



University of the West of England, Bristol

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

Presented to: JESSIE'S FUND
15 PRIORY STREET
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April 6th 2012

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CONTENTS

Introduction	<i>Page 3</i>
Aims	<i>Page 3</i>
Procedures	<i>Page 3</i>
Executive Summary	<i>Page 4</i>
Background	<i>Page 6</i>
Findings	<i>Page 7</i>
1a. Questionnaire for music therapists working in a children's hospice (<i>pages 7 – 12</i>)	
• Summary of the main findings	
1b. Telephone interviews with staff at children's hospices where music therapy services are not currently offered (<i>page 13 – 20</i>)	
• Summary	
• Detailed findings	
Summary of Focus Group Day	<i>Page 21</i>
A mother's reflections	<i>Page 23</i>
References	<i>Page 25</i>
Appendices	<i>Page 26</i>
a) Detailed findings from questionnaire for music therapists working in a children's hospice (<i>page 26-42</i>)	
b) Copy of consent form for the music therapists' questionnaire (<i>page 43</i>)	
c) List of questions for staff at children's hospices where music therapy services are not currently offered (<i>page 44-45</i>)	
d) Copy of consent form for children's hospices not providing music therapy (<i>page 46</i>)	
e) Invitation, Agenda, Questions and Minutes of Focus Day (<i>page 47-55</i>)	
f) Copy of consent form for the Focus Day (<i>page 56</i>)	
g) Study timeline (<i>page 57-58</i>)	

INTRODUCTION

This report summarises and includes the results of an evaluation survey carried out by music therapists Sarah Hodgkinson and Leslie Bunt. The analysis of the responses and writing-up of the report was carried out by music therapist Sarah Hodgkinson (Shooting Star CHASE) and Professors Norma Daykin and Leslie Bunt (UWE). The intention was to provide an overview of the current music therapy provision in children's hospices in the UK.

AIMS

The survey aimed to:

- place the current provision of music therapy provision in the children's hospices within a historical context
- identify the number of hours per week provided by each music therapist at each hospice
- provide a snapshot of the ages and range of conditions of children having music therapy sessions
- summarise the balance and kind of group and individual work
- gather information about the support of families and other hospice staff
- explore the range of music therapy, therapeutic music-making and other musical activities at each hospice
- gather information on future plans for the development or inclusion of music therapy within the children's hospices

PROCEDURES

An initial proposal was submitted to the Jessie's Fund in May 2011. The early fieldwork for the survey began on August 8th 2011 (see timeline – Appendix g) after the award of partial funding in July 2011 by Jessie's Fund and subsequent editing of the original proposal. The evaluation focused on two main approaches:

1a - a questionnaire for all music therapists working in the children's hospices

1b - a telephone consultation for staff at hospices currently without music therapy provision

There was also a Focus Day meeting for music therapists working in the children's hospices to meet with two of the researchers and the Director of Jessie's Fund.

Ethics approval was given by the UWE Faculty's Research Ethics Sub-Committee.

The project was originally planned to end on December 16th 2011. This needed to be extended for more time to be allocated for the analysis of the information and the compilation of the report.

EXECUTIVE SUMMARY

The first music therapy (MT) post was set up by Jessie's Fund (JF) for one day a week in 1994. By 2011 JF had introduced MT into 33 of the 45 children's hospices in the UK; 28 hospices have maintained the service with an average of 13 hours per week of MT.

A questionnaire was sent out to the 28 music therapists working in the hospices with a high return of 22. These therapists offered MT to nearly all the children attending the hospices. Over half of the children referred for music therapy had non-progressive conditions resulting from a severe disability such as cerebral palsy; the next largest group was children with progressive conditions such as muscular dystrophy followed by life-threatening conditions such as cancer and cystic fibrosis.

The main reason for referral to MT was for end of life care with most MT taking place 'in house' and both individual and small-group work. Under a third of the work was identified as long-term. Most therapists work with children attending the hospice; a smaller proportion with siblings and bereaved siblings. The age range was from new-born babies to older family members and grandparents.

The music therapists reported a large amount of parental support including attending sessions. A high proportion of sessions were run with other members of staff. Music therapists were increasingly involved in staff training and other aspects of hospice life such as playing at funerals and involvement in fundraising events.

Music therapists would like to see (and this was confirmed by the 10 therapists who attended the Focus Day meeting) more: outreach work, work with older children and teenagers; staff liaison; work with staff at other hospices; research and networking (such as the support provided by JF).

A second part of the survey focused on telephone interviews. 14 interviews took place with staff of the 15 hospices not currently providing a MT service. Two thirds of the respondents would consider providing MT in the future with half expressing concerns, particularly cost implications.

A wide range of musical activities was reported at nearly all of the hospices without a specific MT input, including access to both internal and external provision. There was an appreciation of the staff training provided by JF and the gift of musical instruments.

The members of staff at these 14 hospices were aware of the benefits of MT, although some concern was expressed that the hospice environment may be inappropriate for the psychotherapeutic and on-going MT process.

Nearly all the staff at hospices without any MT input requested more information about how to access and provide MT.

The music therapists who completed the questionnaire and attended the Focus Day hoped that a team of music therapists could eventually be based in every children's hospice in the UK.

The music therapists considered that their work was challenging a more traditional view of MT with the need to develop new ways of working both individually and in groups, to work with families, siblings, other staff and the wider community. The skill set of the music therapists was stretched by this work, for example through the use of current technology.

It was felt that there is a need to develop more research and disseminate information about the impact of MT more widely.

BACKGROUND

There has been a steady growth of the provision of music therapy in children's hospices in the UK since 1995. Much of this growth can be attributed to the visionary work of Jessie's Fund in providing a period of initial funding of music therapy positions in the hospices. The first ten years of this development was documented in case narratives and descriptions as part of a landmark text published in 2005: 'Music therapy in children's hospices: Jessie's Fund in action.'¹ This was edited by leading music therapist Mercédès Pavlicevic with contributions from many of the music therapists whose work with the children had been supported by Jessie's Fund.

Further developments have taken place in the years following this publication with a growing need, even more so in today's climate of external pressures for demonstrating evidence of effective practice and cost-effectiveness, to carry out a nationwide evaluative survey of the current music therapy provision in the children's hospices.

A preliminary search through twenty databases using the key phrases 'music therapy' and 'children's hospices' only produced a relevant list of five papers and books. One was an Australian study by Katrina McFerran and Janine Sheridan that explored how music therapy can offer opportunities for children in hospices to demonstrate control and choice.² This dearth of publications relating specifically to music therapy in children's hospices is echoed by Kathryn Lidenfelser in her 2005 paper published on the on-line journal *Voices*.³

It is proposed that the findings from this survey will be written up for dissemination in a peer-reviewed journal thereby adding to this small amount of international literature relating to this area of music therapy practice.

FINDINGS

1a. Questionnaire for music therapists working in a children's hospice

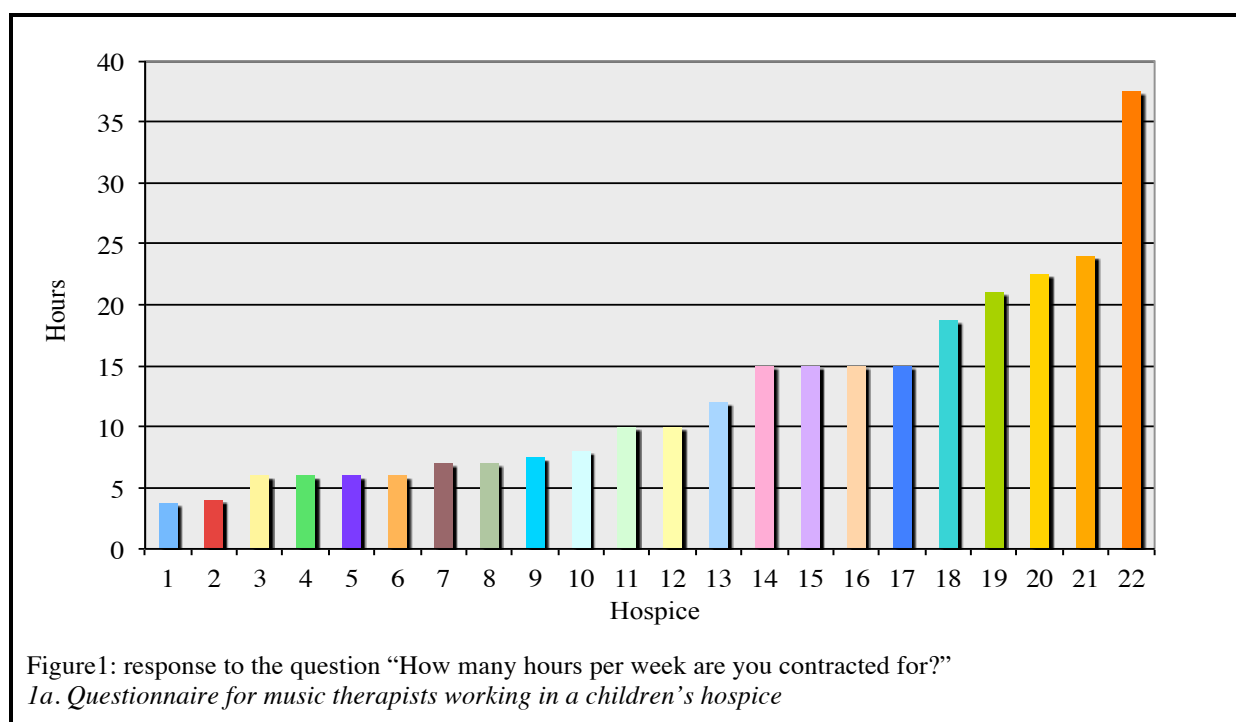
This questionnaire was created by Sarah Hodgkinson who works as a music therapist in one of the children's hospices (see Appendix a). During August 2011 a list of all children's hospices was compiled and of music therapists currently working in the hospices (see timeline – Appendix g). The questionnaire was sent out to 28 music therapists and was returned by 22 therapists (a high return level of 82%). Note that one further children's hospice employed a music therapist after the questionnaires were sent out. This music therapist was not included due to him/her being new in post. The questionnaire included a signed consent form which was completed by all respondents (see Appendix b).

Summary of the main findings

The questionnaire explored five areas (see Appendix a for presentation of answers in graphic form and the detailed analysis):

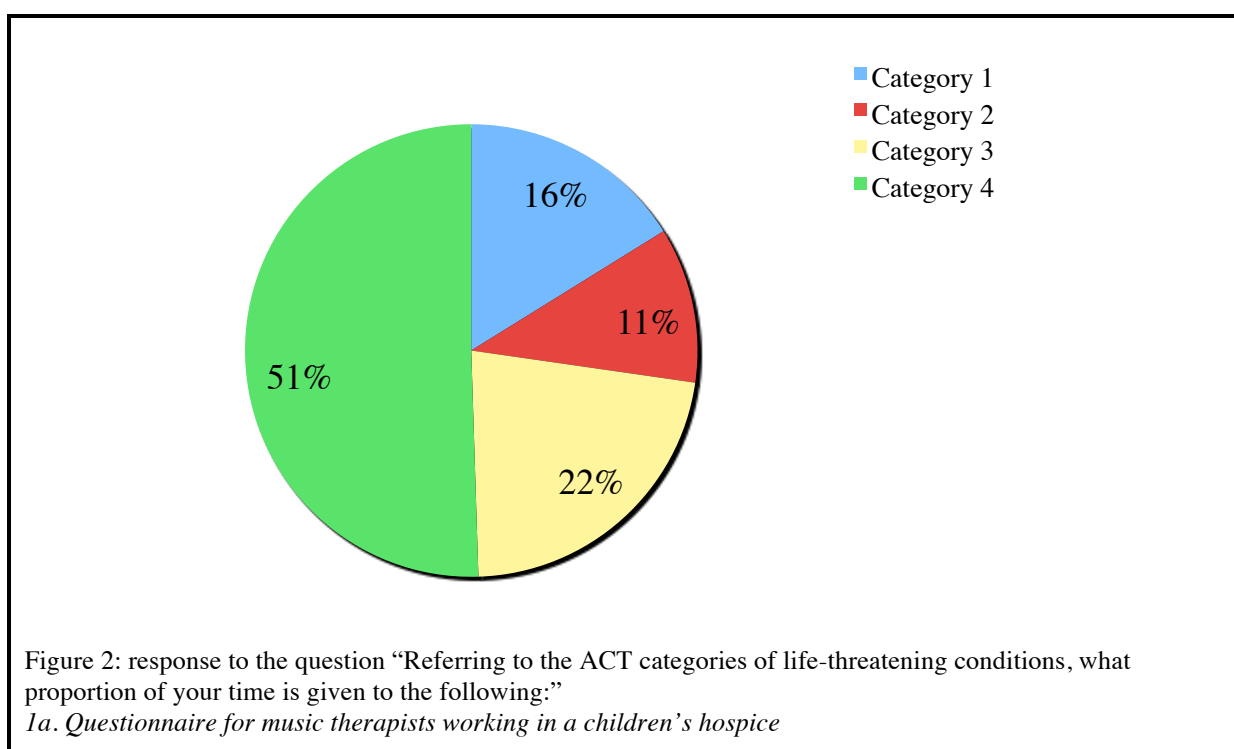
A: Development of music therapy in children's hospices

- In 1994 one therapist worked for one day in one hospice
- In 2011 the 22 therapists averaged 13 hours with a range of 3.5-37.5 hours (see Fig.1)
- At the start of their work 9 therapists (41%) used a space that was mostly dedicated for music therapy; 12 therapists (55%) currently using a mostly dedicated space
- The majority of music therapists chose the same category (excellent and very good) for the resources at the start of their post and the current position. Two therapists felt the resources had improved; five chose a lower category. Note: Jessie's Fund provide the resources and equipment at the beginning of each post



B: A snapshot of the client group

- It appears that music therapy (MT) is offered to nearly all the children using the hospices. The 14% of the therapists who stated that not every child had access to MT used a referral criteria to determine whether MT was appropriate. The music therapists estimated the proportion of time they spend with these client groups. The average percentage per client group was (see Fig.2):
 - 51% : irreversible but non-progressive conditions caused by severe disability, e.g. cerebral palsy (Category 4)
 - 22% : progressive conditions, e.g. muscular dystrophy (Category 3)
 - 16%: life-threatening conditions, e.g. cancer (Category 1)
 - 11%: inevitable premature death, e.g. cystic fibrosis (Category 2)



- The first five main reasons for referral to MT were:
 1. end of life care
 2. liking for music
 3. depression/anxiety
 4. bereavement
 5. coming to terms with diagnosis
- Most MT takes place with children ‘in house’ rather than children referred from the entire hospice caseload
- Just under a third of music therapy work takes place with children referred or identified for long term work
- The bulk of MT takes place directly with children attending the hospices. A smaller proportion takes place with siblings and bereaved siblings currently using the hospice

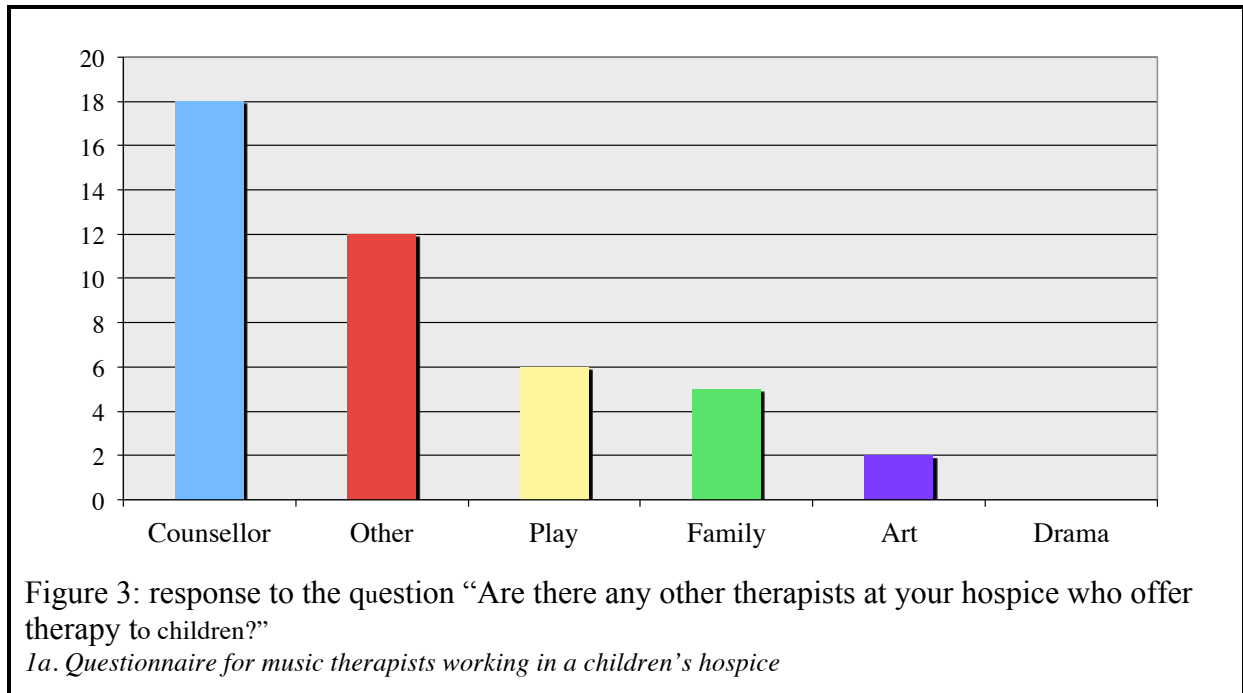
- The age of the youngest child (including newborns) receiving music therapy is much lower than in average MT settings. Examples of work with very young children include creating memories for the parents of a young baby who is only expected to live for a few days
- The age of the oldest client varies from hospice to hospice and relates to whether work is carried out with the whole family, including older relatives in their 70's and 80's

C: Family Support

- Most music therapists welcomed parents, when in house, attending sessions (n=20)
- The attendance of siblings was determined according to the needs of the child and family: just under half encouraged this
- Informal meetings were the most common form of support given to the families by the music therapists
- Other forms of support were: phone/email contact; information documents; support group and included training parents on how to use music at home
- Only 7 music therapists mentioned that they did not attend regular meetings/forums to discuss the family as a whole

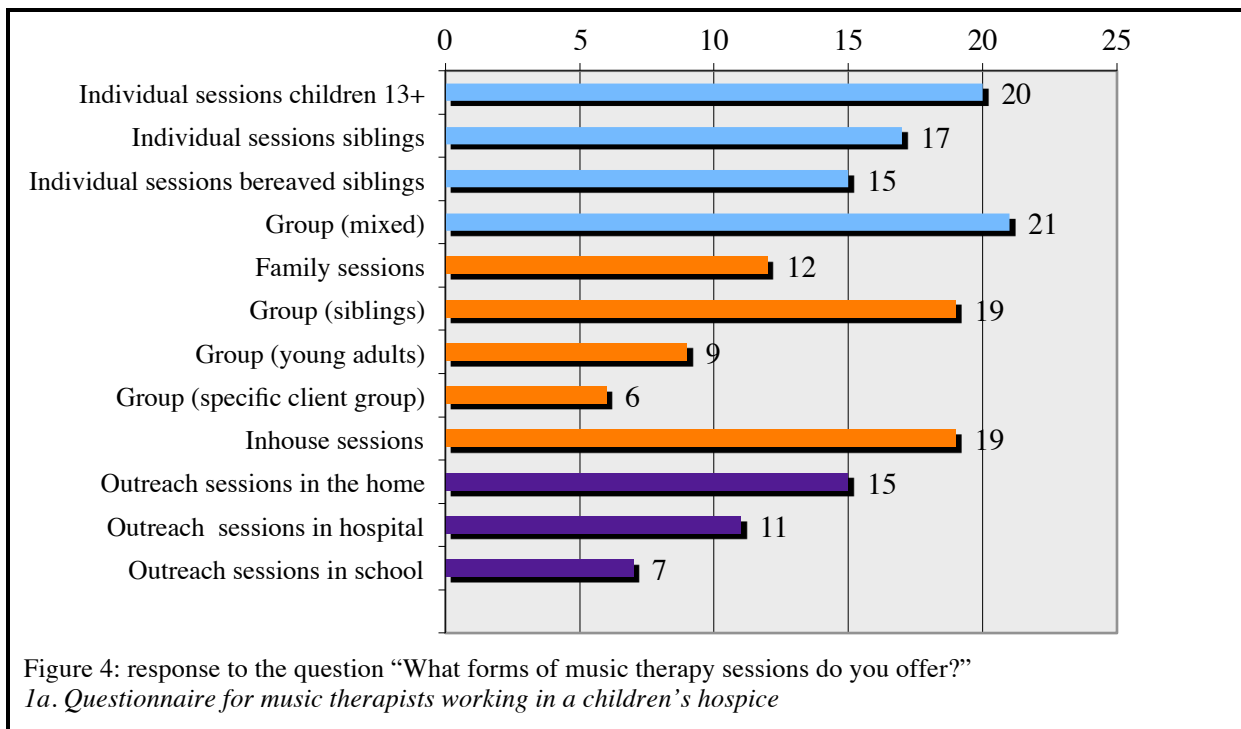
D: Working with colleagues and outside agencies

- Most therapists (n=20) reported that other professional colleagues regularly or occasionally attended sessions. The main reasons for this were: to address nursing/care needs of the children; to assist the MT; to deliver educational benefits
- Most respondents (n=21) reported that their hospice offers some kind of staff training. This was an area where potential benefits from joined up working across the different hospices were identified, e.g. in creating a DVD as a shared teaching resource
- 18 music therapists listed counselling as another therapeutic service offered to the children (see Fig. 3)
- All the music therapists listed a wide range of other professionals working at their hospice including: social worker, siblings worker, psychotherapist, play therapist, occupational therapist, psychologist, nurse with additional training, complimentary therapist and students (see Fig. 3)
- 15 ran joint sessions with other professionals or took part in groups run by other professionals
- 18 considered they were part of teams in their hospice and it appears that, although given different names, MT is part of the general care/support team
- 16 of the music therapists were aware that children also had music therapy at school, this ranged from none to two thirds of the children using the hospice; 7 music therapists were aware of MT organised by other agencies. Only 2 music therapists knew of children who receive MT organised by local Community Adolescent Mental Health Services



E: The format and scope of MT provision (see Fig. 4)

- Individual sessions 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)
- Group sessions in a busy week ranged from 0-6 (average 2)
- 11 of the music therapists offer a series of regular sessions as part of their service with an average of 2 assessment and 8 post assessment sessions
- There is a large scope to the format of sessions offered with group work being the most standard (only one therapist not offering group work)
- There is a high number of family sessions
- In-house is more prolific than outreach but this does depend on the hospice
- Other therapeutic work includes: bereavement projects (13); staff support (13); funerals (12); sibling groups (10); support group (7)
- Other non-therapeutic work includes: trips (5) and parties (7)



The questionnaire also asked the music therapists to itemise what they considered their greatest achievements to be (please see appendix a for details). These included:

- Extended work with families and gaining their trust
- End of life work
- Reaching challenging children
- Work with siblings
- Versatility and adaptability
- MT becoming a fundamental part of the hospice
- Co-working with professionals
- Memorial and funeral services
- Choirs and bands
- Compositions with children
- Music technology development
- Community MT projects
- Recordings and music memorabilia
- Open groups and their impact on families
- Outreach services
- Advocating for children/families
- Support from care staff and management
- Training programmes for staff
- Developing models of working procedures
- Fun and enjoyment

The final question for the music therapists was: ‘How would you like to see MT developing in children’s hospices in the next 25 years?’ Answers included (see appendix a for details):

- More of the same with more hours
- More outreach work and liaison with other agencies
- More bereavement work
- Development of work with babies
- Acceptance of adult work
- More Community MT projects
- Dedicated MT space/MT suite
- More technology: iPads, recording facilities (DVD & CD)
- More resources/time for teenagers
- More involvement with counsellors
- More family work
- More student MT placements
- MT in supervision and team-building
- More staff training
- More respect from senior management
- Research, evidence, publication, conference talks
- Peer supervision
- More frequent meetings with other MTs in this field
- Regional groups for MTs
- A structure for career development
- MT to become more integral (not needing selling)
- Every child hospice to have a MT
- A team of MTs in each hospice
- For MTs to stop worrying if their work is music or MT
- Using MT therapeutic skills in sibling groups
- End of narrow view that MT is 1:1

1b. Telephone interviews with staff at children's hospices where music therapy services are not currently offered

Summary

- Staff in 14 out of 15 hospices where there is currently no music therapist employed took part in a telephone interview.
- Two thirds of the respondents stated that they would consider providing music therapy services in future, although for some this was a longer term aspiration.
- Half of the respondents identified specific concerns about employing a music therapist including costs, lack of funding, demands on the organisation.
- Nearly all of the respondents reported that music was regularly used. Several hospices owned musical instruments, provided by Jessie's Fund in two instances. Music activity was provided by hospices staff, volunteers and family members. The role of Jessie's Fund in supporting staff training was specifically mentioned by two respondents.
- Several hospices made use of external music resources including visiting professional musicians and volunteers offering a wide range of musical genres and activities.
- Respondents reported a range of benefits to children of music. These related to mood, enjoyment, communication, expression, stimulation and achievement. These benefits were attributed to music per-se and not necessarily to music therapy.
- Music therapy was perceived by some as a distinct service with a focus on psychotherapy and therapeutic work. Although respondents identified potential benefits, some respondents seemed to suggest that music therapy would not necessarily fit within the hospice environment.
- A wide range of activities and therapeutic resources were identified as being available to children and families. Where services were not directly provided, respondents were generally able to identify appropriate resources externally, for example, through multidisciplinary teams. All of the respondents were able to identify some form of psychosocial support, such as specialist counselling services. Two thirds of hospices offered complementary therapies, provided by specialists and by hospice staff trained in specific techniques. In relation to creative therapies, specialists were rarely employed although creative and play based activities were widely used.
- Overall, respondents were generally positive about receiving further information about aspects of music therapy including costs; benefits of music therapy services; information about other hospices' experiences of music therapy services; the role of supervision within music therapy; and information about the registration body and where to find music therapists. Two respondents sought such information to support future funding applications, indicating that they might consider setting up a service in the future.

Detailed Findings

Introduction

This section reports results of telephone interviews with staff in hospices where there is at present no music therapist employed. The interviews sought to explore the way in which hospices use music and their perceptions of music therapy in the context of broader provision of psychosocial and creative therapies.

Methods

A sample of 15 hospices where there is currently no music therapist employed was identified. All these hospices were invited to take part in an interview and in 14 a member of staff agreed. In the remaining hospice a senior staff member asked for further written information about the project before taking part.

Before the 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 (see Appendix d). The telephone interviews were undertaken by the lead researcher. Interviews lasted between 10 and 20 minutes. They were not audio recorded but comprehensive notes were taken by the researcher. The statements in italics below are a mixture of some direct quotes and close summaries of participants' responses.

Statistical data are reported descriptively, while open ended responses were subjected to content analysis. The analysis was undertaken by a second researcher. The results are reported below.

Results

Background and roles of staff taking part

Respondents were employed in different roles, but nearly all respondents occupied a senior position or a clinical management role. The majority of respondents were from nursing backgrounds, two exceptions being an activities coordinator and a play specialist. The full list of respondents' job titles is provided in Note 1 below.

Views about the provision of music therapy services

Each interview began with an acknowledgement that no music therapy services were currently provided in the hospice. Respondents were asked whether they would ideally like to provide music therapy in future as part of the hospice service. The responses are described in Table 1. The majority of respondents stated that they would like to provide such services, with one adding the caveat 'eventually', music therapy provision being a longer term rather than a shorter term aspiration. Three respondents didn't have a definite view although on discussion it was revealed that one of these was currently investigating collaborating with a local music therapy charity to provide support.

Table 1. Would you like to provide music therapy services in future?

Yes	No	Maybe	Total
9	2	3	14

Respondents were asked whether they had any specific concerns about employing a music therapist. The responses are presented in Table 2.

Table 2. Do you have any specific concerns about employing a music therapist?

Yes	No	Total
7	7	14

Seven respondents identified specific concerns about employing a music therapist. Three of these mentioned cost issues, including lack of funding for provision and potential costs to the organisation. Another area, mentioned by two respondents related to potential demands on the service in terms of support and supervision. Other responses identified the concern that music therapy provision would either be over and above standard service or would not fit in with the existing service. For example, one respondent raised the issue that music therapy needs to be a continuous service and this is not how the hospice functions. Another emphasised the importance of any new service reflecting and understanding the unique rationale and emphasis as *no two units are the same*. Similarly, one respondent raised a concern that a music therapist would be able to visit children within their homes as well as when resident at the hospice.

The use of music by hospices

Participants were asked whether they currently use music or musicians within the hospice (Table 3).

Table 3. Do you use music or musicians at your hospice?

Yes	No	Total
13	1	14

Only one respondent said that music was not 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. In the other settings, music was used in a range of ways.

In-house musical resources

Several respondents reported having musical instruments that were used on site in music groups and one to one sessions as well as off-site, for example, in home visits. In some instances musical instruments owned by the hospice were used alongside supplementary resources such as DVDs and instruments owned by children.

The role of Jessie's Fund was specifically mentioned, in relation to musical instrument acquisition, by two respondents.

There are instruments in the lounge. There is a piano on the premises. We have a good supply of musical instruments and thanks to Jessie's Fund.

Jessie's Fund provided the instruments

Staff engaged in music activity

As well as musical instruments, some hospices benefitted from having employed staff who were able to lead musical activities either on site or during home visits. In some hospices, music activity was provided 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.

The role of Jessie's Fund in supporting staff to successfully deliver music activity was specifically mentioned by two respondents:

Jessie's Fund provided training for nurses to use the instruments

Some members of staff – nurses, nursery nurses, healthcare assistants have done the Jessie's Fund course

External music resources

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 professional performers, musicians drawn from specialist organisations such as Music in Hospitals, and community musicians, in programme delivery either on or off-site.

Musicians are invited in to play to the children from time to time

Using external music resources enabled the hospices to engage with a wide range of musical genres including rock, pop, samba, urban music and opera. It also enabled them to access a wide range of instruments, such as drumming, and related activities, such as Morris dancing. As well as direct work with children and families, music activities using external resources included team building for staff and public activities such as summer fetes.

Views about the potential benefits of music therapy.

Respondents were asked about their views on the potential benefits of music therapy. The thematic analysis of the responses is summarised in Table 4.

Table 4. Benefits of music therapy to your children and families

Theme	Number of responses
Mood enhancing environment	5
Provides enjoyment	3
Promotes communication and interaction	3
Enables expression	3
Provides stimulation	1
Facilitates achievement	1

Respondents did not seem to frame their responses in terms of music therapy, rather, the responses seem to focus on the benefits of music per se. Several respondents mentioned the mood enhancing qualities of music, which was described as ‘uplifting’, ‘calming’ and ‘relaxing’. Hence music:

Can offer a relaxing and positive environment.

Other respondents focused on enjoyment for both children and staff:

*All children love making and participating in music.
Also the session was enjoyable for the staff.*

Communication and social interaction were emphasised, particularly for children whose ability to communicate may be limited by impairment:

To give an opportunity for non-verbal, severely disabled children to express themselves and have a medium of communication.

Similarly, expression was mentioned an important aspect, particularly in relation to children whose opportunities for expression may be limited:

Music therapy is especially valuable for children with complex health needs. It allows them to express themselves.

Other themes mentioned included stimulation, music being seen as something that:

creates a sensory experience for them ... not just about the hearing – lots of different sensory experiences.

Finally, one respondent emphasised the sense of achievement that children gained from music- making

It was good for the children to realise that they could make music, e.g. a child with limited movements.

Perceptions of music therapy.

As an alternative to the question about the benefits of music therapy participants were asked about their understanding of music therapy. Some responses were similar to those above, for example, emphasising fun, communication, expression and stimulation in relation to the needs of children with impairments

*Bringing music to children at their level, e.g. verbal and sensory impaired children.
Also as a fun activity.*

My understanding is that it is to help children express their feelings.

Other responses seemed more focused on therapeutic aspects, with music therapy perceived as somewhat distinct from music making per se.

My understanding is to use it as psychotherapy or for therapeutic purposes.

My understanding is that they provide therapeutic music to engage children with various complex needs.

If they are working through difficult times it's a means of expressing themselves.

One respondent expressed concern that therapeutically focused work relies on the provision of a continuous service and therefore may not be appropriate in some hospice situations:

But because there is no continuity for the children the therapy side does not seem to work.

This respondent also commented that beyond the benefits of 'music' it may be difficult to ascertain what additional benefits music therapy might provide:

With the complex needs of the children it's difficult to assess what the children need beyond enjoying music.

Respondents were asked about other psychological therapies provided by the hospice, including play therapy, (Table 5). In terms of play therapy, only two hospices directly employed a play therapist. However, two respondents identified specialist staff within broader multidisciplinary teams to whom children could be referred. These staff included nursery nurses with play qualifications as well as play specialists. Five respondents stated that although a play therapist was not employed, there were staff in the hospice who could provide therapeutic play activity. These staff included nurses, care workers and nursery nurses who had received training from a play therapist. In one hospice, a generic 'creativity' person provided related services. In another, services were provided by a generic play worker and volunteers.

Table 5. Employment of therapy staff by the hospice

Therapy/service	Direct provision	Referral/alternative resource available	No current resource identified
Play therapist	2	7	5
Art therapist	1	4	9
Drama therapist	1	1	12
Family therapist	1	7	6
Counsellor	2	12	0
Children's Counsellor	2	11	1
Social worker	4	6	4
Complementary therapist	9	2	3

In relation to art therapy, only one of the hospices directly employed an art therapist. However, one hospice reported hosting art therapy students who provided services and a

further three mentioned that some staff within the hospice had related expertise and experience.

In relation to drama therapy, one respondent reported that drama therapy was offered on a weekly basis. Other than this, drama therapy services were not generally provided.

In terms of family therapy, one respondent stated that there was a specialist family therapist employed by the hospice. However, seven respondents stated that their hospice had access to services provided by family support workers and specialist staff in community teams.

In relation to counselling, four respondents reported that the hospice employed staff with specialist counselling qualifications, although in two cases, these staff members were not necessarily employed in designated counselling roles. One respondent stated that the nature of the organisations' role was provision of palliative care for children and that this included psychological support but not counselling per se.

Seven respondents stated that access to counselling and psycho-social support was also available through community teams, external services and within the wider hospice organisation. Two hospices employed a specialist children's counsellor. Most of the remaining hospices reported having access to such services through community teams and external services or through provision of related services, such as play therapy or a children's bereavement service, within the hospice.

Four respondents reported the presence of specialist social work staff within the hospice. However, in the majority of cases, social work services were identified as being available through the wider hospice community teams.

In terms of complementary therapies, nine respondents reported that specialist provision was available within the hospice. A wide range of therapies were reported including aromatherapy, reflexology, massage, Reiki and cranial-sacral therapy. These services were sometimes provided by members of the care team trained in particular techniques. Three respondents stated that volunteers and parents were involved in complementary therapies, particularly massage. Three respondents stated that no complementary therapies were currently provided. However, two of these had plans to do so in future, one actively exploring accessing relevant skills through the multidisciplinary team. The other respondent stated that although the hospice would like to provide such services, current finances did not allow it.

A range of other services were provided by the hospices. These included complementary therapies such as hydrotherapy; support services and activities for family members; visits to families and children by hospice chaplains; and specialist bereavement support.

Further interest in music therapy services.

Participants were asked whether there were any aspects of music therapy about which they would like further clarification. Specific questions identified four aspects: costs; benefits of music therapy services; information about other hospices' experiences of music therapy services; and the role of supervision within music therapy.

Table 6. Are there any aspects of music therapy you would like further clarification of or more information about?

Topic	Yes	No	Not sure/don't know
Costs	12	2	0
Benefits	13	1	0
Other hospice's experiences	11	1	2
Supervision	11	2	1

Overall, respondents were generally positive about receiving further information. Two respondents sought such information to support future funding applications, indicating that they might consider setting up a service in the future. Additional topics of information identified by respondents as potentially useful included: information about the registration body; and where to find music therapists.

Conclusions

Music provision exists within the context of a wide range of activities and therapeutic resources offered by hospices to children and families. These include services directly provided by hospices and external resources available to hospice staff and clients. While psychosocial support, complementary therapies, and creative, play based activities are widely offered, there is relatively little use of specialist creative therapy professionals within these hospices.

Music is regularly used by hospices using internal and external resources, and a wide range of benefits of music are identified. Specialist organisations such as Jessie's Fund have helped to sustain music making by providing instruments and training.

Senior staff in these hospices are generally open to the idea of providing music therapy services in future, although some specific concerns were identified that might limit future provision. These concerns include costs and funding, potential demands on services and staff, and concerns about whether music therapy services would fit within the hospice organisation and match the mode of provision being offered.

Note 1: Staff roles of interview participants

Head Nurse
 Staff Nurse
 Nurse Team Leader
 Senior Nurse
 Nurse
 Clinical Nurse Manager
 Clinical manager
 Clinical Lead
 Children's Nurse Manager
 Head of Care
 Head of Care
 Care Team Manager
 Activities Coordinator
 Play Specialist

Summary of Focus Group Day

10 music therapists working in the children's hospices attended a Focus Day in November 2011. This included one of the researchers (SH). In addition the day was attended by Lesley Schatzberger (Director of Jessie's Fund - JF) and the lead researcher (LB).

The day was structured into three areas: overviews of the past, present and future with the therapists dividing into three groups to address three questions following a brief introduction to each area.

Past

Lesley Schatzberger outlined: the setting-up of Jessie's Fund; the appointment of the first therapist (1994); provision of instruments for the hospices by JF; the first JF training course for hospice staff (1995). In 2011 music therapy had been introduced by JF into 33 of the 45 children's hospices with 28 maintaining the service.

The music therapists reported on their perceptions of the changes that had taken place as music therapy provision had progressed. These included:

- the broadening of the role of MT
- more positive and trusting perception of the role by hospice staff
- increased involvement in family support work
- increased involvement and emphasis on training
- increasing importance of fundraising events
- developments in the work both within and outside of the hospice, for example family support, playing at funerals
- the increased importance of supervision and support networks, such as those provided by JF

Present

SH presented some of the early findings from the questionnaire to the music therapists (1a).

The music therapists commented that present challenges included:

- communicating the essential aspects of a MT approach to others
- gathering evidence, particularly of a quantitative kind
- timetabling and time management issues
- providing a cost-effective service
- dealing with the emotional impact of the work

The therapists were helped by:

- supervision and support, such as that provided by JF
- the hospices' approach to *living*
- involvement with other, 'non hospice' MT work
- maintaining a healthy work/life balance

Job satisfaction was helped by:

- seeing that their work made a difference to the children and families
- the variety of the work
- team working

Future

LB outlined the professional growth of MT. He commented that he considered music therapists working in the children's hospices to be working 'out of the box'; their work contrasted with traditional approaches to MT where there is an emphasis on sustained individual or small group work.

If more hours were made available the music therapists would use the time to:

- consolidate the work
- develop more outreach and community-based work
- develop research
- develop and share work with other hospices

They saw that future changes and opportunities might include:

- the need to be adaptable and develop flexible ways of working
- linking with schools
- supporting other staff
- continuing to focus on working with the well part of each child
- being confident in thinking and working 'outside of the box'

A MOTHER'S REFLECTIONS¹

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 benefitted 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

¹ Consent has been obtained from this parent so that these reflections can be included in this report.

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.

REFERENCES

- ¹ Pavlicevic, M. (ed.) (2005). *Music Therapy in Children's Hospices: Jessie's Fund in Action*. London: Jessica Kingsley Publishers.
- ² McFerran, K & Sheridan, J. (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.
- ³ Lindenfesler, K. (2005). 'Parents' voices supporting music therapy within pediatric palliative care.' <https://normt.uib.no/index.php/voices/article/view/233/177> (accessed: May 16 2011).

APPENDICES

APPENDIX A Detailed findings from questionnaire for music therapists working in a children's hospice

I a. Questionnaire for music therapists working in a children's hospice

Questionnaire:

- Sent to 28 music therapists in the UK
- Returned by 22 music therapists (82%)

Looking at 5 areas:

A: Development of music therapy in children's hospices

B: A snapshot of the Client Group

C: Family support

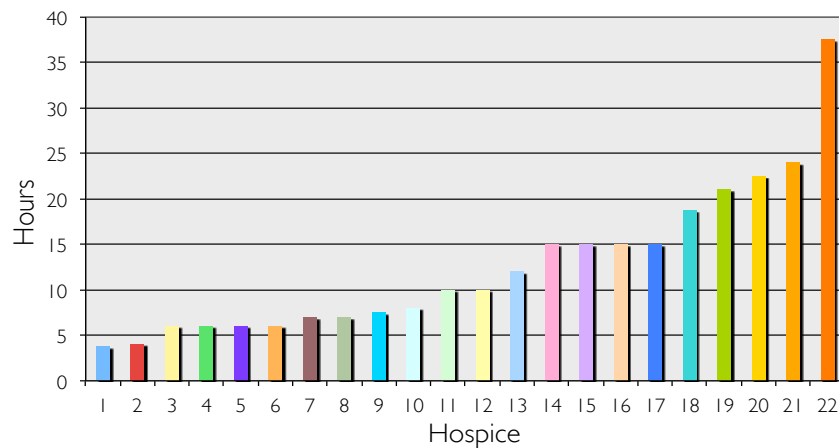
D: Working with colleagues and outside agencies

E: The format and scope of music therapy provision

A: Development of music therapy in children's hospices

All Hours

How many hours per week are you contracted for?



1994 total number of hours: 1 day (1 hospice)

2011 total number of hours: 277 hrs (across the 22 hospices that responded)

2011 ranging from 3.5 - 37.5 hrs

2011 average 13 hrs

A2/3 Space

When you began your post did you have a dedicated space for music therapy? Do you have a dedicated space now?

Space at start

- 9 Mostly music therapy [41%]
- 7 Shared
- 3 No dedicated space

Space at present

- 12 Mostly music therapy [55%]
- 8 Shared
- 2 No dedicated space (one due to refurbishment)

A4/5 Resources

How would you describe the resources you were given when you started your post? How would you describe those you have now?

Resources at start of post:

- 11 Excellent & Very Good [86%]
- 3 Good & Fair [14%]

Current resources:

- 15 Excellent & Very Good [71%]
- 6 Good & Fair [29%]

The majority of MTs chose the same category for resources at the start of their post and the resources they have now..

Of those that changed their score, only two MTs felt their resources had improved. Five chose a lower category for their current resources.

NB. Jessie's Fund provide the resources/equipment at the beginning of each post.

A6 Qualifications

What is your level of qualification?

- | | |
|----|----------------------------|
| 12 | Postgraduate diploma [55%] |
| 4 | Top up masters [18%] |
| 6 | Masters [27%] |

B. A snapshot of the client group

BI Client Group

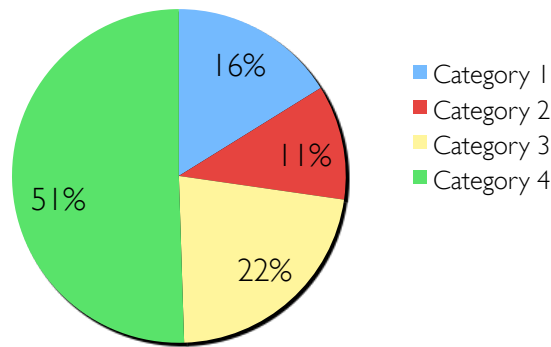
Is music therapy offered to all the children known to your hospice?

19 "Yes, every child" [86%]
 3 Not every child [14%]

Those who stated that not every child could access music therapy described a referral criteria that they use to determine who the service is best used by. However overall MTs in children's hospice appear to offer the service to all children.

BI Client Group

Referring to the ACT categories of life-threatening conditions, what proportion of your time is given to the following?



The MTs estimated the percentage of their client group. The pie chart shows the average percentage from all of the MT's estimates.

Category 1: Life-threatening conditions such as cancer, irreversible organ failure of the heart, liver, kidney

Category 2: Inevitable premature death, for example cystic fibrosis

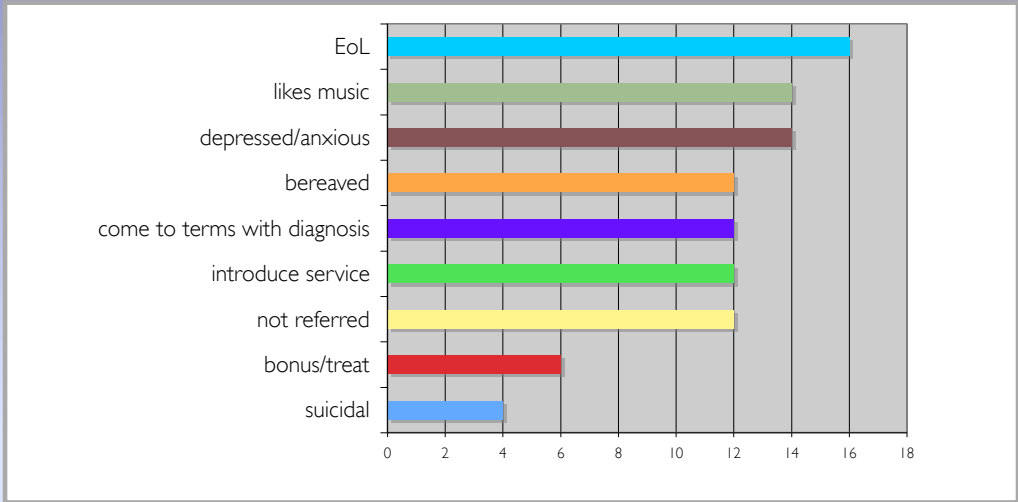
Category 3: Progressive conditions such as Batten's, muscular dystrophies

Category 4: Irreversible but non-progressive conditions causing severe disability, such as cerebral palsy or acquired brain injury

Nb. ACT and CHUK have now merged to become 'Together for Short Lives'.

B3 Referral

What reasons are your clients referred to music therapy?



EOL = End of life

Additional reasons listed under 'other':

"No other outlet for self-expression; isolation"

"Child needs to relax, be stimulated, or have time out from carers"

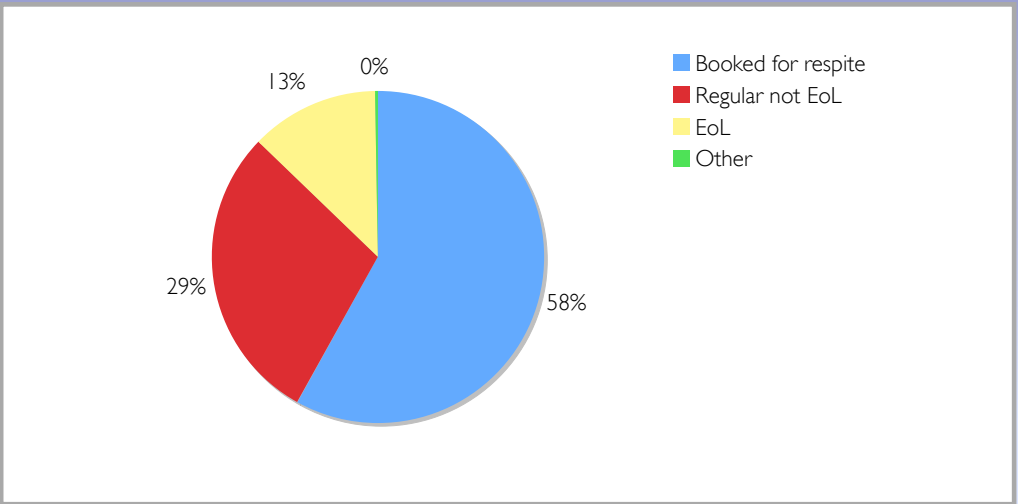
"Memory making with siblings. Increase bonding with mother. Family work. Provide home visits for children referred if unable to access hospice due to medical condition. Develop communication, motor skills, interaction. medium of communication/expressing feelings particularly for non-verbal children."

"To work with parent/care staff to help them to develop a confidence to use musical activities with their child; to promote communication, interaction, develop relationships, to motivate movement and increase muscle strength, to aid relationships etc.."

"To give staff time to catch up with other tasks."

B4 Caseload

"What proportion of your clinical time is given to..."



These are the average percentages taken from all of the MT's estimates.

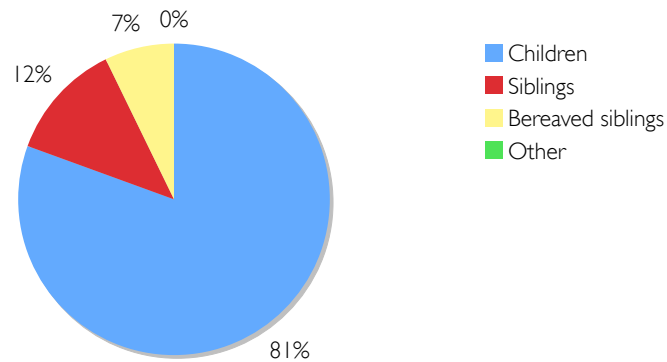
This suggests that 58% of clinical work that takes place is with children that happen to be inhouse, rather than children identified from entire hospice caseload

29% of clinical work is with children referred or identified for longer-term work

One MT included an 'other' namely "sessions for parents"

B5 Caseload

“What proportion of your clinical time is given to....”



'Siblings' refers to those whose brother or sister uses the hospice currently

Other:

“5% Cleaning + sorting room + instruments”

“5% family groups”

“2% Family Days (once a year)”

“5% parents”

B6 Caseload

“What age is the youngest/oldest child/sibling you've given a music therapy session to?”

Youngest client ranged from 0 to 3 years

6 months; birth; 6 months; 2 months; newborn; 3 years; from birth; 6 weeks; 5 days; 2 weeks; 1 week; 2 months; 16 months; 10 days; 18 months; 8 months; few weeks; 2 months; 3 months; birth; no limit; days old

Oldest client ranged from 11 - 70/80 years

17 years; 20 years; 18 years; 21 years; grandparents 70-80 years old; 20+; mid thirties; 22 years; 27 years; 17 years; 22 years; 18 years; 21 years; 17 years; 18 years; 18 years; 25 years; 19 years; 19 years; no limit; 30 years

Answers included to show range and flexibility

'Youngest client' appear significantly lower than average music therapy settings [SH] however the aims of the work may be different, for example the aim could be to create a memory for the parents who have a young baby who is only expected to live for a few days.

'Oldest client' may depend somewhat on the ages accepted by the hospice. This varies from hospice to hospice and overall appears to be extended over time.

C. Family Support

CI/2 In sessions

“Are parents/siblings present in music therapy sessions?”

Parents

- 16 Yes, if they wish [73%]
- 4 Yes, I encourage this [18%]
- 2 No, I discourage this [9%]

Siblings

- 8 Yes, if they wish [36%]
- 1 Yes, I encourage this [4%]
- 3 No, I discourage this [14%]

Parents:

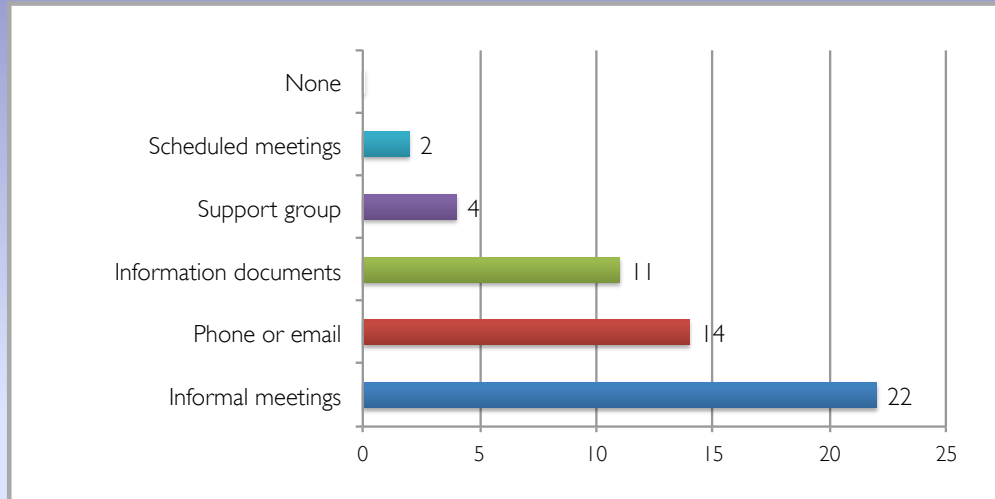
MTs explained that often the parents are not inhouse, however if they are they are encouraged to attend sessions. Again this may differ from other MT settings due to the aims of the work and flexibility of the MTs. One MT said this was more likely if the sessions was about attachment, or learning what the child can do. This may also be due to the number of young children (under 3) accessing music therapy in this setting.

Siblings:

This was determined according to the needs of the child and family.

C3 Support

“What support do you give the family alongside your care for the child?”



Other: reports, training for parents on how to use music at home, recorded sessions sent by post, showing clip of child's session as feedback, informing parents of counselling service available for them

C4 Forums

“Are you involved in meetings/forums that discuss the family as a whole?”

Meetings/forums that discuss the family as a whole:

- 9 Yes [41%]
- 4 Sometimes/ occasionally [18%]
- 1 Rarely [5%]
- 7 No [32%]
- 1 daily handover meetings [5%]

Weekly MDTs and external professionals meetings mentioned

D. Working with colleagues and outside agencies

D1/2 Colleagues

"Are other hospice staff present in music therapy sessions?"

20 MTs regularly or sometimes have colleagues present in sessions [91%]

Top reasons:

Nursing/care needs of the children

Assisting MT

Educational benefits

D3 Colleagues

“Are other hospice staff present in music therapy sessions?”

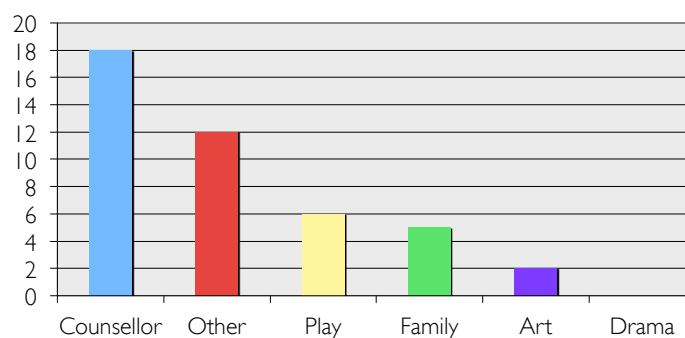
21 MTs offer some form of staff training [95%]

Formats: observation; sessions on training days; new staff inductions; student inductions; workshops; annual report; yearly sessions; informal discussion; music therapy info sessions; information pamphlet; notice-board; presentations; experiential; half a day; specialist music programme for two staff each year; musical modules; joint session with music therapy colleague; training on how to support siblings; seminars

Large variety across hospices. From my experience this can be both timely and invaluable. It may be something the MTs can join together to plan/design. Perhaps a teaching DVD/resource?

D4 Colleagues

“Are there any other therapists at your hospice who offer therapy to children?”



Other included: social worker; siblings worker; physiotherapist; outreach play practitioner; complimentary therapist; play therapist; creative therapist; student art therapist; student counsellors; art and drama workshops; occupational therapist; psychologist; nurses with additional training.

Large variety of professionals demonstrating the multi-disciplinary aspect of children's hospice care teams.

D5 Joint sessions

"Do you run any joint sessions or assist in a different Professional's group?"

15 [68%] answered "yes"

With.... Physiotherapist; complimentary therapist, outreach play practitioners; music and movement (with physiotherapists); play/story-telling and music with play leader; occupational therapist; counsellor; parent and toddler group; play team; creative therapist; play specialist; teacher; bereavement counsellors; art and music

D6 Team

"Are you part of a team within your hospice?"

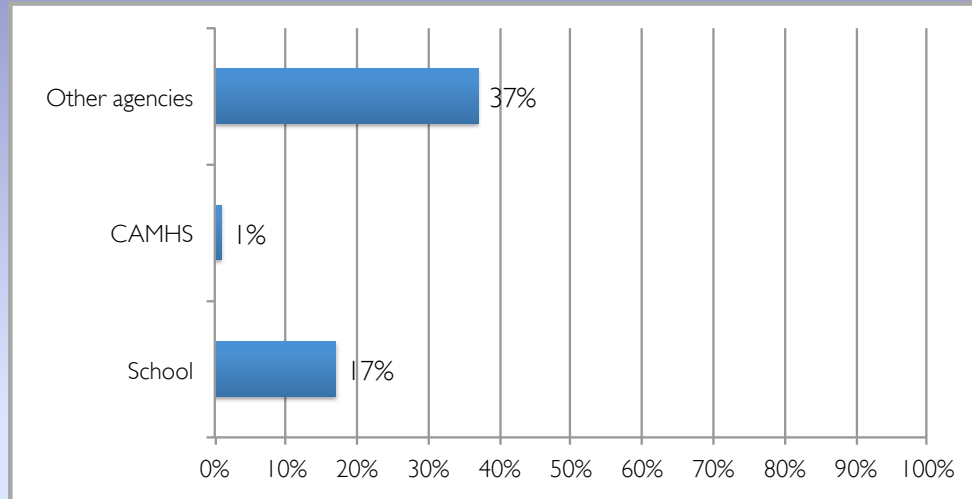
18 answered "yes" [82%]

Counselling and Family Support Team; Therapeutic Services Team; Family Support; Care Team; Activities Team; Therapies Team; Psycho-social Team; Family Support Team; Non-clinical Team; Psychosocial Support Team; Multi-disciplinary Team

Although the teams are given different names it appears that either MTs are part of the general care team, the non-clinical care team or some kind of support/therapy team.

D7/8/9 Agencies

"What proportion of children/siblings at your Hospice receive music therapy at school/CAMHS/other agencies?"



The average percentage receiving music therapy in said setting (taken from the MT's estimates)

16 of the music therapists were aware that children also had music therapy at school, this ranged from none to two thirds of the children using the hospice; 7 music therapists were aware of MT organised by other agencies. Only 2 music therapists knew of children who receive MT organised by local Community Adolescent Mental Health Services. This demonstrates a potential lack of communication between children's hospices and outside agencies.

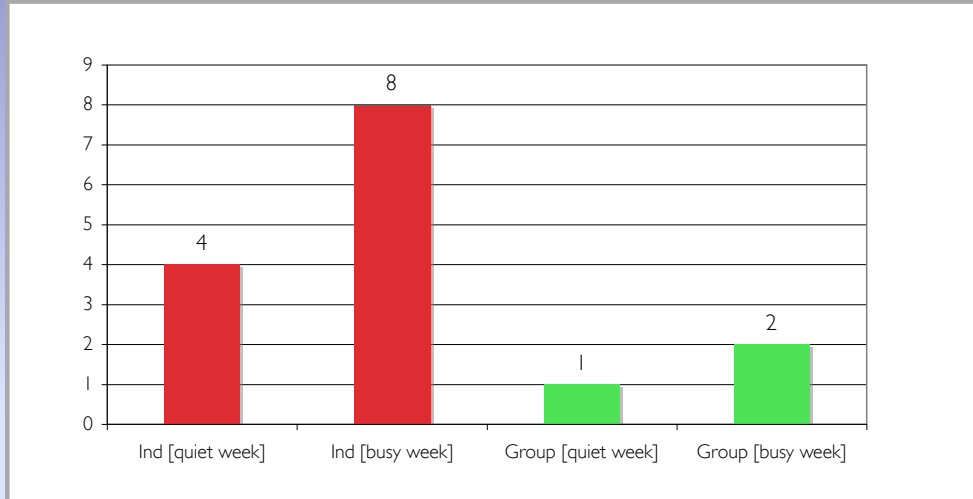
Other agencies included different charities or nearby county music therapy organisations. Whether the child can access music therapy from an outside service appears to be a postcode lottery.

It should be noted that several of my parents do not tell me that their child receives music therapy at school as they would like both services. One children's hospice does not give music therapy to children who already receive this at school.

E. The format and scope of music therapy provision

E1/2 Quantity

"In a quiet/busy week how many sessions would you give?"

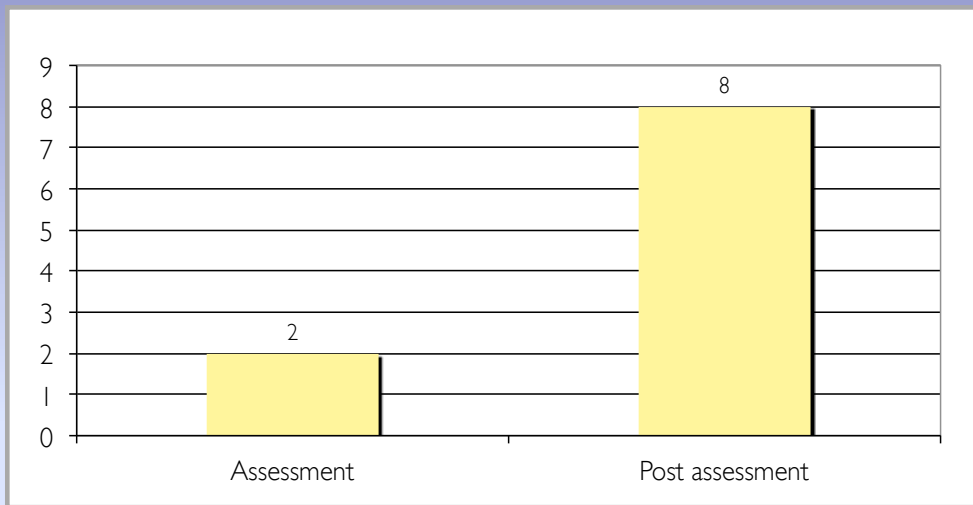


These are the average formed from the answers given
 This doesn't take into account the differing hours of employment but is an overall figure

Individual sessions in a quiet week ranged from 1-7
 Individual sessions in a busy week ranged from 2-10
 Group sessions in a quiet week ranged from 0-3
 Group sessions in a busy week ranged from 0-6

E3 Series

"Do you offer a series of individual sessions? If so, how many do you offer each child/sibling?"

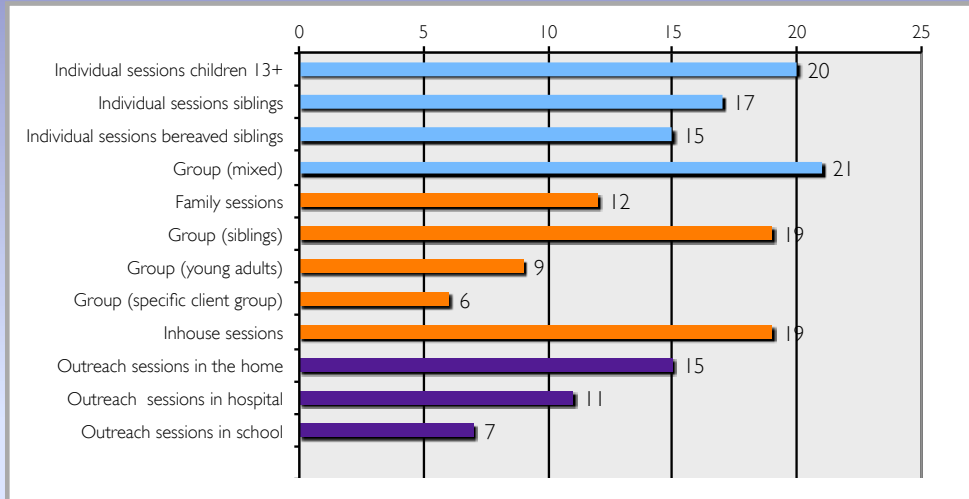


Only 11 [50%] of the MTs answered this question (claiming to offer a series of regular sessions as part of their service)

The above graph shows the average number of assessment and post-assessment sessions from those who answered.

E4 Format

“What formats of music therapy session do you offer?”



Large scope

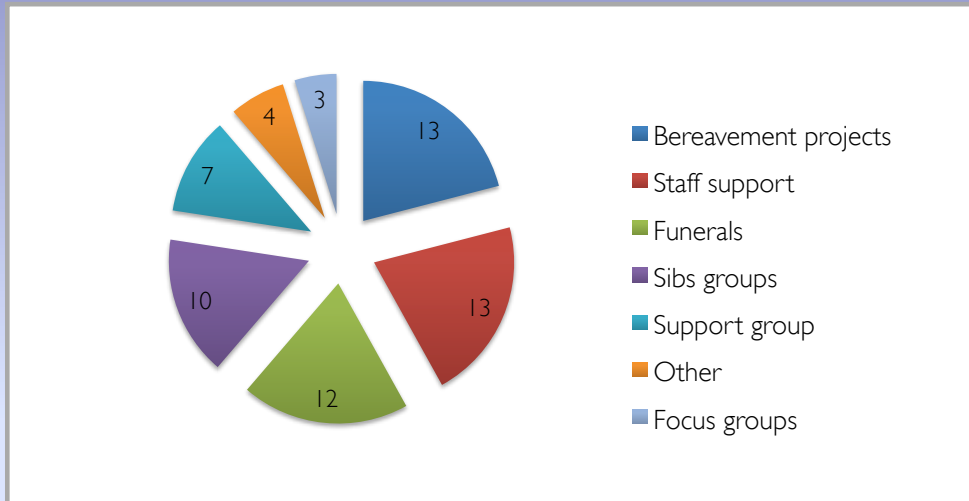
Only one MT did not provide any group work, showing that group work is for the most part standard and popular in this setting.

High number of family sessions

Inhouse is more prolific than outreach. I have found that this largely depends on the hospice and how they support families whether this is dominated by community or inhouse care

E5/6 Other therapeutic

“Are you involved in any other therapeutic work?”



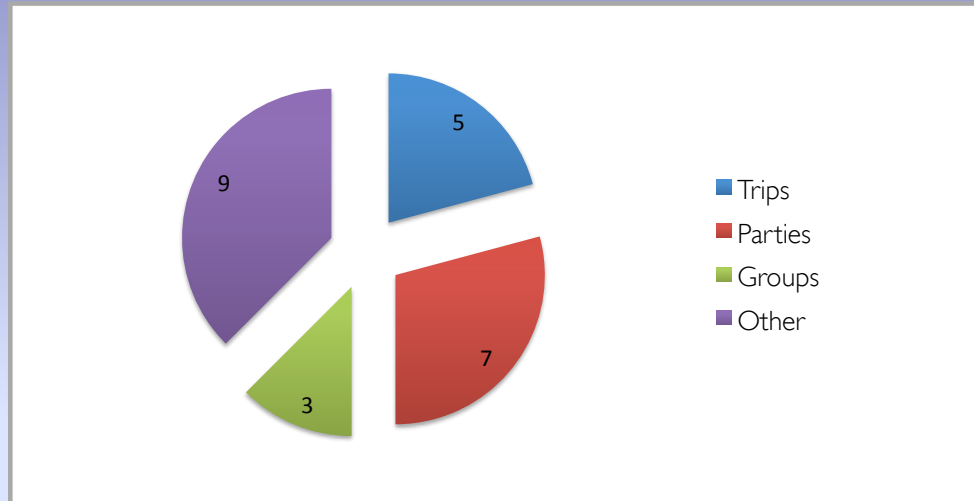
Number of MTs involved in said group

Other: remembrance days, Grandparents Day, training days

Purpose of involvement: support for families; keeping MT a part of the service; to explore emotions in a sibs workshop, advisory; adding musical element to established groups; musical contributions; to hold families in their grief; its team-building to be involved; to get to know staff; to encourage peer interaction; help build the group; provide personal meaningful music; to provide input from a music therapy perspective; general support; staff support; promoting music therapy service; relaxation through music for parents; plan and implement therapeutic perspective; to assess children for individual work; to provide ongoing support to families

E6/7 Non-therapeutic

"Are there any non-therapeutic projects/activities that you are involved with?"



Number of MTs involved in said activity

Other: meals and chatting over coffee; remembering days; Christmas; open days talking to the public; Youth club; Christmas parties for staff; siblings trips; carol concerts; anything that might need music; leaving do's; office openings; organising external musicians to perform; staff choir

Purpose of involvement: general involvement in life at the hospice; to build relationships with staff; to build relationships with families; contact with families; contributing to the team-work; promotion of music therapy; to provide music therapy support; helping with adult-child safety ratios; helpful to have member of staff that the teenagers know; to be a familiar face to siblings and families; to assess children we're concerned about; part of team!

F1 Greatest achievements Summary

"What would you regard as your greatest achievements as a MT in your children's hospice?"

- Extended work with families
- End of life work
- Gaining trust of families
- Reaching challenging children
- Versatility and adaptability
- Music therapy becoming a fundamental part of the hospice
- Co-work with professionals
- Memorial and funeral services
- Choirs and bands
- Compositions with children
- Work with siblings
- Music technology development
- Community music therapy projects
- Recordings and music memorabilia
- Open groups and their impact on families and staff
- Outreach services
- Advocating for children/families
- Support from care staff and management
- Training programs for staff
- Developing models
- Fun and enjoyment

F2 Development Hopes Summary

"How would you like to see music therapy developing in children's hospices in the next 25 yrs?"

- More of the same
- More hours
- More liaison with outside agencies
- More bereavement work
- More outreach work
- Development of work with babies
- Acceptance of adult work
- More Community music therapy projects
- Dedicated music therapy space or a music therapy suite
- More technology and facilities to record sessions (CD & DVD)
- iPads
- More resources/time for teenagers
- More involvement with counselling services
- More family work
- More student MT placements
- MT in supervision and team-building
- More staff training
- More respect from senior management
- Research, evidence, publication, conference talks
- Peer supervision
- More frequently meeting other MTs in this field
- Regional groups for MTs
- A structure for career development
- MT service to become more integral (not needing selling)
- Every child hospice to have a MT
- A team of MTs in each hospice
- For MTs to stop worrying if their work is music or music therapy
- Using MT therapeutic skills in siblings' groups
- End of narrow view that MT is 1 to 1

APPENDIX B: Copy of consent form for the music therapists' questionnaire

Please feel welcome to add any additional comments here.

You may wish to contribute any other thoughts, concerns or questions linked to the development in the provision of music therapy in children's hospices.

We thank you for taking part in this service evaluation. Each contribution is extremely valuable in determining the progress and achievements of music therapy in children's hospices.

Due to the sensitive nature of therapeutic work, your answers will be treated as confidential. We would however like to collate and share the results and themes from this study in an appropriate report and/or publications. Therefore we ask you to tick the box below if you will allow us to anonymise your answers and include these in our findings. This will mean that your answers will not be linked to your name or your hospice.

Yes, I give permission

Name

Date

Children's hospice

Thank you for your time

APPENDIX C: List of questions for staff at children’s hospices where music therapy services are not currently offered

Development in the Provision of Music Therapy in Children's Hospices 2011 [Bunt, Daykin, Hodkinson, Schatzberger]
 Questionnaire 1b. for children's hospices who do not employ a music therapist

Name of hospice			
Name and job title of interviewee		Date	

1. Would you like to provide music therapy as part of your hospice service?

Yes,

Maybe

No

2. Do you have any specific concerns about employing a music therapist?

Yes. Please describe:

No

3. Do you use music or musicians at your hospice in any other capacity?

Yes. Please describe

No

4.a. What do you feel would be the benefits of offering music therapy to your children and families?
Or
4b. What is your understanding of music therapy?

5. Do you provide any other therapies of psychological support for children on your caseload?

- Play therapist
- Art therapist
- Drama therapist
- Family therapist
- Counsellor
- Children's counsellor
- Social worker
- Complementary therapies
- Other. Please describe _____ :

6. Are there any aspects of music therapy you would like further clarification of or more information about?

- Cost/salary
- Benefits
- Other hospices' experiences
- Supervision
- Other. Please describe: _____

APPENDIX D: Copy of consent form for children's hospices not providing music therapy



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West of England



Evaluative Survey of Music Therapy Provision in Children's Hospices in the UK

Consultation 1b: for children's hospices

Consent

We thank you for the recent telephone conversation we shared with you, discussing the topic of music therapy within a children's hospice. Each contribution is extremely valuable in determining an evidence base of best practice.

Your answers will be treated as confidential. We would however like to collate and share the results and themes from this study in an appropriate report and/or publications. Therefore we ask you to tick the box below if you will allow us to anonymise your answers and include these in our findings. This will mean that your answers will not be linked to your name or your hospice.

Yes, I give permission

Name	
Job Title	
Date	
Children's hospice	

We welcome your contact should you wish to ask us any further questions.

Thank you for your time.

Leslie Bunt, Norma Daykin, Sarah Hodkinson, Lesley Schatzberger
 Contact: Sarah.Hodkinson@shootingstar.org.uk 020 8783 2143
 Shooting Star House. The Avenue, Hampton, TW12 3RA
 Version 2, 1st December 2012

APPENDIX E: Invitation, Agenda, Questions and Minutes of Focus Day



University of the West of England



Invitation

Focus Day

Saturday 19th November 2011 |

Dear Music Therapist,

We invite you to be part of our **Focus Day** for music therapists working in children's hospices. We would like to hear your thoughts and knowledge of the progress and future development of this work. We hope too that the Focus Day will be a valuable space for you, providing an opportunity to discuss pressing issues, to consider best practice and to be supported in the work that you do.

If you are able to attend, we will send you a list of topics and questions, so that if you would like to, you are able to consider what your thoughts might be.

Please see the reverse of this invitation for further details.



Focus Day

Date: Saturday 19th November 2011 |

Time: Midday - 4:30pm

Venue: Shooting Star House

The Avenue

Hampton

TW12 3RA

Nearest train station: Hampton

There is a train from London Waterloo to Hampton

All refreshments and a buffet lunch will be provided

Please RSVP by 1st November:

Sarah.Hodkinson@shootingstar.org.uk

020 8783 2143

(Please note that if you have emailed previously you do not need to RSVP again)



University of the West of England





University of the
West of England



Evaluative Survey of Music Therapy Provision in Children's Hospices in the UK
Focus Day for Music Therapists

Saturday 19th November 2011, 11:30 - 16:30
Shooting Star House, The Avenue, Hampton, TW12 3RA

Agenda

- 11:30 Refreshments on arrival
- 12:00 Welcome and introduction
Leslie Bunt
- 12:15 The Past: a short overview of the growth of music therapy in children's hospices
Lesley Schatzberger
- 12:30 Group Work Session 1
- 13:00 Group Feedback
- 13:15 **LUNCH (sandwiches)**
- 14:00 The Present: a glimpse at the data gathered in the recent questionnaires
Sarah Hodgkinson
- 14:15 Group Work Session 2
- 14:45 Group Feedback
- 15:00 **COFFEE BREAK**
- 15:30 The Future: possibilities, trends and challenges to the profession
Leslie Bunt
- 15:45 Group Work Session 3
- 16:15 Group Feedback
- 16:30 Close

Questions for the Focus Day:



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West of England



Past

Q1. How has your role changed since starting your post?

Q2. How has this assisted in the development of your hospice as a whole?

Q3. Are there any factors that hinder or encourage the development of your role? (eg. training, research, management, supervision)



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Present

Q1. What are the challenges you face in your job? (eg. liaising with outside agencies, gathering evidence, family work)

Q2. What helps and enables you to overcome challenges?

Q3. What brings you job satisfaction?



Future

As a group, please discuss the questions below, coming up with a maximum of four main points to answer each question. Please record these on a sheet of paper/card and nominate a person to feed your main points back to the larger group.

Q1. If your hours were doubled today, how would you use this time?

Q2. Do you see any potential for music therapy in children's hospices to lead change and development in the profession or in children's palliative care?

Q3. One thing (about music therapy in children's hospices) that you would want to carry from the past to the future and one thing that you feel should be left in the past.



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Evaluative Survey of Music Therapy Provision in Children's Hospices in the UK

Focus Day for Music Therapists

Saturday 19 November 2011, 11:30 -16:30

Shooting Star House, The Avenue, Hampton, TW12 3RA

Present: Leslie Bunt, Kathryn Barker, Diane Chamberlain-Butt, Neil Eaves, Ruth Ellam, Claire Greaves, Sarah Hodgkinson, Vicky Kammin, Anna Ludwig, Margaret Merriam, Ceridwen Rees, Lesley Schatzberger

Minutes

1. Welcome and introduction

Leslie Bunt welcomed everyone and briefly described the aims of the evaluative survey: to gain

a clear understanding of current music therapy provision in children's hospices, place it in a historical context, and outline indications for future service development. The survey is a partnership between Jessie's Fund and the University of the West of England whose Faculty of Health and Life Science's Research Ethics sub-Committee has approved this project. Leslie stressed that all discussions of the day would be reported with anonymity.

2. The Past

Lesley Schatzberger described how Jessie's Fund was established, and how it was involved in initiating music therapy in children's hospices. In 1994 there were only 6 children's hospices. Jessie, Lesley's daughter, spent her last week at Martin House in Yorkshire, where, coincidentally, one of the nurses was at that time retraining to be a music therapist. Cathy Ibberson returned to Martin House after qualifying and became the first children's hospice music therapist.

Jessie's Fund provided instruments for all the children's hospices, and devised, with the help of Leslie Bunt, a training course which would help care team members to use music in their work even though they may have no previous musical training. This first course took place in 1995.

New children's hospices were opening year by year, and in 2011 there are 45 hospice services for children, 40 of which are primarily residential, and 5 purely hospice-at-home services.

33 of the 45 children's hospices have had music therapists, almost all posts having been established by Jessie's Fund which funded them for a period of three years. Of these, 28 hospices maintain a music therapy service in 2011.

3. Group session looking at music therapy in children's hospices in the past.

Discussions took place in smaller groups, which addressed three questions. Each group was asked to think of up to five points in answer to each question. There were some answers in common from each group.

a. How has your role changed since starting your post?

- It is we who have changed rather than the role.
- Staff perception of the role has changed – it is now more positive and trusting.
- The music therapist has become more integrated into the staff team as people understood the work better.
- Meeting the needs of children and their families has led to changes.
- It's a very different role from the classic music therapy model.
- A broadening into a 'therapeutic music' role, including playing at funerals and memory days, running choirs etc.
- Hours have increased.
- Outreach work has been developed.

- Support from senior management is essential in developing the role.
- b. *How has this assisted in the development of your hospice as a whole?***
- Hospice has developed from a purely palliative care model into providing more holistic care.
 - There is more confidence and flexibility.
 - Music therapist is involved in wider projects: therapies team, family support etc.
 - Music therapy is a sellable 'product', eg. for fundraising and open days.
 - Music therapy is an obvious way to show people the holistic care a hospice offers.
 - Music therapy is used as an introduction to new families – perhaps a child has a music therapy session before even visiting the hospice.
 - Music therapist may provide sessions in the home and be a valuable link between the family and the hospice.
 - Music therapy provides a rare non-medical intervention.
- c. *Are there any factors that hinder or encourage the development of your role?***
- Providing training for other staff helped in getting referrals.
 - Had to be pro-active in gaining support from management by organising meetings to demonstrate work etc.
 - Importance of supervision, support groups, Jessie's Fund network meetings.
 - Educating people: getting them to recognise that music therapist can play a role in other areas of hospice life.
 - In/security: music therapy can be easy for fundraisers to 'sell', but it's under threat from funding cuts as it's sometimes seen as an 'extra'.
 - Relationship with senior management can change either for better or worse.
 - Other staff may not understand and see that the music therapist doesn't do the mundane care tasks so consider the role 'cushy'.
 - Difficulty of gathering evidence based research.

4. The Present: a glimpse at the data gathered in the recent questionnaires

Sarah gave a presentation summarising the information she had gathered from the questionnaires sent out to all the music therapists. There were numerous graphs illustrating her findings. She had had a good response rate to the questionnaire, though there were still a few music therapists from whom she had not heard. Two completed questionnaires had just arrived, after she had prepared the presentation, so these would very slightly alter the statistics.

Rather than giving hand-outs showing the data at this stage, she said she would wait until the survey is completed. This will be in the New Year.

5. Group session looking at music therapy in children's hospices in the present.

Discussions once again took place in smaller groups addressing three questions.

a. What are the challenges you face in your job?

- Assumption of what music therapy is rather than an understanding. Common misconceptions.
- Difficult to show quantifying evidence or to describe work in words.
- Pushing oneself into new areas of work, variety, adapting, changing.
- Getting staff to respect planned sessions – other activities sometimes get organised ignoring these plans.
- Fitting sessions around medications, feeds etc.
- Being expected to see everyone each day.
- Decisions over whether to work with child alone or with child and family
- Gathering quantitative data
- The cost of music therapy
- Sharing of information across agencies and sometimes boroughs
- Time management
- Lack of understanding from senior management
- Working with terminally ill children.
- Dealing with the emotional impact.
- Hospice politics

b. What helps and enables you to overcome challenges?

- Supervision
- Support groups
- Internal hospice support
- Relationships with colleagues – worth putting time and effort into
- Jessie's Fund support
- Financial security
- Seeing a changing perception about children's hospices – all about *living*
- It's ok to try things and not worry about failing
- Most music therapists work in other settings too – the contrast with children's hospice work keeps one fresh.
- Good work-life balance/outside interests
- Time out/processing time/holidays
- Laughter/wine!
- Knowing how worthwhile it is – positive feedback

c. What brings you job satisfaction?

- Knowing what you have done has given a family something to remember
- Making a difference/offering comfort, something positive, hope.
- The privilege of being invited into a family at a very special time in their lives.
- When the 'penny drops' with professionals

- Variety of work
- Reactions from children/seeing changes
- Positive feedback from families/colleagues
- Seeing progress
- Good referrals showing people's understanding
- Working in a good team
- Little perks of working in a hospice: celebrity visits, chocolates etc!

6. The Future: possibilities, trends and challenges to the profession

Leslie talked about this being a period of transitions, with the children's hospice music therapists on the cutting edge of the profession, potentially helping music therapists in all settings in developing services. He looked back on significant moments in the profession: the establishment of the BSMT in 1958: the first post-graduate training in music therapy at Guildhall School of Music and Drama (Juliette Alvin) in 1968: the establishing of the APMT in 1976: the first Career Structure – Whitley Council (Health and Social Services) - in 1982: HPC Registration (alongside art and drama therapists) in 1997. In 2011 the BSMT and APMT merged to form the BAMT. He generously mentioned Jessie's Fund's contribution to the profession. Leslie recalled a presentation by Nigel Osborne at the 2002 World Music Therapy Congress in Oxford in which he talked about three big challenges:

- Music therapists stand on the cutting edge of all that's inspiring and exciting about music in a practical sense.
- Intellectually we're on the edge of a huge debate on what happens in music.
- There is a moral imperative to do this work.

Leslie regards all the children's hospice music therapists as 'out-of-the-box' therapists who need to continually 'think on their feet': an example of one of his music therapy teachers' motto 'adapt or perish'. They have to deal with lots of 'bubbles': children, siblings, parents, different agencies. The work is different from classic models of music therapy – it could look towards a new definition of what music therapy could be.

7. Group session looking at music therapy in children's hospices in the future.

Group discussions once again.

a. If your hours were doubled today, how would you use this time?

- Consolidate and do more of what I do already
- Try to organise time in the community
- Allocate a percentage of time to professional development, eg. training, music tech, video editing, music for teenagers.
- Do more work in schools supporting staff in dealing with bereavement.
- More support groups for parents; eg. in pubs for dads.
- More outreach
- Time for research and career development

- Visit and share with other hospices
- Reflect more; chat more with people.

b. Do you see any potential for music therapy in children's hospices to lead change and development in the profession or in children's palliative care?

- We 'break the rules', which could lead to change
- Potential to lead towards acceptance of more flexible ways of working.
- Having links with schools gives potential for change
- Would like to see growth in awareness in medics of working with 'well' part of a child, ignoring the ill part.
- We'd like to see more awareness of how we work within the BAMT: what we do is a challenge to the status quo in music therapy models.

c. One thing that you would want to carry from the past to the future and one thing you feel should be left in the past.

- Carry forward the flexibility and adaptability
- Continue to be involved in the general life of the hospice
- To continue to experiment and not be afraid of failure
- Support more staff to do music
- Increase empathy, attunement, connection, retaining essence of training.
- To 'dump the debate' – it's just music. Remove preciousness about music therapy – that it can only happen at a certain time, in a certain place.
- Leave behind being so strict with boundaries.
- Leave behind the perception that music therapy is a limited role.
- Leave in the past not have many students on placement – take on more.

After this discussion the formal meeting ended, and there followed a tour of Shooting Star House.

Sarah was thanked for organising the meeting, and for preparing for it so well, and Vicky was thanked for providing the lunch.

APPENDIX F: Copy of consent form for the Focus Day (Appendix e)



University of the
West of England



Evaluative Survey of Music Therapy Provision in Children's Hospices in the UK

Consultation 1c: focus day for music therapists working in the setting

Consent

We thank you for your participation in the Focus Day, Saturday 19th November 2011. Your contribution is extremely valuable in determining best practice and potential future developments.

During the day we will be asking small groups to discuss specific questions. The small groups will then be asked to feedback themes from their discussion. At this point we will take note of your group's answers and we will treat these answers as confidential.

We would however like to collate and share the results and themes from this study in an appropriate report and/or publications. Therefore we ask you to tick the box below if you will allow us to anonymise your group's answers and include these in our findings. This will mean that your answers will not be linked to your name or your hospice.

Yes, I give permission

Name	
Date	
Children's hospice	

We welcome your contact should you wish to ask us any further questions.

Thank you for your time.

Leslie Bunt, Norma Daykin, Sarah Hodkinson, Lesley Schatzberger
Contact: Sarah.Hodkinson@shootingstar.org.uk 020 8783 2143
Shooting Star House, The Avenue, Hampton, TW12 3RA

APPENDIX G: study timeline

Month	Activity	Notes
May - July 2011	Proposal formulated, edited and approved by Jessie's Fund	
August	<p>Research fieldwork SH</p> <ul style="list-style-type: none"> i) Obtain list of children's hospices from ACT/CHUK ii) Email to all hospices to confirm whether they provide a music therapy service and awaited replies iii) Determine music therapist contact (where appropriate) and formulate up-to-date contact table using information from JF, ACT/CHUK and British Association of Music Therapy <p>Design and discuss methods to collect information Obtain approval from team on method proposal 1a. Questionnaire for music therapists 1b. Phone consultation for hospices without music therapy 1c. Focus Day Draft questions for 1a, 1b and 1c</p>	<p>Fieldwork proved more challenging than initially expected due to changes in music therapy provision, maternity cover, some hospices buying in a music therapy service etc...</p> <p>All proposals and designs and questions needed to be approved by Leslie, Norma and Lesley and the JF trustees</p>
September	<p>Design and discuss questions for 1a, 1b and 1c Obtain approval from team on questions for 1a, 1b and 1c; consent form for 1a Collect logos from JF and UWE for printed materials Design and print questionnaire for 1a Design and print consent form for 1a Design and print cover letter for 1a and 1c Locate and confirm venue and date for 1c Design and print invitation for 1c Email to music therapist contact list suggesting 'save the date' for 1c</p>	
October	<p>Mail out of 1a. questionnaire and 1c invitation [asking for return of the questionnaire by 5th November] Planning and designing of 1c Obtaining approval from team on planning for 1c Preparation for 1c [room bookings, refreshments, printing resources, equipment, grouping] Collating RSVPs and returning calls to those making enquiries about 1c Ethics approval sought and obtained from UWE Faculty</p>	
November	<p>5th – 19th November type up questionnaires into confidential spreadsheet and formulate PowerPoint presentation of preliminary results for 1c Final preparations for 1c [email to music therapists, printing materials; setting-up] 19th November 1c Focus Day took place midday – 4:30pm Typing up minutes of Focus Day discussions Collating consent forms for 1c 1b phone consultations began</p>	

	Revision of 1b consent form to allow for a broader range of staff to be interviewed	
December	1b phone consultations continued 1b sending of consent forms and reminder consent form JF assisted with named persons at hospices who have not yet completed 1b	
January 2012	Collecting consent forms for 1b Phone Interviews [chasing up] Typing up of 1a questionnaires that arrived late	
February	Further chasing up of consent forms for 1b Phone Interviews Presentation of data collected in 1a for analysis	
March	Data analysis – SH, ND Compilation of report LB, ND and SH	
April	Submission of Report to Trustees of Jessie's Fund	