Why is this study important?
The purpose of this study is to learn more about how nurses and parents work together to provide optimal pain assessment and management for children with cognitive impairment.

This information will be used to inform current practices and ultimately, improve pain care for children with cognitive impairment in the future.

What about confidentiality and privacy?
If you choose to participate in this study, all information will be kept confidential. Any publications or presentations of the study results will be anonymized and no identifying information about the respondents will be reported.

How do I participate?
If you are interested in participating in this study, please send an email to the PI (Juliana Choueiry) to express your interest. Then, the PI will go over the study information with you and obtain your informed consent to participate. Based on your preference, an interview time, date, and method will be determined with you.

What if I have questions?
If you have any questions about this study, please do not hesitate to contact Juliana Choueiry.

Yours sincerely,

Juliana Choueiry
Registered Nurse, [acute care hospital]
Master of Nursing (student), University of Ottawa

Julie Chartrand
Assistant Professor
School of Nursing
University of Ottawa

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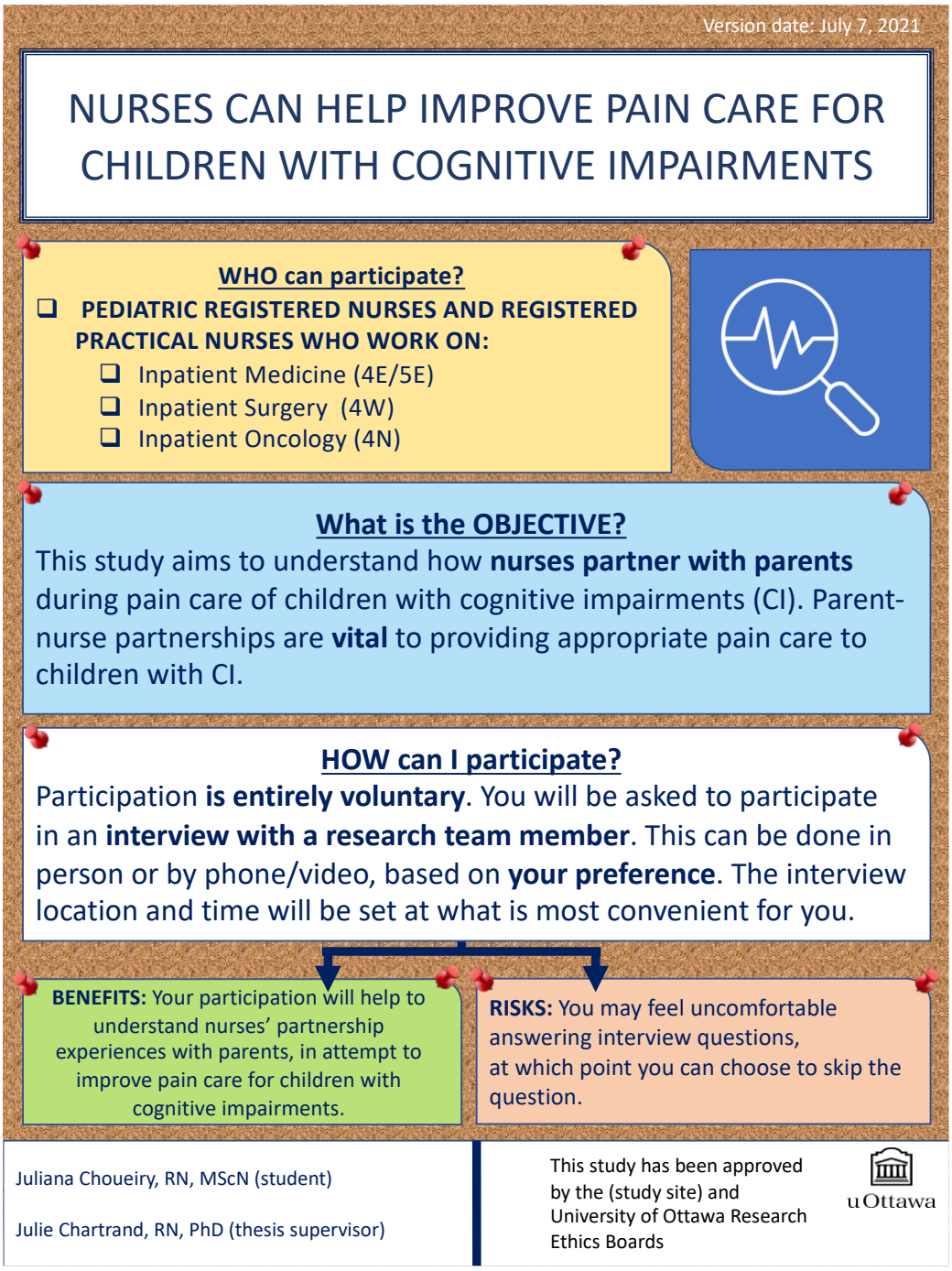
Appendix C: Recruitment Posters



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Appendix D: Sample Consent Forms

Informed Consent Form for Participation in a Research Study

Study Title: Pain Care for Children with Cognitive Impairment: A Parent-Nurse Partnership

Principal Investigator:

Juliana Choueiry, RN, BScN, MScN (student)
Student, Master of Science in Nursing, University of Ottawa
Registered Nurse

Supervisor:
Julie Chartrand, RN, Ph. D
Assistant professor, School of Nursing, University of Ottawa

INTRODUCTION

You are being invited to participate in a research study. You are invited to participate in this study because you are a pediatric nurse that has taken care of a hospitalized child with cognitive impairment (i.e., the child can make sound but not to express oneself through words).

This consent form provides you with information to help you make an informed choice. Please read this document carefully and ask any questions you may have. All your questions should be answered to your satisfaction before you decide whether to participate in this research study.

Please take your time in making your decision. You may find it helpful to discuss it with your friends and family. Taking part in this study is voluntary. You have the option to not participate at all or you may choose to leave the study at any time. Whatever you choose, it will not affect the usual medical care that your child will receive.

IS THERE A CONFLICT OF INTEREST?

There are no conflicts of interest to declare related to this study.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to learn more about how nurses and parents work together to provide optimal pain assessment and management for children with cognitive impairment.
This information will be used to inform current practices and ultimately, improve pain care for children with cognitive impairment in the future.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

It is anticipated that about10 people will take part in this study, from a research site located in Ottawa, Ontario. This study should take about nine months to complete, and the results should be known in about one year.

WHAT WILL HAPPEN DURING THIS STUDY?

You will be asked to participate in one interview. During this interview, you will meet with a member of the research team. Each interview will be about 30 minutes in length and will take place either in-person, via video conference or telephone at a time that is most convenient for you. You will be asked to provide information about your experiences of partnering with nurses for your child's pain care. You will be audio-recorded during the interview.

HOW LONG WILL PARTICIPANTS BE IN THE STUDY?

Your participation on this study will last for the length of the interview.

CAN PARTICIPANTS CHOOSE TO LEAVE THE STUDY?

You can choose to end your participation in this research (called withdrawal) at any time without having to provide a reason. If you choose to withdraw from the study, you are encouraged to contact the research team. You may withdraw your permission to use information that was collected about you for this study at any time by letting the research team know. However, this would also mean that you withdraw from the study. If you decide to leave the study, you can ask that the quotes that was collected about you not be used for the study. Let the research team know if you choose this.

WHAT ARE THE RISKS OR HARMS OF PARTICIPATING IN THIS STUDY?

You may become uncomfortable while discussing your experiences. You may refuse to answer questions or leave the interview at any time for any reason.

WHAT ARE THE BENEFITS OF PARTICIPATING IN THIS STUDY?

The expected benefit from taking part in this study is that you will help inform and potentially improve future practices of partnership with nurses during pain care of children with cognitive impairment. The knowledge provided will potentially help to optimize pain care and improve pain assessment and management for this population.

HOW WILL PARTICIPANT INFORMATION BE KEPT CONFIDENTIAL?

If you decide to participate in this study, the research team will only collect the information they need for this study. Records identifying you at this cent will be kept confidential and, to the extent permitted by the applicable laws, will not be disclosed or made publicly available, except as described in this consent document. Authorized representatives of the following organizations may look at your original (identifiable) interview transcript at the site where these records are held, to check that the information collected for the study is correct and follows proper laws and guidelines.

- The research ethics board who oversees the ethical conduct of this study in Ontario
- This institution and affiliated sites, to oversee the conduct of research at this location.

Information that is collected about you for the study (called study data) may also be sent to the organizations listed above. Representatives of Clinical Trials Ontario, a not-for-profit organization, may see study data that is sent to the research ethics board for this study. Your name, address, email, or other information that may directly identify you will not be used. The records received by these organizations may contain your *participant code and initials.* A copy of the consent form that you sign to enter the study may be included in your health record/hospital chart.

Communication via email is not absolutely secure. We do not recommend that you communicate sensitive personal information via email. During the discussions, participants will be encouraged to refrain from using names. If names or other identifying information is shared during the discussion, it will not be included in the written records.

The /audio recordings will be stored in a secure location and only by members of the research team. The recordings will be kept until graduation of the principal investigator and then they will be destroyed. If the results of this study are published, your identity will remain confidential. It is expected that the information collected during this study will be used in analyses and presented in a thesis defense as well as other research conferences.

Even though the likelihood that someone may identify you from the study data is very small, it can never be eliminated. Data collected using Zoom video conferencing resides on Amazon Web Services the servers and no assurance can be made about its confidentiality or that it will only be used for research purposes. To promote confidentiality, password protection will be used, and interview recordings will be saved on the researcher’s private and secure computer.

WHAT IS THE COST TO PARTICIPANTS?

Participation in this study will not involve any additional costs to you or your private healthcare insurance.

ARE STUDY PARTICIPANTS PAID TO BE IN THIS STUDY?

You will not be paid for taking part in this study. However, you will receive a $10 Starbucks gift card to thank you for your participation.

WHAT ARE THE RIGHTS OF PARTICIPANTS IN A RESEARCH STUDY?

You will be told, in a timely manner, about new information that may be relevant to your willingness to stay in this study. You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please contact the research team.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected. By signing this form, you do not give up any of your legal rights against the researcher or involved institutions for compensation, nor does this form relieve the researcher or their agents of their legal and professional responsibilities.
You will be given a copy of this signed and dated consent form prior to participating.

WHOM DO PARTICIPANTS CONTACT FOR QUESTIONS?

If you have questions about taking part in this study, or if you suffer a research-related injury, you can talk to the research team, or the person who oversees the study at this institution. That person is: **Juliana Choueiry**.

If you have questions about your rights as a participant or about ethical issues related to this study, you can talk to someone who is not involved in the study at all. That person is NAME (REB of Record Information), who can be reached at TELEPHONE.

SIGNATURES

- All of my questions have been answered,
- I understand the information within this informed consent form,
- I do not give up any of my legal rights by signing this consent form,
- I agree to take part in this study.

_____	_____	_____
Signature of Participant	PRINTED NAME	Date
_____	_____	_____
Signature of Person Conducting the Consent Discussion	PRINTED NAME & ROLE	Date

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Appendix E: Interview Guide

PAIN CARE FOR CHILDREN WITH CI: A NURSE-PARENT PARTNERSHIP SEMI-STRUCTURED INTERVIEW GUIDE FOR NURSES (EN)

Preamble

Good morning/afternoon/evening. My name is Juliana Choueiry I am interviewing you today as part of a study that I am conducting at the University of Ottawa. I am interested in learning more about how nurses partner with parents during pain care of hospitalized children with CI. Pain care includes assessment and treatment of the child's pain. As there is very little knowledge about the current practices, this study hopes to generate new findings to better understand the pain care process for these children and optimize the assessment and management of pediatric pain. Before starting this interview, it is important to tell you that your responses are voluntary and will remain confidential on a digital recording. You can opt out of any questions that may make you feel any type of discomfort. Please let me know if you are uncomfortable and we can either move on to another question or stop the interview.

Demographic questions

- To better understand your context, can you please tell me about your work experience as a nurse and what unit you work on?

General questions

- Can you tell me about your experiences with providing pain care to children with CI?
- Can you tell me about ways you work out to know if the child with CI you are caring for is in pain?

Specific questions

- How do you feel about the education you have received (nursing school, at work, etc.) about pain care in children with CI?

- What does partnering with parents of children with CI look like to you?

    - How do you initiate partnership with parents of children with CI?
    - After initiating, how do you proceed next?
    - How do you maintain a partnership with parents of children with CI?

- Can you please tell me about how you communicate with parents about pain care of their child with CI?

- Have you involved children with CI in their pain care?

    - If yes, can you please tell me about how children with CI have participated in their pain care?
    - If not, why not?

- Can you please tell me about the information you provide to parents about pain care?

- Based on previous experiences, what have parents contributed to pain care of children with CI?
- What do you think of parents' contributions to their child's pain care?
- Based on previous experiences, can you tell me how you have supported parents in their roles as advocates for their children with CI?
- Can you tell me about any previous experiences with developing pain care plans for children with CI, in partnership with parents?
- What do you think makes it harder to create a partnership with parents regarding their child's pain care?
- What do you think would make it easier to create a partnership with parents regarding child's pain care?
- Do you have any other comments regarding your experiences of partnering with parents' pain care or questions regarding this subject?

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