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Music therapy in the neonatal intensive care unit: Putting the families at the centre of care

Mark Ettenberger
SONO – Centro de Musicoterapia, and Hospital Centro Policlínico del Olaya, and Universidad Nacional de Colombia, Colombia

Abstract
In this article, the core concepts of family-centred care will be discussed in relation to family-centred Music Therapy with preterm babies and their parents in the neonatal intensive care unit. Then, the basic pillars of a family-centred Music Therapy programme at the neonatal intensive care unit of the Hospital Centro Policlínico del Olaya in Bogotá, Colombia, will be illustrated by selected case vignettes. Parents are considered to be an important ally in caring for their baby in the neonatal intensive care unit and family-centred Music Therapy actively seeks to provide early relational and communicative experiences between parents and their babies. However, family-centred Music Therapy goes beyond the integration of parents and needs to carefully balance out the fluctuating needs of the babies, parents and the emerging relationship between them.

Keywords
bonding, Colombia, family-centred care, music therapy, neonatal intensive care unit (NICU), preterm babies

Introduction

Family-centred care (FCC) is a widely discussed topic among health care professionals, especially in paediatrics (Gooding et al., 2011; Kuo et al., 2012; Shields, 2010; Tallon et al., 2015). FCC can be described as 'a partnership approach to health care decision-making' (Kuo et al., 2012: 298) and 'recognizes the family as the fundamental source of support and considers the deliberate involvement of the family essential to promote the health of all family members' (Mikkelsen and Frederiksen, 2011: 1152). FCC implies several core principles like information sharing, respect and honouring differences, partnership and collaboration, and negotiation and care in context of family and community (Kuo et al., 2012). These principles underlie many of the current approaches in family-centred Music Therapy clinical practice and research. Examples hereof are the work with children with autism spectrum disorder (Thompson, 2012; Thompson et al., 2014), with at-risk families in community settings (Abad and Edwards, 2004; Nicholson et al., 2008), with children with developmental disabilities (Shoemark, 1996; Warren and Nugent, 2010), in child and family psychiatry (Oldfield et al., 2012) or with 'non-clinical' families (Nemesh, 2016). In hospital settings, Shoemark (2004) and Shoemark and Dearn (2008) discussed in detail the possibilities and challenges of providing family-centred Music Therapy in the neonatal and paediatric intensive care unit (ICU).

Why family-centred Music Therapy in the neonatal intensive care unit?

During hospitalization in the neonatal intensive care unit (NICU), both the preterm babies and their parents face multiple challenges that can put in danger their integrity, wellbeing and the development of a healthy and stable relationship between them (Evans et al., 2012). Preterm babies are at higher risk of developing medical complications after birth and are prone to long-term developmental impairments or chronic diseases (Simmons et al., 2010; Soleimani et al., 2014). During hospitalization, preterm babies need to undergo frequent medical procedures, which may increase their stress and may alter their brain development (Vinall et al., 2014) The disorganized and chaotic sound environment of the NICU potentially adds to these challenges and can cause behavioural disorganization, sleep interruption and could lead to an impaired auditory development (Lahav and Skoe, 2014).

Parents of preterm babies, on the other hand, are at risk of experiencing increased levels of stress, anxiety and depressive symptoms during and after their baby's hospitalization (Carson et al., 2015; Shah et al., 2011). The interruption of

Corresponding author:
Mark Ettenberger, SONO – Centro de Musicoterapia, Calle 92 No. 18-62, Bogotá, 110221, Colombia.
Email: mark.ettenberger@gmx.at

daily routines and the increased economic costs that many parents need to assume may intensify these difficulties (Hodek et al., 2011; Rutter, 1995). This can endanger the transition to parenthood for both mothers and fathers of preterm babies (Hutchinson et al., 2012). All these factors can threaten the early parent–infant relationship, which is crucial for the baby's long-term development (De Falco et al., 2014). Recent studies show that high levels of anxiety, parental symptoms of depression and parenting stress in the NICU are significantly correlated with poorer cognitive outcomes of preterm babies at 24 months corrected age (Huhtala et al., 2011; Zelkowitz et al., 2011). Wolke et al. (2014) found that more than 30% of very preterm or very low birth weight babies show disorganized attachment at 18 months of age.

Those providing family-centred Music Therapy in the NICU need to be aware of these potential difficulties and actively seek to provide early relational and communicative experiences between parents and babies in a non-threatening and holding atmosphere. Thus, family-centred Music Therapy does not merely integrate parents into the therapy sessions with the babies, but pursues to carefully balance out the fluctuating needs of the babies, parents and the emerging relationship between them. While families (mostly mother–baby dyads) have been part of research studies regarding Music Therapy in the NICU for more than 30 years (for an overview, see Ettenberger et al., 2016), the more active integration of parents to the therapy process has just recently been reported (e.g. Cevasco, 2008; Ettenberger et al., 2014; Ettenberger et al., 2016; Haslbeck, 2013; Haslbeck et al., 2016; Loewy et al., 2013, Teckenberg-Jansson et al., 2011; Vianna et al., 2011). Lately, fathers are also beginning to be considered in the context of Music Therapy in the NICU (Mondanaro et al., 2016).

During the following section, some reflections based upon a family-centred Music Therapy programme at a NICU in Bogotá, Colombia, will be presented along with a few short case descriptions taken from clinical practice.

Music Therapy at the NICU of the Hospital Centro Policlínico del Olaya – A family-centred approach

Background

The Music Therapy service at the Hospital Centro Policlínico del Olaya (CPO) started in 2012 in the context of a research project about family-centred Music Therapy in the NICU (Ettenberger et al., 2014; Ettenberger et al., 2016). At the same time as the on-going research, other Music Therapy clinical work at the hospital was offered at first in the NICU, and then at other units at the hospital. In 2014, the service was formalized, and today, four certified music therapists work at the NICU, the Paediatric ICU, the Adults ICU and in close collaboration with the maternity unit and the pain unit.

The Level III NICU of the CPO consists of 28 beds distributed on two floors for both intensive and intermediate care. Music Therapy is situated within an interdisciplinary therapy team that includes respiratory therapists, an occupational therapist and a speech and language therapist. Psychological support is available for parents throughout the hospital. The NICU is a semi-open unit, which means that parents cannot stay overnight. Visiting hours are normally from 8:00 a.m. to 6:00 p.m. Emphasizing the hospital's approach regarding humanization of care, a 'grandparents' day' for the NICU was piloted in 2015 and is now fully integrated. Although the CPO is a private hospital, the vast majority of patients originate from poor to very poor areas of Bogotá. This means that many parents in the NICU come from a difficult socio-economic background, with a low proportion of parents who have completed higher education and a high percentage of adolescent parents.

Music Therapy in the NICU is offered on a daily basis according to a case-work model. In general, the Music Therapy team works with three groups of patients (including their parents):

- Preterm babies,
- Babies with neurological risks,
- Babies with psycho-social risks.

While we use a variety of different methods and techniques during our work, an important part of our approach is based on the Rhythm, Breath, Lullaby (RBL) model developed by Joanne Loewy and her team at the Louis Armstrong Center for Music and Medicine in New York (http://www.nicumusictherapy.com). Entrainment – the conscious synchronization and modification of musical elements in relation to the physiological, emotional or behavioural states of the babies or parents – is essential in all our interventions. For a more detailed description of the programme including more case studies, see Ettenberger (in press). Based on some of the main principles of FCC and stressing the importance of the emerging relationship between parents and babies, our interventions centre on several key concepts, which will now be examined and illustrated by selected case vignettes.

Trauma amelioration

We recognize that the hospitalization in the NICU is a potentially traumatic and stressful event for both babies and their families (Jotzo and Poets, 2005; Stewart, 2009a; Stewart, 2009b). While the parents' experiences in the NICU do not

necessarily always match the severity, frequency or specificity of symptoms that might justify a psychiatric diagnosis such as acute stress disorder (ASD) or posttraumatic stress disorder (PTSD), there are nevertheless important overlaps with respect to the symptomatology described (Bryant et al., 2000). This situation can put in danger the family system and the subsequent relationship between the parents and their baby in the NICU. Thus, during Music Therapy, we aim to provide moments of relaxation or distraction through receptive music sessions or by fostering the bond between parents and babies through the use of '*song of kin*' (Loewy, 2015). On many occasions, we also use composition or songwriting with parents aiming at creating opportunities for insight and re-signification. The fact that patients perceive a sense of control with regard to their situation (i.e. locus of control) can be essential when thinking of trauma caused by medical conditions (Ratzer et al., 2014; Rawal et al., 2016). This is something that we found particularly important in the NICU, but also when the mother herself is hospitalized after delivery and initially unable to see her baby:

> *Baby Juan was born at 29 weeks and required immediate intensive care right after birth. His mother Esperanza was hospitalized in the Adults ICU due to her high blood pressure and was not able see him. Initially, Esperanza was referred to Music Therapy due to her agitation and need for relaxation. However, it soon became clear that not being able to see her baby worsened her anxiety and thus threatened her recovery. During the first session, Esperanza was upset and crying. The music therapist proposed a guided relaxation with live music, helping the mother to focus on her breathing. After that, Esperanza was able to explain her worries and disappointment. Thus, the music therapist proposed to send a 'message' to baby Juan in form of a song. Esperanza recalled a traditional nursery rhyme that she was singing to her baby every night during pregnancy. Both agreed that the music therapist could sing this song in the sessions with baby Juan in the NICU. During the next session with Esperanza, the music therapist told her about the positive reactions that baby Juan showed when hearing 'his' song and with the permission of the medical staff the music therapist also showed her a picture of baby Juan. While she was still upset, she stated that this musical 'message' helped her to feel part of Juan's life. She said: 'At least he knows that I think of him, that I love him. I feel that I can do something for him'. After her discharge from the Adults ICU, the nursery rhyme continued to be the main theme with Esperanza and Juan in the NICU.*

Participation and negotiation

Parents' participation in the care of their baby and the subsequent negotiation of their level of involvement are central aspects of FCC (Gooding et al., 2011; Kuo et al., 2012). The same is true for family-centred Music Therapy in the NICU: participation in Music Therapy is always an offer and never a must. Being transparent and communicating effectively the methods, possibilities and limitations of Music Therapy can help to negotiate in which way Music Therapy will be offered and how parents want to participate. Sometimes, parents join in immediately, and sometimes they need more time. Sometimes parents opt to listen, sometimes to sing, sometimes to create the lyrics for a welcome song or sometimes they just feel alright knowing that the music therapist is working with the baby alone. Also, the levels of involvement can fluctuate during hospitalization depending on the parents' and babies' needs and circumstances. Being sensitive and respectful regarding whether, how and when parents want to participate in Music Therapy is paramount and can be especially important during end-of-life care:

> *Sara was born extremely preterm at 24 weeks and with multiple challenges of her early start in life. She was intubated immediately after birth and remained critical for several weeks. Her prognosis was not good and when she was 28 weeks old she was referred to Music Therapy for eventual end-of-life care and for accompanying the parents during this difficult period. During the first encounter, both the mother and the father of Sara stood beside the incubator watching their tiny daughter. After explaining the goals and possibilities of Music Therapy to the parents, they both agreed to participate in an initial first session. While the father of Sara was very optimistic and repeatedly stated that Sara was very strong, the mother seemed to be more pessimistic and reserved. After a couple of minutes, the father had to leave for work, and the music therapist stayed with the mother alone. He asked her about the music she regularly listens to and if there would be some music she would normally choose when being in a difficult situation. She identified a Christian song and said that this music would give her strength. The music therapist asked her if she would feel ok singing a part of the song for Sara. She said: 'No, I just can't … but you can'. The music therapist started to sing gently the first verse of the song, while the mother was sitting in a chair besides the incubator, looking out of the window. However, from time to time the mother took a glimpse at Sara. At the end of the session she stood up and looked at Sara and said: 'Did you like the music, hm? Did you like it?' The music therapist offered to come back the next day to see if she wanted to continue with another session. The parents participated in four Music Therapy sessions before Sara died.*

Empowerment

Family-centred Music Therapy can offer transferable skills to parents who can learn how to use music for their baby during and after hospitalization. This is important, since many parents feel initially nervous when first handling, taking up and interacting with their babies in the NICU. Especially during the first days, parents may be fearful of touching or hurting the babies (Arnold et al., 2013). Besides, the underdeveloped autonomic nervous system of preterm babies makes their behavioural regulation more problematic (Porges and Furman, 2011), which may result in parents perceiving them as more 'difficult' (e.g. crying, being irritable) compared to full-term infants (Sobotková et al., 1996). To know how to use music for their baby through being an active participant in Music Therapy can help parents to feel empowered, to get to

know their babies better and to gain confidence (Ettenberger et al., 2014; Ettenberger et al., 2016). Thus, parental education is an essential part of family-centred Music Therapy in the NICU.

Supporting the family system

The quality of the relationship between parents and health care providers is crucial for their perception of support in the NICU (Van Riper, 2001), and current FCC practice describes various levels of support (Gooding et al., 2011). In addition, support within the family or other social networks can be crucial for parents during their baby's stay in the NICU (e.g. by providing emotional support, or by having someone who helps taking care of other siblings while the parents are in the NICU). While the agents of these support systems are mainly adults, siblings of preterm babies are an important population that has not received much attention yet. From a family-centred perspective, however, they are important current and future agents in the care and development of the preterm baby and may go through particular challenges during the baby's stay in the NICU. Examples of difficulties may be that they cannot visit their baby brother/sister, the limited time resources that parents have left for the siblings and not understanding why the baby is ill. During the Music Therapy assessment, we frequently ask parents about siblings and how they are doing. Through writing a letter for the baby in the NICU, which will then serve as part of the lyrics for a welcome song that can be composed for the baby, we try to integrate siblings (and other family members) into the Music Therapy process:

> *Baby Sebastian was born at 29 weeks with a birth weight of 1270 grams. Although he was very small and fragile, he was medically stable and the parents initiated kangaroo care on the second day of his life. He was referred to Music Therapy to help the parents in bonding and to help him in transitioning more smoothly between his sleep-awake phases. Both parents were happy to participate in Music Therapy and the first sessions started off with gentle singing of traditional nursery rhymes they proposed. After asking them how they knew these songs, they explained that baby Sebastian's sister Juliana used to sing them for her little brother during the mother's pregnancy. They also mentioned that Juliana was quite sad that she could not visit her brother and that she would ask for him every day. Since Sebastian needed to stay another couple of weeks in the NICU, the music therapist proposed to write a welcome song for Sebastian in which Juliana could participate. Both parents agreed immediately. The next session they brought a letter that Juliana wrote to her brother. The text was very moving and clearly expressed her desire to take care of Sebastian. Together with the music therapist, the parents structured the lyrics according to an improvised melody provided by the music therapist. At the end of the session, an initial recording was made so that Juliana could listen to it at home. The next session both parents told me how happy Juliana was to hear 'her' song for Sebastian. They called the song 'The King of our home'. We continued to work on the song for several more sessions and incorporated the suggestions that Juliana made during the process. The song soon became the central theme for the remainder Sebastian's stay in the NICU. Before Sebastian was discharged, the music therapist edited a short video of the song and gave it to the family as a good-bye present.*

Culture

Family-centred Music Therapy is always embedded in context and culture. Thus, family-centred Music Therapy takes into account not only the families' musical preferences but also wider cultural, historical and biographical aspects of the families in the NICU, including expectations regarding social relationships, communication and gender roles (Gilad and Arnon, 2010; Ettenberger et al., 2014; Ettenberger et al., 2016; Shoemark et al., 2015). Additionally, structural, political and socio-economic factors influence how Music Therapy is provided in hospitals in general, and in ICUs specifically. Thus, the 'culture' of each hospital and NICU needs to be taken into account when considering family-centred Music Therapy. A collection of case studies regarding these aspects specifically in the work with fathers in the NICU was published recently (Mondanaro et al., 2016).

Conclusion

The core principals of FCC may provide a useful framework for family-centred Music Therapy approaches in the NICU. So far, Music Therapy in the NICU has only occasionally been discussed in relation to more general care models (Hanson Abromeit, 2003; Shoemark and Dearn, 2008). While FCC can be a useful starting point in this sense, the model has also been criticized due to its lack of evidence (Shields et al., 2007; Shields et al., 2012). A recent attempt to propose alternatives to more traditional FCC can help to develop the model further and provides interesting overlaps to current family-centred Music Therapy practice and research in the NICU (Tallon et al., 2015). In addition, the way in which Music Therapy is delivered in the NICU will depend very much on the structural, organizational and philosophical pillars of each hospital and requires awareness and commitment of all key personnel and staff. Cultural aspects are extremely important to bear in mind, since the success of FCC is directly linked to the culturally, socially and biographically shaped expectations of the involved families. Thus, family-centred Music Therapy in the NICU needs to be embedded in the culture and context not only of the country but also of each specific NICU.

This article suggests that the active integration of parents in the Music Therapy process can help not only to improve the baby's wellbeing but also provides an opportunity to identify and work with the needs of parents and the wider family

systems. Music can be especially powerful in mediating between these different needs and can help to create a space where families in the NICU can meet.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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Author biography

Mark Ettenberger is an Ethno-Music therapist trained in Austria and holds a PhD in Music Therapy from Anglia Ruskin University, England. He certified as a Neonatal Music Therapist at the Louis Armstrong Center for Music and Medicine in New York, United States. He holds a MA in Peace Studies and Conflict Resolution from the United Nations Educational, Scientific and Cultural Organization (UNESCO) Chair of Philosophy for Peace, University Jaume I, Spain. He currently lives and works in Colombia, where he is the director of SONO – Centro de Musicoterapia (http://www.sono.la), a lecturer at the MA in Music Therapy at the Universidad Nacional de Colombia and the coordinator of music therapy at the Hospital Centro Policlínico del Olaya.