Music therapy for supporting informal carers of individuals with life-threatening illness pre- and post-bereavement; A mixed-methods systematic review

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Music therapy for supporting informal carers of individuals with life-threatening illness pre- and post-bereavement; A mixed-methods systematic review

Authors

Lisa Graham-Wisener[1] Noah Potvin[2] Jenny Kirkwood[3] Daniel Thomas[4] Audrey Roulston[5] Margaret Anderson[6] Tracey McConnell[7]

1. Centre for Improving Health-Related Quality of Life, School of Psychology, Queen's University Belfast, Belfast BT7 1NN
2. Mary Pappert School of Music and School of Nursing, Music Therapy, Duquesne University, Pittsburgh, PA 15282
3. Independent Researcher, Northern Ireland
4. CHROMA Therapies, Overross House, Ross Park, Ross on Wye, Herefordshire, HR9 7US
5. School of Social Sciences, Education and Social Work, Queen's University Belfast, Belfast BT7 1NN
6. Cochrane Developmental, Psychosocial and Learning Problems group, Queen's University Belfast, Belfast BT7 1NN
7. School of Nursing & Midwifery, Queen's University Belfast, Belfast BT7 1NN and Marie Curie Hospice Belfast, 1A Kensington Rd, Belfast BT5 6NF

Abstract

Objective: This systematic review will be the first to synthesise and critically evaluate the current state of the evidence-base for music therapy intervention with adult informal carers of individuals with life-threatening illness at pre- and post-bereavement. The objectives of this review are to describe the characteristics, effectiveness and experience of music therapy intervention which aims to improve health-related outcomes addressing whole person health for adult informal carers (pre- and post-bereavement).

Introduction: Music therapy intervention with informal carers of individuals with life-threatening illness at pre- and post-bereavement is an increasingly important clinical area for music therapists. There is, however, uncertainty about music therapy's effectiveness in this context, the mechanisms through which music therapy may influence outcomes, and how music therapy is experienced by adult informal carers.

Inclusion criteria: The review will consider quantitative, qualitative or mixed-methodologies which are empirical studies of music therapy intervention aiming to improve health-related outcomes for adult informal carers of adults with a life-threatening illness approaching end of life, or bereaved carers. The qualitative component will consider studies that explore the experience of music therapy intervention for adult informal carers (pre- and post-bereavement).

Methods: MEDLINE, EMBASE, PsycINFO, RILM Abstracts of Music Literature, CENTRAL and CINAHL will be searched, with no restriction on publication year. Both quantitative and qualitative studies will be screened for inclusion and critically appraised for methodological quality and both types of data extracted using JBI tools for mixed-methods systematic reviews by two independent authors. A convergent segregated approach to synthesis and integration will be used. The findings of the synthesis will be configured according to JBI methodology.

Systematic review registration number (For Protocols ONLY): Prospero registration pending

Introduction

The death of a close person has been described as one of the most common and yet universally distressing lifetime experiences and results in a range of individualised grief responses [1]. The majority of individuals will experience an acute grief response whereby they adjust psychologically with time, without the need for formal support [2]. However, a subgroup of individuals will experience complicated grief [3], a Complex or Prolonged Grief Disorder (PGD [4]), associated with prolonged impairment of psychological and social functioning [5;6]. The prevalence of PGD in adult informal carers is estimated to be between 8% and 30% [7;8]. Authors have reported more severe pre-bereavement deleterious psychological states to predict PGD post-bereavement [8]. This is in line with the increasing recognition that bereavement support needs are to be considered on a continuum; before, during and after a close person dies [9]. International guidelines [10;11] advocate for a public health approach to bereavement support, including early psychosocial intervention and continuity of care to support the normal grieving process (i.e. pre- and post- bereavement). Within this there is acknowledgement of the need to avoid pathologising grief, instead emphasising a resilience-based approach including social support through an appropriate mix of universal, selective and specialist bereavement support services [10;11]. This aligns to a newly developed core outcome set for evaluating bereavement interventions [12], with the two outcomes – 'Ability to cope with grief' and 'Quality of life and mental wellbeing'— reflecting a departure from disease-focused outcomes in previous bereavement research. Here, bereavement is less an experience to be extinguished and rather one to be honoured as a space for deriving meaning from loss.

Developing psychosocial models of care to support adult informal carers through the continuum of bereavement is a prioritised research area within End of Life Care (EoLC), as evidenced in a James Lind Alliance Priority Setting Partnership Exercise with 1403 patients, carers and healthcare professionals [13]. The small number of bereavement support RCTs that do exist have methodological limitations which reduce confidence in the findings [14]. This includes small sample sizes and heterogeneity in study populations, models of care and outcomes. Evidence from a gap analysis indicates components of existing bereavement support interventions rarely map to the modifiable risk and protective factors for PGD [15]. Examples of risk factors across the bereavement continuum include bereavement depression [16], anxiety [17], family conflict at EoL [18], poor perceived social support [19], early non-acceptance of loss [20] and difficulty accessing positive memories [21]. Examples of protective factors include higher spirituality [22], satisfaction with palliative care [22], and perceived preparedness for death [22]. These are risk factors which may be amenable to change through arts-based therapeutic approaches, and notably music therapy.

Music therapy has been defined as the reflexive process of using music and sound by a professionally trained therapist to cultivate therapeutic relationships and facilitate clinical interventions that

promote optimal health, including physical, emotional, spiritual, and psychological well-being [23]. A realist evaluation of a music therapy intervention to improve patient outcomes in EoLC [24] identified several mechanisms of change which align to the above determinants. Examples include music therapy as helping individuals reframe their identities from patients to people with unique pasts, helping patients reconnect with happier memories, to safely express repressed emotions and to transcend to a higher plane. The realist evaluation also identified a key mechanism of change around improving social functioning, with music therapy experienced as strengthening social bonds with loved ones and providing ongoing connections after death [24]. It is an open-question as to whether similar mechanisms to those identified in patients in EoLC may also facilitate improvement in outcomes for informal carers.

This systematic review is important in informing how we respond to several key global challenges. At the time of writing, the COVID-19 global pandemic has resulted in over 1.4 million deaths worldwide. COVID-19 deaths are associated with several risk factors for PGD for the informal carer [25], including not being able to say goodbye, physical distancing resulting in a lack of social support, living alone and loss of income. This mass bereavement event has resulted in heightened recognition of the need for evidence-based bereavement support. Secondly, the global need for palliative care is increasing, with the majority of global deaths relate to adults who die from life-threatening illness [26]. n the next twenty years, the need for EoLC in the UK is projected to increase by a conservative 25 per cent [27]. Developing an evidence-based health care system which responds to the holistic needs of the growing numbers of both patients and their close persons is of utmost importance. The World Health Organisation [28] define palliative care as an approach "*which improves the quality of life of patients and their families*". The role of the arts in improving health and wellbeing by addressing complex problems for which there are not currently adequate solutions was recently highlighted in a WHO evidence synthesis [29]. Music therapy has been used to support individuals at end-of-life care for more than forty years [30]. However, a recent survey identified that a high proportion of UK music therapists who work in EoLC focus their therapeutic practice on family members and loved ones (75.5%) at pre- and post- bereavement [31], which can involve dyadic, family-based or individual interventions either before and/or after the patient's death. These findings indicate a common clinical need, either identified during therapist assessment and/or frequently requested by service users and family members and loved ones in person-centred practice.

Although music therapy with adult informal carers of individuals at end-of-life is an emergent clinical area, evidence for music therapy intervention in this context is thought to be limited [e.g. 32-34] and largely focused on bereaved children and adolescents [35-37]. There is uncertainty around whether music therapy with adult informal carers (at pre- and post-bereavement) is efficacious, the mechanisms through which it may influence outcomes, and how it is experienced by informal carers. The lack of translation to evidence-informed practice limits the ability of music therapists working in this area to maximise best practice and avoid the potential for harm. A further consequence of the limited evidence-base is that music therapy is not referenced in EoLC guidelines [38] and rarely funded as a core service in the NHS [31], thus creating barriers for carers and patients to gain access to music therapy services.

Aims of review

A preliminary search of PROSPERO, MEDLINE, The Open Science Framework (OSF), the Cochrane Database of Systematic Reviews and the JBI Database of Systematic Reviews and Implementation Reports was conducted and no current or underway systematic reviews on the topic were identified.

Music therapy interventions within palliative care settings have been included in a number of systematic reviews [e.g.39-41], however these reviews were limited in their focus on patient outcomes, quantitative evidence and often particular research designs. A recent systematic review of bereavement interventions [14] included relevant studies but was limited to post-bereavement interventions and in countries similar to the UK. To date, no previous reviews have comprehensively examined the range of evidence associated with music therapy with adult informal carers pre- and post-bereavement.

This mixed-methods segregated systematic review will be the first to synthesise and critically evaluate the current state of the evidence-base for music therapy with adult informal carers of individuals with life-threatening illness at pre- and post-bereavement. Inclusion of both qualitative and quantitative research designs will identify a comprehensive range of evidence relating to efficacy and experience of music therapy.

Specifically, the objectives are:

- To describe the characteristics (including mechanisms of change, implementation processes, and economic considerations) and effectiveness of music therapy interventions which aim to improve health-related outcomes for adult informal carers of adults with life-threatening illness (pre- and post-bereavement)
- To describe the experience of music therapy for adult informal carers of adults with life-threatening illness (pre- and post-bereavement)

Review questions

I. What are the characteristics (including mechanisms of change, implementation processes and economic considerations) of music therapy interventions which aim to improve health-related outcomes for adult informal carers of adults with life-threatening illness (pre- and post-bereavement)
II. What is the effectiveness of music therapy interventions which aim to improve health-related outcomes for adult informal carers of adults with life-threatening illness (pre- and post-bereavement)
III. What is the experience of adult informal carers of adults with life-threatening illness (pre- and post-bereavement) receiving music therapy?

Keywords

Bereavement; Music therapy; End of Life Care; Carer; Grief.

Inclusion criteria

Population

This review is interested in the potential of music therapy as a psychosocial-spiritual intervention with informal carers across the bereavement continuum (pre- and post-bereavement). The population of interest therefore is informal carers who are close persons (e.g. spouse, adult children, parent, , sibling, relative, friend or neighbour) of an individual diagnosed with a life-threatening illness (advanced, progressive, incurable) approaching end of life (pre-bereavement), or an informal carer who is bereaved. Both the informal carer and individual diagnosed with a life-threatening illness need to be adults ($\geq$ 18 years old). There are no restrictions on gender or ethnicity.

The authors recognise that there is no agreement on when the pre-bereavement period begins, and so define this as informal carers providing care to individuals with a life-threatening illness approaching EoL using the NICE 'End of Life Care for Adults' guideline [38];
People are considered to be approaching the end of life when they are likely to die within the next 12 months, although this is not always possible to predict. This includes people whose death is imminent, as well as people who:

- *have an advanced incurable illness, such as cancer, dementia or motor neurone disease*
- *are generally frail and have co-existing conditions that mean they are expected to die within 12 months*
- *have existing conditions if they are at risk of dying from a sudden crisis in their condition*
- *have a life-threatening acute condition caused by a sudden catastrophic event, such as an accident, stroke or medical complications.*

There is no restriction on setting. Adults bereaved through unexpected sudden deaths with no life-threatening condition as outlined above (e.g. suicide, homicide, natural disaster, terrorist activity) will be excluded.

Studies of mixed populations where the sample is composed $\geq$ 50% of the target population will be included. Otherwise, studies will be included where participants' data are separately reported and can be extracted.

Intervention

Music therapy interventions aimed at improving adult informal carer health-related outcomes. This will include interventions which i) primarily target patients but record outcomes for carers, ii) are dyadic/family-based (involving at least one adult), or iii) focused primarily on carers (current/bereaved).

Music therapy will be defined as '*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*' [23]. This refers to tailored interventions delivered in an individual/group setting by

professionally trained music therapists or trainees in a professional music therapy training programme . This can involve a number of processes as detailed below, however a clear therapeutic process needs to be present.

- Receptive methods that structure active and intentional listening experiences with pre-composed music via live performance or recordings.
- Recreative methods that draw upon pre-composed music to structure active musicking through instrumental play, singing, movement/dancing and other forms of creative engagement.
- Improvisational methods that structure spontaneous musicking using instruments (percussive and melodic) and singing.
- Compositional methods that facilitate composition of new music, including but not limited to lyrics, melodies, harmonies, and rhythms.

Interventions with any mode of delivery will be eligible, such as face-to-face contact, telephone or online interventions, and we will include individual or group-based interventions. There are also no restrictions on the duration or frequency of interventions.

Comparator

The quantitative component of the review will consider studies that compare music therapy to any other intervention, examples including; bereavement support and social groups, education, psychological support and counselling, befriending and home-visiting support, arts-based approaches, spiritual approaches, complementary therapies or pharmacological therapies. Interventions comparing music therapy to usual care (i.e. as provided by the multidisciplinary team in any care setting) will also be included. Aligned to an inclusive approach regarding study design, studies without a comparison group will also be included.

Outcomes

The quantitative component of this review will consider studies that include any health-related outcome for the informal carer, as defined broadly using the Dodd's et al [42] taxonomy of outcomes in medical research. This includes but is not limited to outcomes of life impact (e.g. health-related quality of life, carer burden, coping, emotional/well-being, delivery of care), resource use, adverse events, physiological/clinical and mortality/survival.

Outcomes can be measured using any validated instrument (via observation, clinician-administered or self-report) and be measured during or immediately after the intervention or at a follow-up period. Regarding the hierarchy of outcome measures, clinician-administered measures will be prioritised and where multiple outcome measures of the same type are used, the outcome measure that is most frequently used across the included studies will be prioritised.

Phenomena of interest

The qualitative component of this review will consider studies that explore the experiences of adult informal carers of music therapy intervention as defined above.

Context

The qualitative component of this review will consider studies from all geographical regions. It will also include all contexts (e.g. primary care, secondary, tertiary, community or home settings).

Types of studies

This review will consider primary quantitative, qualitative and mixed methods studies. Quantitative studies will include both experimental and quasi-experimental study designs, including randomized controlled trials, non-randomized controlled trials, before and after studies, and interrupted time-series studies, analytical observational studies (including prospective and retrospective cohort studies), case-control studies and analytical cross-sectional studies. Qualitative studies will include but are not limited to, designs such as phenomenology, grounded theory, ethnography, qualitative description, action research and feminist research. Mixed method studies will only be considered if relevant data from the quantitative or qualitative components can be clearly extracted.

Studies may be conducted in any country however, only studies published in English are to be included (due to lack of resources for translation).

Studies must be empirical and published in peer-reviewed journals, with a publication year from 1998 to present. This reflects the formal establishment of key music therapy professional bodies and the formal adoption of music therapy as a protected title in the US and UK. In the absence of sufficient research studies, grey literature will be considered (e.g. conference papers and doctoral theses).

Systematic reviews will not be included, however relevant studies will be harvested from them, where relevant. Editorials, opinion papers, case studies (case series or case reviews) and any articles without relevant, original data will be excluded.

Methods

The proposed systematic review will be conducted in accordance with the Joanna Briggs Institute (JBI) methodology for a segregated Mixed Methods Systematic Review [43].

Search strategy

The search strategy will aim to locate both published studies. An initial limited search of MEDLINE and PsycINFO was undertaken to identify articles on the topic using the following initial keywords: Music therapy AND carer OR caregiver OR bereaved AND palliative OR end of life OR advanced illness. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy for MEDLINE with the support of an information specialist (see Appendix 1). The search strategy, including all identified keywords and index terms, will be adapted for each included information source.

The search strategy will be adapted if a) too few results are returned, suggesting that some relevant literature may be being missed, or b) if too many results are found, rendering a meaningful search unfeasible.

Information sources

The databases to be searched will include; MEDLINE® ALL (Ovid), EMBASE (Elsevier), RILM Abstracts of Music Literature (EBSCOhost), CENTRAL (Cochrane), PsycINFO (Ovid) and CINAHL (EBSCOhost). The formal searches will be conducted by an information specialist.

In addition, we will check reference lists of reviews and retrieved articles for additional studies, perform citation searches on key articles, and contact International research leaders in the field. Any review articles identified will be harvested for relevant studies. If a full text paper cannot be identified, the relevant authors will be contacted for follow-up. This will ensure all possible literature is included for review.

If too few studies warrant the inclusion of grey literature, databases of unpublished studies and grey literature to be searched will include Data.gov.uk, National Institute for Health and Social Care (NICE) and ETHOS.

Study selection

Following the search, all identified citations will be collated and uploaded into EndNote [Clarivate Analytics, PA, USA] and duplicates removed. The identified citations will then be exported to Rayyan [44], with titles and abstracts initially screened by two or more independent reviewers for assessment against the inclusion criteria for the review.

Potentially relevant studies will be retrieved in full and their citation details imported into Rayyan [44]. The full text of selected citations will be assessed in detail against the inclusion criteria by two or more independent reviewers. Reasons for exclusion of papers at full text stage will be recorded and reported in the systematic review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion, or with an additional reviewer/s. The results of the search and the study inclusion process will be reported in full in the final systematic review and presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram [45].

Assessment of methodological quality

For the quality appraisal and subsequent processes, the included studies will be imported into the JBI System for the Unified Management, Assessment and Review of Information [JBI SUMARI;46].

Quantitative papers (and quantitative component of mixed methods papers) selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from JBI for randomised controlled trials and quasi-experimental studies [47].

Qualitative papers (and qualitative component of mixed methods papers) selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardized critical appraisal instrument from JBI for qualitative research [48].

Authors of papers will be contacted to request missing or additional data for clarification, where required. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. The results of critical appraisal will be reported in narrative form and in a table.

All studies, regardless of the results of their methodological quality, will undergo data extraction and synthesis (where possible). Quality appraisal will help to indicate the strength of evidence.

Data extraction

For the quantitative component, data will be extracted from quantitative and mixed methods (quantitative component only) studies included in the review by two independent reviewers using the standardized Joanna Briggs Institute data extraction tool in JBI SUMARI and using the Template for intervention description and replication (TIDieR) checklist [49].

For the qualitative component, data will be extracted from qualitative and mixed methods (qualitative component only) studies included in the review by two independent reviewers using the standardized Joanna Briggs Institute data extraction tool in JBI SUMARI. The data extracted will include specific details about the population, context, culture, geographical location, study methods and the phenomena of interest relevant to the review objective. Findings, and their illustrations will be extracted and assigned a level of credibility.

Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

Data synthesis and integration

This review will follow a convergent segregated approach to synthesis and integration according to the JBI methodology for MMSR [43] using JBI SUMARI. This will involve separate quantitative and qualitative synthesis followed by integration of the resultant quantitative evidence and qualitative evidence.

Quantitative synthesis

The findings will be presented in narrative form including tables and figures to aid in data presentation, where appropriate. The narrative will be structured in line with the TIDieR checklist [49]. Outcomes will also be mapped against previously identified predictors of PGD [15].

Studies will, where possible, be pooled with statistical meta-analysis using JBI SUMARI. Effect sizes will be expressed as either odds ratios (for dichotomous data) or weighted (or standardized) final post-intervention mean differences (for continuous data) and their 95% confidence intervals will be calculated for analysis. Heterogeneity will be assessed statistically using the standard chi squared and I2 tests. Statistical analyses will be performed using a random effects model [47]. Subgroup analyses will be conducted where there is sufficient data to investigate. Sensitivity analyses will be conducted

to test decisions made regarding add text as appropriate. A funnel plot will be generated to assess publication bias if there are 10 or more studies included in a meta-analysis. Statistical tests for funnel plot asymmetry (Egger test, Begg test, Harbord test) will be performed where appropriate.

Qualitative synthesis

Qualitative research findings will, where possible be pooled using JBI SUMARI with the meta-aggregation approach [43]. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rated according to their quality, and categorizing these findings based on similarity in meaning (Level 2 findings). These categories are then subjected to a meta-synthesis to produce a single comprehensive set of synthesized findings (Level 3 findings) that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

Integration of quantitative evidence and qualitative evidence

The findings of each single method synthesis included in this review will then be configured according to the JBI methodology for mixed methods systematic reviews [43]. This will involve quantitative evidence and qualitative evidence being juxtaposed together and organized/linked into a line of argument to produce an overall configured analysis. Where configuration is not possible the findings will be presented in narrative form.

Recommendations for practice

This is the first systematic review to synthesise and critically evaluate the current state of the evidence-base for music therapy interventions with adult informal carers of individuals at end of life. The findings, if of sufficient quality, may help to inform clinical practice. Recommendations will also be made to inform high-quality research in the area. To inform readers of the dependability of the overall findings, a GRADE summary of findings table will be provided for the quantitative findings [50] and a ConQual summary of findings table will be provided for the qualitative findings [51].

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Conflicts of interest

There is no conflict of interest in this project.

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Appendices

Appendix I: Search strategy for MEDLINE (Ovid)

Ovid MEDLINE(R) ALL <1946 to March 22, 2021>

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1 Music/

2 Music Therapy/

3 Singing/

4 music$.tw,kf.

5 (sing or singing or song$ or choral$ or choir$).tw,kf.

6 (vibroacoustic$ or vibro-acoustic$).tw,kf.

7 (Bonny$ or guided imag$ or GIM or BMGIM).tw,kf.

8 or/1-7

9 adult children/

10 Caregivers/

11 family/

12 Fathers/

13 grandparents/

14 Mothers/

15 Siblings/

16 Spouses/

17 nuclear family/

18 parents/

19 (carer$ or caregiver$ or care-giver$ or (service$ adj2 user$)).tw,kf.

20 ((brother$ or sister$ or sibling$ or son$ or daughter$) adj5 (take care or taking care or informal$ care or caring or care-giving or caregiving)).tw,kf.

21 ((parent$ or mother$ or father$ or paternal or maternal) adj5 (take care or taking care or informal$ care or caring or care-giving or caregiving)).tw,kf.

22 ((family or families or grandparent$ or grandmother$ or grandfather$ or grand-parent$ or grand-mother$ or grand-father$ or husband$ or partner$ or relative$1 or significant other$ or spouse$ or wife or wives) adj5 (take care or taking care or informal$ care or caring or care-giving or caregiving)).tw,kf.

23 or/9-22

24 8 and 23

25 Advance Care Planning/

26 Attitude to death/

27 bereavement/

28 Death/

29 exp Euthanasia/ not Euthanasia,Animal/

30 Right to die/

31 exp Grief/

32 Hospice care/

33 Life Support Care/

34 Palliative Care/

35 exp Parental death/

36 Suicide, Assisted/

37 terminal care/

38 Terminally Ill/

39 (assisted suicide$ or assisted death).tw,kf.

40 (bereave$ or grief or griev$ or mourn$ or prebereavement or postbereavement or pre-loss or post-loss).tw,kf.

41 dying.ti.

42 (end of life or end stage$).tw,kf.

43 hospice$.tw,kf.

44 palliative$.tw,kf.

45 ((terminal$ or lifelimit$ or life limit$ or life threaten$ or threat to life) adj3 (condition$ or disease$ or ill$)).tw,kf.

46 (terminal stage$1 or end stage$1 or late stage$1).tw,kf.

47 ((after$ or approach$ or before or close or near$) adj1 (death$ or dying)).tw,kf.

48 (advance$1 care adj1 (directive$ or plan$)).tw,kf.

49 or/25-48

50 8 and 49

51 24 or 50

52 limit 51 to english language

53 limit 52 to yr="1998 -Current"

54 exp animals/ not humans/

55 53 not 54