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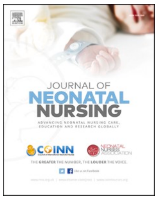

George's Lullaby: A case study of the use of Music Therapy to support parents and their infant on a palliative pathway

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ABSTRACT

Background: Having an infant diagnosed with a life-limiting condition is a stressful time for parents and has been shown to have an impact on parental mental health. Music Therapy, when provided by an HCPC registered Music Therapist with enhanced Neonatal training, can empower parents to share culturally based, personal music with their infant to assist with developmental care and create precious memories. These positive experiences are vital to hold in order to continue bonds after death and assist in processing grief.
Primary diagnosis: This case study presents a full term infant with surfactant deficiency (R192).
Intervention: Weekly Music Therapy was provided on the Neonatal Intensive Care Unit (NICU) with parents and infant following the Rhythm Breath Lullaby: First Sounds approach. It was then used again at the end of the infant's life at the family home.
Outcomes: Music Therapy provided a focus for the family while on the unit and supported family integrated developmental care of the infant. The relationship developed, a long with the music shared, then supported the family emotionally and physically as parent's held their baby at end of life.
Practice recommendations: To our knowledge this is the first time Music Therapy has been provided on the NICU through to end of life at home with the same Music Therapist. Music Therapy on Neonatal Unit is uncommon in the UK but has potential to support infant comfort whilst supporting the sharing of parent identities. Music Therapy has the potential to provide a focus that enables parents, who have a heightened awareness of the proximity of loss, to interpret, play and comfort their infant.

The admission of an infant to the Neonatal Intensive Care Unit (NICU) can be traumatic for parents and impact upon their ability to bond with their infant (Al Maghaireh et al., 2016). Parents report having a heightened awareness of monitors and tubes, being anxious about interacting with their infant who appears fragile and mourning the loss of their expected parental role (Colville. et al., 2009). This is further compounded when an infant is diagnosed with a life-threatening condition; heightened parental stress and awareness of the proximity of loss resulting in increased challenges with interpreting their infant's cues and opportunities for positive memory making (Minde. et al., 1984, Bright. et al., 2013). Research has also shown that parents of critically ill infants are more likely to experience mental health problems than those with typically healthy infants (Fraser. et al., 2021).

It is has been widely demonstrated that Music Therapy can assist with parent-infant bonding, interpreting infant cues and supporting parents experiencing anticipatory grief (Ettenberger. et al., 2016; Lowey., 2015; Mondanaro, 2010). For this reason, Music Therapy is widely used in palliative care settings to support infant, children and their families during and at end of life as well as post-death (Ludwig., 2019; Swan., 2017). In these settings Music Therapy provides opportunity for the infant to be seen as a whole rather than seen for the individual areas of fragility and has the potential to create moments that can be treasured after they have died. Music Therapy on the Neonatal Unit is a growing area of study with research already demonstrating the benefits of Music Therapy for supporting parent-infant attachment as well as documented positive physiological outcomes (Ghetti et al., 2019; Edwards, 2011; Haslbeck et al., 2020; Loewy et al., 2013). The focus of supporting those with life-limited infants, however, is an area which is under researched.

This case study will illustrate the use of Music Therapy during one family's journey from admission to Neonatal Intensive Care through to end-of-life care at the infant's home, at the parent's request. Collaboration between multidisciplinary teams from two hospitals and the hospice enabled the family to experience the best possible death of their infant, with music being a therapeutic intervention which became a part of their lives together, and which underpinned the transition from

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hospital to hospice care. To the best of our knowledge, Music Therapy to support end-of-life care, provided by the same Music Therapist from the neonatal unit through to the hospice, has not been done before. Music Therapy methods were based on principals from the First Sounds Rhythm Breath Lullaby (RBL) approach (Loewy, 2015) and provided by the first author, a Specialist Music Therapist employed by both the Neonatal Unit and Children's Hospice. At the request of the baby's parents, the baby will be referred to by name.

1. George Peace

George was born at full term with presentation of Respiratory Distress Syndrome, suspected sepsis and signs of Persistent Pulmonary Hypertension. He was transferred from his local hospital to University College London Hospital where he was provided with conventional ventilation and Hydrocortisone was started. When George did not respond to the steroids, surfactant deficiency was suspected and so was provided with surfactant. Initially George responded with a reduction in his oxygen requirement, however this was followed by progressive deterioration resulting in a second dose being required. At 14 days of life George's CT scans showed signs of interstitial lung disease and parents were advised to have genetic testing for surfactant protein deficiency. It was also recommended that they begin to receive support from the unit psychoanalyst.

1.1. *Therapeutic intervention*

At 35 days of life and an awareness of George having a terminal illness, a care plan was made for redirection of care. Organ donation, hospice services, post mortem and symptom management were all discussed with parents. Parents requested that family could visit, as due to the restrictions enforced by the COVID-19 pandemic no one other than parents had met George. Redirection of care was then postponed the next day due to some surfactant Protein B found. Whilst awaiting genetic testing results, parents were supported with creating positive memories through bathing, accessing therapies and a meeting with family was arranged in an isolated room.

1.2. *Music Therapy on the neonatal unit*

George was referred to Music Therapy by the unit Physiotherapist. It had been identified by the unit Physiotherapist that although George appeared to be sleeping most of the day, due to his age he would possibly engage with stimulation at a level he could tolerate and would potentially benefit from Music Therapy. The level of stimulation felt to be appropriate was based on principles from Inga Warren's Foundation Toolkit for Family Centred Developmental Care (Warren., 2020). Ways to support the family to build positive experiences together were continually discussed both with parents and the multidisciplinary team in psychosocial meetings, due to the unpredictability of George's condition. George had previously rapidly desaturated when his parents had held him, which had made them feel nervous about how to be with George without causing him distress. The team felt that Music Therapy could support the parents to develop their relationship with George, providing a focal point for interaction.

Initially the Music Therapist met with George's mother at the cot side and discussed the family's connection to music, helping to identify nursery rhymes that would assist them in sharing the family's cultural background with George. Once identified, the therapist returned to the cot side later that day and was taught the song by George's Mother. When ready the Music Therapist observed both George and his vital signs whilst his Mother leaned close to George to sing to him, accompanied quietly by the therapist. On singing to George, autonomic changes including increased oxygen saturation and increased pink colouring were observed and highlighted to his mother to illustrate Georges recognition and enjoyment of mother's voice. George's Mother was able to see the effect of her voice on baby and in the following session was encouraged to continue to sing, repeating her chosen lullaby whilst looking out for changes in George's face and pausing to reflect his reactions. This time further explanation was provided on the effect of slowing the pace of singing and reducing stimulation of songs through a change from singing with words to humming. This provided George's mother with ideas for ways to help soothe and settle her baby during the week by focusing on his attunement to her voice. Music Therapy was advised by the Music Therapist be provided to assist with soothing and settling George, or for play when nurses felt he had managed to achieve a deep sleep and was ready to have a little stimulation. This ensured that George's sleep was protected and increased the potential for parents to notice positive responses.

The family was provided with a one-to-one twenty-minute Music Therapy session once a week whilst they were on the unit. In total seven sessions were provided for the family with the majority having both parents present. After the unit had enabled extended family to meet George in person, parents requested that Rolling Stones' 'Paint it, Black' was shared with George as they had noticed he had responded to this when played a video of his cousin enjoying listening to it. This song was turned into a lullaby for George by the Music Therapist, slowing the pace, using humming rather than words and changing the meter of the song to create a sense of swaying George to the music. George's parents enjoyed having a personalised lullaby for him and chose to begin each of the following sessions on the unit with this song, followed by popular nursery rhymes. On some occasions George was awake during the sessions, moving his arms to play with toys offered and engaging with his parents. When George's gaze focused in the direction of the sound of a parent's voice this was always highlighted to parents to support with bonding, and encourage continued interaction between sessions. When George was unsettled parents were supported with singing at a slow pace to assist with soothing. Each session was adjusted to suit George's state, ranging from singing with words and playful interaction when in a quiet alert state, to slow paced humming to assist with moving from either active or crying states through to quiet sleep.

2. Transfer to paediatric care

Once confirmation of the 19-gene sub-panel associated with surfactant deficiency (R192) was gained, advice was sought from Great Ormond Street Palliative Care and Respiratory teams. A further dose of Methylprednisolone and Hydroxychloroquine was then provided as it was felt that previous steroids may have been affected by an underlying infection at the time. This resulted in improved FiO2 requirements and therefore George became a candidate for further Methylprednisolone. Now at 63 days of life and although continuing to be ventilator dependant, George's FiO2 requirements had reduced to around 50–60% and was considered stable. George was transferred to Great Ormond Street Paediatric Intensive Care Unit (PICU) for tertiary respiratory input and on going management.

At GOSH his medical course was complicated by infections. More steroids were tried when his infections had been treated but despite this over the course of the next month there were no significant improvements. The PICU consultants and the Respiratory team held regular meetings with George's parents to discuss his treatment and ensure communication of medical updates were clear. They were also supported by the Family Liaison Team, Play Specialist, Psychologist and Family support worker and encouraged to be part of his daily care. These elements were felt to be vital in ensuring George's parents had a sense of control in the care of their baby.

At 4 months, PICU, Respiratory, Palliative Care and parents met, and everybody agreed that a tracheostomy and long terms ventilation was not in George's best interest as his underlying lung condition had not responded to treatment. With this in mind, George's parents expressed their wish to have him transferred home for a compassionate extubation.

3. End of life with Music Therapy

George's parents wished for George to experience the garden at the family home. They also requested that the Music Therapist who had been on the unit and available through the local hospice to play George's 'Paint It, Black' lullaby during extubation. It was felt by parents that music had been something that had previously relaxed George, and reminded them of happier times, so would support the best possible end-of-life care for George.

As planned, George was taken home with the support of the Great Ormond Street PICU team, Palliative Care Team, Children's Community Nursing team and Noah's Ark Children's Hospice for extubation. George's parents spent time with George outside, had photographs taken and changed him on his own changing table. When they were ready, they sat together in the area of their home that they had decided they wanted to be, and the lullaby was played live by the Music Therapist through humming accompanied by acoustic guitar while they sat holding each other. When parents felt ready, they signalled the team to come forward and extubate George. Music continued throughout this time, providing a steady pace and a sensory focus for the family to be together in. The Music Therapist created environmental music that assisted deep breathing through improvising on acoustic guitar to provide a slow steady pace, along with fragments of lullabies with improvised held vocal tones to attune breathing to. As George came to the end of his life, the music was simplified and continued in order to support parents as they held George before pausing in stillness.

Together at home.

Following his death, George was placed in the cot the family had prepared together with the local hospice, with a cuddle cot cold blanket. The family were then left to spend the night together alone. The following day, George's body was transferred back to hospital via the family's chosen funeral director for a lung biopsy, which would provide further information for the parents in any future pregnancies.

4. Parent reflections

George's Parents were invited to share some of their thoughts on their experience of Music Therapy and provided the following in writing via their family link worker at Noah's Ark Children's Hospice:

4.1. Music Therapy on the NICU

> *Kirsty spent time with George and us every Monday during our stay at UCLH. That time was invaluable to us. Surrounded by NICU equipment and sounds, we were able to fully immerse ourselves in the moment. No beeping, just us singing songs to our son and watching him, rather than the numbers on the screen.*
>
> *Sadly, George spent all his life in ICU apart from his very last day when we were able to bring him home. We could really tell he enjoyed music and especially the gentle sound of a guitar. At 2 and a half months old, George was transferred to PICU at GOSH and unfortunately due to coronavirus Kirsty wasn't able to see him anymore. It had an impact not having that special time with him during our stay at GOSH, but we were very happy to have Kirsty join us on the day he was extubated.*

4.2. Music Therapy at end of life

> *Kirsty joined us on the day of Georgie's compassionate extubation at home and it was very comforting to know that he was surrounded by familiar pleasant sounds associated with happy and calm times we had together. For one last time we were able to experience being a family of three. Later I asked Kirsty if she could make a recording of some of the music she played for him - she very kindly sent us the recording. We don't always have the strength to think of his last day, but when we really want to go back to that day, listening to the recording really helps. It also helps us think of all the wonderful times we had with our little boy.*
>
> *Thank you for writing about George, we really hope that his and our experience will help make it a standard practise to introduce Music Therapy in NICU/PICU.*

Experiencing being outside.

5. Conclusion

Reflecting upon their experiences the parents felt that they had experienced the best possible death of their baby. The crucial elements they believed to have supported a 'good' death were: bringing George home, Music being provided to focus on and to distract from distressing sounds and the transition to hospice services which enabled them to spend more time with him post death. Due to the Family Liaison Team's awareness of the family's experience of Music Therapy this was offered as an option for being included at end of life when meeting with parents to discuss advanced care plans. The provision of Music Therapy as a continued service from Neonatal Unit through to end of life and post death is currently not a common experience and at the time of this infant's death was the first occurrence the authors are aware of. As Music Therapy on Neonatal Units in the United Kingdom is minimal it would be valuable to study the impact on families' experience of end of life when Music Therapy is offered at end of life after a relationship with a Music Therapist has been established on the Neonatal Unit. Additionally, it would be beneficial to investigate Neonatal Professional's perceptions of children's hospice to consider Music Therapy as a means to support a non-threatening way into referral to hospice and then supporting with future transitions within palliative care.

Building the evidence base underpinning Music Therapy will allow neonatal healthcare professionals to develop best practices, and support families to bond with their infants during critical and end-of-life care.

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