

ARTICLE

Exploring the “thin place” between life and death: Compassion-Focused Relational Music Therapy (CRMT) for terminal agitation in advanced cancer in a hospice setting

Kate Binnie

University of Bristol, UK

ABSTRACT

Delirium and agitation are highly prevalent in the last days of life for cancer patients and can be distressing for patient, family and staff. Although guidelines recommend meticulous assessment of spiritual and psychological factors and a holistic response, in practice sedation is commonly used (particularly in hospital settings) in spite of ethical, professional and family ambivalence and mis-communication around this practice. A Compassion-Focused Relational Music Therapy (CRMT) approach proposes that the “thin place” between life and death can be explored and held within music, potentially reducing patient, family and staff distress (a ‘triangular model of suffering’) and provide an important bridge between care-giving and bereavement. A mindful approach (breath, body-awareness, compassion) integrates with the use of ‘vocal holding’ and ‘lullament’ in order to support the elements of a ‘good death’; safety, peace, love, forgiveness and letting go. This article describes a case study of a CRMT intervention with a hospice patient dying from mesothelioma. It also presents a mixed-methods feasibility study research protocol.

AUTHOR BIOGRAPHY

Kate Binnie is a senior research associate on the Wellcome Funded Life of Breath project and is based in the department for academic primary care, University of Bristol. She runs courses for music therapists and other healthcare professionals: ‘Breath-body-mind integration in supportive and palliative care’ trainings run at the Sobell Centre for Education. She also teaches on the advanced psycho-spiritual module, Palliative Care MSc, King’s College London. [kate.binnie@bristol.ac.uk]

INTRODUCTION

How people die remains in the memory of those who live on
Dame Cicely Saunders

As a hospice-based music therapist, I have often been called to the bedside of an agitated or delirious cancer patient in the last days or hours of their life. Usually the most pressing need is to

KEYWORDS

palliative care,
advanced cancer,
terminal agitation,
music therapy,
mindfulness,
compassion,
spiritual care,
psychological care

Publication history:

Submitted 19 Jul 2018

Accepted 7 Feb 2019

First published 24 Nov 2019

offer support to anxious family members, distressed by their loved one's agitation. Staff may have had this anxiety directed towards them, which can create a stressful atmosphere on the ward.

We know that communication between families, patients and staff in the last days and hours is crucial (Neuberger, 2013). Compassion-Focused Relational Music Therapy (CRMT) aims to support a delicate and potentially fraught relational triangle, which includes patient, family and hospice staff. This music therapy intervention aims to "steady the ship" and provide patient and family with a 'held' space within which meaningful last words and acts can occur.

Staff have told me that music therapy can relieve agitation for the patient, soothes and supports the family and thus relieves their stress. Families have said that they observed a change in, or made an important connection with, their loved one. At post-bereavement meetings, families reported feeling that the intervention helped them to feel calm and less fearful, and that it left them with a lasting positive memory of the death.

Music therapists have been evaluating their work in palliative care for over 40 years (Munro & Mount, 1978), and in 2007 over 60% of US hospices offered music therapy (Bercovitz, Sengupta, Jones & Harris-Kojetin, 2007). Despite evidence of acceptability to other professionals, patients and families (Demmer & Sauer, 2002; O'Kelly & Koffman, 2007), there is limited high-quality evidence reporting effectiveness for palliative care outcomes including pain (Gutsgell, 2013; McConnell, 2016) anxiety (Palmer, Lane, Mayo, Schluchter & Leeming, 2015), quality of life, (Hilliard 2003) and self-reported spirituality (Wlodarczyk, 2007). To date, no evidence of effectiveness exists for music therapy for terminal agitation; although one small, uncontrolled study shows reduction of agitation with prescriptive harp music during the dying process (Freeman, 2006). Another study reports that music therapy and progressive muscle relaxation reduced anxiety and fatigue and increased quality of life in family caregivers of hospice patients, although again the strength of evidence is weak (Choi, 2010).

A review of the qualitative evidence for music therapy in palliative care and oncology describes the meaningfulness and importance of music therapy for patients, their families and staff. (O'Callaghan, 2009) A recent systematic review reported evidence of effectiveness for music therapy and behaviour disorders, anxiety and agitation in advanced dementia. (Gómez-Romero et al., 2017) This may provide enough of a signal to warrant investigation in an advanced cancer population who may share neuro-psychological characteristics at the end-stage, including delirium, agitation, anxiety and cognitive dysfunction (Macleod, 2007).

What is Compassion-Focused Relational Music Therapy (CRMT)?

Compassion-Focused Relational Music Therapy (CRMT) is described in the following case study of a hospice patient in the last days of life. Compassion-focused refers to a mindfulness-based approach to care, grounded in a mindfulness training and in an embodied, daily practice. There is some evidence that introducing mindfulness to hospice teams reduces distress, improves compassion and the ability to be with uncertainty (Bruce & Davies, 2005). Compassion can be described simply as the Buddhist philosophy of "metta" (loving-kindness), generated by practice of self-awareness and self-compassion (Gilbert, 2005). Relational refers to the focus on relationships in the therapy. My thinking about and response to the agitated patient, family in the room and staff dynamics is informed by

attachment theory (Bowlby, 1999) relational psychotherapy (Slochower, 2013) and family systems therapy (Broderick, 1993). The integration of these theoretical and practical techniques – although not necessarily unique – is described here as CRMT and represents the bringing together of Western psychodynamic and Eastern philosophical and practical approaches that I have found helpful in working at “the thin place”.

This paper goes on to describe a clinical encounter with a patient experiencing terminal agitation and his attending family, and a music therapy intervention (CRMT) in a hospice setting. I then present a review of evidence highlighting the complexity of terminal agitation and ethical issues around sedation, and a research protocol which –if funding were secured– could add to a growing evidence base to support the need for creative psycho-social-spiritual interventions such as music therapy to support patients and families at the end of life.

CASE STUDY¹

Richard was an engineer in his 60s with pleural mesothelioma (an aggressive malignant lung disease, usually caused by exposure to asbestos). Richard had been admitted to the hospice in-patient unit for symptom relief and end-of-life care due to refractory breathlessness and anxiety that could not be managed at home. Doctors were prescribing low-dose morphine for the breathlessness and midazolam for the anxiety, and he was on continuous oxygen. I met with Richard soon after his admission and he had enjoyed my singing with a Tibetan bowl, precipitating a conversation about Eastern spirituality and a short, shared mindfulness practice (sitting together, relaxing the body and allowing the breathing to down-regulate). He was not interested in chaplaincy. The session had reduced his anxiety and breathlessness and he had been able to sleep post-session without the aid of anxiolytics.

The day before Richard’s death, the staff requested another music therapy session. The team were concerned about the dynamic in Richard’s room where his current partner and daughter from his first marriage were in attendance. Tensions between the two women were running high; each wanting to be at the forefront, competing for Richard’s attention and to be the most useful, the most loved and loving. Richard was agitated and delirious, attempting to get out of bed, take off his oxygen mask and crying out, exacerbating both family and staff anxiety. The doctor on duty was concerned; Richard was on the maximum dose of sedatives/opioids without being deeply sedated and the situation with the family was becoming hard to manage. Could I come and “do something”?

Before entering Richard’s room – feeling anxious myself at what felt like a huge responsibility – I paused for a moment at the door to use specific mindfulness techniques (watching and steadying my breath, becoming aware of bodily sensations of anxiety and grounding through my feet) in order to arrive in the best possible state, ‘tuned-in’ and ‘tuned up’. Once in the room and after introductions, I suggested these techniques to support the distressed family members (an invitation to sit, to breathe, to relax and steady the body).

¹ People’s names are disguised.

This “held” the situation, alleviating immediate high-octane distress in the caregivers, so that I could then turn my attention to Richard. Being directive in this way afforded a grounding focus for Richard’s family who were feeling helpless and frightened. Once seated close to Richard, and including the by-now settled partner and daughter in the tableau by the bed, I used simple musical tools – voice and guitar tuned to DADGAD (an open chord) – directed towards Richard. The music was initially a non-verbal “vocal holding” (Austin, 2004) which has been described as “lullament” (O’Callaghan, 2008). This combines elements of lullaby (a spacious, three-time simple melody, timed in response to the patient’s breathing, vocalisations and movements) and lament: an expression of sadness and grief (tapping into the emotions of the partner and daughter). This then became sung words and phrases, similar to those described by Kehl (2006) and Byock (1998) as the psycho-spiritual tasks or components of a “good death” (peace, letting go, love, forgiveness, safety). The session lasted about 30 minutes in total and consisted of active music for about 15 minutes (holding the “thin place” for the patient) and verbal support and guidance (steadying the breath, grounding the body) for the partner and daughter. Once Richard was settled and the atmosphere in the room was steady again with both women sitting beside him holding his hands, crying but calm – I left.

Richard died peacefully early the next morning. His partner spent some time outside the room during the intervening hours (relinquishing the space) and the daughter continued to sing and breathe with her father. Both women were with him when he died.

Post-death the daughter and partner reported they found the session helpful for themselves, and perceived it had also facilitated a good death for Richard. At the staff debrief there was a sense of relief that “something happened to make things better” and it was subsequently reported that the relationship between daughter/step-mother had improved around the death and post-bereavement. The intervention also changed staff perception of music therapy from primarily a scheduled therapy with the more well patients, to something that could be useful in acute situations on the ward for symptom management. This led to music therapy being requested routinely on the ward, and the generation of more staff training delivered by myself in how to use simple techniques from the traditions of yoga and mindfulness (breath and body awareness, grounding techniques, qualities of silence) for the support of patients and families during times of distress and agitation, and to manage staff’s own stress and sense of powerlessness.

This case – and subsequent cases over a period of five years of hospice practice – suggests that CRMT can provide an important ‘bridge’ between caregiving and bereavement at the ‘thin place’ (the liminal space of dying) and promote a positive relational legacy for those left behind. In addition, it may support staff dealing with the moral distress of not being able to ‘fix’ a distressing situation, allowing a creative-spiritual space for ‘being’ held by music, rather than a medical space for ‘doing’ when there is really nothing to be done but allow the death to occur as peacefully as possible. The

suggestion is not that music therapy replaces pharmacological interventions, rather that it may be an integrative psycho-social-spiritual complement to best medical practice in the dying phase.

Figure 1 describes the interrelatedness of distress caused by terminal agitation, and the way in which CRMT may support those experiencing it directly or indirectly.

RESEARCH PROTOCOL²

What follows is a research protocol for a mixed-methods feasibility study which aims to explore in some depth the experiences of family caregivers and staff, their perceptions of CRMT for themselves and for the dying patient. The study also aims to explore ethical concerns such as obtaining advanced consent from patients and families, and the feasibility of using quantitative observer-rated measures such as the Communication Capacity Scale and Agitation Distress Scale (Morita, 2001) to assess whether CRMT reduces terminal agitation in patients with advanced cancer.

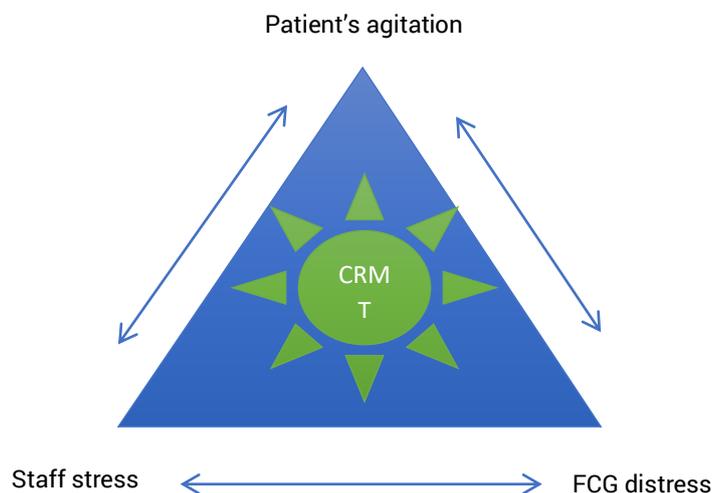


Figure 1: Compassion-Focused Relational Music Therapy (CRMT) and the triangular model of suffering (Cherny, 2010) adapted for terminal agitation in palliative care

Background

Terminal agitation: Definition, prevalence, etiology and risk factors

Terminal agitation or restlessness, often characterised by symptoms of cognitive impairment or delirium, is common in cancer patients in the terminal phase (Macleod, 2007), which is defined in the literature as the “last days of life” (Head & Faul, 2005; Ellershaw & Ward, 2003).

Defining ‘terminal agitation’ is complicated by the common use of interchangeable terms that together comprise a syndrome of symptoms that may include emotional disturbance, verbal or behavioural expressions of anxiety, distressed behaviours including physical irritability and erratic or

² The research protocol presented here is based on an assignment for my MSc in palliative care at the Cicely Saunders Institute, King’s College London (2016).

angry movements, confusion and hallucinations. These are described across the literature as terminal agitation, terminal restlessness and terminal delirium (Kehl, 2004; Kelly, 2006).

Delirium as a specific symptom occurs in up to 88% of cancer patients in the last few days of life, (Agar, 2016; Pereira, 1997) and is characterised by acute onset and fluctuations in consciousness (Macleod, 2007). Non-reversible delirium in palliative care settings is seen as a reliable indicator of impending death (Lawlor & Bush, 2014) and presents as hypoactive (reduction in wakefulness, low affect, often misdiagnosed as depression) or hyperactive (hyperalert, hypervigilant, physically agitated) (Breitbart, 1995).

It is the latter, hyperactive form of delirium that is often described as terminal “agitation” or “restlessness”, yet these terms are not clinically specific. Terminal agitation/restlessness is, then, a pseudo-diagnostic term and appears to be a catch-all for distressing psychological symptoms and behaviours at the end of life.

Prevalence figures for terminal agitation are lacking due to difficulties with definition and reliable tools for screening, but one 20-year-old report states 42% in the last days of life (Lichter & Hunt, 1990), with a more recent survey reporting a mean estimate of 40% (Head & Faul, 2005). This survey of hospice professionals cited perceived psychosocial and spiritual factors more than physical causes. These mirror those in the extant literature; fear, loss of control and dignity, existential anguish, unfinished business, the need for reconciliation (Hall, 2014). Managing these factors well has been identified by a literature review as the components of a “good death” (Kehl, 2006).

Risk factors for non-reversible terminal agitation include an older-aged cancer population, where dementia may be a factor, alcohol and drug withdrawal, history of a pre-existing psychiatric condition, and complex or dysfunctional family dynamics. (Agar, 2012; Bush, 2014)

Treatments – evidence, guidelines and ethical issues

Once the causes of agitation and/or delirium have been addressed by clinical assessment and reversible causes treated, non-pharmacological and environmental strategies are recommended (NHS Scotland, 2014). These may include adjustments to lighting, 1:1 nursing, recorded music, reassurance, touch and spiritual care where appropriate. Involving family caregivers (FCGs) in care has been shown to be helpful in the management of hyperactive delirium in a hospital setting (Meagher, 1996) and a recent review of non-pharmacological interventions for agitation in dementia showed efficacy for music therapy, person-centred care, and sensory intervention (touch) (Livingston, 2014).

Where the agitation remains refractory – causing sustained distress – palliative sedation is recommended. (Claessens, 2008). The European Association for Palliative Care (EAPC) has established a framework for the practice of sedation in Palliative care (Cherny, 2009).

Best practice includes:

- Communication with patient and family to ensure clarity about the goals, risks and benefits of sedation.
- Assessment of social, psychological and spiritual factors for the patient’s distress.
- Addressing family and staff emotional and spiritual distress.

The qualitative literature reveals themes of clinician ambivalence about sedation; causing the loss of a patient's ability to communicate and fulfil the "dying role" (Gawande, 2014) conflicts with the wish to prevent suffering (Brajtman, 2006; Breitbart & Alici, 2008; Morita, 2007). Fears that sedation is hastening death cause moral suffering for families and staff (Morita, 2004); despite evidence to the contrary, including a Cochrane review (Beller, van Driel, McGregor, Truong, & Mitchell, 2015).

UK national guidance

In 2004, NICE guidelines called for improvements in assessment of, and support for, psychological, social and spiritual needs of dying cancer patients (NICE guidance, 2004). Subsequently, and in the wake of the Liverpool Care Pathway's demise (2013), "One chance to get it right" (2013) states that the dying person's spiritual, psychological, and emotional needs must be assessed and reviewed and these outcomes discussed with patient and family. The document also reflects on the findings from the *More Care, Less Pathway* report that sedation may have been routinely used without clear communication with patient/family, thus causing distress.

Patient experience – what do we know?

Understanding patient experience of terminal agitation is difficult for ethical and practical reasons. Hospital patients who recovered from an episode of hyperactive/agitated delirium was recalled by over half the respondents and found to be distressing by 75% (Breitbart, 2002). Bruera (2009) also found that over 81% of patients with advanced cancer experiencing delirium found it distressing. However, there is evidence that not all delirious episodes are negative, and that these liminal experiences may be comforting and spiritually symbolic (Morita 2019; Schofield, 1997; Wright, 2015).

In Japan, Morita (2007) found that up to one third of family members ($n = 242$) perceived delirium as a normal part of the dying process, with hallucinations and incoherent speech as transcendent experiences connected with the patient entering the spirit world. The importance of cultural and spiritual sensitivity to terminal delirium is recognised as being part of a 'good death' (Callanan & Kelley, 1992).

Family caregiver (FCG) distress and bereavement outcomes

FCGs (here defined as those looking after and spending final days with their loved one, whatever their relationship) are profoundly affected by witnessing terminal agitation in the last few days of life, and which, when perceived as distressing, negatively affects bereavement outcomes (Brajtman, 2003; Finucane, 2017). There has been a recent call in the literature for more research and support for FCGs in the patient's dying phase, acknowledging the importance of linking pre-death caring and post-death bereavement (Stroebe & Boerner, 2015; Wee, 2017).

The Textbook of Palliative Nursing (USA) (Ferrell & Coyle, 2005) suggests supporting patients and FCGs by entering into the subjective, symbolic world of the patient whose agitation and non-reversible delirium may be seen as "nearing death awareness" (Callanan & Kelley, 1992). This normalising encourages completion of the "tasks of dying"; I forgive you, Forgive me, Thank you, I

love you, Goodbye, which may help in the achievement of a peaceful death, and FCGs in their bereavement (Byock, 1998).

Staff perspectives

Surveys and a focus group exploring terminal restlessness/agitation/delirium from the perspective of hospice professionals around the world, in Israel (Brajtman, 2006) America (Head & Faul, 2005) and Japan (Morita, 2004), found converging themes about its causes, meaning and treatment. These included a felt lack of understanding and knowledge about TA, which was agreed to be complex and mysterious: 'It's a war, it's a patient's private war' (Brajtman, 2003). There was also ambivalence about treating TA with sedation and reducing the patient's ability to communicate with family (Morita 2004).

Relational distress requires a relational response

The World Health Organisation definition of palliative care embraces the family system, as does Cicely Saunders' concept of the "unit of care". Cherny's "Triangular Model of Suffering" (2010) describes the interrelatedness of suffering in advanced cancer. Wright's 2014 review explored 'relational ethical' dimensions of end-of-life delirium by looking at experiences of relational tension and perceived meanings in delirious agitation. The study found that it is vital for hospices to provide a safe place for dying and that the personhood and dignity of the dying person is of paramount importance. The dominance in current research on pathophysiology, prevalence, detection and management (i.e., a deficit model) has led to end-of-life delirium being conceptualised as a "problem to be managed" rather than a "lived experience" to be understood. "Delirium as letting go" (Wright, 2015) highlights the importance for families and staff to frame changes in the patient's behaviour, consciousness, and personality as natural signs of normal dying. Carolan's (2015) review assessed how distress is conceptualised in families receiving palliative care: research into dyads abound (Braun, 2012; Fleming, 2006; Traa, 2014) yet there is a paucity of research looking at distress as a relational construct. Smith and Carolan (2015) develop the theory for a systemic construct of distress in families receiving palliative care, describing the way that distress "reverberates within the family system" and highlights how poorer family functioning and communication leads to greater distress for patient and FCGs in the terminal phase, thus the need for interventions to address this.

It is into this arena of uncertainty and potential conflict that music therapy may have utility as a non-pharmacological, holistic intervention to support patient, family caregivers and staff.

Aims, objectives and methods

Following the Medical Research Council (Craig, 2008) and MORECare (Higginson, 2013) guidance for the evaluation and development of complex interventions, the proposed study uses Cherny's "triangular model of suffering" (Hanks, 2011) and Smith and Carolan's "Distress as a systemic construct" (2015) as the basis for a conceptual framework. These frameworks describe A) the interrelationship between patient, family and staff distress in advanced cancer, and B) the way distress reverberates throughout family systems in palliative care settings. This links with

attachment and relational theories, which have a long tradition in music therapy practice. To date, these concepts have not been applied to music therapy for terminal agitation in advanced cancer. This feasibility study will seek to develop the theory underpinning the intervention in order to direct future practice and research. The primary aim is to assess whether it is feasible and acceptable to carry out a mixed-methods study in a population of advanced-cancer hospice patients with terminal agitation, and to understand the experiences of the intervention on FCGs and staff.

Objectives

- a) To assess whether it is feasible and ethical to apply the observer-rated Richmond Agitation Distress Scale (Bush, 2014) during the period of the patient's terminal agitation. This will inform issues of measurement validity, feasibility and acceptability.
- b) To understand families' experiences of CRMT and their perceptions of its effect on their agitated relative, their own distress and subsequent bereavement.
- c) To explore staff perceptions and experiences of CRMT.
- d) To develop the theoretical basis for CRMT as a psycho-social-spiritual intervention to support patient, family and staff with terminal agitation. Developing a theory aids intervention fidelity and optimisation, which are important aspects of developing and implementing complex interventions in palliative care (Demiris, 2014).

Methods: Data collection and analysis

Stage A: The observer-rated Richmond Agitation Distress Scale will be applied pre-post the MT intervention by a trained research nurse over a period of six months to a convenience sample. All patients with advanced cancer and a nominated caregiver admitted to the hospice will be offered the opportunity to take part in the study and advanced consent sought. *Stage B:* Families' experiences will be explored via semi-structured post-bereavement interviews with the nominated caregiver. *Stage C:* A focus group will capture staff perceptions at the end of the six-month study period. Data from stages B and C will be analysed, informed by interpretive phenomenological analysis (Chapman & Smith, 2002).

Feasibility data and qualitative findings will be analysed separately, then interpreted and triangulated (Bryman, 2006) to present a multidimensional picture of the effects of CRMT for terminally agitated patients with advanced cancer, their families and hospice staff.

It is hoped that if this study were to take place, integrated data from these mixed-methods approaches would ascertain whether the intervention and study methods are feasible and acceptable to patients, FCGs and staff from an ethical perspective. It would also help understand how CRMT affects agitated patients from the perspective of their FCGs at the time and into bereavement, the impressions of staff, and the interrelationship between all three. Furthermore, research data would offer a theoretical and methodological basis for future research in order to develop evidence-based holistic care for patients at the end of life as per recommendations, and support the provision of music therapy within palliative care settings.

CONCLUSION

Terminal agitation is common at the end of life in advanced cancer. Research into this symptom is highlighted as a priority in NICE guidance (2013) and in a National Survey of Service Users (2015). A recent systematic review of terminal agitation found that supporting caregivers and reducing their distress should be a goal of future intervention studies (Finucane, 2017). CRMT may offer a unique and direct mode of psycho-social-spiritual care for patient and family through the dying process alongside medical management. It is a holistic intervention that acknowledges and celebrates what Viktor Frankl (2011, p. 34) called “wholeness – the integration of spiritual, psychic, somatic and physical aspects” of a person, through lapses in cognitive function and consciousness, via the “thin place” and right to the end of life. Infusing music therapy in palliative care with aspects of mindfulness is an emerging field that warrants further exploration (Lesiuk, 2016). It is this therapist’s experience that integrating mindfulness with music therapy enhances authentic therapeutic relationship, and allows space for a non-religious spiritual aspect to the encounter which, towards the end of life, can be very important for both patient and family, whatever their religious/cultural affiliation. It also supports the therapist’s ability to work sustainably within situations of suffering and heightened distress, such as with agitated patients and families in hospice settings. This in turn has a subtle ripple effect on the multidisciplinary team (Bruce & Davies, 2005), who are often under-supported and lacking in techniques to manage the hidden costs of day-to-day working with suffering. There is potential here for music therapists embedded within medical teams to offer *everyone* they come into contact with a model for a creative, self-aware and compassionate way of being. This may positively affect the working environment and encourage professionals’ confidence to rely on *themselves* and their humanity as a vital clinical tool alongside professional competencies.

ACKNOWLEDGEMENTS

The author would like to thank the Samuel Sebba Foundation for their generous award for the MSc in Palliative Care, King’s College London. Also to the Wellcome Trust Funded Life of Breath project www.lifeofbreath.org for current funding (grant number 103340).

REFERENCES

- Agar, M. (2012). Making decisions about delirium: A qualitative comparison of decision making between nurses working in palliative care, aged care, aged care psychiatry, and oncology. *Palliative Medicine*, 26(7), 887–896.
- Agar, M., Quinn, S. J., Crawford, G.B., Ritchie, C.S. Phillips, J. L., Collier, A., & Currow, D. C. (2016). Predictors of mortality for delirium in palliative care. *Journal of Palliative Medicine*, 19(11), 1205-1209.
- Austin, P., Wiley, S., McEvoy, P. M., & Archer, L. (2011). Depression and anxiety in palliative care inpatients compared with those receiving palliative care at home. *Palliative & Supportive Care*, 9(4), 393-400.
- Beller, E.M., van Driel, M., McGregor, L., Truong, S., & Mitchell, G. (2015). *Palliative pharmacological sedation for terminally ill adults*. Cochrane Database of Systematic Reviews Issue 1. Art. No: CD010206. Retrieved from <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD010206.pub2/abstract>.
- Bercovitz, A., Sengupta, M., Jones, A., & Harris-Kojetin, L. D., (2007). *Complementary and alternative therapies in hospice: national home and hospice care survey, United States*. National health statistics reports; No 33. Hyattsville, MD: National Center for Health Statistics. 2010. Retrieved from <http://www.cdc.gov/nchs/data/nhsr/nhsr033.pdf>.
- Ferrell, B. R., & Coyle, N. (2005). *Textbook of palliative nursing*. New York: Oxford University Press.
- Bowlby, J. (1999). *Attachment and loss* (2nd ed.). New York: Basic Books.
- Brajtman, S. (2003). The impact on the family of terminal restlessness and its management. *Palliative Medicine*, 17(5), 454–60.

- Brajtman, S., Higuchi, K., & McPherson, C. (2006). Caring for patients with terminal delirium: Palliative care unit and home care nurses' experiences. *International Journal of Palliative Nursing, 12*(4), 150–156.
- Braun, M. (2012). Caregiving styles and attachment orientations in couples facing advanced cancer. *Psycho-Oncology, 21*(9), 935–943.
- Breitbart, W. (1995). Identifying patients at risk for, and treatment of major psychiatric complications of cancer. *Supportive Care in Cancer, 3*(1), 45–60.
- Breitbart, W., & Alici, Y. (2008). Agitation and delirium at the end of life: "We couldn't manage him". *JAMA, 300*(24), 2898–2910.
- Breitbart, W., Gibson, C., & Tremblay, A. (2002). The delirium experience: delirium recall and delirium-related distress in hospitalized patients with cancer, their spouses/caregivers, and their nurses. *Psychosomatics, 43*(3), 183–194.
- Broderick, C. B. (1993). *Understanding family process: basics of family systems theory*. Thousand Oaks, CA: Sage Publications.
- Bruce, A., & Davies, B. (2005). Mindfulness in hospice care: Practicing meditation-in-action. *Qualitative Health Research, 15* (10), 1329-1344.
- Bruera, E. (2009). Impact of delirium and recall on the level of distress in patients with advanced cancer and their family caregivers. *Cancer, 115*(9), 2004–2012.
- Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Qualitative Research, 6*(1), 97–113.
- Bush, S.H. (2014). End-of-Life delirium: Issues regarding recognition, optimal management, and the role of sedation in the dying phase. *Journal of Pain and Symptom Management, 48*(2), 215–30.
- Bush, S.H. (2014). The Richmond Agitation-Sedation Scale Modified for Palliative Care Inpatients (RASS-PAL): A pilot study exploring validity and feasibility in clinical practice. *BMC Palliative Care, 13*(1), 17.
- Byock, I. (1998). *Dying well: Peace and possibilities at the end of life* (1st ed). New York: Riverhead Books.
- Callanan, M., & Kelley, P. (1992). *Final gifts: Understanding the special awareness, needs, and communications of the dying*. New York: Simon & Schuster.
- Chapman, E., & Smith, J.A. (2002). Interpretative phenomenological analysis and the new genetics. *Journal of Health Psychology, 7*(2), 125–130.
- Cherny, N.I., Radbruch, L., & Board of the European Association for Palliative Care. (2009). European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. *Palliative Medicine, 23*(7), 581–593.
- Choi, Y.K. (2010). The effect of music and progressive muscle relaxation on anxiety, fatigue, and quality of life in family caregivers of hospice patients. *Journal of Music Therapy, 47*(1), 53–69.
- Claessens, P. (2008). Palliative sedation: A review of the research literature. *Journal of Pain and Symptom Management, 36*(3), 310–333.
- Craig, P. (2008). Developing and evaluating complex interventions: The new medical research council guidance. *British Medical Journal, 337*: a1655.
- Demiris, G. (2014). Implementation science implications for intervention research in hospice and palliative care. *The Gerontologist, 54*(2), 163–171.
- Demmer, C., & Sauer, J. (2002). Assessing complementary therapy services in a hospice program. *The American Journal of Hospice & Palliative Care, 19*(5), 306–314.
- Ellershaw, J., & Ward, C. (2003). Care of the dying patient: The last hours or days of life. *British Medical Journal, 326*(7379), 30–34.
- Finucane, A.M. (2017). The experiences of caregivers of patients with delirium, and their role in its management in palliative care settings: An integrative literature review. *Psycho-Oncology, 26*(3), 291–300.
- Fleming, D.A. (2006). Caregiving at the end of life: Perceptions of health care quality and quality of life among patients and caregivers. *Journal of Pain and Symptom Management, 31*(5), 407–420.
- Frankl, V.E. (2011). *Man's search for ultimate meaning*. London: Rider.
- Freeman, L. (2006). Music thanatology: Prescriptive harp music as palliative care for the dying patient. *The American Journal of Hospice & Palliative Care, 23*(2), 100–104.
- Gawande, A. (2014). *Being mortal* (1st ed). New York: Metropolitan Books.
- Gilbert, P. (2005). *Compassion: Conceptualisations, research and use in psychotherapy*. London: Routledge.
- Gómez-Romero, M., Jiménez-Palomares, M., Rodríguez-Mansilla, J., Flores-Nieto, A., Garrido-Ardila, E. M., & González-LópezArza, M. V. (2017). Benefits of music therapy on behavior disorders in subjects diagnosed with dementia: A systematic review. *Neurologia, 32*(4), 253-263.
- Guntrip, H. (1995). *Personality structure and human interaction: The developing synthesis of psychodynamic theory*. London: Karnac Books.
- Gutgsell, K.J. (2013). Music therapy reduces pain in palliative care patients: A randomized controlled trial. *Journal of Pain and Symptom Management, 45*(5), 822–831.
- Hall, S. (2014). Patterns of dignity-related distress at the end of life: A cross-sectional study of patients with advanced cancer and care home residents. *Palliative Medicine, 28*(9), 1118–27.
- Hanks, G.W.C. (2011). *Oxford textbook of palliative medicine* (4th ed). Oxford: Oxford University Press.
- Head, B., & Faul, A. (2005). Terminal restlessness as perceived by hospice professionals. *American Journal of Hospice and Palliative Medicine, 22*(4), 277–282.
- Higginson, I.J. (2013). Evaluating complex interventions in end of life care: The MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC Medicine, 11*(1), 111.
- Hilliard, R.E. (2003). The effects of music therapy on the quality and length of life of people diagnosed with terminal cancer. *Journal of Music Therapy, 40*(2), 113–37.
- Jones, C.L. (1998). Development of an instrument to measure terminal restlessness. *Palliative Medicine, 12*(2), 99–104.
- Kehl, K.A. (2004). Treatment of terminal restlessness: A review of the evidence. *Journal of Pain & Palliative Care Pharmacotherapy, 18*(1), 5–30.
- Kehl, K.A. (2006). Moving toward peace: An analysis of the concept of a good death. *American Journal of Hospice and Palliative Medicine, 23*(4), 277–286.
- Kelly, B., McClement, S., & Chochinov, H.M. (2006). Measurement of psychological distress in palliative care. *Palliative Medicine, 20*(8), 779–89.

- Lawlor, P.G., & Bush, S.H. (2014). Delirium diagnosis, screening and management. *Current Opinion in Supportive and Palliative Care*, 8(3), 286–295.
- Leadership Alliance for the Care of Dying People. (2013). *One chance to get it right*. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf
- Lesiuk, T. (2016). The development of a Mindfulness-Based Music Therapy (MBMT) program for women receiving adjuvant chemotherapy for breast cancer. *Healthcare*, 4, 3-53.
- Lichter, I., & Hunt, E. (1990). The last 48 hours of life. *Journal of Palliative Care*, 6(4), 7–15.
- Livingston, G. (2014). Non-pharmacological interventions for agitation in dementia: Systematic review of randomised controlled trials. *The British Journal of Psychiatry*, 205(6), 436–442.
- Macleod, S. (2007). *The psychiatry of palliative medicine: The dying mind*. Oxford: Radcliffe.
- McConnell, T., Scott, D., & Porter, S. (2016). Music therapy for end-of-life care: An updated systematic review. *Palliative Medicine*, 30(9), 877–83.
- Meagher, D.J. (1996). The use of environmental strategies and psychotropic medication in the management of delirium. *The British Journal of Psychiatry*, 168(4), 512–515.
- Morita, T. (2001). Communication capacity scale and agitation distress scale to measure the severity of delirium in terminally ill cancer patients: A validation study. *Palliative Medicine* 15(3), 197–206.
- Morita, T. (2004). Emotional burden of nurses in palliative sedation therapy. *Palliative Medicine*, 18(6), 550–557.
- Morita, T. (2004). Family-perceived distress from delirium-related symptoms of terminally ill cancer patients. *Psychosomatics*, 45(2), 107–113.
- Morita, T. (2007). Terminal delirium: Recommendations from bereaved families' experiences. *Journal of Pain and Symptom Management*, 34(6), 579–589.
- Morita, T. (2019). Nationwide Japanese survey about deathbed visions: "My deceased mother took me to heaven". *Journal of Pain and Symptom Management*, 52(5), 646-654.
- Munro, S., & Mount, B. (1978). Music therapy in palliative care. *Canadian Medical Association Journal*, 119(9), 1029–1034.
- National Institute for Clinical Excellence (NICE). (2004). Improving supportive and palliative care for adults with cancer. Retrieved from <https://www.nice.org.uk/guidance/csgsp/evidence/supportive-and-palliative-care-the-manual-2>
- Neuberger, J. (2013). *More care, less pathway: A review of the Liverpool Care Pathway*. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf
- O'Callaghan, C. (2009). Objectivist and constructivist music therapy research in oncology and palliative care: An overview and reflection. *Music and Medicine* 1(1), 41–60.
- O'Callaghan, C. (2008). Lullament: Lullaby and lament therapeutic qualities actualized through music therapy. *The American Journal of Hospice & Palliative Care*, 25(2), 93–99.
- O'Kelly, J., & Koffman, J. (2007). Multidisciplinary perspectives of music therapy in adult palliative care. *Palliative Medicine*, 21(3), 235–241.
- Palmer, J.B., Lane, D., Mayo, D., Schluchter, M., & Leeming, R. (2015). Effects of music therapy on anesthesia requirements and anxiety in women undergoing ambulatory breast surgery for cancer diagnosis and treatment: A randomized controlled trial. *Journal of Clinical Oncology*, 33(28), 3162–3168.
- Pereira, J., Hanson, J., & Bruera, E. (1997). The frequency and clinical course of cognitive impairment in patients with terminal cancer. *Cancer*, 79(4), 835–842.
- Schofield, I. (1997). A small exploratory study of the reaction of older people to an episode of delirium. *Journal of Advanced Nursing*, 25(5), 942–952.
- Scottish Partnership for Palliative Care (2014). *Severe uncontrolled distress*. NHS Scotland. Retrieved from <https://www.palliativecareguidelines.scot.nhs.uk/guidelines/end-of-life-care/severe-uncontrolled-distress.aspx>
- Slochower, J.A. (2013). *Holding and psychoanalysis: A relational perspective* (2nd ed). London: Routledge.
- Smith, A., & Carolan, C.M. (2015). Conceptualizing psychological distress in families in palliative care: Findings from a systematic review. *Palliative Medicine*, 29(7), 605-632.
- Stroebe, M., & Boerner, K. (2015). Caregiving and bereavement research: Bridges over the gap. *Palliative Medicine*, 29(7), 574–576.
- Traa, M.J. (2014). Dyadic coping and relationship functioning in couples coping with cancer: A systematic review. *British Journal of Health Psychology*, 20(1), 85-114.
- Wee, B. (2017). Ambitions for palliative and end of life care: A relentless focus on the person. *European Journal for Person Centered Healthcare* 5(4), 429.
- Włodarczyk, N. (2007). The effect of music therapy on the spirituality of persons in an in-patient hospice unit as measured by self-report. *Journal of Music Therapy*, 44(2), 113–122.
- Wright, D.K. (2015). Delirium as letting go: An ethnographic analysis of hospice care and family moral experience. *Palliative Medicine*, 29(10), 959-966.
- Wright, D.K., Brajtman, S., & Macdonald, M.E. (2014). A relational ethical approach to end-of-life delirium. *Journal of Pain and Symptom Management*, 48(2), 191–198.
- World Health Organization (WHO) (n.d.). *Definition of palliative care*. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>

Αναζητώντας το «λεπτό μέρος» μεταξύ ζωής και θανάτου: Η Σχισιακή Μουσικοθεραπεία με Έμφαση στη Συμπόνια (CFRMT) και η εφαρμογή της στην τελική διέγερση σε προχωρημένο καρκίνο σε ένα πλαίσιο ανακουφιστικής φροντίδας

Katie Binnie

ΠΕΡΙΛΗΨΗ

Το παραλήρημα [delirium] και η διέγερση [agitation] είναι ιδιαίτερα διαδεδομένα τις τελευταίες ημέρες της ζωής για τους ασθενείς με καρκίνο και μπορεί να είναι οδυνηρά για τον ασθενή, την οικογένεια και το προσωπικό. Παρόλο που οι κατευθυντήριες γραμμές συνιστούν τη σχολαστική αξιολόγηση των πνευματικών και ψυχολογικών παραγόντων και μια ολιστική αντιμετώπιση, στην πράξη (ιδίως σε νοσοκομειακά περιβάλλοντα) χρησιμοποιείται συνήθως η καταστολή, παρά τις ηθικές, επαγγελματικές και οικογενειακές αμφιβολίες και την κακή επικοινωνία γύρω από αυτήν την πρακτική. Μια προσέγγιση που βασίζεται στη Σχισιακή Μουσικοθεραπεία με Έμφαση στη Συμπόνια [Compassion-Focused Relational Music Therapy (CRMT)] προτείνει ότι το «λεπτό μέρος» μεταξύ ζωής και θανάτου μπορεί να διερευνηθεί και να κρατηθεί εντός της μουσικής, μειώνοντας ενδεχομένως το άγχος του ασθενή, της οικογένειας και των επαγγελματιών (ένα «τριγωνικό μοντέλο πόνου»), και να προσφέρει μια σημαντική γέφυρα μεταξύ της παροχής φροντίδας και του πένθους. Μια ενσυνείδητη προσέγγιση (αναπνοή, συνείδηση του σώματος, συμπόνια) ενσωματώνεται με τη χρήση του «φωνητικού κρατήματος» και του «νανουρίσματος-μοιρολογιού» [lullament] προκειμένου να υποστηριχθούν τα στοιχεία ενός «καλού θανάτου»: η ασφάλεια, η γαλήνη, η αγάπη, η συγχώρεση και η αποχώρηση. Αυτό το άρθρο περιγράφει μια μελέτη περίπτωσης μιας παρέμβασης CRMT με έναν τερματικό ασθενή που πέθαινε από μεσοθηλίωμα. Παρουσιάζει επίσης το πρωτόκολλο έρευνας μιας μελέτης σκοπιμότητας μεικτής μεθοδολογίας.

ΛΕΞΕΙΣ ΚΛΕΙΔΙΑ

ανακουφιστική φροντίδα, προχωρημένος καρκίνος, τερματική διέγερση [terminal agitation], μουσικοθεραπεία, συνειδητότητα [mindfulness], συμπόνια [compassion], πνευματική φροντίδα, ψυχολογική φροντίδα