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Author: Sarah Hodgkinson Leslie Bunt Norma Daykin

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MUSIC THERAPY IN CHILDREN'S HOSPICES: AN EVALUATIVE SURVEY OF
PROVISION

Sarah Hodgkinson, BA, PGDipMTh^a, Leslie Bunt, MBE, BA, CertEd, LGSM (MT), PhD,
FAMI, FRSA^{b*}, Norma Daykin, BA, PGDipMus, MSc, PhD^b

^a *University of Southampton, University Road, Highfield, Southampton SO17 1BJ, United Kingdom; Shooting Star Chase Children's
Hospice Care, The Avenue, Hampton TW12 3RA, United Kingdom*

^b *University of the West of England, Glenside Campus, Bristol BS16 1DD, United Kingdom*

*Corresponding author. Tel.: +44 117 328 8220.

E-mail address: leslie.bunt@uwe.ac.uk

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.

Keywords: Music therapy; Music; Children's hospices; Creative therapies; Family work

Background

In 2006 Daykin, Bunt and McClean reported on a survey of music provision within UK cancer care organisations offering complementary therapy services (Daykin, Bunt & McClean, 2006). 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, Bunt and McClean (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 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, 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 (Daverson, 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 endeavored 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 Grocke and McFerran (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 (Knap et al., 2009; Lindenfelser, Grocke & McFerran, 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, Hense and McFerran (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, Grocke & McFerran, 2008; Lindenfelser, Hense & McFerran, 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, 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, Grocke and McFerran (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 & 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, Grocke & McFerran, 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.

Methodology

The survey methodology was selected to capture the full scope, utilisation and attitudes towards music therapy across children's hospices in the UK. The survey explored the needs of individual organisations, looking at how children and families who are offered the service choose to utilise it and why some hospices may not include music therapy in their package of care.

Survey Design

The survey focused on two main approaches: a postal questionnaire for music therapists working in the hospices and a telephone consultation for staff at children's hospices identified as not currently offering music therapy provision. In addition, a focus group of music therapists was undertaken.

Following a review of current literature the postal questionnaire was created by one of the researchers who is also a music therapist working in one of the hospices (SH). The postal questionnaire included 17 closed questions with multiple-choice answers and eight closed questions asking the respondents to estimate average numbers or frequency to elicit the scope and format of music therapy work. Eight open-ended questions were included to determine if the respondents were undertaking any joint work with other professionals or non-clinical work. Two open-ended questions concluded the questionnaire, asking the respondents to first share what they considered to be their greatest achievements and second, describe how they envisaged music therapy developing in children's hospices.

The telephone interview included six questions, asking respondents to describe: their provision of family support; musicians utilised by the hospice; interest in developing a music therapy post; any concerns about music therapy.

The interviews were undertaken by one of the university-based researchers (LB). Interviews lasted between 10 and 20 minutes. They were not audio recorded for future transcription but comprehensive notes were taken by the researcher with specific comments transcribed verbatim and checked for accuracy with the interviewee. The interviews sought to explore the way in which hospices use music and staff perceptions of music therapy in the context of broader provision of psychosocial and creative therapies.

The Focus Group design involved three sub-groups. Each group attended three 30-minute sessions focusing on the past, present and future of music therapy provision in children's hospices. Each session contained three suggested questions to promote discussion, for example, "If your hours were doubled today, how would you use this time?" A volunteer spokesperson from each group was asked to share a summary of their discussion with all of the attendees. Minutes of this summary were recorded by the Director of Jessie's Fund and agreed by those in attendance.

Survey Distribution and Study Participants

The study population included 43 children's hospices that were identified from the online directory of hospices kept by Together for Short Lives (www.togetherforshortlives.org.uk/families/services). Initially all 43 hospices listed in the directory were contacted by telephone to confirm whether music therapy provision existed.

This revealed that 28 hospices employ a qualified music therapist in some capacity (sessionally, directly or indirectly contracted) and 15 hospices did not.

The postal questionnaire was sent to the 28 hospices found to employ a music therapist. The questionnaire was sent with a prepaid envelope and respondents were given a reminder one month later by email. The 28 music therapists also received an invitation to attend the focus group. Participants for the telephone consultation were similarly located in the initial search finding 15 hospices where there was currently no music therapist employed. Senior or specialist staff were invited to take part in a telephone interview.

Respondents of the postal questionnaire and focus group were assured of the confidentiality of the process and they indicated consent by signing the relevant consent document. Before the telephone interview all participants were introduced to the consent process, agreed to take part in the interview and sent written consent for their answers to be used in the subsequent report. The overall project was approved by the Ethics Committee of the Faculty of Health and Social Care, University of the West of England, Bristol.

Analysis

Open-ended responses resulting from the postal questionnaire and telephone consultation were subjected to thematic content analysis. Following this the themes of the qualitative data were interrogated for how they related to the development and provision of music therapy in children's hospices, or barriers to this provision. The notes from the telephone interviews were passed to the third member of the research team (ND) for analysis and selection of the themes. Statistical data are reported here descriptively alongside the themes drawn from the open-ended questions. The themes arising from the minutes of the focus group are used in this article to inform the discussion. Time and funding restrictions prevented more extensive

checks for validity, the researchers being aware that full transcripts for future analysis would have been a preferred option.

Results from the Postal Questionnaire and Telephone Consultation

The questionnaire, sent out to 28 music therapists, was returned by 22 therapists (a high 82% return rate). One further questionnaire was received after the deadline from a newly appointed therapist. The results from this questionnaire have not been included in these findings. Senior or specialist staff from 14 of the 15 hospices not currently providing music therapy agreed to take part in a telephone interview. The majority of respondents were from nursing backgrounds, two exceptions being an activities coordinator and a play specialist. Nearly all respondents occupied a senior position or a clinical management role. 10 music therapists participated in a focus group. The data and themes drawn from the focus groups are detailed within the discussion, following the results presented from the survey and telephone interviews.

Music Therapy Provision

Music therapy provision has increased alongside the development of children's hospices within the UK. Between 1994 and 2011 this has grown from one music therapist working for one day a week to 28 music therapists between 43 children's hospices surveyed. The 22 therapists who responded to the questionnaire work an average of 13 hours a week, with a range of 3.5-37.5 hours.

INSERT TABLE 1 HERE

The telephone consultation revealed that hospice staff in the 14 organisations where music therapy was not part of current provision nevertheless had a positive attitude towards the role of music in children's palliative care. Only one of these respondents reported that music was not currently specifically used within the hospice. On further discussion it was revealed that musical activities in this hospice were incorporated into other activities such as play activities and family days. Several respondents reported having musical instruments that were used on site in music groups and one to one sessions, as well as off-site in home visits. Some hospices benefitted from having employed staff who were able to lead musical activities, in other hospices music activity was led by volunteers and family members. However, in most settings, a core group of staff was involved in delivering music activity including nurses, nursery nurses, health care assistants, play and care workers, a chaplain and, in one hospice, a music teacher.

Several hospices also made use of external music resources. In some instances, volunteers performed this role but in the majority of cases, this meant involving guest musicians including community musicians and professional performers drawn from specialist organisations such as Music in Hospitals (2014).

Most of these respondents reported that they would like to provide specialist music therapy services in the future, with one adding the caveat 'eventually'. Three respondents did not have a definite view about providing music therapy, although on discussion it was revealed that one of these was currently investigating collaborating with a local music therapy charity to provide support. Nearly all of the respondents requested more information about how to access and provide music therapy.

Seven of these respondents identified specific concerns that might limit the development of music therapy. Three respondents mentioned cost as a barrier, including the cost of employing a music therapist, the lack of funding for music therapy provision and potential costs to the organisation. Two respondents were concerned about potential demands on existing services that the provision of additional specialist services might place, including demands for support and supervision. Other respondents felt that music therapy provision might be over and above standard service or would not fit in with their existing service. For example, one respondent raised the perception that music therapy needs to be a continuous service, stating that this is not how the hospice functions. Another emphasised the importance of any new service reflecting and understanding the unique rationale of the organisation, emphasising that no two hospices are the same. Similarly, one respondent raised a concern that resources should be sufficient to allow a music therapist to visit children within their homes as well as when resident at the hospice.

The music therapists' caseload.

The music therapists reported that music therapy could be accessed by nearly all of the children known to their hospice. To determine commonalities in this client group, the music therapists were asked to estimate time focused on children with specific life-threatening and life-limiting conditions. The Together for Short Lives categories of life-limiting conditions were used to classify conditions (see Table 2).

INSERT TABLE 2 HERE

According to the music therapists' estimates, over half of the children referred for music therapy in children's hospices have a Category 4, irreversible but non-progressive condition resulting from a severe disability, leading to susceptibility to health complications and likelihood of premature death. The next highest category was children with Category 3 progressive condition without curative treatment options. Categories 1 and 2 were least common.

The five main reasons for referral to music therapy were: support for the child and family during end of life care; the child reporting to have a liking for music; symptoms of depression or anxiety; bereavement; and supporting a child or sibling in coming to terms with a diagnosis. Music therapy took place in the hospice with the children resident at the time, as well as children visiting the hospice specifically for prearranged music therapy appointments. Just under a third of music therapy work took place with children referred or identified for long-term work. A smaller proportion of music therapy takes took place with siblings and bereaved siblings.

Examples were given of work with very young children, including creating memories for the parents of a young baby who was only expected to live for a few days. The age of the oldest client varied from hospice to hospice, and related to whether work was carried out with the whole family, including older relatives in their 70s and 80s.

The music therapists described continued interaction with parents including parents attending sessions and informal support given before and after sessions. Other forms of support given to parents that were mentioned were phone/email contact, information documents, support groups and opportunities for parents to understand how to use music at home. The attendance of siblings was determined according to the needs of the child and family: just

under half of the music therapists encouraged this. Only seven music therapists answered that they did not attend regular meetings/forums to discuss the family as a whole, reflecting the family model of care demonstrated across children's hospices.

Working collaboratively with colleagues and external agencies.

All but two of the music therapists reported that other colleagues regularly or occasionally attend sessions. The music therapists gave a variety of reasons for this, from nurses needing to address the care needs of the children to attending sessions to assist the music therapist. All but one of the therapists reported that their hospice offers some kind of staff training about music therapy. This was an area where potential benefits from joined up working across the different hospices were identified, for example in planning and delivering such training.

The music therapists were asked about other psychological therapies provided by their hospice. They listed a wide range of other professionals working at their hospice including: social workers, siblings workers, psychotherapists, play therapists, occupational therapists, psychologists, nurses with additional training, complimentary therapists and students. A significant proportion (n=15) of the music therapists ran joint sessions with other professionals or took part in groups run by other professionals

Respondents without a music therapy provision were asked about other psychological therapies provided by their hospice. A wide range of activities and therapeutic resources were identified as being available to children and families. Respondents mentioned staff with specialist skills that were able to offer a level of support. All of the respondents were able to identify some form of psychosocial support. Two thirds of hospices offered complementary

therapies, provided by specialists and by hospice staff trained in specific techniques. In relation to creative therapies, only one art therapist, one drama therapist and two play therapists were reported, although creative and play-based activities were widely used. Overall, there is relatively little use of specialist creative therapy professionals within these hospices.

INSERT TABLE 3 HERE

Where services were not directly provided, respondents were generally able to identify appropriate resources externally, for example, through community teams. Sixteen of the music therapists were aware that children known to their hospice also received music therapy at their school. Seven music therapists were aware of music therapy organised by other local agencies. Some concern was expressed that the hospice environment may be inappropriate for the psychotherapeutic and on-going music therapy process. However only two music therapists knew of children eligible to receive music therapy organised by local Community Adolescent Mental Health Services.

The scope and format of therapeutic work.

The music therapists reported to offer both individual and group sessions. The number of individual sessions offered in a quiet week ranged from 1-7 (average 4). Individual sessions in a busy week ranged from 2-10 (average 8). Group sessions in a quiet week ranged from 0-3 (average 1) and from 0-6 (average 2) in a busy week. Half of the music therapists offer a series of regular sessions as part of their service with an average of two assessment and eight post-assessment sessions. Music therapy at the hospices appeared more common than home visits. The music therapists agreed that often their hospice would use music therapy as an

introduction to the service as a whole, to encourage families to visit the hospices and to establish a relationship with families so that more standard services would be taken up.

There is a large scope to the format of sessions offered by the music therapists with group work being the most standard (only one therapist not offering group work). In addition to sessions, therapeutic work included: bereavement projects (n=13); staff support (n=13); funerals (n=12); sibling groups (n=10); support group (n=4). Music therapists are often called on to contribute to non-therapeutic work such as trips (n=5) and parties (n=7).

All of the music therapists were invited to share what they considered their greatest achievements to be, responding with successes of a vast scope of clinical work and a plethora of community music projects contributing to the hospice community. From this it was apparent that the therapists were often surprised at the almost immediate, trusting relationship that they established with children and families in music therapy, particularly within highly sensitive end of life work. The therapists appeared starkly aware of the impact of the work, which they reflected to be not always the case in alternative clinical settings. Children's challenging symptoms and behaviour proved less threatening than expected, within a framework where the therapists demonstrated a high level of flexibility and versatility.

A Discussion of Achievements, Concerns and Challenges Presented by the Focus Groups

When introducing the focus groups, one of the researchers (LB) outlined the professional growth of music therapy. He shared his observation that music therapists working in the children's hospices appear to be working 'out of the box', describing the work to be much broader than traditional approaches to music therapy where there is an emphasis on sustained

individual or small group work. The therapists themselves noted that when they began work in their hospice they, 'started flexible and became even more flexible', illustrating this trend. The therapists acknowledged that some customary boundaries are automatically absent, such as knowing how much time you might have with an individual child, days before the child's impending death. The music therapists described how they developed the confidence to work within such uncertainty, leading to a workforce of highly responsive and flexible therapists.

It was evident from the focus groups that there is a danger of therapists feeling anxious about the flexibility within their work, to the extent in which they may question whether they are practising music therapy or not. The focus groups provided an opportunity for the therapists to recognise what they achieve and to move beyond the debate of whether the work still mirrors pure music therapy models presented during the last century, but rather continue to promote change within the profession towards acceptance of more flexible ways of working. Such flexibility was demonstrated in the written reflections of a bereaved mother shared with the music therapists following the focus groups (see Appendix A).

While the music therapists valued the acceptance of music therapy as a fundamental part of hospice care they reported that it was an ongoing challenge to beware of misconceptions amongst colleagues and management, this being a major factor in hindering further development and, in some cases, powerfully destructive to service development. Communicating the essential aspects of a music therapy approach to others is an ongoing challenge, made easier through the gathering of evidence wherever possible. Further familiar challenges identified by the therapists were timetabling and time management issues, indicating the struggle to provide an optimum, cost-effective service in this environment when hours are limited.

The therapists shared a hope for more hours in order to both consolidate and extend their work, demonstrating no difficulty in identifying potential scope for development but rather reflecting an abundance of possibilities, including the potential to support children and families in neonatal and transition work. While evaluation in palliative care is often, “brief and based mainly on participation.” (McFerran & Shanahan 2011, p. 104), the therapists desired a broad evidence base of impact and greater representation of research within their professional body, echoing what is demanded in current literature (Black & Penrose Thompson, 2012; Amadoru & McFerran, 2007; Lindenfelser, Grocke & McFerran, 2008).

Conclusion

The potential for music therapy to be part of the development of paediatric palliative care, and the value of music therapy in this sector, are both demonstrated by this research. The results presented illustrate the unique aspects of children’s hospices and the means in which music therapists can contribute towards supporting young children and their families. This is reflected in the high number of children with profound disabilities and progressive debilitating conditions who may benefit from a non-verbal means of communicating and the versatility of music therapy in this setting. Working alongside children and families facing often-unknown prognoses and long trajectories of illness provides opportunities for music therapists to establish strong relationships and in depth knowledge of individual children, while shorter occurrences of care utilise the therapists’ ability to maximise each moment to capture a child’s personality and expression through music, often initiating surprising responses.

Finding ways to enhance quality of life is at the core of this work. As a growing and developing field paediatric palliative care continues to be shaped by the needs of children with life-limiting and life-threatening conditions and their families. The current scope and popularity of music therapy demonstrated in this research suggests that music therapists working within the hospices have an opportunity to contribute to the growing knowledge and understanding of enhancing quality of life in paediatric palliative care.

Furthermore music therapists in the focus groups remarked on being aptly programmed to be client-centred, this being at the heart of music therapy training and agreeably an expert skill of music therapists. Music therapists in children's hospices are in a strong position to listen to families and respond accordingly as children's hospices as a whole establish an ever-stronger presence in paediatric palliative care. This review of the progression and current provision of music therapy in children's hospices offers valuable evidence, learning and reflection of what has been achieved and what is to be achieved in the future.

Appendix A: A Mother's Reflections

A bereaved mother of a life-limited child was approached to reflect on her experience of music therapy for the benefit of those participating in the focus groups. The mother's reflections echo the flexibility, variety and impact of the work presented in this paper and are included here.

I believe that without music therapy, our experience of a children's hospice, as well as our overall experience of having a life-limited child, would have been completely different, and far poorer.

As a family, we all benefited from it at different times and in different ways. Our daughter died when she was just over three years old. Born with a rare neurological condition, she was profoundly mentally and physically disabled. In music therapy, we watched our beautiful non-verbal little girl find a special way of communicating. Not only did she learn to interact with the music itself, but also with those of us taking part in the session with her. Sometimes this might be alone with the music therapist, or in a session with other hospice children and members of staff, who would often speak of her singing in the sessions. At other times, when we had music therapy as a family at home or at the hospice itself, she and her older brother, would find a way of interacting and communicating in a way which they only really experienced through music. The sessions were a beautiful gift, encouraging us to be together in a deeper, more profound, more attentive way of being family, when often our life was highly chaotic and the essential thing was simply surviving another day.

We feel confident that when our daughter arrived at the hospice the night before she died, hearing the familiar sounds of the music therapist's flute and guitar helped her to relax, knowing that she was safe in her 'home from home', and enabling her to peacefully surrender to her dying. It was just how we hoped she would die, not with tubes and machines in a hospital environment, but feeling safe and held by the community in which she had spent so much time and in which she felt loved. The music therapist's music that night made an essential contribution to what we would describe as a 'good death' for our daughter.

After she died, her brother continued to have individual sessions with the music therapist for the following year. At the time, he was a highly sensitive nearly five year old, prone to panic and anxiety and anger, not only due to grief, but also due to early separations from me and the traumas associated with his sister's illness. During the course of his music therapy, he learnt to appropriately name his emotions so that he is now better able to describe his feelings verbally than physically. While on a day to day level we also saw a great reduction in anxiety and anger, these feelings are sometimes triggered again by current circumstances, and his sessions have certainly left both him and me better able to manage such feelings.

In addition to our individual sessions, our experience was that having a vibrant music therapy department at the hospice made an enormous difference not only to the overall mood and atmosphere of the place, but shaped ways of being together as a community. Music brought hospice staff, the children and their families together in ways that nothing else did. Music also added a real spiritual and emotional dimension to life at the hospice. Certainly, for us now, it is the music we shared while at the hospice which also sustains our on-going relationship with our daughter and our memories of her. We still sing the songs from the sessions to each other! We listen to the recording of the hospice staff choir singing in her room during her penultimate visit to the hospice, and feel immediately connected to her and that precious time. We have discovered that the music we shared not only deepened our relationships at that time, but continues to sustain them now. There are so many things you have to let go of when your child dies but, cliché as this may be, the music goes on, and for that we will always be so deeply grateful.

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References

- Amadoru, S. & McFerran, K. (2007). The role of music therapy in children's hospices. *European journal of palliative care* 14, 3, 124-127.
- Black, B. P. & Penrose-Thompson, P. (2012). Music as a Therapeutic Resource in End-of-Life Care. *Journal of Hospice & Palliative Nursing*, 14, 2, 118-125.
- Bolton, G. (2005). The healer's art: Music for healing. *Progress in Palliative Care*, 13, 1, 11-14.

- Bradt, J. & Dileo, C. (2010). Music therapy for end-of-life care. *Cochrane Database of Systematic Reviews*, Issue 1. Art. No.: CD007169. DOI: 10.1002/14651858.CD007169.pub2.
- Casey, O. (2012). How can I consider letting my child go to school when I spend all my time trying to keep him alive? In J. Tomlinson, P. Derrington, & A. Oldfield (Eds) *Music Therapy in Schools* (pp. 165-178). London: Jessica Kingsley Publishers.
- Daveson, B.A. & Kennelly, J. (1999). Music Therapy in Palliative Care for Hospitalised Children and Adolescents. *Journal of Palliative Care*, 16, 1, 35-38.
- Duffy, B. & Fuller, R. (2000). Role of Music Therapy in Social Skills Development in Children with Moderate Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, 13, 2, 77-89.
- Daykin, N., Bunt, L. & McClean, S. (2006). Music and healing in cancer care: a survey of supportive care providers. *The Arts in Psychotherapy* 33, 402-413.
- Gillie, B. (2005). The Healer's Art: music for healing. *Progress in Palliative Care* 13,1, 11-14.
- Ibberson, C. (1996). A natural end: one story about Catherine. *British Journal of Music Therapy* 10, 1, 24-31.
- Jessie's Fund (2014). *Jessie's Fund*, [online], Available: <http://www.jessiesfund.org.uk> [accessed 14 April 2014].
- Kammin, V. & Tilley, H. (2013). Rocks and Pebbles: a post-bereavement sibling's support group using music to explore grief. *Bereavement Care*, 32, 1, 31-38.

- Knapp, C., Madden, V., Wang, H., Curtis, C., Sloyer, P. & Shenkman, E. (2009). Music Therapy in an Integrated Pediatric Palliative Care Program. *American Journal of Hospice & Palliative Medicine*, 26, 6, 449-455.
- Lindenfelser, K. (2005). *Parents' voices supporting music therapy within pediatric palliative care*, [online], Available: <https://normt.uib.no/index.php/voices/article/view/233/177> [accessed 16 March 2014].
- Lindenfelser, K., Grocke, D.E. & McFerran, K. (2008). Bereaved parents' experiences of music therapy with their terminally ill child. *Journal of Music Therapy*, 45, 3, 330-348.
- Lindenfelser, K. J., Hense, C. & McFerran, K. (2011). Music Therapy in Pediatric Palliative Care: Family-Centered Care to Enhance Quality of Life. *American Journal of Hospice & Palliative Medicine*, 29, 3, 219-226.
- McFerran & Hogan (2005). Music in Palliative Care. The overture: initiating discussion on the role of music therapy in paediatric palliative care. *Progress in Palliative Care*. 13, 1, 1-3.
- McFerran, K. & Shanahan, E. (2011). Music Therapy Practice in Special Education and Children's Hospice: A systematic comparison of two music therapists' strategies with three preadolescent boys. *Music Therapy Perspectives* 29, 103-111.
- Music in Hospitals (2014). *Music in hospitals England, Wales, Northern Ireland and the Channel islands*, [online], Available: <http://www.music-in-hospitals.org.uk/> [accessed 14 April 2014].

- Pavlicevic, M. (ed.) (2005). *Music Therapy in Children's Hospices: Jessie's Fund in Action*. London: Jessica Kingsley Publishers.
- Register, D. & Hilliard, R (2008). Using Orff-based techniques in children's bereavement groups: A cognitive-behavioural music therapy approach. *Arts in Psychotherapy* 35, 2, 162-170
- Sheridan, J. & McFerran, K. (2004). Exploring the value of opportunities for choice and control in music therapy sessions within a children's hospice. *Australian Journal of Music Therapy*, 15, 18-32.
- Smith, H. (2014) The Concept of Hope in Paediatric Palliative Care. *Relay*. 3, 12-17.
- Together for Short Lives (2012). The Big Study for Life-limited Children and their Families: How well are the palliative care needs of children with life-limiting conditions and their families met by services in the West Midlands?, [online], Available: http://www.togetherforshortlives.org.uk/professionals/projects/project_one [accessed 14 April 2014].
- Woodhead, S. (2011). *A Family Companion*. Bristol: Together for Short Lives. Available from: http://www.togetherforshortlives.org.uk/assets/0000/1080/A_Family_Companion.pdf [accessed 14 April 2014]

Table 1							
<i>Contributors</i>							
Form of participation	<u>Questionnaire</u>	<u>Focus Group</u>	<u>Telephone consultation</u>				
Job title	Music therapists	Music therapists	Nurses	Senior nurses & nurse managers	Heads of care	Activities coordinator	Play specialist
Number	22	10	2	8	2	1	1

Table 1: Contributors

Table 2			
<i>Together for Short Lives Categories of Life Limiting Conditions and Estimated Proportion of Caseload</i>			
<u>Category</u>	<u>Description</u>	<u>Examples</u>	<u>Average proportion of caseload</u>
1	Life-threatening conditions for which curative treatment may be feasible but can fail. Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.	Cancer, irreversible organ failures of heart, liver, kidney.	16%
2	Conditions where premature death is inevitable. There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.	Cystic fibrosis, Duchenne muscular dystrophy	11%
3	Progressive conditions without curative treatment options. Treatment is exclusively palliative and may commonly extend over many years.	Examples: Batten disease, mucopolysaccharidoses.	22%
4	Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.	Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.	51%

Table 2: Together for Short Lives Categories of Life Limiting Conditions and Estimated Proportion of Caseload

Table 3							
<i>Employment of Therapy Staff</i>							
Professional	<u>Music therapist</u>	<u>Play therapist</u>	<u>Art therapist</u>	<u>Drama therapist</u>	<u>Family therapist</u>	<u>Counsellor</u>	<u>Psychologist</u>
Number at the 14 hospices without a music therapist	0	2	1	1	1	4	0
Number at the 22 hospices with a music therapist	22	6	2	0	5	18	1

Table 3: Employment of Therapy Staff

- Highlights
- 22 music therapists took part in a nationwide survey of music therapy provision
- 14 hospices with no music therapy provision took part in telephone interviews
- hospices without music therapy were positive about the use of music and interested in future posts
- flexibility was key in responding to the shifting needs of the families attending the hospices
- parent shares how music deepened a family's relationship and sustains them in grief

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