Music therapy in UK palliative and end-of-life care: a service evaluation

Lisa GRAHAM-WISENER¹, Grace WATTS², Jenny KIRKWOOD³, Craig HARRISON¹,

Joan MCEWAN¹, Sam PORTER⁴, Joanne REID⁵, Tracey MCCONNELL⁶

¹ Marie Curie Northern Ireland, Belfast, UK.

² British Association for Music Therapy, London, UK.

³ Everyday Harmony, N.Ireland Music Therapy Trust, Belfast, UK.

⁴ Social Work & Social Sciences, Bournemouth University, Bournemouth, UK.

⁵School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK.

⁵ School of Social Science, Education and Social Work, Queen's University Belfast, Belfast, UK.

Word Count: 1499

Contribution of authors: Conception or design of the experiment(s), or collection and analysis or interpretation of data: all authors. Drafting the manuscript or revising its intellectual content: all authors. Approval of the final version of the submitted manuscript: all authors.

Short form title: Provision music therapy palliative care

Corresponding author: Lisa Graham-Wisener, Marie Curie Hospice Belfast. 1a Kensington Road, Belfast BT5 6NF, Northern Ireland. Email; lisa.graham@mariecurie.org.uk. Telephone; +44(0)28 90882048.

ABSTRACT

Music therapy aligns to the holistic approach to palliative and end of life care, with an emergent evidence base reporting positive effect on a range of health related outcomes for both patient and family carer alongside high client demand. However, the current service provision and the role of music therapists in supporting individuals receiving palliative and end of life care in the UK is currently unknown.

Objectives

This service evaluation aims to identify the provision, role and perceived impact of UK music therapists in supporting patients receiving palliative and end of life care (PEOLC), their families and health and social care professionals.

Methods

A survey was distributed to the British Association for Music Therapy (BAMT) member mailing list in July 2017. BAMT is the professional body for HCPC registered Music Therapists in the UK.

Results

Fifty respondents identified themselves as music therapists currently working with clients receiving PEOLC. The respondents largely reported (84.7%) less than 10 years' experience working in PEOLC settings, with only a minority receiving statutory funding for their role. Music therapists most commonly reported supporting adults with neurological conditions, cancers and dementia.

Conclusions

Although promising that evidence suggests provision of music therapy in UK PEOLC settings in the past 10 years to have increased, lack of sustainable funding suggests the role to not be consistently accessible in PEOLC.

INTRODUCTION

Music therapy (MT) aligns to the holistic approach of palliative and end of life care (PEOLC) as the 'active total care of patients' [1] and involves 'the use of sounds and music within an evolving relationship between client and therapist to support and encourage physical, mental, social, spiritual and emotional wellbeing' [2]. Rather than the passive use of music as part of therapy, music therapists use music as the agent of therapeutic change [3]. There is rigorous research evidencing the impact of MT on pain in general PEOLC populations [4;5] and across a range of outcomes in distinct clinical populations such as dementia [6]. Although research evidencing the impact of MT on psychosocial outcomes in general PEOLC is as yet unequivocal [4;5], the evidence base for this intervention is otherwise persuasive.

In the United States, MT is one of the two most common forms of complementary therapy provided by hospices [7]. However, the provision and role of music therapists in supporting individuals receiving PEOLC in the UK is currently unknown. With an established evidence base across several outcomes and patient populations [4;5;6] and suggestion of high patient demand [8], information on existing service provision would be valuable to i) assess the extent of MT implementation in practice and ii) understand the current practice of music therapists in PEOLC to ensure prospective research is reflective of this.

This service evaluation aims to identify the provision, role and perceived impact of UK music therapists in supporting patients receiving palliative and end of life care, their families and health and social care professionals.

MATERIALS AND METHODS

A survey was distributed to the British Association for Music Therapy (BAMT) member mailing list in July 2017. BAMT is the professional body for HCPC registered music therapists in the UK. In the UK music therapists have formal Master's level training and are registered with the Health and Care Professionals Council as allied health professionals. An invitation email was circulated to the membership directory, explaining the purpose of the evaluation and containing a link to the survey. Members were invited to respond if they provide support to people receiving PEOLC. A 27-item survey was developed on

SurveyMonkey, an internet data collection service, based on the published literature and input from music therapist clinicians. The survey contained items on the music therapist's role, setting and client base, session format, therapeutic approach and goals, perceived impact of MT, and measurement of impact. Two reminder emails were sent, alongside newsletter and social media reminders, with the survey closing September 2017.

Analysis of descriptive statistics was undertaken with frequency data reported.

RESULTS

Music Therapist Provision

Of the 745 members contacted, the survey received responses from 50 (7%) UK music therapists indicating they provide support to people receiving PEOLC. Respondents were largely full practitioner members n=47 (94%) with a minority n=3 (6%) newly qualified members.

A small number of music therapists (15.2%) had >10 years' experience practicing within a PEOLC setting, with the majority reporting 1-5 years (32.6%) or 6-10 years (34.8%) experience. Including the newly qualified members, 17.4% of respondents were new to a PEOLC setting with <1 year experience.

Music therapists largely worked with PEOLC clients between 2-5 hours (30.4%) or 6-10 hours (28.3%) a week. Only a minority (13%) of music therapists provided >28 hours support a week to PEOLC clients.

Only 10.9% of respondents reported their work with PEOLC clients to be supported through dedicated statutory sector funding. There was however evidence of joint NHS and charity/hospice funding in an additional 10.9% of cases. The majority of music therapists reported being supported through charitable (27.3%) or hospice self-funding (31.8%) with a number of respondents reporting time-limited grant funding (6.8%).

Setting & Client Group

Most respondents supported clients in a hospice (63.6%) or a residential care/nursing home setting (52.3%). Respondents however worked across a disparate range of settings including acute hospital (27.3%), domestic household (27.3%) and community settings (27.3%).

Respondents most commonly reported supporting those aged between 65-85 years (70.4%), with a significant number (63.6%) also reporting working with people > 85 years of age. At the other end of the age scale, 34% of music therapists reported working with infants and young children <5 years of age; 40.9% with children of 6-11 years of age, and 43.2% with adolescents of 12-18 years of age.

In relation to clinical population, respondents most commonly reported working with clients with neurological conditions (68.2%), followed by cancer and haematological malignancies (65.9%), and dementia (56.8%).

Format of Sessions

Respondents delivered MT to PEOLC clients both within individual sessions (97.6%) or group sessions (88.1%), with a smaller proportion also delivering community sessions (35.7%).

Of respondents providing group sessions, 75% reported practice of using 'open groups' (new attendees can join at any time), 52.5% utilised 'closed groups' (fixed membership) and 27.5% 'drop in' (attendance at the group is open to all available to attend on that day at that time) groups.

Respondents reported working jointly and working alone in planning MT sessions in equal measure. Music therapists working jointly with others to plan the MT sessions, most commonly collaborated with a nurse (59%) or a family member (41%).

During the MT session, the majority of respondents reported co-working with another person (59.5%). In the majority of cases this person was the family carer (46.2%) or an employed carer (42.3%).

A high proportion of respondents also reported work focused on the PEOLC family member and loved one (75.6%), mostly for pre-bereavement support (100%), at the time of passing (61.3%), and at post-bereavement (61.3%). Work with family members and loved ones entailed individual and joint sessions with the patient, supporting children who were facing the loss of a parent, supporting parents and siblings facing the loss of a child, preparation for funerals and memory making.

Therapeutic Approach

A person-centred approach to MT (77.7%) was utilised by the majority of respondents. This was followed closely by a psychodynamic approach (70.5%). The majority of respondents (56.8%) reporting utilising a combination of therapeutic approaches in their practice with PEOLC clients. Less common approaches utilised by <5% of respondents included; phenomenological, Gestalt, behavioural, ecological and Guided Imagery and Music.

Therapeutic goals

The most common therapeutic goal in working with PEOLC clients as cited by all respondents was supporting psychological needs (100%), followed by supporting quality of life (93%). The least common therapeutic goal was helping people to be as active as possible until death (34%).

Perceived Impact

The highest level of perceived impact from MT in relation to the PEOLC client was in relation to improving communication/ expression (95%), emotional (93%) and psychological (81%) wellbeing.

The majority of respondents believed MT to impact on a PEOLC setting by offering a space for feelings to be expressed and processed (95%). A large proportion also felt that MT supported relationships between clients and staff (85%), between clients (82.5%), between families and staff (67.5%) along with supporting staff who deliver palliative and end-of-life care (75%).

Measuring impact

Measurement of impact was less well defined, with respondents referring to the use of a tool or quantitative measurements without specifying what they were. Perceived impact appeared to be largely intuitive, with respondents reporting observations of improvements in communication/expression of feelings, mood, pain levels, stress levels and breathing states. Other approaches to measuring impact included staff, patient and/or family feedback along with bespoke tools developed by the music therapist to measure clinical outcomes based on individual goals.

Training

Just over half of respondents (54.5%) offered training to staff (75%), families/carers (21%), and music therapy students (21%) within their work setting. This training consisted mostly of introductions to MT, including the therapeutic approaches used for specific client groups.

DISCUSSION

This service evaluation provides evidence on the current provision of music therapists working to support palliative and end of life care clients across the UK, not available until this point.

It is promising that the evaluation suggests an emergent workforce of music therapists in PEOLC across a range of settings, with the majority of music therapists reported to have started working in PEOLC within the last decade. The survey has a number of limitations, including the small number of respondents which may also reflect a poor response rate. However, it is marked that those responding report an apparent lack of statutory funding of MT provision in PEOLC.

The survey respondents commonly cited improving quality of life as a goal of care in their work with PEOLC clients. As yet the impact of MT on psychosocial outcomes in a general PEOLC population is unequivocal [4;5], providing an impetus for the conduct of rigorous trials in this area [9]. In addition is the finding that evaluation of existing music therapy

services in PEOLC are largely based on informal feedback. This highlights the need for establishing the use of validated outcome measures in routine practice.

CONCLUSION

Although promising that evidence suggests provision of MT in UK PEOLC settings to have increased in last decade, strengthening the evidence base for MT is necessary to encourage more consistent funding for this role.

ACKNOWLEDGEMENTS

The posts of LGW, JMcE and CH are funded by Marie Curie. We would like to thank the members of BAMT for their efforts in responding to the survey.

COMPETING INTERESTS

None to declare.

FUNDING

None.

REFERENCES

- [1] World Health Organization. Cancer pain relief and palliative care. Technical Report Series 804.1990. whqlibdoc.who.int/trs/WHO_TRS_804.pdf Accessed 05 Feb 2016.
- [2] Bunt, L. Music therapy: An art beyond words. New York; Routledge;1994.
- [3] Bruscia KE. Defining music therapy. Gilsum, NH; Barcelona Publishers; 1998.

- [4] McConnell T, Porter S. Music therapy for palliative care: A realist review. *Palliative & supportive care*. 2017 Aug;15(4):454-64.
- [5] McConnell T, Scott D, Porter S. Music therapy for end-of-life care: An updated systematic review. *Palliative Medicine*. 2016 Oct;30(9):877-83.
- [6] Zhang Y, Cai J, An L, Hui F, Ren T, Ma H, Zhao Q. Does music therapy enhance behavioral and cognitive function in elderly dementia patients? A systematic review and meta-analysis. *Ageing research reviews*. 2017 May 31;35:1-1.
- [7] Demmer C. A survey of complementary therapy services provided by hospices. *Journal of Palliative Medicine*. 2004 Aug 1;7(4):510-6.
- [8] Burns DS, Sledge RB, Fuller LA, Daggy JK, Monahan PO. Cancer patients' interest and preferences for music therapy. *Journal of Music Therapy*. 2005 Oct 1;42(3):185-99.
- [9] McConnell T, Graham-Wisener L, Regan J, McKeown M, Kirkwood J, Hughes N, Clarke M, Leitch J, McGrillen K, Porter S. Evaluation of the effectiveness of music therapy in improving the quality of life of palliative care patients: a randomised controlled pilot and feasibility study. *Pilot and feasibility studies*. 2016 Nov 29;2(1):70.