

PARENTAL PREVENTION OF NEWBORN PAIN:
AN EVALUATION OF AN EHEALTH LEARNING PLATFORM TO DETERMINE
ACCEPTABILITY, FEASIBILITY AND UTILIZATION OF PARENT-LED PAIN
MANAGEMENT

by

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DEDICATION PAGE

To my beautiful sister, Darrah.

Always my greatest cheerleader and best friend. Your support, generosity, love, intelligence, and humour were unparalleled, especially throughout this academic journey.

I know you will continue to be with me. I love you very much and miss you every day.

Darrah Marianne Richardson

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ABSTRACT

Introduction: All newborns undergo painful procedures (e.g., injections). Despite strong evidence supporting the efficacy of parent-led pain management (PLPM; e.g., breastfeeding) during procedures, parents remain an underutilized resource. The purpose of this dissertation was to review existing evidence related to parental involvement in infant procedural pain management, as well as to develop and evaluate the eHealth resource Parenting Pain Away (PPA). PPA is a website to enhance parents' access to information and participation in procedural pain management. The first aim of this research was to conduct iterative usability testing with the perinatal population to refine PPA based on target users' identified needs and satisfaction. Secondly, to evaluate the impact of PPA, given during the prenatal period, on feasibility, parental acceptability, knowledge, self-efficacy, and involvement.

Methods: There are two studies within this dissertation. The first study (phase 1) conducted usability testing of PPA with expectant parents and recently postnatal parents. The second study (phase 2) was a quasi-experimental evaluation using a pre/post intervention design with low-risk expectant parents.

Results: In phase 1, ten participants completed two cycles of usability testing (i.e., 5/cycle). After reviewing PPA, participants provided positive, constructive feedback and reported high user satisfaction overall. A total of 41 participants completed phase 2. Providing access to PPA during pregnancy was supported and no major concerns with the website were noted. PPA did not have a statistically significant influence on parental knowledge, self-efficacy, or involvement. Participants reported variation in clinical support with PLPM during needle-related procedures.

Conclusions: This dissertation expands evidence supporting perinatal eHealth interventions and informs pediatric pain research. Engaging target users and key stakeholders in the development process and evaluations significantly enhanced PPA. Providing education on infant pain during the prenatal period was encouraged by parents. This timing promotes PLPM with infants for all procedures after birth. The findings from both project phases highlight parents' appreciation for accessible, evidence-based health information and involvement in all aspects of postnatal care, especially procedural pain management. PPA has great potential to be an effective educational resource, but institutional policies and healthcare provider support are essential for parental involvement in infant pain management.

LIST OF ABBREVIATIONS USED

NICU	Neonatal Intensive Care Unit
NS	Nova Scotia
PEI	Prince Edward Island
VAS	Visual Analog Scale
PIPP	Premature Infant Pain Profile
NNS	Non-Nutritive Sucking
PIPP-R	Premature Infant Pain Profile- Revised
NIPS	Neonatal Infant Pain Scale
DPNB	Dorsal Penile Nerve Block
EMLA	Eutectic Mixture of Analgesics
BFI	Baby Friendly Initiative
WHO	World Health Organization
UNICEF	United Nations International Children's Emergency Fund
SSC	Skin-to-Skin Contact
FICare	Family-Integrated Care
PLPM	Parent-Led Pain Management
mHealth	Mobile Health
Apps	Applications
eHealth	Electronic Health
SMS	Short Message Service
JBI	Joanna Briggs Institute
RCT	Randomized Controlled Trials

GRADE	Grading of Recommendations, Assessment, Development and Evaluation
SoF	Summary of Findings
ANOVA	Analysis of Variance
MANOVA	Multivariate Analysis of Variance
CHREHI	Calgary Health Region Evaluation of Health Information
MAISD	Measure of Adult and Infant Soothing and Distress
NBS	Newborn Blood Screening
MBPS	Modified Behavioral Pain Scale
ImPaC	Implementation of Infant Pain Practice Change
BRIC NS	Building Research for Integrated Primary Care Nova Scotia
MOM-LINC	Mechanisms, Outcomes, Mobilization of maternally-Led Interventions in Newborn Care
PCH	Prince County Hospital
QEH	Queen Elizabeth Hospital
CBC	Canadian Broadcasting Corporation
REB	Research Ethics Board
PSSUQ	Post Study System Usability Questionnaire
REDCap	Research Electronic Data Capture
SPSS	Statistical Package for Social Sciences
KPCS	Karitane Parenting Confidence Scale
PPSE	Perceived Parenting Self-Efficacy
SUS	System Usability Scale
PICH	Pain In Child Health

UX	User Experience
PPA	Parenting Pain Away
HCP	Healthcare Providers
M	Mean
SD	Standard Deviation
NBM	Newborn Metabolic
SEO	Search Engine Optimization
CARD™	Comfort, Ask, Relax, and Distract

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CHAPTER 1 INTRODUCTION

Routine postpartum care requires all infants endure painful procedures in early life and despite widespread evidence supporting proper pain management, these infants often receive little to no pain relieving treatments (American Academy of Pediatrics Committee on Fetus and Newborn, 2016; Cruz et al., 2016). This untreated pain can have detrimental effects on infant behaviour and neurodevelopment (Blount et al., 2006; Grunau et al., 2006; Grunau & Tu, 2007; Hermann et al., 2006; Valeri et al., 2015). Although the majority of previous work related to untreated pain has been done with preterm infants (i.e. < 37 weeks gestation) who experience greater exposure to pain (Johnston et al., 2008), evidence suggests healthy newborns with less exposure still exhibit adverse effects, most notably related to neurological processing of pain and altered perception of subsequent pain, as well as likely links to later needle aversion (Piira et al., 2007; Taddio et al., 1997; Taddio, Goldbach, et al., 1995). Sadly, despite up to 20 possible needle related procedures (i.e., metabolic screening and immunizations) in the first 2 years of life, little attention has been given to healthy full-term infants (i.e., > 37 weeks gestation). Evidence supports multiple ways that parents can reduce their healthy, full term infant's pain such as holding their infant close allowing for skin-to-skin contact or breastfeeding (Benoit et al., 2017; Johnston et al., 2017; Obeidat & Shuriquie, 2015). However, parents may not be aware of how they can help, leading to feelings of frustration due to their perceived limited ability to be involved in pain management (Simons et al., 2001; Ullsten et al., 2021).

Increasingly parents recognize that their participation in pain care is important and know that they require comprehensive information on all aspects of infant pain

(Franck et al., 2012; Orr et al., 2016; Ullsten et al., 2021). Given the distress parents often experience when seeing their child in pain, many are increasingly turning to the Internet for general information on infant pain, as well as infant health and wellbeing (Orr et al., 2016; Sundstrom, 2016). Finding accurate, evidence-based health information that may not always be available or easily accessible on the Internet (Dol et al., 2018; Fahy et al., 2014; Kothari & Moolani, 2015; Scullard et al., 2010). Thus, it is important for perinatal care areas to offer interactive, engaging, and evidence-based information electronically to meet parents' needs in caring for their infant.

This dissertation has been prepared using a manuscript-based format where two published articles and a manuscript (submitted) are integrated throughout. Overall, this dissertation aims to contribute to the literature exploring parental involvement in infant procedural pain management and the influence of eHealth educational modalities.

Chapter 1 contextualizes the current issue of healthy, full term newborns experience with procedural pain and parents' role in pain management strategies. After a description of prevalent pain exposure in all neonates, a brief report of the negative consequences associated with this early pain exposure will follow. This chapter will also describe the provision of education in the postnatal population and use of eHealth strategies to educate parents. Finally, this chapter will demonstrate the need to advance beyond the neonatal intensive care unit (NICU) to scale components of an eHealth solution to also improve family-integrated care practices for the healthy, full-term newborn population.

1.1 UNTREATED INFANT PAIN

From birth and throughout infancy, infants experience numerous painful procedures in early life. As part of routine postpartum care, all infants must receive

Vitamin K by intramuscular injection shortly after birth (American Academy of Pediatrics Committee on Fetus and Newborn, 2016), as well as heel lancing to collect blood specimen for newborn metabolic screening and assessment for hyperbilirubinemia (Barrington & Sankaran, 2018; The Maritime Newborn Screening Program, 2018). Due to their critical conditions, infants in the NICU are known to receive the highest amount of pain exposure, receiving 7-12 painful procedures per day (Cruz et al., 2016; Johnston et al., 2011). Routine procedures in the NICU that cause pain for the neonate include: tissue breaking procedures (i.e., needle insertion, heel lancing, intravenous catheter (IV) insertion) (Fitzgerald & Beggs, 2001; Harrison et al., 2002; Porter et al., 1997; Runefors et al., 2007; Stevens et al., 1999), suctioning (Marceau, 2003), nasogastric tube placement and maintenance, as well as tape removal from skin (American Academy of Pediatrics Committee on Fetus and Newborn, 2016; Porter et al., 1997). While the pain experience of infants admitted to the NICU has been historically the greater focus, healthy newborns either late preterm (i.e., 35-37 weeks gestation) or full term (i.e., greater than 37 weeks gestation) infants also experience considerable amounts of pain exposure in early life. Approximately 60-80% of healthy newborns are diagnosed with hyperbilirubinemia requiring repeated assessments via heel lance to monitor the presence of bilirubin in the blood during treatment (American Academy of Pediatrics, 2004; Chou et al., 2003; Stevenson et al., 2001). Additionally, healthy newborns at risk of hypoglycemia can receive upwards of ten repeated heel lances to monitor blood glucose levels (Barrington & Sankaran, 2018; Williams, 1997; 2005). Outside of postpartum care, in Canada infants also experience at least four sessions of intramuscular injections for

vaccinations throughout their first year of life to protect and enhance their immune systems (Public Health Agency of Canada, 2023).

The importance of proper pain management is widely recognized and efforts to determine effective treatment options have been ongoing in research since the 1990's, yet infants are still not consistently treated for pain during procedures (American Academy of Pediatrics Committee on Fetus and Newborn, 2016; Cruz et al., 2016; Taddio, Chambers, et al., 2009). Untreated pain in early life influences physiological and neurological responses that can lead to adverse physiological, behavioural, or cognitive outcomes in infants including associated implications from increased inflammatory hormone release caused by stress (Holsti et al., 2006; Mörelius et al., 2005; Shorey et al., 2016). For the NICU population, pain can have detrimental effects, including heightened pain response in infancy and childhood, impairments in their neurodevelopment, and altered behaviour regulation (Grunau et al., 2006; Grunau & Tu, 2007; Hermann et al., 2006; Johnston & Stevens, 1996; Taddio et al., 2002; Valeri et al., 2015). Although yet to be investigated as thoroughly as critically ill or preterm infants, there is evidence to support that healthy newborns are highly sensitive to pain exposure due to rapid neurological development during the immediate postnatal period (Gokulu et al., 2016; Taddio et al., 1997, 2002; Taddio, Shah, et al., 2009). Healthy, full term newborns experience adverse outcomes related to untreated acute pain including heightened pain and fear response to subsequent painful stimuli in infancy and childhood (Ozawa et al., 2011; Piira et al., 2007; Taddio et al., 2002; Taddio, Shah, et al., 2009). There is evidence to support the efficacy of pharmacological and non-pharmacological pain management interventions, specifically for infants experiencing pain caused by tissue-

breaking procedures (Chambers et al., 2009; Harrison, Reszel, et al., 2016; Shah et al., 2009; Stevens et al., 2016; Taddio, Ilersich, et al., 2009). However, pain management is often overlooked in clinical practice where almost half of infants fail to receive any treatment for pain relief (Cruz et al., 2016; Johnston et al., 2011; Orovec et al., 2019; Taddio et al., 2007).

1.2 PARENTS' POTENTIAL

There are effective pharmacological and non-pharmacological treatments for procedural pain experienced by infants, including topical anesthetics (Jain & Rutter, 2000; Kaur et al., 2003), analgesics (e.g. acetaminophen or opioids) (Hall & Anand, 2014), sucrose (24%) oral solution (Bueno, Ballantyne, Campbell-Yeo, et al., 2023; Stevens et al., 2016, 2018), breastfeeding (Benoit et al., 2017; Harrison, Reszel, et al., 2016; Shah et al., 2023), and skin-to-skin contact (Johnston et al., 2017). Many of these interventions can be provided directly by parents, who are easily accessible and feasible to use in clinical practice yet are highly underutilized resource (Ullsten et al., 2021).

Although family-integrated care is gaining recognition for its positive influence on family health outcomes, it is still a relatively new concept and has been primarily targeted for NICU environments. Thus, many parents are still unaware about their capacity to provide pain relief during procedures for their infants which poses a great barrier to incorporating parent-led pain management in practice (Christensen & Fatchett, 2002; Corlett & Twycross, 2006; Parvez et al., 2010; Taddio et al., 2007; Ullsten et al., 2021). Parents are motivated to be engaged in their infant's care, specifically with pain management during procedures (Franck et al., 2012; Jones et al., 2005; Orr et al., 2016; Pölkki et al., 2002), reporting a decrease in stress and increase in confidence when involved (Shorey et al.,

2016; Ullsten et al., 2021). Recently, there has been increasing focus on parental engagement in pain management with pediatric and NICU populations through the development of parent-targeted educational resources. For instance, Chez NICU Home, a sophisticated, secure, web-based platform that combines tailored and interactive parent education, remote communication, and individualized feedback and analytics to optimize outcomes and experiences of families whose infants require hospitalization in the NICU at IWK Health in Halifax, Nova Scotia (NS) (IWK Health, 2023b). However, to date, no comparable programs have been developed to target or engage parents of healthy, full term infants.

1.3 PROVISION OF EDUCATION IN POSTNATAL POPULATIONS

The postpartum period is often a busy time for parents where printed education materials on infant pain care are often set aside and at times forgotten completely (Skene et al., 2012). Structured postnatal educational programs focus on crucial, yet broader factors to support infant growth and wellbeing, enhanced parent-infant attachment, and maternal physical and psychosocial wellbeing (Bryanton et al., 2013) with little attention to infant procedural pain management, if any. Regardless of the specific content, delivery of postnatal care and education remains inconsistent across Canada (Dol, Hughes, et al., 2022). Parents access formal (e.g., healthcare providers) and informal (e.g., peer groups) sources to gather the information and support they require during the postnatal period (Aston et al., 2018; Dol, Hughes, et al., 2022; Price et al., 2018), with an increasing trend towards using sources available on the Internet (Slomian et al., 2017).

1.4 USE OF EHEALTH STRATEGIES

Since 2016, there have been several evidence-based syntheses evaluating the quality and impact of parent-targeted eHealth resources. Davis and colleagues sought to examine mobile health (mHealth) applications (apps) available related to all aspects of parenting (Davis et al., 2017). This review determined that there were significant issues related to credibility and functionality of mHealth apps and suggested developers focus on providing evidence-based health information in an engaging manner before healthcare providers could endorse the apps identified in their review (Davis et al., 2017). These findings were echoed in systematic reviews of websites and mHealth apps targeted to parents of infants in the NICU (Dol et al., 2018; Richardson, Dol, et al., 2019). In a systematic review evaluating studies reporting on eHealth interventions targeted to parents with infants in the NICU, parents reported eHealth interventions to be acceptable and actively used these resources within the NICU setting (Dol et al., 2017). Despite aiming to gather information on a variety of parental and neonatal outcomes, there was limited evidence assessing the impact of eHealth interventions on neonatal outcomes provided within the included studies (Dol et al., 2017). Similarly, in a scoping review evaluating parent-targeted eHealth educational interventions in the NICU, Anwar Siani and colleagues (2017) found little evidence to address the impact of eHealth resources on neonatal outcomes, however there were improvements identified in various parental outcomes including satisfaction, confidence, and knowledge uptake.

Today's parents have identified a clear preference in using the Internet or smartphone to access health information generally and specifically with regards to infant pain management (Fahy et al., 2014; Kamali et al., 2018; Monaghan et al., 2020; Orr et al., 2016; Slomian et al., 2017; Sundstrom, 2016). However, recent syntheses of websites

and mHealth apps targeted to parents of preterm infants found issues related to their credibility and moderate overall quality, with less than 11% providing any information on infant pain (Dol et al., 2018; Richardson, Dol, et al., 2019). While online resources are favoured by parents, they recognize and appreciate the legitimacy of education delivered directly by healthcare providers and would highly value a website created by health institutions that provides information on parent-led interventions for infant pain relief (Monaghan et al., 2020; Orr et al., 2016).

1.5 RESEARCH PURPOSE AND SIGNIFICANCE

Although information concerning parental involvement with pain relieving interventions in the healthy, full term newborn population is limited, what is available suggests positive parental and neonatal outcomes, including decreased parental stress and decreased infant pain response (Johnston et al., 2017; Pillai Riddell et al., 2023; Shorey et al., 2016). Specifically related to parental use of technology and learning, again most of the available literature is from the NICU population (Anwar Siani et al., 2017; Monaghan et al., 2020; Orr et al., 2016). Despite little attention to the learning needs of parents of healthy newborns, there is emerging literature evaluating eHealth resources on parent and infant outcomes, primarily related to breastfeeding (Abbass-Dick et al., 2017, 2018; Geoghegan-Morphet et al., 2014), yet a dearth of literature remains specifically with eHealth resources on procedural pain care (Hughes, Benoit, et al., 2023). Therefore, this dissertation presents a timely opportunity to bring focus to the healthy, full term newborn population and to contribute to the paucity of current evidence on the influence of eHealth learning platforms on parental attitudes and involvement in infant pain management. Building on an established eHealth learning platform, Chez NICU Home,

the dissertation project sought to adapt the existing educational chapter on infant pain to target parents of healthy newborns. Further, this dissertation project aimed to share information on infant pain in an accessible and meaningful way to encourage parents' engagement in reducing their infant's pain during procedures.

While structural changes have been implemented in health institutions to increase accountability and use of pain management for infants (Latimer et al., 2010), it still is not consistently practiced, thus identifying a need to shift pain management onto the parental role. The purpose of this dissertation is to explore the influence of eHealth education by gaining valuable insight on the acceptability, uptake and impact of a parent-targeted resource on infant procedural pain management provided antenatally and during brief hospital stays at regional non-tertiary hospitals in a rural Canadian setting. Using a phased approach, the dissertation project seeks to address the following research questions: 1) Among parents of healthy newborns, what is the acceptability and feasibility of an eHealth educational resource on parent-led procedural pain management? and 2) Among parents of healthy newborns, does an eHealth educational resource on parent-led procedural pain management influence parental knowledge, self-efficacy, and active involvement in pain management? The following objectives will guide the project to evaluate the overall impact of the eHealth educational resource given antenatally: 1) To evaluate usability of the eHealth educational resource; 2) To evaluate if the eHealth educational resource is acceptable to parents and a feasible intervention to administer prenatally; and 3) To determine if the eHealth educational resource influences parental knowledge, perceived self-efficacy and involvement in pain management during early life.

This dissertation contributes to the evidence base related to eHealth, especially with consideration of user experience by including expectant parents, parents, and key stakeholders in the developmental process of the intervention to identify parental satisfaction, preferences, perceived barriers and facilitators with the educational intervention. Simultaneously this project serves to inform the field of pediatric pain by gathering evidence related to the impact of delivering pain education prenatally. Perinatal eHealth interventions have been found to improve parental and neonatal outcomes by enhancing the accessibility of evidence-based information (Daly et al., 2018). Given the long-term effects of untreated pain on newborns is it critical to provide parents with the necessary knowledge and skills using this novel approach (Baulch, 2010).

Chapter 2 provides further detail on concepts outlined in this chapter to provide a comprehensive overview of related literature, including a published systematic review about pre-existing eHealth educational resources on infant procedural pain management, as well as the theoretical underpinnings that supported this dissertation. In Chapter 2 the following concepts will be discussed: consequences of untreated pain exposure in early life; infant pain management; eHealth education implementation; and parent-targeted educational resources on infant pain. Overall methods of the dissertation project are described in Chapter 3. The study findings of phase 1 (usability testing) are presented in Chapter 4 as an article published in *Paediatric and Neonatal Pain*. Chapter 5 provides the findings for phase 2, presented as a manuscript submitted to the *Scandinavian Journal of Caring Sciences*. Finally, the conclusion to this dissertation is found in Chapter 6, along with a general discussion, outline of strengths and limitations of this work, as well as implications and recommendation for research and practice.

CHAPTER 2 LITERATURE REVIEW

Chapter 2 provides further detail on concepts introduced in the introductory chapter to outline the practical and theoretical foundation required for this dissertation. This chapter will be divided into eight sections, beginning with a detailed overview of the current evidence related to infant procedural pain including adverse outcomes of untreated pain and pain management strategies (sections 2.1 - 2.3). The fourth section will discuss parent-targeted educational resources on infant pain during the perinatal period (section 2.4). The fifth and sixth sections will focus on eHealth learning during the perinatal period (section 2.5), specifically exploring the current availability of parent-targeted eHealth educational resources about infant pain management through a systematic review (section 2.6). The systematic review in the sixth section has been published in *JBIM Evidence Synthesis* journal and therefore is embedded in this chapter structured as per journal requirements. A summary of the literature (section 2.7) will be provided prior to the final the section of this chapter which also describes the conceptual model that informed the theoretical underpinnings of this study (section 2.8).

2.1 CONSEQUENCES OF EXPOSURE TO PAIN IN EARLY LIFE

2.1.1 Preterm Infants

Infants born preterm that are admitted to the NICU frequently endure painful procedures as a part of critical care, yet these infants are highly vulnerable to neurophysiological alterations caused by untreated pain because they are in a period of rapid development (Anand & Scalzo, 2000; Brummelte et al., 2012; Ranger & Grunau, 2014). Repeated pain exposure in preterm infants has been found to impair the development of somatosensory and central nervous systems associated with negative

consequences occurring in early infancy and throughout childhood (Abdulkader et al., 2008; Duerden et al., 2018; Hermann et al., 2006; Johnston & Stevens, 1996; Walker, 2019). Compared to term infants, alterations in neurodevelopment associated with early pain exposure in preterm infants include reduced cortical thickness (Ranger et al., 2013), impaired thalamus development (Duerden et al., 2018; Schneider et al., 2018), reduced volume of subregions within the limbic system and basal ganglia at 8 years old (Chau et al., 2019), and reduction of white and gray matter volumes and reduced maturation evident to adolescence (Brummelte et al., 2012; Nosarti et al., 2002, 2008; Ranger et al., 2013). Impaired brain structure and function as a result of pain exposure in preterm infants has also been found to precipitate alterations in motor, cognitive, and behavioural development such as impairments in postnatal growth (Vinall et al., 2012), visual perceptual abilities at school age (Chau et al., 2019; Doesburg et al., 2013), early language outcomes (Chau et al., 2019; Vinall et al., 2015), sensitivity and response to subsequent pain exposure (Grunau et al., 2001, 2005; Hermann et al., 2006; Johnston & Stevens, 1996; Vinall & Grunau, 2014; Walker, 2019), and cortisol regulation due to alterations of the hypothalamic-pituitary-adrenal axis (Grunau et al., 2005). Additionally, depressive or anxious behaviours (i.e., internalizing behaviours) at 18 months corrected age has been linked with increased exposure to early pain and found to remain beyond school age (Ranger et al., 2013, 2014; Vinall & Grunau, 2014; Walker, 2019).

Behavioural and cognitive outcomes from exposure to pain in early life with the preterm population can also be influenced by certain genotypes thus, further investigation is required to gain greater understanding of these complex interactions (Chau et al., 2019; Walker, 2019).

2.1.2 Healthy, Full Term Infants

Implications of pain exposure in healthy, full term infants have not yet been studied as extensively as the preterm population, however current evidence suggests that early, untreated pain is associated with heightened pain responses to subsequent painful events (Taddio & Katz, 2005). This was found in studies that evaluated pain experienced by healthy, full term infants from circumcision (Taddio et al., 1997; Taddio, Goldbach, et al., 1995), burns (Wollgarten-Hadamek et al., 2009), major surgery (Andrews & Fitzgerald, 2002), and repeated acute pain (Gokulu et al., 2016; Piira et al., 2007; Taddio et al., 2002; Taddio, Shah, et al., 2009)

Taddio and colleagues evaluated the consequences of pain experienced from circumcision in newborn males in 1995 and 1997. Their initial study evaluating 42 full term infants who did not receive any treatment for pain during circumcision, found that these infants demonstrated an increased pain response at their 4 and 6 month immunizations compared to infants who had not received a circumcision (Taddio, Goldbach, et al., 1995). Due to a low sample size the authors cautioned the interpretation of these results and conducted another study to further evaluate the effects of circumcision pain on later pain response (Taddio et al., 1997; Taddio, Goldbach, et al., 1995). Their second study evaluated three cohorts of newborns (n=87); infants who do not have a circumcision or infants who either received a circumcision with topical anesthetic treatment (i.e., lidocaine and prilocaine ointment) or a placebo. Pain response was evaluated on three behavioural outcomes measures including facial grimacing, crying time, and visual analog scale (VAS) scores during the 4 and 6 month immunizations. Overall, an increased pain response was found for the circumcised infants

compared to infants who had not been circumcised, yet with significantly lower VAS scores for the circumcised infants who received topical treatment compared to the placebo cohort (Taddio et al., 1997). Given that uncircumcised infants did not demonstrate a heightened pain response for subsequent procedures, the findings from this study supports the recommendation to either limit procedures when possible or ensure pain management has been used accordingly (American Academy of Pediatrics Committee on Fetus and Newborn, 2016; Taddio & Katz, 2005; Walker, 2019).

The relationship between exposure to burns in infancy at 6-24 months old and later pain response was evaluated by (Wollgarten-Hadamek et al., 2009). When compared with children who had no prior injuries or hospitalization, the children who experienced moderate pain in infancy demonstrated heightened responses to mechanical pain stimuli including higher pain detection thresholds and pain perceptual sensitization, and lower pain tolerance (Wollgarten-Hadamek et al., 2009). Later pain response was also evaluated in three studies with infants who experienced surgery in early life (Andrews & Fitzgerald, 2002; Peters et al., 2003; Schmelzle-Lubiecki et al., 2007). Andrews and Fitzgerald (2002) evaluated sensitivity to pain stimuli for infants who received abdominal surgery compared to infants who had not endured surgery, finding sustained hypersensitivity over 24 hours immediately post-operative. However, hypersensitivity was not found to persist beyond the acute post-operative period in Schmelzle-Lubiecki and colleagues (2007) study exploring pain sensitivity of children who had experienced cardiac surgery in infancy. Similarly, there was no difference between infants who experienced surgery early in life and the control across behavioural and physiological pain responses during immunizations (Peters et al., 2003).

Healthy, full term infants commonly experience repeated acute pain as a result of needle-related procedures including heel lance and venipuncture. Taddio and colleagues (2002) explored the effects of repeated procedures on pain response with infants of mothers with diabetes (n=21) who required close monitoring of blood glucose levels via heel lance. Compared to infants with no to little pain exposure (n=21), infants who endured multiple heel lances demonstrated statistically significantly higher facial pain response when their skin was initially cleansed and during the procedure, while also higher crying time percentage and VAS pain scores (Taddio et al., 2002). While the authors urge the results to be interpreted with caution because of the low sample size, findings suggest infants with high exposure to pain in early life exhibit an anticipatory response and elevated pain during procedures (Taddio et al., 2002). Building on this, Taddio and colleagues (2009) conducted a randomized controlled trial evaluating the effect of 24% oral sucrose on a similar infant population. Infants were randomized to receive sucrose for every painful procedure experienced during the study period and pain response was evaluated using the Premature Infant Pain Profile (PIPP), percentage of crying time, and VAS pain measures. Their findings were similar to the previous study, whereby infants with high exposure in early life demonstrated statistically significant higher scores on the PIPP and VAS measures compared to infants with little pain experience (Taddio, Shah, et al., 2009). When comparing infants who received sucrose for procedures, sucrose did not appear to mitigate consequences from repeated procedures as there was no difference found between infants with high pain exposure and those without (Taddio, Shah, et al., 2009). Piira and colleagues (2007) found an association between higher pain response as measure by the Neonatal Facial Coding

Scale during venipuncture and high exposure to procedures within the first four days of life. Similarly, Gokulu and colleagues (2016), using bio-behavioural measures and the Neonatal Infant Pain Scale (NIPS), found significantly higher pain responses during the newborn metabolic screening when comparing between infants deemed large for gestational age who endured five or more painful procedures and healthy full-term infants. In contrast, Ozawa and colleagues (2011) did not find a significant difference in pain response during venipuncture across various behavioural and neuro-physiological pain measures when comparing between infants with high exposure to painful procedures and with no pain experience.

While fewer studies have evaluated the effects of procedural pain in full term infants, current evidence supports the need to establish policies requiring routine pain management for all painful procedures for this population until further research has been conducted.

2.1.3 Vaccine Hesitancy

Injection pain has been documented as one of the primary reasons that parents hesitate to vaccinate their children (Kennedy et al., 2011; Parvez et al., 2010; Taddio et al., 2007, 2013; Taddio, Ilersich, et al., 2009). In a study assessing the attitudes of parents in the United States related to vaccinations, the most common concern identified by parents was pain during the procedure (Kennedy et al., 2011). Parents in this study ranked pain as a concern more frequently than the concerns related to misinformation of acute and long-term effects that have been widely publicized including vaccines causing development conditions (e.g., Autism Spectrum Disorder) (Kennedy et al., 2011). Parents and clinicians alike have reported deviating from vaccination schedules to avoid infant

pain and distress experienced from multiple injections (Abbotts & Osborn, 1993; Askew et al., 1995; Gonzalez et al., 1989; Harrington et al., 1999, 2000; Madlon-Kay, 1994; Roberts et al., 1995; Samad et al., 2006; Taddio, Ipp, et al., 2012; Woodin et al., 1995). Untreated pain in children has been found to increase anticipatory fear of subsequent procedures due to the memories associated with the negative experience (Noel et al., 2012; Taddio, Ipp, et al., 2012; Vinall et al., 2018). Moreover, untreated pain during needle-related procedures in childhood has been associated with needle phobia (McMurtry et al., 2015; Taddio et al., 2010; Taddio, Ilersich, et al., 2009). Needle phobia has been found to increase the likelihood for avoidance behaviours related to seeking necessary and elective health services (Nir et al., 2003), including immunizations, that persists into adulthood (Wright et al., 2009). In 2012, Taddio and colleagues explored the relationship between needle fears in parents and children and non-compliance of vaccinations finding that, out of 883 Canadian parents and 1024 children, 24% and 63% reported a fear of needles, respectively (Taddio, Ipp, et al., 2012). This study also found a statistically significant relationship between non-compliance of vaccinations in parents and children due to their fear of needles, with 5% of parents reported delaying or avoiding at least one immunization for the same reason (Taddio, Ipp, et al., 2012). In this same cohort, when attitudes about vaccination pain management was assessed, 60% of parents disagreed that pain did not require treatment because it was a normal part of the procedure and 84% of parents believe healthcare providers should help reduce pain during vaccinations (Taddio, Ipp, et al., 2012). While the relationship between untreated pain from needle-related procedures, needle fear, and vaccine compliance is complex and requires further evaluation, there appears to be consensus across the literature that

adequate pain management during immunizations is a critical first step towards addressing vaccine hesitancy in parents and children (Lafnitzegger & Gaviria-Agudelo, 2022).

2.2 INFANT PROCEDURAL PAIN MANAGEMENT

While preterm and healthy, full term infants may differ in physiological and neurological adverse responses to pain exposure, the treatment of acute pain is the relatively consistent across all newborns. Consensus guidelines have been developed across national bodies to increase the use of evidence informed infant pain assessment and management across clinicians in all health settings (American Academy of Pediatrics Committee on Fetus and Newborn, 2016; Barrington et al., 2007).

2.2.1 Pharmacological Interventions

A variety of pharmacological interventions exist for pain experienced during procedures. Topical anesthetics have been found effective to reduce pain caused by some tissue breaking procedures such as venipuncture (Jain & Rutter, 2000), lumbar puncture and IV insertion (Kaur et al., 2003; Moore, 2001). These anesthetics have not been found to reduce pain associated with heel lancing procedures. One postulation of this is that the primary pain stimulus is related to the pressure from healthcare providers squeezing the heel for blood droplets (Jain et al., 2001; Lindh et al., 1999; Stevens et al., 1999). Dorsal penile nerve block (DPNB) and eutectic mixture of analgesics (EMLA) were found to reduce infant pain response during circumcision compared to a placebo, with greater effects demonstrated from DPNB, however both treatments did not completely reduce infant pain (Brady-Fryer et al., 2004). Moreover, a recent systematic review of eight randomized controlled trials that evaluating the effectiveness of topical anesthetics

(n=506 preterm and full term infants) found insufficient evidence to definitively support its use for needle-related procedures (Foster et al., 2017). Thus, further investigation is needed to evaluate the use of topical anesthetics for pain management in infants. Similarly, Ohlsson and Shah (2016) were not able to determine effectiveness of acetaminophen for procedural pain management in newborns based on insufficient evidence from nine studies (n=728 preterm and full term infants). Findings from a recent trial evaluating the analgesic effect of oral morphine for infants born preterm or with a low birth weight (i.e., <1501g) found no statistically significant difference in pain response during heel lance or eye examination when compared to the placebo (Hartley et al., 2018). Also, infants in this study experienced respiratory adverse effects such that recruitment was discontinued (Hartley et al., 2018). While regional anesthetics and analgesics, including acetaminophen and opioids, are routinely used to reduce procedural pain, there are still concerns related to the safety and efficacy of these interventions in newborns thus warranting greater use of effective non-pharmacological interventions, when applicable (Hall & Anand, 2014).

2.2.2 Sweet Tasting Solutions

Sweet tasting solutions have been widely evaluated as a treatment for pain reduction and is believed to be effective for its influence on endogenous opioid pathways in infants (Blass et al., 1994). Sucrose is one of the leading treatments for acute pain in terms of focus in research over the last three decades and current use in practice (Bueno, Ballantyne, Campbell-Yeo, et al., 2023; Bueno, Ballantyne, Campbell-Yeo, et al., 2023; Stevens et al., 2016; Yamada et al., 2023). Effectiveness of this sweet oral solution as an intervention for infant procedural pain has recently been evaluated in a meta-analysis

(Stevens et al., 2016). Based on data from 74 randomized controlled trials (n= 7049 neonates), findings from their Cochrane systematic review report that oral sucrose is an effective treatment for infant pain caused by single procedures (Stevens et al., 2016).

Specifically for heel lance procedures with preterm and full term neonates, a 2023 Cochrane systematic review evaluated 55 randomized controlled trials (n= 6273 neonates) to assess effectiveness of sucrose for pain management (Yamada et al., 2023). Yamada and colleagues (2023) found moderate evidence supports that sucrose (20-30%, 0.1-2mL; with or without pacifier for non-nutritive sucking [NNS]) reduces pain scores (i.e., Premature Infant Pain Profile [PIPP] and Neonatal Infant Pain Scale [NIPS] validated instruments) during single heel lance procedure when compared to controls (i.e., water, placebo, no intervention). This review found great uncertainty in the evidence when sucrose with and without NNS was compared to NNS alone, as well as sucrose compared to breastfeeding, laser acupuncture, facilitated tucking (Yamada et al., 2023). Currently there is moderate to high-quality evidence that suggests sucrose given orally (0.1mL or 2mL) or in combination with a pacifier for NNS is effective in reducing behavioural pain response experienced by heel lancing procedures, venipuncture and intramuscular injections in preterm and full term infants (Pillai Riddell et al., 2023; Stevens et al., 2016; Yamada et al., 2023). For heel lance procedures in neonates, Stevens and colleagues (2018) conducted a prospective, multi-center randomized controlled trial exploring the effectiveness of commonly delivered dosages of 24% oral sucrose, including 0.1mL, 0.5mL, and 1.0mL. Their study found no significant difference on PIPP-R (i.e., Premature Infant Pain Profile- Revised) pain scores across dosages, thus determined that the lowest dose that remains effective as an analgesia is 0.1mL of 24%

oral sucrose (B. Stevens et al., 2018). A recent longitudinal study explored the sustained effectiveness of 24% oral sucrose for needle-related procedures (e.g., heel lance, IV insertion) at four different time points during hospital stays in the NICU (Bueno, Ballantyne, Campbell-Yeo, et al., 2023). Using PIPP-R, Bueno and colleagues (2023) found low pain scores suggesting that 0.12mL of 24% sucrose remains effective as analgesia for subsequent procedures in preterm populations (i.e., born less than 32 weeks gestation).

Additional common solutions with varying degrees of sweetness that have been used to provide pain relief include glucose, fructose, and lactose (Bueno et al., 2013; Harrison et al., 2010). Bueno and colleagues (2013) synthesized data from 38 studies evaluating the effectiveness of these sweet tasting solutions on procedural pain experienced by preterm and full term neonates (n= 3785 infants). With the majority of studies evaluating glucose (n=35), this review was able to meta-analyze study findings, reporting that 1-2ml of 20-30% oral glucose is effective in reducing infant pain response for single heel lance and venipunctures, and suggest potential analgesic effects for other needle-related procedures (i.e. subcutaneous injections, intramuscular injections) and pharyngeal suctioning (Bueno et al., 2013). Non-nutritive sucking, breastfeeding, or skin-to-skin contact have also been found to augment the effects of glucose for pain reduction during heel lances for preterm and full term populations (Bueno et al., 2013).

Out of the possible sweet tasting solutions used for procedural pain, sucrose and glucose have been evaluated more frequently and are reported to be more effective than other solutions with less sweet content (Harrison et al., 2010; Harrison & Bueno, 2023). The analgesic effect of sweet tasting solutions may decrease in older infants beyond the

neonatal period (Harrison et al., 2010) and currently more evidence is required to evaluate its effectiveness in the pediatric population (i.e., children ages 1-4 years) (Harrison, Yamada, et al., 2015). Sweet tasting solutions were not found to be effective analgesia for more invasive procedures including circumcision or eye examinations for retinopathy of prematurity in systematic reviews by Stevens (2016), Bueno (2013) and Harrison (2010). When compared with breastmilk alone, sucrose was found to be more effective in reducing procedural pain in infants thus suggesting that if breastfeeding is not available, sucrose should be administered prior to and/or during needle-related procedures (Stevens et al., 2016). This evidence is important to consider with health institutions that have designation from the Baby Friendly Initiative (BFI), originally developed by WHO and UNICEF in 1991, and have committed to support breastfeeding. However, administering sucrose instead of breastmilk provides the most analgesic effect and still adheres to the International BFI Code as sucrose is not used as a supplement for nutrition or feeding (WHO, 2009).

Many facets related to sweet tasting solutions as analgesia will be better understood from further investigation including optimal dose, efficacy for repeated painful procedures, and long-term outcomes related to treatment (Bueno, Ballantyne, Campbell-Yeo, et al., 2023; Harrison et al., 2010; Stevens et al., 2016, 2018; Taddio, Shah, et al., 2009). However, sufficient evidence supports that sweet-tasting solutions should currently be considered as standard care, when breastfeeding is not available, during needle-related procedures (Bueno, Ballantyne, Campbell-Yeo, et al., 2023; Campbell-Yeo, 2016; Harrison et al., 2010; Stevens et al., 2016; Yamada et al., 2023).

2.2.3 Nonpharmacological Interventions

Breastfeeding and breastmilk

Breastfeeding offers a multidimensional treatment for procedural pain (Harrison, Reszel, et al., 2016; Shah et al., 2023). Recently there have been multiple evidence syntheses exploring the analgesic effect of breastfeeding or expressed breastmilk for acute pain from procedures including, but not limited to, venipuncture, heel lance, and intramuscular injection in newborns (Benoit et al., 2017; Shah et al., 2023), as well as focused on intramuscular injections given in infancy after the neonatal period (i.e., first 28 days of life) (Harrison, Reszel, et al., 2016). In a review conducted by Benoit and colleagues (2017), breastfeeding during a painful procedure was found to be more effective than swaddling, maternal holding or skin-to-skin contact, topical anesthetics, cooling sprays, non-nutritive sucking, music therapy, placebo, or no intervention, and was as or more effective than sucrose. The most recent Cochrane systematic review by Shah and colleagues (2023) assessed 66 studies exploring the effectiveness of either breastfeeding or breastmilk as pain management in neonates. While there is variable certainty of the evidence, the review findings cautiously suggest that breastfeeding may reduce procedural pain when compared to no intervention, holding by mother, SSC, bottle feeding with expressed breastmilk, sucrose or glucose (20%-30%), rocking, heel warming, music, topical anesthetics (i.e., EMLA cream), swaddling, swaddling and holding combined, non-nutritive sucking, and positioning (Shah et al., 2023). The majority of studies that examined expressed breastmilk found it to be no more effective than sweet tasting solutions for reducing procedural pain in both full term and preterm infants (Benoit et al., 2017; Shah et al., 2023). This is believed to occur as breastmilk alone is not comparable to concentrated sweet tasting solutions, such as 24% oral sucrose

(Joesten et al., 2007), and additionally expressed breastmilk does not provide the same multisensorial effect as direct breastfeeding in relation to maternal closeness (Matthiesen et al., 2001; Nelson & Panksepp, 1998), sucking (Anseloni et al., 2004; Carbajal et al., 2005), skin-to- skin contact (Johnston et al., 2017), and olfactory stimulation by the mother (Marlier et al., 1998; Rattaz et al., 2005; Schaal et al., 1998; Varendi et al., 1998). When compared to no intervention or water, expressed breastmilk may reduce pain responses including heart rate and crying duration (Shah et al., 2023).

From the Cochrane systematic review by Harrison and colleagues (2016), data from 10 studies (n= 1066 infants beyond neonatal period) found that breastfeeding reduced cry time and behavioural pain scores during vaccination compared against cuddling, oral glucose, topical anaesthetic, massage, cooling sprats, oral water, and no treatment (Harrison, Reszel, et al., 2016). As evidenced by these reviews, when feasible, breastfeeding is an effective non-pharmacological treatment for acute procedural pain from heel lance, venipuncture, and intramuscular injections. Benoit and colleagues (2017) postulate that breastfeeding is the preferred analgesic for full term infants given its effect on pain coupled with various additional health benefits, however effectiveness for subsequent procedures has not yet been determined (Shah et al., 2023).

Skin-to-skin contact

Like breastfeeding, skin-to-skin (SSC) contact also provides multisensorial stimulation through systems related to maternal closeness (Campbell-Yeo et al., 2011). Skin-to-skin contact, when an infant is placed directly on the chest of their parent, acts as an effective pain-relieving treatment that simultaneously enhances family-centred care as well as overall infant and parent wellbeing (Campbell-Yeo et al., 2015; Jones &

Santamaria, 2017). The idea for the use of SSC for pain management stemmed from its efficacy in increasing the time infants spent in a quiet sleep state which in itself is related to decreased pain response (Grunau & Craig, 1987; Kostandy et al., 2008; Ludington-Hoe et al., 1992; Ludington-Hoe & Al., 2006; Michelsson et al., 1996; Stevens et al., 1996).

Throughout nearly two decades of research focusing on SSC as an intervention for procedural pain in full term and preterm infants, SSC has been found to be a safe and effective method for pain relief during procedures by numerous evidence syntheses exploring non-pharmacological interventions for infant procedural pain management (Campbell-Yeo et al., 2011; Cignacco et al., 2007; Johnston et al., 2017; Pillai Riddell et al., 2023; Warnock et al., 2010; Yamada et al., 2008). A dose of SSC of 30 minutes was reported as more effective across pain indicators when compared against alternative durations (Cong et al., 2011, 2012), however further investigation is required before a conclusive dose can be determined. The most recent Cochrane systematic review on SSC for procedural pain in infants evaluated 25 studies (n=2001 infants) that demonstrated SSC alone is more effective in reducing bio-behavioural pain response compared to usual care or even sucrose. Additionally, SSC was found to provide benefits specifically in the full term population when used in combination with breastfeeding or a sweet tasting solution (Johnston et al., 2017).

Facilitated tucking

Facilitated tucking is an additional non-pharmacological method of pain management in infants. It is practiced during painful procedures when a care provider gently puts their hands on the infant's head and lower limbs to contain the infant in a

flexed position. Facilitated tucking can be provided by nurses or parents (Axelin et al., 2006, 2010) of both healthy, full term and preterm infants, however, is more commonly used in the preterm population. In a recent Cochrane systematic review evaluating non-pharmacological interventions for procedural pain in infants, Pillai Riddell and colleagues (2023), found that facilitated tucking may be an effective intervention for reducing infant pain reactivity (i.e., responses directly after painful stimulus; 12 studies, n=733) or immediate pain regulation (i.e. the initial pain response period; 10 studies, n=557) in preterm neonates who received facilitated tucking alone (Pillai Riddell et al., 2023). Facilitated tucking may reduce pain reactivity in healthy, full term newborns with the hepatitis B vaccinations (1 study; n=60) (Kucukoglu et al., 2015). The efficacy of facilitated tucking for pain treatment is based on low to very low certainty of evidence and limited research exists exploring this strategy with full term infants (Pillai Riddell et al., 2023).

2.3 PARENT-LED PAIN MANAGEMENT

From the interventions described in the previous section it is evident that parents have an important role as a direct provider or advocate for infant procedural pain management. Protecting their infant from harm is an instinctual response from parents but often they are separated from their infant to be cared by health professionals or parents are not fully equipped with the knowledge and skills needed to become involved in pain management (Campbell-Yeo et al., 2008; Franck et al., 2012; Ullsten et al., 2021). However, family-integrated care (FICare), an extension of family-centred care, is increasingly being adopted internationally as a philosophy and practice model emphasizing the importance of partnerships among healthcare professionals and families

in healthcare systems. Noteworthy for promoting health and well-being, FICare aims to empower families by keeping them together, acknowledging the family as an expert in their care and including them in all aspects of decision-making and care (Benzies, 2016; Franck et al., 2020). Adopting the FICare in NICUs has shown to improve health outcomes for infants (i.e., weight gain, duration of receiving breast milk) and parents (i.e., low maternal stress and anxiety) (Franck et al., 2020).

While there is not yet clear epidemiological evidence reporting on the frequency of parental involvement in infant pain management, many studies evaluating educational resources on infant pain management assess parents' prior involvement in pain management to determine if the educational resource influences parental behaviour. Out of a sample of these studies, parental involvement in pain management in preterm and healthy, full term populations ranged from 2% to 72% of parents that reported using either sucrose, breastfeeding, or skin-to-skin contact to provide pain relief during procedures (Bueno et al., 2018; Campbell-Yeo et al., 2017; Harrison et al., 2017; Harrison, Wilding, et al., 2016; Venegas et al., 2019). However, given the heterogeneity of these studies and potential for confounding factors, reliable data on the frequency of parental involvement in pain management remains unknown.

2.3.1 Benefits

Parental involvement in preterm infant care has been shown to reduce parental stress and anxiety, increase their sense of competency as caregivers and enhance their attachment to their infant (Feeley et al., 2013; Franck et al., 2011, 2012; Heinemann et al., 2013; Jiang et al., 2014; Martel et al., 2016; Russell et al., 2014; Skene et al., 2012). Additionally, preterm infants demonstrated enhanced motor development, decreased

infant stress, and less irritability upon handling (Reynolds et al., 2013) when parents were more involved. Similarly, studies evaluating parental involvement with pain relieving interventions in the healthy, full term population suggests positive parental and neonatal outcomes, including decreased parental stress and decreased infant pain response (Johnston et al., 2017; Pillai Riddell et al., 2023; Shorey et al., 2016). Moreover, specific parent-led pain management techniques, such as breastfeeding, have been found to improve infant pain response indicators including heart rate, cry duration, behavioural facial response, as well as lower scores on validated infant pain assessment tools for both preterm and term infants (Benoit et al., 2017; Shah et al., 2023).

2.3.2 Harms

Although certain pain management interventions may be contraindicated depending on the infant's condition, such as a preterm infant who is unable to breastfeed, there are various effective interventions that can be used as an alternative. Psychological harm is possible, as some parents report experiencing distress when invited to be involved with pain management, and thus they prefer not to be present during painful procedures (Axelin et al., 2010; Franck et al., 2012). However, parents who feel this way reported still wanting to help their infant. Parent-led pain management (PLPM) encompasses parents directly providing pain relief through non-pharmacological interventions (e.g., breastfeeding, SSC) and advocating for treatment if they are unable (e.g., 24% oral sucrose) and thus, should be involved in any discussions related to pain management (Axelin et al., 2010).

2.3.3 Parental opinions on pain management

In a study exploring parents' perceptions of infant pain in the NICU, parents described that they felt various emotions including sadness, frustration, and guilt when their baby experienced pain (Gale et al., 2004). The authors attributed these strong emotions to parents being unprepared for infant pain, further perpetuated by parents feeling isolated from staff when seeking information about pain management (Gale et al., 2004). This finding was echoed in a study by Franck and colleagues (2012) that explored NICU parents' perceptions and feelings related to infant pain management. Additionally, some parents in this study expressed concern that their child may associate their presence with pain when they were involved with pain management or perceived pain management to be the healthcare providers responsibility. However, once these parents received information about the mechanisms of PLPM, more parents reported wanting complete involvement (Franck et al., 2012).

In a study exploring mothers experiences with their child during immunizations, mothers of children ranging from under two years of age to older than eight years (excluding newborns infants) have reported a preference in non-pharmacological interventions for pain, stating they feel more comfortable with providing pain relieving strategies such as breastfeeding, holding, or distraction ahead of medications (Parvez et al., 2010). However, their preference for non-pharmacological interventions has been attributed to a lack of confidence in pain assessment for their infants resulting in hesitation to implement pharmacological pain management (Parvez et al., 2010). In the same study, all mothers felt distressed during the event but tried to mitigate this by using non-pharmacological strategies for pain (Parvez et al., 2010). While it is a positive finding that all mothers tried to provide pain relief in some capacity, the authors of this

study emphasized that focused education and skill development is still needed to ensure parents use these strategies appropriately and consistently (Parvez et al., 2010). Parvez and colleagues (2010) suggest that comprehensive education aimed to further support parents' natural instinct to reduce pain during immunizations and increase awareness specifically regarding appropriate pain assessment and pharmacological management of pain should be targeted to healthcare providers and parents alike.

There is a paucity of literature describing parent's experiences with procedural pain management immediately postpartum in the healthy, full term population. To address that, in 2019 and 2020, we conducted a study using online surveys to gain understand of the postpartum experience for women in the Maritime provinces (i.e., Prince Edward Island [PEI], NS, and New Brunswick) (Dol, Hughes, et al., 2022; Dol, Richardson, Aston, et al., 2021; Dol, Richardson, Grant, et al., 2021). As part of that study, we also explored parental knowledge, involvement, and experience with newborn procedural pain management (*manuscript in progress*). Preliminary results from the 2019 survey suggested that mothers' have a moderate understanding of infant procedural pain management strategies, knowing that breastfeeding was an effective comfort strategy (89.8% of mothers) but fewer knew about the pain-relieving effects of sucrose (41.4%) (Richardson, Dol, et al., 2021). Previous use of pain management strategies varied with mothers reporting that they or their partners, if applicable, use skin-to-skin contact (84.8%), breastfeeding (65.6%) or oral sucrose (20.1%) (Richardson, Dol, et al., 2021).

2.3.4 Contextual factors

Offering PLPM during procedures has been recognized as a standard policy across various health settings globally (American Academy of Pediatrics Committee on

Fetus and Newborn, 2016; World Health Organization, 2015). Yet there are many contextual factors which influence pain experiences of infants receiving care in different settings, such as the NICU, postnatal units, or primary care centres. There are many complex factors in the NICU that act as either barriers or facilitators to parental involvement, including the environment, communication, family wellbeing, and parental knowledge and attitudes (Axelin et al., 2015; Franck et al., 2012; Palomaa et al., 2016; Pölkki et al., 2015). Many parents experience overwhelming fear due the foreign environment, health status of the infant, and complex technologies that may be used to support the infant (Skene et al., 2012). The NICU environment can be intimidating to someone who is unfamiliar with the setting and thus, parents often wait to be invited by the healthcare team to engage with their infants (Benzies, 2016; Flacking et al., 2012). Unless receiving education from the NICU healthcare team upon admission, it was found that parents remained unaware of their infant experiencing pain or that they even had the ability to help minimize pain (Franck et al., 2012; Skene et al., 2012). In instances where education is provided to parents, miscommunication can still arise between nurses and parents in which parents may not understand the how to appropriately deliver pain management (Pölkki et al., 2015). In addition to staff facilitating involvement, parents emotional state, the severity of their infants' condition, NICU setting, and external demands influenced the parents' ability to achieve their desired level of involvement (Franck et al., 2012). Outside of the NICU, while the environment or infant's health is less of a concern, parents in postnatal or primary care settings also often lack sufficient knowledge or confidence to initiate pain relieving interventions during procedures if healthcare providers do not engage parents (Parvez et al., 2010; Taddio et al., 2007;

Taddio, Ipp, et al., 2014; Ullsten et al., 2021). Healthcare providers may not invite parents to be involved for pragmatic reasons such availability of a parent, infant positioning for procedures, or presence of additional staff to support PLPM (Harrison, 2021; McNair et al., 2013). However, with advanced planning and consistent practice in these care settings, sufficient resources should be available to support successful involvement of parents during their infant's painful procedures (Harrison, 2021; McNair et al., 2013).

2.3.5 Parental learning needs

In 2012, Franck and colleagues explored parental attitudes related to infant pain management in the NICU setting. The participants in this study were included in a randomized controlled trial where the intervention group received an educational booklet on pain and comforting infants in the NICU and two visits from a nurse to facilitate use of the comfort techniques described in the booklet. The control group received two visits from a nurse who would prompt parents to share their experience on the NICU generally. Half of all included participants expressed what they wanted to know about infant pain. In the control group, parents identified learning needs included information about what caused infant pain, how infants experienced pain, if there were long-term effects associated with pain, how to assessment, prevent or treat infant pain in hospital and at home, and how parents could provide relief (Franck et al., 2012). Additionally, some parents requested information on how clinicians decide on appropriate pain management and why treatment is not consistently used in practice. As the booklet given to parents in the intervention group provided comprehensive information on infant pain manifestation, assessment, treatment, and how to partner with the NICU to facilitate pain relief, these

parents only identified wanting more information about long-term effects of pain and management at home. Findings from this study are consistent with other evidence supporting parents strong desire information about all aspects of infant pain and pain management (Franck et al., 2012; Gale et al., 2004; Taddio, Hogan, et al., 2012). Moreover, this study also provides substantial insight on specific content areas which should be included in the development of future parent-targeted educational resources about infant pain management in the NICU to meet parent's identified needs. While not yet assessed in parents of the healthy, full-term infant population, it should be assumed that these parents desire the same information and educational resources should be tailored to appropriately describe pain and pain management in healthy, full term infants.

2.3.6 Support for parental involvement in pain management

It is crucial that parents be properly supported by healthcare providers to be actively involved in their child's pain care and decisions making (Axelin et al., 2015; Franck et al., 2012; Palomaa et al., 2016; Ullsten et al., 2021). Nurses have been found to differ in professional beliefs and practice regarding partnering with parents in pain care. Some nurses report feeling that including parents increased their workload and prolonged the procedure (Axelin et al., 2015). While these nurses had difficulty relinquishing control, often their actions were well intended as they chose not to include parents to protect them from unnecessary harm by being present for their baby's painful procedure (Axelin et al., 2015). For nurses who regularly include parents in pain relieving activities, nurses believed this strengthened the trusting relationship between themselves and the parents, and enhanced parental role attainment (Axelin et al., 2015). There is evidence to support that being invited to be involved in pain management empowers

parents and reinforces the parenting role naturally aimed at protecting their child (Axelin et al., 2015; Franck et al., 2004; Gale et al., 2004; Gates et al., 2018; Skene et al., 2012). Yet passively waiting for healthcare providers invitation may not occur in all settings, especially if their beliefs are incongruous to partnering with families. Nurses have agreed that providing information on infant pain management would be beneficial to include in discharge teaching from postpartum units to prepare parents for future immunizations, but nurses also stated that this period in hospital provides an opportunity to reinforce parents' knowledge and skills with pain management (Taddio, Shah, et al., 2015). Offering education about newborn procedural pain management to parents at various timepoints (e.g. prenatally, postnatal on unit, and postnatally in clinics) using various methods (e.g. video, web-based, paper-based materials, etc.) should increase the likelihood that parents digest this information and are simultaneously supported by healthcare providers to apply this knowledge into practice (Jordan & Chambers, 2017; Taddio et al., 2013).

Educating parents on procedural pain management is essential beyond the long-term neurophysiological and behavioural consequences for untreated children, but also to mitigate the serious impact procedural pain has on population health. Addressing methods to reduce pain with parents has been shown to increase parental satisfaction specifically related to vaccines and enhances parents' trust with healthcare providers. Thus, leading to increased likelihood of adherence to vaccine schedules and overall enhanced wellbeing (Taddio, Ipp, et al., 2014). Acknowledging this, parent-targeted education about pain management becomes an essential component in the pursuit to meet nationwide goals of vaccination coverage in Canada by 2025 (Public Health Agency of

Canada, 2022). Parents typically make decisions related to their plan for vaccinations during pregnancy (Vannice et al., 2011) suggesting that the prenatal period would be an optimal time to deliver education specifically related to procedural pain management strategies that emphasize the active parent role and partnership with healthcare providers.

2.3.7 Summary of infant pain

Given the consequences of untreated pain on newborns it is essential to further develop this field of research and explore innovative methods to establish procedural pain management practices consistently across health settings. Infant pain management can be implemented in a variety of ways, many of which include interventions that are directly provided by parents. As previously discussed, breastfeeding, skin-to-skin care, and sweet tasting solutions are considered to be the leading interventions against infant procedural pain, yet often parents do not have sufficient information or support to use these strategies. While there are many complex contextual factors that can influence utilization of parents as a resource for pain management, the literature suggests that ultimately parents want to be informed about infant pain and involved in decisions about management. Efforts continue to be made to understand parental perceptions of pain management for procedures in the NICU and for immunizations yet there is a dearth of literature related to parents of healthy, full term infants with routine needle-related procedures in the immediate postpartum period. To mitigate negative consequences of untreated procedural pain in this population as well, more investigation on the experiences of parents of healthy newborns is warranted.

2.4 PARENT-TARGETED EDUCATIONAL RESOURCES ON INFANT PAIN

2.4.1 Pain education during the perinatal period

Knowledge is power (Bacon, 1597). This famous phrase rings true when applied to parents who have been taught about infant pain and pain management. When provided with essential information on infant pain management, parents have been empowered to actively provide or advocate for pain relieving strategies in painful procedures (Gates et al., 2018; Taddio, Ipp, et al., 2014). While healthcare providers are situated well to provide verbal instruction to parents in perinatal and public health centres (Taddio, McMurtry, et al., 2015), a range of educational techniques are often used in healthcare to maximize knowledge uptake across all learning styles (Collins, 2004). To gain insight on educational techniques used with this population, our team conducted a scoping review that identified available educational interventions about infant procedural pain targeted to parents throughout the perinatal period (Richardson et al., 2020). In this scoping review, our team gathered evidence on the types of parent-targeted educational interventions that exist, implementation strategies used, and common outcomes measured (Richardson et al., 2020). In brief, the results of this review have been summarized below.

2.4.2 Available educational resources on infant pain

Despite parent-led interventions being widely recognized to reduce pain (Benoit et al., 2017; Johnston et al., 2017; Obeidat & Shuriquie, 2015), only nine studies were found that reported on, described or evaluated parent-targeted educational interventions on infant pain and management strategies during the perinatal period (Richardson et al., 2020). Of those, five studies targeted parents of full term infants who were in hospital receiving immediate postnatal care (Smart et al., 2012; Taddio et al., 2013; Taddio, Ipp, et al., 2014; Taddio, Parikh, et al., 2014) and only one evaluated an educational intervention that was delivered prenatally in the community (Taddio, Smart, et al., 2014).

These interventions were implemented through written materials only (i.e., factsheets) (Smart et al., 2012; Taddio, Ipp, et al., 2014) or written combined with either pictorial information, verbal discussion, demonstration, and/or video education (Taddio et al., 2013; Taddio, Parikh, et al., 2014; Taddio, Smart, et al., 2014). Beyond video education, no studies included alternative eHealth components to their intervention. In an era where information consumption occurs predominantly on the Internet or through smart devices (Gates et al., 2018) utilizing digital media facilitates increased accessibility and knowledge uptake. Scoping reviews do not typically evaluate the impact of interventions however, based on our review, parental knowledge about infant pain was found to increase across all studies, as well perceived self-efficacy (Taddio et al., 2013; Taddio, Ipp, et al., 2014) and parental involvement or intention to be involved in subsequent painful procedures were found to increase after exposure to the educational intervention (Skene et al., 2012; Smart et al., 2012; Taddio et al., 2013; Taddio, Ipp, et al., 2014; Taddio, Parikh, et al., 2014; Taddio, Smart, et al., 2014). Additionally, the one intervention delivered prenatally was found to have sustained efficacy in utilization of PLPM interventions at their 2-month immunization appointment (Taddio, Smart, et al., 2014) whereas no difference in PLPM for this appointment was found for two studies that implemented the educational intervention in the postpartum period.

This scoping review provided an opportunity to better understand the current gap in consistent newborn pain practice from parents' perspective. Although Taddio and colleagues have made significant contributions to the field of infant procedural pain, their work is largely focused on increasing pain management during immunizations which does not account for all of the painful procedures an infant must endure before their

vaccination schedule. This review found that the majority of educational interventions were delivered postnatally during a critical period of physical and psychosocial transition for parents, and often occurred during the brief hospitalization period for postpartum care. Given the increased use of technology in healthcare delivery and trends in parental preference in accessing health information digitally (Orr et al., 2016; Sundstrom, 2016), it was surprising that this review did not retrieve more studies exploring eHealth approaches to their educational interventions. However, the eligibility criteria of this review restricted studies evaluating educational interventions outside of the perinatal period and consequently excluded two parent-targeted eHealth educational resources on parent-led pain interventions: *The Power of a Parent's Touch* (Campbell-Yeo et al., 2017) and *Be Sweet to Babies* (Harrison et al., 2017). These resources used YouTube as a platform for knowledge translation, providing parents with information in an engaging and widely accessible format. Accessible, multimodal tools, including YouTube videos, are considered as an emerging approach to education as portable and innovative formats to increase knowledge uptake across different learning styles (Collins, 2004; Gates et al., 2018; Taddio et al., 2013).

2.4.3 Summary of parent-targeted educational resources on infant pain

Parent-targeted education alone may not eradicate mismanagement of infant procedural pain as systemic factors that contribute to barriers to utilizing these in practice, such as limited resources of interventions (e.g., time, staff, sucrose, topical anesthetics). However, knowledge does give parents the power to advocate for their children which could either increase the use of non-pharmacological interventions, including SSC or breastfeeding, in clinical settings or lead to increased supply of

resources by voicing the need. Although significant strides have been made towards increased parent-targeted education about non-pharmacological and pharmacological interventions for procedural pain (Campbell-Yeo et al., 2017; Franck et al., 2012; Gates et al., 2018; Harrison et al., 2017; Taddio et al., 2013; Taddio, Parikh, et al., 2014), there is widespread consensus that additional research and development of sustainable parent-targeted knowledge translation tools are warranted.

2.5 PARENT-TARGETED PERINATAL EHEALTH EDUCATION

Parents increasingly report accessing the Internet when seeking more health information related to pregnancy, childbirth, infant care practices, and beyond (Aston et al., 2018; Guerra-Reyes et al., 2016; Kamali et al., 2018; Monaghan et al., 2020; Morton & Hsu, 2007; Orr et al., 2016). Many voice their preference in accessing perinatal health information on the Internet, often through their smartphones (Bensley et al., 2014; Gao et al., 2013; Kamali et al., 2018; Monaghan et al., 2020; Orr et al., 2016; Salonen et al., 2014; Tohotoa et al., 2008). Yet parents have also reported perceiving the Internet to be overwhelming and unreliable at times, limiting their ability to trust this platform as an information resource (Slomian et al., 2017). These concerns have been confirmed in recent literature where health information on the Internet has been found of poor to moderate quality (Dol et al., 2018; Fahy et al., 2014). Nevertheless, technology can enhance healthcare delivery, promote autonomy, and increase accessibility of information and support (Nagel et al., 2013). Thus, recognizing that this is how parents already gather health information and the potential eHealth technologies have in influencing positive health outcomes, reputable perinatal care areas have been developing eHealth interventions to enhance the parenting support needed (Aston et al., 2018; Darvill et al.,

2010; Seefat-van Teeffelen et al., 2011; Soltani et al., 2017). To date, there have been multiple published reviews evaluating various aspects of perinatal eHealth interventions including but not limited to eHealth resources available for parents with infants requiring intensive care (Anwar Siani et al., 2017; Dol et al., 2017), prenatal education (Daly et al., 2018), perinatal weight loss (Sherifali et al., 2017), and maternal psychosocial wellbeing (Dol, Aston, et al., 2022; Sprenger et al., 2017). The findings of these reviews suggest positive parental outcomes with utilization of perinatal eHealth resources. However, what is lacking from existing syntheses is a focused evaluation on the influence of implementation strategies on parental and infant outcomes, which will provide insight for the development of future perinatal eHealth resources. Thus, the lead researcher conducted a scoping review in 2018, as part of the comprehensive examination requirements for this dissertation, to identify available eHealth perinatal educational interventions and understand what implementation strategies were used to educate parents.

2.5.1 Synthesis of current perinatal eHealth educational resources

This scoping review identified 66 studies that evaluated the influence of parent-targeted eHealth educational interventions focused on promoting health and wellbeing during the perinatal period. The majority of identified studies were published in 2018, suggesting that perinatal eHealth education is rapidly emerging and that this review presented a timely analysis to build a foundation of knowledge on the implementation strategies. Evidence revealed that the movement towards utilizing eHealth in this population is being championed by the United States, with over half of the identified interventions being developed and evaluated in America. da Fonseca and colleagues

(2021) explored eHealth generally through a systematic review noting that there was a great increase in publications in 2019 (n=250) compared to 2014-2018 which averaged 39 publications per year. This systematic review also found the majority of eHealth research emerged from the United States which is credited to greater infrastructure and resources to support research interest and feasibility to pursue eHealth initiatives (da Fonseca et al., 2021). Two thirds of the studies included in the scoping review targeted mothers only, nearly 30% of the studies included both parents, when applicable, and 5% of studies targeted partners only. Many studies targeted parents of differing language, race, ethnicity and socioeconomic status, with two studies also explicitly addressed their eHealth intervention to be inclusive of same-sex parents (Abbass-Dick et al., 2017; Shahid & Johnson, 2018). While not the focus of the scoping review, it is worth highlighting that greater focus on co-parenting and increased recognition of unique family systems that are prevalent today is required to reduce barriers experienced specifically with perinatal eHealth resources (Richardson et al., 2018). In terms of the infant population identified in the included studies, the number of studies targeting full term and preterm infants were comparable; however, there were 24 studies that did not specifically disclose the gestational age at birth. This was speculated as a result of interventions that were implemented in the prenatal period and focused solely on parental outcomes. The theoretical frameworks identified by various studies were appropriately applied and found to align with the intentions of the eHealth interventions as behaviour change agents and promoters of self-efficacy. Use of theory and reporting intervention fidelity can support researchers to distinguish which mechanisms within an intervention influences its effectiveness, feasibility and sustainability in practice (Gearing et al., 2010;

Michie et al., 2014; Murphy & Gutman, 2012; Poorman et al., 2015). However, there were issues noted in the ability to monitor or control fidelity, as many of the parent-targeted interventions were self-directed and thus researchers were unable to completely standardize implementation, uptake, and usage.

2.5.2 Implementation strategies

One of the most notable benefits of eHealth interventions is enhanced accessibility to evidence-based health information and support. Accessibility continues to grow in importance, given increasing time demands for healthcare providers and patients, financial constraints, and overwhelming amount of information available from unreliable resources. Thus, unlimited remote access to evidence-based eHealth educational interventions is important. This scoping review found that over 80% of identified interventions were accessible to parents through their own devices and did not require travelling to a healthcare centre to receive education. Of those that were implemented in a healthcare centre, attention was paid to not increase the burden experienced by parents. Interventions were introduced while parents were attending prenatal care assessments or educational sessions, while in hospital receiving postpartum care or intensive care for their infant, as well as prior to regular postnatal assessments. All studies evaluating interventions that were administered in a clinic setting provided video education, where parents were given a private space and all necessary equipment to watch the intervention. If they were not finished reviewing the video prior to their appointment, parents were able to resume afterwards or given a DVD to finish at home. Parents found these interventions easy to use, deeming them to be acceptable and feasible resources by parents as well as clinic staff (Goodman et al., 2015; Hallas et al., 2015; Kellams et al.,

2016; Moon et al., 2017; Taşar et al., 2015). For interventions in the hospital setting, eHealth methods including video, web-based platforms, and mHealth apps were used. These interventions were reported to be useful in facilitating education and often were described by parents as an overall pleasant experience (Banerjee et al., 2018; Bueno et al., 2018; Jallo et al., 2017). In-hospital eHealth educational interventions are feasible resources that give parents access to more information which healthcare providers are not able to provide due to time constraints and workload demands. The remaining interventions were remotely accessible to parents through at least one of the eHealth methods identified in this review (i.e., websites, video, mHealth apps, text messaging, telehealth, simulation, or email). While there were specific interventions that received higher evaluations, most methods using remote access were deemed usable, acceptable and feasible by parents. Some concerns specifically related to functionality or educational content (Abbass-Dick et al., 2017; Jallo et al., 2017; Skar et al., 2018) were addressed however, parents still expressed acceptance of the interventions.

While remote access is important to reach a widespread audience, this can also be a critical limitation for eHealth interventions if members of the target populations do not have the necessary devices. As per 2018 data, 93.6% of Canadian have access to the internet at home of which 88.1% have a smartphone (Statistics Canada, 2019). When exploring the typical age range of the perinatal population, 97.9% of Canadians between the ages of 15-24 years have a smartphone with 97.1% between ages 25-44 years (Statistics Canada, 2019). While smartphone ownership is high in Canada, the digital divide is still prevalent as of 2018 with 24% of Canadians 15 years or older report having no or minimal internet usage (Statistics Canada, 2021b). While this limitation should not

hinder development or refinement of eHealth educational interventions, it is important to be cognizant of potential inequity and strive to mitigate potential barriers in access, which was identified across many of the studies included in this scoping review.

Effectiveness of an intervention was evaluated on timing of delivery in only one study, comparing implementation prenatally, 48 hours prior to discharge from the postpartum care unit, and 7 days post discharge (Taşar et al., 2015). The intervention was found to be significantly more effective on increasing maternal knowledge and improving behaviour when implemented prenatally or 7 days post discharge compared to 48 hours prior to discharge. Of those that received the intervention 48 hours prior to discharge, significantly less mothers found the intervention useful compared to the other groups. With limited evidence to support or contradict this finding, eHealth interventions could likely be more effective when implemented during those time points. Given the mass education currently being provided to this population, specifically in the fast-paced postpartum care unit environment, future research evaluating timing of intervention delivery is crucial.

2.5.3 eHealth methods

The studies included in this scoping review used a range of eHealth methods including web-based platforms, video, mHealth apps, text messages, telehealth, simulation, and email. Web-based platforms were the most common method of the identified implementation strategies. This method is consistent with how parents prefer to access health information and can provide comprehensive self-directed education that could employ a range of design variations, interactive components, and complementary visual or audio assets to support different learning styles (Lau et al., 2016). Additional

notable features that increased user satisfaction and acceptability were including a diary section, ability to input data which will display sequentially to facilitate monitoring, and the ability to share content through social media, text messages, or email (Biediger Friedman et al., 2018). Use of interactive components in eHealth education was found to increase parents' knowledge and feelings of support during the perinatal period (Connor et al., 2018; Danbjørg et al., 2015; De Graaf et al., 2013). Parents reported having the ability to access websites through their mobile device (e.g., smartphone) supported engagement. However, when websites were not designed to be adapted for mobile devices, there was lower user engagement and satisfaction noted which is consistent with contemporary web design principles (Wroblewski, 2011). Similar features can be applied to interventions delivered through mobile devices where apps or text messaging can offer comprehensive education conveniently available directly in their hands (Lupton & Pedersen, 2016; Wellde & Miller, 2016). Supporting the findings of this scoping review, da Fonseca and colleagues (2021) determined the most common eHealth delivery methods between 2014-2019 were mHealth, telehealth (i.e., video conference with practitioners through various devices such as smartphone, computer, tablet), or technology which was defined as access to consume health information online.

2.5.4 Impact of perinatal eHealth resources

Although scoping review methodology does not require an evaluation on the effectiveness of the interventions, this review aimed to gather preliminary evidence on the impact of eHealth educational intervention strategies on parental, infant and eHealth-related outcomes (The Joanna Briggs Institute, 2015). Parental outcomes of the reviewed studies primarily included behaviour (n=28), knowledge (n=19), or self-efficacy (n=15).

Studies reported on parental outcomes a total of 79 times, of which 72% reported a significant improvement because of the eHealth educational intervention. Infant outcomes were measured less across the studies included in this review through only breastfeeding exclusivity (n=6) and neonatal length of hospital stay (n=2). Studies reported on infant outcomes a total of 8 times, of which 75% reported a significant improvement as a result of the eHealth educational intervention. As for eHealth-related measures, studies reported outcomes that have been synthesized into five categories including satisfaction (n=19), acceptance (n=18), usage (n=16), technical experience (n=8), and feasibility (n=3). Studies reported on eHealth-related outcomes a total of 64 times, of which 72% reported a significant improvement as a result of the eHealth educational intervention.

All of the identified eHealth educational interventions were reported to either have a positive effect on parental, infant, and eHealth-related outcomes or result in no change. Of the most measured outcomes, findings suggest that the eHealth strategies employed to deliver perinatal education have the potential to improve parental behaviour, increase knowledge acquisition, enhance parental self-efficacy, and increase breastfeeding exclusivity (as applicable). This is further supported given the overall positive reports on eHealth-related outcomes. While significant improvements were found in approximately three quarters of the studies for parental, infant, and eHealth identified outcomes, there was little use of standardized measures thus limiting the ability to meta-analyze findings in future effectiveness syntheses. The issue of heterogeneity across studies has been prevalent in other evidence syntheses on the perinatal population in terms of general antenatal (Gagnon & Sandall, 2007) and postnatal education

(Bryanton et al., 2013), as well as specifically regarding perinatal eHealth interventions (Anwar Siani et al., 2017; Daly et al., 2018; Dol et al., 2017; O'Brien et al., 2014).

2.5.5 Summary of parent-targeted perinatal eHealth education

This scoping review provided a comprehensive evaluation of the impact of perinatal eHealth interventions on parental and infant outcomes, with a focus on intervention implementation strategies. The results of which suggests that eHealth interventions delivered prenatally, postnatally, or while in a healthcare centre can improve parental knowledge, self-efficacy, and infant care practices. Optimal timing of eHealth intervention delivery remains unclear as this review found only one study examining various time periods, thus further research is required. While the most effective implementation strategy of eHealth education interventions was not determined, key features of interventions that influenced usability, acceptability, and feasibility were highlighted which will inform future development of high quality, evidence-based eHealth educational interventions. The majority of interventions identified in this scoping review used a web-based platform and were found to increase parental knowledge, self-efficacy, and improve infant care practices. Web-based interventions were found to have the ability to utilize other identified eHealth methods (e.g., video, email) within one platform allowing for increased engagement from users with differing learning styles. Internet use, social media, and smartphone ownership rates in Canada continue to climb, suggesting that health education delivered through web-based platforms, mHealth apps, or text messaging could be effective and sustainable strategies (Statistics Canada, 2021a, 2023d). In light of this, the current evidence suggests that future eHealth interventions use a web-based platform, designed to be accessible by a computer, tablet or mobile

device, that employs high quality design elements and interactive components. An update of this scoping review exploring perinatal eHealth resources would be beneficial, especially in consideration of the dramatic shift to technology use during the COVID-19 pandemic and life after.

2.6 PARENT TARGETED EHEALTH EDUCATION ON INFANT PAIN

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Statement of manuscript contribution: BH conceived the review with input from MCY. KR, a librarian with Nova Scotia Health Authority, developed the search strategy for the systematic review and BH, BB (Assistant Professor, Rankin School of Nursing, St. Francis Xavier University) and JD (Postdoctoral Fellow, IWK Health) completed the systematic review process with support from MCY, as needed. BH drafted the review protocol and final review manuscript. BB, KR, JD, MCY, RMM, ML, MS, and PM contributed to revising the protocol and final review manuscripts. Copyright details can be found in the Chapter 2 Appendix.

2.6.1 Abstract

Objective: The objective of this review was to determine whether electronic health (eHealth) educational interventions about infant procedural pain and pain management impact parental outcomes (e.g., mental health, knowledge uptake), eHealth outcomes

(e.g., acceptance, use), and pain management outcomes (e.g., parental involvement, infant pain response).

Introduction: Pain in infants is a common concern for parents. Routine postpartum care for infants in early life requires them to endure painful procedures, such as immunizations, yet infants often receive little to no pain management. Parents are an essential component of effective pain management, although they may not be aware of the roles they play. Despite the increased number of eHealth resources available to educate parents about infant pain management, their impact has yet to be synthesized.

Inclusion criteria: This review considered studies that evaluated eHealth educational interventions targeted at parents during pregnancy and up to 1 year postpartum.

Interventions included, but were not limited to, mobile applications, web-based applications, websites, videos, interactive training, hands-on direct simulation, short message service (SMS), and desktop applications. Primary outcomes included parental outcomes (e.g., stress or anxiety, self-efficacy, knowledge, attitudes), eHealth outcomes (e.g., acceptance, use), and pain management outcomes (e.g., parental involvement, infant pain response). Experimental, quasi-experimental, and observational study designs were included.

Methods: MEDLINE, CINAHL, PsycINFO, Embase, Scopus, Web of Science, and SciELO were searched for studies published in English up to June 14, 2021. Citation lists of relevant reviews and included studies were also searched for additional peer-reviewed articles. Two independent reviewers conducted critical appraisal using standardized tools from JBI, and data extraction, using a data extraction form designed by the authors.

Statistical pooling of quantitative data was not possible due to heterogeneity; thus, the findings were reported narratively.

Results: A total of 4163 unique studies were screened, with 11 studies ultimately included for synthesis. Five articles were randomized controlled trials, 5 articles were analytical cross-sectional studies, and 1 article was quasi- experimental. Studies reported on 4 unique eHealth educational interventions, all of which used video format and primarily targeted the postnatal period. The findings for all primary outcomes were mixed but suggested either improvements in outcomes or no impact. The certainty of evidence was determined as low or very low across primary outcomes for reasons related to imprecision, risk of bias, and indirectness.

Conclusions: Although heterogeneity of findings limited quantitative synthesis of data, this review suggests that short and engaging educational videos have the potential to positively impact parents' knowledge, confidence, and desire to be involved in procedural pain management for their children. Most of the interventions presented in this review describe evidence-based information about procedural pain management strategies that are known to be effective for infant populations. Thus, it is reasonable to assume that infant pain response should be lower when parents appropriately apply the strategies. However, the findings of this review were not able to confirm this assumption. More research is needed to evaluate the impact of parent-targeted pain management education on infant pain response.

2.6.2 Introduction

During early life, routine postnatal care for infants includes tissue-breaking procedures, most notably, intramuscular injections to provide vitamin K or

immunizations and heel lancing to collect blood specimens to rule out metabolic disease, hypoglycaemia, or unconjugated hyperbilirubinemia. If an infant's health status is compromised, they may require additional painful procedures such as intravenous catheter insertion, venepuncture, suctioning, nasogastric tube placement, or tape removal (American Academy of Pediatrics: Committee on Fetus and Newborn et al., 2006). The importance of procedural pain management has been well established in neonatal research, yet still infants do not consistently receive effective pain-relieving treatment in clinical practice (American Academy of Pediatrics: Committee on Fetus and Newborn et al., 2006; Ullsten et al., 2021). When untreated, acute pain causes immediate pain and activates stress responses in infants, which can also lead to impairments in their neurodevelopment and behavior regulation (Grunau et al., 2006; Grunau & Tu, 2007; Hermann et al., 2006; Piira et al., 2007; Taddio et al., 2002; Taddio, Goldbach, et al., 1995; Taddio, Ipp, et al., 2014; Taddio, Shah, et al., 2009; Valeri et al., 2015).

Parental involvement during procedures, such as providing skin-to-skin contact or breastfeeding (Benoit et al., 2017; Johnston et al., 2017; Obeidat & Shuriquie, 2015; Ullsten et al., 2021), effectively reduces pain experienced during acute procedures. Although parents are concerned with how to protect their infants from pain or stress in early life (Franck et al., 2004, 2012; Orr et al., 2016; Ullsten et al., 2021), they often are not aware of their capacity with procedural pain management (Franck et al., 2012; Orr et al., 2016). Online search engines (e.g., Google) and social media (e.g., Facebook, Instagram) are often the first resources parents use when seeking health information (Hamm et al., 2013; Pretorius et al., 2019; Sundstrom, 2016), and this was true of parents of infants in the neonatal intensive care unit (NICU) who wanted to help their children

with pain relief (Orr et al., 2016). However, in reviews of online sources targeting parents with infants in the NICU, only 5.1% of websites retrieved through Google and 11.1% of mobile health (mHealth) applications (apps) contained any information related to infant pain (Dol et al., 2018; Richardson, Dol, et al., 2019). Although pain-related content on websites or mHealth apps targeting healthy, full-term infants has yet to be explored, it is assumed that there is limited information about infant pain management, as found with the NICU population, leaving parents with little opportunity to directly access this information.

For decades, electronic health (eHealth) has been a growing field that leverages information and communication technologies to facilitate delivery of health care services and accessibility of health promotive activities (Boogerd et al., 2015; World Health Organization, 2018). eHealth interventions can be developed as various formats including video conferencing, mHealth apps, web-based platforms, videos, interactive training, simulation, and short message service (SMS) (Boogerd et al., 2015). Credited with greater accessibility, promotion of health autonomy, and efficient information sharing, eHealth resources have increased in popularity and value from health consumers and practitioners alike (Dol et al., 2018; Fahy et al., 2014; Nagel et al., 2013). To support the journey through parenthood, eHealth interventions have been found to be a valuable approach to provide education on a spectrum of topics (Davis et al., 2017; Orr et al., 2016; Sampson et al., 2013). Unlimited access to eHealth resources gives parents the flexibility to learn at their own pace, which is important when their time is often consumed by competing demands, such as caring for children (Baumel & Schueller, 2016). Parents with infants in the NICU reported a preference to accessing the internet

with their smartphone when seeking information about their infant's health (De Rouck & Leys, 2009; Gabbert et al., 2013; Orr et al., 2016). Yet, there are concerns about the reliability and credibility of health information provided on websites or mHealth apps (Dol et al., 2018; Richardson, Dol, et al., 2019).

The quality and impact of parent-targeted eHealth resources has been reviewed in several recent syntheses (Anwar Siani et al., 2017; Davis et al., 2017; Dol et al., 2017; Richardson, Dol, et al., 2019); however, there are few reviews evaluating eHealth resources related to pediatric pain (Badawy et al., 2018; Connelly et al., 2018; Lalloo et al., 2017). In a scoping review of educational videos about pediatric needle-related pain management available through YouTube, Farkas and colleagues (2015) found that approximately 64% of videos targeted parents of infants or toddlers, but their effectiveness was not explored. In a multi-phased review evaluating pain-related mHealth apps, a total of 47 publications reporting on 34 pain-related mHealth apps were found, with 64.7% of the apps targeting adult pain and no apps focusing on acute pain experienced by children younger than 3 years (de la Vega & Miró, 2014). This review further explored the availability of mHealth apps, finding 283 pain-related apps listed in app stores across Canada, Spain, or the United States; however, none of apps were reported in the 47 reviewed publications (de la Vega & Miró, 2014). The discrepancy between empirical evaluation and accessibility of mHealth interventions is a common limitation across this field of eHealth (Lalloo et al., 2015; Masterson Creber et al., 2016; Owens et al., 2018; Richardson, Dol, et al., 2019; Tinschert et al., 2017). In recent evidence syntheses evaluating general eHealth interventions in the NICU, parents deemed the eHealth interventions to be acceptable and useful in the NICU setting (Dol et

al., 2017), and eHealth interventions were found to positively influence parental satisfaction, confidence, and knowledge uptake (Anwar Siani et al., 2017).

To date, there has been no systematic review concerning parent-targeted eHealth educational interventions specific to infant pain and pain management. The current review sought to address this gap in knowledge and provide a comprehensive analysis of the impact of parent-targeted eHealth educational interventions about infant procedural pain management on parental (e.g., mental health, knowledge uptake), eHealth (e.g., acceptance, use), and pain management outcomes (e.g., parental involvement, infant pain response). The following databases/sources were searched for existing systematic reviews on the topic, and no current or underway reviews were identified: PROSPERO, PubMed, Cochrane Database of Systematic Reviews, and JBI Database of Systematic Reviews and Implementation Report. With increasing need for parent-targeted eHealth interventions to disseminate infant procedural pain-related information, this review provides a timely synthesis of empirically evaluated resources.

2.6.3 Review questions

The primary objective of this review was to determine whether parent-targeted eHealth educational interventions for infant procedural pain and pain management impact parental, eHealth, or pain management outcomes.

- i) Do parent-targeted eHealth educational interventions for infant procedural pain and pain management impact parental outcomes, including stress or anxiety, self-efficacy, knowledge, and attitudes?

- ii) Do parent-targeted eHealth educational interventions for infant procedural pain and pain management impact eHealth outcomes, including usage and acceptance?
- iii) Do parent-targeted eHealth educational interventions for infant procedural pain and pain management impact pain management outcomes, including parental involvement with infant pain management and infant bio-behavioral pain response?

This review also considered whether parent-targeted eHealth educational interventions for infant procedural pain and pain management impact infant outcomes through the following question:

- iv) Do parent-targeted eHealth educational interventions for infant procedural pain and pain management impact infant outcomes, including neonatal morbidity, feeding, and length of stay in hospital?

2.6.4 Inclusion criteria

Participants: The review considered studies that included eHealth educational interventions targeted at expectant parents, or parents or primary caregivers of infants up to 1 year of age. Parents were defined as biological, adoptive, or foster parents. Studies with parents of infants born preterm or full term were included to ensure a comprehensive evaluation of all parent-targeted eHealth educational interventions specifically about infant pain management. Because the focus of this review was to evaluate parent-targeted educational interventions, studies or interventions targeting health care providers or community health workers were excluded.

Interventions: eHealth educational interventions included, but were not limited to, mobile applications, web-based applications, websites, videos, interactive training, hands-on direct simulation, SMS, and desktop applications. This review focused specifically on parents' experiences with infant procedural pain, thus interventions with content related to pain management for children older than 1 year were excluded. Studies that evaluated interventions that are solely for information collection (e.g., data collection) were also excluded because these do not contain any educational content.

Comparators: This review considered studies that compared the intervention to any comparator, including, but not limited to, standard care (e.g., education given to parents verbally by a health care provider), practice before intervention exposure (e.g., pre-post studies), or a control group receiving printed educational material.

Outcomes: To understand the impact of parent-targeted eHealth educational interventions, this review considered several primary outcomes. Outcomes of interest were originally described in the protocol (Richardson, Benoit, et al., 2019), as parental outcomes (mental health outcomes, knowledge outcomes, and parental involvement in care outcomes) and infant outcomes (morbidity outcomes, pain outcomes, and health system outcomes [i.e., length of hospital stay]). For greater clarity in reporting the findings in this review, the primary outcomes have been categorized as parental outcomes, eHealth outcomes, and pain management outcomes, described in detail below. Of the primary outcomes of interest identified in the protocol (Richardson, Benoit, et al., 2019), the parental outcome on parental stress and anxiety (defined as parents' experience of stress and/or anxiety) was not reported by any study included in this

review. The remaining primary outcomes were reported by at least one study and are described narratively in this review.

Primary outcomes

Parental outcomes:

- Parental stress and anxiety, defined as parents' experience of stress and/or anxiety.
- Parental self-efficacy or confidence, defined according to each study, measured by self-report questionnaires immediately post-intervention and control exposure, as applicable.
- Parental knowledge, defined according to each study, measured by self-report questionnaires or other measures as reported by each study (e.g., true/false) pre- and post-intervention and control exposure, as applicable.
- Parental attitudes, defined according to each study, measured by self-report questionnaires immediately post-intervention and control exposure, as applicable.

eHealth outcomes:

- eHealth educational intervention usage, defined as frequency and characteristics of intervention use by the parent, immediately post-intervention and control exposure, as applicable.
- Parental acceptance of eHealth educational intervention, defined as parental satisfaction with the eHealth intervention, measured by self-report questionnaires or other measures as reported by each study (e.g., Calgary Health Region Evaluation of Health Information (J. Kim & Park, 2012) immediately post-intervention and control exposure, as applicable.

Pain management outcomes:

- Involvement in parent-led pain management, defined as a parent providing pain relief (e.g., breastfeeding, skin-to-skin contact) or advocating for pain relief (e.g., oral sucrose) during procedures, measured by observation, self-report, or other measures pre- and post-intervention and control exposure, as reported by each study.
- Infant pain response, defined as response to an invasive procedural (i.e., during procedure and/or after procedure), as measured by at least one of the following post-intervention or control exposure, as applicable:
 - Validated composite biobehavioral pain scores, including a combination of behavioral, physiological, and contextual indicators (e.g., Modified Behavioral Pain Scale) (Taddio, Nulman, et al., 1995).
 - Behavioral indicators (audible cry duration in seconds or milliseconds).
 - Physiological indicator changes from baseline in heart rate, respiratory rate, oxygen saturation/transcutaneous oxygen tension, and brain-based physiological measures. These measures should be reported before, during, and after the procedure.
 - Hormonal indicators (salivary cortisol, serum beta-endorphins) obtained from body fluids (saliva, serum) with description of analyses (e.g., radio-immune assay techniques).

Secondary outcomes

Of the secondary outcomes of interest identified in the protocol (Richardson, Benoit, et al., 2019), only the following was reported by one study and is described narratively in this review:

- Type of feeding (i.e., breastfed, formula-fed, alternative supplements), measured by self-report or observation post-intervention exposure.

The remaining secondary outcomes of interest were not considered in any study included in this review:

- Neonatal morbidity, defined and reported according to each study (e.g., infection, need for readmission).
- Length of stay in hospital, defined as total number of days spent in hospital.

Types of studies

This review considered both experimental and quasi-experimental study designs, including randomized controlled trials (RCTs), non-randomized controlled trials, before and after studies, and interrupted time-series studies. In addition, analytical observational studies including prospective and retrospective cohort studies, case-control studies, and analytical cross-sectional studies were considered for inclusion. This review also considered descriptive observational study designs including case series, individual case reports, and descriptive cross-sectional studies. Consistent with the emergence of eHealth, only studies published after 2000 were included (Latulippe et al., 2017). Studies published in English were included (Morrison et al., 2012).

2.6.5 Methods

This systematic review was conducted in accordance with the JBI methodology for systematic reviews of effectiveness (Tufanaru et al., 2017) and followed an a priori

protocol (Richardson, Benoit, et al., 2019). The protocol was registered in PROSPERO (CRD42020151569).

Search strategy

The search strategy aimed to find both published and unpublished studies. An initial limited search of MEDLINE (PubMed) was conducted to identify keywords and subject headings commonly used to index articles within this field of study. This informed the development of a full search strategy by a health sciences librarian (KR), which was peer reviewed by a second librarian and updated in June 2021. A search strategy tailored to each database (Appendix 2.1) was utilized for each of the following: MEDLINE (PubMed), PsycINFO (EBSCO), CINAHL (EBSCO), Embase, Scopus, Web of Science, and SciELO. Results were not limited to academic journal articles; conference abstracts and theses were included to ensure published and unpublished search results were returned. The ProQuest Dissertations and Theses Global database (ProQuest via institutional library platform) was also searched for additional unpublished studies. Finally, the citation lists of relevant reviews were searched (Anwar Siani et al., 2017; Chambers et al., 2009; Dol et al., 2017; Farkas et al., 2015; M. M. Gagnon et al., 2020; Richardson et al., 2020). as well as forward and backward searching of the included studies to identify any additional studies for consideration.

Study selection

Following the search, all identified citations were collated and uploaded into Covidence (Veritas Health Information, Melbourne, Australia) and duplicates removed. Titles and abstracts were screened by three independent reviewers for assessment against the inclusion criteria (BH, JD, BB). Studies that met or could potentially meet the

inclusion criteria were retrieved and assessed in detail in Covidence at the full-text screening stage. Full-text studies that did not meet the inclusion criteria were excluded and reasons for exclusion are provided in Appendix 2.2. Each study was assessed by two reviewers at this stage (among BH, JD, and BB). Any disagreements that arose between the reviewers regarding their assessment on study eligibility were resolved through discussion or with an additional reviewer (MCY). The results of the search are presented in a PRISMA flow diagram (Figure 2.1). Studies included after full-text screening were imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia).

Assessment of methodological quality

Eligible studies were critically appraised by independent reviewers at the study level for methodological quality using standardized critical appraisal instruments from JBI for experimental, quasi-experimental, and observational studies. Critical appraisal was completed using both JBI SUMARI (BH, JD) and the paper-based JBI critical appraisal checklists (BH, BB). Any disagreements that arose between the reviewers regarding their assessment on study quality were resolved through discussion. Following critical appraisal, studies were included if they received a score above 50% on the applicable critical appraisal instrument, which indicated meeting the quality threshold (Tufanaru et al., 2017).

Data extraction

Data were extracted from each study included in the review by two independent reviewers (among BH, JD, and BB) using a data extraction tool developed by the review team (Appendix 2.3). The data extracted included specific details about the interventions,

populations, study methods, and outcomes of significance to the review question and specific objectives. Any disagreements that arose between reviewers were resolved through discussion or with an additional reviewer (MCY).

Data synthesis

Due to heterogeneity across studies related to study designs, primary outcomes, and sample populations, no statistical meta-analysis was possible. The findings of all studies are presented narratively, with an accompanying table to describe the study characteristics (Appendix 2.4). Due to insufficient data, there was no opportunity to conduct subgroup analyses based on intervention administration (i.e., prenatal period, postpartum period, or across the perinatal period up to when the infant is 1 year of age), infant gestational age at birth (i.e., preterm or full-term), or method of implementation (i.e., website versus mHealth app).

Assessing certainty in the findings

The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) approach for grading the quality of evidence was followed (Oxman & GRADE Working Group, 2004), and a Summary of Findings (SoF; Appendix 2.5) was created using GRADEpro GDT (McMaster University, ON, Canada). The SoF presents the following information, where appropriate: a ranking of the quality of the evidence based on the risk of bias, directness, precision, and publication bias of the review results. Because this review considered various study designs (i.e., experimental, quasi-experimental, and observational studies), the initial rank of quality of evidence was determined to be high if the outcome was based solely on evidence from experimental studies, whereas outcomes with evidence from observational studies would begin with a

low rank. For outcomes that considered evidence from both experimental and observational studies, the initial quality of evidence was determined to be low to align with the lowest quality of all included studies. The ranking of observational studies could have increased based on defined factors per the GRADE approach (i.e., large magnitude of effect, dose-response gradient, effect of plausible residual confounding); however, the evidence included in these studies did not meet the criteria (Oxman & GRADE Working Group, 2004).

All primary outcomes with findings from included studies are reported in the SoF: i) parental self-efficacy, parental knowledge, and parental attitudes related to pain management; ii) eHealth educational intervention usage and eHealth intervention acceptability; and iii) parental involvement in pain management and infant bio-behavioral pain response. Of note, the secondary outcome with evidence from one study included in this review (i.e., type of feeding) was not included in the SoF because it exceeded the maximum allowance for outcomes (i.e., seven outcomes) and was deemed of limited importance for decision-makers given that effective procedural pain management can be delivered with parental involvement regardless of method of feeding (Higgins et al., 2022; Ullsten et al., 2021).

2.6.6 Results

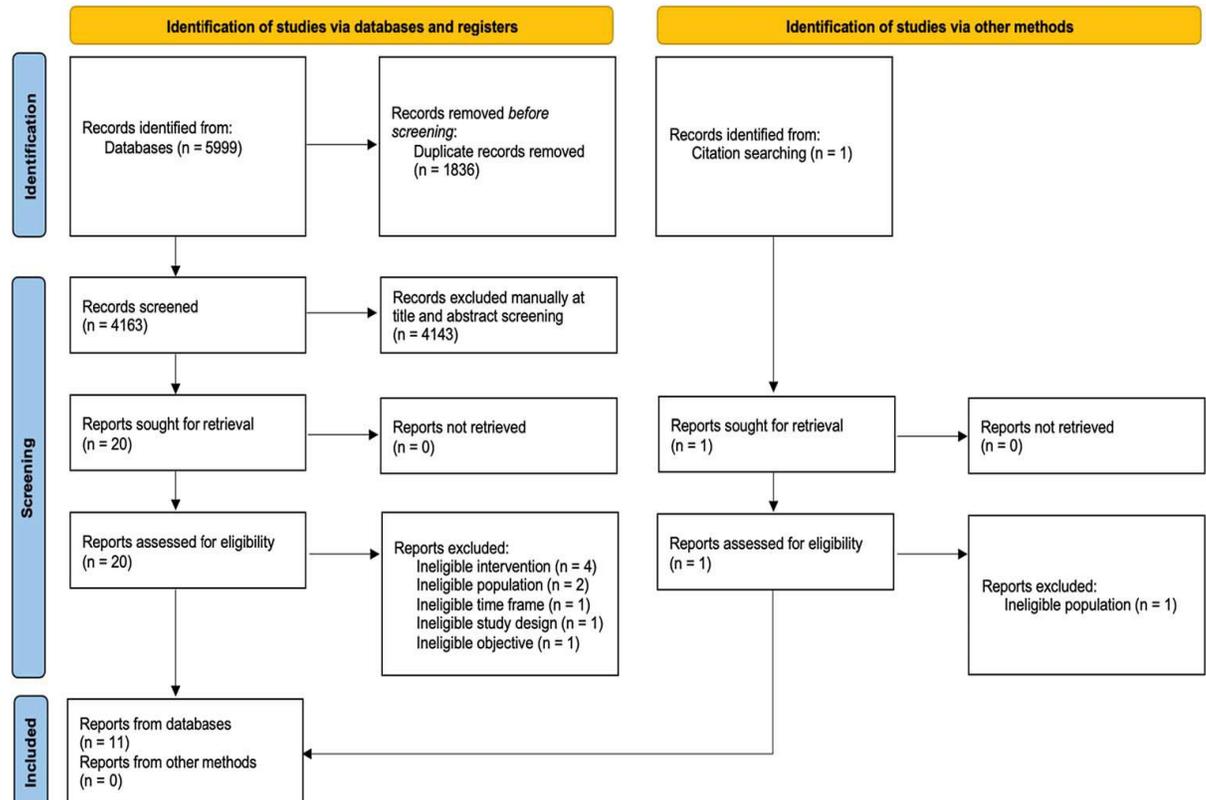
Study inclusion

Database searches identified 5999 records. After removal of 1836 duplicates, the search yielded 4163 articles that were screened by title and abstract. A total of 4143 articles were excluded, resulting in 20 articles eligible for full-text review. Upon full-text review, 11 studies met eligibility criteria, all of which were critically appraised and

included for synthesis in this review. The PRISMA flow diagram (Figure 2.1) outlines the search process for this review. The rationale for nine excluded articles at full-text review is provided in Appendix 2.2.

Figure 2.1

Search Results and Study Selection and Inclusion Process (Page et al., 2021)



Methodological quality

The 11 studies deemed eligible for inclusion in this synthesis were assessed for quality of study design using the following JBI appraisal tools: RCT, analytical cross-sectional study, and quasi-experimental study (Tufanaru et al., 2017). Five studies were RCTs, five were analytical cross-sectional studies, and the remaining study was quasi-experimental. No studies were excluded based on methodological quality as determined

by the 50% score threshold stated in the protocol. Critical appraisal scores for the five included RCTs ranged from 62% to 100% (Table 2.2) (Riddell et al., 2018; Taddio et al., 2017, 2018; Taddio, Parikh, et al., 2015; Venegas et al., 2019). Concerns of methodological quality were predominantly related to blinding participants and treatment administrators. The pilot RCT conducted by Lavin Venegas et al. (2019) received the lowest score due to additional concerns with blinding of participants, treatment administrators, and outcome assessors, as well as comparability of treatment groups and reliable outcome measures. The five articles reporting on cross-sectional studies received scores ranging from 75% to 100% with concerns largely related to confounding factors (Table 2.3) (Bueno et al., 2018; Campbell-Yeo et al., 2017; Harrison et al., 2017; Harrison, Wilding, et al., 2016; Taddio et al., 2013). The one quasi-experimental study received a score of 78% based on concerns related to outcome measurement (Table 2.4) (Korki de Candido et al., 2020).

Table 2.2

Critical Appraisal of Included Randomized Controlled Trials

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	%
Lavin Venegas et al., 2019	Y	Y	Y	N	N	N	N	Y	Y	Y	N	Y	Y	62
Riddell et al., 2018	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	92
Taddio et al., 2015	Y	N	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	85
Taddio et al., 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100
Taddio et al., 2018	Y	NA	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	92
Total %	100	75	100	60	40	80	80	100	100	100	80	100	100	

Y, yes; N, no; NA, not applicable.

JBI critical appraisal checklist for randomized controlled trials:

Q1 = Was true randomization used for assignment of participants to treatment groups? Q2 = Was allocation to treatment groups concealed? Q3 = Were treatment groups similar at baseline? Q4 = Were participants blind to treatment assignment? Q5 = Were those delivering treatment blind to treatment assignment? Q6 = Were outcome assessors blind to treatment assignment? Q7 = Were treatment groups treated identically other than the intervention of interest? Q8 = Was follow-up complete, and if not, were strategies to address incomplete follow-up utilized? Q9 = Were participants analyzed in the groups to which they were randomized? Q10 = Were outcomes measured in the same way for treatment groups? Q11 = Were outcomes measured in a reliable way? Q12 = Was appropriate statistical analysis used? Q13 = Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?

Table 2.3*Critical Appraisal of Included Analytical Cross-Sectional Studies*

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	%
Bueno et al., 2018	Y	Y	Y	Y	N	N	Y	Y	75
Campbell-Yeo et al., 2017	Y	Y	Y	Y	N	N	Y	Y	75
Harrison et al., 2017	Y	Y	Y	Y	Y	Y	Y	Y	100
Harrison et al., 2016	Y	Y	Y	Y	N	N	Y	Y	75
Taddio et al., 2013	Y	N	Y	NA	Y	Y	Y	Y	86
Total %	100	80	100	100	40	40	100	100	

Y, yes; N, no; NA, not applicable.

JBIC critical appraisal checklist for analytical cross-sectional studies: Q1 = Were the criteria for inclusion in the sample clearly defined? Q2 = Were the study subjects and the setting described in detail? Q3 = Was the exposure measured in a valid and reliable way? Q4 = Were objective, standard criteria used for measurement of the condition? Q5 = Were confounding factors identified? Q6 = Were strategies to deal with confounding factors stated? Q7 = Were the outcomes measured in a valid and reliable way? Q8 = Was appropriate statistical analysis used?

Table 2.4*Critical Appraisal of the Included Quasi-Experimental Study*

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	%
Korki de Candido et al., 2020	Y	Y	Y	Y	N	Y	Y	U	Y	78

Y, yes; N, no; U, unclear.

JBIC critical appraisal checklist for quasi-experimental studies:

Q1 = Is it clear in the study what is the "cause" and what is the "effect" (ie, there is no confusion about which variable comes first)? Q2 = Were the participants included in any comparisons similar? Q3 = Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest? Q4 = Was there a control group? Q5 = Were there multiple measurements of the outcome both pre and post intervention/exposure? Q6 = Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analyzed? Q7 = Were the outcomes of participants included in any comparisons measured in the same way? Q8 = Were outcomes measured in a reliable way? Q9 = Was appropriate statistical analysis used?

Characteristics of included studies

The 11 included studies were published within the previous decade, ranging from 2013-2020, with the majority published after 2017 (n=8). The studies were conducted in Brazil (Bueno et al., 2018; Korki de Candido et al., 2020), or Canada (Campbell-Yeo et al., 2017; Harrison et al., 2017; Harrison, Wilding, et al., 2016; Riddell et al., 2018; Taddio et al., 2013, 2018; Taddio, Parikh, et al., 2015; Venegas et al., 2019), and nine studies targeted the postnatal period. Canadian-based studies by Campbell-Yeo et al.

(2017) and Harrison, Wilding, et al. 2016 reported on eHealth interventions that were accessible globally through YouTube and identified viewers from 154 countries and 175 countries, respectively. All studies reported on eHealth educational interventions that were targeted at parents of infants. Nine of the 11 studies were conducted during the postnatal period, and two studies did not specify a targeted time during the perinatal period for intervention administration (Campbell-Yeo et al., 2017; Harrison, Wilding, et al., 2016). Of the studies that targeted the postnatal period, seven included parents of infants in the postnatal unit following birth (Korki de Candido et al., 2020; Taddio et al., 2013, 2018; Venegas et al., 2019) or in community health centers (Riddell et al., 2018; Taddio et al., 2017; Taddio, McMurtry, et al., 2015), and two included parents of infants requiring NICU care (Bueno et al., 2018; Harrison et al., 2017). Participants identified as mother, father, or partner in seven studies, and four studies included mothers only (Korki de Candido et al., 2020; Taddio et al., 2013, 2017, 2018). All studies used a video approach for their study intervention.

There were four eHealth educational interventions evaluated in the included studies. Some eHealth educational interventions were evaluated across multiple studies included in this review. The first intervention, entitled *Be Sweet to Babies*, is a video that describes the use of breastfeeding, skin-to-skin contact, and oral sucrose for treating acute pain in infants. *Be Sweet to Babies* was evaluated in varying adaptations as a 5-minute video available in English and French (Harrison et al., 2017; Venegas et al., 2019), a shorter video (1 min, 35 sec) accessible through YouTube in the same languages (Harrison, Wilding, et al., 2016), and a 6-minute video available in Portuguese (Bueno et al., 2018; Korki de Candido et al., 2020). The intervention entitled *HELPinKIDS* is a

video (9 to 13 minutes in length) that provides information about pain management interventions for infants, such as topical anesthetics, and was evaluated in three studies led by Taddio and colleagues (Taddio et al., 2013, 2018; Taddio, McMurtry, et al., 2015). The ABCDs of Pain Management 5-minute video guided parents to provide pain relief based on the following ABCD acronym: Assess anxiety/worry; Belly breathe; Calm, close cuddle; and Distraction. The ABCDs of Pain Management was evaluated in two RCTs (Riddell et al., 2018; Taddio et al., 2017). The final intervention, The Power of a Parent's Touch (2 min, 39 sec), is the second video in the "It Doesn't Have to Hurt" YouTube series, which was developed and evaluated by Campbell-Yeo and colleagues (Campbell-Yeo et al., 2017). The length of interventions ranged from 1 to 13 minutes. Two studies made the interventions freely accessible through YouTube, where they evaluated YouTube analytic data and prompted viewers to complete a survey through embedded links in the videos (Campbell-Yeo et al., 2017; Harrison, Wilding, et al., 2016). The remaining studies administered the intervention with assistance of the research team using a variety of devices including smart devices (e.g., tablet, electronic notebook), portable DVD players, or televisions in waiting areas.

Six studies used a comparator in their evaluation of the eHealth educational intervention. In their non-randomized pragmatic trial, Korke de Candido (2020) evaluated Be Sweet to Babies (Portuguese version) against a control group that consisted of mothers in the postnatal unit who had not watched the intervention video or attended a nurse-led educational session on procedural pain management but did receive a pamphlet with the same information. In an RCT evaluating the same intervention (English/French version), Lavin Venegas (2019) used a control group that received standard care that may

have included verbal instruction related to pain management in alignment with institutional policies offering sucrose to infants for minor procedures. In the first RCT evaluating the HELPinKIDS educational package (i.e., HELPinKIDS video and pamphlet with specific information about implementing procedural pain management), the control group received standard care that included a pamphlet providing general information about immunizations (Taddio, McMurtry, et al., 2015). The second RCT had two intervention groups, with the first group receiving the HELPinKIDS educational package and the second group receiving the pain-specific pamphlet and a video with general information related to immunizations (Taddio et al., 2018). The control group for this study received a pamphlet and video with general information about immunizations (Taddio et al., 2018). Finally, the two RCTs evaluating the ABCDs of Pain Management compared the intervention against a control video that provided neutral information presented in the same format as the intervention: i) Act in their child's best interest, ii) Be aware that needles are distressing, iii) Carry out what they think is best, and iv) Do their best to help their young child (Riddell et al., 2018; Taddio et al., 2017). The characteristics of each study are further outlined in Appendix 2.4.

Review findings

The aim of this review was to determine if parent-targeted eHealth educational interventions about infant procedural pain management impact parental, eHealth, and pain management outcomes. Of the 11 studies included, each reported on at least one of the primary outcomes of interest to this review, except for parental stress and anxiety, and only one study reported on a secondary outcome related to feeding type (Korki de Candido et al., 2020). For ease and clarity of reporting, the primary outcomes have been

categorized as follows: i) parental outcomes, ii) eHealth outcomes, and iii) pain management outcomes. Due to heterogeneity of measurement methods and methodology, meta-analysis of data was not possible. Subgroup analyses related to intervention administration time, infant population (e.g., preterm vs. full-term), and method of intervention were also not possible. Review findings have been narratively summarized under parental, eHealth, or pain management outcomes.

Parental outcomes

Ten of the included studies reported on parental outcomes of interest, including self-efficacy or confidence, knowledge about infant pain, and attitudes related to infant pain. The primary outcome of parental stress or anxiety was not reported by any study included in this review.

Parental self-efficacy or confidence:

Confidence was evaluated in two studies through study-specific questions (Campbell-Yeo et al., 2017; Taddio et al., 2018). Campbell-Yeo et al. (2017) conducted a cross-sectional analysis to evaluate the impact of The Power of a Parent's Touch YouTube video. Using a 5-point Likert scale (1 = least confident to 5 = most confident), the authors (Campbell-Yeo et al., 2017) found that after viewing the YouTube video, on average, parents felt highly confident about comforting their infant during needle-related procedures ($M = 4.5$, $SD = 0.82$; $n = 32$) and that their infant's subsequent needle would be less painful and distressing when they were involved ($M = 4.25$, $SD = 1.00$; $n = 32$).

Taddio et al. (2018) evaluated the effectiveness of the HELPinKIDS educational package (i.e., video and pamphlet) specifically for pain management during immunizations through an RCT. In this study, Taddio et al. (2018) assessed confidence in

ability to manage vaccination pain as reported by participants using a numerical rating scale (0-10). The authors found a significant difference in confidence for participants who received the educational package (M = 7.6, SD = 2.0; n = 832) or the pamphlet only (M = 7.4, SD = 2.1; n = 873) when compared to the control (M = 7.0, SD = 2.2; n = 820) who received a pamphlet with general information about immunizations ($P < 0.001$). However, there was no significant difference between the group that received the educational package compared with the group that received only the pain-specific pamphlet.

Parental knowledge:

Knowledge of infant pain and pain management practices was evaluated across five studies using study-specific measurements (Bueno et al., 2018; Harrison et al., 2017; Taddio et al., 2013, 2018; Venegas et al., 2019). Three studies that used variations of the Be Sweet to Babies video intervention measured parental knowledge using the same question about previous awareness of three pain management strategies (i.e., breastfeeding, skin-to-skin contact, and oral sucrose) but did not evaluate knowledge uptake post-intervention administration (Bueno et al., 2018; Harrison et al., 2017; Venegas et al., 2019). Thus, the impact of Be Sweet to Babies on parental knowledge cannot be further assessed.

The impact of the intervention HELPinKIDS educational package on parental knowledge was evaluated in 2013 by Taddio and colleagues (Taddio et al., 2013) in a cross-sectional survey and again in 2018 through a longitudinal RCT by the same research lead (Taddio et al., 2018). In both studies, parental knowledge was measured using study-specific true-or-false questionnaires. In 2013, Taddio et al. used a 10-item

questionnaire that asked participants to evaluate the effectiveness of pain management strategies (e.g., giving sugar water can reduce pain and distress), which was administered at three time points: baseline, after pamphlet, and after video. Further, the authors evaluated the participant level of certainty for their responses using a 5-point Likert scale (1 = very sure to 5 = very unsure). Taddio and colleagues (2013) found the average number of correct responses and certainty scores increased across time points: baseline (correct responses: $M = 5.4$, $SD = 1.7$; certainty: $M = 2.0$, $SD = 1.9$); after pamphlet (correct responses: $M = 8.1$, $SD = 1.2$; certainty: $M = 6.1$, $SD = 2.1$); and after video (correct responses: $M = 8.5$, $SD = 0.8$; certainty: $M = 7.2$, $SD = 1.6$). Using repeated measures analysis of variance (ANOVA), the authors compared the mean number of correct responses across the time points. The increase in average number of correct responses was found to be significant between baseline to after-pamphlet review ($P < 0.001$) and between after-pamphlet and after-video review ($P = 0.012$), suggesting greater knowledge uptake after receiving the video intervention when compared with baseline (i.e., control) and after reviewing the pamphlet alone (Taddio et al., 2013). When analyzing only the responses where participants were certain (reported as “very sure”) with their responses to true-or-false questions, the authors also found a significant increase between baseline to after-pamphlet review ($P < 0.001$) and between after-pamphlet and after-video review ($P = 0.001$).

In the 2018 RCT, using the same intervention, Taddio et al. evaluated knowledge about pain management across three groups: control (i.e., received pamphlet and video with general information about immunizations); intervention 1 (i.e., received pamphlet about specific pain management practices); and intervention 2 (i.e., received pamphlet

and video about specific pain management practices). The authors used a three-item true-or-false questionnaire for parents to identify sucrose, breastfeeding, and topical anesthetics as effective treatments for pain. Participants received 1 point for each correct response, with a potential range of 0 to 3 in total (Taddio et al., 2018). The authors found no significant differences in average knowledge scores across the intervention groups, pamphlet only (M = 1.3, SD = 1.0), and pamphlet plus video (M = 1.4, SD = 1.0), although it was significant when compared with the control group (M = 1.1, SD = 0.9; $P < 0.001$).

Parental attitudes:

Four studies reported on parental attitudes regarding infant pain management, including preferred pain management strategies (Bueno et al., 2018), perceptions (Taddio et al., 2018), and satisfaction with pain management (Taddio et al., 2017, 2018; Taddio, McMurtry, et al., 2015). No standardized measurements were used to measure parental attitudes, with only study-specific questions related to pain management strategies or the educational content shared in the eHealth interventions.

After Bueno and colleagues administered the Be Sweet to Babies intervention, participants identified their preferred pain management strategy: 7% chose either breastfeeding or skin-to-skin contact, 2% chose breastfeeding only, and 1% chose skin-to-skin contact only (Bueno et al., 2018).

Parental satisfaction with pain management was assessed in three RCTs: two studies by Taddio et al. (2015, 2018) in their evaluations of the HELPinKIDS package and another study by Taddio et al. (2017) evaluating the ABCDs of Pain Management intervention. In the 2015 HELPinKIDS study (Taddio, McMurtry, et al., 2015), parents

were asked to rate their level of satisfaction related to infant comfort during injections at their two- and four-month vaccination appointments. At the first vaccination (2 months of age), parental satisfaction was significantly greater in the intervention group, with 71% of participants reporting as “very satisfied” compared with 51% of participants in the control group ($P < 0.001$); however, there was no significant difference at the four-month appointment between intervention and control (65% vs. 64%, $P = 0.72$) (Taddio, McMurtry, et al., 2015).

In the 2018 evaluation of HELPinKIDS (Taddio et al., 2018), the majority of participants in the control (87.2%) group and two intervention groups (pamphlet only, 91.0%; pamphlet and video, 91.4%) reported being satisfied with pain management. A significant difference in satisfaction was found between the intervention groups and the control group ($P = 0.007$) but not between the intervention groups.

In the RCT evaluating the ABCDs of Pain Management intervention, the authors (Taddio et al., 2017) assessed parental satisfaction using a 5-point Likert scale (1 = very dissatisfied to 5 = very satisfied) for the control group (i.e., placebo) and three intervention groups (i.e., video only; video and sucrose; and video, sucrose, and lidocaine) across four time points aligning with infant immunization schedules (2, 4, 6, and 12 months). Parents reported moderate to high satisfaction across all time points in the control group. While no significant differences in average parental satisfaction were found between groups, satisfaction did increase significantly across time points within each group ($P < 0.001$) (Taddio et al., 2017).

The 2018 evaluation of HELPinKIDS (Taddio et al., 2018) also assessed parental attitudes related to their feelings of managing vaccination pain and the usefulness of their

role in pain management. Most participants in the control (81.5%) group and two intervention groups (pamphlet only, 86.5%; pamphlet and video, 88.2%) reported that they felt that vaccination pain is important to treat. Similarly, many believed that the pain management practices they used were helpful, which was reported by 85.2% of the control group, 88.1% who received the pamphlet only, and 90.3% who received the pamphlet and video (intervention groups). A significant difference in the perceptions of pain management was found between the intervention groups and the control group ($P < 0.001$; $P = 0.005$, respectively) but not between the intervention groups.

eHealth outcomes

Six studies reported on outcomes related to eHealth usage and user acceptance.

eHealth intervention usage:

Usage of eHealth interventions was reported by three studies. Campbell-Yeo et al. (2017) and Harrison et al. (2016) obtained detailed usage data from analytics computed by the YouTube platform and their unique study surveys, including total view time, location of viewers, and device used. In Campbell-Yeo et al.'s (2017) evaluation of The Power of a Parent's Touch, a 2 minute and 39 second YouTube video, the average total viewing time was 1 minute and 27 seconds, with some countries' average viewing time reaching 1 minute and 56 seconds (i.e., United Kingdom, Portugal, New Zealand, Australia, Canada, United States). Viewers did not use subtitles 41% of the time; otherwise, Portuguese (52%), English (5%), and Spanish (1%) subtitles were used. Viewers who completed the study survey and identified as parents primarily were located in Canada (63%), the United States (25%), or unspecified countries (13%). The video was accessed primarily using a desktop computer (67.7%), of which 62.2% used a

Windows operating system. Similarly, Harrison et al. (2016) evaluated their Be Sweet to Babies YouTube intervention (1 minute and 35 seconds), finding that, on average, viewers watched 65% of the video (1 minute and 2 seconds). Viewers were located across 175 countries, primarily from the United States (24%), Canada (16%), Saudi Arabia (6%), the United Kingdom (4%), and India (4%) (Harrison, Wilding, et al., 2016).

Finally, in determining feasibility and intervention fidelity through their pilot RCT in a Canadian postnatal unit, Lavin Venegas and colleagues (2019) reported that 100% of participants watched the entire intervention video, Be Sweet to Babies (5 minutes, available in English/French).

Acceptance of eHealth interventions:

Five of the included studies evaluated parents' acceptance of three interventions, including The Power of a Parent's Touch (Campbell-Yeo et al., 2017), Be Sweet to Babies (Bueno et al., 2018; Harrison et al., 2017; Venegas et al., 2019), and the HELPinKIDS package (Taddio et al., 2013). Using a 5-point Likert scale (1 = least positive to 5 = most positive), on average, parents reported that they liked The Power of a Parent's Touch video ($M = 4.78$; $SD = 0.55$) and they found it helpful ($M = 4.4$; $SD = 0.88$) (Campbell-Yeo et al., 2017). The variations of Be Sweet to Babies were found to be an ideal length by most NICU parents in Canada (86%) (Harrison et al., 2017) and Brazil (92%) (Bueno et al., 2018) and parents receiving postnatal care (98%) (Venegas et al., 2019). Some NICU parents in Canada (14%) and Brazil (4%) found the video to be too long, with the Canadian participants suggesting separate videos for English and French rather than the bilingual version (Harrison et al., 2017). In studies that asked whether parents would recommend Be Sweet to Babies, 100% of parents indicated that they

would (Bueno et al., 2018; Harrison et al., 2017). Four NICU parents in Canada (8%) questioned the timing of intervention administration and reported that the video should be provided to parents prior to hospital admission (e.g., during pregnancy or immediately following birth) (Harrison et al., 2017), Taddio and colleagues (2013) used the Calgary Health Region Evaluation of Health Information (CHREHI) standardized instrument to measure parental acceptance of the HELPinKIDS package. Using the CHREHI, the authors found that most parents understood the health information presented in the video (87%) and felt the amount of information was adequate (81%), with slightly fewer parents reporting the same of the pamphlet (78% for both aspects) (Taddio et al., 2013).

Pain management outcomes

All studies reported on pain management outcomes.

Involvement in pain management:

Ten studies reported on parent-led involvement in pain management, with nine studies reporting actual involvement prior to or following intervention exposure (Bueno et al., 2018; Campbell-Yeo et al., 2017; Harrison et al., 2017; Harrison, Wilding, et al., 2016; Korki de Candido et al., 2020; Riddell et al., 2018; Taddio, McMurtry, et al., 2015; Venegas et al., 2019) and seven reporting intention to use pain management for subsequent procedures (Bueno et al., 2018; Campbell-Yeo et al., 2017; Harrison et al., 2017; Harrison, Wilding, et al., 2016; Korki de Candido et al., 2020; Taddio et al., 2013; Venegas et al., 2019). The Measure of Adult and Infant Soothing and Distress (MAISD) was used in the sample assessed by Riddell and colleagues (2018). The remaining studies reported the proportion of participants who were involved in pain management (Bueno et al., 2018; Campbell-Yeo et al., 2017; Harrison et al., 2017; Harrison, Wilding, et al.,

2016; Korke de Candido et al., 2020; Taddio et al., 2018; Taddio, McMurtry, et al., 2015; Venegas et al., 2019) or who desired to be involved in the future (Bueno et al., 2018; Campbell-Yeo et al., 2017; Harrison et al., 2017; Harrison, Wilding, et al., 2016; Korke de Candido et al., 2020; Taddio et al., 2013; Venegas et al., 2019).

Riddell et al. (2018) conducted an RCT to determine the impact of the ABCDs of Pain Management intervention on parent soothing behaviors (e.g., distraction, physical comforting, rocking) for immunizations with children at 6 months and 18 months of age. For this review, only the infant data (6 months of age) were extracted and synthesized because the data from those 18 months of age are beyond the scope. Using MAISD, the authors reported pain reactivity 15 seconds after infants received an injection and pain regulation at three 1-minute intervals post-injection (Riddell et al., 2018). Parent soothing behavior between intervention and control (i.e., video with general information) groups was compared through multivariate analysis of variance (MANOVA) for each time point, with a significant age and group effect for physical comfort and rocking at two minutes post-injection (age effect: Pillai's trace = 0.06, $F = 2.90$, $df = [3, 120]$, $P = 0.03$; group effect: Pillai's trace = 0.08, $F = 3.46$, $df = [3, 120]$, $P = 0.01$) (Riddell et al., 2018). The findings suggest that parents of infants and parents that received the ABCDs of Pain Management intervention provided greater comfort to their children two minutes after the injection (Riddell et al., 2018).

Campbell-Yeo et al. (2017) found that out of the 32 parents who responded to the survey, 56% had used skin-to-skin contact and 72% had used breastfeeding to manage their infant's pain before watching The Power of a Parent's Touch YouTube video. When asked about their intention to be involved in pain management for future procedures, 72%

of parents reported they would use skin-to-skin contact or breastfeeding. While intention to be involved increased, there was no statistically significant difference found for either pain management strategy (skin-to-skin contact: $P = 0.33$; breastfeeding: $P = 1.00$).

Parental involvement in pain management was evaluated across all studies that used the Be Sweet to Babies intervention (Bueno et al., 2018; Harrison et al., 2017; Harrison, Wilding, et al., 2016; Korke de Candido et al., 2020; Venegas et al., 2019). Harrison and colleagues (2016) found that, out of the 66 survey respondents, 14% of parents used sweet solutions (e.g., sucrose, glucose) and 38% used breastfeeding to manage their infant's pain before watching the YouTube video. After watching the video, 73% of parents reported they intended to use sweet solutions and 85% would use breastfeeding during future procedures. In the pilot evaluation of the bilingual version of Be Sweet to Babies with Canadian NICU parents, 64% had previously used sucrose, 18% used skin-to-skin contact, and 12% used breastfeeding to manage their infant's procedural pain (Harrison et al., 2017). Additionally, more parents with other children had used each strategy compared to first-time parents, with a statistically significant difference between those who used skin-to-skin contact (first-time parents: 4%; experienced parents: 33%, $P = 0.007$) (Harrison et al., 2017). After watching the video, 96% of parents reported they would use or advocate for sucrose, skin-to-skin contact, or breastfeeding for subsequent procedures (Harrison et al., 2017). Actual parental involvement in procedural pain management was not assessed after receiving the Be Sweet to Babies intervention in these two studies; thus, a comparison cannot be made to determine the impact of the intervention. However, the authors used intention for involvement in pain management

with future procedures as a proxy to suggest a positive impact because the majority of both study samples reported intention for future use.

Using the same bilingual intervention in a pilot RCT with parents admitted to a Canadian postnatal unit, 26% of parents in the intervention group and 20% in the control group reported that they had previously used at least one pain management strategy during procedures, with most in both groups having used breastfeeding (16% each) (Venegas et al., 2019). For the intervention group, after reviewing *Be Sweet to Babies*, 100% of parents reported intention to use at least one pain management strategy for their newborn's blood screening (NBS), with most desiring to use skin-to-skin contact (92%), followed by breastfeeding (90%) and sucrose (66%) (Venegas et al., 2019). For the NBS procedure, 60% of parents in the intervention group and 67.4% in the control group used at least one pain management strategy, for an absolute difference of -7.4 (95% CI -26.2 to 11.5 ; non-significant). Sucrose was primarily used to manage pain for both groups during the NBS (intervention: 58.0%; control: 61.2%). Breastfeeding was used by 2% of parents in the intervention group and 6.1% in the control group, and skin-to-skin contact was used only in the intervention group (4%) (Venegas et al., 2019). Lavin Venegas and colleagues (2019) noted that 22% of infants received sucrose during the NBS; however, this was against the parents' identified preference for pain management strategy.

The Portuguese version of *Be Sweet to Babies* was evaluated in Brazilian health centers by Bueno et al. (2018) with NICU parents and by Korki de Candido et al. (2020) with parents receiving postnatal care in hospital. Prior to watching the intervention video, 11% of Brazilian NICU parents had previously used skin-to-skin contact to manage their infant's pain, another 7% had used breastfeeding, and 2% had used sucrose (Bueno et al.,

2018). Despite low previous usage of pain interventions in this sample, all of the parents reported they would use or advocate for these strategies. Of the three strategies, 90% of parents said they would use any of the strategies and the remaining 10% specified a preference for a strategy (as previously reported under the "Parental Attitudes" section) (Bueno et al., 2018). Bueno and colleagues did not assess actual involvement in pain management during procedures following intervention administration, but presented intention for involvement to suggest impact of the intervention.

Korki de Candido et al. (2020) conducted a quasi-experimental trial evaluating the impact of Be Sweet to Babies (Portuguese version) on the use of pain management during the NBS. All mothers received a pamphlet with information about pain management strategies and were also invited to join a daily education session led by registered nurses on the postpartum unit where the study intervention would be provided. Mothers who viewed the video in the education session constituted the intervention group, and the control group was mothers who received the pamphlet only (Korki de Candido et al., 2020). Use of pain management during NBS did not significantly differ between the intervention and control groups (40% vs. 24%, $P = 0.13$; OR 2.1, CI 95% 0.78 to 5.89) (Korki de Candido et al., 2020). The author (Korki de Candido et al., 2020) found that breastfeeding was primarily used by both groups (intervention: 31%, control: 24%) and other strategies, including skin-to-skin contact and non-nutritive sucking, were used only by the intervention group (skin-to-skin contact: 6%, control: 0%; non-nutritive sucking: 3% vs. control: 0%). Sweet-tasting solutions (e.g., oral sucrose, glucose) were not used by either group. Intention to use pain management for subsequent procedures was evaluated in both groups, and while not statistically significant ($P = 0.49$), all mothers in

the intervention group and 95% of mothers in the control group reported a desire to use breastfeeding, skin-to-skin contact, or sweet-tasting solutions in the future (Korki de Candido et al., 2020).

Each study that evaluated the HELPinKIDS package explored the impact of the intervention on parental involvement in pain management (Taddio et al., 2013, 2018; Taddio, McMurtry, et al., 2015). After engagement with the HELPinKIDS package, parents' intention to use pain management strategies for future immunizations was evaluated using a 5-point Likert scale (1 = very unlikely to 5 = very likely) in the 2013 cross-sectional survey by Taddio and colleagues (2013). All survey respondents reported intention to use the strategies described in the intervention, of which 80% reported being “very likely” to apply the strategies for future procedures (Taddio et al., 2013).

In 2015, Taddio et al. conducted a longitudinal RCT and reported parental use of pain management during immunizations measured by video observation of use at their initial appointment (study enrollment) and at follow-up two months later. There were statistically significant differences of parental involvement in pain management between the intervention and control group with specific strategies such as holding (51% vs 19%, $P=0.001$) and breastfeeding (25% vs 8%, $P = 0.001$); however, oral sucrose was used only by the intervention group (15%) and neither group used topical anesthetics (Taddio, McMurtry, et al., 2015). At follow-up two months later, statistically significant differences remained between the intervention and control group with holding (47% vs 26%, $P = 0.001$) and breastfeeding (18% vs 6%, $P = 0.002$); however, oral sucrose and topical anesthetics were used only by the intervention group (3% each) (Taddio, McMurtry, et al., 2015).

Finally, in another longitudinal RCT by the same research lead in 2018, Taddio et al. (2018) evaluated parental involvement by self-report of use of any strategy across three time points (2, 4, and 6 months) and compared between groups, including control, pamphlet only, and HELPinKIDS package (i.e., pamphlet and video). The authors (Taddio et al., 2018) found that use of any strategy and specific strategies were significantly higher in the two intervention groups compared with the control group. Use of any pain management strategy differed significantly between the control (53.2%) and pamphlet-only (61.4%) and HELPinKIDS package (63.0%) intervention groups ($P < 0.001$). In terms of specific strategies, breastfeeding was used the most (control: 51.2%; pamphlet only: 57.3%; HELPinKIDS: 56.0%, $P = 0.03$), followed by oral sucrose (control: 3.0%; pamphlet only: 8.1%; HELPinKIDS: 9.6%, $P < 0.001$) and topical anesthetics (control: 1.8%; pamphlet only: 3.0%; HELPinKIDS: 4.9%, $P = 0.002$). Looking at use of any pain management strategies at each time point, significant differences were found at the two-month (control: 55.8%; pamphlet only: 64.4%; HELPinKIDS: 64.9%, $P = 0.03$) and four-month immunizations (control: 53.6%; pamphlet only: 63.2%; HELPinKIDS: 65.7%, $P = 0.007$), but not at the six-month immunization (control: 49.6%; pamphlet only: 56.0%; HELPinKIDS: 57.4%, $P = 0.2$) (Taddio et al., 2018).

Infant pain response:

The final primary outcome of interest in this review, infant pain response, was evaluated by three studies using behavioral measures such as the Modified Behavioral Pain Scale (MBPS) (Riddell et al., 2018; Taddio et al., 2017; Taddio, McMurtry, et al., 2015), which provides a score out of 10 based on three sections (i.e., facial expression,

cry, and body movement) or cry duration (Taddio et al., 2017; Taddio, Parikh, et al., 2015).

For the ABCDs of Pain Management intervention, infant pain response was evaluated in the RCT conducted by Riddell and colleagues (2018). Using the MBPS, the authors reported pain reactivity 15 seconds after infants received an injection and pain regulation at three intervals post-injection (Riddell et al., 2018). For the infant group, the MBPS scores varied between the intervention and control groups for pain reactivity at 15 seconds ($M = 6.25$, $SD = 2.42$; $M = 5.37$, $SD = 2.46$, respectively), pain regulation 1 at one minute post-injection ($M = 2.85$, $SD = 1.26$; $M = 2.29$, $SD = 0.69$, respectively), pain regulation 2 at two minutes ($M = 2.46$, $SD = 0.83$; $M = 2.54$, $SD = 1.02$, respectively), and pain regulation 3 at three minutes ($M = 2.42$, $SD = 0.92$; $M = 2.54$, $SD = 1.17$, respectively). Multivariate results indicate no significant effects for the infant pain response at any time point, suggesting that the ABCDs of Pain Management intervention did not reduce pain experienced by infants (Riddell et al., 2018).

In Taddio et al.'s (2017) evaluation of ABCDs of Pain Management, infant pain response was also measured using the MBPS at four time points for immunizations throughout infancy (i.e., 2, 4, 6, and 12 months) between the four study groups: control (placebo video intervention), video only, video–sucrose, and video–sucrose–lidocaine. Infant pain was measured using the MBPS by blinded coders viewing a video recording of each injection, as well as by direct researcher observation during the injections. Based on video data, the MBPS scores between study groups varied across each procedure phase (i.e., baseline, needle, recovery) with no significant difference found at baseline ($P = 0.4$), but a significant difference was noted within groups when comparing across each

time point ($P < 0.001$) (Taddio et al., 2017). During the needle phase, significant differences were found between groups ($P = 0.003$) and within groups across time points ($P < 0.001$), with significantly lower scores for only the video–sucrose–lidocaine group when compared between the control ($P < 0.001$), video ($P = 0.003$), and video–sucrose ($P = 0.005$) groups (Taddio et al., 2017). For the final phase, there was no significant difference between groups for recovery pain scores ($P = 0.97$) but a difference was found between groups compared by time points ($P < 0.001$) (Taddio et al., 2017). The average direct observer MBPS scores across all time points varied between the control group (2 m: $M = 8.1$, $SD = 1.2$; 4 m: $M = 5.1$, $SD = 1.9$; 6 m: $M = 5.1$, $SD = 2.3$; 12 m: $M = 6.8$, $SD = 2.0$), video group (2 m: $M = 8.3$, $SD = 1.1$; 4 m: $M = 6.9$, $SD = 1.5$; 6 m: $M = 4.5$, $SD = 2.0$; 12 m: $M = 7.0$, $SD = 1.9$), video–sucrose group (2 m: $M = 8.0$, $SD = 1.3$; 4 m: $M = 5.8$, $SD = 1.6$; 6 m: $M = 5.2$, $SD = 2.2$; 12 m: $M = 7.1$, $SD = 2.0$), and video–sucrose–lidocaine group (2 m: $M = 7.7$, $SD = 1.3$; 4 m: $M = 6.4$, $SD = 1.5$; 6 m: $M = 4.4$, $SD = 2.2$; 12 m: $M = 6.6$, $SD = 2.2$). A significant difference was noted for the video–sucrose–lidocaine group compared to the others ($P = 0.004$), and scores differed within groups comparing across the time points ($P < 0.001$) (Taddio et al., 2017). The average cry duration (up to 30 seconds post-injection) across all time points varied between the control group (2 m: $M = 23.2$, $SD = 6.1$; 4 m: $M = 18.1$, $SD = 7.4$; 6 m: $M = 7.9$, $SD = 9.5$; 12 m: $M = 18.3$, $SD = 2.0$), video group (2 m: $M = 22.9$, $SD = 5.9$; 4 m: $M = 16.0$, $SD = 7.5$; 6 m: $M = 6.0$, $SD = 8.4$; 12 m: $M = 19.3$, $SD = 10.2$), video–sucrose group (2 m: $M = 22.5$, $SD = 6.1$; 4 m: $M = 15.3$, $SD = 8.1$; 6 m: $M = 7.8$, $SD = 8.7$; 12 m: $M = 19.9$, $SD = 9.8$), and video–sucrose–lidocaine (2 m: $M = 21.4$, $SD = 6.9$; 4 m: $M = 14.4$, $SD = 7.0$; 6 m: $M = 6.0$, $SD = 9.7$; 12 m: $M = 17.3$, $SD = 10.8$) (Taddio et al., 2017). In

terms of cry duration, the authors found no significant difference between groups ($P = 0.05$), but a significant difference within groups was found when comparing across each time point ($P < 0.001$) (Taddio et al., 2017).

Finally, Taddio and colleagues (Taddio, Parikh, et al., 2015) reported the impact of the HELPinKIDS package on infant pain response as measured by the MBPS and cry duration at the initial appointment and follow-up two months later. For the MBPS scores, there was no significant difference found between the control ($M = 8.5$, $SD = 1.0$) and the intervention ($M = 8.3$, $SD = 1.3$; $P = 0.11$) at the initial appointment; however, scores differed significantly at the two-month follow-up ($M = 8.2$, $SD = 1.4$; $M = 7.8$, $SD = 1.3$, respectively; $P = 0.002$). With cry duration, the authors founds that there were no significant differences between the control ($M = 41.1$, $SD = 26.5$) and the intervention ($M = 44.1$, $SD = 28.9$; $P = 0.02$; P value set to 0.008 to meet Bonferroni correction factor) at the initial appointment or at the two-month follow-up ($M = 48.3$, $SD = 30.4$; $M = 47.2$, $SD = 27.8$, respectively; $P = 0.62$) (Taddio, Parikh, et al., 2015).

Secondary outcomes

Korki de Candido and colleagues (2020) was the only study to report on a secondary outcome of interest: type of feeding. In their quasi-experimental trial evaluating the Portuguese version of Be Sweet to Babies in the Brazilian postnatal population, no significant difference was found between the intervention and control groups for infants who were exclusively breastfed (97% vs. 95%, $P = 1.00$) or received supplementation (3% vs. 5%, $P = 1.00$). None of the included studies reported on the remaining secondary outcomes: neonatal morbidity or length of hospital stay.

2.6.7 Discussion

This review sought to evaluate the impact of parent-targeted eHealth educational interventions about infant procedural pain management on various parental outcomes (stress and anxiety, self-efficacy, knowledge, attitudes), eHealth outcomes (usage, acceptance), and infant pain management outcomes (parental involvement, infant pain response). Despite a surge in evidence about parent-delivered pain management (Ullsten et al., 2021), there are relatively few studies that evaluate parent-targeted educational interventions on the topic as identified from this review and a previous scoping review (Richardson et al., 2020). This review found 11 studies that explored the effectiveness of eHealth educational interventions. When specified, the eHealth educational interventions were delivered in the postnatal period. Echoing our previous scoping review on parent-targeted resources for pain management (Richardson et al., 2020), administering education prenatally could enhance knowledge uptake and utilization of caregiving behaviors (Fuchs et al., 2021; Gagnon & Sandall, 2007; Hui et al., 2021; Silva et al., 2016). Given the timing of many routine procedures (e.g., immediately after birth for vitamin K injections or heel lances), prenatal education about pain management may influence greater application of pain management strategies. In a recent scoping review of the effectiveness and experience of parent-delivered pain management strategies, Ullsten and colleagues (2021) found that parents want to learn about their comforting role well in advance of procedures, supporting that an ideal time to begin discussion of procedural pain management could begin prenatally during the third trimester.

The 11 studies included in this review reported on four unique eHealth educational interventions, all in video format, which have been developed by recognized leaders of pediatric pain research from Canada and Brazil. It is well documented that

parents are searching the internet with the intention to learn more about parenting and infant well-being (Aston et al., 2017; Davis et al., 2017; De Rouck & Leys, 2009; Fahy et al., 2014; Gabbert et al., 2013; Guerra-Reyes et al., 2016; Hamm et al., 2013; Kamali et al., 2018; Morton & Hsu, 2007; Orr et al., 2016; Price et al., 2018; Sundstrom, 2016). Based on parents' information needs, Orr and colleagues (2016) recommended that educational resources about infant procedural pain management be developed by credible health care institutions and made accessible on the internet. This review presents studies that have answered the call for credible resources, and it is evident that efforts have been focused on increasing the reach of evidence-based information through accessible educational videos. Social media and video platforms, such as YouTube, have been recognized as effective knowledge dissemination methods in health research because of their widespread reach (Chambers et al., 2020; Lim, 2010; Maloney et al., 2015). Of the eHealth educational interventions presented in this review, nearly all are currently accessible on YouTube, uploaded to their respective institutional channels (i.e., IWK Health, CHEO, SickKids AboutKidsHealth), with the exception of the ABCDs of Pain Management intervention, which instead is described as part of a TEDx Talk available via YouTube (TEDx Talks, 2015). Accessibility has been further enhanced, with subtitles available in 19 languages for The Power of a Parent's Touch (Campbell-Yeo et al., 2017) and 11 languages for Be Sweet to Babies (Harrison, Wilding, et al., 2016).

The findings of this review align with previous evidence amplifying parents' wish to be involved in infant pain management during procedures (Franck et al., 2012; Ullsten et al., 2021). Although there are insufficient data to make concrete insights about the impact of the evaluated eHealth educational interventions on parental outcomes, this

review found that parents felt satisfied when they were involved in pain management and that targeted education positively influenced their confidence and knowledge. Parents' baseline knowledge and use of effective infant pain management strategies (i.e., breastfeeding, skin-to-skin contact, sweet solutions) prior to viewing the video interventions varied across studies. Few studies evaluated knowledge before and after administering the video intervention, which limits the ability to comment on knowledge uptake. However, after viewing the video interventions, parents felt confident in their ability to manage pain during subsequent procedures and, when assessed, gained greater understanding about pain management. While a change in knowledge was not often evaluated, parents' confidence, involvement, or intention to be involved in subsequent painful procedures could suggest knowledge uptake (MacKenzie et al., 2021c).

The scoping review by Ullsten and colleagues (2021) identified 10 studies that described the experience of comforting during procedures, suggesting a connection between parents' confidence in parenting and pain management when equipped with sufficient knowledge and adequate support by the health care team. Ullsten and colleagues (2021) note that parents require timely guidance on their role in pain management through various formats, as well as individualized educational approaches. In this current review and that by Ullsten et al., (2021) the timing of education administration was impactful to parents, particularly with first-time parents, as they need sufficient information well in advance of procedures to understand the efficacy of their role (Harrison et al., 2017; Richardson et al., 2020). Involvement in pain management is identified as a way for parents to cope with the often stressful experience of seeing their child in pain while building greater confidence and attachment in parenting on a broader

level (Ullsten et al., 2021). Ullsten et al.'s (2021) findings are in alignment with the conceptual model Parental Involvement in Infant Pain Management by Franck and colleagues (2012) whereby honoring parental desire to be involved and providing sufficient information act as facilitators in parents' overall confidence with caregiving. The educational interventions evaluated in this review follow Franck et al.'s (2012) conceptual model by providing evidence-based information in a format that is easily consumed by parents and establishes a solid foundation for further discussion and individualized learning with the health care team.

Alongside the necessity and growing use of technology in daily life, eHealth education is becoming an established complement to augment effective care delivery (Penedo et al., 2020), especially to neonatal care (Anwar Siani et al., 2017; Dol et al., 2017; Monaghan et al., 2020). Not only can eHealth complement existing care, the interventions can be modified to fit specific needs. For instance, the length of interventions varied across the studies included in this review, ranging between 1 and 13 minutes, with the duration of specific interventions (e.g., Be Sweet to Babies) changing across studies to include more or less detailed health information as needed in the context (Harrison et al., 2017; Harrison, Wilding, et al., 2016; Venegas et al., 2019). Another important modification included translating the content as required for the study setting (Bueno et al., 2018; Korke de Candido et al., 2020). The content of all interventions comprised evidence-based information utilizing clinical practice guidelines and international recommendations on leading pharmacological and non-pharmacological pain management techniques, including breastfeeding, skin-to-skin contact, and sweet-

tasting solutions (American Academy of Pediatrics Committee on Fetus and Newborn, 2016; Lee et al., 2014).

In this review, parents reported high acceptance of the content and format of the interventions, in particular with the length of videos, although generally favoring shorter videos. Parents' preference of shorter videos aligns with current best practice guidelines for instructional videos, which suggest that short, engaging videos are more likely to have higher viewership (Harley, 2020; Wormald, 2012). Market research exploring the determinants of effective videos found that viewers reported being highly satisfied with instructional or informational videos under 20 minutes, with more than half of viewers preferring short videos between three to six minutes (TechSmith, 2019). Video education is convenient and easily implemented in the clinical setting or remotely, as well as an effective method to facilitate knowledge uptake and health behavior change (Ahmet et al., 2018; Dahodwala et al., 2018). Using YouTube to educate parents about pediatric procedural pain management specifically has been recognized as a valuable method to deliver evidence-based information to a widespread audience (Farkas et al., 2015; Jordan & Chambers, 2017). Farkas and colleagues (2015) note that leveraging YouTube to deliver information related to pediatric pain management could help the general public become more familiar with this topic and enhance its adoption into consistent clinical practice. This prediction was echoed in a recent study by Chambers and colleagues (2020) in their evaluation of another parent-targeted video in the *It Doesn't Have to Hurt* series, which focused on procedures for children (i.e., toddler and school-age). The YouTube video by Chambers et al. (2020) was evaluated over a five-year period and found that parents accepted this resource. The video significantly impacted parents'

intention to use the described pain management strategies for future procedures. These findings follow a similar trend with the studies included in this review, suggesting that accessible, parent-targeted, video-based education could improve procedural pain management practices in neonates and children (Chambers et al., 2020).

Although videos can provide comprehensive instruction in an engaging and brief manner, there is limited ability to update professionally produced videos as new evidence is discovered without sufficient resources (e.g., time, finances, infrastructure) (Higgins et al., 2018). Additionally, video format typically offers one-way communication, so further discussion or instruction may be necessary to reinforce learning and application of health concepts (Anwar Siani et al., 2017; Goodman et al., 2015; Harley, 2020; Kellams et al., 2016). Health information that is accessible in a variety of formats enhances the likelihood of knowledge uptake across different learning styles, as found in the studies that used a pamphlet to complement the intervention video (Gates et al., 2018; Harley, 2020; Taddio et al., 2013, 2018; Taddio, Parikh, et al., 2015). Written and graphic instruction about pediatric pain management that is accessible online and widely promoted through social media has been found to effectively increase perceived relevancy of information, confidence, and use of comfort strategies during vaccinations (MacKenzie et al., 2021c). Alternative eHealth resources, such as web-based platforms or mHealth interventions, could utilize motivational and persuasive system design features that are known to support rich learning in virtual environments by engaging users through aesthetically pleasing designs and interactive content (e.g., automated reminders, social learning, self-monitoring, praise)(Kim et al., 2016; Plass & Kaplan, 2016). While resources are also needed to sustain other eHealth educational formats (e.g., web-based

platforms, mHealth), there may be greater flexibility to update these interventions, rather than videos, as technology and health evidence evolve (K. S. Higgins et al., 2018).

Parental involvement in infant pain management prior to exposure to the video interventions varied across studies, ranging from 2% to 72% reported use. Inconsistent use of effective strategies, including parent-led pain management (e.g., breastfeeding, skin-to-skin contact), has been called out in previous studies (Birnie et al., 2014; Stevens et al., 2011, 2012; Taddio, Chambers, et al., 2009), thus validating the influx in knowledge translation activities targeting parents of infants, as demonstrated in the included studies, as well as older children (Chambers et al., 2020; MacKenzie et al., 2021c). Actual use of pain management strategies was often not significantly influenced by the video interventions in the included studies. This could be attributed to strategies aligning with parents' natural instinct to comfort their child (e.g., physical comfort and rocking during needle) (Riddell et al., 2018), pre-established hospital policies related to neonatal pain management (Harrison et al., 2017; Venegas et al., 2019), health care providers' previous exposure to study interventions (Korki de Candido et al., 2020), or that control groups received similar information in written format (Korki de Candido et al., 2020).

The types of strategies used during procedures understandably depended on the content within each intervention, but current best practice strategies were often used. One included study noted a discrepancy between parents' preferred strategy and the strategy actually used during the procedure, in which sucrose was primarily used despite most parents' reported desire to use breastfeeding or skin-to-skin contact (Venegas et al., 2019). In this situation, the institutional policies recommended that sucrose and

complementary pain management strategies (e.g., breastfeeding, skin-to-skin contact, rocking, swaddling, non-nutritive sucking) be provided to infants during procedures (Venegas et al., 2019), and previous provincial data indicate that sucrose was more commonly used in practice (Harrison, Reszel, et al., 2015). Clinical practice guidelines emphasize the effectiveness of breastfeeding, skin-to-skin contact, sucrose, and combined approaches (e.g., skin-to-skin contact plus sucrose plus non-nutritive sucking) for pain management. However, breastfeeding and skin-to-skin contact are often not practiced by health care providers due to perceived barriers to proper procedure technique (Harrison, Reszel, et al., 2015), insufficient time to prepare, or hospital environments and routines preventing family from being present (Benoit et al., 2016).

With intention to mitigate barriers such as these, a web-based platform called Implementation of Infant Pain Practice Change (ImPaC) has recently been developed to enhance health care providers' uptake and use of evidence-based pain assessment and management practices (Bueno, Stevens, Barwick, et al., 2020; Bueno, Stevens, Rao, et al., 2020). Recent usability testing determined that the ImPaC resource was accepted by users and feasible to implement in practice, and its effectiveness is now being evaluated through a national, multi-center cluster RCT (Bueno, Stevens, Barwick, et al., 2020; Bueno, Stevens, Rao, et al., 2020). Implementation of enhanced infant pain management in clinical practice is a multi-dimensional goal that requires collaborative effort between parents, clinicians, researchers, and health systems (Franck et al., 2012; Ullsten et al., 2021). Educational interventions targeting parents, including those identified in this review, and health care providers (e.g., ImPaC), are promising methods to achieve this goal.

Parents' intention to be involved in future procedures was generally high after viewing the interventions, which could suggest knowledge uptake or positive attitudes toward to pain management information. In a recent study exploring influential factors for pediatric pain management use, MacKenzie and colleagues (2021b) found that intention for future use of strategies did not predict actual use at subsequent immunizations following engagement with a knowledge translation tool about pediatric pain management (i.e., written summary) (MacKenzie et al., 2021c). However, the authors (MacKenzie et al., 2021c) did find that parents were more likely to use strategies if they felt the educational information about pain management was relevant and they felt confident applying the information. Relevancy and confidence may be critical outcomes to assess for existing or future educational interventions about infant pain management to enhance the likelihood for consistent use of a strategy (MacKenzie et al., 2021c).

Infant pain response was evaluated in few studies included in this review. Because the educational interventions describe evidence-based information about pain management strategies known to be effective, it is reasonable to assume that infant pain response should be lower when parents appropriately apply the strategies. The influence of the educational interventions on infant pain response was not significant at most time points across studies, but lower pain responses were related to the type of pain management used, with significant differences found when complementary strategies were applied (e.g., sucrose and lidocaine) (Taddio et al., 2017). Two of the studies in this review that reported infant pain response used the ABCDs of Pain Management intervention (Riddell et al., 2018; Taddio et al., 2017). Although the ABCDs of Pain Management provides strong evidence-based information, it is important to note that the

pain management strategies described in this video do not include the recommended strategies effective for infant procedural pain relief specifically. Recent evidence syntheses demonstrate the efficacy of breastfeeding and skin-to-skin contact for infants, which is further supported by clinical practice guidelines for pain management (Benoit et al., 2017; Harrison, Reszel, et al., 2016; Johnston et al., 2017; Shah et al., 2012; Ullsten et al., 2021). Ullsten and colleagues (2021) emphasize the importance of amplifying the efficacy of breastfeeding and skin-to-skin contact through educational efforts targeting parents and through support by health care providers to apply these strategies.

In terms of secondary outcomes, only one study reported on feeding type. Rates of exclusive breastfeeding were noted to be high in the Brazilian sample evaluated by Korki de Candido and colleagues (2020), which aligned with the primary pain management strategy applied in the study. Breastfeeding may not be possible for all parents to use as pain management during procedures, because not all parents are able to or choose to breastfeed their infant. Conversely, parents who breastfeed may not be supported in using this strategy because of perceived barriers (e.g., ergonomics) for health care providers conducting the procedure (Venegas et al., 2019). Future studies evaluating infant procedural pain management may consider assessing feeding type as an outcome to better understand the use of breastfeeding for pain relief. The other identified secondary outcomes of interest, length of hospital stay and neonatal morbidity, were not reported.

Limitations

All studies included in this review evaluated educational interventions about infant procedural pain management that were presented in video format. Due to

heterogeneity in terms of primary outcomes, populations studied, and measurement approaches across the studies, there are insufficient data to determine the overall effectiveness of these eHealth educational interventions. This review applied a rigorous search strategy; however, the eligibility criteria were restricted to only studies published in English, which may result in language bias and exclusion of relevant eHealth educational interventions that were published in other languages. Additionally, not all educational interventions have been empirically evaluated; for example, the Comfort Promise Learning Hub, embedded in the AboutKidsHealth website created by SickKids Hospital based in Ontario, Canada (SickKids | About Kids Health, 2021). Similar to a previous scoping review on the same topic (Richardson et al., 2020), studies that reported on pain management strategies but did not disclose how parents were educated to apply these strategies were excluded from this review. Therefore, this review may not capture all evidence-based eHealth educational interventions that exist in practice.

Methodological approaches used in the included studies were primarily cross-sectional or pilot studies, which may have limited their ability to discern significant findings. Larger trials assessing the efficacy of parent-targeted eHealth educational interventions are warranted to understand the value of these knowledge translation activities and contribute to the growing field of infant pain research.

2.6.8 Conclusions

Given the significant variability in quality of information on the internet related to parental participation in neonatal pain and notable interest by parents, evidenced-based eHealth resources are needed to enhance effective parental involvement in infant pain management. This review found four unique interventions on the topic, all of which used

videos for content delivery. In light of the heterogeneity identified across the included studies with respect to intervention administration and outcome measurement, the review findings must be interpreted with caution. Although limited, the review findings suggest that short and engaging educational videos have the potential to positively impact parents' knowledge, confidence, and desire to be involved in pain management for their children. Alternative educational resources that utilize different eHealth formats may be warranted to increase accessibility to evidence-based information for all learning styles.

Recommendations for practice

Clinicians and health centers should provide families with information about infant procedural pain management and facilitate use of effective strategies, as recommended by clinical practice guidelines and described in the eHealth educational interventions in this review. Although the findings of this review are inconclusive and based on low-quality evidence, our synthesis suggests that there is increased parental confidence, knowledge, and attitudes, as well as utilization of procedural pain management strategies when families are introduced to these eHealth interventions (Grade B Recommendation). This review found that eHealth educational interventions positively impact eHealth usage and acceptance, suggesting that parents may value interventions delivered through eHealth methods (Grade B Recommendation). Although the evidence related to the impact of eHealth educational interventions on infant pain response during procedures was mixed, findings suggest potential improvements in infant pain (Grade B Recommendation).

Although the overall quality of evidence is low, equipping parents with information about infant procedural pain management has the potential for benefits,

including greater parental involvement and provision of effective pain management, which outweighs the risks of infants not receiving procedural pain management. Thus, incorporating eHealth interventions developed based on high-quality evidence into practice to complement clinician-provided education is recommended.

Recommendations for research

Nearly all of the studies included in the review specifically administered the interventions in the postnatal period. Given that neonates experience painful procedures shortly after birth, we recommend that future research evaluate parent-targeted eHealth educational interventions that are administered prenatally and assess the impact postnatally. Future research may also consider evaluating parental knowledge and behavior pre- and post-intervention administration to better understand the influence of eHealth educational interventions on knowledge uptake and behavior change. To enhance overall understanding of the impact of eHealth interventions, additional outcomes for consideration include confidence and attitudes (perceived relevancy of information), as well as eHealth outcomes (usage, acceptance) and pain management outcomes (strategy use, infant pain response).

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Systematic Review Training Program through the New Ventures Fund. MCY is supported by a Canadian Institutes of Health Research New Investigator Award. The authors are grateful for the support of librarian Katie McLean who completed the PRESS peer review of the search strategy used in this review.

Declarations

MCY, JD and BB are authors of one of the included studies reporting on one of the eHealth interventions. For this study, JD completed screening (title and abstract; full-text), BB completed the critical appraisal and data extraction, and BH acted as the second reviewer for all stages to ensure objectivity. MCY was not directly involved in the screening, appraisal, or data extraction stages for this study.

Conflicts of interest

RM-M is an associate editor of JBI Evidence Synthesis and was not involved in the editorial processing of this manuscript. The other authors declare no conflicts of interest.

2.7 SUMMARY OF LITERATURE REVIEW

Due to inconsistent infant pain management in practice, parents of newborns require more information about their capacity to provide or advocate for pain relief. Much of the existing literature explores the experience of parents with infants in the NICU or related to immunizations, with little focus on the experience of parents of healthy, full term newborns with painful procedures in the immediate postpartum period. Overall, there are few parent-targeted educational interventions about infant pain management. The reviewed literature demonstrates that further research is needed to address the gap in understanding parental informational needs on infant pain and

assessment of the effectiveness of parent-targeted eHealth educational methods. Strides have been made to increase healthcare providers knowledge and skills in infant pain assessment and management utilizing various forms of health education however, matched efforts targeting parents is essential.

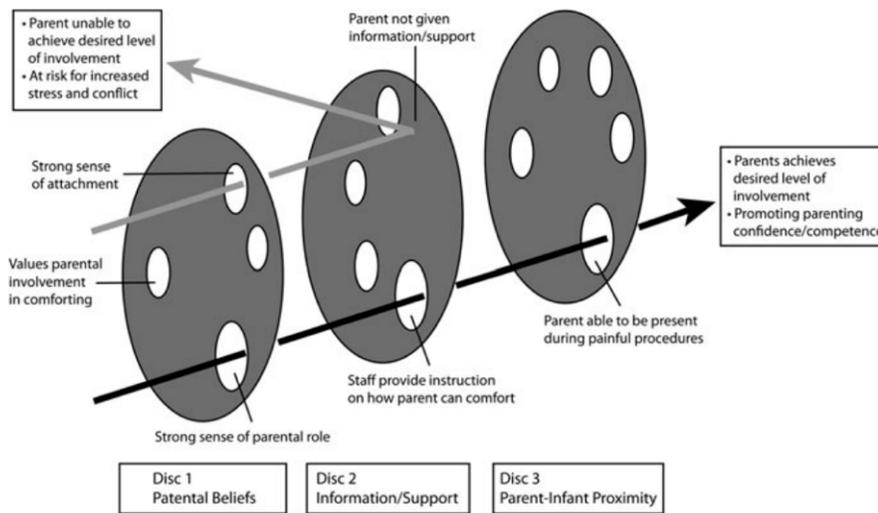
2.8 CONCEPTUAL FRAMEWORK

This dissertation is guided by the Conceptual Model of Parental Involvement in Infant Pain Management, as it uniquely informs the research design, successful implementation of the intervention and overall goal of this project. The Conceptual Model of Parent Involvement in Infant Pain Management by Franck and colleagues (2012) presents a systematic framework outlining the barriers and facilitators to parental involvement in infant pain management, divided across three specific domains: parental beliefs; information and support; and parent-infant proximity (See Figure 2.2). Although initially developed for use in the context of the NICU, the integrity of the conceptual model is maintained when applied to parents with healthy, full term newborns receiving perinatal care as the overarching experiences are similar in this population. The three discs in the model represent factors that act as facilitators (i.e., holes in disc) or barriers (i.e., hard disc surfaces) of parental involvement in pain management. The overall goal of this model is to ensure that the holes in the discs align to allow parents to achieve their desired level of involvement (Franck et al., 2012). This model highlights the influence that parental values and beliefs, the degree of support from healthcare providers and emotional availability of parents has on the level of involvement in newborn pain management. Following this conceptual model, the content within the eHealth educational resource (i.e., intervention of focus for this dissertation), Parenting Pain

Away, aimed to support parents in achieving their desired level of involvement in pain management by providing them with sufficient information and to mitigate against potential barriers of involvement that could result in emotional stress or interpersonal conflict (Franck et al., 2012).

Figure 2.2

Conceptual Model of Parental Involvement with Infant Pain Management



2.9 CONCLUSION

Preterm and healthy, full term infants must endure painful procedures in early life as a part of routine care. Despite known pharmacological and non-pharmacological interventions to reduce procedural pain, infants often fail to receive treatment. Adverse outcomes as a result of untreated procedural pain can cause negative consequences to infant development and wellbeing, some of which can persist into adulthood. The reviewed literature on infant pain management demonstrates that parents have the capacity to provide effective non-pharmacological pain relief during procedures yet are still an underutilized resource in clinical care. Parents believe their role in pain

management is important but often report not receiving sufficient information or support to be involved during procedures. The literature supports parents desire for comprehensive information on infant pain and pain management, yet few parent-targeted educational resources exist with even less resources using innovative methods (i.e., web-based platforms). Greater efforts must be made to provide parents with current, unbiased, evidence-based information about infant pain management.

This dissertation sought to enhance parent-targeted education about infant procedural pain management by developing an eHealth educational resource guided by a conceptual model specific to parental involvement in pain management. To date, no studies have evaluated an eHealth educational resource about infant pain management provided to parents in the prenatal period. As a branch of the larger Chez NICU Home project, based at IWK Health, the dissertation project aimed to develop an eHealth educational resource that is targeted to parents expecting to give birth to healthy, full term infants. Since this resource was designed to be provided antenatally, it is likely that some infants may require intensive care after birth, however this eHealth resource would provide foundational information to promote parent-led pain management and support further discussion about pain management in the NICU. The overall goal of this dissertation project was to explore the influence of eHealth education by gaining valuable insight on the acceptability, uptake and impact of a parent-targeted resource on infant procedural pain management provided antenatally and during brief hospital stays at regional non-tertiary hospitals. The next chapter fully describes the research design and methods which were employed to conduct all phases of this project.

CHAPTER 3 RESEARCH DESIGN

Chapter 3 provides an outline of methods and procedures that were used for this dissertation project. Beginning with an introduction to the novel eHealth solution designed to support and educate parents with infants in the IWK Health NICU, which acted as the template for the intervention in this study. Following that, a detailed description of the overall objectives, research questions, and research design of each project phase is presented. Finally, limitations, ethical considerations and knowledge translation activities for the project are outlined.

3.1 CHEZ NICU HOME

IWK Health, a tertiary care teaching hospital in Halifax, Nova Scotia provides evidence-based, high quality care to families across Nova Scotia, New Brunswick, and Prince Edward Island (IWK Health, 2023a). The MOM-LINC (Mechanisms, Outcomes, Mobilization of maternally-Led Interventions in Newborn Care) Lab, an interdisciplinary research team based out of IWK Health, developed Chez NICU Home, a complex innovative solution that provides families with a novel virtual platform that is accessible through a network of devices and technologies. The development of the Chez NICU Home project, led by Dr. Marsha Campbell-Yeo, was supported by the Atlantic Canada Opportunities Agency, Cisco Canada, and IWK Health. Whether in hospital or at home, families and caregivers can connect virtually through video conferencing technology, as well as access the Chez NICU Home educational library and social support interfaces. The educational component with Chez NICU Home provides a learning platform primarily for parents to become informed about their essential contribution to their child's wellbeing, to build capacity, and to teach skills on how to care for their infant

(IWK Health, 2022). Maintaining the Public Health Agency of Canada's position on Family-Centred Maternity and Newborn Care in Canada and FICare principles, Chez NICU Home aims to promote early parent-infant attachment, collaboration with all care providers, and an enhanced role for families in decision making by providing greater access to evidence-based health information (Bracht et al., 2013; Public Health Agency of Canada, 2017). The platform does not fully replace face-to-face instruction but reduces redundancy and extends standardized instructions across the multiple health providers that interact with families. In this secure virtual platform, parents have unlimited access to an interactive, educational platform consisting of different topics, including infant procedural pain management.

Although currently designed for neonatal populations for use in a tertiary NICU, Chez NICU Home was forecasted to be adapted for parents of infants in various care areas to improve family-integrated care practices overall. Many elements of the educational library are also applicable to healthy, full term infants and can be tailored to suit the needs of this population. Currently, there are no comparable programs in Atlantic Canada providing evidence-based education on care practices for healthy, full term infants. Given the long-term effects of untreated infant pain specifically, it is essential to attend to the informational needs of all parents utilizing innovative designs to help them become more actively involved in reducing their infant's pain associated with needle-related procedures. In partnership with Chez NICU Home and IWK Health, this project aimed to increase parental confidence and capacity to provide and advocate for pain relief in the healthy newborn population and throughout infancy. Consistent with IWK Health's

mission, this study branched beyond NS to provide innovative care extending to healthy, full term newborns in PEI to support parents of newborns across the Maritimes.

3.2 OBJECTIVES

The following objectives guided this project evaluating the overall impact of the eHealth educational resource about infant procedural pain management given antenatally:

1. To evaluate usability of the eHealth educational resource.
2. To evaluate if the eHealth educational resource is acceptable to parents and a feasible intervention to administer prenatally.
3. To determine if the eHealth educational resource influences parental knowledge, perceived self-efficacy and involvement in pain management during early life.

3.3 RESEARCH QUESTIONS

Using a phased approach, the project sought to address the following research questions:

1. Among parents of healthy newborns, what is the acceptability and feasibility of an eHealth educational resource on parent-led procedural pain management?
2. Among parents of healthy newborns, does an eHealth educational resource on parent-led procedural pain management influence parental knowledge, self-efficacy, and active involvement in pain management?

3.4 RESEARCH DESIGN

The dissertation project employed a phased approach to develop and evaluate the impact of Parenting Pain Away, the eHealth educational resource (i.e., website; project intervention) on infant pain and pain management strategies. The development phase of

the eHealth educational resource occurred using current scientific evidence, adapted educational content from Chez NICU Home, and consultation with key stakeholders. A committee of stakeholders comprised of parents, designers, local perinatal clinicians and administrators, and researchers in perinatal health care areas reviewed Parenting Pain Away and informed the study plan prior to seeking ethical approval. Phase 1 addressed objective 1 through usability testing with parents to gather a thorough assessment of ease of use and satisfaction of the resource. Parents or expectant parents were recruited to participate in individual interviews where participants were asked to interact with the resource and provide verbal and written feedback using validated data collection methods. Objectives 2 and 3 were addressed in phase 2 through an evaluation to determine if parents like the resource, if it is practical to use in clinical settings and if, after using the resource, parents have greater knowledge and confidence with pain management, and use pain relieving techniques during their newborn's procedures. Further details about each phase are provided in the sections that follow.

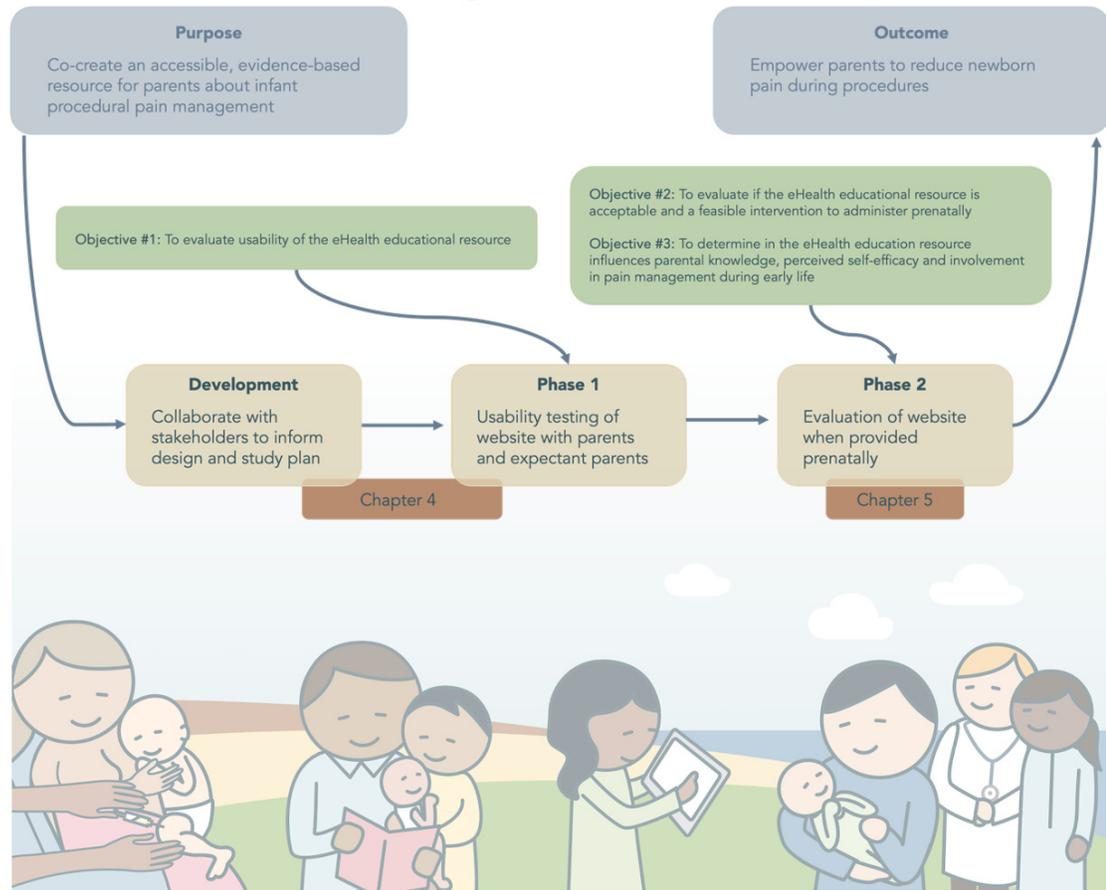
3.5 METHODS

This study received ethical approval from the Dalhousie and Health PEI Research Ethics Boards. The following figure provides a visual depiction of the project phases in relation to the objectives and where the results are reported in this dissertation.

Figure 3.1

Diagram of Study Phases

Parenting Pain Away



3.5.1 Project Setting

All phases of this project occurred in Prince Edward Island. PEI currently has a population of 176, 250 (Statistics Canada, 2023a) and holds the second highest growth rate across Canada (Prince Edward Island Statistics Bureau, 2023). Residents of PEI predominantly speak English as their first language (95.9%) and do not identify as a visible minority (90.5%) (Statistics Canada, 2023b). Being Canada's smallest province, PEI has a higher population density at 27.2 people per square kilometer compared to 4.2 nationwide (Statistics Canada, 2022c, 2022b). As of 2021, there were 55,440 people of

typical childbearing age (i.e., 15-44) in PEI, representing 35.9% of the provincial population (Statistics Canada, 2023b). Birth rates have fluctuated during the dissertation project period with 1292 births in 2020 and 1448 births in 2021(Statistics Canada, 2022a, 2023c), exhibiting the greatest increase when compared across all provinces and territories (Statistics Canada, 2022a). PEI was chosen as the project setting primarily as it is included for coverage by IWK Health (i.e., developer of Chez NICU Home) (IWK Health, 2023a), but also since there had been no studies related to infant pain management focusing on the PEI population(Hughes, Benoit, et al., 2023; Richardson et al., 2020). Most related Canadian studies targeted populations in urban areas (e.g., Toronto) with readily access to tertiary health centres that have well-established infant procedural pain management policies (e.g., SickKids). Using PEI as the target population for this project presented the opportunity to model current practices and capacity for rural areas roughly 300 kilometers away from the nearest tertiary health centre.

3.5.2 Development Phase

Aim

The development phase created Parenting Pain Away which is the project website about infant procedural pain and pain management targeting parents during the prenatal period. The objective of this phase was to adapt and update the existing Chez NICU Home educational chapter focused on infant procedural pain management strategies for the healthy newborn population (i.e., greater than 37 weeks gestational age and not requiring intensive care). Additionally, to consult with key stakeholders to ensure the project website would effectively meet the target populations needs.

Procedures

The content for Parenting Pain Away was prepared using current evidence from knowledge syntheses of relevant literature, as outlined in chapter two, and clinical practice guidelines regarding infant pain management during procedures developed by Taddio and colleagues (2015) and Lago and colleagues (2017), as well as position statements prepared by the Canadian Paediatric Society (2017) and the American Academy of Pediatrics (2016). Expert input by parents, clinicians, designers, administrators, and perinatal researchers, as well as the doctoral supervisory committee members, was gathered prior to the submission for ethical approval to ensure that the prototype captured all necessary evidence-based information on procedural pain management for infants and effective design for information consumption. As Parenting Pain Away was adapted from an existing resource that previously went through extensive user-centred evaluation with parents of infants requiring intensive care, participants were not recruited for website development in this phase.

Squarespace, an online website designer, was used to develop Parenting Pain Away. Along with providing a unique domain, Squarespace has built-in functionality to collect data on specific website metrics that supported feasibility outcomes in phase 2, including but not limited to user visits, site pathways, and popular content. To mitigate potential barriers to use prior to phase 1 (usability testing with participants) a graphic designer with expertise in user experience and emotional design was hired as a consultant to review Parenting Pain Away and further refine the website design. Collaboration with a designer is essential as their unique skillset in user experience enhances the likelihood for overall user satisfaction, usage, and knowledge uptake (Kim et al., 2016; Kim & Lim, 2013; Pătruț & Spatariu, 2016; Plass & Kaplan, 2016).

Anticipated Outcomes

The intention for the eHealth educational resource, Parenting Pain Away, was not to replace healthcare provider guidance on newborn pain management, however it sought to provide standardized care instructions for families while still attending to different learning needs through innovative methods. This intervention is unique as it focuses on empowering parents by providing unlimited access to an eHealth resource that promotes family-integrated care in infant pain management by clearly outlining what parents can do to reduce pain experienced during needle-related procedures, as opposed to describing the healthcare provider's role. The overall dissertation project was feasible to conduct as the lead researcher was supported by funding through a Doctoral Research Award with the Canadian Institutes of Health Research and BRIC NS, which was sufficient to pay for Squarespace, consultation services with a user experience designer, the collaboration meeting with stakeholder committee, and conduct the subsequent project phases.

3.5.3 Phase 1 Usability Testing

Aim

The aim of phase 1 was to test the Parenting Pain Away prototype and gather insight on parental satisfaction and ease of use of the resource. The research objective was to evaluate usability of the Parenting Pain Away prototype.

Methods

Refinement of Parenting Pain Away was conducted using iterative usability testing with expectant parents and parents of healthy, full term newborns using the "Think Aloud" approach as they navigate through the website (Kushniruk & Patel, 2004).

All parental feedback was coded, analyzed and appropriately incorporated to complete the final design of Parenting Pain Away.

Procedures

Inclusion and exclusion criteria. The criteria for inclusion were parents or expectant parents who can speak, read and write in English and have given birth in the past two months or were expected to give birth at Prince County Hospital (PCH) or Queen Elizabeth Hospital (QEH) in PEI. Parents of infants who required care for eight hours or more in the NICU or infants that were separated from their parents postpartum (e.g., adopted; apprehended) were not eligible for study participation. Infants who required care in the NICU for greater than eight hours are often considered as more of a high-risk population and their experiences with painful procedures and pain management would differ to align with their critical care needs. As the project website targeted the low-risk perinatal population parents of infants that did not require critical care were recruited. For the purposes of this project (i.e., phases 1 & 2), biological, non-biological or adoptive parents were considered, which also included same sex parents or single parents. Couples could participate in this project phases together, but data was collected separately to ensure their unique experience was captured. A partner of a person who has given birth, or is expected to give birth, could participate alone should they have wished.

Sample population. Up to 15 individual parents or expectant parents were recruited online and from various Health Centres across PEI to participate in iterative testing cycles for this phase. This sample size was based on Nielsen's Law of Diminishing Return to identify usability issues (Nielsen & Landauer, 1993). A purposive sampling method was employed to strive for maximum variation selection for a study

sample of parents or expectant parents with varying characteristics including but not limited to age, sex, gender, ethnicity, and geographical location of their home address (i.e., rural or urban) (Breakey et al., 2013; Jibb et al., 2017).

Recruitment and consent procedures. Recruitment was initiated through online advertisements promoting the study via social media, (e.g., Twitter, Facebook, Instagram), online classifieds (e.g., Kijiji), and email to key stakeholders who could promote the study (e.g., Project stakeholders committee, Health PEI, PEI Public Health, Public Health Agency of Canada, CBC PEI). The lead researcher also contacted CBC PEI for a radio interview about the study, which was found to be an effective method for recruitment in the PEI context with previous studies. No in-person or community-based recruitment was conducted as phase 1 occurred during a time which COVID-19 restrictions were evolving. Interested parents were instructed to contact the lead researcher by email or telephone for more information about the study, including the reason the study is being conducted, how the study will be conducted, what participation in the study would involve, and the risks and benefits of participation. The lead researcher emphasized to parents that participation is voluntary, and that they could withdraw from the study at any time without consequence or be referred to contact Health PEI Research Ethics Board (REB) and/or Dalhousie REB. If the parents wanted to participate, the lead researcher scheduled a virtual meeting to conduct usability testing interviews and emailed the consent form to parents, if applicable, so they could review prior to the meeting. The meetings occurred virtually using Zoom videoconferencing technology (Zoom Video Communications, 2023). At the beginning of the virtual meeting the lead researcher reiterated that participation is voluntary and completed the

process of obtaining informed consent, in accordance with tri-council policies. When the prospective participant agreed to enroll in the study, they were requested to sign the consent form and email the signed form back to the lead researcher. In cases where the participant did not have the ability to print and scan the informed consent form or provide an electronic signature, verbal consent was attained and recorded during the meeting using Zoom. Please see Appendix 3.1 for the phase 1 recruitment materials (e.g., scripts, posters, consent forms).

Outcome measures and variables. A questionnaire was given to participants to obtain specific information about the sample characteristics on demographic data including gender, race, age, education level, employment status, socioeconomic status proxy, birth mode (if applicable), and family data. After navigating through Parenting Pain Away, all participants completed the Post Study System Usability Questionnaire (PSSUQ) (Lewis, 1995) to gather information on user acceptability and user satisfaction of the resource. The PSSUQ is a widely used usability assessment questionnaire with strong psychometric properties (Lewis, 1995, 2002; Rotolo, 2017). It is a 16-item, 7-point scale questionnaire that yields an overall score and can be divided into three subscales: System Usefulness, Information Quality and Interface Quality. The PSSUQ has excellent reliability, with an alpha coefficient of 0.97. It is sensitive to user group and system differences and valid, based on significant correlation with other measures of user satisfaction. An additional two questions were posed to get participant's perspectives which informed the plan for phase 2 (e.g., After you give birth, would you receiving a brief daily survey be a burden while you are in hospital?).

Data collection. Refinement of Parenting Pain Away was conducted through iterative cycles of usability testing. To facilitate data analysis, the laptop screen and participant (through the laptop camera) were recorded during the testing sessions. This simple yet robust approach allows the researcher to capture all user interactions with the resource to discern the participants impressions about the content, look and feel, navigation, and functionality. The lead researcher offered participants to watch a sample video, created by the Nielsen Norman Group, to demonstrate what the “Think Aloud” approach entails (Nielsen, 2014). Five individual interviews per cycle were conducted until data saturation was reached. The individual interviews took place virtually using Zoom videoconferencing technology. Each participant was asked to share their screen so the lead researcher was also able to view their personal computer or laptop screen as they navigated through Parenting Pain Away. All questionnaire invitations were emailed to the participants and questionnaires were completed through REDCap (Research Electronic Data Capture); a secure web-based data management software housed on Dalhousie University’s private servers (Harris et al., 2009, 2019). Testing sessions followed a semi-structured script to guide parents as they navigate through the resource. Please see Appendix 3.1 for all data collection materials.

Data analysis. Questionnaire data was analyzed by the lead researcher using Statistical Package for Social Sciences (SPSS) version 26 (IBM Corporation, 2023). Demographic characteristics were expressed in means and standard deviations and percentages, as applicable. Descriptive statistics were reported as appropriate for the PSSUQ measure. A p value of 0.05 was considered significant for all outcomes. Video data was coded adhering to a standardized coding scheme established by previous

usability testing in our research lab using Noldus software for video data analysis (Noldus Information Technology, 2018). This coding scheme categorized positive or negative data related to various aspects of the project intervention (i.e., Parenting Pain Away website) including the look and feel, navigation, content, and features. Video data is necessary to support participant report and provide greater context to participant's experience interacting with the project intervention. For example, if a participant has an issue navigating between sections of the website, the video data will show exactly where the participant went which enhances their verbal description and will facilitate refinement of website navigation. Video data is typically gathered with the Think Aloud method during usability testing to uncover rich data that will inform website refinement, such as participant facial expressions and cursor pathways. After analysis was completed, parental feedback was incorporated into the final design of Parenting Pain Away.

Anticipated Outcomes

As the Parenting Pain Away prototype was developed with consultation from a User Experience designer, minimal issues with program usability, high user satisfaction and acceptance was anticipated in phase 1. User feedback on the navigation, content, look and feel, and functionality was anticipated to be positive and include suggestions for improvement.

3.5.4 Phase 2 Evaluation

Aim

In phase 2, the aim was to evaluate the impact of Parenting Pain Away, given during the prenatal period, on feasibility, parental acceptability, knowledge, attitudes, and behaviour. Phase 2 was guided by two research objectives:

1. To evaluate if the eHealth educational resource is acceptable to parents and a feasible intervention to administer prenatally.
2. To determine if the eHealth educational resource influences parental knowledge, perceived self-efficacy and involvement in pain management during early life.

Phase 2 sought to answer the following research questions:

1. Among parents of healthy newborns, what is the acceptability and feasibility of an eHealth educational resource on parent-led procedural pain management?
2. Among parents of healthy newborns, does an eHealth educational resource on parent-led procedural pain management influence parental knowledge, self-efficacy, and active involvement in pain management?

Methods

A quasi-experimental evaluation of Parenting Pain Away was conducted using a pre/post intervention design to test acceptability, feasibility, and utilization of parent-led pain management.

Procedures

Inclusion and exclusion criteria. The project intervention was intended to be used during the antenatal period. Thus, low-risk expectant parents and their partners (when applicable) in the community, who had access to the Internet, can speak, read, and write in English and were anticipated to give birth at PCH or QEH in PEI were eligible for inclusion in phase 2. As the study aimed to evaluate outcomes after parents have given birth, parents of infants who required care for eight hours or more in the NICU

would continue to participate in the study, however their data would be analyzed separately to adjust for contextual differences. Infants that were separated from their parents postpartum (e.g., adopted; apprehended) would no longer be eligible for study participation.

Sample population. At least 40 individual expecting parents were planned to be recruited prenatally from 32 weeks of pregnancy and up to birth through online methods and through various health settings, including public health prenatal education classes and routine prenatal assessments at the main obstetrician clinics and primary care Health Centres across PEI. The goal was to have a sample size of minimally 40 participants, which is consistent with previous feasibility studies (Billingham et al., 2013). Thus, more participants were recruited to ensure retention of required sample size throughout the study. A maximum sample size was not specified.

Recruitment and consent procedures. During phase 2, recruitment was conducted through online methods and locally at various health settings across PEI. The study was promoted by posting advertisements to social media, (e.g., Twitter, Facebook, Instagram), online classifieds (e.g., Kijiji), and through email to key stakeholders (e.g., Project stakeholders committee, Health PEI, PEI Public Health, Public Health Agency of Canada, CBC PEI). Again, the lead researcher conducted a radio interview with CBC PEI for this study phase. The web-based recruitment strategy instructed interested expecting parents to contact the lead researcher for more information about the study. When interested expectant parents reached out, the lead researcher asked questions to determine their eligibility for the study (e.g., if 32 weeks gestation and still expecting; planned location of birth). If the expecting parents were deemed eligible, they were sent a link to

access the consent form and initiate the informed consent process through. If preferred, potential participants could also have texted “interested” to a study specific number, provided by Twilio (Twilio, 2023), where they received a response that requested their name and screened for eligibility. Their phone number was collected since they texted through their device.

Recruitment also occurred in several prenatal settings including public health nursing, obstetrics clinics, and primary care clinics. Study posters were hung throughout the care areas where patients could review them. Additionally, administration support at the main obstetric clinics was sought to identify prospective participants that met the eligibility criteria and clinic staff approached those that were eligible to determine if expecting parents were willing to learn more about the study.

Obstetrical Administration Support Process:

1. Clinic staff would review patient demographics to determine their eligibility for the study (i.e., low-risk expecting parent, at least 32 weeks gestation, proficient in English, and are anticipated to give birth at a provincial hospital).
2. If expectant parents met the eligibility criteria, the clinic staff would offer the information sheet to expectant parents (i.e., infographic) so they had the opportunity to learn more if they wish.
3. If the expecting parents expressed interest, clinic staff would direct them to learn more by contacting the lead researcher by email or text message, as outlined on the information sheet.
4. Consistent with the web-based recruitment strategy, when interested expectant parents contacted the lead researcher, they were asked questions to determine

their eligibility for the study (e.g., if at least 32 weeks gestation and still expecting; planned location of birth). If the expecting parents were deemed eligible, they were sent a link to access the consent form and initiate the informed consent process through REDCap.

To clarify and standardize this process, an instructional document was created and given to clinic staff to support recruitment in phase 2. Please Appendix 3.2 for all phase 2 materials.

Outcome measurements. The following measures aim to address objectives two and three of the overall study. Objective two aims to evaluate if Parenting Pain Away is acceptable to parents and a feasible intervention to deliver prenatally and objective three aims to determine if Parenting Pain Away influences knowledge, self-efficacy and utilization of parent-led pain management. All measures used to assess outcomes in phase 2 are provided in Appendix 3.2. Table 3.1 provides an overview of all outcomes of interest, measures, and timing of data collection, followed by a detailed description of each below.

Table 3.1

Data Collection Timeline

Outcome variable	Measure	Enrolment (prenatal)	Postpartum
1. Demographics	Survey	✓	
2. Newborn Pain Management Knowledge	Survey	✓	✓
3. Self-Efficacy	Karitane Parenting Confidence Scale		✓

4. Feasibility and Acceptability	System Usability Scale; Survey	✓
5. Parent-led pain management	Survey; Parent Diaries	✓

1. **Demographics:** A questionnaire was given to participants to obtain specific information about the sample characteristics on demographic data including gender, race, age, education level, employment status, socioeconomic status proxy, newborn birth mode, family data and experience with technology. This questionnaire was administered at baseline, pre intervention exposure, and would take parents approximately two minutes to complete.
2. **Newborn Pain Management Knowledge:** Parental knowledge of newborn pain management was measured pre and post intervention exposure using a study specific questionnaire with items compiled from three original standardized measurements; developed and validated by Taddio and colleagues (Taddio et al., 2013), Harrison and colleagues (Harrison et al., 2017), and Orr and colleagues (Orr et al., 2016). This questionnaire has 17 items and would take parents approximately five minutes to complete.
3. **Self-efficacy:** Parental self-efficacy was measured post intervention exposure using the Karitane Parenting Confidence Scale (KPCS) (Črnčec et al., 2008). The KPCS is a 15-item tool that assesses perceived self-efficacy of parents of newborns birth to twelve months of age. The KPCS has acceptable internal consistent (Cronbach's alpha = 0.81) and test-retest reliability ($r = 0.88$) (Črnčec et al., 2008). Each question is rated on a 4-point scale with the following possible item responses: no, hardly ever; no, not very often; yes, some of the time; yes,

most of them. Total scores for this tool ranging from 0-45, where higher scores indicate a higher level of perceived self-efficacy. Črnčec and colleagues (2008) states that a score of 39 or less (out of a possible 45) is determined to be a clinically low perceived parenting self-efficacy (PPSE) (Črnčec et al., 2008). The KPCS would take approximately five minutes for parents to complete.

4. **Feasibility and Acceptability:** These outcomes were measured at follow-up data collection, post intervention exposure, using a study specific questionnaire that compiles the System Usability Scale, a standardized, reliable, and widely validated questionnaire with 10 items each ranked on a Likert scale (Bangor et al., 2008; Brooke, 1996; Lewis, 2018), and 10 additional items related to the timing of intervention delivery, resource content, staff support and intentions for parent-led pain management with future painful procedures. Parental usage of learning material was gathered through parental self-report of interaction with the materials, as well as analytics from Parenting Pain Away website. This questionnaire would take approximately 10 minutes for parents to complete.
5. **Utilization of parent-led pain management:** Parent-led pain management during painful procedures occurring in hospital (e.g., Vitamin K injection, metabolic newborn screening) was measured on whether parents were involved. This outcome was measured by self-report through follow-up data collection, post intervention exposure. Parental diaries were also collected to evaluate the degree of parental involvement with all painful procedures experienced by their newborn in hospital.

Data collection procedures. Data collection was conducted until sample size requirements were met (i.e., minimum of 40 participants retained). Following consent, participants completed a questionnaire to gather baseline characteristics, including demographic information (e.g., age, gender, biological sex, parity, education, postal code, experience with technological devices) and newborn pain management knowledge. Baseline data collection occurred after the participant consents to the study, through REDCap (Harris et al., 2009, 2019). In the event that a couple participated, both partners were given access to Parenting Pain Away and were required to complete questionnaires separately. It would take approximately seven minutes to complete baseline data collection. After completing the baseline questionnaire, all participants were provided with instructions on how to use the eHealth educational resource, Parenting Pain Away. Participants were instructed to use the resource as often as they would like prior to the birth of their baby. The lead researcher also shared their contact information in case participants require technical assistance with Parenting Pain Away (also listed on Parenting Pain Away website).

As follow-up data collection began after participants have given birth, the lead researcher had requested additional consents and documentation to support follow-up procedures. To reduce burden, participants were sent a single reminder (by email or text, as per participant preference) one week prior to their expected date of delivery (see Appendix 3.2 for reminder script). To reduce need for repeated reminders and potential participant burden, yet ensure retention, the research team planned additional strategies for follow-up data collection:

1. Participants were given a digital card at enrolment that states they are participating in this study. The lead researcher suggested that participants bring this card to the hospital so unit clinical lead will be aware that they enrolled in this study and could check for their signed consent prior to notifying the lead researcher to begin follow-up data collection.
2. The lead researcher requested participant consent to contact their primary prenatal care provider to attach a special study label to their prenatal record that indicates they are a study participant.
3. The lead researcher requested additional consent giving the hospital postnatal unit clinical lead, at either PCH or QEH, permission to notify me once they have given birth. The lead researcher ensured that each hospital had a copy of participant's signed consent. The hospital postnatal unit clinical lead would not notify the lead researcher of a participant's birth status without the participant's signed consent.
4. Physical posters were at each postnatal unit, to remind participants to text or email "BIRTH" to initiate follow-up data collection.

Once the lead researcher was alerted by participants or hospital staff at PCH and QEH that the participants have given birth, parents received a daily email or text while in hospital. This daily email/text prompted participants to complete a diary entry reporting on how many painful procedures were conducted on their infant that day, if they were involved in pain management, and if so, what strategy did they use (e.g., skin-to-skin contact). The daily diaries were created and sent to participants emails using REDCap. At one week postpartum, a final survey was sent to parents using REDCap. Participants were asked to provide a self-report on whether they were involved in a parent-led pain

management intervention (e.g., breastfeeding, skin-to-skin care, advocate for sucrose) during the vitamin K injection immediately following birth and the routine newborn metabolic screening. Additionally, participants completed the newborn pain management knowledge and self-efficacy questionnaires, as well as a feasibility and acceptability survey. It would take approximately 25 minutes for participants to complete follow-up data collection postpartum. Data related to parental usage of the resource was gathered through Parenting Pain Away website analytics. If participants did not complete the online survey by two weeks postpartum, the lead researcher followed up to gently remind parents to complete the online survey.

Data analysis. Analysis of outcome data was using IBM SPSS software version 29.0 (IBM Corporation, 2023) and Microsoft Excel (Microsoft Corporation, 2023). Data from the daily diaries were analyzed through content analysis and coded into broader categories (Polit & Tatano Beck, 2020). Descriptive statistics and assessment of frequency distributions were calculated to describe and synthesize all variables of interest, including demographic characteristics of participants. Analysis was conducted using one-way analysis of variance to determine the effect of the eHealth educational resource (i.e., Parenting Pain Away) on parental knowledge and perceived self-efficacy scores. Knowledge questionnaires were compared using dependent t-test and comparisons using independent t-tests and chi-square to determine associations with parent demographics and uptake of parent-led pain management interventions. Sub-analyses were performed, using regression analysis, to determine if there are any associations between parent characteristics on outcomes based on demographics (e.g.,

age, parity, gender, sex, race, etc.) or differences between responses across couples, when applicable.

Anticipated Outcomes

In phase 2 of this project, Parenting Pain Away had gone through preliminary usability evaluations with the target demographic and thus was anticipated to be highly rated in terms of user satisfaction, acceptability, and feasibility. Parental knowledge about infant pain management was anticipated to increase after intervention exposure, which is consistent with studies evaluating similar eHealth educational interventions targeting infant pain management. While the ultimate goal of this project phase was to influence knowledge uptake and involvement in parent-led pain management during procedures, there could also be barriers related to current clinical practice in PEI that may impact parents' ability to be involved. The potential barriers are discussed further in the following limitations section.

3.6 LIMITATIONS

While special attention was paid to mitigate any issues during the project period, there were some potential limitations that were considered prior to starting. For phase 2, there could have been difficulty accessing the target population for recruitment however, the lead researcher is a registered nurse from PEI with an established relationship with public health and various prenatal care providers across the province. Additionally, the relationships developed through the key stakeholders committee meeting significantly enhanced access to potential participants and study support during recruitment and data collection phases. Social desirability bias was possible, whereby participants may report only positive feedback during usability testing in phase 1 and on the acceptability

questionnaires in both phases (i.e., PSSUQ; SUS). To avoid this, participants were reminded that positive and negative feedback is beneficial for the refinement and overall success of the intervention. As phase 2 aimed to assess feasibility and acceptability of the intervention through an evaluation, the ability to determine the direct impact of the intervention on study outcomes is limited but this study builds a strong foundation to inform future effectiveness trials. Finally, parent-led newborn pain management has been recognized as an essential component of evidence-based newborn care and is clearly articulated in a policy for all staff and healthcare providers within the health authorities in Nova Scotia (IWK Health, 2020). To our knowledge, no such policy exists within Health PEI yet (the Infant Pain Committee is currently developing one), thus education and staff competencies may differ from what is practiced in Nova Scotia. This was anticipated as a potential barrier in phase 2 for parents to use the pain-relieving techniques described in the project intervention but the experience of participants will help shed light on policy adherence and the power of parents as advocates for their newborn's care. To mitigate this potential barrier, the lead researcher met with Laboratory Services at QEH to discuss supporting parents in providing pain management during the newborn blood specimen collection. Additionally, the nurse managers and educators on both hospital postpartum care units were championing this study and actively encouraging staff to provide effective procedural pain management as per best evidence.

3.7 ETHICAL CONSIDERATION

The sampling and setting included human participants within health centres and the community in PEI and therefore required review and approval from Dalhousie University and the PEI REBs prior to initiation of phases 1 and 2 of the project. Prior to

submitting to each REB, the lead researcher received letters of support from PEI Public Health, PCH, QEH, and the Charlottetown Obstetrical Clinic. Upon approval of REB with each institution, the lead researcher followed procedures for obtaining informed consent in accordance with tri-council policies for all prospective participants in phase 1 and 2. In each phase, informed consent was achieved by disclosing the intent of the study, providing an explanation of how this study may be of benefit to them, their child, and future families, and providing a detailed description of any risks that could arise through the study. The lead researcher ensured participants understood that they were able to withdraw from the study at any time and if they agreed to move forward, participants were required to sign an informed consent form to confirm their participation in the study (Creswell, 2013). Maintaining participant privacy and confidentiality was of the utmost importance for all phase of this study. After downloading the data from REDCap, any identifying information was separated from the data file which will remain de-identified for analysis. Files with the identifying information (e.g., consent forms, email addresses, video recordings) were stored as encrypted files on Dalhousie's One Drive. Any physical documents were stored in a locked cabinet in the lead researchers locked office until the end of the study. Once the study was completed, all physical documents were scanned and saved to Dalhousie's One Drive, and the physical files will be destroyed through Iron Mountain services. Email addresses were separated based on whether parents provided their email addresses to be informed of the study results.

Potential risks for participants included feeling discomfort, annoyed, overwhelmed with the data collection procedures during the postnatal period. If there were any questions in the survey that participants preferred not to answer, they were able

to skip these by selecting the option “prefer not to answer” where applicable. Additionally, if participants preferred not to complete the daily diaries during the immediate postnatal period, they were able to select the “opt-out” option. The perinatal period can be an overwhelming experience for parents which could cause psychological distress. The research team provided parents with a recommendation to contact their healthcare provider or a public health nurse if they had any concerns. Additionally, the research team provided information on credible support resources available locally and online in the consent forms for both project phases and on the Parenting Pain Away website.

3.8 KNOWLEDGE TRANSLATION

The Knowledge-to-Action Cycle is a key framework in knowledge translation and thus was used to inform this project in its journey through intervention development and evaluation (Graham et al., 2006; Straus et al., 2013). As discussed in Chapter 2, knowledge syntheses of parent-targeted resources on infant pain management, generally and specifically focused on eHealth interventions, were conducted to gather a baseline of the current available evidence and identify gaps in knowledge (Straus & Holroyd-Leduc, 2008). Additionally, to understand the local context, a comprehensive assessment of mothers in the Maritime Provinces (i.e., NS, New Brunswick, and PEI) was conducted to gain insight into their experience of support and education during the postpartum period (Dol, Aston, et al., 2022; Dol, Hughes, et al., 2022; Dol, Richardson, Grant, et al., 2021), including a focused survey on involvement with newborn pain management (Richardson, Dol, et al., 2021). Collaboration with key stakeholders was integral to tailoring the project intervention to the target population, as well as identifying and overcoming

barriers to implementation. The supervisory committee for this project was comprised of stakeholders in technology, health care practice and research sectors, whose expertise informed the project overall. To provide greater local insight stakeholders, including parents (an expectant first-time parent; parents of children of varying ages), administrators and clinicians in public health, obstetrical centres and the primary health care networks, were consulted to enrich the project intervention prototype and adapt the study procedures for a high likelihood of success. As the project intervention is a parent-targeted educational resource focused on parent-led infant pain management, engaging parents in the stakeholder committee and as participants in phase 1 provided invaluable insight to the development and feasibility of the Parenting Pain Away. Consistent with the knowledge-to-action framework, the impact of Parenting Pain Away was assessed through an evaluation in phase 2 of the study (Straus et al., 2013). The findings from the phase 2 evaluation provided further information on any barriers or facilitators related to intervention administration and user satisfaction, as well as highlighted areas of Parenting Pain Away that may require improvement to better support knowledge uptake. While infant procedural pain management policies are still not formally present in clinical practice at the study settings, the results of this project will help to further contextualize and emphasize the importance of implementing a policy to support families across PEI. A full trial exploring the effectiveness of Parenting Pain Away is a possibility for the future to ensure the research team has developed an intervention capable of sustaining knowledge use, however this would not be essential for adopting parent-led infant procedural pain management into routine practice.

Knowledge translation activities to disseminate overall project findings will be conducted to increase awareness and inform behavior, attitudes, clinical practice and future research. Traditional techniques, including peer-reviewed publications and conference presentations will be used to disseminate study findings. With these techniques, all attempts will be made to increase the accessibility of the findings to the broader public through open access publications and presentations at a variety of local, national, and International conferences (e.g., International Symposium on Pediatric Pain, Pain In Child Health, Canadian Association of Perinatal and Women's Health Nurses, Canadian National Perinatal Research Meeting, Primary Health Care Research Day, College of Registered Nurses and Midwives of Prince Edward Island). Additional dissemination strategies will be tailored for specific audiences, including parents, researchers, and local healthcare professionals. For parents, the lead researcher aims to host a session at Chances Family Centre PEI, a local non-profit organization aimed to enhance parenting skills and child wellbeing. Additionally, to circulate dissemination materials (e.g., parent-targeted infographic) through social media platforms (i.e., Facebook, X) and public health prenatal resource packages to further promote the use of parent-led infant pain management during needle-related procedures. Knowledge translation activities targeting researchers will also occur on social media using tailored dissemination materials (e.g., infographic) and the lead researcher will seek to present project findings to an International network of pediatric pain researchers through a webinar with Pain In Child Health (PICH) program. Project findings will be disseminated by email to the stakeholder committee members, as well as Health PEI employees at the Primary Health Care Networks, Public Health Nursing, and perinatal

care centres to inform local healthcare providers. As Parenting Pain Away was found to be a feasible resource, the lead researcher will collaborate with Chez NICU Home to plan to maintain the website as a freely accessible resource. These knowledge translation activities are anticipated to be feasible with the support of the lead researcher's doctoral funding, and additional funding will be sought as needed to ensure project findings are successfully disseminated to the broader population.

CHAPTER 4 PARENTING PAIN AWAY: DEVELOPMENT AND USABILITY TESTING OF AN EDUCATIONAL WEBSITE ABOUT INFANT PROCEDURAL PAIN MANAGEMENT

Chapter 4 is presented as a manuscript that was published in *Paediatric and Neonatal Pain* as: Hughes, B., Martin Misener, R., Latimer, M., Smit, M., McGrath, P., & Campbell-Yeo, M. (2023). Parenting pain away: Development and usability testing of an educational website about infant procedural pain management. *Paediatric and Neonatal Pain*, 00; 1-20. DOI: 10.1002/pne2.12096.

Contribution statement: BH developed the study with input and support from MCY, RMM, ML, MS, and PM. BH conducted the data collection, analyzed the data and drafted manuscript. MCY, RMM, ML, MS, and PM contributed to revising the final manuscript. Copyright details can be found in the Chapter 4 Appendix.

4.1 ABSTRACT

Introduction: All newborns undergo minor painful procedures (e.g., injections). Despite strong evidence supporting parents' efficacy to reduce procedural pain (e.g., breastfeeding), parents remain an underutilized resource. Limited evidence-based resources about infant procedural pain management targeting parents in the perinatal period exist. We co-created Parenting Pain Away, a website to enhance parents' access to information and participation in procedural pain management following birth. This study aimed to conduct iterative usability testing with the perinatal population to refine Parenting Pain Away based on target users' identified needs and satisfaction.

Methods: In 2020, parents of healthy newborns or expectant parents from an Atlantic Canadian Province, participated in two iterative cycles of usability testing of Parenting Pain Away. Through recorded interviews, participants were directed to use the “Think Aloud” approach (e.g., verbalize what they see, think, feel) as they navigated through the website. Participants completed online questionnaires related to demographics and user satisfaction, measured by the Post Study System Usability Questionnaire (PSSUQ). Descriptive statistics and content analysis were conducted to analyze the data.

Results: In total, there were ten participants with average age of 29.9 years (SD=3.9). Participants identified as mothers (n=7) or fathers (n=3) and were expecting (n=6) or had a newborn (n=4). The PSSUQ overall scores were 1.84 (SD=0.55) and 1.34 (SD=0.49) in Cycle 1 and 2, respectively, indicating high user satisfaction on the 7-point scale. When comparing between the two cycles, the average overall score was lower in Cycle 2, suggesting improved satisfaction. Participants provided positive feedback about the website and suggested major refinements to simplify content and site navigation.

Conclusions: Findings from usability testing cycles were used to inform refinements of the Parenting Pain Away in response to participant satisfaction and feedback. Engaging target users in the development process enhanced this website in preparation for further effectiveness testing.

Keywords: eHealth interventions; neonatal pain management; parental involvement; procedural pain

4.2 INTRODUCTION

All newborns undergo painful needle related procedures (e.g., injections; heel lance) in early life and infancy. There is strong evidence supporting parents' efficacy to reduce procedural pain (e.g., breastfeeding, skin-to-skin care) (Ullsten et al., 2021) and while significant efforts have been made to understand and enhance family involvement with procedural pain management (Ullsten et al., 2021), especially with neonates who require intensive care (Palomaa et al., 2016; Pierrat et al., 2020; Pölkki et al., 2018), parents often remain an underutilized resource (McNair et al., 2013; Taddio, Chambers, et al., 2009; Ullsten et al., 2021). When aware of their capacity to provide pain relief during procedures, parents recognize that their involvement is important and desire comprehensive information about infant procedural pain (Franck et al., 2012; Orr et al., 2016; Ullsten et al., 2021). Parents often search the internet for information related to their child's health (Aston et al., 2018; Monaghan et al., 2020; Price et al., 2018; Sundstrom, 2016), as well as how to provide pain relief during procedures (Orr et al., 2016). However, two previous reviews found limited information about neonatal procedural pain available through relevant Internet sources retrieved by Google (Dol et al., 2018) or mobile health (mHealth) applications (apps) (Richardson, Dol, et al., 2019), (e.g., parenting websites; websites and apps targeting parents of neonates receiving intensive care), with only 5.1% of websites and 11.1% of apps containing any information on the topic. The limited information on infant pain available virtually coupled with widespread uncertainty of the credibility of websites and apps targeting new parents (Dol et al., 2018; Fahy et al., 2014; Kothari & Moolani, 2015; Richardson, Dol, et al., 2019; Scullard et al., 2010), impacts parents ability to find credible, evidence-

based health information through virtual sources. At the time of this study, few accessible, evidence-based resources about infant procedural pain management targeting parents in the antenatal and perinatal period, defined as the period during pregnancy and the period immediately preceding and after birth, existed (Gagnon et al., 2020; Richardson et al., 2020). Of the evidence-based resources that were available, most were provided to parents in the postnatal period despite routine painful procedures occurring no more than six hours after birth (Ng & Loewy, 2018). Parents endure a significant transition during the postnatal period (Isaacs, 2018) and they often receive an overwhelming amount of education related to infant feeding and safety (e.g., child maltreatment; sudden infant death syndrome), as well as postpartum physiological and psychological care (e.g., monitoring for infection or postpartum depression) (Public Health Agency of Canada, 2009; Public Health Agency of Canada & Canadian Paediatric Society, 2020). Parents desire guidance on their role with pain management well in advance of painful procedures so they have sufficient time to process this information (Ullsten et al., 2021). Given the timing of routine procedures for newborns and competing demands for parents attention postnatally, education about pain management should target the antenatal period.

To address this resource gap, our team co-created Parenting Pain Away, a website targeting expectant parents that provides evidence-based education on procedural pain management practices to enhance parents' access to information during the antenatal/perinatal period and participation in procedural pain management following birth.

A critical component to effective website design and knowledge translation is having high quality user experience (UX) (Richardson, Campbell-Yeo, et al., 2021). When a website prioritizes UX, it fosters an engaging virtual environment that seamlessly supports user interactions with the website, especially in terms of usability, functionality, aesthetics, and reliability (Hassenzahl & Monk, 2010; Norman, 2013; Norman & Nielsen, 2018; Reeves & Nass, 2000; Tullis & Albert, 2013; Turner, 2008). In response to this, users typically report high satisfaction, trust and information uptake (Eysenbach et al., 2002; Liu, 2020). The importance of high quality design in educational websites cannot be emphasized enough. Users quickly discern whether a website interests them based on the homepage design and aesthetics (Lindgaard et al., 2011). Furthermore, aesthetic design is related to how users perceive information quality and usability of websites (Colborne & Smit, 2020; Eysenbach et al., 2002; Fogg et al., 2002; Hassenzahl & Monk, 2010; Lazard & Mackert, 2015; Liu, 2020). Usability testing with target website users serves to inform website design to enhance the likelihood for favourable UX and information uptake (Krug, 2014), a practice not often acknowledged in eHealth interventions (Maramba et al., 2019; Richardson et al., 2018).

Intervention Development

The primary goal of Parenting Pain Away is to empower families to feel confident in partnering with healthcare teams to manage infant pain experienced during routine procedures by providing unlimited access to evidence-informed information. Parenting Pain Away was designed and housed on the Squarespace platform, a prominent website builder accessible to the general population. Parenting Pain Away was developed using current scientific evidence (American Academy of Pediatrics: Committee on Fetus and

Newborn et al., 2006; Lago et al., 2017; Taddio, McMurtry, et al., 2015), consultation with key stakeholders, and adapted educational content from an existing eHealth platform created by members of the research team, entitled Chez NICU Home (Atlantic Canada Opportunities Agency, 2017). The Chez NICU Home platform provides families admitted to a neonatal intensive care unit (NICU) with comprehensive information to engage and support families throughout their NICU experience (Atlantic Canada Opportunities Agency, 2017). The pain-specific educational content from Chez NICU Home, which previously went through rigorous usability testing, was adapted to suit the target audience from the broader perinatal population (i.e., expectant parents, parents of healthy full-term infants, and NICU parents). Content within the original Parenting Pain Away prototype encompassed subjects determined to be of high importance to website design standards and parental involvement in procedural pain management, including but not limited to: About (i.e., general information about the website and research team); Learn (i.e., outlines various lessons related to procedural pain management); Comfort Strategies; and Resources. Please see Appendix 4.2 for the full list of subjects and sub-topics included in the original website prototype. Following best practices of UX, the website was developed in consultation with a graphic designer with expertise in health information dissemination and UX. The overall research project was prepared in collaboration with a committee of key stakeholders comprised of an expectant parent as well as clinicians, administrators, and researchers in perinatal health care areas. The lead researcher invited key stakeholders to participate in this project by providing information about the study (e.g., background, aim, proposed methods for usability testing and evaluation studies) and proposed website (i.e., Parenting Pain Away). The lead researcher

developed the website prototype and circulated the website link and all relevant study documents for the stakeholders to review in advance of an in-person team meeting. Stakeholders engaged in productive discussion at the team meeting, especially related to website name, content, and the feasibility and impact of this project at the local health institutions. Collaborating with the stakeholder group directly informed the website design by providing additional reassurance that the content was credible and relevant, and that user satisfaction and information uptake would be likely (Aguarón & Avendaño-solá, 2016; Kim et al., 2016; Plass & Kaplan, 2016). Additionally, the research team has expertise across a range of relevant research and clinical topics which contribute to the predicted success of Parenting Pain Away, including evidence syntheses related to eHealth and neonatal pain management educational interventions (Dol et al., 2018; Richardson, Dol, et al., 2019; Richardson et al., 2018, 2020), perinatal experience (Dol, Campbell-Yeo, et al., 2019; Dol, Richardson, Aston, et al., 2021; Dol, Richardson, Grant, et al., 2021), UX (Richardson, Campbell-Yeo, et al., 2021), and equity considerations in eHealth technologies (Richardson et al., 2018). Although Parenting Pain Away was co-created with a robust team of stakeholders, usability testing was still necessary to enhance the website design as target users often quickly identify errors or inefficiencies which may have been overlooked by the stakeholder committee (Krug, 2014). Additionally, target users meaningfully inform the website design through their unique perspectives and experiences (Nielsen, 1993, 2012; Walsh et al., 2022).

Objective

This study aimed to conduct iterative usability testing with the perinatal population to refine Parenting Pain Away based on target users' identified needs and satisfaction.

4.3 METHODS

Study Design, Setting, and Sample Selection

We used a mixed-method approach employing iterative cycles of usability testing to gather a thorough assessment of ease of use and user satisfaction of Parenting Pain Away. The “Think Aloud” approach, a widely adopted and effective usability method where participants verbalize what they see, think, and feel as they navigate through a technological system (e.g., website), was applied in this study design (Kushniruk & Patel, 2004). We aimed to complete two cycles of 5 participants each. For small and medium-sized projects, a usability cycle with five users is expected to find 85% of usability problems. The second cycle identifies any issues introduced by changes proposed in the initial cycle, issues obscured by other problems during the first cycle, and most of the rest of the original problems present in the first cycle. Prospective participants were eligible if they were childbearing individuals and/or their partners and parents (i.e., biological, non-biological or adoptive) who were expected to give birth or had given birth in the past two months at a regional hospital, and could read and write in English. The study was conducted in Prince Edward Island (PEI), Canada's smallest province with an average of 1356 births annually, with both urban and rural settings (Prince Edward Island Statistics Bureau, 2021). Self-selection and purposive sampling were used to recruit participants. Purposive sampling method was employed to strive for maximum variation selection for a study sample with varying characteristics including but not limited to age, sex, gender,

ethnicity, and geographical location within PEI (i.e., urban and rural settings) (Breakey et al., 2013; Jibb et al., 2017). Ethical approval was granted for this study by Dalhousie University and Health PEI research ethics boards.

Study Procedures

Given the COVID-19 pandemic-related restrictions set by provincial health authorities at the time of study in 2020, recruitment occurred only through online advertisements promoting the study via social media, (e.g., Twitter, Facebook, Instagram), online classifieds (e.g., Kijiji), and email to key stakeholders (e.g., Study stakeholder committee, Health PEI, PEI Public Health, CBC PEI). Interested parents were instructed to contact the lead researcher (first author) by email or telephone for more information about the study and confirm eligibility. If parents agreed to participate, the lead researcher scheduled a virtual meeting to conduct usability testing interviews and emailed the study information letter and consent form for parents to review prior to the meeting. All virtual meetings (i.e., usability testing sessions) occurred using Zoom videoconferencing technology and were conducted by the lead researcher. At the beginning of each virtual meeting, the lead researcher reiterated that participation was voluntary and completed the process of obtaining informed consent.

To facilitate data analysis, all usability testing sessions were video recorded. Participants were required to share their screen so the lead researcher could view their personal computer or laptop screen as they navigated through the Parenting Pain Away. The lead researcher has significant experience using Zoom videoconferencing technology. The data collection method was tested with a colleague to ensure its feasibility prior to conducting the first testing session. Following completion of usability

testing sessions, participants were emailed a \$20 Amazon gift card in recognition of their contributions to the study.

Data Collection

Participants completed a questionnaire to obtain specific information related to sample characteristics on demographic data including gender, race, age, education level, employment status, a socioeconomic status proxy (i.e., postal code), birth mode (i.e., vaginal or caesarean birth), and family data.

Narrative data were collected during the recorded usability testing sessions using the “Think Aloud” approach to elicit feedback. Each usability testing session followed a semi-structured script to minimally guide parents as they navigated through the website. All participants began at the website homepage and then were instructed to explore the website as they wished. Please see Appendix 4.1 for the usability testing script. Video recording provided a simple yet robust approach for researchers to capture all user interactions with Parenting Pain Away to discern the participants’ impressions about the content, look and feel, navigation, and functionality.

Following the usability testing session, all parents completed the Post Study System Usability Questionnaire (PSSUQ) (Lewis, 1995) to gather information on user acceptability and user satisfaction. The PSSUQ is a widely used usability assessment questionnaire with strong psychometric properties (Lewis, 1995, 2002; Rotolo, 2017). It is a 16-item, 7-point scale questionnaire ranging from 1: Strongly Agree to 7: Strongly Disagree, that yields an overall score and can be divided into three subscales: System Usefulness, Information Quality and Interface Quality. The PSSUQ has excellent reliability, with an alpha coefficient of 0.97. It is sensitive to user group and system

differences and valid, based on significant correlation with other measures of user satisfaction. With PSSUQ, lower scores indicate higher satisfaction (J. Lewis, 1995, 2002). Participants completed questionnaires through REDCap (Research Electronic Data Capture), a secure web-based data management software.

Data Analysis

Questionnaire data were analyzed using SPSS (Statistical Package for Social Sciences) version 26 (IBM SPSS Statistics, 2020). Demographic characteristics were expressed descriptively, in means and standard deviations and percentages, as applicable. Video data from usability testing sessions were reviewed and coded following a standardized coding scheme, established by previous usability testing by the research team, directly using Noldus software (Noldus Information Technology, 2018). The coding scheme facilitates analysis of usability by categorizing the data in four pre-determined themes including Look and Feel, Navigation, Content, and Features. The theme Look and Feel encompasses the aesthetic qualities of the website, including colour scheme, fonts, page layout, images, symbols, and text boxes. Navigation considers the ease of interacting with the website through the ability to access site pages, locate buttons or links, and the intuitiveness of the website structure. Content focuses on the information provided throughout the Parenting Pain Away including site page topics (e.g., Empowering Parents) and specific educational content from the lessons (e.g., Common Procedures). The final theme, Features, addresses aspects which augment the interactivity of website, such as videos, linked social media accounts, and functions which allow the user to control the information that they would like to consume (e.g., dropdown button to expand/collapse content). Analysis of video data was completed after each cycle and

participant feedback was incorporated into the website design prior to the next testing cycle or final update of Parenting Pain Away. Data from the PSSUQ measure were reported as descriptive statistics and comparative analyses by independent t-tests (with an alpha value of .05).

4.4 RESULTS

Participant Characteristics

A total of ten participants were included in two iterative cycles, with five participants in each cycle. The average age was similar in both cycles with 29.4 (SD= 4.7) Cycle 1 and 30.4 (SD= 3.4) Cycle 2. There was a mix of participants that identified as mother or father in both cycles (n= 7 mothers, n= 3 fathers). All participants identified as white and married or common law, except for one participant in Cycle 1 who reported being in a relationship. All participants had post-secondary education completed through a college diploma program (n=4), university degree (n= 5), or graduate degree (n=1). At the time of the interviews in Cycle 1, all participants were expecting (i.e., they or their partner were pregnant) whereas in Cycle 2, four participants had recently given birth (80%). In total, three participants (30%) were considered first-time parents (n=2 Cycle 1; n=1 Cycle 2). Seven participants (70%) had older children, of which five participants (50%) had toddlers (i.e., 1-2 years), two (20%) had early school aged children (i.e., 5-8 years), two with young teens (i.e., 12-15 years), and one participant with an older teen (16-19 years). Please see Table 4.1 for participant characteristics.

Table 4.1

Participant Characteristics

<i>Demographics</i>	<i>Cycle 1</i>	<i>Cycle 2</i>
<i>Age, Mean (SD)</i>	29.4 (4.7)	30.4 (3.4)
<i>Parent Type, n (%)</i>		
<i>Mother</i>	3 (60%)	4 (80%)
<i>Father</i>	2 (40%)	1 (20%)
<i>Race, n (%)</i>		
<i>White</i>	5 (100%)	5 (100%)
<i>Relationship Type, n (%)</i>		
<i>Married or Common Law</i>	4 (80%)	5 (100%)
<i>In a relationship</i>	1 (20%)	0 (0%)
<i>Education, n (%)</i>		
<i>College Diploma</i>	2 (40%)	2 (40%)
<i>University Degree</i>	2 (40%)	3 (60%)
<i>Graduate Degree</i>	1 (20%)	0 (0%)
<i>Employment, n (%)</i>		
	5 (100%)	5 (100%)
<i>Postal Code, n (%)</i>		
<i>City</i>	3 (60%)	4 (80%)
<i>Rural</i>	2 (40%)	1 (20%)
<i>Perinatal status, n (%)</i>		
<i>Pregnant</i>	5 (100%)	1 (20%)
<i>Postpartum</i>	0 (0%)	4 (80%)
<i>Primipara, n (%)</i>		
	2 (40%)	1 (20%)
<i>Multipara, n (%)</i>		
<i>1 other children</i>	1 (20%)	3 (60%)
<i>2 other children</i>	2 (40%)	0 (0%)
<i>3 other children</i>	0 (0%)	1 (20%)

Usability Testing of Study Intervention

Usability testing of Parenting Pain Away occurred through two iterative cycles. Cycle 1 was conducted between August 12 to 26, 2020 and Cycle 2 began November 25,

2020, until January 16, 2021. The qualitative and quantitative data from each cycle are presented below.

Narrative Feedback.

Data analysis of the recorded interviews was conducted following each cycle. By using the “Think Aloud” approach in usability testing sessions, each participant provided a verbal description of their thoughts and feelings while using Parenting Pain Away.

Narrative participant feedback was analyzed and categorized within four pre-determined themes (i.e., Look and Feel, Navigation, Content, and Features) as presented below.

Look and Feel.

Across both cycles, participants offered primarily positive feedback but also made specific suggestions for how the website design could be improved to better engage users. All participants positively commented on the visual assets within the site, most notably the graphics and photos.

In Cycle 1, participants noted representation of different family dynamics and cultures represented through these visual assets. One participant displayed obvious excitement for seeing themselves represented on the website, stating “*Ehhh, there’s a dad!*” (Participant 5, Cycle 1). Participants acknowledged the website’s modern design, speaking to its uniform layout and “*trendy*” font (Participant 2, Cycle 1). Participant 3 described the website colours using terms such as “*nice; soft; fresh*” and appeared to value that the overall colour scheme differed from other “*mommy groups*” that would primarily use pink. For an example of the branding scheme, please see the Parenting Pain Away Logo in Figure 4.1 in Appendix 4.3. Website elements like the dropdown feature

to reveal content were noted to support the modern design and one participant valued the control that the dropdown feature offered them (Participant 3, Cycle 1).

Parenting Pain Away follows the user experience best-practice of presenting information in a visual hierarchy, and participants noticed. Typographic embellishments (e.g., bolding) and content organization (e.g., bullet points) were highlighted by participants as helpful methods to present important information with one participant commenting that they “*would rather read information from bullet points than paragraphs*” (Participant 4, Cycle 1). Participant 4 also noted that the bolded content was empowering to them (e.g., “You Protect Your Baby” bolded page title) and they felt this sentiment would be shared by others. Significant changes were made based on Cycle 1 participant feedback including redesigning the homepage, with consultation from the project’s graphic designer, to make it more engaging and action-oriented by prompting users to explore specific sections of the website. Additionally, content was reduced and more visual assets (i.e., photos, graphics) were integrated to support the content.

In Cycle 2, participants continued to positively reflect on website elements like the colour choice (e.g., “[colours are] not harsh, soothing”, Participant 2, Cycle 2), content organization (e.g., bullet points, dropdown feature, and clean page layouts), use of visuals and typographical embellishments. Participant 2 considered the graphics to be “*simple and appealing*”, evident of diversity and unique to the website (i.e., not stock photos). The same participant stressed the importance of bolding font for important information, stating it is especially important with the perinatal population where the user is likely a tired parent that would not have the capacity or desire to read a lot of content (Participant 2). Several participants commented on excessive blank space on the

homepage, noting that it was not engaging for users (Participants 1, 2, 3, and 5; See Figure 4.2 in Appendix 4.3 for the homepage design iterations). Participants recommended to reduce content as possible and increase use of dropdown features, bullet points and colour to emphasize important information. All recommendations were applied in the second round of revisions, with further significant changes made to the homepage to enhance engagement.

Content.

As previously described, Parenting Pain Away presented content organized by the following main subjects: About; Learn; Comfort Strategies; and Resources. While the main subjects remained the same across both cycles, sub-topics were adjusted based on participant feedback. To help better understand the finalized content within Parenting Pain Away, please see Appendix 4.2 for a detailed outline of all site pages. All participants reported that it would be helpful to have access to Parenting Pain Away during the prenatal period, with two specifically commenting that it would also benefit parents as a refresher in the postnatal period (n=1 Cycle 1; n=1 Cycle 2). One participant suggested that this website is particularly beneficial in the current context where in-person prenatal education was not available due to pandemic restrictions. Four participants reported that they had never known about infant pain or parents' ability to provide procedural pain management (n=3 Cycle 1; n=1 Cycle 2), with one reporting never seeing this information in other perinatal educational materials (Participant 3, Cycle 1).

In Cycle 1, participants demonstrated appreciation for the variety of content offered in Parenting Pain Away, such as the About Us section, Lessons, Glossary, and

Resources. Two participants (Participant 1 and 3) noted that the About Us section provides an opportunity to build trust with users, with Participant 3 stating that they habitually review this section of websites to gain a sense of the organization's values. In terms of the Lessons, Participant 5 noted that the content engages parents immediately and emphasizes that parents should be included in care. This participant felt welcomed and empowered by the website content, sharing that in other health settings they sometimes feel *"at the will of the healthcare provider and don't feel like you have a say."* Along the same vein, another participant commented that they liked the small sections that prompt users to "Ask a Nurse" which appears frequently throughout Lessons, stating that this *"written reassurance"* encourages users to believe that there are not any *"silly questions and nurses are there to help."* (Participant 3). One participant with an older child had prior knowledge about one procedural pain management strategy, based on previous experience with public health nursing encouraging parents to breastfeed after infants receive immunizations. However, this participant was not familiar with the other strategies and felt that the website contained important information, stating *"You're doing a great job...anything you can offer new moms, because it's stressful, it'll help."* (Participant 1).

Participant 5 shared his perspective as a father, commenting that most of the procedural pain management strategies were something he felt he could *"actually do"*. Participants frequently shared positive utterances and facial expressions while reading through the content with the Learn section (contains various lessons). Participant 2 stated *"I like the depth of information"* and noted that it was not an overwhelming amount of information. In contrast, Participants 3 and 4 reported that large paragraphs were difficult

to process. Participants 2 and 3 valued having a reference list provided on each page as reassurance that this information comes from legitimate and trusted sources.

The Glossary and Resources pages were also found to be important contributions to accessibility, as Participant 3 shared that it often can be difficult to find this information elsewhere. Participants recommended that a short description be added to photos of procedures being administered, as well as that a guide be provided that directed parents which procedural pain management strategy they should implement first. Additionally, participants recommended that the website clearly states in the About Us section that both parents can provide pain relief during procedures, not just mothers. To accomplish this while remaining inclusive, a statement identifying that “moms, dads, and zazas” can be involved in procedural pain management was included. Zazas was used as a term to represent non-binary or gender-neutral parents (United Nations, n.d.). The recommendations were addressed in the first round of revisions, most notably by integrating a knowledge translation tool (MacKenzie et al., 2021b) recently developed by local researchers, that provides a brief guide for procedural pain management strategies in children.

Feedback from Cycle 2 was largely complimentary and similar to Cycle 1. Participants spoke to the credibility, usefulness and empowerment offered by the website. Participants felt supported by the content, with one mother commenting “*I love this line*” in reference to the statement “You are the best person for your baby” within the website (Participant 1). Again, a participant noted this information was especially supportive for fathers, acknowledging that much of the caregiver responsibilities are often directed to mothers, but procedural pain management was a way for him to participate in infant care

(Participant 4). Procedural pain management was novel to some participants, as Participant 5 describes “*It’s something I have never thought of... I heard that vaccination day can be a bad day for baby, they are unsettled...but I hadn’t heard that there was something you could do about it.*”. However, one participant with professional experience in a related field, reported feeling that the website was “*heavy handed*” for average parents with a low-risk pregnancy because of the depth and amount of information provided on the website (Participant 2). While this participant believed that it would be a suitable resource during the prenatal period, they suggested it may be better to target parents who anticipated their newborn would need more procedures beyond routine care. For example, infants that may require care in a NICU or additional blood glucose testing due to hypoglycemia risk factors (e.g., gestational diabetes, small-for-gestational age or large-for-gestational age). Revisions after this cycle focused on reducing content amount, ensuring all content was clearly linked to procedural pain management and routinely preformed painful procedures, and creating a ‘Highlights’ section on the homepage so that users can quickly access a summary of the website. Please see Figure 4.3 in Appendix 4.3 for an example of the prompt for the summary page.

Navigation.

All participants were able to navigate freely through the website, with minimal prompting to ensure that participants reviewed at least one page providing directions for procedural pain management practices (i.e., skin-to-skin care). Overall, participants reported feeling the website was user friendly, but there were aspects of the navigation which confused participants in both cycles. In Cycle 1, participants reported that navigation features encouraged users to continue reading through the website’s intended

pathway with use of prompt buttons at the bottom of each page and embedded links opening into new browser tabs. However, it was noted that some pages were not listed in the primary menu causing confusion for some. While there was not a large amount of feedback for this category compared to others, what participants in Cycle 1 reported substantially improved the website. Thus, substantial revisions were made to the website navigation to ensure that all pages also correlated with the primary navigation strategy and provided clear directions for how to advance through the website (e.g., prompts at the bottom, breadcrumb navigations). Participants in Cycle 2 continued to review navigation with a critical lens. Participant 2 recognized that the prompts at the bottom of some pages used different language than the corresponding page titles (e.g., mission vs goals), noting that this could cause confusion for users. Participants also recommended that the bottom prompts of each page in the Learn section take them back to a landing page so they could choose what they would like to learn next and be confident that they were not missing any important information. Further revisions were made based on their feedback, including ensuring that the bottom navigation prompts used consistent language with page titles and that the bottom navigation prompts in the Learn section pages returned users to a page with all lesson options to facilitate user autonomy. Please see Figure 4.2 in Appendix 4.3 for an example of the evolution of the homepage design in an effort to enhance navigation.

Features.

This category had the least amount of data, however participants provided validation for key features and minor suggestions for improvement. Overall, the embedded videos were widely valued by participants, as well as the search function and

dropdown feature to expand content. Participant 3 in Cycle 1 suggested including a progress indicator on each page, so users see that the amount of information to read was manageable. In Cycle 1, certain terms within lessons were linked to the Glossary section, however a participant recommended definitions of terms be displayed through a pop-up function rather than taking the user to a different page within the website. After Cycle 1 a progress indicator and pop-up functionality were coded into the website design. In Cycle 2, participants reported positively about the pop-up feature (Participant 1, 2, 3, and 5). Finally, the dropdown feature used a plus sign to indicate expandable content, but Participant 5 suggested that this switch to a minus sign when the additional content is revealed so users knew they could click that minus sign to collapse the content again. Coding was updated for the dropdown feature to include this suggestion (please see Figure 4.4 in Appendix 4.3 for an example of this change).

Post Study System Usability Questionnaire.

Participants' satisfaction with Parenting Pain Away was measured using the PSSUQ, yielding an overall score and data based on its three subscales: System Usefulness (i.e., how useful or functionable is Parenting Pain Away), Information Quality (i.e., related to the content) and Interface Quality (i.e., was Parenting Pain Away pleasant and up to their expectations) (J. Lewis, 1995, 2002). Participant satisfaction was near the top of the 7-point scale, with PSSUQ scores of 1.84 (SD=0.55) and 1.34 (SD=0.49) in Cycle 1 and 2, respectively. While no significant difference for PSSUQ scores was found across the cycles ($p=.65$), the average score in Cycle 2 suggests improved satisfaction. The greatest difference between the cycles was found within the Information Quality subscale with an average of 2.29 (SD=0.88) in Cycle 1 and 1.40 (SD=0.44) in Cycle 2.

The following two specific questions in the Information Quality subscale contributed most to this difference: “The information provided with Parenting Pain Away was clear” (M= 2.2, SD=1.09 Cycle 1; M= 1.2, SD=0.44 Cycle 2) and “Organization of information on Parenting Pain Away was clear” (M= 2.4, SD=1.14 Cycle 1; M= 1.4, SD=0.54 Cycle 2). The improvement in satisfaction related to the Information Quality subscale was expected as there were significant changes made to the amount of content and how the information was presented throughout the website based on the narrative feedback from participants in Cycle 1. Please see Table 4.2 for PSSUQ scores.

Table 4.2

Post Study System Usability Scale Scores

Post Study System Usability Questionnaire	Cycle 1	Cycle 2
Overall Average	1.84 (0.55)	1.34 (0.49)
System Usefulness	1.76 (0.55)	1.36 (0.54)
Information Quality	2.29 (0.88)	1.4 (0.44)
Interface Quality	1.4 (0.44)	1.26 (0.58)

4.5 DISCUSSION

This study engaged parents and expectant parents to examine the usability of a perinatal educational website about infant procedural pain management. Overall, participating parents were satisfied with Parenting Pain Away and supported its relevancy for the prenatal period. Parenting Pain Away was significantly refined by engaging the target population in two iterative cycles of usability testing, a process recognized for its consistency and significant impact in website design (Nielsen, 2012; Nielsen &

Landauer, 1993). The Think Aloud approach gave the research team first-hand information on how users from the target population would use this new tool. This study used a semi-structured guide for usability testing sessions rather than specific case scenarios, which are often used in this approach (Nielsen, 2012; Nielsen & Landauer, 1993). As an informational website, it was anticipated that users would explore Parenting Pain Away at their leisure and in a manner that was intuitive to them. Allowing participants to explore the website at their discretion, with minimal guidance and prompts, provided insight into user behaviour, as well as site navigation and content issues.

The quantitative data derived from PSSUQ matched the narrative findings analyzed through usability interviews at each cycle. Narrative feedback was largely positive, corresponding with the high satisfaction scores, and constructive criticism was shared by participants primarily regarding the organization, clarity, and amount of information provided in Parenting Pain Away. Consistent with previous evidence related to effective health educational resources (Findeis & Patyk, 2020) and website design (Gibbons & Gordon, 2021; Hartley, 2016; Nielsen, 2020), participants wanted a modern design which organized the content in a manner that would engage users and not overwhelm them. As noted by some participants, this was especially important for the perinatal population whose mental load may already be overwhelmed by competing caregiver demands and exhaustion during prenatal and postnatal periods (Dean et al., 2021; Lévesque et al., 2020; Robertson et al., 2019). Previous research by the authors related to equitable eHealth resources in perinatal areas (Richardson et al., 2018; Richardson, Price, et al., 2019) significantly informed the development of Parenting Pain

Away, which was recognized by participants during usability testing. Participants highly valued equitable representation demonstrated throughout the Parenting Pain Away, acknowledging diversity across visual assets (i.e., graphics, photographs) and intentional language to include all parents, regardless of sex and/or gender identity. Fathers included in this study saw themselves reflected throughout the website and felt empowered to be involved in procedural pain management. While perinatal resources are often directed solely to mothers (Richardson et al., 2018), including fathers and partners has been found to improve other perinatal outcomes, such as breastfeeding rates (e.g., initiation, duration, and exclusivity) (Abbass-Dick et al., 2017, 2018). Moreover, in the current social climate families are not solely constituted by heterosexual, cis-gender dyads (Goldberg et al., 2011; MacDonald et al., 2016; Richardson et al., 2018). Thus, inclusivity is an essential consideration in designing perinatal educational resources.

Participants in this study felt that Parenting Pain Away would be relevant to parents during the prenatal period, which supports propositions made by recent scoping reviews related to optimal time for procedural pain management education (Richardson et al., 2020; Ullsten et al., 2021). Additionally, prenatal education has been found to enhance knowledge uptake and application in early postpartum caregiving responsibilities (Fuchs et al., 2021; Gagnon & Sandall, 2007; Hui et al., 2021). Feedback related to the depth of information provided through Parenting Pain Away was mixed. Four participants specifically reported a preference for the depth of information provided, whereas one participant reported that they believed the content exceeded what parents with low-risk pregnancies would require. Differences between user preferences for depth of health information in websites is not unique to this study (Yardley et al., 2010).

Considering potential differences in preferred learning styles and desired depth of information, a website which provides comprehensive information about procedural pain management, in a variety of accessible and engaging formats, using a layered approach to accessing information, offers a rich learning environment with greater autonomy for users to choose what information they consume, while still ensuring that salient information is readily available, is important (Kim et al., 2016; Plass & Kaplan, 2016).

Future Evaluation

While this study engaged target users to refine Parenting Pain Away, our research team is in the process of assessing the impact of this website with the PEI perinatal population. We are conducting a quasi-experimental evaluation to determine clinical feasibility, parental acceptability, self-efficacy, knowledge uptake, and parental involvement in procedural pain management. Parenting Pain Away is intended to improve procedural pain management practices for all newborns. Thus, we aimed to equip expectant parents with comprehensive, evidence-based information about infant procedural pain management. In the evaluation study, participants receive access to Parenting Pain Away prenatally and are directed to use the website at their discretion. Following consent, participants complete a questionnaire to gather baseline characteristics, including demographic information and newborn procedural pain management knowledge. After the birth of their baby, the impact of Parenting Pain Away is evaluated through daily diaries about procedures and pain management when parents are still admitted to a postnatal unit and then again at one week postpartum. The evaluation study aims to enhance parental involvement in procedural pain management within the PEI population and identify areas which could be strengthened prior to

implementation and evaluation at the national and/or international levels. The evaluation study also intends to further inform the practicality of the data collection procedures for application in future studies across the perinatal population globally.

Strengths and Limitations

Prioritizing UX across the development and usability testing of Parenting Pain Away provided significant strength to this study. The development of Parenting Pain Away was a collaborative effort which engaged the target population, design experts, interdisciplinary researchers and healthcare providers with expertise in perinatal care and/or pediatric procedural pain management. Inclusion of nursing scholars, clinicians, and families as part of the development team offered opportunity for greater attention to health equity and clinical relevancy based on their unique lens and relationship with the target population (Richardson et al., 2018). A description of the development team was provided within Parenting Pain Away to convey credibility and establish a learning space that could enhance parents' and other users' trust (Kaley & Nielsen, 2019; Walter, 2011). This was found to be an important factor for participants in this study, as they reported that the information on the About Us section enhanced trustworthiness of the website.

Limitations of this study included recruitment, sample characteristics, data collection and analysis. There was slow uptake of participants in the second cycle of usability testing, which may have been influenced by the concurrent COVID-19 pandemic. The extended recruitment negatively impacted the study efficiency (i.e., time to reach data analysis stage), however, this did not impact the overall intervention refinement. Despite some variation in identified parent role (i.e., mother, father), other demographic factors of the study sample were homogenous such as race, education level,

socioeconomic status, and partner support. Lack of diversity is a common limitation noted across studies in similar contexts (Dol, Tomblin Murphy, et al., 2021; Monaghan et al., 2020) but not entirely reflective of the study population (Statistics Canada, 2017). Inclusivity was a priority at the onset of developing Parenting Pain Away, which evident through diversity across the visual assets (i.e., photos, graphics) and inclusive language use. Still, greater efforts to engage participants of differing characteristics and experiences are needed for future evaluation of the website and perinatal research broadly. While participants appeared to have high digital literacy skills, data on technology usage was not collected in the demographic questionnaire. Additionally, this study only evaluated the usability of Parenting Pain Away through desktop computers or laptops. This could present a limitation for future evaluation as previous evidence suggests that this population accesses online health information (Aston et al., 2017; Davis et al., 2017; Orr et al., 2016; Price et al., 2018; Sundstrom, 2016) often using mobile devices (Bensley et al., 2014; Gao et al., 2013; Kamali et al., 2018; Orr et al., 2016). However, to address this limitation throughout the refinement of Parenting Pain Away, the research team reviewed the mobile version to ensure it remained consistent with best practices in mobile design (Wroblewski, 2011). Finally, although efforts were made to reduce social desirability bias (e.g., explicitly requesting constructive criticism) and experimenter bias (e.g., standardized coding theme), these biases could be considered limitations of this study.

4.6 CONCLUSION

Findings from usability testing cycles refined Parenting Pain Away in response to narrative feedback and user satisfaction. Engaging target users from antenatal/perinatal

populations and relevant stakeholders throughout the development and refinement process substantively improved this website in advance of a more thorough effectiveness evaluation.

CHAPTER 5 PARENTING PAIN AWAY: EVALUATION OF AN EHEALTH LEARNING PLATFORM TO EVALUATE ACCEPTABILITY, FEASIBILITY, & UTILIZATION OF PARENT-LED PAIN MANAGEMENT

Chapter 5 is presented as a manuscript that was submitted to the *Scandinavian Journal of Caring Sciences*.

Contribution statement: BH developed the study with input and support from MCY, RMM, ML, MS, and PM. BH conducted the data collection, analyzed the data and drafted manuscript. MCY, RMM, ML, MS, and PM contributed to revising the final manuscript.

5.1 ABSTRACT

Aim: To evaluate the impact of an eHealth educational resource about infant procedural pain management, given during the prenatal period, on feasibility, acceptability, knowledge, self-efficacy, and involvement.

Background: Routine health care requires newborns to have painful procedures (e.g., intramuscular injection). The impacts of untreated pain in neonates are widely recognized but adoption of effective procedural pain management strategies in clinical practice varies. There is clear evidence supporting the effectiveness of parent-led pain management during procedures (e.g., skin-to-skin care) and reputable resources to raise awareness among parents are warranted. Our team co-created Parenting Pain Away, a website to equip parents with evidence to assist with managing the pain of procedures and empower them to be involved.

Methods: A quasi-experimental evaluation using a pre/post intervention design with low-risk expectant parents.

Results: Of the 41 participants, before intervention exposure participants were familiar or had used skin-to-skin care (n=33), breastfeeding (n=30) and sucrose (n=13) as pain management. Most participants (n=38) desired more information on how to be involved. Providing access to Parenting Pain Away during pregnancy was supported and participants ranked the website above average using the System Usability Scale. Parenting Pain Away did not have a statistically significant influence on outcomes. Participants reported variation in clinical support with parent-led pain management.

Conclusion: A multifaceted approach is recommended to maintain infant procedural pain management.

Implications for the Profession and Patient Care: Equipping parents with knowledge related to infant pain management using an eHealth approach satisfied their information desires. The study findings are important considerations for perinatal care providers, policy makers, and families to finally achieve adequate procedural pain management.

Reporting Method: This study used the STROBE checklist, adhering to EQUATOR guidelines.

Patient and Public Contribution: A stakeholder group (expectant parents, parents, perinatal researchers, clinicians, administrators) was created to inform the study design and intervention.

What does this paper contribute to the wider global clinical community?

- Highlights benefits of providing parents and caregivers with infant pain management education during the prenatal period in advance of procedures.
- Emphasizes persistent need for consistent infant pain management during procedures in clinical practice.
- Calls for mandatory parent-led pain management policies to be included in all clinical areas caring for infants.

Keywords: eHealth interventions; neonatal pain management; parental involvement, procedural pain; prenatal education

5.2 BACKGROUND

In the first hours of life, newborns require tissue-breaking procedures to help support and assess their healthy development (American Academy of Pediatrics Committee on Fetus and Newborn, 2016; Barrington et al., 2016). The number of procedures varies dependent on gestational age at birth and health status. Even healthy, term-born infants (i.e., 37-40 weeks gestation) can receive up to 20 procedures including vitamin K intramuscular injection as prophylaxis against bleeding (Ng & Loewy, 2018), newborn metabolic (NBM) screening (Lemyre et al., 2018), bilirubin and glucose

monitoring (American Academy of Pediatrics, 2004; Narvey et al., 2019), and immunizations (Public Health Agency of Canada, 2023). These procedures are significant as untreated pain alters brain development, reaction to subsequent pain, as well as cognitive functioning (Grunau, RE & Tu, 2007; Piira et al., 2007; Taddio et al., 2002). There are several effective strategies for managing infant procedural pain, including parent-led pain management (PLPM) strategies, such as breastfeeding (Shah et al., 2023), skin-to-skin care (SSC) (Johnston et al., 2017; Ullsten et al., 2021), and sucrose (Bueno, Ballantyne, Campbell-Yeo, et al., 2023; Yamada et al., 2023). Application of procedural pain management and engagement of parents has varied in clinical settings (Sampson et al., 2013; Taddio et al., 2009) despite available clinical practice guidelines and frequent calls to action (Balice-Bourgeois et al., 2020; Harrison, 2021; McNair et al., 2020; Taddio et al., 2015). Parents want to comfort their children and they highly value this role reducing their infant's pain (Skene et al., 2012; Ullsten et al., 2021). Education delivered to parents in the perinatal period has been shown to increase procedural pain management in infants (Hughes et al., 2023; Mcnair et al., 2022). Yet, there is limited evidence on the effectiveness of parental education in the prenatal period (Hughes et al., 2023).

Recognizing the potential of anticipatory guidance to parents about procedural pain management in advance of their baby's arrival, our team developed the website Parenting Pain Away (PPA). This website was designed to target expectant parents during the prenatal period to provide comprehensive evidence about infant procedural pain and pain management strategies (Hughes et al., 2023). PPA was developed collaboratively through consultation with stakeholders (e.g., expectant parent, clinicians, researchers, administrators), as well as a graphic designer proficient in health

dissemination. Usability testing with a mix of expectant parents and parents in the postpartum period further refined PPA. These participants ultimately felt satisfied with PPA and encouraged its integration into prenatal education (Hughes et al., 2023).

Aim

Building on previous work, this study aimed to evaluate the impact of the PPA website, offered to expectant parents during the prenatal period, on feasibility, parental acceptability, knowledge, self-efficacy, and involvement.

5.3 METHODS

Study Design

A quasi-experimental evaluation of PPA was conducted using a pre/post intervention design to answer the following questions:

1. Among parents of healthy newborns, what is the feasibility and acceptability of PPA on parent-led procedural pain management?
2. Among parents of healthy newborns, does PPA influence parental knowledge, self-efficacy, and active involvement in pain management?

Setting and Sample

This study took place in the province of Prince Edward Island (PEI), located in Eastern Canada, with two hospitals providing obstetrical care for approximately 1400 births annually. Eligibility criteria included low-risk expectant parents (at least 32 weeks gestation) and/or their partners (if applicable), with internet access, proficiency in English and planning to give birth in a provincial hospital. Recruitment occurred only through online advertisements promoting the study via social media, (e.g., Twitter, Facebook, Instagram), online classifieds (e.g., Kijiji), and email to key stakeholders (e.g., Study

stakeholder committee), as well as posters at relevant care areas (e.g., obstetrics clinic) and community centres (e.g., coffee shops). Interested parents were instructed to contact the lead researcher (first author) by email or text message for more information about the study and confirm eligibility. The goal was to recruit a minimum of 40 participants, consistent with previous feasibility studies (Billingham et al., 2013).

Outcomes

Outcomes of interest were feasibility and acceptability of PPA, newborn pain management knowledge, parental perceived self-efficacy, and involvement in PLPM during procedures. For the purposes of this study, PLPM included any strategy where parents could be involved with their infant, such as breastfeeding, SSC, sucrose (advocating for its use), topical anesthetics, facilitated tucking, and holding the baby clothed. Feasibility and acceptability were measured post intervention exposure, using a study specific survey compiling the System Usability Scale (SUS), a standardized, reliable, and widely validated questionnaire (Brooke, 1996; Lewis, 2018), and 10 additional items related to intervention delivery timing, resource content, intervention use, staff support and intentions for PLPM with future procedures. Intervention usage was also gathered through website analytics. Knowledge of newborn pain management was measured pre and post intervention exposure using a study specific questionnaire with items compiled from three original standardized measurements; developed and validated by Taddio and colleagues (Taddio et al., 2013), Harrison and colleagues (Harrison et al., 2017), and Orr and colleagues (Orr et al., 2016). Parental perceived self-efficacy was measured post intervention exposure using the Karitane Parenting Confidence Scale (KPCS) (Črnčec et al., 2008), a 15-item tool that assesses perceived

self-efficacy of parents of newborns. Involvement in PLPM during procedures occurring in hospital (i.e., vitamin K injection, NBM screening) was measured through self-report post intervention exposure. Parental diaries were also collected to gather details related to procedures while in hospital.

Data Collection

At study enrolment, participants completed an online questionnaire to gather baseline characteristics (e.g., demographics, technology use and behaviours) and newborn pain management knowledge. Participants were then provided with instructions on how to use the PPA website. Follow-up data collection began after participants gave birth with a daily prompt to complete a diary entry describing needle-related procedures conducted on their infant. One week postpartum, participants completed the final survey. All participant data were collected using surveys via REDCap (Research Electronic Data Capture), a software platform hosted by Dalhousie University (Harris et al., 2009, 2019).

Data Analysis

Analysis was conducted using IBM SPSS software version 29.0 and Microsoft Excel (IBM Corporation, 2023; Microsoft Corporation, 2023). Descriptive statistics and frequency were calculated to describe variables of interest. One-way analysis of variance was conducted to determine the effect of PPA on parental knowledge and perceived self-efficacy scores. Knowledge questionnaires were compared using dependent t-test and independent t-tests to determine associations with demographics and uptake of PLPM. Sub-analyses were performed, using chi-square and binary logistic regression, to further explore possible associations with uptake of PLPM based on demographics. All data was de-identified during analysis to reduce risk of bias.

Ethical Considerations

This study was approved by Dalhousie University (REB #2020-5079) and Health PEI Research Ethics Boards. All participants provided informed consent following the Tri-Council Policy Statement.

5.4 RESULTS

Through March to October 2021, 51 participants were enrolled, of which 41 completed all aspects of the study. The sample included mothers (n=34, 82.3%) and fathers (n=7, 17.1%), predominantly with participants who identified as White, married or common law, and had completed varying levels of post-secondary education. The sample included 16 first-time parents (36.0%) and 25 parents with other children (61.0%) (Table 1).

In terms of technological preferences and behaviour, nearly all participants (n=40, 97.6%) reported using their mobile device (e.g., smartphone) to access the internet with most using daily (n=39, 97.5%). Just over half of participants used their laptop to access the internet (n=24, 58.5%) but only seven participants did this daily (17.1%). All but one participant confirmed that they search for health information on the internet, with most preferring to use their mobile device (n=35, 85.4%). Over half of participants identified using Google (n=24, 58.5%) as their first source to search, followed by medical journal websites (n=6, 14.6%), health websites (e.g., Mayo Clinic; n=6, 14.6%), or hospital/university-based websites (n=3, 7.3%) with one participant specifying a Facebook group (2.4%). Most participants checked information they found on the internet with formal or informal sources, with the top sources being family physicians

(n=30, 73.2%), friends/family in healthcare (n=27, 65.9%), family (n=27, 65.9%), friends (n=22, 53.7%), or a pharmacist (n=14, 34.1%).

Prior to the PPA intervention exposure, many participants were familiar with or used SSC (n=33, 80.5%) and breastfeeding (n=30, 73.2%) for infant procedural pain management, however fewer were familiar with or used sucrose (n=13, 31.7%) and one participant (2.4%) preferred not to respond. In total, 34 participants (82.9%) had either used or knew about the effectiveness of at least one of these strategies. Sixteen participants (39.0%) reported that a healthcare provider (HCP) educated them on comfort strategies when their baby experienced pain during procedures. Twenty-one participants (51.2%) felt like they had sufficient information to provide comfort during procedures, but 38 participants (92.7%) wanted more information on how to be actively involved. Only 10 participants (24.4%) used the internet to access information about managing their infant’s pain, with nine reporting it as useful (22.0%) and most searched via Google (n=7, 70%). Please see Table 2 for an outline of previous knowledge or use of PLPM strategies, categorized by parity.

Table 5.1

Participant Characteristics

Demographics	n (%)
Age	32 (3.43)*
Parent Type	
Mother	34 (82.9%)
Father	7 (17.1%)
Race	
White	40 (97.6%)
Asian	1 (2.4%)

Relationship Type	
Married or Common Law	35 (85.4%)
In a relationship	5 (12.2%)
Without a partner	1 (2.4%)
Education	
High School Diploma	5 (12.2%)
College Diploma	11 (26.8%)
University Degree	17 (41.5%)
Graduate Degree	7 (17.1%)
Employment	36 (87.8%)
Geographic location	
Urban	21 (51.2%)
Rural	20 (48.8%)
Parity	
Primipara	16 (39.0%)
Multipara	25 (61.0%)

*Mean (Standard deviation)

Table 5.2

Previous Knowledge or Use of PLPM Strategies

PLPM Strategies	Total (N=41), n (%)	First-Time Parents (n=16), n (%)	Parents with Other Children (n=25), n (%)
Breastfeeding	30 (73.2%)	11 (68.8%)	19 (76%)
SSC	33 (80.5%)	12 (75%)	21 (84%)
Sucrose	13 (31.7%)	2 (12.5%)	11 (44%)
Received HCP Education	16 (39.0%)	3 (18.8%)	13 (52%)

Abbreviations: Skin-to-skin care, SSC; Healthcare provider, HCP

Acceptability and Feasibility

During the study period, 172 unique devices (mobile device [n=117, 52%]; desktop/laptop [n=106, 48%]) accessed PPA with a total 223 visits as captured using website analytics. Most devices were in Canada (n=123, 55.2%), but there were also devices which accessed the site from other countries. Self-reported frequency of website use varied with participants reporting they never used PPA (n=14, 35%), rarely did (n=11, 27.5%), or used PPA at least once every two weeks (n=15, 37.5%). The average on the SUS was 71.04 (standard deviation = 26.83), which is characterized as above average and just below “Good”.

Just over half of participants (n=23, 56.1%) felt the evidence-based information provided on the website was relevant during pregnancy, while six participants disagreed (14.6%) and the remaining preferred not to respond (n=12, 29.3%). Participants had the opportunity to comment further on this response. Those in agreement predominantly felt it supports preparation, with one participant sharing that “it helped you feel more comfortable in being able to handle any complications that might come with babe when it’s born and is a great resource for new or experienced parents!” (first-time parent) and another acknowledging “I didn’t actually use the website because I forgot about it. It was a hectic few days weeks leading up to birth. But using it after I see the value in prepping new parents for painful procedures for their newborn while in hospital” (first-time parent). Participants also felt PPA helped increase awareness and provided “clear and concise ways to lower stress and pain for babies, not all I was fully aware of before starting to read” (parent with other children). Of those who did not feel the website was relevant during pregnancy, this was attributed to time being limited “I didn’t really get

time to use it before baby came.” (parent with other children) or participants were already overwhelmed “it’s good general information but until you need it, it’s just something else to read up on when you’re already overwhelmed preparing for a newborn. Definitely a good resource but better to go over and read after baby is born.” (first-time parent).

When asked if the study or website could be changed to improve participants’ experience, 20 responded with no (48.8%). There were some suggestions for more prompts to interact with the resource, with one participant recommending a different delivery format: “Maybe to have an app which prompts you to use it. I forgot about this when I had my baby and had to come back after the fact to complete the surveys” (first-time parent).

Influence of the Parenting Pain Away Website

Several analyses were completed to explore if PPA influenced knowledge, self-efficacy, or involvement in procedural pain management. Results from the newborn pain management knowledge questionnaire found that on average, parent knowledge scores were slightly higher at follow-up postpartum (Mean [M] = 6.88, Standard Deviation [SD] = 1.10), but no significant statistical difference was found from the baseline assessment (M = 6.61, SD = 1.14), $t(40) = -1.68$, $p = .102$. Postpartum knowledge scores were analyzed based on frequency use of PPA, categorized into three groups: 1) never used PPA (n=14; 35.0%); 2) rarely used PPA (n=11, 27.5%); 3) used PPA at least once every two weeks (n=15; 37.5%). One participant was excluded from this analysis as they preferred not to specify the frequency that they visited PPA. On average postpartum knowledge scores were similar between group 1 (never used; M = 6.93, SD = 0.83), group 2 (rarely used; M = 6.91, SD = 1.38), and group 3 (used at least once per two

weeks; 6.87, SD = 1.19), and no significant difference was found between groups, $F(2, 39) = .011, p = .989$. Additional analyses related to knowledge scores are presented in Tables 3 and 4.

Perceived self-efficacy scores ranged from 33 to 44 (out of a possible total of 45) with an average of 40.8 and median of 42. Most participants demonstrated confidence, with three participants (7.3%) meeting moderate clinical range (i.e., 31-35 score) and nine (22.0%) meeting mild clinical range (i.e., 36-39 scores) suggesting possible lower levels of confidence in parenting. Perceived self-efficacy scores were again analyzed based on frequency of PPA use. On average perceived self-efficacy scores varied slightly between group 1 (never used; $M = 39.07, SD = 7.14$), group 2 (rarely used; $M = 41.27, SD = 1.85$), and group 3 (used at least once per two weeks; $M = 40.20, SD = 3.41$), but there was no significant statistical difference between groups, $F(2, 39) = .648, p = .529$.

Table 5.3

Association Between Baseline Knowledge Scores and Parent Demographics

Parent Demographics	Total, n (%)	Baseline Knowledge Score, Mean (SD)	P^a
Education	40 (97.6%)*		.636 ^a
High School	5 (12.5%)	6.00 (1.58)	
College Diploma	11 (27.5%)	6.64 (1.29)	
University Degree	17 (42.5%)	6.76 (1.15)	
Graduate Degree	7 (17.5%)	6.63 (1.15)	
Parity	41 (100%)		.627 ^b
Primipara	16 (39.0%)	6.5 (1.21)	
Multipara	25 (61.0%)	6.68 (1.11)	
Previous Knowledge/Use of PLPM Strategies	40 (97.6%)*		.925 ^b
No previous PLPM	6 (15.0%)	6.67 (1.51)	
Previous PLPM	34 (85.0%)	6.62 (1.10)	

*Participant excluded from analysis as they preferred not to respond to question.

^a One-Way ANOVA

^b Independent t-test

Abbreviations: Parent-led pain management, PLPM; Standard deviation, SD

Table 5.4

Associations Between Postpartum Knowledge Scores and Uptake of PLPM

Uptake of PLPM*	Total (N=41), n (%)	Postpartum Knowledge Score, Mean (SD)	<i>P</i> ^a
No PLPM	15 (36.6%)	7.00 (0.76)	.596
PLPM	26 (63.4%)	6.81 (1.27)	

*Uptake of PLPM for either the vitamin K injection or newborn metabolic screening.

^a Independent t-test

Abbreviations: Parent-led pain management, PLPM; Standard deviation, SD

For parental involvement with pain management during the vitamin K injection or NBM screening, 26 participants (63.4%) were involved in at least one procedure of which 12 (29.3%) were involved in both. Specifically with the vitamin K injection, 15 participants (36.6%) were involved, while 24 participants (58.6%) reported that they were not, and two preferred not to respond (4.9%). Twenty-three participants (56.1%) were involved with the NBM screening, and the remaining 18 participants (43.9%) were not. Thirty-five participants (85.4%) completed at least one diary entry, of which 19 participants (54.3%) reported being involved in at least one procedure during their hospital stay (i.e., not solely the vitamin K injection or NBM screening). Participants reported using the following pain management strategies: holding (n=15, 78.9%), skin-to-skin care (n=13, 68.4%), breastfeeding (n=11, 57.9%), sucrose (n=10, 52.6%), facilitated tucking (n=2, 10.5%), and topical anesthetics (n=1, 5.3%). Of note, one participant required brief NICU care (< 4 hours) for their baby and reported sucrose being administered for three procedures during that time. Of the six participants (14.6%) with

no previous experience or awareness of PLPM, four (66.7%) used PLPM while in hospital. Ten participants (24.4%) reported that HCPs (e.g., registered nurse, laboratory technician) invited them to be involved during procedures, however 28 (68.3%) participants were not invited, and three preferred not to respond (7.3%). Chi-square analyses were conducted, but there were no significant associations found with use of any PLPM at the vitamin K injection or NBM screening and parity, previous use of parent-led pain management, education, or use of PPA. Binary logistic regression was conducted to explore if use of any PLPM at the vitamin K injection or NBM screening could be predicted by the same set of demographic variables or use of PPA. However, no variable significantly affected the model. Many participants reported intentions to use breastfeeding (n=29, 70.7%) and SSC (n=25, 61.0%) for future procedures (e.g., 2-month vaccinations), and 16 participants (39.0%) intended to use sucrose. Of these participants, four had no previous knowledge or use of breastfeeding (13.8%) and SSC (16%), and ten (62.5%) had no previous knowledge or use of sucrose.

Parental Involvement Patterns

Focusing on the three leading PLPM strategies (i.e., breastfeeding, SSC, sucrose), we asked whether parents had concerns about using the strategies during procedures. Only a few participants shared concerns related to each strategy. Three main themes emerged from the concerns: Lack of Support, Physiological Barriers, and Skepticism. The first theme was Lack of Support. Participants felt their healthcare team did not engage them during procedures with one participant reporting, “we were not given the option to hold the baby during these procedures. They had taken the baby to the bassinet to do it.” (parent with other children) and another stating “I didn’t feel like I was allowed

to breastfeed during the heel prick [NBM screening]. The person doing the heel prick was not supportive of me even holding my baby, but I did it anyway.” (parent with other children). The second theme was Physiological Barriers which was specific to breastfeeding. One participant noted that breastfeeding is “not always possible with a c-section baby, as I [father] was present for the vitamin K while mother was in recovery.” (parent with other children). Another participant highlighted breastmilk supply as a barrier, sharing: “I have low milk supply and worried I wouldn’t have any milk for my babe.” (parent with other children). The final theme was Skepticism related to sucrose. One participant commented “it seemed like unnecessary sugar, and I wasn’t familiar with the ingredients, so didn’t want to use it as an option when there are others available.” (parent with other children) and another participant said, “it only temporarily boost[s] dopamine in the brain, not sustainable method.” (first-time parent). One participant reported that their concerns had been alleviated, sharing: “before doing the research, I was concerned about the impact of sucrose on their ‘fresh’ digestive tract but now I have more confidence that benefits outweigh the risks with this practice.” (parent with other children).

Participants were asked to elaborate on their responses for intention to use PLPM strategies for upcoming procedures, as presented above in the influence of PPA results. Many were in favour of breastfeeding, noting that this was their practice previously, so they intended to continue or that they believed in its comforting effect, with one participant commenting that they found it “soothing for both babe and mom” (parent with other children). Reasons to not try breastfeeding were predominantly that participants were no longer using this method in their feeding plan. As for SSC, many participants

supported using this strategy in the future, with some stating the caveat of using SSC only if breastfeeding was not an option. Participants expressed a desire to support their baby and noted the ease of this strategy, especially for fathers, with one participant sharing “it is easy to do, and possible for the father to do” (parent with other children). Those not planning to use SSC disclosed feeling uncomfortable with the necessary setup and positioning, one participant commenting that they are “not ok with being exposed that much in a public setting” (parent with other children). Of the 39% who intended to use sucrose, participants felt that it is a reliable option if breastfeeding or SSC cannot be used and highlighted evidence in its efficacy. For those who indicated they would not use sucrose, many simply shared a preference for breastfeeding or SSC, but some also wondered about its availability in the clinical setting. One participant reported, “never have I seen a nurse use it at public health, so I wonder if they even have it” (parent with other children).

Participants not invited by HCPs to be involved in procedures were asked if they felt comfortable advocating to be involved. Many participants simply said yes but some reported not having the opportunity to advocate because the procedures were done without their knowledge, while they were separated from their newborn, or not supported. One participant shared “Vitamin K and glucose monitoring were done when the baby was not with me (I was being brought to my room) so I did not have a chance to speak up. Heel stick [NBM screening] was done by a lab tech who requested baby be left in her bed so [we] were only able to comfort her with touch... I feel that educating this field of professionals on the benefits of breastfeeding/comfort techniques during blood draws could be very beneficial to new babies and parents as well as the staff doing the

testing” (parent with other children). Other participants felt like the transition to postpartum was too overwhelming, with one noting that “No [to advocate for involvement in procedures], it was very overwhelming after just having given birth and everything happened so fast. If the option had of been presented to me, I would have preferred to breastfeed at the time” (parent with other children).

5.5 DISCUSSION

Searching for health information on the internet is ubiquitous (Bach & Wenz, 2020), especially in perinatal populations (Alianmoghaddam et al., 2019; Aston et al., 2018; Dol, Richardson, Aston, et al., 2021; Graseck & Leitner, 2021), as further demonstrated in this study. Yet, infant pain management strategies remain a topic that is not frequently explored (Orr et al., 2016). Awareness or previous use of PLPM strategies was relatively high for breastfeeding and SSC in our sample but less for sucrose. These findings contrast results from Harrison and colleagues (Harrison et al., 2017) where 68% of their sample knew about the analgesic effect of sucrose for procedures. While all participants did not share where they learned about PLPM, under 40% had an HCP educate them about pain management. The HCPs role is paramount in successfully achieving PLPM during infant procedures (McNair et al., 2020), yet there are still challenges with engaging parents consistently. Challenges to changing this practice are partially attributed to HCPs level of awareness or perceived value of PLPM (Marfurt-Russenberger et al., 2016; McNair et al., 2020). Nearly all participants wanted more information on their role with procedural pain management and HCP support, a finding which has been found across numerous studies (McNair et al., 2020; Orr et al., 2016;

Ullsten et al., 2021) and is specifically recognized as a critical component to parental involvement (Franck et al., 2012).

PPA analytics must be interpreted with caution as the website was accessible by others not participating in the study. Study participants perceived PPA as roughly “good”, as per the SUS score, which exceeds benchmarks at similar development stages for educational websites (Bangor et al., 2008; Vlachogianni & Tselios, 2022). However, there was evidence that the information could burden expectant parents who are already overwhelmed. To address this, future iterations of PPA might consider using nudging theory (Thaler & Sunstein, 2009, 2021) to provide small pieces of information at a time, or the use of trained generative artificial intelligence (e.g., ChatGPT) to offer a conversational approach to sharing information.

Despite many participants acknowledging that they rarely or never used the website, over half still felt that the information PPA offered was relevant during pregnancy. In consideration of the results and current trends in health information seeking (Dol et al., 2021; Graseck & Leitner, 2021), mobile delivery of PLPM information during pregnancy is supported (Hughes et al., 2023). PPA could be redesigned to reduce content or be integrated with broader perinatal education endorsed by local health institutions. PLPM information could be integrated with prenatal care at various time points, such as the initial appointment with a primary prenatal care provider (e.g., nurse practitioner, family physician, midwife, OBGYN), at 34 weeks gestation (i.e., common time for transfer of care to OBGYN), and at term (37-40 weeks gestation). Integration with prenatal care provides the reminder to review parent-targeted resources (e.g., PPA), as suggested by participants.

The PPA website had no statistically significant influence on parental knowledge, perceived self-efficacy or involvement in PLPM during routine procedures. While it is not clear that participants learned about PLPM solely from PPA, our data suggests that PPA addressed an information deficit for some with no previous knowledge or use of PLPM which influenced their pain management application and planning. A resounding theme from participants' comments was the variation in engagement and support by HCPs, a common challenge also identified in related research (Harrison, 2021; McNair et al., 2020). When HCPs invite parents to be involved in pain management it creates an opportunity to address potential concerns (e.g., perceived low milk supply or neurological impacts of sucrose) and empower parents by providing alternate PLPM options or discussing current evidence (Bueno, Ballantyne, Campbell-Yeo, et al., 2023; Harrison, 2021). As reported in this study, a common barrier to PLPM is procedures occurring while the parent is not present (Harrison, 2021). There is evidence suggesting that HCPs prefer to complete needle-related procedures without parents being present, often as an effort to protect parents (Harrison, 2021; McNair et al., 2020). An additional reason is challenges in adjusting unit routine (Harrison, 2021). Another common barrier, also found in this study, is the refusal of PLPM during procedures due to perceived challenges with ergonomics (Harrison, 2021). There are freely available educational resources targeted to HCPs addressing ergonomics to support PLPM during procedures, including a YouTube video by Harrison and colleagues (Harrison, 2021; Harrison & Children's Hospital of Eastern Ontario, 2019). Institutional policies, as well as further education and support targeting HCPs remains highly warranted to mitigate barriers to PLPM.

Study limitations include the small sample which met feasibility sample requirements but did not have sufficient power to find significant differences in the statistical analyses. A subsequent study with a larger sample is required to determine effectiveness of PPA. Further, the sample was homogenous especially in terms of education and socioeconomic status, which is not representative of the broader childbearing population. Research on appropriate timing of PPA access during the prenatal period, impact with underrepresented groups, and overall effectiveness on PLPM uptake is needed. However, policy changes in the study setting are crucial prior to initiating future studies about parental involvement in infant pain management.

5.6 CONCLUSION

PPA was recognized as a good resource to prepare for postnatal experiences. Our goal was to empower parents by directly equipping them with trustworthy PLPM information. However, there were instances where parents were not invited to be involved, challenged when they advocated for involvement, or were unaware of when procedures occurred. In this study, many parents were not optimally supported to manage their babies' pain, an omission which requires immediate attention. A multifaceted approach is recommended for practice change, including institutional infant pain management policy adoption, integration of PLPM information into prenatal education, access to parent-targeted educational resources (e.g., PPA), and postnatal care providers who engage parents in the care of their infant.

CHAPTER 6 DISCUSSION

Chapter 6 provides the overall discussion and presentation of strengths and limitations in relation to the dissertation project. Following that, implications for research and practice are described to contextualize future directions for parental involvement in procedural pain management with their infants.

6.1 OVERALL DISCUSSION

This dissertation gives an in-depth exploration into the parental role with infant procedural pain management and ways to support parental involvement in comfort strategies. Additionally, this dissertation describes the development and evaluation of a new eHealth educational resource, the Parenting Pain Away (PPA) website. This website is aimed at empowering parents and enhancing their capacity and confidence in parent-led pain management (PLPM) during needle-related procedures with their newborns. Chapter 4 (i.e., Development and Usability Testing of PPA; phase 1 of dissertation project) described the collaborative approach in developing PPA by creating a stakeholder committee comprised of an expectant parent and experts across a variety of disciplines (i.e., researchers in pediatric pain, information management, perinatal care; public health, primary care, and perinatal clinicians; administrators in community and perinatal acute care settings), of which many held dual roles in being parents themselves. Refinement of PPA occurred through a usability testing study (i.e., study phase 1) where expectant parents and recently postpartum parents (i.e., at most 2 months postpartum) participated in interviews reviewing and evaluating the website. This study found that participants were generally satisfied with PPA, showing greater satisfaction as the website design evolved. Participants emphasize the importance of efficient information

delivery to mitigate additional burden on parents experiencing mental fatigue and championed PPA as an eHealth resource that is accessible, inclusive, reliable, and contemporary. The development and refinement of PPA was strongly guided by User Experience (UX) principles (Krug, 2014; Morville, 2004, 2016). Designing for UX is an essential consideration for technological endeavors, much akin to family-centered care practice in healthcare. Participants supported PPA as a prenatal education resource, which gave the researcher team further confidence to evaluate PPA when delivered during the prenatal period for phase 2 of the dissertation project.

Chapter 5 (i.e., Evaluation of PPA; phase 2 of dissertation project) explored parental acceptability and clinical feasibility of providing parents with access to PPA during the prenatal period. Additionally, Chapter 5 assessed the impact of PPA on parents' knowledge about procedural pain management in newborns, parents perceived self-efficacy, and active involvement in procedural pain management. At enrolment, nearly all of the participants reported using the internet to search for health-related information, many of which went to Google as their first point of search. This finding is not surprising, as Google has long since been an important function in our society. So much so that the act of using this search engine turned into its own verb being popularized on an episode of Buffy the Vampire Slayer in 2002 (Arthur, 2012). For most, googling is a daily act, and using this search engine should not necessarily be viewed negatively as many credible, reputable sources can be retrieved through a quick Google search. However, this is not always the case, as demonstrated in a review, conducted by members of our team, assessing the quality and reliability of websites targeting parents of preterm infants that were accessible through Google (Dol et al., 2018). Out of 197

websites, this review found that websites ranked moderately in overall quality and reliability (Dol et al., 2018). It is important to note that scientific sources (e.g., peer-reviewed publications) were excluded as those sources did not align with the aim of the 2018 review (i.e., parent-targeted websites) and based on the fact that payment or affiliation with an academic institution is often required to access the full source (Dol et al., 2018). Dol and colleagues (2018) also found that infant pain was identified in only 5% of reviewed websites which minimizes an important and frequent experience for families with an infant in the NICU. On the day of writing, an informal Google search of ‘infant pain management during procedures’ retrieved numerous results and on the first page all appeared appropriately related to the search, including an encouraging featured snippet (i.e., brief, relevant description of website): “If your newborn undergoes a painful procedure, their doctor or nurse may suggest you breastfeed or hold your baby skin-to-skin if possible, or give them a sugar (sucrose) solution. These techniques are proven to have a calming and pain relieving effect on infants.” (Australian Government, 2022). The first ten results from this informal Google search varied in terms of recency (i.e., sources ranging from 2011-2023) and target audience (i.e., 2/10 parent-targeted sources) but accessibility appeared to be permissive with academic sources published as open access. Of course, Google searches made by different individuals likely will not retrieve the same results, as the powerful search engine considers user geographic location, language, device being used, and previous search history, as well as Search Engine Optimization (SEO) when ranking the search results (Google Developers, 2023; Google Support, 2023). Further evaluating search practices and source availability via Google is beyond the scope of this dissertation but an interesting point to highlight when considering the

health information seeking behaviour demonstrated by participants in phase 2 of this dissertation project.

In phase 2, prior to using the PPA website, many participants had previously heard of or used PLPM strategies, including skin-to-skin care (SSC; n=33, 80.5%), breastfeeding (n=30, 73.2%), and sucrose (n=13, 31.7%). While these are relatively high rates of awareness or previous utilization compared to existing studies (Hughes, Benoit, et al., 2023), especially with SSC and breastfeeding, rates were not carried over to PLPM implementation during the vitamin K injection (n=15, 36.6%) or newborn metabolic (NBM) screening (n=23, 56.1%). This disconnect in implementing knowledge to practice is not unique to this study, but consistent with similar projects evaluating parent-targeted educational resources about infant procedural pain management (Hughes, Benoit, et al., 2023) and clinical practice broadly (Harrison & Bueno, 2023). For example, in a study evaluating the impact of Be Sweet to Babies (i.e., YouTube video), regardless of previous awareness/use of PLPM, after reviewing the resource all participants intended to use PLPM strategies (i.e., breastfeeding, SSC, or sucrose) yet actual involvement only occurred in 60% of the sample (Venegas et al., 2019). From those that were involved in managing pain during procedures, 22% had sucrose administered despite those participants previously stating that they wanted to breastfeed or give SSC (Venegas et al., 2019). Consistent with existing literature, participants with other children in the phase 2 study had higher rates of awareness or previous use of PLPM when compared to first-time parents (Harrison et al., 2017). This finding is understandable especially given that experienced parents may have provided PLPM with previous children and many of these

parents specified previously receiving pain-related education by an HCP (n=13, 52%) compared to first-time parents (n=3, 18.8%).

Frequency of actual use of PPA in phase 2 varied across participants with some acknowledging they never accessed the website. Factors believed to influence frequency of use include time of study enrolment and granting PPA access in relation to birth, mental state or perceived mental load, as well as perceived relevancy and values of the information throughout PPA. In a study exploring parents' use of another educational resource related to pediatric vaccination pain management (i.e., *Needles Don't Have to Hurt*, infographic), the authors noted that when parents felt the information was relevant, most implemented pain management strategies described in the resource at vaccination appointments (MacKenzie et al., 2021b). The same authors further expanded on this finding in a qualitative study analyzing factors related to educational resource use (MacKenzie et al., 2021a). MacKenzie and colleagues (2021a) found that parents felt validated when seeing a comfort strategy that they recognized or had previously used which supported the likelihood of them continuing to use this practice for future procedures, but this was not as apparent in our study. MacKenzie and colleagues (2021a) also noted "alignment with personal value and experiences" (p. 6) as a key factor for PLPM. While our study did not specifically inquire about values related to procedural pain management, many participants expressed a desire to learn more about PLPM which could suggest value on this topic.

Despite variation in use of PPA, the System Usability Scale (SUS) score derived from participant responses ranked this website 71.04 which lies within the 50th percentile as per SUS interpretation categories (Bangor et al., 2009). When comparing across SUS

benchmarks, PPA is considered above average for being in the infancy of its development as a website and educational technology (Bangor et al., 2008; Vlachogianni & Tselios, 2022). Without consideration of the users experience and understanding of design principles, eHealth resources will not likely help in meeting learning objectives (Vlachogianni & Tselios, 2022). Utilizing the PSSUQ and SUS measurement tools in this dissertation project was essential to gain insight into perceived usability of PPA and, in turn, its future potential.

Given the high rates of awareness and previous use of PLPM in phase 2, as well as unlimited access to PPA, and participation in this study, it could be assumed that there would also be high rates of PLPM at the vitamin K injection or NBM screening, but as previously mentioned, the findings do not support this assumption. One overarching theme noted from this study, was the lack of support from HCPs. Supportive HCPs and environments have consistently been recognized as important determinants in parents' involvement in procedural pain management (Harrison & Bueno, 2023; MacKenzie et al., 2021b; Ullsten et al., 2021). To provide greater understanding of contextual factors in our sample, at the time of data collection for phase 2, neither postnatal unit at the two provincial hospitals included in this study had a formal policy or practice directive on infant pain management during procedures beyond heel warming prior to heel lance. However, during the course of data collection, one postnatal unit did create an Infant Pain Committee tasked at developing a policy for infant procedural pain management. While the policy has not been finalized yet, this committee encouraged registered nurses or parents to administer oral sucrose during needle-related procedures (i.e., vitamin K injection, heel lance) and lab technicians complete blood collection while the infant is

SSC or swaddled with non-nutritive sucking (H. Walker, personal communication, November 24, 2023). This change in policy could have meant that infants of study participants received sucrose for pain management during procedures, but participants were not unaware. It is unlikely that HCPs administered sucrose without disclosing to the parents, however participants often reported how overwhelmed they felt with the transitions immediately postpartum, which is when routine needle-related procedures occur, so they may not have processed if sucrose was administered. Generally, the sample in phase 2 was highly educated and had readily access to health information and HCPs (e.g., prenatal care providers), yet not all participants were engaged in PLPM or felt like they could advocate for involvement. Considering people who may be more vulnerable, without HCP support and engagement parents face a great barrier in participating in pain management.

While many participants intended to use PLPM for future procedures, there were some salient points noted by those who were hesitant about using PLPM, especially related to personal comfort in different clinical settings. Understandably, parents often desire environments which support ease of breastfeeding or providing SSC and maintain privacy, a known important factor (MacKenzie et al., 2021a). Offering private areas is not always possible in clinical settings (e.g., influenza vaccine clinics) but consideration of the physical environment should occur to support PLPM while maintaining parents' right to privacy and dignity. Additionally, availability of sucrose at public health clinics (i.e., typical setting for infant immunizations in Canada) was questioned in this study. To address this point, the lead researcher contacted the local public health nurse manager to inquire about pain management options. The nurse manager shared that currently no

sucrose is available but the practice for pain management for young infants has been to give the rotovirus oral vaccine prior to injectable vaccines at the 2- and 4-month immunization appointments (C. Dunn, personal communication, November 20, 2023). As sucrose is an ingredient within the rotovirus vaccine, it is assumed to maintain pain management properties and has been recommended as analgesia for the 2- and 4-month vaccinations since no difference was found when compared to use of oral sucrose (Taddio, Flanders, et al., 2015). There have been no trials exploring the impact of breastfeeding during the injected vaccines following the rotovirus vaccine administration. It would be beneficial to have evidence to understand how breastfeeding augments the pain relief properties of the rotovirus vaccine and sustains pain management for all subsequent vaccines provided at 2- and 4-months. Additionally, PEI public health has integrated the CARD™ System (C. Dunn, personal communication, November 20, 2023). The CARD™ System focuses on reducing pain and fear related to needle procedures, predominantly vaccinations, using the acronym to represent Comfort, Ask, Relax, and Distract (Taddio et al., 2021). While its original intention was to support vaccination in school settings, this system is not unique to children but appropriate for adults as well (Taddio et al., 2021). The system also highlights PLPM strategies specifically for infants in guidance documents for parents (i.e., “CARD Checklist for Children up to 3 years of age) (SickKids, 2023). The CARD™ System includes a framework aimed at HCPs to facilitate vaccination administration which emphasizes the inclusion of parents in pain management and importance of clinical environments in fostering a positive experience, such as allowing for privacy (Taddio et al., 2021).

As described in Chapter 5, participants were often not invited or supported to provide PLPM, or they were not present during procedures. Before beginning phase 2 of this dissertation project the lead researcher collaborated closely with the nurse managers of both perinatal units at the included provincial hospitals (also members of the project stakeholder committee) and met with laboratory services to discuss the study and gain support for PLPM during the NBM screening, which is performed by technicians from laboratory services. Naturally, during this meeting with laboratory services, concerns were noted about how PLPM could impact ergonomics, privacy, and timeliness of the procedure. These were potential barriers anticipated by the lead researcher as there has been previous reports of similar concerns (Harrison, 2021), and thus resources were shared with laboratory services to support practice uptake including the YouTube video: “Be Sweet to Moms and Babies: Performing baby blood tests while breastfeeding or holding skin to skin” (Harrison & Children’s Hospital of Eastern Ontario, 2019). It is not surprising that some participants in this study still experienced resistance when requesting to breastfeed or provide SSC with their infant during the NBM screen. Changing clinical practice related to infant procedural pain management continues to take time despite an abundance of evidence (Balice-Bourgeois et al., 2020; Harrison, 2021; Harrison & Bueno, 2023). A recent commentary emphasizing the need for shared decision making in pediatric pain management, reported that caregivers (e.g., parents) are often excluded from decision making in acute pediatric pain matters which impacts their ability to learn PLPM or advocate for consistent, effective pain management during procedures (MacKenzie et al., 2023). Findings shared throughout this dissertation support

the strong endorsement for parents and caregivers to be involved in decision making, especial with regards to infant pain management for all procedures.

6.2 STRENGTHS AND LIMITATIONS

There are many strengths and limitations to discuss in consideration of the overall dissertation. In terms of its strengths, this dissertation builds on previous calls for consistent procedural pain management for infants by summarizing current evidence related to pediatric pain management and parent-targeted educational resources about infant pain management, as well as emphasizing the importance of pain management within the PPA website. Regardless of use, most participants in both study phases felt that PPA was a beneficial resource which either provided new information or reinforced their understanding about infant pain management strategies. Since clinical practice still varies in application of infant procedural pain management and involvement of parents with such, this dissertation is highly relevant and valuable to further advocate for change.

The second strength is the collaborative development of PPA, guided by UX design principles. This approach enhanced user satisfaction, which was evident in the positive findings from phases 1 (i.e., PSSUQ) and 2 (i.e., SUS score) of the overall dissertation. Much of the content throughout PPA was previously created and evaluated with experts and parents from the Chez NICU Home project which provided a strong basis and confidence when tailoring the information to target expectant parents in the community. Gathering a committee of stakeholders to review and refine PPA further contributed to this strength in co-creating the eHealth educational resource. Additionally, engaging local clinicians, researchers, and administrators into the stakeholder group

facilitated ease and overall success of data collection throughout both phases of the dissertation project.

Another strength of this work is the timing focus for information delivery. While most similar studies provided education in postnatal care areas, targeting the prenatal period to provide key information about infant pain during procedures and pain management strategies was believed to empower parents and equip them with appropriate skills in advance of any procedures. This assumption had merit and most participants in both study phases strongly supported access to infant pain related information in the prenatal period.

Finally, the findings from study phase 2 provided a wealth of insight related to the current experience of PLPM during procedures in postnatal settings that can be used to improve infant pain management and parental involvement in local health centres, which may also be relatable to the broader perinatal population.

Several limitations were also noted throughout this dissertation. First, as a consequence of restrictions related public health protection during the COVID-19 pandemic, recruitment procedures for both study phases were adjusted to occur solely online (e.g., social media) or passively using posters at appropriate health care centres. This recruitment approach may have been a factor in the resulting homogenous samples in study phases 1 and 2, as over representation of white women and/or highly educated populations is common with online recruitment (Benedict et al., 2019; Shaver et al., 2019; Simó et al., 2022; Whitaker et al., 2017), despite being an accessible method to engage a widespread population (Dol, Tutelman, et al., 2019; Wozney et al., 2019). Leveraging social media for study recruitment is still worthwhile (Dol, Tutelman, et al.,

2019), however complementing that with an in-person strategy may enhance the likelihood for a more diverse representation.

The remaining limitations are specific to phase 2, which were not previously described in Chapter 5. Specific to the data collected, this study asked participants to report whether they had previously heard of or used PLPM combined in one response. It would have been more informative to have separated that into two questions to isolate the number of participants who had knowledge only versus experience of PLPM. Additionally, the exact timing of study intervention delivery (i.e., access to PPA) was not consistent as participants could enroll in the study any time between 32 weeks gestation and birth. Receiving access to PPA too close to birth could have been a factor in why some participants never used the website, thus considering intervention consistency and fidelity is an important step for any future evaluations. The final limitation was not having complete buy-in from HCPs about PLPM during procedures in the postnatal units prior to phase 2. While strong efforts were made to mitigate conflict with participants using PLPM (i.e., stakeholder committee; meeting with hospital laboratory services), hospital policies related to infant procedural pain management were not in place when the study began so there was no clear directive to facilitate PLPM. The strengths and limitations that have emerged from this dissertation shed light on implications for research and practice related to infant procedural pain management and perinatal education targeting parents and HCPs.

6.3 IMPLICATIONS FOR RESEARCH

In consideration of the previous chapters in this dissertation, there are several recommendations for future research. First to understand how the conceptual model of

Parental Involvement in Infant Pain Management could be reconsidered to reflect alternative timing and delivery of information to parents. This doctoral project builds on work by Franck and colleagues by using their conceptual model to guide the development and implementation of a parent-targeted eHealth resource focusing on a different population. Targeting the childbearing population was inspired by the original research that informed the development of this conceptual model, from the theme: *Improving the timing of information giving and involvement in opportunities for parents* (Franck et al., 2012). A few aspects related to this project and PPA inform this model. In creating an eHealth resource that is aimed at empowering and educating parents during the prenatal period, this could alter the order of the discs presented in the model, where disc 2 (Information/Support) is presented first to help shape parental beliefs including their sense of attachment and parental role, as well as their values in being involved in pain management during procedures. The intention being that providing this information and support in a virtual space expands the holes on both of the first two discs (reimagined order as 1: Information/Support; 2: Parental Beliefs) to increase the likelihood that parents achieve their desired involvement. Parenting Pain Away sought to reduce barriers related to disc 3 (Parent-Infant Proximity) by providing parents with anticipatory guidance about collaborating with their healthcare team for procedures, sharing approximate timing for procedures (e.g., Vitamin K injection, NBM screening), and emphasizing that partners can provide PLPM as well (not just the childbearing parent). This doctoral project also may influence disc 3 (Parent-Infant Proximity) when considering parents of newborns not requiring NICU admission, as typically the general postnatal population are roomed/cared for together throughout the entirety of their

hospital stay. Additionally, the emotional proximity of the general postnatal population may differ from NICU parents where the health status of their infant is not as fragile. Where prenatal eHealth resources (e.g., PPA) fall short is being able to ensure healthcare provider support and parental presence for procedures postnatally so parents can actually apply their desired involvement. This doctoral project validates barriers proposed by the conceptual model including parents only accessing information from external sources (e.g., PPA; Disc 2) and parents are often excluded or not encouraged to participate in infant procedural pain management (Franck et al., 2012). As suggested by the original report describing the conceptual model of Parental Involvement in Infant Pain Management, we have reimaged this conceptual model to broaden the population of interest and enhance opportunities for involvement throughout the pursuit of this doctoral project. An empirical update of the conceptual model reflecting these insights would be beneficial.

Additional recommendations for research are to gain greater insight into accessible information, health-information seeking behaviours, and current clinical practice, as well as promoting parental involvement in pain management. Conducting a review and content analysis of sources related to infant pain management accessible through Google is warranted, to elicit clarity on the information parents can freely access. In the same vein, expanding the study of parents' health-information seeking behaviours (Dol, Richardson, Aston, et al., 2021) to specifically inquire which sources from a Google search will parents view first (e.g., top ranked link, academic publications, etc.). At the local level, assessing parents' values and beliefs around infant procedural pain and PLPM, similar to the study completed by MacKenzie and colleagues (2021a), could

highlight opportunities for tailored education or awareness campaigns. Additionally, a study evaluating current pain management practices for infants admitted to postnatal units and routine public health appointments to capture potential barriers and facilitators would inform future use of pain-relieving strategies in hospital and in the community. Specific to the PPA website, a first step would be to consult with IWK Health about maintaining this resource for future evaluations. This could include a study in partnership with prenatal care providers (across the Maritime provinces) to integrate discussion of PLPM and encouragement for expectant parents to review PPA at multiple prenatal care appointments (e.g., initial prenatal appointment, at 34 weeks gestation, and between 37-40 weeks gestation), as recommended in Chapter 5. Best efforts to have representative samples for proposed studies with participants is essential for greater generalizability.

6.4 IMPLICATIONS FOR PRACTICE

The findings from both study phases validate parents' desire for more information on their role in infant pain management during procedures (Harrison & Bueno, 2023; Ullsten et al., 2021) and support the argument for providing education about PLPM during the prenatal period (Hughes, Benoit, et al., 2023). Participants appreciated having access to PPA to learn about this topic, but some cautioned against overwhelming expectant parents with too much information. Reports from phase 2 revealed inconsistencies in the support and engagement HCPs offered to parents during procedures with their infants in postnatal units and community settings (i.e., public health clinics). Therefore, collaboration with perinatal clinical settings (i.e., primary care, prenatal care centres, postnatal units, public health) and hospital laboratory services is necessary to facilitate the adoption of consistent infant procedural pain management. The knowledge

translation activities previously described in Chapter 3 will facilitate collaboration opportunities and promote clinical practice change. These activities will include sharing the phase 2 study findings (i.e., manuscript and an engaging summary infographic) by email to relevant stakeholder committee members and Health PEI employees that are well positioned to foster practice change.

6.5 CONCLUSION

This dissertation expands the availability of educational resources, about infant procedural pain, targeting parents of healthy, full term newborns while using eHealth methods to further increase accessibility. Guided by the Conceptual Model of Parental Involvement in Infant Pain Management, the PPA website was designed to empower and educate expectant parents to use their capacity to provide or advocate for procedural pain management, as a response to the mounting evidence of inconsistent pain treatment in health institutions. Findings from the dissertation project suggest that expectant parents saw value in PPA and considered it a feasible resource to use, with consideration of ample time prior to birth and their current perceived mental load. Further evaluation is warranted to gather more evidence about the influence of PPA on parental knowledge, perceived self-efficacy, and parental involvement in pain management. However, the participants in this project shared details in their experiences with PLPM which enrich current understanding on parental involvement in pain management, especially with routine procedures for newborns occurring in regional non-tertiary hospitals in a rural Canadian setting.

This dissertation adds to the evidence supporting perinatal eHealth interventions and collaborative development to enhance user experience. This project further informs

pediatric pain research and clinical practice on the practicality of delivering pain education prenatally to promote PLPM with all infants, whether they require routine or intensive care. Driven by theory and best practice standards, this dissertation sought to amplify family-centered care practice and enhance parental involvement in infant procedural pain management through the development of an evidence-based eHealth educational resource.

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CHAPTER 2 APPENDICES

Chapter 2.6 Review Appendices

APPENDIX 2.1 SEARCH STRATEGY

MEDLINE via PubMed

Date searched: June 14, 2021. Results retrieved: 785.

- 1 pain[mh]
- 2 "pain management"[mh]
- 3 "pain measurement"[mh]
- 4 pain*[tiab]
- 5 #1 or #2 or #3 or #4
- 6 infant[mh]
- 7 infan*[tiab]
- 8 newborn*[tiab]
- 9 new-born*[tiab]
- 10 perinat*[tiab]
- 11 neonat*[tiab]
- 12 baby[tiab]
- 13 babies[tiab]
- 14 "low birth weight"[tiab]
- 15 prematur*[tiab] or pre-mature*[tiab]
- 16 preterm*[tiab] or pre-term*[tiab]
- 17 #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16
- 18 education[mh]

- 19 teaching[mh]
- 20 learning[mh]
- 21 educat*[tiab]
- 22 teach*[tiab]
- 23 learn*[tiab]
- 24 training[tiab]
- 25 elearn*[tiab]
- 26 e-learn*[tiab]
- 27 "electronic learning"[tiab]
- 28 ehealth[tiab] or mhealth[tiab]
- 29 e-health[tiab] or m-health[tiab]
- 30 "electronic health"[tiab]
- 31 #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29
or #30
- 32 parents[mh]
- 33 fathers[mh]
- 34 mothers[mh]
- 35 parent*[tiab]
- 36 father*[tiab]
- 37 mother*[tiab]
- 38 paternal*[tiab]
- 39 maternal*[tiab]
- 40 guardian[tiab]

- 41 guardians[tiab]
- 42 guardianship[tiab]
- 43 #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42
- 44 #5 and #17 and #31 and #43
- 45 #44 AND (("2000/01/01"[PDAT] : "2021/06/14"[PDAT]) AND English[lang])

CINAHL via EBSCO

Date searched: June 14, 2021. Results retrieved: 685.

- 1 (MM ‘‘Pain+’’)
- 2 (MM ‘‘Pain Management’’)
- 3 (MM ‘‘Pain Measurement’’)
- 4 TI (pain*) OR AB (pain*)
- 5 S1 OR S2 OR S3 OR S4
- 6 (MH "Infant+")
- 7 (MH "Perinatal Care+")
- 8 (MH "Infant Care+")
- 9 TI Infan* OR AB Infan*
- 10 TI newborn* OR AB newborn* OR TI new-born* OR AB new-born*
- 11 TI perinat* OR AB perinat*
- 12 TI neonat* OR AB neonat*
- 13 TI baby OR AB baby OR TI babies OR AB babies
- 14 TI "low birth weight" OR AB "low birth weight"
- 15 TI prematur* OR AB prematur* OR TI pre-matur* OR AB pre-matur*

16 TI preterm* OR AB preterm* OR TI pre-term* OR AB pre-term*

17 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR
S16

18 (MH "Education+")

19 (MH "Teaching+")

20 (MH "Learning+")

21 TI educat* OR AB educat*

22 TI teach* OR AB teach*

23 TI learn* OR AB learn*

24 TI training OR AB training

25 TI elearn OR AB elearn OR TI e-learn OR AB e-learn OR TI "electronic
learning" OR AB "electronic learning"

26 TI "electronic health" OR AB "electronic health" OR TI ehealth OR AB ehealth
OR TI e-health OR AB e-health OR TI mhealth OR AB mhealth OR TI m-health OR AB
m-health

27 S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26

28 (MH "Parents+")

29 (MH "Fathers+")

30 (MH "Mothers+")

31 TI parent* OR AB parent*

32 TI father* OR AB father*

33 TI mother* OR AB mother*

34 TI paternal* OR AB paternal*

- 35 TI maternal* OR AB maternal*
- 36 TI guardian OR AB guardian OR TI guardians or AB guardians or TI guardianship or AB guardianship
- 37 S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 O S36
- 38 S5 AND S17 AND S27 AND S37
- 39 38 AND Published Date: 20000101-20210630; English Language

PsycINFO via EBSCO

Date searched: June 14, 2021. Results retrieved: 200.

- 1 DE "Pain"
- 2 DE "Pain Management"
- 3 DE "Pain Measurement"
- 4 TI (pain*) OR AB (pain*)
- 5 S1 OR S2 OR S3 OR S4
- 6 DE "Infant Development"
- 7 DE "Perinatal Period"
- 8 DE "Neonatal Development"
- 9 TI Infan* OR AB Infan*
- 10 TI newborn* OR AB newborn* OR TI new-born* OR AB new-born*
- 11 TI perinat* OR AB perinat*
- 12 TI neonat* OR AB neonat*
- 13 TI baby OR AB baby OR TI babies OR AB babies
- 14 TI "low birth weight" OR AB "low birth weight"

- 15 TI prematur* OR AB prematur* OR TI pre-matur* OR AB pre-matur*
- 16 TI preterm* OR AB preterm* OR TI pre-term* OR AB pre-term*
- 17 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR
S16
- 18 DE "Education"
- 19 DE "Teaching"
- 20 DE "Learning"
- 21 TI educat* OR AB educat*
- 22 TI teach* OR AB teach*
- 23 TI learn* OR AB learn*
- 24 TI training OR AB training
- 25 TI elearn OR AB elearn OR TI e-learn OR AB e-learn OR TI "electronic
learning" OR AB "electronic learning"
- 26 TI "electronic health" OR AB "electronic health" OR TI ehealth OR AB ehealth
OR TI e-health OR AB e-health OR TI mhealth OR TI m-health OR AB mhealth OR AB
m-health
- 27 S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26
- 28 DE "Parents" OR DE "Adoptive Parents" OR DE "Expectant Parents" OR DE
"Fathers" OR DE "Foster Parents" OR DE "Homosexual Parents" OR DE "Mothers" OR
DE "Parental Characteristics" OR DE "Single Parents" OR DE "Stepparents" OR DE
"Surrogate Parents (Humans)"
- 29 DE "Fathers" OR DE "Adolescent Fathers" OR DE "Single Fathers"

- 30 DE "Mothers" OR DE "Adolescent Mothers" OR DE "Primipara" OR DE
 "Schizophrenogenic Mothers" OR DE "Single Mothers" OR DE "Unwed Mothers"
- 31 TI parent* OR AB parent*
- 32 TI father* OR AB father*
- 33 TI mother* OR AB mother*
- 34 TI paternal* OR AB paternal*
- 35 TI maternal* OR AB maternal*
- 36 TI guardian OR AB guardian OR TI guardians OR AB guardians OR TI
 guardianship OR AB guardianship
- 37 S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36
- 38 S5 AND S17 AND S27 AND S37
- 39 S38 AND Published Date: 20000101-20210631; English Language

Embase

Date searched: June 14, 2021. Results retrieved: 2019.

- 1 pain/exp
- 2 "pain management"/exp
- 3 "pain measurement"/exp
- 4 pain:ti,ab
- 5 #1 OR #2 OR #3 OR #4
- 6 infant'/exp
- 7 perinatal development'/exp
- 8 perinatal period'/exp

- 9 perinatal care'/exp
- 10 infan*:ti,ab
- 11 newborn*:ti,ab OR new-born*:ti,ab
- 12 perinat*:ti,ab
- 13 neonat*:ti,ab
- 14 baby:ti,ab OR babies:ti,ab
- 15 "low birth weight":ti,ab
- 16 prematur*:ti,ab OR pre-matur*:ti,ab
- 17 preterm*:ti,ab or pre-term*:ti,ab
- 18 #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR
#16 OR #17
- 19 education/exp
- 20 teaching/exp
- 21 learning/exp
- 22 educat*:ti,ab
- 23 teach*:ti,ab
- 24 learn*:ti,ab
- 25 training:ti,ab
- 26 elearn*:ti,ab
- 27 e-learn*:ti,ab
- 28 "electronic learning":ti,ab
- 29 ehealth:ti,ab OR mhealth;ti,ab
- 30 e-health:ti,ab OR m-health;ti,ab

31 "electronic health":ti,ab
32 #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28
OR #29 OR #30 OR #31
33 parent/exp
34 father/exp
35 mother/exp
36 parent*:ti,ab
37 father*:ti,ab
38 mother*:ti,ab
39 paternal*:ti,ab
40 maternal*:ti,ab
41 guardian:ti,ab
42 guardians:ti,ab
43 guardianship:ti,ab
44 #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42
OR #43
45 #5 AND #18 AND #32 AND #44
46 #44 AND [1-1-2000]/sd NOT [15-6-2021]/sd AND [English]/lim

Scopus

Date searched: June 14, 2021. Results retrieved 56.

1 ALL ("pain")
2 ALL ("pain management")

3 ALL ("pain measurement")
4 TITLE-ABS(pain)
5 #1 or #2 or #3 or #4
6 TITLE-ABS(perinat*)
7 TITLE-ABS(infan*)
8 TITLE-ABS(newborn*) or TITLE-ABS(new-born*)
9 TITLE-ABS(neonat*)
10 TITLE-ABS(baby) or TITLE-ABS(babies)
11 TITLE-ABS("low birth weight")
12 TITLE-ABS(prematur*) or TITLE-ABS(pre-matur*)
13 TITLE-ABS(preterm*) or TITLE-ABS(pre-term*)
14 #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13
15 ALL ("education")
16 ALL ("teaching")
17 ALL ("learning")
18 TITLE-ABS(educat*)
19 TITLE-ABS(teach*)
20 TITLE-ABS(learn*)
21 TITLE-ABS(training)
22 TITLE-ABS(elearn*)
23 TITLE-ABS(e-learn*)
24 TITLE-ABS(electronic learning)
25 TITLE-ABS(ehealth) or TITLE-ABS(e-health)

26 TITLE-ABS(mhealth) or TITLE-ABS(m-health)

27 TITLE-ABS(electronic health)

28 #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26
or #27

29 TITLE-ABS(parent*)

30 TITLE-ABS(father*)

31 TITLE-ABS(mother*)

32 TITLE-ABS(paternal*)

33 TITLE-ABS(maternal*)

34 TITLE-ABS(guardian)

35 TITLE-ABS(guardians)

36 TITLE-ABS(guardianship)

37 #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36

38 #5 AND #14 AND #28 AND #37

39 #38 AND (LIMIT-TO (LANGUAGE , "English")) AND (Limit-to (Pubyear,
2000-2021)

Web of Science

Date searched: June 14, 2021. Results retrieved: 1615.

1 KP=(pain)

2 KP=(pain management)

3 KP=(pain measurement)

4 TI=(pain) OR AB=(pain)

5 #1 OR #2 OR #3 OR #4

6 [omit]

7 TI=(perinat*) OR AB=(perinat*)

8 TI=(infan*) OR AB=(infan*)

9 TI=(newborn*) OR AB=(newborn*)

10 TI=(new-born*) OR AB=(new-born*)

11 TI=(neonat*) OR AB=(neonat*)

12 TI=(baby) OR AB=(baby)

13 TI=(babies) OR AB=(babies)

14 TI=("low birth weight") OR AB=("low birth weight")

15 TI=(prematu*) OR AB=(prematu*) OR TI=(pre-matu*) OR AB=(pre-matu*)

16 TI=(preterm*) OR AB=(preterm*) OR TI=(pre-term*) OR AB=(pre-term*)

17 #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16

18 KP=(education)

19 KP=(teaching)

20 KP=(learning)

21 TI=(educat*) OR AB=(educat*)

22 TI=(teach*) OR AB=(teach*)

23 TI=(learn*) OR AB=(learn*)

24 TI=(training) OR AB=(training*)

25 TI=(elearn*) OR AB=(elearn*)

26 TI=(e-learn*) OR AB=(e-learn*)

27 TI=("electronic learning") OR AB=("electronic learning")

28 TI=(ehealth) OR AB=(ehealth) OR TI=(mhealth) OR AB=(mhealth)

29 TI=(e-health) OR AB=(e-health) OR TI=(m-health) OR AB=(m-health)

30 TI=("electronic health") OR AB=("electronic health")

31 #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27

OR #28 OR #29 OR #30

32 TI=(parent*) OR AB=(parent*)

33 TI=(father*) OR AB=(father*)

34 TI=(mother*) OR AB=(mother*)

35 TI=(paternal*) OR AB=(paternal*)

36 TI=(maternal*) OR AB=(maternal*)

37 TI=(guardian) OR AB=(guardian)

38 TI=(guardians) OR AB=(guardians)

39 TI=(guardianship) OR AB=(guardianship)

40 #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39

41 #5 AND #17 AND #31 AND #40

42 #41 AND LANGUAGE: (English) AND Timespan=2000-2021

SciELO Citation Index

Date searched: June 14, 2021. Results retrieved: 37.

1 pain

2 "pain management"

3 "pain measurement"

4 ti:pain OR ab:pain

5 #1 OR #2 OR #3 OR #4
6 ti:perinat* OR ab:perinat*
7 ti:infan* OR ab:infan*
8 ti:newborn* OR ab:newborn*
9 ti:new-born* OR ab:new-born*
10 ti:neonat* OR ab:neonat*
11 ti:baby OR ab:baby
12 ti:babies OR ab:babies
13 ti:"low birth weight" OR ab:"low birth weight"
14 ti:prematu* OR ab:prematu* OR ti:pre-matur* OR ab:pre-matur*
15 ti:preterm* OR ab:preterm* OR ti:pre-term* OR ab:pre-term*
16 #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15
17 education
18 teaching
19 learning
20 ti:educat* OR ab:educat*
21 ti:teach* OR ab:teach*
22 ti:learn* OR ab:learn*
23 ti:training OR ab:training
24 ti:elearn* OR ab:elearn*
25 ti:e-learn* OR ab:e-learn*
26 ti:"electronic learning" OR ab:"electronic learning"
27 ti:ehealth OR ab:ehealth OR ti:mhealth OR ab:mhealth

28 ti:e-health OR ab:e-health OR ti:m-health OR ab:m-health
29 ti:"electronic health" OR ab:"electronic health"
30 #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26
OR #27 OR #28 OR #29
31 ti:parent* OR ab:parent*
32 ti:father* OR ab:father*
33 ti:mother* OR ab:mother*
34 ti:paternal* OR ab:paternal*
35 ti:maternal* OR ab:maternal*
36 ti:guardian OR ab:guardian
37 ti:guardians OR ab:guardians
38 ti:guardianship OR ab:guardianship
39 #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38
40 #5 AND #16 AND #30 AND #39
41 AND la:("en")

ProQuest Dissertations and Theses Global

Date searched: June 14, 2021. Results retrieved: 602.

1 pain
2 "pain management"
3 "pain measurement"
4 au(pain) OR ti(pain)
5 S1 OR S2 OR S3 OR S4

- 6 au(perinat*) OR ti(perinat*)
- 7 au(infan*) OR ti(infan*)
- 8 au(newborn*) OR ti(newborn*)
- 9 au(new-born*) OR ti(new-born*)
- 10 au(neonat*) OR ti(neonat*)
- 11 au(baby) OR ti(baby)
- 12 au(babies) OR ti(babies)
- 13 au("low birth weight") OR ti("low birth weight")
- 14 au(prematur*) OR ti(prematur*)
- 15 au(pre-matur*) OR ti(pre-matur*)
- 16 au(preterm*) OR ti(preterm*)
- 17 au(pre-term*) OR ti(pre-term*)
- 18 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR
S16 OR S17
- 19 education
- 20 teaching
- 21 learning
- 22 au(educat*) OR ti(educat*)
- 23 au(teach*) OR ti(teach*)
- 24 au(learn*) OR ti(learn*)
- 25 au(training) OR ti(training)
- 26 au(elearn*) OR ti(elearn*)
- 27 au(e-learn*) OR ti(e-learn*)

- 28 au("electronic learning") OR ti("electronic learning")
- 29 au(ehealth) OR ti(ehealth)
- 30 au(e-health) OR ti(e-health)
- 31 au(m-health) OR ti(m-health)
- 32 au(mhealth) OR ti(mhealth)
- 33 S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28
or S29 or S30 OR S31 OR S32
- 34 au(parent*) OR ti(parent*)
- 35 au(father*) OR ti(father*)
- 36 au(mother*) OR ti(mother*)
- 37 au(paternal*) OR ti(paternal*)
- 38 au(maternal*) OR ti(maternal*)
- 39 au(guardian) OR ti(guardian)
- 40 au(guardians) OR ti(guardians)
- 41 au(guardianship) OR ti(guardianship)
- 42 S34 OR S35 OR S36 OR S37 OR S38 OR S39 S40 OR S41
- 43 S5 AND S18 AND S33 AND S42

2000-01-01 - 2021-06-30

English

APPENDIX 2.2 STUDIES INELIGIBLE FOLLOWING FULL-TEXT REVIEW

Ineligible intervention:

Cwynar CM, Osborne K. Immunization-associated pain: taking research to the Bedside. *J Pediatr Heal Care*. 2019;33(4):446–54.

Harrison D, Joly C, Chretien C, Cochrane S, Ellis J, Lamontagne C, et al. Pain prevalence in a pediatric hospital: raising awareness during Pain Awareness Week. *Pain Res Manag*. 2014;19(1):e24–30.

Reid S, Neto G, Tse S, Farion KJ, Marvizi A, Smith L, et al. Education in the waiting room: description of a pediatric emergency department educational initiative. *Pediatr Emerg Care*. 2017;33(10):E87–91.

Taddio A, Smart S, Sheedy M, Yoon EW, Vyas C, Parikh C, et al. Impact of prenatal education on maternal utilization of analgesic interventions at future infant vaccinations: a cluster randomized trial. *Pain*. 2014;155(7):1288–92.

Ineligible population:

Dunbar M, Paton G, Singhal A. An educational video improves consent in pediatric lumbar puncture: a randomized control trial. *Pediatr Neurol*. 2019;100:74–9.

French L. Can simple interventions by parents reduce infant pain from immunizations?
Evidence-Based Pract. 2000;3(10):9.

Ineligible time frame:

Taddio A, Riddell RP, Ipp M, Moss S, Baker S, Tolkin J, et al. A longitudinal randomized trial of the effect of consistent pain management for infant vaccinations on future vaccination distress. 2017;18(9):1060-1066.

Ineligible study design:

American Association of Critical-Care Nurses. Pain management education may help parents of preemies. AACN Bold Voices. 2011;3(12):7.

Ineligible objective:

Gennis H, Riddell RP, O'Neill MC, Katz J, Taddio A, Garfield H, et al. Parental psychological distress moderates the impact of a video intervention to help parents manage young child vaccination pain. J Pediatr Psychol. 2018;43(10):1170–8.

APPENDIX 2.3 DATA EXTRACTION TEMPLATE

Article Overview

Reviewer Initials	Reviewer Author	Publication Year	Article title	Country	Additional Details	Study Objective	Methodology	Notes
Initials	Initials				Part of another study? Time period of data collection	Discipline (e.g. Nursing)	Study design (e.g. RCT)	

Intervention

Reviewer Initials	Reviewer Author, year	Intervention type	Timing of intervention delivery	Location of intervention delivery	Intervention content related to pain management	Intervention duration	Intervention administration	Additional details about intervention
Initials	Initials	(e.g. apps, video, SMS)	(e.g. prenatal, postnatal)	(e.g. health clinic, home, postnatal unit)	(e.g. breastfeeding, SSC, sucrose, combination, etc)	length of intervention (e.g. 5 minute video)	Was the intervention self administered (e.g. website, youtube video) or did a HCP administer (e.g. video in postnatal unit)	

Control description	Notes
NA if not applicable	

Outcome

Reviewer Initials	Reviewer Author, year	Intervention: # of participants recruited	Intervention: # of participants completed	Control: # of participants recruited	Control: # of participants completed	Follow-up duration	Participant type	Infant Information	Notes
Initials	Initials					(e.g. discharge, 2 months, 4 months)	(e.g. mothers only, partners only, both parents, not specified)	(e.g. full term, preterm, NICU admission)	

Parental Stress, Anxiety	Measurement method	Intervention	Control	Findings	Parental self-efficacy	Measurement method	Intervention	Control	Findings	Parental knowledge (gain)	Measurement method	Intervention	Control	Findings
(yes=Y; no=N)	(e.g. PSS:NICU)	(e.g. mean, SD, median, etc)	(CI: p)	(yes=Y; no=N)	(e.g. Karliane Parenting Confidence Scale) etc)	(e.g. mean, SD, median, etc)	(CI: p)	(yes=Y; no=N)	(e.g. study specific pre/post)	(e.g. mean, SD, median, etc)				(CI: p)

Parental attitudes	Measurement method	Intervention	Control	Findings	eHealth intervention usage	Measurement method	Intervention	Control	Findings	Parental acceptance of Health Intervention	Measurement method	Intervention	Control	Findings
(yes=Y; no=N)	(e.g. Parental Attitudes about Infant Nociception)	(e.g. mean, SD, median, etc)	(CI: p)	(yes=Y; no=N)	(e.g. frequency counts)	(e.g. mean, SD, median, etc)	(CI: p)	(yes=Y; no=N)	(e.g. Technology Acceptance Model)	(e.g. mean, SD, median, etc)				(CI: p)

Parent-led pain management	Measurement method	Intervention	Control	Findings	Infant pain response	Measurement method	Intervention	Control	Findings
(yes=Y; no=N)	(e.g. observation, self-report)	(e.g. mean, SD, median, etc)	(CI: p)	(yes=Y; no=N)	(e.g. PIPP-R; behavioural indicators)	(e.g. mean, SD, median, etc)			(CI: p)

Neonatal morbidity	Type of morbidity	Intervention	Control	Findings	Type of feeding method	Feeding method	Intervention	Control	Findings	Length of stay in hospital	Measurement method	Intervention	Control	Findings
(yes=Y; no=N)	(e.g. infection; hypoglycaemia) etc)	(e.g. mean, SD, median, etc)	(CI: p)	(yes=Y; no=N)	Breast vs. formula	(e.g. mean, SD, median, etc)	(CI: p)	(yes=Y; no=N)	(e.g. days; hours)	(e.g. mean, SD, median, etc)				(CI: p)

APPENDIX 2.4 CHARACTERISTICS OF INCLUDED STUDIES

Study	Study design	Country	Participants (sample size)	Intervention	Comparator	Administration timing, location, & details	Outcomes
Bueno et al. 2018	Analytical cross-sectional	Brazil	Parents of infants (n=100; 75% mothers, 25% fathers)	“Be Sweet to Babies” YouTube video (6 minutes), Portuguese version. Provided specific information about use of breastfeeding, skin-to-skin contact, and sweet-tasting solutions for procedural pain management.	NA	Postnatal NICU (Level III)	Knowledge, attitudes, acceptance, involvement
Campbell-Yeo et al. 2017	Analytical cross-sectional	Global (authors based in Canada)	Childbearing or parents of children (n=32, 91% mothers, 9% fathers)	“The Power of a Parent’s Touch” YouTube video (2 minutes, 39 seconds). Provided specific information about use of breastfeeding and skin-to-skin contact for procedural pain management.	NA	Self-administered via YouTube	Self-efficacy, eHealth usage, acceptance, involvement (intent), use of pain management (previous)
Harrison et al., 2017	Analytical cross-sectional	Canada	Parents of infants	“Be Sweet to Babies” YouTube video (5 minutes), bilingual	NA	Postnatal NICU (Level III)	Knowledge, acceptance, involvement

Study	Study design	Country	Participants (sample size)	Intervention	Comparator	Administration timing, location, & details	Outcomes
Korki de Candido et al., 2020	Quasi-experimental (nonrandomized pragmatic trial)	Brazil	Mothers of full-term infants (n=73)	“Be Sweet to Babies” YouTube video (6 minutes), Portuguese version. Provided specific information about use of breastfeeding, skin-to-skin contact, and sweet-tasting solutions for procedural pain management.	Mothers who did not attend the educational session or did not watch the “Be Sweet to Babies” video.	Postnatal Postnatal unit Video provided at group education session on the unit.	Involvement, involvement (intent), feeding type (secondary)
Harrison et al. 2016	Analytical cross-sectional	Global (authors based in Canada)	Parents of children (n=66, demographics not collected)	“Be Sweet to Babies” YouTube video (1 minute 35 seconds), bilingual version. Provided specific information about use of breastfeeding and sweet-tasting solutions (sucrose) for pain management during immunizations.	NA	Self-administered via YouTube	Knowledge, attitudes, eHealth usage, involvement (intent), use of pain management (previous)

Study	Study design	Country	Participants (sample size)	Intervention	Comparator	Administration timing, location, & details	Outcomes
Lavin Venegas et al., 2019	Randomized controlled trial (pilot)	Canada	Parents of full-term infants (n=100, 75% mothers, 25% mother's partner)	"Be Sweet to Babies" YouTube video (5 minutes), bilingual version. Provided specific information about use of breastfeeding, skin-to-skin contact, and sweet-tasting solutions for procedural pain management. (n=51 with feasibility outcome, n=50 effectiveness outcome)	Standard care (n=49)	Postnatal	Knowledge, eHealth usage, acceptance, involvement, involvement (intent)
Riddell et al., 2018	Randomized controlled trial	Canada	Parents of infants receiving immunizations	Parents watched a video (5 minutes) with specific information about procedural pain	Parents watched a video (5 minutes) with neutral	Postnatal Pediatric clinic	Involvement, infant pain response

Study	Study design	Country	Participants (sample size)	Intervention	Comparator	Administration timing, location, & details	Outcomes
Taddio et al., 2013	Analytical cross-sectional	Canada	Parents of full-term infants (n=37, 70.3% mothers, 29.7% fathers)	Parents were given the “HELPPinkIDS” educational package. This includes a video (9 minutes) and pamphlet (2 pages) with specific information about implementing procedural pain management based on pharmacological	NA	Postnatal unit	Knowledge, acceptance, involvement (intent)
				management, called “The ABCDs of Pain Management”: 1) Assess anxiety, 2) Belly breathe, 3) Calm, and 4) Distraction. (n=64)	information (ABCD format): 1) Act in their child’s best interest, 2) Be aware that needles are distressing, 3) Carry out what they think is best, and 4) Do their best to help their young child. (n=64)	Intervention/control video administered by researcher on a portable DVD player in clinic waiting room.	

Study	Study design	Country	Participants (sample size)	Intervention	Comparator	Administration timing, location, & details	Outcomes
Taddio et al., 2015	Randomized controlled trial (Longitudinal)	Canada	Mothers of full-term infants receiving immunizations (n=126)	Parents were given the “HELPinKIDS” educational package. This includes a video (9 minutes) and pamphlet (2 pages) with specific information about implementing procedural pain management based on pharmacological (topical anaesthetic, sucrose), physical (hold, breastfeeding) and psychological (deep breaths, distract) interventions.	Parents were given a pamphlet with general information related to immunizations. (n=66)	Postnatal Pediatric clinic Intervention video was administered by a researcher using a television in the clinic waiting room.	Attitudes, involvement, infant pain response

Study	Study design	Country	Participants (sample size)	Intervention	Comparator	Administration timing, location, & details	Outcomes
Taddio et al., 2017	Randomized controlled trial (longitudinal)	Canada	Mothers of infants, born full-term and healthy, receiving immunizations (n=298)	Parents watched a video (5 minutes) with specific information about procedural pain management called “The ABCDs of Pain Management”: 1) Assess anxiety, 2) Belly breathe, 3) Calm, and 4) Distraction.	Parents watched a video (5 minutes) with neutral information (ABCD format): 1) Act in their child’s best interest, 2) Be aware that needles are distressing, 3) Carry out what they think is best, and 4) Do their best to help their water or placebo) and all infants received topical cream (active lidocaine 4% or placebo) before vaccinations.	Postnatal Pediatric clinic Intervention/control video self-administered using a portable DVD player.	Attitudes, acceptance, infant pain response
				Infants in the intervention group were also randomized to receive additional pain management: oral solution (24% sucrose in water or placebo) and all infants received topical cream (active lidocaine 4% or placebo) before vaccinations.	Infants in the control group also received additional		Infant pain response was measured at four time points: 2, 4, 6, and 12 months.

Study	Study design	Country	Participants (sample size)	Intervention	Comparator	Administration timing, location, & details	Outcomes
Taddio et al., 2019	Randomized controlled trial (longitudinal)	Canada	Mothers of full-term infants receiving immunizations (n=2549)	<p>There were two intervention groups. In group 1, parents were given the “HELPIKIDS” educational package. This includes a video (13 minutes) and</p> <p>Video–sucrose–lidocaine: 2 m, n=86 4 m, n=76 6 m, n=74 12 m, n=71</p> <p>Video–sucrose: 2 m, n=87 4 m, n=78 6 m, n=79 12 m, n=77</p> <p>Placebo: 2 m, n=88 4 m, n=82 6 m, n=80 12 m, n=75</p>	<p>before vaccinations.</p> <p>Infant pain response was measured at four time points: 2, 4, 6, and 12 months.</p>	<p>Parents were given a pamphlet and video with general information related to immunizations.</p> <p>Postnatal unit</p>	<p>Self-efficacy, knowledge, attitudes, involvement, infant pain response</p>

Study	Study design	Country	Participants (sample size)	Intervention	Comparator	Administration timing, location, & details	Outcomes
				pamphlet (2 pages) with specific information about implementing procedural pain management based on pharmacological (topical anaesthetic, sucrose), physical (hold, breastfeeding), and psychological (deep breaths, distract) interventions. Group 2 received the pain-specific pamphlet and a video with general information related to immunizations.	Parental involvement was measured at three time points: 2, 4, and 6 months. 2 m, n=303 4 m, n=280 6m, n=238	researcher. Parents were asked to independently review the materials. Video was administered using a television in their room.	
				Parental involvement was measured at three time points: 2, 4, and 6 months.			
				Pain-specific pamphlet and video: 2 m, n= 305 4 m, n = 289			

Study	Study design	Country	Participants (sample size)	Intervention	Comparator	Administration timing, location, & details	Outcomes
				6 m, n = 249			
				Pain-specific pamphlet and general information video: 2 m, n= 309 4 m, n = 299 6 m, n = 268			
NA, not applicable; NICU, neonatal intensive care unit							

APPENDIX 2.5 SUMMARY OF FINDINGS

eHealth educational interventions about infant pain management compared to usual care or control for enhanced parental and neonatal outcomes			
Bibliography: Hughes B, Benoit B, Rutledge K, Dol J, Martin Misener R, Latimer M, Smit M, McGrath P, Campbell-Yeo M. The impact of parent-targeted eHealth educational interventions on infant procedural pain management: a systematic review. <i>JBIEvid Synth.</i> 2023;21(4):669-712.			
Outcomes	Impact	Nº of participants (studies)	Certainty of the evidence (GRADE)
Parental Self-Efficacy	Both studies found a positive impact on confidence. The RCT found a significant difference on confidence when compared to the control.	3420 (1 RCT) 32 (1 observational study)	⊕○○○ Very low ^a
Parental Knowledge	Knowledge outcome measurements were mixed. The two studies found a positive impact on parental knowledge, both with statistically significant increases in favour of the video intervention when compared to the control.	3420 (1 RCT) 37 (1 observational study)	⊕○○○ Very low ^{a,b,c}
Parental Attitudes	Four studies reported on varying aspects which fall under parental attitudes. Three studies reported on satisfaction with pain management, where two found a positive impact and one reported no significant impact. One study found a positive impact on parents' perceptions that the intervention content was relevant and their role in pain management was important. No further comparisons were possible.	3897 (2 RCTs) 166 (2 observational studies)	⊕○○○ Very low ^{a,b,d}
eHealth Usage	Three studies reported a positive impact on eHealth usage. No comparisons were possible.	51 (1 RCT) 98 (2 observational studies)	⊕○○○ Very low ^{a,b,e,f}

eHealth educational interventions about infant pain management compared to usual care or control for enhanced parental and neonatal outcomes			
Bibliography: Hughes B, Benoit B, Rutledge K, Dol J, Martin Misener R, Latimer M, Smit M, McGrath P, Campbell-Yeo M. The impact of parent-targeted eHealth educational interventions on infant procedural pain management: a systematic review. <i>JBIEvid Synth.</i> 2023;21(4):669-712.			
Outcomes	Impact	Nº of participants (studies)	Certainty of the evidence (GRADE)
Acceptance of eHealth	Five studies found positive impacts on factors related to parental acceptance of eHealth interventions.	51 (1 RCT) 219 (4 observational studies)	⊕○○○ Very low ^{a,b,d,e}
Involvement in Pain Management	Involvement was measured differently across studies. Nine studies reported on actual involvement in pain management pre and/or post-intervention exposure and one reported intention to be involved in future procedures only. Of the studies evaluating parental involvement pre and post-intervention exposure, three studies found a positive impact and two studies found no significant difference when compared to the controls. The remaining studies reported involvement in pain management pre-intervention but reported intention of involvement for future procedures, thus providing no comparison of impact.	3797 (5 RCTs) 285 (5 observational studies)	⊕○○○ Very low ^{a,b,c,d,e,g}
Infant Pain Response	One study found a positive impact on infant pain response across timepoints and only between groups during the injection. Another study found a positive impact on infant pain response at the second follow-up only. One study reported no significant difference on infant pain response.	605 (3 RCTs)	⊕⊕○○ Low ^{a,g}

eHealth educational interventions about infant pain management compared to usual care or control for enhanced parental and neonatal outcomes

Bibliography: Hughes B, Benoit B, Rutledge K, Dol J, Martin Misener R, Latimer M, Smit M, McGrath P, Campbell-Yeo M. The impact of parent-targeted eHealth educational interventions on infant procedural pain management: a systematic review. JBI Evid Synth. 2023;21(4):669-712.

Outcomes	Impact	Nº of participants (studies)	Certainty of the evidence (GRADE)
----------	--------	------------------------------	-----------------------------------

The outcomes of interest are related to parental, eHealth, and pain management outcomes which pooling of data was not possible and only a narrative synthesis of the evidence was provided.

RCT: randomized controlled trial

GRADE Working Group grades of evidence

High certainty: we are very confident that the true effect lies close to that of the estimate of the effect.

Moderate certainty: we are moderately confident in the effect estimate: the true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.

Low certainty: our confidence in the effect estimate is limited: the true effect may be substantially different from the estimate of the effect.

Very low certainty: we have very little confidence in the effect estimate: the true effect is likely to be substantially different from the estimate of effect.

Explanations

- a. Narrative synthesis; no effect sizes available.
- b. Concerns related to confounding factors.
- c. Concerns related to blinding to treatment assignment.
- d. Studies have varying definitions of the outcome.
- e. Pilot trial.
- f. Populations may not be applicable to the question.
- g. Intervention of one study includes a description of pain management strategies that are not best evidence for the population



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 **Wolters Kluwer**

Impact of parent-targeted eHealth educational interventions on infant procedural pain management: a systematic review

Author: Brianna Hughes (née Richardson), Britney Benoit, Kallen Rutledge, et al
Publication: JBI Evidence Synthesis
Publisher: Wolters Kluwer Health, Inc.
Date: Jan 2, 2023

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BACK CLOSE WINDOW

CHAPTER 3 APPENDICES

APPENDIX 3.1 PHASE 1

Phase 1 Recruitment

Primary Recruitment Script to Parents- COVID 19 (Online Text: Social Media and Online Classifieds)

[study poster image]

Are you or your currently pregnant and living on Prince Edward Island?

If you're a parent, have you or your partner given birth in the past 2 months at Prince County Hospital or Queen Elizabeth Hospital?

If yes, a team of researchers from Dalhousie University would like your input on a prenatal educational website that we are developing.

If you agree to participate, you would be interviewed by someone on our research team about to get your feedback on the website we are developing. You would also be asked to complete a brief survey. Your responses will be kept confidential and if there are any questions you prefer not to answer you don't have to.

It should only take an hour of your time and interviews will take place virtually at a time that is convenient for you. In appreciation of your time, you will be given a \$20 Amazon e-gift card.

If you are interested or have any questions, please contact Brianna Richardson at brianna.richardson@dal.ca or 902-229-7299.

Stakeholders (Stakeholder Emails)

Hello [name of stakeholder],

My name is Brianna Richardson and I am part of a team of researchers from Dalhousie University who are developing a website to provide parents with information about infant procedural pain management. Before we finish developing the website, we would like input from parents of infants and expectant parents to ensure this educational resource meets their needs. As an organization with access to parents across PEI, could you please help to circulate the attached invitation to parents and expectant parents?

Please let me know if you have any questions or would like to discuss anything further.

Thank you for your consideration of this request,

Brianna

Brianna Richardson, BScN RN PhD(c)
PhD in Nursing Candidate
Dalhousie University
Tel: (902) 229-7299

[study poster and recruitment script attached]

Posters (To be posted in Health Centres – 3 options)

Are you a new or expectant parent from PEI?

Participate in an interview to help us design a website about newborn pain management for parents like you.

For more information, contact brianna.richardson@dal.ca

DALHOUSIE UNIVERSITY
MOM-LING LAB
Multisensory, Openness, Mindfulness and Intentionally Led Interventions in Neonatal Care

Health PEI
One Island Health System

Are you a new or expectant parent from PEI?



Participate
in an interview
**to help us design
a website**
about newborn
pain management
for parents like you.



For more information, contact
brianna.richardson@dal.ca



Are you a new or expectant parent from PEI?



Participate
in an interview
**to help us design
a website**
about newborn
pain management
for parents like you.



For more information, contact
brianna.richardson@dal.ca



Once potential participants contact the lead researcher after seeing the study posters (without the online recruitment script), the researcher will provide more information about the study, including who is conducting the study, what we are asking participants to do, the time commitment, and honorarium.

Phase 1 Consent Form



CONSENT FORM

Project title: Parental Prevention of Newborn Pain: Usability testing of an eHealth learning platform about infant pain management

Lead researcher: Brianna Richardson, BScN RN PhD(c)
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5869 University Avenue/PO Box 15000 Halifax, NS B3H 4R2
brianna.richardson@dal.ca; 902-229-7299

Other researchers

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Introduction

We invite you to take part in a research study led by Brianna Richardson, a student at Dalhousie University, as part of her PhD in Nursing. Choosing to take part in this research is your choice. Your health services will not change if you decide not to participate. We are doing this study to create an online learning resource that teaches parents about pain relief with newborns. The information below tells you about the research, what you would be asked to do, and about any potential benefits or risks.

You should discuss any questions you have about this study with Brianna, the lead researcher. Please ask as many questions as you like. If you have questions later contact Brianna by phone or email.

Purpose and Outline of the Research Study

All newborns have painful procedures as a part of their regular care to make sure they are healthy. When pain is not managed well, evidence tells us that it can change how babies' brains grow and develop, and how they feel and react to pain. Still, many babies do not get the best type of pain relief. Research has found ways that parents can lower their baby's pain during needle procedures, like by breastfeeding, but many parents may not know how they can help. With the stress parents often have when seeing their child in pain, many go to the Internet to search for health information. Some websites may have information that is difficult to understand or isn't correct. So, it is important for healthcare areas to offer accessible, evidence-based information that parents can trust. We plan to create an eHealth learning resource (website) to teach parents about newborn pain relief and how parents can help. Before we can finish the website, we need about 15 parents or expecting parents to look through the website and give us feedback. This way, we can make sure that the website meets the needs of families like you.

Who Can Take Part in the Research Study

You may take part in this study if the answer is **YES** to the following:

- You can speak, read, and write in English
 - You gave birth to a baby in the past 2 months at either the Prince County Hospital or Queen Elizabeth Hospital
- OR
- You or your partner are currently pregnant and anticipate giving birth at either the Prince County Hospital or Queen Elizabeth Hospital

But, if the answer to any of the following is **YES**, you should **not** take part in this study:

- Your baby was in the neonatal intensive care unit for more than 8 hours after birth
- You and your partner (if applicable) were separated from your baby for more than 8 hours after birth

What You Will Be Asked to Do

We have created a website to give parents information about newborn pain relief during procedures (bloodwork, vaccinations). Before we finish this site, we would like any suggestions you may have to help make the website better. If you choose to participate in this study, you will be asked to meet virtually with the lead researcher, Brianna, to go through the website. Virtual meetings will take place online using Zoom video technology. You will also be asked to share your screen so Brianna will be able to see your personal computer or laptop screen. When you explore the website, you will be asked to talk out loud and describe your thoughts and feelings. The meeting will be video recorded so we can add your suggestions to the final website design. You will also be asked to complete surveys about your general background and how you liked the website. We will also ask two questions that will help us prepare to test this website with parents in a future study. All surveys will be completed online.

Possible Benefits, Risks and Discomforts

Participating could help you know more about pain relief for your baby during procedures. Also, by participating in this study you will help us learn how to best support families.

The risks in this study are low, and there are no known risks for participating in this research other than being bored or tired. So, you will be offered breaks to lower these risks. If there are any questions in the surveys that you would prefer not to answer, you can skip these or select prefer not to answer.

While we do not expect that you will be harmed in this study, pregnancy or early parenthood can be an overwhelming experience for parents which could cause stress. If you would like more information about the health of you or your baby, here are sources to contact:

- Your health care provider (family physician, nurse practitioner, nurse, OB/GYN)
- A local public health nurse:
<https://www.princeedwardisland.ca/en/information/health-pei/public-health-nursing>
- Women's Wellness Program & Sexual Health Services:
<https://www.princeedwardisland.ca/en/information/health-pei/pregnancy-counselling-and-support>
- Canadian Mental Health Association of Prince Edward Island: <https://pei.cmha.ca>
- PEI's 811 Telehealth line (dial 8-1-1 or 7-1-1 if you are hard of hearing)
- Call Island Helpline: 1-800-218-2885

- Community Mental Health Walk-in Clinic:
<https://www.princeedwardisland.ca/en/information/health-pe/mental-health-walk-in-clinics>
- Postpartum Support International (postpartum is the period after giving birth):
<https://www.postpartum.net/get-help/locations/international/canada/>

Compensation / Reimbursement

To thank you for participating, we will give you an Amazon e-gift card for \$20. You will not need to give this e-gift card back if you leave the study.

How your information will be protected:

Privacy: Your privacy is very important to us. Meetings will be in a private area. Only members of the research team will have access to information that could identify you. All information will be stored in a secure location.

Anonymity: If you choose to participate, you will be given a study ID number. This ID number will be used for all study documents (surveys). Any documents with information that identifies you (name, email address) will be saved as a password-protected file stored on One Drive. One Drive is a secure server at Dalhousie University. No one will know who you are.

Confidentiality: We will keep your personal information confidential. We will use only the study ID number on documents that are sent from the secure server. No information that identifies you (name) will be sent from the secure server. If the results of this study are presented at a meeting or published, no one will know that you were in the study.

All study documents will be kept for 5 years as password-protected files that will be stored on a secure server. Any paper documents will be kept in a locked office. After 5 years, any documents with information that identifies you (videos, names) will be deleted. The other files will be stored on a password-protected hard drive for another 5 years. The hard drive will stay in a secure area in Dr. Campbell-Yeo's office at the IWK Health Centre. After 10 years, Brianna will delete all study documents.

We will not let anyone know that you participated in this research unless we must by law. That is, in the unlikely event that we witness abuse, or suspect it, we must contact authorities.

Data retention: Information that you give us will be kept private. We will share the study findings in a thesis, presentations, public media, and journal articles. We will be very careful to only talk about group results so that no one will be identified. This means that *you will not be identified in any way in our reports.*

If You Decide to Stop Participating

You are free to leave the study at any time. If you decide to stop participating, you can also choose if you want the information that you already gave to be deleted. You can also contact us for up to 1 month if you want us to remove your data. After 1 month, it will become impossible for us to remove it because your data will already be analyzed.

How to Obtain Results

We will write a short description of group results when the study is finished. No individual results will be provided. You can get these results by visiting www.mom-linc.ca in the Summer of 2021. If you would also like to get a copy of an article reporting on the study, please include your email at the end of this consent form.

Questions

We will answer any questions you have before you choose to sign this consent. If you have questions or concerns about the study at any time, please contact Brianna or Dr. Campbell-Yeo. We will also tell you if new information comes up that could change your decision to participate.

Brianna Richardson: 902 229-7299, brianna.richardson@dal.ca

Dr. Marsha Campbell-Yeo: 902 430-6447, marsha.campbell-yeo@dal.ca

If you have any ethical concerns about your participation in this research, you may also contact Research Ethics. This study has been approved by Research Ethics Boards at Dalhousie University and Health PEI.

Please use the following information to contact the Research Ethics Boards:

- Dalhousie University at (902) 494-1462, or email: ethics@dal.ca (and reference REB file # 2020-5079)
- Health PEI Research Ethics Board at (902) 569-0576, or email: reb@ihis.org (and reference Parental Prevention of Newborn Pain Study – Principal Investigator: Brianna Richardson).

Signature Page

Project title: Parental Prevention of Newborn Pain: Usability testing of an eHealth learning platform about infant pain management

Lead researcher: Brianna Richardson, BScN RN PhD(c)

Faculty of Health, School of Nursing, Dalhousie University
5869 University Avenue/PO Box 15000 Halifax, NS B3H 4R2
brianna.richardson@dal.ca; 902-229-7299

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I have been asked to take part in one interview that will occur virtually, and that those interviews will be video recorded. I understand direct quotes of things I say may be used without identifying me. I agree to take part in this study. My participation is voluntary and I understand that I am free to withdraw from the study at any time, until 1 month after my data has been collected.

Name

Signature

Date

I agree that my interview will be video-recorded Yes No

I agree that direct quotes from my interview may be used without identifying me Yes
No

Name

Signature

Date

Obtaining Final Results

If you would like to read the final results, please provide your email below and we will send the article once the study is complete.

Phase 1 Usability Testing Script

Prototype of *Parenting Pain Away* website

Intro – 10min

Offer water, washrooms.

Ask for permission to record (start recording).

What is your understanding about what Parental Prevention of Newborn Pain is?

Give Parenting Pain Away Overview

Intro website – I'll help walk you through it

Try to think aloud as you go through the website – we are looking for a running commentary.

Talk about what you're trying to do and what you think about what you are doing.

Please don't hold back!

Today we'll be looking at a prototype of *Parenting Pain Away*, a resource that provides information on parental involvement with infant pain management. As we are still designing the website, some sections may not be clickable yet, but I will let you know.

Any questions before we begin?

Prototype – 25 min

Tell me about what you see here?

What's the overall feeling you get from this screen?

Are there any elements that stand out or you find notable?

Please continue to navigate through the site in whatever order you would like.

Wrap up (5 minutes)

What were some of your favourite features?

What didn't you like?

What you add?

Would you have found this learning platform helpful before the birth of your baby? (*If postpartum participant*)

Would find this learning platform helpful for you now during your pregnancy? (*If childbearing participant*)

Follow up questionnaires (20 minutes)

Give overview of the questionnaire.

Post Study System Usability Questionnaire: this questionnaire will be used to evaluate how satisfied you were with resource. There will be an additional two questionnaires

asking for your insight on how we should prepare to test the usefulness of this website with parents.

Do you have any more questions or comments?

Provide thanks and for their participation.

Phase 1 Outcome Measurements

Parent Demographics

Parental Prevention of Newborn Pain

Study ID #: _____

Date: _____

Thank you for taking the time to answer this form about general demographic information. Please write or click your response where appropriate.

1. What are the first 3 digits of your postal code? _____

2. What is your year of birth?
Please select a response:
[Drop down]
 - Prefer not to answer
 - 1969 - 2004

3. Do you consider yourself:
 - White
 - Black or African Canadian
 - Indigenous
 - Asian
 - Arab
 - Other: _____
 - Prefer not to answer

4. What is the highest level of education you have completed?
 - Primary school
 - Some high school
 - High school diploma
 - Some college but no diploma
 - College Diploma
 - Some university but no degree
 - University degree (BA, BSc)
 - Graduate degree (MSc, MA, PhD)
 - Post-graduate
 - Prefer not to answer

5. Please indicate your household income:
Please select a response:
[Drop down]
- Prefer not to answer
 - <20,000 - >200,000
6. What is your current marital status?
- In a relationship
 - Married or Common Law
 - Without a partner
 - Prefer not to answer
7. Are you currently employed outside the home?
- No
 - Yes
 - If yes, please identify occupation: _____
 - Prefer not to answer
8. Are you or your partner currently:
- Pregnant
 - Recently had a baby (in the past 2 months)
9. Are you currently on parental leave?
- No, I am not employed outside the home
 - Yes, but it is not paid
 - Yes, it is a paid leave
 - If yes, how many months do you plan on taking: _____
 - Prefer not to answer
10. How would you best describe your relationship to your newborn: *[If pregnant, question will be skipped]*
- Mother
 - Father
 - Step-Mother
 - Step-Father
 - Adoptive Mother
 - Adoptive Father
 - Parent (gender neutral)
 - Other: _____
 - Prefer not to answer
11. When did you give birth to your latest newborn? *[If pregnant, question will be skipped]*
Month: [dropdown]

Year: [dropdown, 2019]

12. How was your baby delivered? [If pregnant, question will be skipped]
- Vaginally
 - Planned C-Birth
 - Unplanned C-Birth
 - Don't know/remember
 - Prefer not to answer
13. How many other children live in your household?
- 0
 - 1
 - 2
 - 3
 - 4
 - 5
 - More than 6, How many? _____
 - Prefer not to answer
14. In which age bracket do other children in your household belong? *[If responds "0" to question 13; this question will be skipped]*
- Baby (less than 1 year), How many? _____
 - Toddler (1-2 years), How many? _____
 - Preschooler (3-4 years), How many? _____
 - Early school age (5-8 years), How many? _____
 - Adolescent (9-11 years), How many? _____
 - Young teen (12-15 years), How many? _____
 - Older teen (16-19 years), How many? _____
 - 19 or older, How many? _____
 - Prefer not to answer
15. If you were participating in a study that was testing the usefulness of this website during pregnancy, would you mind receiving a reminder from the researchers telling you to let the hospital staff know that you are participating in this study?
- No
 - Yes
 - Prefer not to answer
16. If you were participating in a study that was testing the usefulness of this website during pregnancy, would you complete a brief daily diary while in hospital after the birth of your baby that asks about pain management?
- No

- Yes
- Prefer not to answer

Post Study System Usability Questionnaire (Lewis, 1995)

On a scale between **Strongly Agree** to **Strongly Disagree**, please rate the following statements:

		Strongly Agree				Strongly Disagree			
		1	2	3	4	5	6	7	NA
1	Overall, I am satisfied with how easy it is to use <i>Parenting Pain Away</i> .								
2	It was simple to use <i>Parenting Pain Away</i> .								
3	I was able to complete the tasks and scenarios quickly using <i>Parenting Pain Away</i> .								
4	I felt comfortable using <i>Parenting Pain Away</i> .								
5	It was easy to learn to use <i>Parenting Pain Away</i> .								
6	I believe I could become productive quickly using <i>Parenting Pain Away</i> .								
7	<i>Parenting Pain Away</i> gave error messages that clearly told me how to fix problems.								
8	Whenever I made a mistake using <i>Parenting Pain Away</i> , I could recover easily and quickly.								
9	The information (such as online help, on-screen messages and other documentation) provided with <i>Parenting Pain Away</i> was clear.								
10	It was easy for me to find the information I needed.								
11	The information was effective in helping me complete the tasks and scenarios.								

12	The organization of information in <i>Parenting Pain Away</i> was clear.								
13	The look and feel of <i>Parenting Pain Away</i> was pleasant.								
14	I liked using Parenting Pain Away.								
15	<i>Parenting Pain Away</i> has all the functions and capabilities I expect to have.								
16	Overall, I am satisfied with <i>Parenting Pain Away</i> .								

APPENDIX 3.2 PHASE 2

Phase 2 Recruitment & Screening

Recruitment Script to Parents (Online Text: Social Media and Online Classifieds) [images]

Are you or your partner expecting a baby sometime within the next 2 months?

Do you plan to give birth at Prince County Hospital or Queen Elizabeth Hospital in Prince Edward Island?

If yes, a team of researchers from Dalhousie University would like you to help by using our new website *Parenting Pain Away!* With this website, we want to educate parents on how they can reduce their baby’s pain during needles and similar procedures. Your using *Parenting Pain Away* will help us learn more about parents’ involvement in their baby’s pain management and how best to give parents current, evidence-based information.

If you agree to participate, you would be given access to *Parenting Pain Away* and asked to use the website as much as you’d like until the end of the study. You would also be asked to complete short online surveys before and after your baby is born. Your responses will be kept confidential and if there are any questions you prefer not to answer you don’t have to. In appreciation of your time, you will be given a \$40 Amazon e-gift card.

If you are interested or have any questions, please text “interested” to 902-900-9478 or contact Brianna Richardson at brianna.richardson@dal.ca.

Stakeholders (Stakeholder Emails)

Hello [name of stakeholder],
My name is Brianna Richardson and I am part of a team of researchers from Dalhousie University who have developed a website, entitled *Parenting Pain Away*, to provide parents with information about infant procedural pain management. We are currently recruiting for our evaluation to determine if parents find this website acceptable and feasible, and if it influences parents knowledge, confidence, and involvement with their baby's pain management. As an organization with access to parents across PEI, could you please help to circulate the attached invitation to parents?

Please let me know if you have any questions or would like to discuss anything further.

Thank you for your consideration of this request,

Brianna

Brianna Richardson, BScN RN PhD(c)
PhD in Nursing Candidate
Dalhousie University
Tel: (902) 229-7299

[study poster and recruitment script attached]

Healthcare providers (in-person)

Hello [name],
My name is Brianna Richardson and I am a PhD Candidate in the School of Nursing at Dalhousie University under the supervision of Dr. Marsha Campbell-Yeo. With help from Island parents, I have developed a website, entitled *Parenting Pain Away*, that provides up-to-date evidence-based information on children's pain management. The website is intended to help parents be involved or advocate for treatment for pain during their child's needle or similar procedures.

We are currently recruiting for our evaluation to determine if parents find this website acceptable and feasible, and if it influences parents knowledge, confidence, and involvement with their baby's pain management. As a healthcare provider caring for parents during the prenatal period, we are asking for your help recruiting parents. Eligibility for this study includes: low risk pregnant individuals and their partners (if applicable), at least 32 weeks gestation, who have access to the Internet, can read and write in English and are anticipated to give birth at PCH or QEH.

If you are able to help our recruitment, could you identify parents that meet the eligibility criteria and ask if parents would like to know more about the study? If so, you can provide parents with an information sheet with additional details about the study and let parents know that they can text "interested" to 902-900-9478 or contact Brianna Richardson at brianna.richardson@dal.ca for more information.

If you have any questions, please do not hesitate to ask. Thank you for your consideration of this request.

Instructions for Clinic Administration Support



Meet Brianna Richardson, she's a PHD Candidate in the School of Nursing at Dalhousie University (and supervised by Dr. Marsha Campbell-Yeo).

Brianna's research interests have led her study ways to improve pain management for children.

Thank you for helping her recruit participants for her study!

Here is how you can help Brianna recruit:

1. Review patient information to see if they are eligible to participant in the study. Does the patient and/or their partner meet the following criteria:
 - Low-risk pregnancy
 - At least 32 weeks gestation
 - Proficient in English
 - Anticipated to give birth at a provincial hospital (QEH/PCH)
2. If the patient and/or their partner meets that criteria, offer the study infographic to them.
3. Direct them to learn more by contacting the lead researcher by email or text message, as outlined at the bottom of the infographic.

Any questions?

Feel free to contact Brianna any time @ 902-229-7299 or brianna.richardson@dal.ca

Information Sheet for Parents

The following page is an infographic that provides information about the study. This infographic was given to eligible expectant parents at health centres (e.g., Obstetrical clinic) by centre staff if expectant parents demonstrated interest in the study.



Meet Brianna Richardson, she's a PHD Candidate in the School of Nursing at Dalhousie University (and supervised by Dr. Marsha Campbell-Yeo).

Brianna's research interests have led her study ways to improve pain management for children.

With the help of Island parents, a new website called Parenting Pain Away is being created.

The website focuses on:

PROVIDING UP-TO-DATE
EVIDENCE-BASED
INFORMATION ON CHILDREN'S
PAIN MANAGEMENT



HELPING PARENTS BE INVOLVED OR
ADVOCATE FOR TREATMENT FOR PAIN
DURING THEIR CHILD'S NEEDLES OR
SIMILAR PROCEDURES

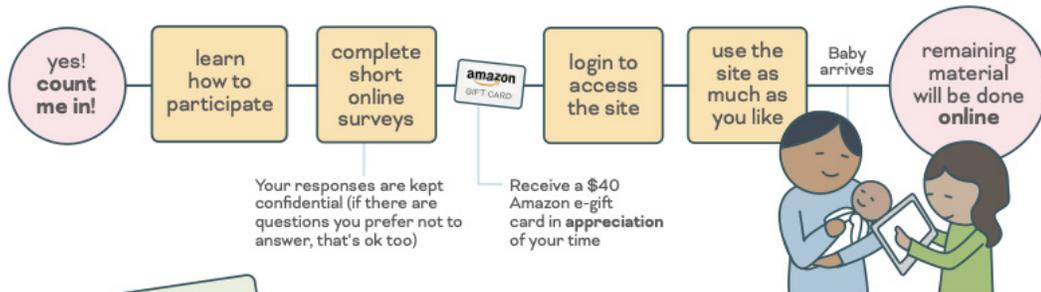
Your feedback will help to select content which is most important and useful for parents.

how you feel
about the
website overall

if the information helps to get
parents involved in their baby's
pain management

if you feel the content
is useful to receive
during pregnancy

It's easy to participate!



Brianna Richardson,
BScN RN PhD(c)
PhD in Nursing Candidate
Dalhousie University

Interested in lending your voice to Parenting Pain Away?

Text "interested" to 902-900-9478 or contact Brianna at Brianna.Richardson@dal.ca, to learn more.

Posters (To be posted in Health Centres – 2 options)

Are you an expectant parent from PEI?



Participate in a study to help us understand the impact of a **new website for parents** about newborn pain management.



For more information, text "interested" to 902-900-9478 or contact Brianna at brianna.richardson@dal.ca

Are you an expectant parent in PEI?



Participate in a study to help us understand the impact of a **new website for parents** about newborn pain management.



For more information, text "interested" to 902-900-9478 or contact Brianna at brianna.richardson@dal.ca

Once potential participants contacted the lead researcher after seeing the study posters (without the online recruitment script), the researcher will provide more information about the study, including who is conducting the study, what we are asking participants to do, the time commitment, and honorarium.

Email or Text Message Recruitment & Screening Process

Email Process

[potential participant emails the lead researcher]

Thank you for your interest! We are excited to tell you more about our study!

If you participate in this study, you will have access to a website that provides information about how to manage newborn pain during procedures, like blood tests. You will also have to fill out surveys before and after the birth of your baby. You will also have to fill out surveys before and after the birth of your baby.

You are eligible for this study if the answer is YES to all of the following:

- You can speak, read, and write in English
- You or your partner will give birth at either the Prince County Hospital or Queen Elizabeth Hospital
- You are a low-risk pregnant individual or partner of a low-risk pregnant individual (e.g., single baby, not planning to need care in the neonatal intensive care unit)
- You or your partner are at least 32 weeks pregnant and have not given birth yet

If you answered yes to all of the points above, then congratulations! You are currently eligible to participate. Please click this link to enroll in our study: [REDCap consent + survey link]

If you have any questions, please feel free to let me know.

Best,
Brianna

Text Process

[potential participant texts “interested” to study number]

Thank you for your interest! We are excited to tell you more about our study! But first, we want to let you know that the information that you give in these messages will be stored in secure servers in the United States. Are you okay with continuing? Reply “yes” to continue or “no” to stop.

[Unknown response] Sorry, we didn't understand that. Please reply with "yes" or "no".

[No] – We understand! Thanks for your interest in our study. You will not receive any more messages. Take care! [End]

[Yes] - Great!

If you participate in this study, you will have access to a website that provides information about how to manage newborn pain during procedures, like blood tests. You will also have to fill out surveys before and after the birth of your baby. You will also have to fill out surveys before and after the birth of your baby.

[Unknown response] Sorry, we didn't understand that. Please reply with "yes" or "no".

[No] - Thanks anyways! [End]

[Yes] - Thank you for your interest! What is your first name?

[Participant responds with name] Thank you @results.mothersname. We will now ask you a few eligibility questions. First, can you read and write in English comfortably?

[Unknown response] Sorry, we didn't understand that. Please reply with "yes" or "no".

[No] – Sorry, we are looking for participants who can read and write English. [End]

[Yes] Great. Do you plan to give birth at the Prince County Hospital or Queen Elizabeth Hospital?

[Unknown response] Sorry, we didn't understand that. Please reply with "yes" or "no".

[No] – Sorry, we are only looking for participants who live in Prince Edward Island and plan to give birth at one of these hospitals. [End]

[Yes] – Wonderful! Are you considered a “high risk” pregnancy? For example expecting twins or to need care in the neonatal intensive care unit.

[Unknown response] Sorry, we didn't understand that. Please reply with "yes" or "no".

[No] – Great. How many weeks pregnant are you right now?

[Yes] – Sorry, we are only look for participants who are considered low-risk at this time. [End]

[Under 32] - Sorry, we are looking for participants who are at least 32 weeks pregnant. When you're 32 weeks, you can text 'interested' again to this number!

[Above 32] – Congratulations! You are currently eligible to participate. Please click this link to enroll in our study: [REDCap consent + survey link]

Potential participants that previously texted “interested” and reported as above 36 weeks gestation prior to the approval of the amendment requested on April 27th, 2021 that extended the eligibility criteria:

Hi there! Thank you for being interested in our study. We have changed our criteria and you are now eligible to participate! If your baby has not been born yet and you are still interested, please click this link to enroll in our study: [REDCap consent + survey link]

Phase 2 Consent Form



CONSENT FORM (provided through REDCap)

Thank you for your interest in our study! You are invited to participate in this research study to help us create an online learning resource that teaches parents about pain relief with newborns.

Informed Consent

Project title: Parental Prevention of Newborn Pain: Evaluation of an eHealth learning platform to evaluate acceptability, feasibility, and utilization of parent-led pain management

Lead researcher: Brianna Richardson, BScN RN PhDI

Faculty of Health, School of Nursing, Dalhousie University
5869 University Avenue/PO Box 15000 Halifax, NS B3H 4R2
brianna.richardson@dal.ca; 902-229-7299

Other researchers

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Faculty of Health, School of Nursing, Dalhousie University, 5869 University Avenue
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Dr. Ruth Martin-Misener, NP PhD

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PO Box 15000 Halifax, NS B3H 4R2, ruth.martin-misener@dal.ca; 902-494-2250

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Dr. Michael Smit, PhD
School of Information Management, Dalhousie University, 6100 University Avenue, PO
Box 15000, Halifax, NS B3H 4R2, Mike.smit@dal.ca; 902-494-1901

Dr. Patrick McGrath, PhD
Department of Psychiatry, 5909 Veterans Memorial Lane, Halifax, NS B3H 2E2
Patrick.mcgrath@iwk.nshealth.ca; 902-473-2507

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Introduction

We invite you to take part in a research study led by Brianna Richardson, a student at Dalhousie University, as part of her PhD in Nursing. Choosing to take part in this research is your choice. Your health services will not change if you decide not to participate. We are doing this study to create an online learning resource that teaches parents about pain relief with newborns. The information below tells you about the research, what you would be asked to do and about any benefits or risks.

You should discuss any questions you have about this study with Brianna, the lead researcher. Please ask as many questions as you like. If you have questions later please contact Brianna by phone or email.

Purpose and Outline of the Research Study

All newborns have painful procedures as a part of their regular care to make sure they are healthy. When pain is not managed well, evidence tells us that it can change how babies' brains grow and develop, and how they feel and react to pain. Still, many babies do not receive the best type for pain relief. Research has found many ways that parents can lower their baby's pain during needle procedures, like by breastfeeding, but many parents may not know how they can help. With the stress parents often have when seeing their child in pain, many go to the Internet to search for health information. Some websites may have information that is difficult to understand or isn't correct. So, it is important for healthcare areas to offer offering accessible, evidence-based information that parents can trust. We have created a website to teach parents about newborn pain relief. We want at least 40 expectant parents to use the site in this study so we can see if they like the website, and if it changes their knowledge, confidence, or involvement in pain relief.

Who Can Take Part in the Research Study

You may take part in this study if the answer is YES to all of the following:

- You can speak, read, and write in English
- You are a low-risk pregnant individual or partner of a low-risk pregnant individual
- You have access to the Internet
- You or your partner will give birth at either the Prince County Hospital or Queen Elizabeth Hospital

But, if the answer to any of the following is YES, you should not take part in this study:

- If you and your partner (if applicable) anticipate being separated from your baby for more than 8 hours after your baby is born

What You Will Be Asked to Do

We have created a website to give parents information about newborn pain relief during procedures (blood work, vaccinations). If you choose to participate in this study, you will have unlimited access to the website. We ask that you use the website as often as you like until the end of the study. You will be asked to complete two surveys at the start of the study and then fill out daily diaries after the birth of your baby while in hospital. Finally, there will be four more surveys one week after your baby is born. These surveys and diaries should take about 30 minutes total.

If you choose to participate in the study, we will contact your care provider to ask them to put a label on your prenatal record that says you are in this study. After you give birth, you can text or email “BIRTH” to the lead researcher or let your nurse know you are in this study so that Brianna can send you the diaries and four surveys. You will be asked questions that help us understand your background and what you know about pain relief in newborns. We will also ask questions about your confidence and your thoughts about the website. All of the surveys and diaries will be sent through email or text message and completed online. The study should take less than one-hour total to finish all surveys, plus more time going through the website.

Possible Benefits, Risks and Discomforts

Participating in this study could help you know more about pain relief for your baby during procedures. Also, by participating in this study you will help us learn how to best support families.

The risks in this study are low, and potential risks for participating in this research include being bored or tired, feeling overwhelmed with data collection after your baby is born. However, you will be able to save your survey responses and take breaks to lower these risks. If there are any questions in the surveys that you would prefer not to answer, you can skip these or select prefer not to answer.

While we do not expect that you will be harmed in this study, pregnancy and early parenthood can be an overwhelming experience for parents which could cause stress. If

you would like more information about the health of you or your baby, here are sources to contact:

- Your health care provider (family physician, nurse practitioner, nurse, OB/GYN)
- A local public health nurse:
<https://www.princeedwardisland.ca/en/information/health-pei/public-health-nursing>
- Women's Wellness Program & Sexual Health Services:
<https://www.princeedwardisland.ca/en/information/health-pei/pregnancy-counselling-and-support>
- Canadian Mental Health Association of Prince Edward Island: <https://pei.cmha.ca>
- PEI's 811 Telehealth line (dial 8-1-1 or 7-1-1 if you are hard of hearing)
- Call Island Helpline: 1-800-218-2885
- Community Mental Health Walk-in Clinic:
<https://www.princeedwardisland.ca/en/information/health-pei/mental-health-walk-in-clinics>
- Postpartum Support International (postpartum is the period after giving birth):
<https://www.postpartum.net/get-help/locations/international/325anada/>

Compensation / Reimbursement

There are no costs to participate in this study. If you use a mobile device to access the website, please make sure that you are connected to WIFI to avoid any additional charges for data. To thank you for participating, we will give you an Amazon e-gift card for \$40. You will not need to give this e-gift card back if you leave the study.

How your information will be protected:

Privacy: Your privacy is very important to us. Only members of the research team will have access to any information that could identify you. All information will be stored in a secure location.

Anonymity: If you choose to participate, you will be given a study ID number. This ID number will be used for all study documents. You will be asked to provide your telephone number when answering a survey. Your telephone number will be used so we can link all of your survey responses together. This consent form and all surveys are saved in REDCap, a secure server at Dalhousie University. Any documents with information that identifies you, (name, email address, phone number) will be saved as a password-protected file stored on One Drive. One Drive is a secure server at Dalhousie University. If you preferred to communicate with us by text message, the information that

you give us will be stored in secure servers in the United States through the TextIt platform. All of these servers are encrypted to protect your information. No one will know who you are.

Confidentiality: We will keep your personal information confidential. We will use only study ID number on any documents that are sent outside the lead researcher's locked office from the secure servers. No information that identifies you (name, number) will be sent from the secure server. If the results of this study are presented at a meeting, or published, no one will know that you were in the study. The hospital postnatal unit clinical lead will notify the lead researcher and only confirm that your baby has been born so the lead researcher can send the follow-up questionnaires and daily diaries. The hospital postnatal unit clinical lead will not give the lead researcher any other personal health information.

All study documents will be kept for 5 years as password-protected files that will be stored on a secure server. Any paper documents will be kept in a locked office. After 5 years, any documents with information that identifies you (names, numbers) will be deleted. The other files will be stored on a password-protected hard drive for another 5 years. The hard drive will stay in a secure area in Dr. Campbell-Yeo's office at the IWK Health Centre. After 10 years, Brianna will delete all study documents.

We will not let anyone know that you participated in this research unless we must by law. That is, in the unlikely event that we witness abuse, or suspect it, we must contact authorities.

Data retention: Information that you give us will be kept private. We will share the study findings in a thesis, presentations, public media, and journal articles. We will be very careful to only talk about group results so that no one will be identified. This means that *you will not be identified in any way in our reports.*

If You Decide to Stop Participating

You are free to leave the study at any time. If you decide to stop participating, you can also choose if you want the information that you already gave to be deleted. You can also contact us for up to 1 month if you want us to remove your data. After 1 month, it will become impossible for us to remove your data because it will already be analyzed.

How to Obtain Results

We will write a short description of group results when the study is finished. No individual results will be provided. You can get these results by visiting www.mom-linc.ca in the Summer of 2022. If you would like to receive a copy of an article reporting on the study, please include your email at the end of this consent form.

Questions

We will answer any questions you have before you choose to sign this consent. If you have questions or concerns about the study at any time, please contact Brianna or Dr.

Campbell-Yeo. We will also tell you if new information comes up that could change your decision to participate.

Brianna Richardson: 902 229-7299, brianna.richardson@dal.ca

Dr. Marsha Campbell-Yeo: 902 430-6447, marsha.campbell-yeo@dal.ca

If you have any ethical concerns about your participation in this research, you may also contact Research Ethics. This study has been approved by Research Ethics Boards at Dalhousie University and Health PEI.

Please use the following information to contact the Research Ethics Boards:

- Dalhousie University at (902) 494-1462, or email: ethics@dal.ca (and reference REB file # 2020-5079)
- Health PEI Research Ethics Board at (902) 569-0576, or email: reb@ihis.org (and reference Parental Prevention of Newborn Pain Study – Principal Investigator: Brianna Richardson).

I consent to participate in this study

Yes No

[If participate chooses ‘yes’ they will be directed to the signature page; should they choose ‘no’ they will be directed to a thank you message and prompted to close the browser]

Obtaining Final Results

If you would like to read the final results, please provide your email below and we will send the article once the study is complete.

Email

Additional Consent for Hospital Postnatal Unit

Project title: Parental Prevention of Newborn Pain: Evaluation of an eHealth learning platform to evaluate acceptability, feasibility, and utilization of parent-led pain management

Lead researcher: Brianna Richardson, BScN RN PhD
Faculty of Health, School of Nursing, Dalhousie University
5869 University Avenue/PO Box 15000 Halifax, NS B3H 4R2
brianna.richardson@dal.ca; 902-229-7299

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that the clinical lead from the hospital postnatal unit will notify the lead researcher that I or my partner has given birth so the lead researcher can send the four follow-up questions and daily diaries. I understand that the hospital postnatal unit clinical lead will only confirm that my baby has been born so the lead researcher can send the follow-up questionnaires and daily diaries. I understand that the hospital postnatal unit clinical lead will not provide the lead researcher with any other personal health information.

Name

Signature

Date

Phase 2 Participant Reminders

Participant Digital Card



Participant Text/Email Reminders

[To be sent 1 week prior to expected date of delivery]

Via Text Message:

Hi there, it's Brianna from the Parental Prevention of Newborn Pain research team. Looks like you are getting close to your due date! Just sending a reminder for you to text "BIRTH" after having your baby or let your nurse at QEH/PCH [*depending on participant*] know that you are participating in this study. If you have already had your baby, let us know by replying "BIRTH". We will be in touch again after your baby arrives! Take care!

If at any point you wish to stop participating in this study, please reply "Leave study" or contact Brianna anytime at brianna.richardson@dal.ca.

[Unknown response] Sorry, we didn't understand that. Please let us know if you gave "birth" or if you are still waiting, reply "still waiting".

Via Email:

Hi there, it's Brianna from the Parental Prevention of Newborn Pain research team. Looks like you are getting close to your due date! Just sending a reminder for you to email "BIRTH" after having your baby or let your nurse at QEH/PCH [*depending on participant*] know that you are participating in this study. If you have already had your baby, let us know by replying "BIRTH". We will be in touch again after your baby arrives! Take care!

If at any point you wish to stop participating in this study, please reply "Leave study".

In-unit Study Reminder Posters

[Physical posters to be displayed in hospital postnatal units]



[participant texts BIRTH to initiate follow-up data collection]

Congratulations @fields.name! Next you will need to fill out short daily diaries while you are in the hospital and then in one week you finish the last survey. Please click this link to fill out today's diary: [REDCap survey link]

Phase 2 Outcome Measurements

Email/Text with questionnaire link

Thank you so much for participating in our study. At this point in the study we will need you to complete two short surveys. The first one asks for information about yourself and

your family, and the second asks about what you know about newborn pain management. Please click the link below to access the surveys.

If at any point you wish to stop participating in this study, please reply “Leave study” to this email/text or contact Brianna anytime at brianna.richardson@dal.ca or 902-900-9478.

Parent Demographics
Parental Prevention of Newborn Pain

Telephone #: _____ Date: _____

Thank you for taking the time to answer this form about general demographic information. Please write or click your response where appropriate.

1. What are the first 3 digits of your postal code? _____

2. What is your year of birth?
Please select a response:
[Drop down]
 - Prefer not to answer
 - 1969 - 2004

3. Do you consider yourself:
 - White
 - Black or African Canadian
 - Indigenous
 - Asian
 - Arab
 - Other: _____
 - Prefer not to answer

4. What is the highest level of education you have completed?
 - Primary school
 - Some high school
 - High school diploma
 - Some college but no diploma
 - College Diploma
 - Some university but no degree
 - University degree (BA, BSc)
 - Graduate degree (MSc, MA, PhD)
 - Post-graduate
 - Prefer not to answer

5. Please indicate your household income:
Please select a response:

[Drop down]

- Prefer not to answer
- <20,000 - >200,000

6. What is your current marital status?
- In a relationship
 - Married or Common Law
 - Without a partner
 - Prefer not to answer
7. Are you currently employed outside the home?
- No
 - Yes
 - If yes, please identify occupation: _____
 - Prefer not to answer
8. How would you best describe your relationship to your baby:
- Mother
 - Father
 - Step-Mother
 - Step-Father
 - Adoptive Mother
 - Adoptive Father
 - Parent (gender neutral)
 - Other: _____
 - Prefer not to answer
9. Which hospital do you plan to give birth at?
- Prince County Hospital
 - Queen Elizabeth Hospital
10. When is your baby's due date? _____
11. How many other children live in your household?
- 0
 - 1
 - 2
 - 3
 - 4
 - 5
 - More than 6, How many? _____
 - Prefer not to answer

12. If you indicated other children live in your household, in which age bracket do other children in your household belong?
- Baby (less than 1 year), How many? _____
 - Toddler (1-2 years), How many? _____
 - Preschooler (3-4 years), How many? _____
 - Early school age (5-8 years), How many? _____
 - Adolescent (9-11 years), How many? _____
 - Young teen (12-15 years), How many? _____
 - Older teen (16-19 years), How many? _____
 - 19 or older, How many? _____
 - Prefer not to answer
13. Which device do you use to access the Internet? Please choose all that apply.
- Desktop computer
 - Laptop
 - Tablet
 - Mobile phone
 - Other: _____
 - Prefer not to answer
14. If applicable, how often do you use your computer or laptop to access the Internet?
- Every day
 - 2-5 times a week
 - Once a week
 - Once every two weeks
 - Rarely
 - Prefer not to answer
15. How often do you use your mobile phone to access the Internet?
- Not applicable
 - Every day
 - 2-5 times a week
 - Once a week
 - Once every two weeks
 - Rarely
 - Prefer not to answer
16. Do you search for health information on the Internet?
- Yes
 - No
 - Prefer not to answer

17. Which device do you prefer to use to search for health information on the Internet?
- Desktop computer
 - Laptop
 - Tablet
 - Mobile phone
 - Not applicable
 - Other: _____
 - Prefer not to answer
18. If you use your mobile phone most often to search for health information on the Internet, do you prefer to use:
- Websites
 - Mobile apps
 - Not applicable
 - Prefer not to answer
19. Which of the following websites are you familiar with?
- Hospital/university-based websites (eg. AboutKidsHealth)
 - Medical journal/reference websites (eg. Medscape, PubMed, eMedicine)
 - Public search engines (eg. Google)
 - Other health websites (eg. MayoClinic, WebMD)
 - Popular parenting websites (eg. Today's Parent)
 - Other: _____
 - Prefer not to answer
20. Which of the following do you go to FIRST when searching for information around your child's health?
- Hospital/university-based websites (eg. AboutKidsHealth)
 - Medical journal/reference websites (eg. Medscape, PubMed, eMedicine)
 - Public search engines (eg. Google)
 - Other health websites (eg. MayoClinic, WebMD)
 - Popular parenting websites (eg. Today's Parent)
 - Other: _____
 - Prefer not to answer
21. Is there anyone you check information you find on websites with? Choose all that apply.
- Family Physician
 - Pediatrician
 - Nurse Practitioner
 - Registered Nurse
 - Naturopathic Doctor

- Pharmacist
- Friends
- Family
- Friends/Family that work in healthcare
- Spiritual Adviser
- Other: _____
- Prefer not to answer

Newborn Pain Management Knowledge

[This questionnaire is sent automatically after the demographic questionnaire is completed by participants]

This scale has 17 questions. We are interested in your current knowledge and health seeking behaviours related to newborn pain management.

Please answer either True or False to answer the following questions:

1. Giving sugar water (Sucrose) can reduce pain during procedures (e.g. vitamin K injection, blood draw, vaccinations) for babies
 - True
 - False
 - Prefer not to answer

2. Using medicines like acetaminophen (Tylenol) or ibuprofen (Advil) can reduce pain during procedures for babies
 - True
 - False
 - Prefer not to answer

3. Putting ice on the skin can reduce pain during procedures for babies
 - True
 - False
 - Prefer not to answer

4. Breastfeeding can reduce pain during procedures for babies
 - True
 - False
 - Prefer not to answer

5. Bottle feeding can reduce pain during procedures for babies
 - True
 - False
 - Prefer not to answer

6. Holding the baby can reduce pain during procedures for babies

- True
 - False
 - Prefer not to answer
7. Using numbing (anesthetic) medicines can reduce pain during procedures for babies
- True
 - False
 - Prefer not to answer
8. Distracting the baby can reduce pain during procedures for babies
- True
 - False
 - Prefer not to answer
9. Acting calm can reduce pain during procedures for babies
- True
 - False
 - Prefer not answer
10. Rubbing the skin can reduce pain during procedures for babies
- True
 - False
 - Prefer not to answer

Please answer either Yes or No to answer the following questions:

11. Have you or your partner (if applicable) ever heard about or used the following strategies for your baby during a painful procedure?
- a) Breastfeeding
 - Yes
 - No
 - Prefer not to answer
 - b) Skin to skin care
 - Yes
 - No
 - Prefer not to answer
 - c) Sugar water (sucrose)
 - Yes
 - No
 - Prefer not to answer

12. Have you received information on how to comfort your baby when they are distressed or experiencing pain by a healthcare provider?
- Yes
 - No
 - Prefer not to answer
13. Do you feel like you have enough information to comfort your baby when they are distressed or experiencing pain (e.g. the vitamin K injection or during a vaccination)?
- Yes
 - No
 - Prefer not to answer
14. Would you like to have more information about how you be actively involved in comforting your baby during painful procedures?
- Yes
 - No
 - Prefer not to answer
15. Have you looked up information on how to help your child cope with pain on the Internet?
- Yes
 - No
 - Prefer not to answer
16. If so, where did you find this information (e.g. Google, Youtube, social media sites)? [open-ended]
- Not applicable
 - Prefer not to answer
17. Did you find the information online useful/valuable?
- Yes
 - No
 - Not applicable
 - Prefer not to answer

Parental Daily Diary (completed during hospital stay)

(First diary email/text message)

Congratulations on the birth of your baby!

You are participating in a study entitled “Parental Prevention of Newborn Pain: An evaluation of an eHealth learning platform to determine acceptability, feasibility and utilization of parent-led pain management”. In this part of the study we would like you to complete a short diary entry each day you are in the hospital. This diary focuses on any painful procedures your baby has while in hospital. Please complete each question as best you can [survey link].

If at any point you wish to stop participating in this study, please reply “Leave study” to this email/text or contact Brianna anytime at brianna.richardson@dal.ca or 902-900-9478.

(Subsequent diary email/text messages)

Hi again, it’s the research team from “Parental Prevention of Newborn Pain”. We hope that you and your baby are doing well! Please complete today’s diary entry as best as you can [survey link].

If at any point you wish to stop participating in this study, please reply “Leave study” to this email/text or contact Brianna anytime at brianna.richardson@dal.ca or 902-900-9478.

Telephone #: _____

Prefer not to answer? Opt-out here [button]

Are you and your baby:

- Still in the hospital (*directed to following questions*)
- Home sweet home (*redirected to the ‘thank you’ page*)

Did your baby have a painful procedure today?

- Yes
- No
- Prefer not to answer

If yes, please complete the following questions:

Please click which procedure they had and indicate how many times they had that procedure today:

- Heel stick (e.g. blood work) x _____
- Injection (e.g. vaccination) x _____
- IV insertion x _____

Were you involved in your baby’s pain management during the procedure?

- Yes
- No
- Prefer not to answer

If yes, please click what type of parent-led pain management did you do during their procedure today:

- Skin-to-skin
- Breastfeeding _____
- Holding
- Facilitated tucking
- Advocate for sucrose

How did you feel about your baby's experience with the procedure? (open ended)

- Prefer not to answer

Thank you for today's diary entry!
(Submit button)

(Separate 'Thank You' page, if parents are home)

Thank you for completing the daily diaries! The last survey will be sent in one week. This survey will take less than 30 minutes of your time and you will be able to pause and save your responses if you need to take a break. We will be in touch soon. Congratulations on being home with your new baby!

Email/Text with Questionnaire Link

Congratulations again on your new baby! You are participating in a study entitled "*Parental Prevention of Newborn Pain: Evaluation of an eHealth learning platform to determine acceptability, feasibility and utilization of parent-led pain management*".

In this study, you used the *Parenting Pain Away* website during the final weeks of your pregnancy. We have three final surveys for you to complete, which should only take about 20 minutes of your time.

If at any point you wish to stop participating in this study, please reply "Leave study" to this email/text or contact Brianna anytime at brianna.richardson@dal.ca or 902-900-9478.

For the first survey, we are interested in your current knowledge and health seeking behaviours related to newborn pain management. This survey has 17 questions and all fields are required. Please complete it below.

Thank you!

[Newborn Pain Management Knowledge – Follow up]

Telephone #: _____

Thanks for completing this survey about newborn pain management. Please click "submit" to go to the next survey. Remember, if you need to take a break you can always click "Save & Return Later"!

Karitane Parenting Confidence Scale

[This questionnaire is sent automatically after the follow up knowledge questionnaire is completed by participants]

This survey asks you about how confident you feel as a parent. Please answer the questions as best as you can. ***Thank you!***

This scale has 15 items. Please select the answer that comes closest to how you generally feel. Here is an example already completed: e.g., I am confident about holding my baby:

- No, hardly ever
- No, not very often
- Yes, some of the time
- Yes, most of the time
- Prefer not to answer

This would mean “I feel confident about holding my baby some of the time”
Please complete the other questions in the same way.

1. I am confident about feeding my baby
2. I can settle my baby
3. I am confident about helping my baby to establish a good sleep routine
4. I know what to do when my baby cries
5. I understand what my baby is trying to tell me
6. I can sooth my baby when he/she is distressed
7. I am confident about playing with my baby
8. If my baby has a cold or slight fever, I am confident about handling this
9. I feel sure that my partner will be there for me when I need support
 - a. Not applicable (I don't have a partner)
10. I am confident that my baby is doing well

11. I can make decisions about the care of my baby
12. Being a parent is very stressful for me
13. I feel I am doing a good job as a parent
14. Other people think I am doing a good job as a parent
15. I feel sure that people will be there for me when I need support

Thanks for sharing information about your confidence in this survey! Please click "submit" to go to the last survey. Remember, if you need to take a break you can always click "Save & Return Later"!

Feasibility and Acceptability Questionnaire

[This questionnaire is sent automatically after the confidence scale is completed by participants]

You just participated in a study entitled “Parental Prevention of Newborn Pain: An evaluation of an eHealth learning platform to determine acceptability, feasibility and utilization of parent-led pain management”.

In this study, you used *Parenting Pain Away* website during the final weeks of your pregnancy. The following questionnaire asks about what you think about the website. Please answer the questions below to the best of your ability.

The System Usability Scale (Brooke, 1996)

Strongly Disagree -----Strongly Agree

		1	2	3	4	5
1	I think that I would like to use this system frequently.					
2	I found the system unnecessarily complex.					
3	I thought the system was easy to use.					
4	I think that I would need the support of a technical person to be able to use this system.					
5	I found the various functions in this system were well integrated.					
6	I thought there was too much inconsistency in this system.					
7	I would imagine that most people would learn to use this system very quickly.					
8	I found the system very awkward to use.					
9	I felt very confident using the system.					
10	I needed to learn a lot of things before I could get going with this system.					

17. How often did you use *Parenting Pain Away* before the birth of your baby?
- Every day
 - 2-5 times a week
 - Once a week
 - Once every two weeks
 - Rarely
 - Never
 - Prefer not to answer
18. Do you feel the information in *Parenting Pain Away* was relevant during pregnancy?
- a. If yes, why?
 - If no, why?
 - Prefer not to answer
19. Did you have any concerns about breastfeeding your baby during the painful procedure (e.g. Vitamin K injection after birth or newborn metabolic screening)? If yes, please describe.
- Prefer not to answer
20. Do you think you will use breastfeeding for pain relief in the future (for example, during your baby's immunizations or any other procedures).
- a. If yes, why?
 - If no, why?
 - Prefer not to answer
21. Did you have any concerns about giving skin-to-skin with your baby during the painful procedure (e.g. Vitamin K injection after birth or newborn metabolic screening)? If yes, please describe.
- Prefer not to answer
22. Do you think you will use skin-to-skin for pain relief in the future (for example, during your baby's immunizations or any other procedures).

- a. If yes, why?
 - If no, why?
 - Prefer not to answer
23. Did you have any concerns about your baby receiving sucrose during the painful procedure (e.g. Vitamin K injection after birth or newborn metabolic screening)? If yes, please describe.
- Prefer not to answer
24. Do you think you will advocate for sucrose for pain relief in the future (for example, during your baby's immunizations or any other procedures).
- If yes, why?
 - If no, why?
 - Prefer not to answer
25. Did the staff invite you to be involved with pain management during procedures?
- a. Yes
 - If no, did you feel comfortable advocating to be involved?
 - Prefer not to answer
26. Is there anything that could have been changed about this study or the *Parenting Pain Away* website to improve the experience?
- Prefer not to answer

Utilization of Parent-led Pain Management

Were you involved in your baby's pain management during their vitamin K injection?

- Yes
- No
- Prefer not to answer

Were you involved in your baby's pain management during the newborn blood screening?

- Yes
- No
- Prefer not to answer

Thank you so much for completing all of the surveys included in this study! We are so grateful that you participated in our study and used the Parenting Pain Away website. Your participation and feedback will help to understand Island parents experience with newborn pain management and improve our website!

If you have any questions, feel free to email me at brianna.richardson@dal.ca.

Best,

Brianna

Brianna Richardson, BScN RN PhD(c)

Parental Prevention of Newborn Pain Research Team

School of Nursing, Dalhousie University

(902) 229-7299

CHAPTER 4 APPENDICES

Article Appendices

APPENDIX 4.1 USABILITY TESTING SCRIPT

In the following usability testing script, the italics font provides direction for the researcher, whereas the regular font represents the comments and questions that were presented to each participant.

Introduction – approx. 10min

Welcome participant.

Reiterate that their participation is voluntary and outline plan for this usability testing session.

Ask for permission to record (start recording).

What is your understanding about what Parental Prevention of Newborn Pain [the study] is?

Give Parenting Pain Away Overview

Intro website – I'll help walk you through it

Try to think aloud as you go through the website – we are looking for a running commentary.

Talk about what you're trying to do and what you think about what you are doing. Please don't hold back!

Today we'll be looking at a prototype of Parenting Pain Away, a resource that provides information on parental involvement with infant pain management. As we are still designing the website, some sections may not be clickable yet, but I will let you know.

Any questions before we begin?

Prototype Review – approx. 25 min

Tell me about what you see here?

What's the overall feeling you get from this screen?

Are there any elements that stand out or you find notable?

Please continue to navigate through the site in whatever order you would like.

Wrap up (5 minutes)

What were some of your favourite features?

What didn't you like?

What you add?

Would you have found this learning platform helpful before the birth of your baby? (*If postpartum participant*)

Would find this learning platform helpful for you now during your pregnancy? (*If childbearing participant*)

Follow up questionnaires (20 minutes)

Give overview of the questionnaire.

Post Study System Usability Questionnaire: this questionnaire will be used to evaluate how satisfied you were with resource. There will be an additional two questions asking for your insight on how we should prepare to test the usefulness of this website with parents.

Do you have any more questions or comments?

Provide thanks and for their participation.

APPENDIX 4.2 ADDITIONAL ARTICLE TABLES

Table 4.3

Original Parenting Pain Away Prototype: Website Content Subjects

<i>Main Subjects</i>	<i>Sub-topics</i>
<i>Homepage</i>	NA
<i>About</i>	About Us Goals Team Chez NICU Home
<i>Learn</i>	Parents as Partners Family-Centred Care Common Procedures Comforting Your Baby Where to Begin Communicating With Your Baby Infant States to Know Learning Common Cues Recognizing Pain Summary

<i>Comfort Strategies</i>	<ul style="list-style-type: none"> Skin-to-Skin Care How to Do Skin-to-Skin Care Breastfeeding Sweet Tasting Solutions Familiar Touch Medications
<i>Thank you [for participating in this research]</i>	NA
<i>Resources</i>	<ul style="list-style-type: none"> Local Resources Additional Resources Glossary Contact Frequently Asked Questions
<i>Website Support</i>	<ul style="list-style-type: none"> Contact Frequently Asked Questions Privacy Statement Terms of Service

NA: Not applicable

Table 4.34

Detailed Outline of the Finalized Website Content

Subject and Sub-Topics	Description	Example
Homepage	Initial landing page aimed to engage and introduce users to the website.	
About Us	Describes the mission of the website and research team.	<p>Mission</p> <p>This resource was designed to help you and your family be confident in partnering with your healthcare team to lower your baby's pain during procedures.</p> <p>About us</p> <p>Welcome to your virtual guide on parent-led pain management! This resource is made for you, because parents have power! Parenting Pain Away is a secure eHealth resource developed by a team of parents, clinicians, and researchers to help make painful procedures a more positive experience.</p> <div style="display: flex; justify-content: space-around;"> <div style="border: 1px solid #ccc; padding: 5px;"> <p>You are your baby's</p> <ul style="list-style-type: none"> ○ Protector ○ Advocate ○ Guardian ○ Defender </div> <div style="border: 1px solid #ccc; padding: 5px;"> <p>Being involve can</p> <ul style="list-style-type: none"> ○ Reduce your baby's pain ○ Lower your stress ○ Strengthen your bond </div> </div>
Goal	Emphasizes that the website's goal is to empower parents through sharing evidence-based information.	<p>home about us goal</p> <div style="display: flex;">  <div style="margin-left: 20px;"> <p>Goal of Parenting Pain Away.</p> <p>We want you to know the scientific evidence... because it's no use for us to keep it to ourselves! Really, the bottom line is simple: Parents have Power! Research tells us that parental presence and support are essential for the best outcomes for a baby.</p> <p>The main goal of Parenting Pain Away is to innovate healthcare for growing families through parental involvement. This innovation allows us to make the best use of resources and to provide accessible support for families.</p> <p>This website will be available 24/7 on whatever device you prefer, whether it is a computer, smartphone, or tablet.</p> <p>Parenting Pain Away provides you with the best evidence in the learn section and shows exactly how you can get involved through different comfort strategies.</p> </div> </div>
Team	Provides information about the website developers and research team.	<p>home about us team</p> <h2 style="text-align: center;">Hello!</h2> <p style="text-align: center;">These are only some of the faces behind Parenting Pain Away. We are thrilled to support the journey of your growing family!</p> <div style="display: flex; justify-content: center; gap: 20px;">   </div>
Learn Lessons	Landing page for the five educational lessons.	

Parents have Power

You are the best person to comfort your baby during painful procedures. Learn about your power in the lessons below!



The Evidence Parents as Partners Your baby's cues

The Evidence Description of research related to parent-led procedural pain management.

You protect your baby.

For a long time people believed that babies didn't feel or remember pain, but we now know that isn't true. Babies experience pain and when it's not treated early in life, it can change how your baby reacts to pain throughout their childhood. As a parent, you have the power to comfort your baby when they are in pain. Research tells us that families have better outcomes when parents are involved in pain management with their babies during procedures. (1)(2)



All babies experience pain during procedures, like their first blood test, in the first few days after being born.

Healthy babies may have 20 painful procedures during their first year.

You really have special abilities to manage this pain!

Parents as Partners Outlines the importance of family-centred care.

Parents as partners.

Your involvement in your baby's pain care makes a difference

Having a baby can sometimes be intimidating, so take a deep breath: you are not alone! It is okay to feel overwhelmed with these changes and a bit unsure what your role is with their care while in hospital. The healthcare team wants to work closely with you to provide the best care for your baby. (1)(2)

The healthcare team will support you and your family to remain close to your baby, as we know minimal separation is important for physical, emotional and social wellbeing of both you and your baby. Keeping families together is important now, but also long term! (1)(2)

Always remember, you are the best person to care for your baby. You can provide the familiar comfort to your baby that no one else can

Your Baby's Cues Outlines common cues and recognizes pain in babies.

Your baby's cues.

Babies have amazing ways of communicating with you, even when they can't talk yet

Babies communicate using body language, known as cues. These cues can tell us many things, like when they are happy, hungry, uncomfortable, tired, or in pain.



Common Procedures Describes common procedures during the newborn stage.

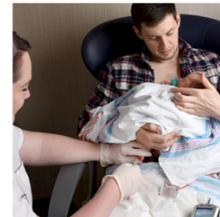
Common procedures.

Your baby will experience a number of procedures during the first few days of life and over the next few years. Some of these procedures may be stressful for them.

In their first year, every baby will have:

- Vitamin K injection
- Newborn metabolic screening
- Routine bilirubin screening
- Immunizations

Some of these procedures will happen shortly after your baby is born in hospital and some, like immunizations, will take place in the community with public health or your primary care provider.



This baby is getting their blood sugar tested.

Comforting Your Baby

Reiterates parent-led procedural pain management.

Comforting your baby.

During your baby's stay in the hospital, it is likely that they will experience pain and stress as part of their routine care.^(1,2)

- Babies feel and remember pain.⁽³⁾
- Newborns don't have many ways to cope with pain yet.⁽³⁾

Without the ability to tell us what hurts or how to make it better, they can become easily overwhelmed and stressed. This stress can change how your baby's brain grows and develops.

Untreated pain can affect how your baby experiences pain later in life.^(3,10)

With untreated pain, your baby might:

- Feel more pain during other procedures
- Feel anxious before experiencing a painful procedure
- Develop a fear of needles

You can help your baby feel less pain and experience less stress by providing them with your familiar comfort!

Comfort Strategies Ways to Comfort

Landing page for explanations on five comfort strategies.

Learning these special strategies to comfort your baby during procedures



Skin-to-Skin Contact

Skin-to-skin contact has many health benefits and comforts during painful procedures.

Breastfeeding

Breastfeeding can soothe your baby and increase bonding during painful procedures.

Sweet Tasting Solutions

The sweet taste of sugar water can help your baby manage pain.

Skin-to-Skin Contact

Describes Skin-to-Skin Contact.

Skin-to-skin contact.

The best environment for any newborn is skin-to-skin contact

Skin-to-skin contact is one of the first things you will do with your new baby. There are so many benefits when you or your loved ones struggle your baby in skin-to-skin contact!

Benefits of skin-to-skin

- Benefits for Baby⁽¹⁾
- Benefits for Parents/Caregivers⁽²⁾



Breastfeeding

Describes Breastfeeding.

Breastfeeding.

Breastfeeding can be one of the most effective ways to reduce your baby's pain, especially when they are undressed and in skin-to-skin contact on your chest.^(1,3)

Breast milk provides your baby with the nutrition they need for healthy growth and development, but breastfeeding offers more than just the amazing nutrition of breast milk!^(4,5)



Sweet Tasting Solutions

Describes Sweet Tasting Solutions (e.g., oral sucrose).

Sweet tasting solutions.

You know how chocolate gives you that happy feeling? The same thing happens to babies!

Although breastfeeding and skin-to-skin contact are recommended as the best way to comfort your baby during painful procedures, sweet tasting solutions can also reduce their pain during procedures.

If you are nervous about being with your baby for the procedure, sweet tasting solutions are a great way to provide pain relief when you can't be there.



Sweet tasting solutions, sometimes called sugar water, come in different solutions that are given in your baby's mouth.^(1,4)

- Sucrose
- Glucose
- Fructose or Lactose

Medications

Describes Medications (e.g., topical anaesthetics).

Needle procedures

A topical anaesthetic is recommended to be put on your baby's skin 30 - 60 minutes before the needle procedure, depending on the type.

A topical anaesthetic is a special, over the counter medication that freezes an area of your baby's skin where the needle will go.

You can get this medication at your local pharmacy as a cream, gel, or patch. These medications are safe to use but remember to always read the package directions to make sure that you are applying it correctly.

Types of topical anaesthetics include:

- EMLA
- Ametop
- Maxilene



Familiar Touch

Describes Familiar Touch (e.g., Holding; Facilitated Tucking).

Your familiar touch.

Your gentle touch is soothing to your baby

Your touch and presence is very comforting for your baby! Simply holding your baby during painful procedures will help them feel calm and secure.

Listed below are two ways that you can hold your baby, and some suggestions for how to make holding more effective at relieving pain.

Holding

Holding your baby during procedures helps your baby know they are safe and feel secure.

Although breastfeeding and skin-to-skin contact are recommended first, if you can't, holding your baby while using a sweet tasting solution is a good option.



Summary

Summarizes important information outlined in the five comfort strategies explanations.



You have learned a lot from this website! If you forget exactly how to comfort your baby during procedures, you can always ask your nurse for support. They are there to help you and your baby! Also to refresh your memory, you can watch this short video to see the top 3 easy ways to comfort babies during painful procedures!

1. Breastfeeding
2. Skin-to-skin contact
3. Sweet tasting solution

Building skills for many years

Parenting Pain Away has listed many ways that will help lower your baby's pain during procedures throughout their first year.



Resources Local Resources

Lists relevant resources available to the PEI population.

Women's Wellness Program

The Women's Wellness Program provides safe and supportive reproductive and sexual health services for Islanders. Services are offered in Souris, Charlottetown, Summerside, O'Leary, and Alberton without a referral needed. Visit their website or call 1-844-365-8258 for more information.

Public health

Public Health Nursing offers services and programs to support healthy growth and development for families, especially during pregnancy and the first year of life. Public health nurses are accessible to provide you with services like prenatal classes, New Beginnings program, breastfeeding drop-in clinics and immunizations across the island. Check their website for more details on all services and contact information for the public health clinic nearest you.

PEI Perinatal Program

The PEI Reproductive Care Program links you with essential information for people who are planning a pregnancy, currently pregnant, or have recently had their baby. If you are currently expecting a baby and have a health concern, you can contact the hospital directly to speak with a nurse. For the Maternal Child Care Unit at Prince County Hospital, call 902-433-4652, and for the Obstetrics Unit at Queen Elizabeth Hospital, call 902-894-2264.

Additional Resources

Describes other resources related to pediatric procedural pain management.

Additional Resources

There are many researchers and healthcare providers in Canada and worldwide that are all working to making procedures less painful for children. If you are interested in finding out more, here are just some of the amazing Canadian resources available to you!

Chez NICU Home is a multi-faceted project led by Dr. Marsha Campbell-Yeo at the IWK Health Centre. Chez NICU Home offers a secure, web-based platform that provides families in the neonatal intensive care unit (NICU) with the education and resources they need to become more active participants in the care of their baby. For more information, contact ChezNICUHome@iwknshealth.ca.



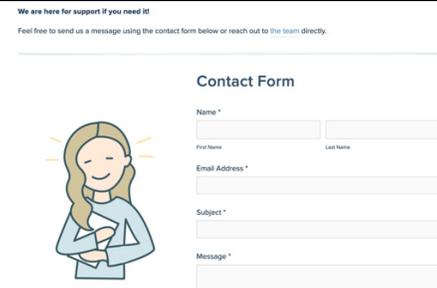
Glossary

Definition of key terms.



Website Support Contact

Communication form for users to contact the team.



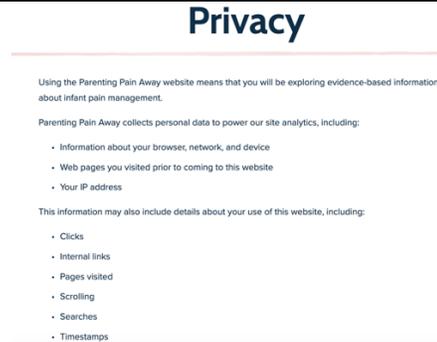
Frequently Asked Questions

More information to help users.



Privacy Statement

Privacy disclosure statement for users to review.



Terms of Service

Terms of Service for users to review.



APPENDIX 4.3 ARTICLE FIGURES

Figure 4.1

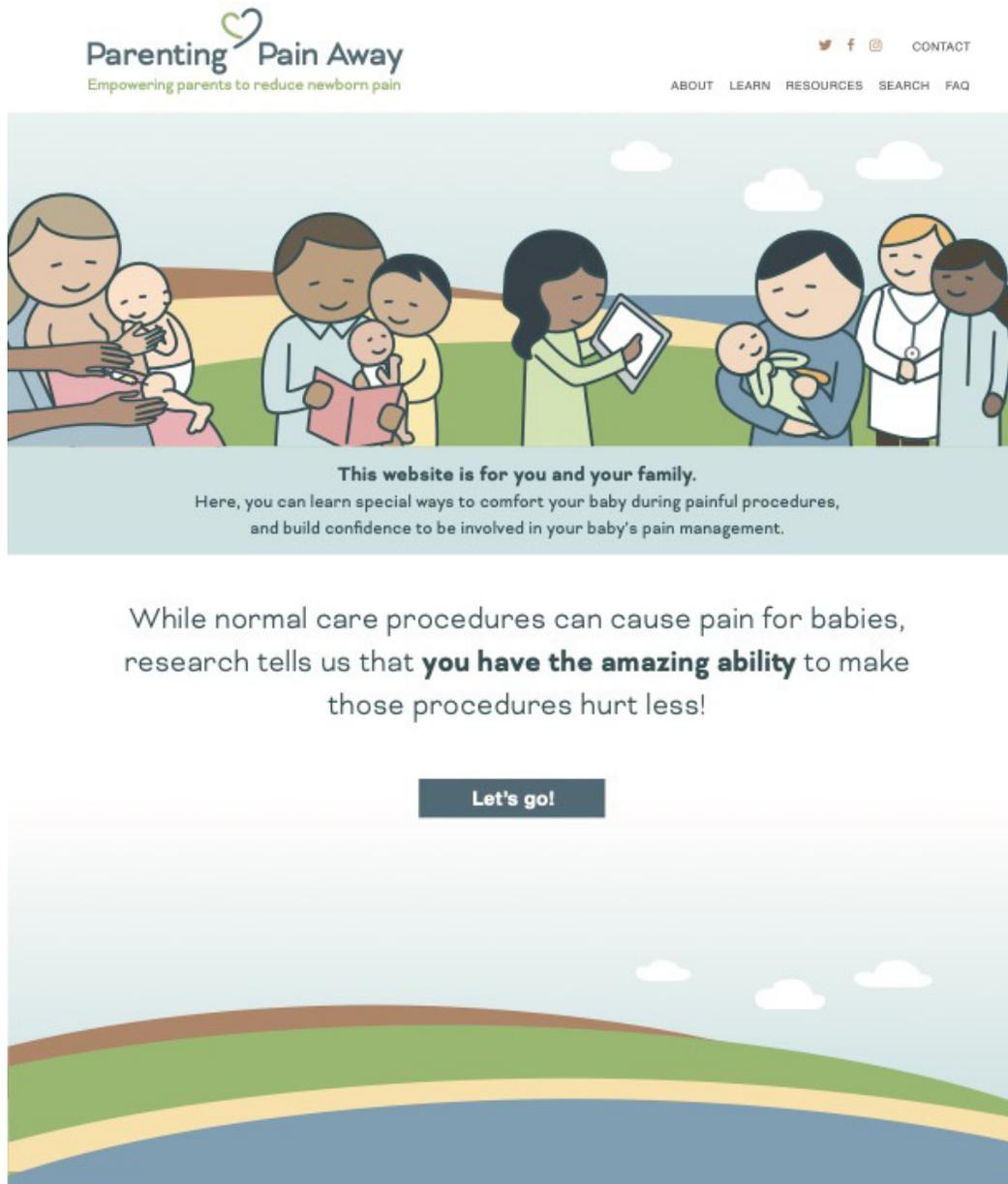
Parenting Pain Away Logo



Figure 4.2

Evolution of the Homepage Design

Cycle 1:



While normal care procedures can cause pain for babies, research tells us that **you have the amazing ability** to make those procedures hurt less!

Let's go!

Finalized Version:

Empowering Parents

Parenting Pain Away is a space for families to learn special ways to comfort babies during painful procedures. We believe all babies need pain management and families have the power to do that!



While normal care procedures can cause pain for babies, you have the **amazing ability** to make those procedures hurt less!

Your Journey





Explore who we are and why we are committed to **empowering parents**

[about us](#)



Understand **why** you are the most important person for lowering your baby's pain

[learn](#)



Dive into five **special ways** you can comfort your baby and lowering their pain during procedures

[comfort strategies](#)



Short on Time?

Here's the lowdown



[PRIVACY](#) [TERMS OF SERVICE](#) [CONTACT](#) [FAQ](#)



Powered by [Squarespace](#)

This website has been created using the Chez NICU Home platform, which is owned and copyrighted by the IWK Health Centre.

Site last updated: March 1, 2021

Figure 4.3

Prompt for the Quick Summary Page



Figure 4.4

Example of Dropdown Revision (post Cycle 2)

Parents help protect their baby from pain & stress by: ^(1,11)

- + Skin-to-skin contact
- + Breastfeeding
- + Sweet tasting solutions
- + Medicine
- + Familiar Touch

Parents help protect their baby from pain & stress by: ^(1,11)

- + Skin-to-skin contact
- Breastfeeding

Feeding a baby breast milk directly from a parent's breast. One of the **most powerful** ways to comfort your baby during procedures.

Start breastfeeding at least **2 - 5 minutes before** a painful procedure and continue feeding during for the best effect. [Learn more!](#)

- + Sweet tasting solutions
- + Medicine
- + Familiar Touch

APPENDIX 4.4 COPYRIGHT RELEASE - PAEDIATRIC AND NEONATAL PAIN

Chapter 4 is a manuscript version of “[Parenting Pain Away: Development and usability testing of an educational website about infant procedural pain management](#)” by Hughes and colleagues. This paper has been published in the journal *Paediatric and Neonatal Pain* published by John Wiley & Sons Ltd. and is licensed under the [BY-NC-ND 4.0 license](#). © 2023 The Authors. The full citation for the article is listed below:

Hughes, B., Martin-Misener, R., Latimer, M., Smit, M., McGrath, P., & Campbell-Yeo, M. (2023). Parenting Pain Away: Development and usability testing of an educational website about infant procedural pain management. *Paediatric and Neonatal Pain*, February 2022, 1–20. <https://doi.org/10.1002/pne2.12096>

There have been minor changes from the published article that are presented in the manuscript version, including: citation style and formatting to match APA 7th Edition; and renamed table titles. The changes were made to align with this thesis.

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