



## Music therapy in children's hospices: An evaluative survey of provision



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### ARTICLE INFO

#### Article history:

Available online 13 October 2014

#### Keywords:

Music therapy  
Music  
Children's hospices  
Creative therapies  
Family work

### ABSTRACT

This paper presents the results of a survey of the range of music therapy practice in children's hospices in the UK. Music therapists are challenged to work with children with life-limiting and life-threatening conditions during short periods of respite care over several years or at end of life. Flexibility is fundamental to working both individually and in small groups in response to the shifting needs of the children and their families. In the context of a children's hospice music therapists are called upon to work creatively with siblings and family members and members of the multidisciplinary team in addition to the children themselves. A questionnaire and focus group for music therapists working in the children's hospices provided evidence of the range of work, priorities and future plans for development. Telephone interviews with specialist staff at children's hospices where music therapists were not currently working provided evidence of how music and musical activities were perceived and utilised, with any plans for future provision for a music therapy service and some of the practical and resource issues being itemised.

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### Background

Daykin, Bunt, and McClean (2006) reported on a survey of music provision within UK cancer care organisations offering complementary therapy services. The survey examined the extent and type of music provision and explored these providers' views about the role and contribution of music and music therapy in healing. Daykin et al. (2006) found that cancer care providers offering complementary therapy services included an assortment of music activities and on occasion this included employing a registered music therapist. What was striking, however, was that without exception, all of the children's hospices included in the sample employed a registered music therapist. To better understand the role and development of music therapy services in children's cancer care, a nationwide evaluative survey of UK children's hospices took place. This paper reports on the findings of this survey.

Children's hospices care for only a small proportion of children with a cancer diagnosis. These hospices are accessible to children and young people with a variety of medical conditions or disabilities that are life-limiting or life-threatening, whereby the child or

young person is not expected to reach their nineteenth birthday. Together for Short Lives, a leading UK charity in paediatric palliative care, sampled children across the West Midlands, a central area of England, to see which disorders are most predominant within this population (2012). They found congenital and chromosomal disorders or static encephalopathy, for example severe cerebral palsy, were the most common diagnoses for children with life-limiting or life-threatening disorders. Consequently, the caseloads and care provided by children's hospices are very different to those of adult hospices. In the former, life-limiting and life-threatening illnesses often have long trajectories and physical impairment as well as intellectual disabilities can be profound (Smith, 2014). Forms of respite care are offered in children's hospice services, although the multi-disciplinary support services they offer extend beyond basic respite care (Woodhead, 2011).

Children's hospices in the UK are fortunate to benefit from Jessie's Fund, a charity that supports the design, implementation and development of provision of music therapy services for children (Bolton, 2005; Jessie's Fund, 2014). Since Jessie's Fund enabled the first appointment of a music therapist in a children's hospice in 1994, there has been a steady growth in the popularity and provision of music therapy in this setting. By 2011 Jessie's Fund had introduced music therapy into 33 of the 45 children's hospices in the UK. The charity supports hospices in this provision by

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subsidising the music therapist's salary in decreasing increments over the first three years with 28 hospices maintaining the service through their own funding.

This exploratory survey of music therapy in children's hospices aims to unpin the successes, challenges, subtleties and unique aspects of music therapy provision in this setting, complementing and furthering the knowledge gained in the former survey of cancer care. This paper begins with a description of the literature presented on this topic, followed by a presentation of the research methodology and results. The views of the music therapists involved in the research are included in a discussion of achievements, concerns and challenges faced by this field of clinical work.

### Music therapy in children's hospices

In a systematic review of music therapy and end of life care, [Bradt and Dileo \(2010\)](#) confidently state that there is a lack of evidence-based research. It is perhaps then not surprising to find that in the smaller population of paediatric palliative care, there is a greater paucity of evidence surrounding the role and impact of music therapy ([Daveson & Kennelly, 1999](#); [Duffy & Fuller, 2000](#); [Ibberson, 1996](#); [Knapp et al., 2009](#); [Lindenfelser, Grocke, & McFerran, 2008](#); [McFerran & Hogan, 2005](#)). Evidence gathering is challenging due to small sample sizes and the complex ethical issues that present themselves when researching this palliative care population ([Black & Penrose Thompson, 2012](#)).

The initial years of development of music therapy services are documented in case narratives and descriptions ([Daveson & Kennelly, 1999](#); [Gillie, 2005](#); [McFerran & Hogan, 2005](#); [Pavlicevic, 2005](#); [Sheridan & McFerran, 2004](#)). [Pavlicevic's 2005](#) book, which details case narratives, remains the leading text on music therapy in the children's hospices in the UK. The subject occasionally features as a chapter in a book, such as in the educational text by [Casey \(2012\)](#). Other authors have explored aspects of practice in children's palliative care contexts, as in the paper by [McFerran and Shanahan \(2011\)](#). While these contributions are useful, there has been no attempt to develop a comprehensive text since [Pavlicevic's](#) contribution.

Internationally practitioners have endeavoured to evaluate music therapy in children's services by eliciting feedback from staff and clients. For example, [Amadoru and McFerran \(2007\)](#) explore the perceptions of staff, while [Lindenfelser et al. \(2008\)](#) report on interviews with bereaved parents about their experiences of receiving music therapy with their child. Parents receiving a paediatric palliative care service have been surveyed to determine their level of satisfaction and the impact of services on their quality of life ([Knapp et al., 2009](#); [Lindenfelser et al., 2008](#); [Lindenfelser, Hense, & McFerran, 2011](#)). Music therapy bereavement projects for family members such as siblings have also been evaluated to determine impact ([Kammin & Tilley, 2013](#); [Register & Hilliard, 2008](#)).

It is clear from this literature that paediatric palliative care, as distinct from adult palliative care, requires a unique understanding. [Lindenfelser et al. \(2011\)](#) describe children and families accessing paediatric care to be, "one of the most at-risk populations within the palliative care field" (p. 223). Children's hospices strive to create experiences that enhance the child's quality of life, normalising the high input of care necessary and making it as accessible and attractive as possible ([Sheridan & McFerran, 2004](#)). Emotional issues can be complex; the referral criteria for children's hospices set out above highlights the likelihood of disorders being chronic and lengthy, with the reality of the child's potential to die being constantly present up until the child may transition to adult care. Within this uncertainty, music therapists are challenged to work in a manner that is exceedingly flexible.

The highly valued outcomes of the music therapy services discussed within the literature have a strong focus on enhancing quality of life ([Lindenfelser et al., 2008, 2011](#); [McFerran & Shanahan, 2011](#); [Sheridan & McFerran, 2004](#); [Smith, 2014](#)). In children's hospices, music therapy seeks to impact emotional wellbeing and to facilitate self-expression. There is an effort to explore and alleviate feelings of fear, pain and loss, to find mutuality in groups and family sessions and meaningful musical interactions with the therapist. Children who are non-verbal often readily respond to opportunities to communicate through music, demonstrating increased responsiveness and intentionality. Although relationships between patient and therapist can be developed over a long period of time, typically each session stands alone, with uninterrupted focus on the child and the creation of musical experiences ([McFerran & Shanahan, 2011](#); [Sheridan & McFerran, 2004](#)). At the heart of this work appears to be the creation of repeated opportunities for the child to express choice and experience a sense of control, to somewhat counteract the lack of control experienced in their illness and treatment ([Amadoru & McFerran, 2007](#); [Bolton, 2005](#); [Lindenfelser et al., 2011](#); [McFerran & Hogan, 2005](#); [Sheridan & McFerran, 2004](#)). This is deemed, "critical for best practice as the family grapples with the implications of their child's life-threatening or life-limiting illness" ([McFerran & Hogan, 2005, p. 2](#)).

In 2012 *Together for Short Lives* conducted a regional survey (with input from five academic institutions in the West Midlands) aiming to determine how well palliative care needs are met for children. The provision of comprehensive emotional support from diagnosis to bereavement was identified as a priority action for the future of paediatric palliative care ([Together for Short Lives, 2012, p. 23](#)). In response, children's hospices appear to be ideal institutions to benefit from music therapy. [Lindenfelser et al. \(2008\)](#) remark that the aims of music therapy are, "remarkably similar to those set out by the World Health Organization for paediatric palliative care" (p. 332), in particular the perceived impact on quality of life through the art of music. Dame Cicely Saunders, when founding the hospice movement, imparted a doctrine focused on enhancing quality of life that has continued to dominate hospices. The way in which music therapy fosters opportunities for choice and control that facilitate self-expression and emotional release, powerfully enacts this doctrine ([Sheridan & McFerran, 2004](#)).

Despite the potential of music therapy in children's hospices, this short summary of publications demonstrates that relatively little research of this work exists to inform future development, in particular development of music therapy in children's hospices in the UK. Gathering evidence of this kind is arguably a necessary task in today's climate, whereby there is external pressure for demonstrating evidence of effective practice and cost-effectiveness. Authors, remarking on the dearth of evidence plead for an expansion of research, ([Black and Penrose Thompson, 2012](#)), including collaborative research ([Amadoru & McFerran, 2007](#)) and an evidence base demonstrating the direct impact on parents and siblings through specific interventions ([Lindenfelser et al., 2008](#)). A small but growing evidence base of research within adult palliative care in Australia has led to palliative care guidance recommending that community and in-patient services fund, "0.5 effective full-time music therapy positions per 100,000 population and 0.25 effective full-time music therapy positions per 6.7 acute hospital/hospice beds" ([McFerran & Hogan, 2005, p. 1](#)). Recognising the insufficiency of case narratives, internationally music therapists are called to set an agenda for providing evidence of outcomes, beginning with data retrieval to determine current levels of service provision ([McFerran & Hogan, 2005](#)). No further evidence has been provided to embark on this task and therefore this serves to be the purpose of this paper.

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