Music Therapy and the Advancement of Family-Centred Care in the Neonatal Intensive Care Unit: A Philosophical Inquiry

Carol Wiedemann

A Thesis

in

The Department

of

Creative Arts Therapies

Presented in Partial Fulfillment of the Requirements

for the Degree of Master of Arts (Creative Arts Therapies, Music Therapy Option)

Concordia University

Montreal, Quebec, Canada

April 2022

CONCORDIA UNIVERSITY

School of Graduate Studies

This is to certify that the thesis prepared

By: Carol Wiedemann

Entitled: Music Therapy and the Advancement of Family-Centred Care in the Neonatal Intensive Care Unit: A Philosophical Inquiry

and submitted in partial fulfillment of the requirements for the degree of

Master of Arts (Creative Arts Therapies, Music Therapy Option)

complies with the regulations of the University and meets the accepted standards with respect to originality and quality.

Signed by the final Examining Committee:

_____ Chair
Cynthia Bruce

_____ Examiner
Guylaine Vaillancourt

_____ Examiner
Stephen Venkatarangam

_____ Supervisor
Cynthia Bruce

Approved by _____
Guylaine Vaillancourt, Chair, Department of Creative Arts Therapies

2022 YEAR _____
Annie Gérin, Dean, Faculty of Fine Arts

ABSTRACT

Music Therapy and the Advancement of Family-Centred Care in the Neonatal Intensive Care Unit: A Philosophical Inquiry

Carol Wiedemann

The purpose of this philosophical inquiry was to understand and articulate the barriers to Family-Centred Care (FCC) implementation, to connect Neonatal Intensive Care Unit Music Therapy (NICU MT) to the principles of FCC, and to position music therapy as a unique and important contributor to the advancement of FCC principles within the Canadian NICU context. Since the inception of NICU MT as an area of specialization in the 1990's, the shift towards FCC perspectives has been reflected in music therapy research, with significant outcomes for both improved physical parameters of fragile infants and the reduced anxiety and stress of parents. While NICU MT alignment with a FCC approach has become common, there has been limited explicit discourse on this alignment. This inquiry provides a comprehensive alignment of NICU MT's research and approaches with the four FCC principles of *Dignity and Respect*, *Information Sharing, Participation, and Collaboration,* while articulating some of the systemic barriers that have impeded the full implementation of FCC. Canada's unique health care system, in combination with the burgeoning NICU MT field worldwide, sets the stage for new and innovative models of care that are truly family centred.

ACKNOWLEDGEMENTS

A profound thanks to my family and friends for your ongoing love and encouragement.

To my academic colleagues near and far who have kept me going through pandemic bubbles, texts, zoom calls, and across time zones, I am in awe of your brilliance and so very grateful for your humour.

To my advisor, Dr. Cynthia Bruce, for challenging the way I think about research and music therapy. I am grateful for your thoughtful guidance, ferocity of spirit, and generosity of time.

Thank you to the Concordia Music Therapy Faculty for inspiring in me a renewed passion for and perspective on the amazing field of music therapy.

Finally, deep gratitude to all the courageous, resilient NICU families that I have the honour of working with, and the team of dedicated colleagues I am proud to be a part of.

Table of Contents

Chapter 1. Introduction

In mid-March of 2020, a dramatic shift occurred in Canadian hospitals in response to the COVID-19 pandemic. Highly restrictive hospital access policies were put in place that altered the status of patients' families from 'essential care partners' to 'visitors', revealing the fragility of Family-Centred Care (FCC) and exposing systemic barriers in Canadian healthcare and abroad (Fancott et al., 2021). While restrictions were easing up at the time of writing this research, anticipated pandemic waves and subsequent healthcare responses are still likely to be seen (Dokken et al., 2021). In Neonatal Intensive Care Units (NICU), parents in an already challenging situation found themselves having to choose which parent would stay with their medically fragile infant and who would stay with siblings who were no longer allowed on site, while missing the direct support of extended family who were also declared 'visitors' (Bainter et al., 2020). Within these challenging healthcare parameters, the field of NICU music therapy has responded with flexibility and innovation by quickly adapting interventions, moving sessions to online platforms, and designing new programs to inclusively meet the needs of the most vulnerable patients and families (Duff et al., 2021; Negrete, 2020).

Significance and Need

In 2020, there were over fourteen thousand neonates requiring care in Canadian NICUs, making up 4% of all Canadian live births that year (Canadian Neonatal Network, 2021; Statistics Canada, 2021). Due to ever-advancing improvements in medical care, infants born as early as 22 weeks' gestation now have a chance at survival (Canadian Neonatal Network, 2021). However, these survival rates also pose a greater risk of long-term NICU stays, adverse neurodevelopmental outcomes, and potential language delays for these fragile infants (Adams-Chapman et al., 2015).

Having an infant in the NICU can also result in increased stress for parents (Feely et al., 2007). Compared to parents of healthy infants, parents of NICU infants have been shown to experience higher levels of depression (Miles et al., 2007), anxiety (Feeley et al., 2007), and post-traumatic stress disorder (Misund et al., 2014); all of which can interfere with parental bonding (Edwards et al., 2017). In consideration of these challenges, NICUs have recognized the need to create a supportive environment for both infants and their families (Gooding et al., 2011).

As a response to these needs, Neonatal Intensive Care Unit Music Therapy (NICU MT) began to emerge as a unique clinical specialization and research focus in the early 1990's (Nöcker-Ribaupierre, 2015; Standley & Mardsen, 1990). Since its inception, music therapy research has shown beneficial effects on preterm infants' pacification and stabilization (Haslbeck, 2012; Standley, 2012), physiologic parameters of respiratory rate (Bieleninik, et al., 2016), and sleep quality and oral feeding (Chorna et al., 2014; Loewy et al., 2013). More recently, music therapy's impact on caregivers' mental health has shown significantly reduced maternal anxiety (Bieleninik, et al., 2016; Ettenberger et al., 2017), decreased parental stress (Kehl et al., 2021; Loewy et al., 2013), and improved infant-parent bonding (Haslbeck, 2015; Kehl et al., 2021). International research and clinical practice have led to the development of three distinct training programs in NICU music therapy: NICU-MT from The National Institute for Infant and Child Medical Music Therapy in Tallahassee, Florida (Standley, 2012), First Sounds: Rhythm, Breath and Lullaby (RBL) training from the Beth Israel Medical Center in New York (Loewy et al., 2013), and Creative Music Therapy (CMT) from the Institut für Musiktherapie in Munich, Germany (Haslbeck & Bassler, 2020).

At the same time as this music therapy specialization was emerging, the concept of Family-Centred Care (FCC) was created and articulated as a philosophical approach and set of principles that aimed to improve outcomes for infants and their families in the NICU (Gooding et al., 2011; Harrison, 1993; Kuo et al., 2012). The core principles of FCC include: (a) dignity and respect, (b) information sharing, (c) participation, and (d) collaboration (Institute for Patient- and Family-Centred Care [IPFCC], n.d.). Recognized world-wide as the standard for pediatric healthcare, FCC research in the NICU clearly indicates that infants and their parents have better outcomes when parents are consistently present (Keilty et al., 2014).

The move towards an alignment with FCC was evidenced in the shifting focus of NICU MT research and clinical practice (Ettenberger et al., 2017). While there is currently a positioning of NICU MT with FCC principles, there has been limited explicit discourse on this alignment, which adds to the significance of and need for this study.

Personal Relationship to the Topic

As a certified music therapist, having both specialized NICU-MT training from Florida State University combined with over fourteen years of pediatric and maternity music therapy experience, I was well-situated to develop and implement a Canadian NICU MT program. I have witnessed the 'family-centredness' of music therapy in its ability to adapt and respond in innovative ways to consistently support the health of patients, build resilience in families, and creatively collaborate with staff.

As a Canadian NICU music therapist, I have observed that despite the establishment of FCC principles, they are not always fully implemented in NICU settings that claim to centre them. For example, open-bay NICUs, which are NICUs that do not have any private patient rooms, do not provide space for parents to stay overnight with their infant, even though FCC emphasizes the importance of parents as primary caregivers (Gooding et al., 2011). This lack of support for parents is also presented by Franck and O'Brien (2019) who note that, "despite the evidence and ongoing interest, parent involvement in the delivery of care for preterm and low birthweight infants has not been fully realized in most NICU settings" (p. 1045). The COVID-19 pandemic has amplified and made evident the gaps in FCC implementation in Canada (Fancott et al., 2021). Yet importantly, it has also led to vital observation of the flexible response and continued contribution that NICU MT can and does make toward the realization of FCC. My experience coupled with the literature in this domain (Ettenberger et al., 2017; Haslbeck & Bassler, 2020; Kuo et al., 2012) suggests that music therapy can circumvent some of the systemic barriers inherent in the medical model to advance FCC in ways that will be examined in this research. As this area of specialization develops, Canadian music therapists need to consider their unique role in the NICU, how this practice is shaped by the Canadian healthcare landscape, and how the field of music therapy is uniquely situated to contribute to the advancement of FCC.

Purpose

To examine the potential for music therapy in the Canadian NICU context and its close alignment with the principles of FCC, the purpose of this philosophical inquiry was threefold. First, to determine and articulate the barriers to FCC implementation in the Canadian NICU context. Second, to connect NICU MT clearly and explicitly to the stated

principles of FCC. Finally, to position music therapy as a unique and important contributor to the advancement of FCC principles within the Canadian NICU context.

Research Questions

The primary research question explored in this study was: How is NICU Music Therapy uniquely situated to contribute to the advancement of Family-Centred Care in the Canadian Neonatal Intensive Care Unit? The subsidiary research questions were as follows: 1) What systemic barriers impede the implementation of FCC in the NICU? 2) How is NICU MT aligned with the principles of FCC? and 3) How does NICU MT contribute to the advancement of FCC principles within the Canadian NICU context?

Assumptions

There were a number of assumptions that grounded this research. First, with over 20 years of research specific to this population, it was assumed that NICU MT, as an evidence-based practice, benefits patients and their families (Bieleninik et al. 2016; Standley & Gutierrez, 2020). Second, because there are specific evidence-based trainings designed for music therapists to develop skills in this area (Haslbeck & Bassler, 2020; Loewy, 2004; Standley & Walworth, 2010; Ullsten et al., 2020), the researcher assumed that most music therapists who work in the NICU have had specialized training in this area.

Key Terms

While certain terms are explained or expanded upon elsewhere, concise definitions are provided here to contextualize the information articulated in upcoming chapters.

Neonatal Intensive Care Unit (NICU) is a specialized inpatient unit that "provides medical and surgical care for babies after birth who need special attention. Some of the reasons include preterm birth, low birth weight, breathing difficulty, and infection" (BC Women's Hospital & Health Centre, 2022, Neonatal Intensive Care).

NICU Music Therapy (NICU MT) is the generalized term that will be used throughout this study to refer to advanced practice in music therapy offered by certified music therapists with specialized training in premature and fragile infant development and care, specialized interventions and protocols, and awareness of parental needs in the NICU (Standley, 2012).

Family-Centred Care (FCC) is an approach that supports collaboration and communication between families and the NICU health care team to create better outcomes for infants through a set of guiding principles that will be explicated in depth in chapter 4 (Gooding et al., 2011; Kuo et al., 2012).

Family will be used throughout this research to include persons most important to the care of the infant, or as self-defined by the family themselves. This may include but is not limited to parents, siblings, grandparents, caregivers, and/or foster parents (IPFCC, n.d.).

For this research, *Systemic Barriers* are defined as issues inherent within the healthcare system that get in the way of delivering care. For example, within neonatal intensive care, systemic issues may include inconsistency of communication between the care team and families, a context that excludes families from being involved in their infant's care, and a lack of cultural safety and support (Gooding et al., 2011).

Chapter Summaries

Following this introduction, chapter two describes philosophical inquiry (Aigen, 2005a; Stige & Strand, 2016) and its rationale as the methodology for this thesis. It also explicates materials used, data collection approaches, and data analysis strategies. Chapter three establishes the foundation for this inquiry and uses literature as the primary data source. Chapter four aligns NICU MT with the principles of FCC and contains a critical analysis of the literature to argue for the importance of NICU MT as uniquely situated to contribute to the advancement of FCC in the Canadian NICU. Chapter five discusses implications of the results regarding future music therapy practice, education, research, and advocacy; and identifies limitations of the present inquiry.

Chapter 2. Methodology

Philosophical inquiry was the methodology used to answer the principle and subsidiary research questions of this study. This chapter articulates the research design, data collection strategies, materials used, data analysis procedures, and the delimitations imposed by the researcher.

Research Design

This philosophical inquiry was grounded in Aigen's (2005a) assertion that the aim of qualitative research is to establish inquiry as research. Philosophical inquiry questions assumptions and utilizes argument to clarify a philosophical perspective, while contrast, comparison, and exploration of viewpoints are used to construct this perspective (Aigen, 2005a). To shape the argument put forth in this study, philosophical inquiry was an ideal methodology to compare and align NICU MT with the principles of FCC, and to articulate its importance in the advancement of FCC where full implementation has not been realized.

In philosophical inquiry, the researcher draws on multiple modes of critical analysis to construct and articulate an argument. “It is up to the researcher to persuade the reader that the findings faithfully represent the phenomena under study” (Aigen, 2005b, p. 216). This is accomplished with thorough detail and an open-minded examination of the data to generate a synthesis and logically communicate results (Aigen, 2005b). Critical thinking and examination of the data with “deductive, inductive and retroductive reasoning” (Aigen, 2005a, p. 529) produces not only a deeper comprehension but also a new perspective to shape practice and direct future inquiry (Aigen, 2005a).

Rooted in a constructivist epistemology, a worldview that examines multiple perspectives and meaning based on human experience, this philosophical inquiry pursued a greater understanding of the challenges experienced by NICU infants and families, the systemic barriers that impede full implementation of FCC, and music therapy’s role in realizing FCC principles. In the context of this master’s thesis, constructivist epistomology focused on generating an understanding of perspectives and a multiplicity of experiences within social and historical contexts, as shaped by the researcher’s uniquely Canadian history, experience and perspective (Creswell & Creswell, 2018).

Critical thinking was used to evaluate and analyse literature from both FCC and NICU MT, to uncover underlying assumptions and challenges in answering the research questions, and to distill the resulting data to its most salient points (Aigen, 2005a). Argument propelled the inquiry forward by aligning NICU MT with FCC principles and examined relevant research to make a case for NICU MT as uniquely situated to contribute to the advancement of FCC (Aigen, 2005a). Ultimately, by examining the data and identifying the relationship between NICU MT and FCC, this research sought to generate knowledge that will stimulate interdisciplinary dialogue, one of the primary tasks of philosophical inquiry identified by Aigen (2005a).

Materials

Materials included peer reviewed journal articles, scholarly book chapters, relevant books, master's theses, and key organizational and government websites. This literature was tracked using Zotero software and then organized and synthesized in an excel spreadsheet. Throughout the process, a research journal was used to record emerging thoughts and ideas about the topic. The collected data was saved on a password protected laptop and securely backed up to a password protected external hard drive.

Data Collection

To address the research questions, a comprehensive review of relevant scholarly journals was conducted and database searches were undertaken. Research databases and search engines utilized included Concordia University Library's Sofia Discovery tool, PsychInfo, PubMed, EBSCOhost, Proquest, and Google Scholar. Concordia University's Spectrum Research Repository was used to find relevant master's theses.

The research questions guided the process of delineating the framework for inclusion and exclusion of literature and the generation of possible search terms. Search terms in varied combinations included: music therapy, NICU, neonatal intensive care, family centered/centred care, family integrated care, family, parents, caregivers, premature infants, barriers to care, and systemic barriers. Music therapy peer-reviewed journals such as *Voices: A World Forum for Music Therapy,* the *Nordic Journal of Music Therapy,* the *Journal of Music Therapy,* and *Music Therapy Perspectives* were comprehensively reviewed. Pertinent articles relating to FCC and the needs of families were searched in non-music therapy journals such as *Pediatrics, Pediatric Nursing, and The Lancet Child*

& Adolescent Health. Zotero, a literature search log, was used to collect and record research findings and any initial notes pertaining to the research. Retrieved information was then compiled into an excel spreadsheet organized by authors, APA reference, information summary, in-text citation, theme, and reflective notes (Efron & Ravid, 2019). The researcher's thoughts and assumptions were documented throughout the process in a reflexive journal.

Data Analysis

Philosophical inquiry positions the researcher as *key instrument;* the one who gathers, examines, and interprets the data (Creswell & Creswell, 2018). Stige and Strand (2016) and Aigen (2005a) identify four procedures for philosophical inquiry that include: (a) clarifying terms; (b) uncovering underlying assumptions; (c) systematically relating and connecting ideas; and (d) using argument to present the findings. Throughout the literature search, terms and concepts were clarified. A spreadsheet was utilized to summarize articles, synthesize the extracted data, and formulate evidence for the argument (Efron & Ravid, 2019).

Through rigorous examination of the information, the themes that emerged directed further analysis of the data (Creswell & Creswell, 2018). This analysis included categorizing themes based on the research questions and aligning the information with either FCC, NICU MT, or the intersection of the two categories. Only sources that contained supporting and contrasting viewpoints congruent to the research questions were included in the data, and then analyzed and refined to build the argument. A reflexive journal was used to recognize assumptions and identify connections throughout the research process, although this journal was not used as data (Aigen, 2005a).

Delimitations

The scope and timeline of a master's thesis, in addition to the research design chosen, necessitated a number of delimitations. As a philosophical inquiry, information was the primary data source, and research participants were not included. Data sources were delimited to peer reviewed journal articles and relevant book chapters published in English between 2008-2022, with exceptions for historically relevant information that provided context for current research. Only government websites and websites from reputable organizations that referenced their sources, for example, the Institute for

Patient- and Family-Centered Care, were included in the data collection. Finally, to narrow the scope, the population for this research was delimited to infants and families in the NICU and did not include hospitalized infants in other pediatric units.

Chapter 3: Establishing the Foundation

This chapter examines relevant research from the literature to establish a foundation for this philosophical inquiry. First, an overview of FCC in the NICU starting with the Canadian NICU context is presented. This is followed by an explication of FCC principles, implementation of interventions, and salient research. Challenges and systemic barriers that impede FCC implementation will be described, thereby addressing the first subsidiary research question. This is followed by three care models that have been developed as a response to these barriers. Second, an overview of the development of NICU MT and its benefits will be presented which will include the varied approaches and trainings offered globally and an explication of what is known about the Canadian NICU MT context. Finally, NICU MT will be situated in connection to FCC and current research trends to show the need for a comprehensive, articulated alignment of NICU MT and the principles of FCC.

Overview of FCC in the Neonatal Intensive Care Unit

Although medical advances have improved outcomes for preterm and high-risk infants, there remains a need to support families as they deal with the uncertainty and stress associated with having a fragile infant and the often-lengthy hospital stays that ensue. Parents of NICU infants have been shown to experience higher levels of distress compared to parents of full-term healthy infants (Schappin et al., 2013). Having an infant admitted to the NICU for an undetermined amount of time may mean parents face the complex and uncertain needs of their infant, ongoing fatigue, mental health issues, and social challenges (Serlachius et al., 2018).

Canadian NICU Context

To provide care and support for fragile infants and meet the unique needs of families, Canadian pediatric hospitals began introducing the principles of FCC in the late 20th century (Keilty et al., 2014). With a publicly funded healthcare system that provides universal coverage for care that is deemed ‘necessary’, all care in Canadian NICUs is provided free of cost (Government of Canada, n.d.). As of 2020, there are 33 Canadian NICUs situated in either pediatric or maternity hospitals that provide FCC for fragile infants and their families (Canadian Neonatal Network, 2021). Canadian NICUs are rated as either level two or three, depending on the level of care an infant requires after birth.

Level 2 infants are born at a gestational age of 32 weeks or higher, weigh 1500g or more, and are expected to recover quickly; while level 3 care encompasses all infants, regardless of gestational age or weight, and provides the highest level of medical care for the most vulnerable (Canadian Neonatal Network, 2021). These NICU infants may be critically ill, suffering from effects of prematurity such as requiring respiratory and gastric support, or require surgical procedures, before they are stable enough to be discharged home (Critical Care Ontario, n.d.). The physical environment of Canadian NICUs are either 'open bay', with two or more infants in an open ward and limited space reserved for family members; or 'single bay', which means each infant has their own room with space for a family member to stay with them at all times (van Veenendaal, 2020).

What is FCC

Family-Centred Care originated in the 1990's as a response to NICU families who felt excluded from their infant's care and medical decision-making and as a result, did not feel confident providing care when discharged (Harrison, 1993). FCC is both a philosophy and a set of principles that aim to improve outcomes for patients through collaboration and communication between patients, families and their interdisciplinary healthcare team (Gooding et al., 2011; Kuo et al., 2012). As a philosophy, FCC recognizes families as essential allies to provide the best possible care for patients, and it seeks to build family confidence and resilience as primary caregivers for their infant (IPFCC, n.d.). FCC affirms the ability of families to define "family" in their own terms and recognizes the importance of treating the infant within the context of the needs and strengths of this family (Lissauer et al., 2020). Importantly, outcomes for infants and satisfaction of parents have been shown to improve with the implementation of FCC by providing greater integration of families in the care of their hospitalized children (Ding et al., 2019).

Four core principles of FCC are briefly summarized here to provide context and then are further explicated in chapter four:

Dignity and Respect. FCC respects each infant and their family's values, beliefs, and knowledge (IPFCC, n.d.). It similarly honours the diverse identities and experiences

of each family in relation to race, ethnicity, religion, cultural background, and other lived experience (Frank & O'Brien, 2019; IPFCC, n.d.).

Information Sharing. FCC requires healthcare practitioners to communicate honest, timely and unbiased information with families in ways that are empowering and promote mutual understanding (IPFCC, 2020).

Participation. FCC supports active engagement of families at their chosen level of participation in their infant's care and in decision-making (IPFCC, 2020). This includes recognizing and building on a family's confidence and strengths (Frank & O'Brien, 2019).

Collaboration. FCC supports interdisciplinary care providers and families to work in partnership at all levels of healthcare. This includes the delivery of care, policy and program development and implementation, facility design, and professional education (IPFCC, n.d.).

Recognized world-wide as the standard for pediatric healthcare, the implementation of these FCC principles results in improved outcomes for infants and the families that care for them (Keilty et al., 2014). A systematic review and meta-analysis of randomized controlled trials by Ding et al. (2019) rigorously examined the effects of FCC interventions, and their findings indicate significant infant outcomes of increased weight gain and reduced return admissions. FCC outcomes for parents included increased confidence, skills, and applied knowledge to continue care once discharged, as well as decreased anxiety, stress and depression (Ding et al., 2019).

While FCC is described as an approach rather than a model of care, FCC interventions have been developed based on FCC principles. These include educational support to build parental skills and knowledge, participation and involvement in care of the infant, personalized care of the family that respects their unique needs and perspectives, psychological and accessibility support for parents, clear systems of ongoing communication between parents and care team, and a NICU environment that supports family presence (Altimer & Philips, 2013; Craig et al., 2015; Ding et al., 2019). For example, research indicates that infants have better outcomes when parents are consistently present, and this can be achieved through the physical design of single-family rooms (Kuo et al., 2012) and the use of interventions, such as Kangaroo Care, that

build attachment and parental confidence in their ability to care for their infant (Cho et al., 2016).

Barriers to Realizing FCC

While FCC principles are widely accepted globally, "the reality remains that in many countries, parents have limited access to neonatal intensive care units (NICUs) and limited involvement in the care of their infant" (Ding et al., 2019, p. 64). The barriers preventing a full realization of FCC can be attributed to an inconsistency in the implementation and interpretation of FCC principles, the need for updates to the physical environment, a systemic culture and power imbalance that excludes families, a lack of cultural respect and humility, the persistent presence of racism, and a deficiency of emotional and mental supports for families (Altimer & Philips, 2013; Frank & O'Brien, 2019; Gooding et al., 2011; Serlachius et al., 2018).

Comprised of a broad set of principles that some consider too vague, the FCC approach has been criticized for lacking clear systems to translate these principles into action and for being open to interpretation that varies between countries, health systems and hospitals (Frank & O'Brien, 2019; Gooding et al., 2011; Ullsten et al., 2020). Although FCC has been recognized as the ideal philosophy to provide increased parental collaboration and improved infant health outcomes, "fundamental misunderstandings persist about what FCC is, how to implement FCC, and how to determine the family-centeredness of care" (Kuo et al., 2012, p. 298). This has led to the development of more focused models of care that will be further explicated later in this chapter.

The physical environment of the NICU varies worldwide in its set up, even from hospital to hospital within the same country (Altimer & Philips, 2013). While FCC recommends single family rooms in NICUs to promote the presence of at least one caregiver with the infant at all times, it can take years to approve upgrades to hospitals that would provide appropriate space for parent accommodations (Altimer & Philips, 2013). In a year-long survey study conducted by Raiskila et al. (2017) that included 328 parents across eleven NICUs in six European countries, having a NICU where parents could stay overnight in single-family rooms was shown to be one of the biggest factors affecting the amount of time parents spent physically close to their infant. Similarly, in Canadian NICUs, even though single room designs have been the standard since the

emergence of FCC, the barriers of available space and prohibitive building costs means several NICUs are still using an open bay design as they wait for hospital rebuilds (Canadian Neonatal Network, 2021; Frank & O'Brien, 2019).

There has also been criticism that FCC involves parents but does not go far enough to meet their unique needs or empower them to provide care for their infant (O'Brien et al, 2015). Parents struggle to thrive in their new role when faced with a lack of medical education and an isolating and challenging environment (Loscalzo et al., 2021; Shoemark & Dearn, 2008). Indeed, in their meta-analysis of literature examining the effectiveness of interventions for parents of preterm infants, Puthussery et al. (2018) found that parent-delivered interventions remain underutilized in most NICU settings, even though there is moderate-to-strong evidence that parents can successfully provide a substantial amount of care for their infant.

In 2020, the COVID-19 pandemic disrupted hospital and NICU operations throughout the world and led professionals in healthcare settings to make abrupt changes in policies that frequently opposed the FCC principles of participation, collaboration, and respect; changes that exposed many existing systemic barriers (Bainter et al., 2020; Healthcare Excellence Canada, 2020). While most Canadian hospitals have had 'open family presence' policies in place since 2015, Canada's COVID-19 response created barriers to FCC in the NICU when 'blanket visitor restrictions' were put in place that allowed only 2 primary caregivers at the bedside of the infant, which led to the exclusion of siblings, extended family and family supports (Healthcare Excellence Canada, 2020). This had far-reaching implications for families, and caused increased anxiety and stress, separation and isolation, interrupted bonding, and decreased care, support, and learning opportunities; all of which had potentially long-lasting effects on infants and the mental health of family members (Bainter et al., 2020).

The pandemic response also exposed systemic barriers to FCC related to power imbalances within healthcare. The medical model often reinforces an 'expert-focused' perspective that establishes professionals from the NICU team as the primary caregivers, rather than empowering parents to assume this role (O'Brien et al, 2015). While FCC principles emphasize respect for a diversity of cultures and values, power imbalances may still surface when there are cultural and value differences between families and staff,

and even between staff, and this imbalance creates a reality where the experiences of families can be inadvertently subjugated to that expert discourse (Hellmann, 2014). For example, when faced with an infant with a life-threatening condition, Hellmann (2014) describes the challenge it may present for staff to recognize and respect a family's culture and choices when they differ from their own and the impact this may have on families as "the emotional suffering that parents endure when their values, beliefs and views are explored, scrutinized and challenged" (p. 239). This highlights the potential power differential in the NICU and the ways that those expert frameworks can fail to make space for care that affirms cultural difference or attends to parental stress that arises from that reality (Hellman, 2014).

In addition to barriers that impede respect for cultural differences, systemic racism in healthcare must also be acknowledged. For example, The Calls to Action outlined in the Truth and Reconciliation Commission of Canada, a report identifying the race-based inequities embedded within Canadian systems, demands that healthcare practitioners provide culturally safe care for Indigenous people (Truth & Reconciliation Commission of Canada, 2015). Speaking directly to the work clinicians need to do within the NICU setting, Wright et al. (2020) state "this paternalistic and colonial history continues to impact Indigenous mothers who are subjected to power imbalances and feel a lack of safety and control" (p. 8). Within Canada's multicultural society and NICU contexts, it must be up to families, not healthcare practitioners, to determine how and when they feel truly safe (Vernon & Papps, 2015).

The barriers to FCC are diverse and far-reaching, and they are embedded in systems that are slow to change. This slower than desirable but necessary change is relevant to physical structures and pervasive power imbalances. Cultural safety, humility, respect, and support are essential components of FCC that can be lacking during times of crisis for individual families and on a larger scale, during global health pandemics. These identified barriers to care have stimulated a number of healthcare-based responses that will be discussed in the following section.

Responses to FCC Barriers

Medical system responses to the challenges of realizing FCC include the development of focused models of care to help clarify and implement the principles of

FCC. While these models have created a more standardized implementation of specific aspects of FCC, they have not been able to fully address existing barriers (Frank & O'Brien, 2019). Three such models that will be explicated in this chapter include Kangaroo Care (Cho et al., 2016), the Neonatal Integrative Developmental Care Model (Altimer & Philips, 2013), and Family Integrated Care (O'Brien et al., 2015).

Kangaroo Care (KC) Also referred to as Skin-to-Skin Contact (SSC), KC is an early intervention that promotes bonding and active participation of primary caregivers with their infants (Cañadas et al., 2022). It became the focus of research and practice in NICUs worldwide after its initial use in Columbia in 1978 when premature infants were placed skin-to-skin with their mothers 24 hours a day during an incubator shortage. The results were greater infant survival rates and earlier infant discharges than expected (Cho et al., 2016). Cho et al. (2016) used a quasi-experimental design with pre- and post-tests to examine the effects of KC on the physiology of preterm infants, maternal-infant attachment and maternal stress. The researchers found that daily KC had stabilizing effects on preterm infants' respiratory rate, oxygenation, and temperature; increased mother-infant attachment, and reduced maternal stress.

Neonatal Integrative Developmental Care and Assessment Program (NIDCAP). Developed originally as a model of nursing care, NIDCAP focuses on the neuroplasticity of the developing infant brain to inform its interventions (Altimer & Philips, 2013; Craig et al., 2015). These interventions aim to improve the infant's ability to cope with stimulation through reduction of negative stimulation in the environment and support of families to learn to understand and respond to their infant's unique developmental needs (Altimer & Philips, 2013). The NIDCAP interventions, grouped into seven 'neuroprotective measures', include partnering with families, grouping activities of positioning and handling, minimizing stress and pain in procedures, safeguarding sleep through clustered interventions, protecting skin, nutrition, and creating a positive sensory environment (Altimer & Philips, 2013). A non-randomized controlled study by Sannino et al. (2016) examined maternal participation in care and infant development to evaluate the effectiveness of NIPCAP. This research indicated a significant increase in maternal involvement and confidence in the care of their infants,

with implications for improved short term neurofunctional development of the infants (Sannino et al., 2016).

Family Integrated Care (FIC). While FCC sees the infant and family as central to communication and care in the NICU, the FIC model takes this concept even further by supporting parents to become primary caregivers within the hospital environment (Lissauer et al., 2020). FIC was developed as a Canadian initiative, in response to the current Canadian NICU environment (O'Brien et al., 2015). As a model of care, the four pillars of FIC are more directive than the principles of FCC and include staff training for communicating with families, parent education to promote care for their infant, a NICU environment that supports families' presence, and psychosocial support to reduce parental stress (Franck & O'Brien, 2019; Lissauer et al., 2020). Large-scale international research findings on the FIC model involving NICUs in Canada, Australia and New Zealand were published in 2018 (O'Brien et al., 2018). This involved an international cluster-randomized controlled trial involving 25 Level III NICUs, infants born at 33 weeks' gestation or earlier, and parents who committed to be present for at least six hours per day, attend education sessions, and actively care for their infant (O'Brien et al., 2018). FIC was found to be of benefit both to parents in decreasing stress and anxiety, and to infants in improving weight gain and breast feeding (O'Brien et al., 2018).

While this new FIC model looks promising, as with FCC, systemic change and support is still required to ensure its success. The research results are based on at least one caregiver being at the bedside of the infant at least six hours per day (O'Brien et al., 2018), which is very challenging for parents with other children to care for or with infants in NICUs that are still open-bay with no space provided for overnight stays (Altimer & Philips, 2013). As Frank & O'Brien (2019) state, "more needs to be done to support prolonged caregiver presence and engagement, which requires commitment and resources on the part of hospitals to make the FIC model "the new normal" in NICUs" (p. 1052).

Overview of NICU Music Therapy

Parallel to the development of FCC, NICU MT has been a growing field of specialization and research internationally since its early beginnings in the United States in the 1990's (Nöcker-Ribaupierre, 2015; Standley & Madsen, 1990). It can be defined as an advanced practice of music therapy, with specialized interventions and protocols,

training in premature infant development and care, and comprehension of the needs of families within the NICU environment (Standley, 2012). Since its inception, NICU MT research has produced an ever-growing knowledge base in this area, systematically showing the effects that music therapy can have on improving the health of NICU infants (Ettenberger et al., 2014; Loewy et al., 2013; Whipple, 2000), and more recently, showing the positive effects of music therapy on parents' mental health (Ettenberger et al., 2017; Haslbeck & Bassler, 2020; Loewy et al., 2021; Maclean et al., 2019).

Benefits of NICU Music Therapy

Early research established the benefits of music therapy in the NICU and set the stage for the development of crucial NICU MT interventions. Systematic reviews of research literature point to music therapy's beneficial effects on preterm infants' pacification and stabilization (Haslbeck, 2012; Standley, 2012), and physiologic parameters of heart rate, sleep quality and oral feeding (Anderson and Patel, 2018; van der Heijden et al., 2016). A meta-analysis of randomized control trials also showed the significant effects of music therapy interventions on maternal anxiety when live music therapy supported the mother during Kangaroo Care (Bieleninik et al., 2016). Research in this field has also led to the evolution of evidence-based approaches with specialized training for NICU MT.

NICU MT Approaches and Trainings

NICU MT is an advanced practice of music therapy, with specialized training taking place after certification as a music therapist is obtained (Haslbeck, 2015). The majority of NICU MT programs worldwide stem from three primary standardized approaches that were developed into advanced trainings specifically for the NICU music therapist (Ullsten et al., 2020). These include Neonatal Intensive Care Music Therapy (Standley, 2012), First Sounds: Rhythm, Breath, and Lullaby (Loewy et al., 2013), and Creative Music Therapy (Haslbeck, 2013).

Neonatal Intensive Care Music Therapy (NICU-MT) was created by Jayne Standley and her team at Florida State University in Tallahassee, Florida, USA (Standley & Gutierrez, 2020). This is an advanced, specialized training offered to music therapists who are board certified (or the equivalent from other countries) and aligns with a behavioral, neurodevelopmental, and medical model orientation (Standley & Gutierrez,

2020). NICU-MT teaches specific evidence-based protocols that include music-enhanced non-nutritive sucking to promote feeding using a Pacifier-Activated-Lullaby device (PAL) (Cevasco & Grant, 2005; Standley, 2003), Multimodal Neurological Enhancement (MNE) to support homeostasis and sensory integration (Standley, 1998; Walworth et al., 2012; Whipple, 2005), passive music listening (Standley, 2012), and live contingent singing and guitar to reduce pain and stress (Standley & Gutierrez, 2020).

First Sounds: Rhythm, Breath, and Lullaby (RBL) was created by music therapist Joanne Loewy and her team as a specialized NICU MT training program at the Beth Israel Medical Center, New York, USA (Haslbeck & Costes, 2011). RBL training aligns with a medical model, music psychotherapy orientation (Loewy, 2015). This training utilizes an ocean drum to mimic the intrauterine auditory environment of the preterm infant, and a Gato box to mimic the sounds of the mother's heartbeat to promote breathing entrainment (Loewy et al., 2013). Music therapists are also trained to work with an infant's 'song of kin', a song that is special to the family and incorporated into the music therapy interventions with that family (Loewy et al., 2013).

Creative Music Therapy (CMT*)* is a Nordic approach created by Friederike Haslbeck in Sweden in 2010 (Haslbeck, 2013). CMT emerged from influences of RBL and Nordoff-Robbins' philosophy of 'music as therapy', which recognizes the innate, human response to music regardless of age or condition (Haslbeck & Bassler, 2020; Nordoff & Robbins, 1977). CMT is an individualized, interactive, resource- and needs-oriented approach (Haslbeck and Bassler, 2018). This specialized training program at the Institut für Musiktherapie in Munich, Germany focuses on contingent singing in an infant-directed, improvised lullaby style, assessing and matching subtle cues from the infant to construct a musical vocal response, while sometimes accompanied by a monochord (stringed, open-tuned instrument) (Haslbeck & Bassler, 2020). This infant-directed singing is often implemented while a parent is in skin to skin contact or cuddling the infant, to foster parent-infant bonding and encourage parent participation (Haslbeck & Hugoson, 2017).

These international NICU MT approaches have influenced music therapists around the world with their research and training. Canada's proximity to the United

States makes accessing this training feasible for Canadian music therapists interested in this area of specialization.

NICU MT in Canada

Canadian NICU MT is a small but growing field. At the time of writing, there were 33 NICUs in Canada (Canadian Neonatal Network, 2021) and eight of these NICUs had NICU MT programs that were confirmed with this writer through personal correspondence with Canadian NICU music therapists (October 2021). All eight of these NICU music therapists, including this writer, have specialized, advanced-practice NICU MT training from RBL and/or NICU-MT, because NICU MT is recognized as advanced music therapy practice by all three approaches (Haslbeck, 2015; Loewy, 2015; Standley & Gutierrez, 2020). In the Canadian context, music therapists study an advanced practice after they have completed their full training and received certification (Canadian Association of Music Therapists, n.d.).

There are very few publications that centre Canadian NICU MT. A thorough search of the literature resulted in only 2 published articles about NICU MT by a Canadian music therapist, both by Amy Clements-Cortès. These articles describe an overview of the NICU MT field with recommendations for Canadian music therapists (Clements-Cortès, 2015), and the use of a Pacifier Activated Lullaby (PAL) device and how this may be applicable in Canadian NICU MT programs (Clements-Cortès, 2012). Preliminary qualitative descriptive research by a Canadian music therapist that focused specifically on the Canadian NICU context was documented in an unpublished thesis (Hastings, 2019). This research examined the practices and perspectives of 3 Canadian NICU music therapists, with recommendations to establish a Canadian NICU MT training program, to foster Canadian NICU MT research, and to create national NICU MT professional guidelines specifically for the Canadian healthcare context to ensure the highest levels of care (Hastings, 2019). Currently, there is very little literature connecting NICU MT to the Canadian healthcare context, and a clear lack of published literature connecting NICU music therapy to the advancement of FCC in the Canadian NICU context.

NICU MT and FCC

Since the inception of NICU MT as an area of specialization, it has followed the shifting NICU trends towards an FCC approach. This is indicated in current international NICU MT research and the evolving clinical approaches that claim to be 'family-centred' or aligned with FCC philosophies. While there has been some discussion as to the meaning of these claims, there has been limits on the extent of explicit alignment, which adds to the importance of this study.

The move towards FCC perspectives has been reflected in the shifting focus of music therapy research from infant health to also include the experience and wellness of parents. Cevasco (2008) conducted a mixed methods study that is an early example of this FCC shift in research from infant focus to an inclusion of the mother's experience. This research examined the effects of mothers' singing on their bonding and confidence with their infants within the first two weeks after birth (Cevasco, 2008). While this study did not produce significant results in maternal confidence or bonding, this early shift in focus to include parents was recognized as an important pivot point in MT research (Ettenberger, 2017). Since this study, there has been considerable research worldwide that provides evidence of music therapy's positive impacts on caregivers' mental health, as outlined in several systematic reviews and meta-analyses (Bieleninik, et al., 2016; Ding et al., 2019; Haslbeck, 2012; Standley, 2012).

In alignment with the shifting perspective of NICU research, clinical approaches, and the goals of NICU MT have also shifted from a patient-focused approach (Standley & Madsen, 1990) to a family-centred approach (Shoemark & Dearn, 2008). Shoemark and Dearn (2008) were the first to write about music therapy with hospitalized infants as 'family centred music therapy' in a discussion paper, using this pivotal article "to frame clinical practice in a way that is not yet represented in the literature" (p. 7). Through highlighting themes based on reflections on their work and interviews with families, they articulated the importance of building partnerships and therapeutic relationships with parents in the care of their fragile infants (Shoemark & Dearn, 2008). They concluded by calling on NICU music therapists to shift their approach to a full integration of family-centred interventions (Shoemark & Dearn, 2008). In a commentary on this article, Hanson Abromeit (2008) emphasized its significance by stating "this article contributes

to both the family centred care and music therapy literature through examination of the experience from the parents' perspective" (p. 25).

Since this pivotal work, there has been a shift in NICU MT approaches, CMT, RBL and NICU-MT, to position themselves in alignment with FCC or FIC in current research (Ettenberger et al., 2017; Haslbeck & Hugoson, 2017; Standley & Gutierrez, 2020). Haslbeck and Bassler (2020) have aligned with FIC in their clinical practice protocols for CMT, going so far as to define FIC and then emphatically state that

> music therapy in neonatal care is exactly that [FIC]: an early and promising intervention to stabilize and nurture the infant as well as to promote connectedness at a time when many other interventions are still at risk to overwhelm the fragile infant. (p.1)

While recent NICU MT literature clearly evidences a strong link with FCC (Ettenberger et al., 2017; Haslbeck & Bassler, 2020; Standley & Gutierrez, 2020), there has been very little explicit analysis of how music therapy approaches and interventions align with FCC in the NICU since Shoemark and Dearn's first examination in 2008. This important gap in analysis establishes the foundation for this research and a more comprehensive alignment in chapter four.

Conclusion

The principles of FCC have been prominent in NICU care globally since the 1990's, and research has demonstrated its value and efficacy through improved outcomes for patients and their families. However, systemic barriers to implementation, interpretation, and the unique needs of families have stood in the way of fully realizing this philosophy of care. As a response, models of care to help with specific implementation strategies have developed, including Kangaroo Care, NIPCAP, and FIC. However, many of the same systemic barriers also hamper full implementation of these models.

At the same time as the emergence of FCC, NICU MT was developed in recognition of the needs of NICU infants and their families. NICU MT has established a strong connection with FCC, as first identified by Shoemark and Dearn (2008), and it is also evident in the shifting focus of research at that time. While NICU MT approaches and research claim an FCC philosophy, a comprehensive analysis is needed to explicate

an alignment. Originating in the United States, NICU MT is practiced worldwide, with three primary research-based approaches and trainings that have emerged. These include RBL and NICU-MT in the United States and CMT in Europe. There is currently no Canadian-based training and very little written about the unique Canadian NICU context and how this might shape NICU MT programs across Canada. Using relevant literature and examples, chapter 4 will delve into NICU MT and the principles of FCC, and explicate how NICU MT is situated to realize and advance MT and FCC in the Canadian NICU.

Chapter 4. The Findings

This chapter addresses the second and third subsidiary questions of this inquiry to build an argument for NICU MT as uniquely situated to contribute to the advancement of FCC in the Canadian NICU context. To systematically align NICU MT with the principles of FCC, the four principles of FCC will first be explicated. Each principle will then be followed by an analysis of music therapy literature and its contribution to the realization and advancement of each principle through a synthesis of NICU MT approaches, interventions and research. Finally, a summary of the findings will set the stage for the culmination of ideas in the discussion of chapter five.

NICU MT and the principles of FCC

This section brings together the salient research from chapter three in a deeper analysis of the alignment of NICU MT and FCC. The aim is to synthesize and articulate the vital role music therapy can play in the realization and advancement of FCC. The four core FCC principles that will be explicated include (a) dignity and respect, (b) information sharing, (c) participation, and (d) collaboration.

FCC Principle of Dignity and Respect

This principle emphasizes the need for cultural safety in the provision of care through the development of trusting, non-judgemental relationships, and an awareness of the historical, political, social, and cultural contexts that impact infants and their families (Wright et al., 2020). The realization of FCC in the NICU begins with the recognition that each infant and their needs are unique, as are the families that surround them (IPFCC, n.d.). Recognizing their distinctiveness, FCC looks to caregivers to define what and whom is family (IPFCC, n.d.). Importantly, FCC respects the values, perspectives, culture, and choices of families, and it honours lived experience and a strengths-based approach (Frank & O'Brien, 2019; Gooding et al., 2011; Kuo et al., 2012).

Cultural safety and humility in Canadian healthcare is exemplified by the need to identify and close the gaps in health equity for indigenous, and other minoritized peoples at all levels of healthcare (McNally & Martin, 2017; Turpel-Lafond, 2020). While there are many minoritized peoples in Canada's multicultural society with infants in the NICU, due to the scope of this study and the significant focus in the literature, the barrier of systemic racism towards indigenous peoples on Turtle Island/ in Canada will be

emphasized. The Calls to Action outlined in the Truth and Reconciliation Commission of Canada (2015) explicitly call for a dismantling of racism and an examination of unconscious bias that perpetuates colonization in Canadian health care. They call for healthcare professionals and the system to value indigenous perspectives and knowledge. Wright et al. (2020) explored, in a qualitative study, the experiences of indigenous mothers in a Canadian NICU and found that, "Mothers believed that a holistic approach to the care of their infant, including meeting emotional and spiritual needs, was necessary to promote their infants' future health and wellness" (p. 7). While FCC aims to support the advancement of health equity, a lack of cultural safety and humility in Canadian NICUs has been documented, especially for indigenous families (Turpel-Lafond, 2020; Wright et al.,2020).

NICU MT and the FCC Principle of Dignity and Respect

Music therapy is strongly situated to support, and even lead, in efforts to establish dignified, respectful, relevant and culturally safe care. Through relevant music and approaches, MT assesses and flexibly responds to each family's unique culture and needs. NICU MT is dynamically positioned to provide benefits for both the infant and the caregiver, with an emphasis on building a non-judgemental, therapeutic relationship with the family (Shoemark & Dearn, 2016).

NICU MT aligns with the principle of dignity and respect by viewing the infant not only as a patient but as a child at the centre of a unique family system (Haslbeck & Bassler, 2020; Ullsten et al., 2020). For example, to promote the centrality of the family, if parents have to be away from their infants NICU-MTs record the parent singing and speaking to the infant in their preferred language, and these recordings can be played by staff in the parent's absence (Standley & Gutierrez, 2020). This intervention empowers parents to offer comfort and personal care, and it acknowledges their irreplaceable, central role in the care of their infant (Cevasco, 2008).

NICU MT assessment processes aim to recognize the individual needs and contexts of each family and to incorporate their choices of favourite musical styles and/ or lullabies into MT sessions (Haslbeck & Bassler, 2020; Loewy, 2015; Loewy et al., 2013). Lullaby singing has many features that are recognized across cultures and languages. These include a slower tempo, simple and repetitive rhythm and melody, soft,

breathy vocal timbre, and accompaniment of gentle synchronized movements or rocking (Haslbeck & Hugoson, 2017). In RBL familial musical preferences, a concept termed "song of kin" by Loewy et al. (2013), the music therapist honours a family's culture, community or musical history and gives personal meaning to the music shared with their infant. This music in a preferred language can be sung live or sourced from recordings which empowers parents to bond with their infant and expand their culture into the sound environment of the NICU (Kehl et al., 2021; Shoemark & Dearn, 2008). In these ways, music therapy can be an important contributor to raising awareness of and creating a safe space for culture within the NICU context.

In addition to the integration of culturally relevant music, creating a culturally safe music therapy practice for NICU families necessitates ongoing self-awareness of unconscious biases, unexamined assumptions, and the potential power imbalances that exist between families and healthcare practitioners (Hutchings, 2021; Wright, 2020). There is an urgent need, as Hadley and Norris (2016) have identified, for transformational learning. They state, "this process of working toward multicultural awareness, unlike the concept of achieving competencies, is ongoing and requires continual commitment and vigilance" on the part of music therapists (p. 129). To respond to this need for culturally relevant practice and cultural humility, NICU music therapy builds on flexibility, awareness, and ongoing adaptability to offer unique support for infants and families (Haslbeck & Bassler, 2020). Live music is most often utilized by all three of the NICU MT approaches due to its cultural sensitivity and engagement with both infants and caregivers (Ettenberger et al., 2017; Haslbeck, 2012; Loewy, 2015; Standley & Gutierrez, 2020). Roa and Ettenberger (2018) best exemplified cultural responsiveness and adaptability in a clinical pilot intervention when they utilized live music in a group music therapy context to support parental mental health. The music therapists (Roa & Ettenberger) chose this flexible, interactive approach because it best responded to the needs, culture, and mood expressed in the moment by group participants. "Furthermore," stated Roa and Ettenberger (2018), "considering the 'collective' nature of Colombian society, the active and interactive participation of parents was considered to be more culturally appropriate" (p. 7). This research resulted in improved levels of parental stress and anxiety.

By utilizing interventions that recognize and responsively support a family's unique culture and individuality, NICU MT advances dignity and respect in the face of systemic barriers that would impede this principle. This calls on NICU music therapists to cultivate ongoing self-awareness and exploration of unconscious biases and power differentials. Early interventions that assess and respond creatively to incorporate a family's values and needs, both within family and group contexts, exemplify NICU MT's vital role in advancing FCC. Dignity and respect are essential components of the first FCC principle, and they are also critical to the establishment of clear communication lines for information sharing.

FCC Principle of Information Sharing

The need for sharing information is based on the inclusion of families as primary caregivers to their infant. As identified in chapter three, an imbalance of power exists when care providers are seen only as the experts who control the information and control the flow of information in only one direction, rather than reciprocally.

In line with respecting family strengths and communication styles, preferences for how to communicate information, how much to communicate and how often, are indicated by the family (IPFCC, n.d.). In FCC, families are a central part of the healthcare team and as such, receive complete and unbiased information regularly (IPFCC, n.d.). When healthcare practitioners integrate cultural sensitivity into this FCC principle, there is a recognition and respect for different forms of knowledge (Wright et al., 2020). This creates a reciprocal exchange of knowledge between the family and healthcare practitioners, with support offered to help integrate the information received (Hellmann, 2014).

NICU MT and the FCC Principle of Information Sharing

In the exchange of different forms of knowledge, a vital reciprocal dialogue takes place in music therapy which decreases the power imbalance inherent in the medical model structure. Through verbal and nonverbal interventions, music therapy increases a family's capacity to receive and share information, and confidently utilize resources that promote bonding.

Rich cultural knowledge, values and personal history can be gleaned through therapeutic sharing of a family's values, musical interests, and song of kin (Loewy et al.,

2013). This also creates uniquely flexible opportunities to respond to information shared, making sessions much more personalized when a family's culture and choices are reflected back to them (Ullsten et al., 2020). In a group music therapy setting such as a parental relaxation group, as previously identified in the clinical pilot intervention researched by Roa and Ettenberger (2018), families share information and make much needed connections with their peers, allowing "parents to share not only their current struggles and difficulties, but also ways to cope with them." (Roa & Ettenberger, 2018, p.7).

NICU MT creates a crucial exchange of knowledge that is experiential and reciprocal through both nonverbal and verbal modalities, in both music and conversation (Haslbeck & Hugoson, 2017; Malloch et al., 2012; Shoemark et al., 2015). CMT utilizes modelling, explanation, and sensitive coaching to help parents gain an understanding of their infant's emotional needs and of how contingent singing and talking can be used to support development and bonding (Haslbeck & Hugoson, 2017; Malloch et al., 2012; Shoemark et al., 2015). Once parents gain confidence in singing to their infant and understanding the cues and responses for overstimulation, parents will often reciprocally share their experiences and observations with the music therapist and other staff, thereby increasing the team's understanding of their infant (Haslbeck & Hugoson, 2017). In this way, NICU MT facilitates vital connections for families and staff, ensures the centrality of parents in the care of their infant, and circumvents the barrier of one-way flow of information.

Music therapy supports the vital information sharing necessary for FCC in ways that extend beyond the sessions which supports a parent's empowerment and access. Shoemark and Dearn (2016) recommend providing resources for families that can be used and accessed in their own time to support musical interactions with their infant, such as printed lyrics, recordings of compositions, baby books, and guidelines for volume, timing and duration of recorded music.

Having an infant in the NICU sometimes gives rise to difficult conversations that require challenging decisions for families and ongoing processing of new information (Loewy et al. 2021). NICU MT provides essential and unique support for families throughout ongoing information sharing. It provides a safe musical space for emotional

and nonverbal processing, a chance to discuss the information intermittently, or a way to refocus on positive bonding moments with their infant (Haslbeck & Hugoson, 2017).

The reciprocal approach of NICU MT ensures information sharing is respectful and supportive. This vital exchange of knowledge and information creates a framework for families to confidently participate in their infant's care and their own wellness.

FCC Principle of Participation

As partners in providing care for their hospitalized infant, families require support to participate in care and decision-making to their fullest capacity and as early as possible in the process (IPFCC, n.d.; Gooding et al., 2011). Faced with the challenges of having an infant in the NICU, caregivers often require emotional and mental health supports to decrease stress and anxiety and build confidence in their ability to be present and to provide care for their baby (Frank & O'Brien, 2019; Serlachius et al., 2018).

FCC recommends creating an environment of light, sound, touch and space that is supportive of parents' participation in their infant's care (Altimer & Philips, 2013). A physical space where at least one caregiver feels they can stay with the infant at all times is ideal because this has been shown to increase confidence and bonding (Raiskila et al., 2017).

NICU MT and the FCC Principle of Participation

NICU MT is strongly situated to provide early opportunities for families to participate in the care of their fragile infant. Importantly, research shows it can improve outcomes for both parents and infants in ways that could not be realized without music therapy (Bieleninik et al., 2016). NICU MT provides familial support that is inclusive of extended family and siblings, and can facilitate much needed engagement as a family. Subsequently, it can also ameliorate the often harsh and overwhelming NICU sound environment that creates barriers to care. Finally, NICU MT provides vital supports during challenging times to build the confidence and resilience necessary for a successful transition to home.

NICU MT research, in alignment with FCC, has expanded from an infant focus to a focus on integrating families into the therapeutic process by providing vital emotional, social and developmental support (Bieleninik et al., 2016; Haslbeck, 2012; Standley, 2012). Shoemark and Dearn (2008) introduced the importance of supporting parents

when they stated, "the music therapist has the opportunity to ensure that the potency of the relationship with parents is not an incidental by-product of service to their infant, but a pivotal service to the parents themselves" (p. 20). NICU MT interventions, integrating parental-preferred lullabies into the live music therapy process, have been shown to enhance bonding between parent and infant and decrease parental stress and anxiety (Ettenberger et al., 2017; Ettenberger et al., 2021; Loewy et al., 2013; Mondanaro et al., 2016).

NICU MT is an early intervention that starts with stable premature infants as early as 28 weeks gestational age, offering a safe intervention because of its sensitivity to infant responses and specific protocols to integrate stimulation (Standley & Walworth, 2010). At a time when parents may be feeling distress, trauma, separation, and helplessness related to being unable to care for their infant (Yaman & Altay, 2015), these interventions support a sense of identity and empowerment of parents through early musical engagements (Ettenberger et al., 2017; Maclean et al., 2019).

Every NICU MT approach highlights the importance of using voice and song to support parental participation, with live singing as the most accessible and readily available intervention (Haslbeck, 2013; Loewy et al., 2013; Standley & Gutierrez, 2020). CMT utilizes improvised, communicative infant-directed singing to support infants and empower parents to actively participate (Haslbeck & Bassler, 2020). Lullaby singing is an integral part of the NICU-MT developmental multimodal stimulation protocol in which parents participate according to their comfort level, including holding the infant, learning sequential movements, singing with pacing and volume, and most importantly learning to understand their infant's cues in response to the stimuli (Walworth et al., 2012). With a similar premise, a central practice in RBL teaches parents to tune to or 'entrain' to the varying states of their infant and use parent-selected music or songs of kin to promote bonding and regulation (Loewy et al., 2013; Ettenberger et al., 2017).

Kangaroo Care (KC) and Skin to Skin Care (SSC) are both highly effective FCC interventions that have been shown to improve both infant and parental outcomes (Frank & O'Brien, 2019; IPFCC, n.d.). Several studies that examined KC combined with NICU MT live singing, as compared with KC alone showed significantly reduced maternal anxiety, improved infant physiological parameters, and self-reported parental well-being

and bonding for the KC and MT groups (Bieleninik et al. 2016; Ettenberger et al., 2017; Kostilainen, 2020; Teckenberg-Jansson et al. 2011). This shows a clear advancement of FCC principles in ways that could not be realized without NICU MT.

NICU MT is a crucial resource to advance the realization of the FCC principle of participation, especially when working to improve the auditory environment of the NICU (Kehl et al., 2021). NICU MT is uniquely adaptable and can be effective in both open bay NICUs and single-family rooms as an intervention to support a family's engagement with their infant (Loewy, 2015; Shoemark & Dearn, 2016). A mixed-methods pilot study by Kehl et al. (2021) that evaluated the effects of CMT on the mental health of parents and the bonding process with their infants revealed a quantitative reduction in parental anxiety and depression, and significant increases in attachment. The qualitative inquiry showed parents' increased participation and bonding with their infant, often through a shift in the auditory environment: "the parents mentioned that the music facilitated a protective and enveloping space for them and their infants and allowed them to fade out the alarms' beeping and the restless hospital atmosphere for a moment" (Kehl et al., 2021, p. 12).

It is also in these musical moments that positive hospital memories can be created. In the NICU where many experiences can be stressful, it is essential for parents to participate in beautiful, bonding moments that create positive memories of this time with their infant, and help reduce future trauma (Loewy et al., 2021). Essentially, as Shoemark and Dearn (2008) so clearly describe:

> In the long and often frustrating journey towards discharge, the music therapist is one of a handful of people who builds a collection of joyful experiences for infants and their parents. They repeatedly return to the family to keep the possibility and potential of these experiences available. (p. 12)

These memory-building moments of connection can be even more essential when an infant's chances of survival are uncertain because they build resilience in the family and create a safe space for both joy and grief (Haslbeck & Bassler, 2020; Loewy et al., 2021).

NICU MT can also help prepare families for what life may be like when they return to the home environment with their infant (Kehl et al., 2021); another important aspect of improving outcomes for families through FCC (Frank & O'Brien, 2019;

Gooding et al., 2011). Providing MT resources that parents can confidently use both in the NICU and later at home can be part of this preparation because it builds agency in families to use music in their home space, to feel confident comforting and engaging their infant, and to incorporate familiar songs that are inclusive of siblings (Shoemark & Dearn, 2016; Standley & Gutierrez, 2020).

Analysing the literature through the lens of the principle of participation revealed NICU MT's flexibility and inclusivity to safely support a family's participation to their fullest capacity. NICU MT has the unique capacity to support families throughout NICU stays, in varied environments, as an early intervention from 28 weeks gestational age all the way through to the transition home. This support is particularly needed to encourage connection and create meaningful family memories during challenging and sometimes life-limiting times. Finally, it is argued here that NICU MT not only realizes but advances FCC principles as demonstrated in multiple studies showing that KC and SSC have significantly greater results for both infants and parents when combined with NICU MT (Bieleninik et al. 2016; Ettenberger et al., 2017; Kostilainen, 2020; Teckenberg-Jansson et al. 2011).

FCC Principle of Collaboration

In FCC, collaboration occurs when healthcare practitioners and families work in partnership to develop and implement programs at all levels of care to meet the needs of patients and families (IPFCC, n.d.; Kuo et al., 2012). These collaborations value the unique and diverse perspectives of families' lived experiences, and they honour and implement family choices while educating parents to care for their infant (Frank & O'Brien, 2019). This principle also highlights the need to strengthen connections within families to build resilience, and to commit to collaborations among care providers to ensure clear communication of care (Hellmann, 2014).

NICU MT and the FCC Principle of Collaboration

NICU MT is collaborative and inclusive by its very nature because music can be easily shared with multiple people at a time and is often co-created with those participating (Ettenberger, 2017). This section examines how parents, siblings and extended family, the music therapist, and clinical staff collaborate to create improved, family-centred outcomes for infants and their families.

Shoemark and Dearn (2016) highlight the pivotal role of music therapists as partners or collaborators with parents who are working to understand and to know their infant. Live singing is the most accessible and readily available intervention utilized by the music therapist to intentionally include parents, siblings, extended family, and staff in addition to the infant (Haslbeck& Hugoson, 2017; Shoemark & Dearn, 2016; Standley & Gutierrez, 2020). This can occur in single family rooms or in an open bay NICU, whether present in the space with the infant or even virtually to create a shared, interactive experience (Duff et al., 2021). While most NICU MT is with individual infants and their families, music therapists can also collaborate with multiple families to create groups that meet specific needs such as parental self-care (Roa & Ettenberger, 2018) or infant development (Standley & Gutierrez, 2020). This collaboration supports connections within families, connections between parents, as well as supports the parent's ability to observe other NICU infants (Ettenberger et al., 2017). In addition, collaboration ensures the flexibility that is necessary to respond to the needs of the group that arise in the moment (Ettenberger et al., 2017; Negrete, 2020).

To support families, NICU interdisciplinary teams need clear communication and collaboration (Brødsgaard et al., 2019; Gooding et al., 2011). NICU MT has the opportunity to be visible and to model collaboration with families, often building a bridge of connection between care providers and the families through music therapy interventions that can incorporate staff participation (Haslbeck & Hugoson, 2017).

The physical environment of the NICU becomes collaborative when it honours the diversity and uniqueness of each family (Loewy et al., 2021). For example, when families choose the music or style of songs that become part of sessions, or recorded music that they play in between sessions, this can completely shift the way staff respond when they enter the room, immediately affected by the sound (Loewy et al., 2021). This creates an opportunity for healthcare staff to know the family better through a personalized environment that reflects a glimpse of who they are outside of the hospital. Environmental Music Therapy (EMT) is an approach that attends to the expression of the family within the NICU environment and utilizes collaboration to create a welcoming space (Loewy et al., 2021; Rossetti, 2020).

A key component of collaboration in FCC includes parental education (Frank & O'Brien, 2019) which is also recognized as a key intervention in the NICU-MT approach (Standley & Gutierrez, 2020). Conversely, CMT takes a different stance, identifying NICU music therapy as "collaboration rather than intervention" (Haslbeck & Bassler, 2020, p. 7). Haslbeck and Bassler (2020) argue that the aim of NICU MT is to "enable intuitive parental roles to emerge through interactions with their infants more than to explicitly teach new skills" (p.7). Similarly, they go on to indicate that "the music therapist should act as a facilitator and collaborator, rather than as an educator or expert" (Haslbeck & Bassler, 2020, p. 8). This differentiation in CMT addresses the barrier of NICU staff as experts or gate keepers and creates a compelling argument for the elucidation and advancement of music therapy collaboration with families that may not be easily realized otherwise in the NICU context.

Ultimately, the flexibility and applicability of music therapy creates inclusivity for collaboration, where families can be empowered to affect their environment, gain confidence in their parenting role, and collaborate on an equal footing with staff and other families.

NICU MT in the Advancement of FCC

The previous analysis of NICU MT literature and its alignment with the four FCC principles strongly situates NICU MT as a vital resource to realize and advance FCC in ways that offer unique and important strategies to circumvent systemic and local healthcare barriers. An analysis of the literature through the first FCC principle of *Dignity and Respect* revealed NICU MT's strong support of cultural safety and humility by assessing the unique needs of families and providing opportunities for choice, control, and flexibility through interventions such as Song of Kin (Loewy et al., 2013).

Evidence indicates that music therapy has an important capacity to support and enhance *Information Sharing,* principle two, through the creative facilitation of reciprocal communication using both verbal and musical strategies. This exchange of knowledge and understanding can be easily accessible through culture and interventions such as contingent singing (Haslbeck & Hugoson, 2017). NICU MT is essential to FCC in providing emotional support to families surrounding difficult decisions and processing of information in ways that are unique to music therapy.

The third principle, *Participation*, clearly exemplifies NICU MT's advancement of FCC through improved infant outcomes (Bieleninik et al., 2016; Haslbeck, 2012) and decreased parental anxiety and stress (Bieleninik et al., 2016; Ettenberger et al., 2017; Kehl et al., 2021). NICU MT is, importantly, a safe, early intervention for stable infants as early as 28 weeks' gestational age, at a time when many other non-medical interventions are unavailable (Standley & Walworth, 2010). Most critical to the advancement of FCC is participation in a combination of NICU MT and KC, as compared to KC alone, which research has consistently shown amplifies the positive physiological effects for infants and reduces anxiety and improves the well-being of parents (Bieleninik et al., 2016; Ettenberger et al., 2017; Kostilainen, 2020; Teckenberg-Jansson et al. 2011). This clearly demonstrates an advancement of FCC that is tied to the inclusion of NICU MT.

Finally, the fourth principle, *Collaboration*, highlights one of NICU MT's most valuable contributions, the inherent flexibility and accessibility that is the very essence of music. While providing education and instruction is a valuable component of FCC, Haslbeck and Bassler (2020) make a strong case for going beyond this to utilize NICU MT as a vital modelling and coaching resource for parents who want to foster their own intuitive connection with their infant and not simply rely on being educated by 'experts'. Collaboration can be structured or improvised, available individually or in groups, and this fosters critical connections with the healthcare team, connections within families, and importantly, connections with other families experiencing similar stressors.

NICU MT's evidenced capacity for innovation, problem-solving, and adaptability has never been more obvious or necessary than during the additional strain experienced by families with infants in the NICU during the COVID-19 pandemic. Negrete (2020) provides a compelling illustration of how music therapy provided key support for the realization of FCC in restricted pandemic conditions, through her work as a NICU music therapist at a San Francisco pediatric hospital. Similar to Canada, in the United States NICU family presence was restricted to one caregiver at a time at the bedside. Furthermore, neither siblings nor extended family were permitted to visit, and all groups were canceled. In response to the challenges of increased isolation and anxiety, Negrete created a virtual group to meet the developmental and social needs of infants and

families. She collaborated with families to develop the group format and timing. The group provided opportunities for parent-infant bonding, parent to parent information sharing and support, and connections with other family members. As an unexpected result, more infants and parents than usual were attended the online group, as there was a strong need for social support and families could connect while still staying in their rooms. A virtual class allowed additional family members to participate or observe the class, creating a feeling of connection to an infant they may never have met due to restrictions. Without having to wear masks online, parents were more easily able to connect and maintain these connections outside of the group and infants were able to respond to a variety of faces and expressions (Negrete, 2020).

This exemplifies NICU MT's ability to adapt and respond in innovative ways to consistently support the health of patients, build resilience in families, and creatively collaborate with staff during the COVID-19 pandemic, providing essential FCC to support families when the healthcare system was clearly unable to do so. Music therapy's innovative interventions and approaches as examined in over thirty years of research have the capacity to not only realize FCC but also to advance it, even in the face of change and challenge.

Conclusion

Examination and synthesis of NICU MT literature as it aligns with FCC has revealed a realization and advancement of these principles in ways that are unique to this field. Chapter five of this thesis will provide a discussion of these findings and revisit the primary and subsidiary research questions that guided this philosophical inquiry.

Chapter 5. Discussion

This chapter provides a synthesis of the information analyzed during this philosophical inquiry. The intent is to strengthen key concepts and make important connections while articulating implications for Canadian NICU MT and FCC. It will also identify the limitations of this research.

The purpose of this philosophical inquiry was to determine and articulate the barriers to FCC implementation in the Canadian NICU context, to connect NICU MT clearly to the stated principles of FCC, and finally, to situate music therapy as a unique and important contributor to the advancement of FCC principles within the Canadian NICU context. The primary question this inquiry sought to answer was: how is NICU MT uniquely situated to contribute to the advancement of FCC in the Canadian NICU? This primary question was broken down into three subsidiary questions: 1) What systemic barriers impede the implementation of FCC in the NICU? 2) How is NICU MT aligned with the principles of FCC? and 3) How does NICU MT contribute to the advancement of FCC principles within the Canadian NICU context?

NICU MT has a knowledge base comprised of over 30 years of specialized research which has supported the establishment of music therapy-based approaches, trainings, and improved outcomes for infants and families worldwide (Haslbeck 2013; Loewy et al., 2013; Standley, 2012). Developed over a similar timeline as FCC, NICU MT also has its origins in the United States. However, it has expanded with the development of three primary approaches to research and practice and their affiliated trainings. These three approaches were utilized in great part in the findings of this philosophical inquiry to support data analysis and to make a case for the realization of FCC in the NICU. To address the subsidiary questions this philosophical inquiry explored and articulated barriers to care and some of the key systemic responses that supported the development of care models to further the implementation of FCC principles. These care models, however, are also hampered by similar systemic barriers to FCC (Frank & O'Brien, 2018). In response to subsidiary questions two and three, NICU MT was examined through the lens of FCC and examples were provided throughout to demonstrate the deep connection NICU MT has to the principles of FCC, the effectiveness of music therapy's interventions, and how these principles are not only fully

realized but, in some cases, such as the combination of NICU MT and KC, advanced beyond where they would be without music therapy. Mclean et al. (2019) summed up the need for music therapy: "creating situations in which parents can continue to nurture and care for their baby is paramount to the infant's development and the caregivers' emotional well-being" (p. 78), and this is exactly what music therapy has the capacity to do. There is much potential for further integration of FCC in the NICU hospital environment through NICU MT's flexible, innovative approaches and solid base of ongoing, specialized research.

Implications for Canadian NICU MT

Canada has a unique healthcare landscape, with a public healthcare system that resembles a European context. New approaches and research have been expanding in the Nordic countries out of need for a culture-centred approach for Nordic NICU MT (Haslbeck, 2013; Ullsten et al., 2018). While Canadian NICU music therapists primarily have training in either RBL, NICU-MT, or both, these American approaches do not always fit the cultural and healthcare contexts necessary to meet the needs of Canadian families (Ullsten et al., 2018). While Canada has greater access to free essential healthcare, Canadian families also face systemic barriers as discussed in chapter three. FCC's first principle of *Dignity and Respect* calls for provision of cultural safety and humility, recognizing the individuality and unique needs of each family. As the Canadian context highlights and the COVID-19 pandemic has made glaringly evident, NICU music therapists need to examine themselves and their practice to ensure they do not contribute to the maintenance and perpetuation of power inequities inherent in the Canadian healthcare system. Similarly, they must work to recognize the uniqueness and diversity of all NICU families. Canadian NICU music therapists are strongly positioned to contribute to the advancement of FCC when they support cultural exchange, respect and honouring of NICU families.

While not specifically noted in the literature, the clinical experience of this researcher has demonstrated that music therapy advances *Collaboration* in ways that bring NICU staff and parents to a level of equality by revealing cultural expression, values, and strengths previously unrecognized, such as a family's spirituality or a nurse's creativity. This collaborative team approach can be engaged, for example, during

procedural support where the intervention of lullaby singing (directly connected to a family's preferred musical culture) includes a parent cuddling and soothing the infant, the music therapist as facilitator, and a bedside nurse, respiratory therapist and doctor completing the procedure, all singing and working together to reduce the pain and distress of the infant.

Canadian music therapists need to consider and write about their unique role in the NICU, how this practice is shaped by the Canadian healthcare landscape, and how the field of music therapy is uniquely situated to contribute to the advancement of FCC. Through an examination of international NICU MT research in alignment with FCC, this inquiry highlights the need to generate evidence that supports and recognizes music therapists as leaders in the advancement of FCC.

Limitations

While this research has important implications, there are some key limitations that must be acknowledged. This research is limited by the scope and time frame of a master's thesis. It is also important to recognize that the author has completed the NICU-MT training but does not have formal training in the other NICU MT approaches (RBL and CMT) centred in this research. Finally, while this research has focused on relevant literature that centres the voice of families, it is essential to recognize the limitation of writing about FCC without including direct collaboration with NICU families, laying the groundwork for future research.

Implications for Future Research and Practice

Any research focused on the family experience must respect culture and diversity and should be designed in collaboration with families. Although NICU MT is an expanding field in Canada, there is very little research that explores NICU MT in the unique Canadian healthcare context. Recommendations for foundational research include the exploration of the Canadian NICU MT identity and an examination of the practices of Canadian NICU music therapists. This could be realized through a formalization of a Canadian NICU MT network to foster academic writing and collaborative cross-Canada research. Future research may lead to the development of a Canadian NICU MT approach based on the Canadian healthcare landscape and a uniquely Canadian music therapy response.

Canada's unique health care system, in combination with the burgeoning NICU MT field worldwide, sets the stage for new and innovative models of care that are truly family centred. Accordingly, this research suggests that all neonatal intensive care units should be utilizing music therapy as a vital resource in the realization and advancement of FCC to create improved outcomes for patients and families.

References

Adams-Chapman, I., Bann, C., Carter, S., & Stoll, B. (2015). Language outcomes among ELBW infants in early childhood. *Early Human Development*, *91*, 373–379.

Aigen, K. (2005a). Philosophical inquiry. In B. L. Wheeler (Ed.), *Music therapy research* (2nd ed., pp. 526-539). Barcelona Publishers.

Aigen, K. (2005b). Writing the qualitative research report. In B. L. Wheeler (Ed.), *Music therapy research* (2nd ed., pp. 210-225). Barcelona Publishers.

Altimier, L., & Phillips, R. M. (2013). The neonatal integrative developmental care model: Seven neuroprotective core measures for family-centered developmental care. *Newborn and Infant Nursing Reviews, 13*(1), 9–22. https://doi.org/10.1053/j.nainr.2012

Bainter, J., Fry, M., Miller, B., Miller, T., Nyberg, A., O'Dell, A., Shaffer, G., & Vernon, L. (2020). Family presence in the NICU: Constraints and opportunities in the COVID-19 era. *Pediatric Nursing, 46*(5), 256-259.

BC Women's Hospital & Health Centre (2022). *Neonatal intensive care*. http://www.bcwomens.ca/our-services/neonatal-care/neonatal-intensive-care

Bieleninik, Ł., Ghetti, C., Gold, C. (2016). Music therapy for preterm infants and their parents: A meta-analysis. *Pediatrics 138*, e20160971. https://doi.org/10.1542/peds.2016-0971

Brødsgaard, A., Pedersen, J. T., Larsen, P., & Weis, J. (2019). Parents' and nurses' experiences of partnership in neonatal intensive care units: A qualitative review and meta-synthesis. *Journal of Clinical Nursing, 28*(17–18), 3117–3139. https://doi.org/10.1111/jocn.14920

Cristóbal Cañadas, D., Bonillo Perales, A., Galera Martínez, R., Casado-Belmonte, M., Parrón Carreño, T. (2022). Effects of Kangaroo Mother Care in the NICU on the physiological stress parameters of premature infants: A meta-analysis of RCTs. *International Journal of Environmental Research and Public Health*,*19*(1), 1-12. https://doi.org/10.3390/ijerph19010583

Canadian Association of Music Therapists (n.d.). *MTA credentials and members*. https://www.musictherapy.ca/about-camt-music-therapy/mta-credentials-members/

Canadian Neonatal Network (2021). *The Canadian neonatal network annual report 2020*. https://www.canadianneonatalnetwork.org/portal/Portals/0/2020%20CNN%20report_Oct%201%20Final.pdf

Cho, E., Kim, S., Kwon, M., Cho, H., Kim, E. H., Jun, E. M., & Lee, S. (2016). The effects of kangaroo care in the neonatal intensive care unit on the physiological functions of preterm infants, maternal–infant attachment, and maternal stress. *Journal of Pediatric Nursing, 31*(4), 430–438. https://doi.org/10.1016/j.pedn.2016.02.007

Chorna, O., Slaughter, J., Wang, L., Stark, A., Maitre, N. (2014). A pacifier-activated music player with mother's voice improves oral feeding in preterm infants. *Pediatrics 133*(3), 462–468. https://doi.org/10.1542/peds.2013-2547

Clements-Cortès, A. (2012). The pacifier activated lullaby device. *Canadian Music Educator / Musicien Educateur au Canada*, *54*(2), 55-57.

Clements-Cortès, A. (2015). Music therapy with premature infants in the NICU. *Canadian Music Educator*, *56*(3), 31-32.

Craig, J., Glick, C., Phillips, R., Hall, S., Smith, J., & Browne, J. (2015). Recommendations for involving the family in developmental care of the NICU baby. *Journal of Perinatology, 35*(S1), S5–S8. https://doi.org/10.1038/jp.2015.142

Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). SAGE Publications.

Critical Care Services Ontario (n.d.). *Neonatal intensive care*. https://criticalcareontario.ca/about/neonatal-intensive-care/

Ding, X., Zhu, L., Zhang, R., Wang, L., Wang, T., & Latour, J. (2019). Effects of family-centred care interventions on preterm infants and parents in neonatal intensive care units: A systematic review and meta-analysis of randomised controlled trials. *Australian Critical Care, 32*(1), 63–75. https://doi.org/10.1016/j.aucc.2018.10.007

Dokken, D. L., Johnson, B. H., President, I., & Markwell, H. J. (2021). *Family presence during a pandemic: Guidance for decision-making*. Institute for Patient- and

Family-Centered Care. https://www.ipfcc.org/bestpractices/covid-19/IPFCC_Family_Presence.pdf

Duff, J., Curnen, K., Reed, A., & Kranz, C. (2021). Engaging parents of hospitalized neonates during a pandemic. *Journal of Neonatal Nursing, 27*(3), 185–187. https://doi.org/10.1016/j.jnn.2020.11.013

Edwards, H., Phillips, C., Esterman, A., Buisman-Pijlman, F., & Gordon, A. (2017). Risk factors and assessment tools for mother-infant bonding: a scoping review to assist future research. *Evidence Based Midwifery, 4,* 128.

Ettenberger, M. (2017). Music therapy in the neonatal intensive care unit: Putting the families at the center of care. *British Journal of Music Therapy, 31*(1), 12–17. https://doi.org/10.1177/1359457516685881

Ettenberger, M., Bieleninik, Ł., Epstein, S., & Elefant, C. (2021). Defining attachment and bonding: Overlaps, differences and implications for music therapy clinical practice and research in the neonatal intensive care unit (NICU). *International Journal of Environmental Research and Public Health, 18*(4), 1733. https://doi.org/10.3390/ijerph18041733

Ettenberger, M., Odell-Miller, H., Rojas Cárdenas, C., & Parker, M. (2017). Family-centred music therapy with preterm infants and their parents in the Neonatal Intensive Care Unit (NICU) in Colombia: A mixed-methods study. *Nordic Journal of Music Therapy, 26*(3), 207–234. https://doi.org/10.1080/08098131.2016.1205650

Fancott, C., Yonadam, A., Checkley, J., Drury, J., Hahn-Goldberg, S., Warren, H., Biggs, A., & Judd, M. (2021). Advancing family presence policies and practices in the Canadian health and care context: COVID-19 and beyond. *Healthcare Quarterly, 24*(1), 14–21. https://doi.org/10.12927/hcq.2021.26470

Franck, L., & O'Brien, K. (2019). The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. *Birth Defects Research, 111*(15), 1044–1059. https://doi.org/10.1002/bdr2.1521 C

Feeley, N., Gottlieb, L., & Zelkowitz, P. (2007). Mothers and fathers of very low-birthweight infants: Similarities and differences in the first year after birth.

Journal of Obstetric, Gynecologic, & Neonatal Nursing, 36(6), 558–567. https://doi.org/10.1111/j.1552-6909.2007.00186.x

Gooding, J., Cooper, L., Blaine, A., Franck, L., Howse, J. & Berns, S. (2011). Family support and family-centered care in the neonatal intensive care unit: Origins, advances, impact. *Seminars in perinatology, 35*(1), 20–28. https://doi.org/10.1053/j.semperi.2010.10.004

Government of Canada (2019, September 17). *Canada's health care system.* https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/health-care-system/canada.html

Hadley, S., & Norris, M. (2016). Musical multicultural competency in music therapy: The first step. *Music Therapy Perspectives, 34*(2), 129–137. https://doi.org/10.1093/mtp/miv045

Hanson-Abromeit, D. (2008). Family centred music therapy: A commentary on Shoemark and Dearn's 2008 article. *Australian Journal of Music Therapy, 19*, 25–26.

Harrison, H. (1993). The principles for family-centered neonatal care. *Pediatrics*, *92*(5), 643–650.

Haslbeck, F. (2012). Music therapy for premature infants and their parents: An integrative review. *Nordic Journal of Music Therapy, 21*(3), 203-226. https://doi.org/10.1080/08098131.2011.648653

Haslbeck, F. B. (2013). The interactive potential of creative music therapy with premature infants and their parents: A qualitative analysis. *Nordic Journal of Music Therapy, 23*(1), 36–70. https://doi.org/10.1080/08098131.2013.790918

Haslbeck, F. (2015). Empowerment and empowering self: Using creative music therapy to reconnect premature infants and their mothers. In C. Dileo (Ed.), *Advanced practice in medical music therapy: Case reports* (pp. 20–32). Jeffrey Books.

Haslbeck, F. B., & Bassler, D. (2020). Clinical practice protocol of Creative Music Therapy for preterm infants and their parents in the neonatal intensive care unit. *JOVE (Journal of Visualized Experiments), 155*, e60412. https://doi.org/10.3791/60412

Haslbeck, F., & Costes, T. (2011). Advanced training in music therapy with premature infants: Impressions from the United States and a starting point for Europe. *British Journal of Music Therapy, 25*(2), 19–31. https://doi.org/10.1177%2F135945751102500203

Haslbeck, F., & Hugoson, P. (2017). Sounding together: Family-centered music therapy as facilitator for parental singing during skin-to-skin contact. In M. Filippa, P. Kuhn, & B. Westrup (Eds.), *Early vocal contact and preterm infant brain development: Bridging the gaps between research and practice* (pp. 217–238). Springer International Publishing. https://doi.org/10.1007/978-3-319-65077-7_13

Hastings, Laura (2019). *Practices and perspectives of music therapists working with infants in Canadian neonatal intensive care units*. [Unpublished master's thesis]. Department of Creative Arts Therapies, Concordia University.

Healthcare Excellence Canada. (2020, July). *Re-Integration of family caregivers as essential partners in care in a time of COVID-19*. Canadian Foundation for Healthcare Improvement. https://www.cfhi-fcass.ca/innovations-tools-resources/item-detail/2020/07/08/re-integration-of-family-caregivers-as-essential-partners-in-care-in-a-time-of-covid-19

Hutchings, S. (2021). Decolonise this space. *Voices: A World Forum for Music Therapy, 21*(3). https://doi.org/10.15845/voices.v21i3.3350

Institute for Patient and Family-Centered Care (IPFCC). (n.d.). *What is PFCC?* www.ipfcc.org/about/pfcc.html

Johnson, B., Abraham, M., Simmons, L., Edgman-Levitan, S., Sodomka, P., Schlucter, J., & Ford, D. (2008). *Partnering with patients and families to design a patient- and family-centered health care system: Recommendations and promising practices*. Institute for Patient- and Family-Centered Care. http://www.ipfcc.org/resources/PartneringwithPatientsandFamilies.pdf

Kehl, S., La Marca-Ghaemmaghami, P., Haller, M., Pichler-Stachl, E., Bucher, H., Bassler, D., Haslbeck, F. (2021). Creative Music Therapy with premature infants and their parents: A mixed-method pilot study on parents' anxiety, stress and depressive symptoms and parent–infant attachment. *International Journal of*

Environmental Research and Public Health, 18(1), 265. https://doi.org/10.3390/ijerph18010265

Keilty, K., Nicholas, D., Sappleton, K., & Karmali, K. (2014). Paediatric patient-centred care at SickKids: Advancing child & family-centred care. In R. Zlotnik Shaul (Ed.), *Paediatric patient and family-centred care: Ethical and legal issues* (pp. 129–143). Springer. https://doi.org/10.1007/978-1-4939-0323-8_8

Kostilainen, K., Mikkola, K., Erkkilä, J., & Huotilainen, M. (2020). Effects of maternal singing during kangaroo care on maternal anxiety, wellbeing, and mother-infant relationship after preterm birth: A mixed methods study. *Nordic Journal of Music Therapy, 30*(4), 1–20. https://doi.org/10.1080/08098131.2020.1837210

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

Loewy, J., Stewart, A., Dassler, Telsey, A., & Homel, P. (2013). The effects of music therapy on vital signs, feeding and sleep in premature infants. *Pediatrics, 131*(5), 902–918. https://doi.org/10.1542/peds.2012-1367d

Loewy, J., Rossetti, A., Dassler, A., & Telsey, A. (2021). Assessing & treating trauma: Music psychotherapy for parents of neonates. *Music and Medicine, 13*(2), 12. https://doi.org/10.47513/mmd.v13i2.829

Loewy, J. (2004). A clinical model of music therapy in the NICU. In M. Nöcker-Ribaupierre (Ed.), *Music therapy for premature and newborn infants* (pp. 159–176). Barcelona Publishers.

Loewy, J. (2015). NICU music therapy: Song of kin as critical lullaby in research and practice. *Annals of the New York Academy of Sciences, 1337*(1), 178–185. https://doi.org/10.1111/nyas.12648

Loscalzo, Y., Antichi, L., Cipriani, G., Magi, L., & Giannini, M. (2021). Premature Triadic Music Therapy (PT-MT) for babies and their parents: A pilot study. *Journal of Reproductive and Infant Psychology*, 1–20. https://doi.org/10.1080/02646838.2021.1979199

McLean, E., McFerran, K., & Thompson, G. (2019). Parents' musical engagement with their baby in the neonatal unit to support emerging parental identity: A grounded theory study. *Journal of Neonatal Nursing, 25*(2), 78–85. https://doi.org/10.1016/j.jnn.2018.09.005

Malloch, S., Shoemark, H., Črnčec, R., Newnham, C., Paul, C., Prior, M., & Burnham, D. (2012). Music therapy with hospitalized infants - the art and science of communicative musicality. *Infant Mental Health Journal, 33*(4), 386–399. https://doi.org/10.1002/imhj.21346

McNally, M., & Martin, D. (2017). First Nations, Inuit and Métis health: Considerations for Canadian health leaders in the wake of the Truth and Reconciliation Commission of Canada report. *Healthcare Management Forum, 30*(2), 117–122. https://doi.org/10.1177/0840470416680445

Miles, M., Holditch-Davis, D., Schwartz, T., & Scher, M. (2007). Depressive symptoms in mothers of prematurely born infants. *Journal of Developmental & Behavioral Pediatrics, 28*(1), 36–44. https://doi.org/10.1097/01.DBP.0000257517.52459.7a

Misund, A., Nerdrum, P., & Diseth, T. (2014). Mental health in women experiencing preterm birth. *BMC Pregnancy and Childbirth, 14*, 263. https://doi.org/10.1186/1471-2393-14-263

Mondanaro, J., Ettenberger, M., Park, L. (2016). Mars rising: Music therapy and the increasing presence of fathers in the NICU. *Music & Medicine, 8*(3), 96–107. https://doi.org/10.47513/mmd.v8i3.440

Negrete, B. (2020). Meeting the challenges of the COVID- 19 pandemic: Virtual developmental music therapy class for infants in the neonatal intensive care unit. *Pediatric Nursing, 46(*4), 198-201, 206. http://www.pediatricnursing.net/news/FamilyMatters_JA_20.pdf

Nöcker-Ribaupierre, M. (2015). Internationale musiktherapeutische ansätze für frühgeborene kinder/ International music therapy approaches with premature Infants. *Musiktherapeutische Umschau, 36*(2), 106–118. https://doi.org/10.13109/muum.2015.36.2.106

Nordoff, P., & Robbins, C. (1977). *Creative music therapy: Individualized treatment for the handicapped child.* John Day Company.

O'Brien, K., Bracht, M., Robson, K., Ye, X. Y., Mirea, L., Cruz, M., Ng, E., Monterrosa, L., Soraisham, A., Alvaro, R., Narvey, M., Da Silva, O., Lui, K., Tarnow-Mordi, W., & Lee, S. K. (2015). Evaluation of the Family Integrated Care model of neonatal intensive care: A cluster randomized controlled trial in Canada and Australia. *BMC Pediatrics, 15*(1), 210. https://doi.org/10.1186/s12887-015-0527-0

O'Brien, K., Robson, K., Bracht, M., Cruz, M., Lui, K., Alvaro, R., da Silva, O., Monterrosa, L., Narvey, M., Ng, E., Soraisham, A., Ye, X. Y., Mirea, L., Tarnow-Mordi, W., Lee, S. K., O'Brien, K., Lee, S., Bracht, M., Caouette, G., Hales, D. (2018). Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: A multicentre, multinational, cluster-randomised controlled trial. *The Lancet Child & Adolescent Health, 2*(4), 245–254. https://doi.org/10.1016/S2352-4642(18)30039-7

Palazzi, A., Meschini, R., & Piccinini, C. (2021). NICU music therapy effects on maternal mental health and preterm infant's emotional arousal. *Infant Mental Health Journal, 42*(5), 672-689. https://doi.org/10.1002/imhj.21938

Puthussery, S., Chutiyami, M., Tseng, P.-C., Kilby, L., & Kapadia, J. (2018). Effectiveness of early intervention programs for parents of preterm infants: A meta-review of systematic reviews. *BMC Pediatrics, 18*(1), 223. https://doi.org/10.1186/s12887-018-1205-9

Raiskila, S., Axelin, A., Toome, L., Caballero, S., Tandberg, B., Montirosso, R., Normann, E., Hallberg, B., Westrup B., Ewald, U., & Lehtonen, L. (2017). Parents' presence and parent-infant closeness in 11 neonatal intensive care units in six European countries vary between and within the countries. *Acta Paediatrica, 106*(6), 878–888. https://doi.org/10.1111/apa.13798

Roa, E., & Ettenberger, M. (2018). Music therapy self-care group for parents of preterm infants in the neonatal intensive care unit: A clinical pilot intervention. *Medicines, 5*(4), 134. https://doi.org/10.3390/medicines5040134

Rolvsjord, R. (2010). *Resource-oriented music therapy in mental health care*. Gilsum, NH: Barcelona.

Rossetti, A. (2020). Environmental music therapy (EMT): Music's contribution to changing hospital atmospheres and perceptions of environments. *Music and Medicine, 12*(2), 130–141. https://doi.org/10.47513/mmd.v12i2.742

Sannino, P., Giannì, M., De Bon, G., Fontana, C., Picciolini, O., Plevani, L., Fumagalli, M., Consonni, D., & Mosca, F. (2016). Support to mothers of premature babies using NIDCAP method: A non-randomized controlled trial. *Early Human Development*, *95*, 15–20. https://doi.org/10.1016/j.earlhumdev.2016.01.016

Serlachius, A., Hames, J., Juth, V., Garton, D., Rowley, S., & Petrie, K. (2018). Parental experiences of family-centred care from admission to discharge in the neonatal intensive care unit. *Journal of Paediatrics and Child Health, 54*(11), 1227–1233. https://doi.org/10.1111/jpc.14063

Shoemark, H. (2008). Infant-directed singing as a vehicle for regulation rehearsal in the medically fragile full-term infant. *Voices: A world forum for music therapy. 8*(2). https://doi.org/10.15845/voices.v8i2.437

Shoemark, H., Dearn, T. (2008). Keeping parents at the centre of family-centred music therapy with hospitalised infants. *The Australian Journal of Music Therapy, 19*, 3–24.

Shoemark, H. & Dearn, T. (2016). Music therapy in the medical care of infants. In J. Edwards (Ed.), *The Oxford handbook of music therapy* (pp. 24-52). Oxford University Press.

Smith, W. (2018). Concept analysis of family-centered care of hospitalized pediatric patients. *Journal of Pediatric Nursing, 42*, 57–64. https://doi.org/10.1016/j.pedn.2018.06.014

Standley, J. (2003). The effect of contingent music to increase non-nutritive sucking of premature infants. *Pediatric Nursing, 26*, 493-495, 498-499.

Standley, J. (2012): Music therapy research in the NICU: An updated meta-analysis. *Neonatal Network, 31*(5), 311-316. https://doi.org/10.1891/0730-0832.31.5.311

Standley, J., & Gutierrez, C. (2020). Benefits of a comprehensive evidence-based NICU-MT program: Family-centered, neurodevelopmental music therapy for premature infants. *Pediatric Nursing, 46*(1), 40–46. https://www.proquest.com/docview/2355332692?accountid=10246

Standley, J., & Madsen, C. (1990). Comparison of infant preferences and responses to auditory stimuli: Music, mother, and other female voice. *Journal of Music Therapy, 27*(2), 54–97.

Standley, J., & Walworth, D. (2010). *Music therapy with premature infants: research and developmental interventions* (2nd ed.). American Music Therapy Association.

Statistics Canada. (2021, September 28). *Births, 2020*. https://www150.statcan.gc.ca/n1/daily-quotidien/210928/dq210928d-eng.htm

Stige, B. & Strand, R. (2016). Philosophical inquiries. In K. M. Murphy & B. L. Wheeler (Eds.), *Music therapy research* (3rd ed., Ch 64). Barcelona Publishers.

Teckenberg-Jansson, P., Huotilainen, M., Pölkki, T., Lipsanen, J., & Järvenpää, A.-L. (2011). Rapid effects of neonatal music therapy combined with kangaroo care on prematurely-born infants. *Nordic Journal of Music Therapy, 20*(1), 22–42. https://doi.org/10.1080/08098131003768123

Truth and Reconciliation Commission of Canada. (2015). *Truth and reconciliation commission of Canada: Calls to action.* National Centre for Truth and Reconciliation. https://nctr.ca/records/reports/#trc-reports

Turpel-Lafond, M. E. (2020). *In plain sight: Addressing Indigenous-specific racism and discrimination in B.C. health care.* Government of British Columbia. https://engage.gov.bc.ca/app/uploads/sites/613/2020/11/In-Plain-Sight-Full-Report.pdf

Ullsten, A., Eriksson, M., Klässbo, M., & Volgsten, U. (2018). Singing, sharing, soothing – biopsychosocial rationales for parental infant-directed singing in neonatal pain management: A theoretical approach. *Music & Science, 1*, 1–13. https://doi.org/10.1177/2059204318780841

Ullsten, A., Gaden, T., & Mangersnes, J. (2020). Development of family-centred care informing Nordic neonatal music therapy. In L. O. Bonde & K. Johansson (Eds.), *Music in paediatric hospitals – Nordic perspectives* (pp. 1–25). Norwegian Academy of Music.

van Veenendaal, N. R., van Kempen, A. A., Franck, L., O'Brien, K., Limpens, J., van der Lee, J. H., van Goudoever, J. B., & van der Schoor, S. R. (2020). Hospitalising preterm infants in single family rooms versus open bay units: A systematic review

and meta-analysis of impact on parents. *EClinicalMedicine*, *23*, 100388. https://doi.org/10.1016/j.eclinm.2020.100388

Vernon, R., & Papps, E. (2015). Cultural safety and continuing competence. In D. Wepa (Ed.), *Cultural safety in Aotearoa New Zealand*. Cambridge University Press.

Walworth, D., Standley, J. M., Robertson, A., Smith, A., Swedberg, O., & Peyton, J. J. (2012). Effects of neurodevelopmental stimulation on premature infants in neonatal intensive care: Randomized controlled trial. *Journal of Neonatal Nursing, 18*(6), 210–216. https://doi.org/10.1016/j.jnn.2012.01.001

Whipple, J. (2000). The effect of parent training in music and multimodal stimulation on parent-neonate interactions in the neonatal intensive care unit. *Journal of Music Therapy, 37*(4), 250–268.

Whipple, J. (2005). Music and multimodal stimulation as developmental intervention in neonatal intensive care. *Music Therapy Perspectives, 23*(2), 100–105.

Wright, A. L., Ballantyne, M., & Wahoush, O. (2020). Caring for Indigenous families in the neonatal intensive care unit. *Nursing Inquiry, 27*(2). https://doi.org/10.1111/nin.12338

Yakobson, D.; Gold, C.; Beck, B.; Elefant, C.; Bauer-Rusek, S.; Arnon, S. (2021). Effects of live music therapy on autonomic stability in preterm infants: A cluster-randomized controlled trial. *Children, 8*(11),1077. https://doi.org/10.3390/children8111077

Yaman, S., Altay, N. (2015). Posttraumatic stress and experiences of parents with a new-born in the neonatal intensive care unit. *Journal of Reproductive and Infant Psychology, 33*(2), 140–152. https://doi.org/10.1080/02646838.2014.990872