

Development of family-centred care informing Nordic neonatal music therapy

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Abstract

Since the 1990s, the concept of family-centred care, where the family and healthcare staff share responsibility for the infant's hospital care, has been part of an ongoing paradigm shift in neonatal care globally. The public health care system with family-friendly parental leave policies might be one of the reasons that the Nordic countries today are at the forefront of welcoming and including parents and partners in the care of their infant round the clock. When implementing neonatal music therapy (NICU MT) in the context of Nordic health care, music therapy models of practice as well as research ought to be defined and shaped by the family-centred care model, which today is considered best practice. The Nordic context also offers favourable conditions for further developing NICU MT approaches in line with family-centred care. NICU MT was first developed in the USA in the 1980s and the interventions were infant-focused, emphasising the infant's physical and medical needs, which was the existing care focus in neonatal care at that time. Neonatal music therapy and research in the Nordic countries is still in its infancy. Systematic implementation work was first initiated in Karlstad, Sweden in 2010 and in Akershus and Oslo, Norway in 2017.

This essay provides the international music therapy field as well as other professionals in paediatric and neonatal health care an insight into the evolving Nordic approach of NICU MT. The conclusion of this essay is that the family-centred care approach in the Nordic NICUs, combined with the progressive family politics in the Nordic countries with generous parental leave schemes and gender equality in childcare, afford important prerequisites to further develop NICU MT as a truly family-centred approach.

Keywords: *neonatal music therapy, Nordic perspective, family-centred care, infants, pain management*

Introduction

Imagine being an infant or a small child, left alone in a huge, unfamiliar place that smells and sounds frightening with strangers taking care of you without any chance of meeting or hugging your parents¹ for weeks, months or even years! Imagine being that parent who must abandon your critically ill child during long periods. In the 1940s and 1950s, infants and children were hospitalised for long time periods, especially for chronic illnesses. A hospital stay could be extended for several years where the child and the parents had no or little physical and emotional contact. The parents were either not allowed to visit or were just allowed to visit once per week and then perhaps just seeing their child behind a windowpane. Both Spitz (1945, 1946) and Bowlby (1958) revealed the devastating effects on infants' and children's emotional well-being of separation from their parents in routine hospital care. There are many traumatic stories about these family separations (Jolley & Shields, 2009).

The infant's brain is sensitive to both beneficial and harmful influences in infancy (Hart, 2011). Much of brain growth takes place while the infant is dependent on the parent. Developmental neuroplasticity allows for adaptation, preparing the infant for a challenging environment, but it also bears a risk for maladaptation in extreme or mismatched environmental conditions (Brummelte, 2017). Early-life adversity and trauma involve a substantial risk for the developing brain, whereas a stimulating and enriched environment on the other hand, has long-term effect on infants' neurological structure and neurochemistry, enlarging or altering the infant's brain (Schore, 2001; Hart, 2008, 2011). The parent's attuned care regulates the infant's brain development and the parent's voice, which is intrinsic in the interplay between parents and infants, is the primary source of bonding along with touch, eye contact, smell, taste and movement (Hart, 2011). Music therapy and music-based interventions, both live and recorded, have been found to have a measurable positive short-term physiological and behavioural impact on hospitalised infants and on their parents (for more detailed reviews see Ullsten, Eriksson, Klässbo & Volgsten, 2018 and Stegeman, Geretsegger, Phan Quoc, Riedl & Smetana, 2019). A growing body of research now shows that hospitalisation of an infant is a very stressful experience for the whole family and that parents and the parents' vocal stimulation are underutilised tools in the care of the hospitalised infant (Griffin, 2006).

This essay provides a historical background of the development of family-centred care, which has laid the foundation for the evolving Nordic approach with parental involvement

1 A note on terminology is in place here. In this article we refer to parents as the legal guardians and we include single parents, fathers, partners and other primary caregivers.

in neonatal music therapy (NICU MT). This essay also introduces the current clinical situation and research of Nordic NICU MT, all within the framework of family-centred care. When viewed from a global perspective, the Nordic health care systems in Sweden, Norway, Denmark, Finland and Iceland are quite similar with for example family-friendly parental leave policies. However, our position in this essay is based on our own pioneering research and clinical work as well as implementation processes within a Swedish and Norwegian context. This explains the emphasis in this essay on NICU MT in Sweden and Norway. The overall structure of the essay is chronological, starting with a historic overview of the evolution of the concept of family-centred care within global and Nordic paediatric and neonatal health care. The published literature on family-centred care was systematically reviewed in the databases CINAHL, PubMed and Google Scholar using the keywords “family-centred care”, “NICU”, “parents” and “history”. The essay continues with a historical review of the development of NICU MT and the Nordic cultural adaption process of NICU MT in Sweden and Norway. We reflect upon and discuss the efforts and benefits of complying with the principles of family-centred care when establishing a Nordic NICU MT approach with parental participation. A snowballing search method was used for reviewing literature in the neonatal music therapy sections. The paragraph about music therapy in neonatal pain management, which is an area in great need of active methods to involve parents, is based on research by the first author of this essay. The essay concludes with implications for future NICU MT practice and research within a Nordic family-centred care context.

Development of family-centred care

Family-centred care (FCC) is considered a cornerstone philosophy of current paediatric health care globally and there is an international agreement about the importance of family-centred care in neonatal and paediatric settings (Dennis, Baxter, Ploeg & Blatz, 2017). FCC is an approach to health care rather than a care model that is respectful of and responsive to individual family values, emphasising the patient’s and family’s emotional, social, and developmental needs (Davidson et al., 2017; Ding et al., 2019). The core concepts in FCC are dignity and respect, information sharing, participation and collaboration in care (Institute for Patient and Family-Centred Care, 2010). FCC ensures that care is planned around the whole family, not just the individual child, and that all the family members are recognised as care recipients. FCC also comprises for example a culturally competent and respectfully supportive parent-professional collaboration and continuous information sharing (Jolley & Shields, 2009).

In the middle of the 20th century, paediatric care was generally unaware of the child's developmental, social and psychological needs. It was highly focused on the child's physical and medical needs (Jolley & Shields, 2009). Nursing and medicine were slow to change, but after World War II and with the help of the two British theorists and investigators, John Bowlby and James Robertson, who researched and elucidated the traumatic effects of separation of mother and child, various models of FCC started to gain ground globally (Jolley & Shields, 2009). Parents gradually became highly influential in improving the care for their hospitalised children. In 1959, the British government published a report of an inquiry into conditions in children's hospitals, commonly known as the "Platt Report". British parents who were committed to ensuring the recommendations of the Platt Report were put in place, formed one of the world's first health consumer organisations (Jolley & Shields, 2009).

In the United States, FCC in *neonatal* care was evolving as a grassroots consumer-driven movement in the early 1990s as patients and families began to seek more control over their care (Harrison, 1993; Johnson, 2000; Gooding et al., 2011). In 1992, a group of American parents who were knowledgeable about the neonatal intensive care units (NICUs) from personal experiences and from their work in support organisations, disability rights groups and hospital ethics committees, met with physicians and discussed the problems described by parents and explored possible solutions (Harrison, 1993). Parents were frustrated over the way they and their infants were treated in the NICU. The parents spoke for instance about difficulties in obtaining accurate information about their infant's conditions, treatments, and prognoses, of parental exclusion from medical and ethical decision-making and of the undertreatment of infants' pain. A document of ten principles, "The Principles for Family-Centered Neonatal Care," was the beginning of a paradigm shift (Harrison, 1993).

In the Nordic countries the shift towards FCC followed almost the same path as in the UK and in the USA. Until the 1940s and 1950s, most of the children in the Nordic countries were born at home. After that time, home births decreased and the infants were born in hospitals where infection control and medical interventions increasingly led to improved health outcomes in perinatal care (Jackson & Wigert, 2013). Care for the mother and infant shifted during this time from in-home, patient-, and family-focused care to the hospital and staff as gatekeepers of the infant, with families treated as bystanders. Parents were only allowed to visit their infants during certain visiting hours and see the child through a windowpane. There were no high-tech intensive care units for premature born and sick newborns in Sweden until the 1970s (Jackson & Wigert, 2013). In Norway, the first neonatal unit was established at Rikshospitalet in the late 1960s. In the 1970s, many county hospitals still did not have separate children's wards or neonatal units, and the most recently founded unit in Norway was not established until 1988 (Moen, 2017). In the 1980s and 1990s, there

was a shift of focus in neonatal care towards a more family-centred approach based on respect for the infant's and parents' needs, cooperation with the parents and sharing of information (Fegran, Helseth & Slettebø, 2006). Even though FCC was introduced in the Swedish NICUs in the 1990s, it was not until the 21st century that the neonatal intensive care units started to more actively include both parents, and possible siblings in the infant's care round the clock.

According to The Norwegian Neonatal Healthcare Atlas (Moen, 2017), Sweden and Norway have some of the world's best treatment results for preterm infants measured in survival. In this Norwegian analysis of admissions and treatments of infants at NICUs in Norway, the factors which contribute to this fortunate situation are stated as; "good antenatal care", "good foetal medicine follow-up" and the "high level of expertise among Swedish and Norwegian obstetricians and neonatologist" (Moen, 2017, p. 22). This report only mentions FCC once, in the context of "other factors that have been documented to have an effect on the length of stay" (Moen, 2017, p. 66). Recent systematic reviews and meta-analysis have linked FCC to improved infant's weight gain, shorter length of stay in the hospital and improved survival quality among hospitalised preterm infants as well as improved parent-reported outcomes, parent satisfaction, skills, and knowledge (Ding et al., 2019; Yu & Zhang, 2019). However, FCC is a broad concept and clinicians have varied perceptions of and expectations about what the core concepts of FCC comprise and how to translate these values into action (Dennis et al., 2017). Since standardised FCC interventions and core outcome measures are still lacking, research has difficulties comparing results to show the clinical effectiveness of FCC (Ding et al., 2019). FCC still has some groundbreaking work left to do.

Nordic family friendly policies reinforce family-centred neonatal care

Even if most infants are still cared for in traditional multi-bed, open-bay NICUs, the Nordic countries are at the forefront of welcoming and including parents in the everyday care of their infant. In Sweden, Norway, Denmark, Finland and Iceland, the awareness of family-centred care is very high and in constant growth. Parents are welcome to stay close to their infant most of the time with no restrictions in visiting hours. More and more NICUs in the Nordic hospitals are today built (or rebuilt) to welcome parents round the clock, with separate family rooms, couplet care for mother and infant with zero-separation, bedside rounds and opportunities for siblings to stay in family rooms with no restrictions on visiting hours.

The public healthcare system is an important factor in this paradigm shift and for the sustainability of the implementation of FCC in the Nordic countries. According to the general social security system in the Nordic countries, hospitalised children have a legal

right to have at least one parent present during hospitalisation. If a child is seriously ill and there is a significant threat to the child's life or if the child receives treatment for their illness and the child's life is in danger without this treatment, both parents have the right to compensation with paid care leave to be with their child for an unlimited number of days (Sweden) or for a total of 1300 days (Norway). The doctor must write a statement which includes a diagnosis and a description of the child's illness and treatment. Other factors in this implementation process were the introduction of international rules and conventions in the 1980s and 1990s. The Nordic network for children's rights and needs in health care (NOBAB) was founded in 1980 in Norway. This Nordic standard stated that sick children have the rights to have their parents present during hospitalisation and they should have the same opportunities as healthy children to develop through play, schooling and social connections with loved ones (NOBAB §§ 2, 3, 6, 7). In 1989, the United Nations Convention on the Rights of the Child was adopted and ratified a year later. Nations that ratified this convention are bound to it by international law. All Nordic countries have ratified the convention, which for example states that infants and children should not be separated from their parents against their will.

Today, we know from research how important the physical facilities in the NICU are in establishing physical and emotional parent–infant closeness. Physical closeness refers to being spatially close and emotional closeness refers to parental feelings of being emotionally connected to the infant, experiencing feelings of love, warmth and affection (Flacking et al., 2012). The most important factor supporting parent–infant closeness is the opportunity for the parents to stay overnight. Having other children or a long travel distance from home to the hospital have no impact on parent–infant closeness (Raiskila et al., 2017). In most parts of Europe, the fathers are not actively involved in the care of a sick hospitalised infant. In the Nordic countries, the situation is reverse. The fathers with the highest proportion of parental presence in Europe were in the Swedish neonatal units with 96,1% of the fathers present in the NICU, with Norway on 80,4% (Raiskila et al., 2016). The possibility for Nordic fathers to partake in skin-to-skin contact (SSC) with their hospitalised infant facilitates a more equal parenthood (Olsson, Eriksson & Anderzén-Carlsson, 2017). Fathers experiencing SSC express a feeling of improved self-esteem, closeness to their infant and a feeling of equality with the mother, compared to fathers of a healthy newborn where the father returns to work soon after the birth (Olsson et al., 2017). Both the hospitalisation of the newborn and the social benefits in the health care system offer the fathers in the Nordic countries a chance to be even more involved in their infant's development (Olsson et al., 2017), as well as in music therapy interventions.

Implementation of music therapy in Nordic paediatric and neonatal care

The first music therapy inspired project in Sweden was introduced in paediatric habilitation in the beginning of the 1980s (Westerholm, 1983). Music therapy service is today available in a few paediatric² wards in Sweden (Säfsten, 2017; Uggla et al., 2016, 2018). In Norway, music therapy was first introduced in paediatrics in the late 1990s (Ærø & Aasgaard, 2011) and is now relatively established in the paediatric departments at five out of six university hospitals in Norway. In Finland, one music therapist is working in a paediatric hospital, but the music therapy practice is located within child psychiatry. In Denmark, music therapy is for example represented in paediatric oncology research (Sanfi, 2015). However, there are currently no permanent music therapy positions in paediatric care in Denmark.

NICU MT is an even younger discipline in paediatric care. Globally, NICU MT is still in its initial stages of development (Shah et al., 2017), and in its infancy in Nordic neonatal care. In NICU MT, the music therapist specialised in neonatal music therapy methods coaches the parents to use their voices to sing with their infant to enhance mutual co-regulation, interaction, attachment and promote the social, emotional and neurological development of the hospitalised infant. The first research findings that showed that premature infants in the NICU benefit from auditory stimulation were published in nursing research in the 1970s (Katz, 1971). Neonatal music therapy research began in the 1980s and 1990s with the pioneering work of Jayne Standley at Florida State University, USA. The existing care focus in neonatal care at that time, which also influenced NICU MT, emphasised the infant's physical and medical needs. The study undertaken by Standley's student Janel Caine (Caine, 1991), who used a study design with recorded auditory stimulation, opened up a new context of practice for music therapy (Shoemark & Dearn, 2016). Professionals in the NICU were protective of their fragile patients and initially there was resistance to music being present in the NICU since all sounds were perceived as noise (Standley, 2014). Research from the music therapy field, traditionally not included in medical treatment in the NICU, was met with scepticism (Standley, 2014). NICU MT developed in different parts of the world from the late 1990s and onwards in the USA (Loewy, 2000), Germany (Nöcker-Ribaupierre, 1999), and Australia (Shoemark, 1999).

The first systematic Nordic NICU MT implementation process started in Sweden at Central-sjukhuset in Karlstad by the music therapist and first author, Alexandra Ullsten, with the first referrals in March 2010. The first Swedish NICU research project was initiated by the

² Music therapy practice and research in child psychiatry is beyond the scope of this article.

first author in 2012 (Ullsten et al., 2016, 2017b, 2018), followed by another ongoing NICU MT research project in Stockholm starting in 2014 (Haslbeck & Hugosson, 2017). Recently, two temporary music therapy services in paediatric care/NICU was initiated in Uppsala and Stockholm. In Norway, a few music therapists have for shorter periods worked in neonatal intensive care (e.g. Kvalbein, 2011), and a few master projects have contributed with initial clinical experiences (e.g. Oveland, 1998; Dahl, 2012; Rundgren, 2013). These experiences form an important background for recent, more systematic efforts for implementation, which started in 2017 at Akershus University Hospital. Music therapist Tora S. Gaden initiated a 2-year project on program development and implementation with funding from Extrastiftelsen (now led by Catharina Janner) (Gaden & Overå, 2018). Julie Mangersnes followed with initiating NICU MT services at Oslo University Hospital, Rikshospitalet in Norway later in 2017. NICU MT research in Norway began with a meta-analysis (Bieleninik, Ghetti & Gold, 2016). In 2017, the international multi-site RCT “Longitudinal Study of music Therapy’s Effectiveness on Premature infants and their parents” (LongSTEP) was launched, which will be the first study to investigate the long-term effects of music therapy on parent-infant bonding (Ghetti et al., 2019). In Finland, the first NICU MT research was introduced in 2006 (Teckenberg-Jansson, Huotilainen, Pölkki, Lipsanen & Järvenpää, 2011). The NICU MT service in Finland today is voluntary and research project-based (Kostilainen et al., 2018; Virtala & Partanen, 2018). In Denmark, the first pilot study with NICU MT investigated the effects of live music therapy on infants’ stress and parental wellbeing at Aalborg University Hospital (Haslund, 2015), but there are no music therapists working in the NICU field today.

Challenges for neonatal music therapy in Sweden and Norway

When the first author initiated music therapy in a Swedish NICU back in 2010, there were various predictable as well as unforeseen challenges on parallel levels. On the organisational level there were abrupt changes in leadership and staff and the physical facilities offered a multi-bed, open-bay unit where parents were jammed in between the cots. On a professional level, the possibilities for NICU MT training were limited to the USA and did not exist in Europe. The dearth of Swedish context-sensitive and family-centred NICU MT interventions and research became an issue for the implementation phase, when existing research literature and models of practice were infant-focused and lacked parental involvement. It became obvious that models of practice are not directly transferable across cultural contexts and health care systems. And then there was the noise issue which posed the challenging question: “To add more sound to an already noisy environment, how can that improve the situation for the premature infants?” A couple of years later, in 2013, the newly built NICU opened at Centralsjukhuset in Karlstad, which was designed to support parent-infant closeness and couplet care with separate family-rooms. The implementation

work with music therapy changed dramatically for the better. From now on, music therapy service could be offered individually with each family including siblings, in their family room.

The Norwegian Music Therapy Association has contributed to rapidly increasing interest among the Norwegian music therapists to work with premature and ill term infants and their families. The association has the past years arranged introductory courses in the model “First Sounds: Rhythm, Breath, Lullaby (RBL)” (Loewy, 2016) with Joanne Loewy from New York, providing a theoretical base for NICU MT work. These courses in combination with a steadily growing body of international research in NICU MT have presumably contributed to the implementation processes in Norway at Akershus University Hospital and at Oslo University Hospital Rikshospitalet. These two processes have continued parallel at each site with the second and third authors supervising each other along the way. To be two music therapists in the work of implementation is to occupy a fortunate position. The initial challenges from the implementation process in Sweden concerning the cultural adaption of NICU MT have been observed in Norway as well. Though, adding music to the NICU environment has mostly been accepted among staff.

The current situation with highly involved parents seems to be ideal for the Nordic family-centred neonatal music therapist to work in partnership with parents, guiding them to be equally involved in the infant-directed communication and facilitating a chance for also the fathers and partners to form an early attachment with the infant. The family-centred neonatal music therapist faces both cultural and musical challenges daily (cf. Zimmerman & Bauersachs, 2012, cf. Haslbeck, 2014). Sweden and Norway are today culturally diverse societies. There were for example an increased number of refugees during 2015 and 2016. Yet, every family in the NICU, regardless of heritage, could be considered as a unique entity, a “subculture”, with its own musical history, musical preferences and with unique inter-generationally transmitted attachment patterns (Shah, Fonagy & Strathearn, 2010). This gives cause for the neonatal music therapist to individualise and tailor the music therapy interventions. The music chosen for the music therapy interventions is culturally sensitive with a base in the family’s own musical preferences. Live singing is used as a developmental stimulus as well as a relational act of love and care. It is a resource parents always have available, yet, not always in active use. In these cases, the music therapist may work as a facilitator in empowering parents to communicate with their infant in an infant-directed mode. The interactions with the neonatal music therapist also give the family a possibility to get to know new songs and for siblings to learn how to engage with the vulnerable infant. The visit from the family-centred music therapist offers a chance to share musical backgrounds and “songs of kin” – melodies that has been used within a family’s history or are representative of the culture of that family’s community (Loewy et al., 2013).

NICU MT is used to promote normalisation in an advanced medical environment. The NICU MT in Sweden and Norway is humanistic resource-oriented (Rolvjord, 2016) and informed by developmental psychology and attachment theories (e.g. Trevarthen, 1980; Stern, 2000; Schore & Schore, 2008; Malloch & Trevarthen, 2009), the biopsychosocial model (Engel, 1977, 1980) and the biopsychosocial neuroaffective developmental psychology model (Hart, 2008, 2011). The RBL-model is the basis for music therapy practice in both Sweden and Norway but has been modified to fit routines and needs of the specific units and the context of the Swedish and Norwegian welfare system, culture and health care. The role of the music therapist is as guide, supervisor and role model for the parents, also offering family support and psychoeducation. Working as a music therapist in the context of family-centred care is not always about offering musical experiences. It also involves being available to parents as a supportive, present, empathic part (Shoemark & Dearn, 2008).

Theoretical foundations of family-centred care

Parents' protests, as mentioned above, against being separated from their critically ill term or premature infants can be seen as an enactment of common sense as well as being in line with theories of infant development and parent-infant bonding. This includes the transaction model of development (Sameroff, 2009), attachment theory (cf. Bowlby, 2008), the notion of parental mentalisation as foundation for care giving sensitivity (Fonagy et al., 2002), and the psychological preparation for parenthood (Berg Brodén, 2004; Raphael-Leff, 2018). Infants need their parents, and parents demonstrate the need to be with their infant. The infant represents hope for the future and the parents are motivated to do their very best to provide their child with optimal conditions for development (Gaden & Trondalen, 2018). Infants are born with an innate capacity and the need for social interaction and communication and are dependent on sensitive, emotionally available parents to regulate them and respond to their needs in order to develop the capacity of self-regulation and develop a sense of self (Schore, 2001; Stern, 2000; Fonagy et al., 2002). Parental availability, presence and sensitivity are all crucial elements for healthy development of the emotional bond between parent and infant (Hansen, 2010). However, entering parenthood is also entering a period of vulnerability associated with an increased risk of depression and other mental health problems that can impact parents' capacity to care for their infant (Slinning, Hansen, Moe & Smith, 2010). Stern (1995) suggests that with the birth of a child, the mother enters into a new psychic organisation – the motherhood constellation – that will shape a new set of action tendencies, sensibilities, fantasies, fears and wishes (pp. 171). A preterm birth does not only result in premature infants; parents also enter parenthood prematurely.

The time for mental preparation and psychological changes that normally occur during pregnancy up until birth are shortened and many parents feel overwhelmed and unprepared. Parents of preterm infants are at greater risk of experiencing stress, anxiety and depressive symptoms which in turn affect their ability to sensitively care for their child (Korja et al., 2008; Shaw et al., 2009). In addition, preterm and ill newborns are not fully fit for social interaction. Their social signals can be weak and hence difficult to understand and their physiology difficult to regulate.

Both infants and parents are particularly vulnerable during NICU hospitalisation, in a high-tech environment where stress and isolation is part of everyday life (Ramezani, Shirazi, Sarvestani & Moattari, 2014). This indicates a need for additional support in communication, regulation and an environment that fosters physical and emotional closeness. It would be inconsistent with the values of FCC to separate infants and parents. In family-centred care the family has the greatest influence over the child's health and well-being, and because of this influence, families must be supported in their role as caregivers (Johnson, 2000).

Family-centred neonatal pain management

From a family-centred care perspective parents are an underused resource in neonatal pain management. FCC has come a long way in welcoming and including parents in the everyday care of their infant. However, the role of the parents in infant pain management is a relatively new area of research and practice, even in the Nordic context (Palomaa, Korhonen & Pölkki, 2016). Parental participation in neonatal pain relief is associated with improved infant pain care (Axelin et al., 2015; Courtois et al., 2016; Palomaa et al., 2016) and lower pain scores (Courtois et al., 2016).

Infants cared for in the NICU experience on average between 7 and 17 painful procedures per day and very few receive appropriate pharmacological and nonpharmacological analgesic therapy (Carbajal et al., 2015; Roofthoof, Simons, Anand, Tibboel & van Dijk, 2014; Cruz, Fernandes & Oliveira, 2016). Repeated, cumulative and inadequately treated procedural pain in addition to separation from the parent, will not just harm the infant physically and psychologically in the short term, but might also jeopardise the new family's attachment process and mental health in the long term.

Infant pain and pain management became a strongly disputed subject in the late 1980s when it was established that newborn infants, both premature and term born, are capable

of experiencing pain (Anand & Hickey, 1987), and implicitly remembering trauma (Noel et al., 2015). For decades, the prevailing belief in the medical community was that infants have no memories of painful experiences, nor a present perception or localisation of pain, or that infants are capable of experiencing pain in a manner similar to that of adults, and therefore the human infant is not capable of perceiving pain (Anand & Hickey, 1987). As a consequence of these traditional views, infants underwent numerous painful and invasive procedures, including surgery, without any pain treatment (Anand & Hickey, 1987). Today, about 30 years later, despite increased knowledge and the existence of international and national guidelines, pain management and pain assessment are not optimally provided in neonatal care. Too often, pain still goes untreated in the infant population admitted to the NICU and infants and parents are still separated during painful procedures, despite an increasing awareness regarding pharmacological and non-pharmacological analgesic strategies (Carbajal et al., 2008).

Parents' participation in infant pain management has quite recently become a focus for research in nursing pain science. Hopefully, the family-centred advances in neonatal pain care will also inform neonatal music therapy. NICU MT in neonatal pain management and pain research is not yet fully evidence-based and far from being family-centred. In the neonatal pain research literature, there is a dearth of music therapy studies and a domination of music medicine research, which usually uses pre-recorded music offered by medical personnel without the presence of the parents. In procedural pain management, recorded lullabies and recorded maternal voice have shown to have certain positive effects on infants' behavioural pain indicators (Bo & Callaghan, 2000; Butt & Kisilevsky, 2000; Chou, Wang, Chen & Pai, 2003; Tramo et al., 2011; Bergomi et al., 2014; Pölkki & Korhonen, 2014; Azarmnejad et al., 2015; Shabani et al., 2016; Chirico et al., 2017; Qiu et al., 2017; Shah et al., 2017; Shukla et al., 2018). In music medicine research, recorded music during skin puncture is considered to be a simple, convenient, inexpensive and complication-free intervention (Azarmnejad et al., 2015; Kurdahi Badr et al., 2017; Shah et al., 2017). The first author of this article has elsewhere argued against this uninformed use of music in neonatal pain management (Ullsten, 2017a).

The research by Ullsten et al. (2016, 2017b) was the first RCT to measure the pain-relieving effects of *live* lullaby singing on behavioural and physiological pain responses during venipuncture in preterm and term neonates. By providing standard pain management for all involved infants only additive effects of the live lullaby singing could be assessed. The results did not show any significant pain-alleviating effects on the infants' pain responses during venipuncture, but the lullaby singing significantly calmed the infants' respiration before venipuncture and also showed a non-significant trend towards higher oxygen saturation

levels during the whole procedure in the lullaby intervention versus the control condition. There were non-significant indications of fewer and shorter skin punctures with lullaby singing. There were no indications in the data that live lullaby singing was harmful or stressful (Ullsten et al., 2017b). The live lullaby singing in this study was not performed by a parent but by a music therapy student in training.

Implications for future research and practice

NICU MT implementation in the Nordic countries has been initiated by single music therapists. When the implementation process started in Sweden 2010 and seven years later in Norway, the only available research results (as well as the only available NICU MT training and models of practice) were still infant-focused and came from American or Australian NICU care contexts. The three authors of this article have all trained in the RBL-model from New York. We have had some initial struggles to implement NICU MT into the Nordic family-centred neonatal care and adapt the models of practice to find a more culturally sensitive Nordic approach to our clinical work. We know from research that cultural sensitivity and context is of crucial importance for knowledge translation (Squires et al., 2015). Working in a Nordic NICU where families are present 24/7 puts new demands on the music therapist and requires other music therapy skills, even music psychotherapy skills. Every NICU MT intervention that is initiated must be acted and mediated through and together with the parents, in addition to a continuous negotiation with the staff and the leadership of the NICU.

Emotional support for the parents is found to be the least developed aspect of FCC globally (Raiskila et al., 2016; Davidson et al., 2017). Both nurses and parents have acknowledged that providing emotional support is a challenge for the NICU staff, which opens up an opportunity for new skills and actors to provide parental emotional support (Raiskila et al., 2016). This function could be one of the more important ones for the Nordic NICU music therapist to pursue and to research. The music therapist can provide emotional verbal and non-verbal support for the whole family, not just the parents, but the parents *together* with the hospitalised infant and possible siblings. In their meta-analysis, Bieleninik et al. (2016) found that maternal anxiety was significantly reduced for mothers of premature infants who participated in music therapy during kangaroo care (KC) compared to KC alone. As elevated maternal anxiety is associated with post-partum depression and impaired parenting, this aspect of NICU MT is important to emphasise in both clinical practice and NICU MT research. The ongoing research study LongSTEP, investigates music therapy's

effectiveness on parent-infant bonding, parent well-being and infant development during the child's first two years of life, and will fill a gap in the research literature by providing insight into longer-term impact of music therapy with premature infants and their caregivers (Ghetti et al., 2019).

Another research field of great interest for the Nordic NICU music therapist is the hospitalised infant's language development. The sensory deprivation and paucity of language exposure experienced by hospitalised preterm infants are problematic also in the Nordic NICUs. Music therapists are well suited to promote optimal input, and to train parents and staff in how to increase language exposure safely and appropriately (Sanchez & Spittle, 2019).

Neonatal music therapists in the Nordic countries can be truly family-centred also in neonatal pain management research. No study, as far as we are aware, has so far assessed the pain-alleviating effects of infant-directed *live* singing performed by a *parent* during venipuncture. When we study the theoretical rationales for including family-centred NICU MT in neonatal pain management, the arguments are overwhelming for starting to prescribe parents as their infant's pain management! Emotionally available and well-informed parents have the biopsychosocial and multimodal resources to alleviate their infant's pain through infant-directed singing (Ullsten et al., 2018). The multimodal parental infant-directed singing offers the parent–infant dyad experiences of pleasure, happiness, love and joy instead of pain, worry and stress. Shared pleasure has the capacity to dissolve a negative painful affective spiral (Ullsten et al., 2018). We suggest future research to further investigate what kinds of NICU MT interventions, combinations and methods that are effective in a painful context and the role of the music therapist in neonatal pain management. Nordic music therapy researchers have a huge opportunity to claim this new and fairly unexplored pain management field of family-centred NICU MT. The trend in neonatal nursing research nowadays is to invite the parents already at the planning stage when designing clinical studies. Participatory action research (PAR) is a method often used in knowledge translation, where researchers and participants/parents collaborate to understand a problem and change it for the better. PAR might be an exciting new path to research music therapy in family-centred pain care, allowing parents to guide the music therapists to find efficacious pain-alleviating music therapy interventions and perhaps make it easier to implement research results in clinical practice.

Now is the time to build on and deepen our predecessors' work from the past. We need to develop a Nordic family-centred perspective on neonatal music therapy in clinical programs, research and specialised training, which are culturally sensitive to the Nordic public health care systems. As music therapists, we find it essential that Nordic family-centred

neonatal care should offer music therapy to their patients and families. But, as of present, our services are rarely requested. It is not enough to have specialised training in NICU MT within the music therapy community. Other professions and programs need to be informed of NICU MT services in order to create a demand. Research and training go hand in hand and may create more positions for neonatal music therapists in the Nordic countries. Culturally sensitive Nordic neonatal music therapy research that involves parents and staff is important to spread the word and build new models of practice. We suggest that Nordic NICU MT defines the specific neonatal care goals that only music therapy may bring about, like for example emotional support for the whole family including siblings. When these music therapy interventions, that respond to specific care needs, are evidence based within a Nordic health care context, a demand for NICU MT might grow resulting in more positions in the field. We have previously seen how FCC started as a grassroots movement in the UK and in the USA and then spread globally to finally be considered as best practice. Perhaps Nordic NICU MT needs to partner up with the Nordic parent patient organisations to gain legitimacy and together with the parents articulate the need for music therapy in the NICU. The circumstances for the neonatal music therapists in the Nordic countries are advantageous, with the parents present 24/7. We need to take advantage of that framework and create a win-win situation for the infants and families, the neonatal care and neonatal music therapy.

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