

'Experiences of Music Therapy in Paediatric Palliative Care from multiple stakeholder perspectives'

I began my PhD in October 2020 at the University of York with the Martin House Research Centre which is a multi-disciplinary centre for research on the care and support of children and young people with life limiting conditions or medical complexity, their families and the workforce that care for them.

The funding I received from The Music Therapy Chairty has contributed to the completion of my systematic review chapter for my thesis where I have written up my review of the literature which focusses on experiences of music therapy in paediatric palliative care. In addition I summarised this chapter to submit to the Journal of Palliative Medicine in December 2022, this is currently being peer reviewed and I hope to hear the outcome on this very soon.

In this review I systematically identified and critically appraised all the research in this area with a view to this informing my next stage of research. The aims and objectives of the systematic review were as follows:

- Research what is known about the experience of music therapy in paediatric palliative care from multiple stakeholder perspectives.
- Systematically review the literature to identify qualitative studies which examine the experiences of music therapy in paediatric palliative care from different stakeholder perspectives.
- Synthesise findings to gain a deeper understanding of this topic to inform further research.

Review question:

- What is the experience of music therapy in paediatric palliative care from multiple stakeholder perspectives?
- What can we learn from this to inform intervention development and music therapy contribution to paediatric palliative care?

What was already known before the review:

- The provision of music therapy services in paediatric palliative care differs across countries, in the UK this has largely been developed by the third sector.
- There is no international review of qualitative studies of multiple stakeholder experiences of music therapy in paediatric palliative care and no UK based studies in this area.
- Little is known about stakeholder experiences of this clinical intervention as a basis for service development

Conclusions of review:

- Reported unique benefits of music therapy in this clinical area particularly in supporting family wellbeing and their ability to thrive.
- Awareness that the therapeutic relationship, interpersonal skills of the therapist and experience in paediatric palliative care are central to positive outcomes.

- Evidence of the benefits of this clinical intervention for this population for funding purposes and future development of provision.

Implications for practice, theory or policy:

- Paediatric palliative care settings should strive for music therapy provision for children and families using their services, in order to support family wellbeing.
- Music therapists should be recruited with interpersonal skills and experience as central to the recruitment process.
- Further high-quality research that captures the voices of the child and family articulating their own experiences of music therapy is recommended, positioning these voices as central to service development and provision.

I have consulted three times with the Family Advisory Board at Martin House (which includes parents, young people and other adult family members of children and young people with life-limiting conditions) on the outcomes of my review and next stage of my research and will continue to consult with them throughout the study.

I had my Thesis Progression Board in September where I presented my work and discussed my progress which was chaired by Professor Kate Flemming, head of the Health Sciences department at the University of York who is internationally known for leading research and service innovation in palliative care nursing. She works with the WHO on the use of qualitative evidence synthesis to inform guideline development for complex interventions which is the method I used for my systematic review. This was very successful, and I was congratulated on my progress and robust and accessible review, we engaged in a very useful discussion about the next stages of my research, predominantly the methodology.

I presented my systematic review at the Maruzza international congress on paediatric palliative care in Rome in May 2022 (see poster attached) and as you know at the Music Therapy Charity conference in October at the Guildhall, London. At all opportunities for dissemination, I have/will credit The Music Therapy Charity for their generous support.

I am now onto the next steps of my PhD which is my own study based on the gaps in the literature that were highlighted in my systematic review, most importantly hearing the voices of children and families reporting their own experiences of music therapy in children's hospices to inform service development. This will be the first UK based study in this area. I am currently writing my research protocol and putting together my ethics application. The title of my study is: Understanding Child and Parent Experience of receiving Music Therapy in a Children's Hospice setting: a qualitative study of child and parent experiences and perspectives.

I continue to be so grateful for the support of The Music Therapy Charity which has helped to progress my research to this stage and I hope will help to influence policy, practice and therefore future funding and support for music therapy in paediatric palliative care.

V.Kammin March 2023