

Saying it in song: music therapy as a carer support intervention

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There are an estimated 6.8 million adult carers in 5 million homes in the UK (Office for National Statistics (ONS), 2002). The role of carers in supporting the health and welfare of those they care for cannot be underestimated, nor can the savings they make for statutory health and social care providers. For example, in Scotland, just under a third of carers are the main support for the people they care for, providing high levels of practical support, with 51% of carers in the same household providing personal care, and 57% providing physical help such as assistance with walking (Holzhausen, 2002).

The emotional and general health consequences for becoming a carer may be considerable. While the individual with a terminal illness may experience a range of physical symptoms, their informal caregivers may experience a greater level of anxiety (Higginson et al, 1990; Axelsson and Sjoden, 1998). Palliative care studies have documented the loss in income (Addington-Hall and McCarthy, 1991) and emotional strain (Seamark et al, 2004) carers experience, and the physical consequences of caring, including fatigue, insomnia, weight loss, burnout, and general deterioration in health (Barg et al, 1998; Stajduhar, and Davies, 1998; Oberst et al, 1989; Schulz et al, 1990). Together with other forms of psychological morbidity, including diminished self-esteem (Reid et al, 2005) and depression (Higginson et al, 1990; Axelsson and Sjoden, 1998), the effects of informal caring could result in further demands on the NHS. Furthermore, the changes in carers' social situations may cause added difficulties arising from isolation (Seamark et al, 2004; Hepworth, 2005), lower income, altered routines and a reduction in leisure time (Stajduhar and Davies, 1998).

Despite statutory carer support initiatives, it is likely that carers of individuals with advanced illness have a variety of unmet needs, with one study reporting 84% of caregivers

Abstract

The burdens experienced by informal caregivers are likely to increase in the context of the UK's ageing demographic, and the movement towards more home-based care for those with long-term, chronic or palliative illnesses. This article combines an overview of our understanding of caregiving and carer support interventions, with an outline of the evidence base for music therapy in palliative care. Case material from the author's experiences of songwriting with a carer is used to provide a practical insight into how this emerging palliative care discipline may have the potential to alleviate carer burden, and enhance wellness. More research to explore the efficacy of music therapy as a carer support intervention is recommended.

experience above normal levels of psychological distress (Payne et al, 1999).

Alongside the growing tendency for informal carers to be perceived as 'co-workers' in service conceptualisations of care delivery (Twigg, 1989; Harding and Higginson, 2003), there is a growing body of literature exploring the experience of informal caregiving in which the concepts of caregiver burnout, burden and strain are focused upon (Robinson, 1983; Twigg, 1989; Payne et al, 1999; Van den Heuvel et al, 2001; Seamark et al, 2004).

For some, the positive outcomes of becoming a carer may provide a balance to the burdens they experience, such as the opportunities to express love through care, which may heighten feelings of self-worth (Grbich et al, 2001). Other studies have highlighted the importance of meaningfulness (Axelsson and Sjoden, 1998), self-esteem and reciprocity (Reid et al, 2005) in carers' relationships with their loved ones. An exploration of family caregivers' experiences by Schumacher et al found that caregiver depression was mediated by social support and coping (Schumacher et al, 1993). Useful reported coping strategies include maintaining previous interests and social networks, and taking short breaks away from the place of care. The absence of such breaks or support, including music listening

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and talking to others, can result in the experience of 'functioning on automatic' (Hull, 1992; Grbich et al, 2001), and may ultimately result in burnout.

Harding and Higginson conducted a systematic review of 22 interventions, including respite services, home nursing care, and activity enhancement programmes targeted at carers. They concluded that the literature to date provides useful information on the feasibility and acceptability of schemes, although methodological failings, such as a lack of outcome evaluation and small sample sizes, suggest the need for more vigorous efficacy studies. In terms of feasibility and acceptability, they suggest that a variety of different models are appropriate, as no single model of care can meet the varying needs of carers (Harding and Higginson, 2003).

Music therapy in palliative care

Leslie Bunt provides a broad definition that most closely reflects UK practice:

'Music therapy is 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.' (Bunt, 1994)

The holistic, humanistic approach of music therapy has much in common with the contemporary notion of 'wellness', defined by Micozzi as 'a focus on engaging the inner resources of each individual as an active and conscious participant in the maintenance of his or her own health' (Micozzi, 1996).

Music therapy has been organised as a professional discipline since the 1950s, and is now registered by the Health Professions Council alongside art, drama and dance therapy. The profession has developed from pioneering work in special needs education (Nordoff and Robbins, 1971) to work within many areas of health care, including mental health, elderly care services, and neurological rehabilitation.

As palliative care has grown internationally, music therapy has become an increasingly popular addition to multidisciplinary care teams (O'Kelly, 2002). In the UK alone there are currently 21 adult palliative care music therapy posts in total, representing a four-fold increase since 2000 (O'Kelly and Koffman, 2007), with a further 25 posts in children's palliative care. Practitioners have developed techniques such as song writing (O'Callaghan, 1994) and musical improvisation (Lee, 1996) for use in

the holistic support of patients, carers and the bereaved.

To date, empirical work on the effectiveness of music therapy in palliative care has been largely based on work in North America. Hilliard's systematic review of music therapy in palliative care demonstrated that it contributed to reduction in pain and fatigue, improved mood, and facilitated increased relaxation, physical comfort, spirituality, and enhanced quality of life (Hilliard, 2005).

Qualitative studies have demonstrated similar benefits. The author's recent study, involving an analysis of interviews with 20 multidisciplinary colleagues of UK music therapists, suggests music therapy offers a supportive therapeutic relationship, within which emotional awareness, expression, and catharsis are facilitated (O'Kelly and Koffman, 2007).

A larger Australian study, using grounded theory analysis of questionnaire answers from staff, visitors, 128 music therapy clients and 27 patients who had witnessed music therapy, elicited the following recurring effects in the data: enjoyment/joy (35%); relaxation (33%); and pleasure (26%) (O'Callaghan, 2001). The findings of these patient-based studies provide a useful reference point in terms of the relevance of music therapy support for carers experiencing psychological distress.

Music therapy with carers

There is a paucity of rigorous research exploring the use of music therapy with carers in palliative care or any other field, although case study and descriptive literature suggest that music therapy may provide an effective holistic support intervention (Murrant et al, 2000; Krout, 2003; Stewart, 2005). One empirical study of music therapy with professional hospice caregivers provides evidence of significant team-building benefits (Hilliard, 2006). Krout, an Australian clinician, reports that responses to music therapy interventions with family caregivers include: decreased anxiety; shared positive experiences and improved communication; more open expression of feelings; stimulation of shared life review; enhanced relaxation capacity; increased sense of community support; and the development of a more humanistic view of medical personnel (Krout, 2003).

There is evidence that music-making, listening and music therapy can cause positive changes in survival (Bygren, 1996) and biological markers of immunity and stress (McCarty, 1996; Burns et al, 2001); assist in the treatment of depression (Hanser and Thompson, 1994; Schmid and Aldridge, 2004); and improve cop-

Box 1. Ten steps in the songwriting process**Steps: process taken by therapist in writing song****Role of client**

Step 1. Determine focus of song by examining the clinical need	The clinical needs of the client(s) should drive the songwriting process. The client may be involved in this process of determining if songwriting is an experience in which they would like to be involved. Sarah's clinical needs centred on her need to express her conflicting emotions, and access her creativity and sense of self, which had been lost through the demands of caring. Songwriting was a natural choice given her skills as a writer
Step 2. Decide who is writing the song and why	The therapist needs to determine if the song will be written with the client or by the therapist for use clinically with the client. Sarah was very capable of writing the basic structure and lyrical content of a song in this case
Step 3. Decide which will come first, lyrics or music	We agreed on lyrics first, which were to be distilled from Sarah's reflexive diary
Step 4. Rough out lyrics for content without worrying about exact words, rhythm or rhyme	Sarah achieved this by writing a reflexive diary covering her thoughts and feelings over one week
Step 5. Choose style and feel for the song, using the rough lyrics as a starting point	The style of a folk ballad was chosen, as this was felt as an appropriate genre for capturing Sarah's story of her sometimes turbulent relationship with Alan
Step 6. Craft and design lyric rhythm and rhyme Step 7. Determine chords and use lyrics to talk over chords	The material from Sarah's diary lent itself to a description of the 'ups and downs' of her relationship with Alan. Her words seemed to flow without the need for rhyming, providing lyrical material for a verse, a refrain 'Because of the way we are', which summed up the strength of their relationship. The rhythm of this refrain when spoken inspired a chorus melody composed by Sarah in free vocal improvisation
Step 8. Add melody over chords	I suggested a number of different chord progressions to suit the chorus melody. Once the chord changes were selected, steps 6–8 were repeated with the verse lyrics, and a bridge section was composed using metaphor to describe the difficult times in Sarah's relationship with Alan
Step 9. Combine 7–9 above in verse chorus song form	The final structure and order of verses, chorus and bridge were agreed, and a rough audio recording was made, and converted to CD
Step 10. Add additional accompaniment and stylistic features to make song unique (Krout, 2005)	We decided to arrange the song for voice, piano and flute. The flute part would provide melodic embellishments suggested by Sarah in vocal improvisations which emerged from listening to the rough recording of the song

ing (Kenny and Faunce, 2004). This suggests the potential for music therapy as an appropriate carer support intervention.

Songwriting

Music therapists have a wide range of techniques at their disposal to offer carers as a means of emotional, social and spiritual support, including improvisation, songwriting, guided imagery in music, singing or revisiting previous musical interests, and group work (Bunt and Hoskyns, 2002). For the purposes of this article, I have chosen to focus on songwriting, a technique increasingly adopted by therapists in a variety of fields (Baker and Wigram, 2005). Leading US clinician, Bruscia, eloquently presents the potential of song:

'Songs are ways that human beings explore emotions. They express who we are and how

we feel, they bring us closer to others, they keep us company when we are alone. They articulate our beliefs and values...as the years pass, songs bear witness to our lives...They are our musical diaries, our life stories.' (Bruscia, 1998)

Songwriting in music therapy is a versatile medium capable of meeting a variety of clinical goals, from giving a client permission to express difficult emotions, to stimulating reflection and creativity, and increasing self-awareness. In the field of work with carers, these goals may be used within the overall aim of providing emotional support to enhance wellness and protect carers from burnout. The following case study illustrates how this technique is used in practice. All names have been changed to protect confidentiality.

Box 2. Because of the way we are

Verse 1:

It's not for me to say why the rivers run dry,
It's not for me to say why there's tears in your eyes,
But I know, that I'll stay, I'll stay by your side,

Because of the way we are
Because of the way we are

There was another time our sun forgot to shine,
We lost our way in the dark
But now we step into the light holding hands

Because of the way we are
Because of the way we are

Bridge

Sometimes the day is harsh,
Sometimes a stray dog barks
Sometimes the wind comes rushing low
That's when we face the world

Give it all we've got
Above the blues
Because of the way we are
Because of the way we are

Case study

Sarah's song: 'Because of the Way We Are'

Sarah had been the full-time carer for her husband, Alan, since his diagnosis of motor neurone disease (MND) five years previously. I received a referral to provide music therapy for Sarah from the day hospice social worker. At a meeting with her, Sarah described feeling 'burnt out' and depressed by the strenuous demands of caring for Alan, who had lost his speech and most of his mobility. Before Alan's diagnosis, Sarah had enjoyed an active social life and worked as a freelance writer, a job which gave her many opportunities to express her creativity, travel and meet people from all walks of life. Her relationship with Alan had at times been turbulent, and following a period of separation, they had only had irregular contact in the period before his diagnosis. The diagnosis led to what Sarah described as a 'turning point' in her life, where she followed her instinct to support Alan and her family as his disease progressed.

At our first music therapy session, I outlined the various techniques I would use in therapy, and highlighted the confidential nature of the work, i.e. that music therapy could offer her a safe setting in which to express herself. The first session provided Sarah with an opportunity to articulate her feelings surrounding her dual roles of carer and partner of Alan. While she found the daily routine of washing, toileting and feeding Alan left her feeling

'overloaded', she also talked about her love for him, which in many ways had become deeper through her role as carer.

Sarah found it hard to reconcile the conflicting emotions she had been experiencing recently. On the one hand, she longed to escape the drudgery of caring, and reclaim her previously fulfilling and creative way of life; but on the other, she also felt a new, unconditional love for Alan, which transcended any relationship difficulties they had experienced in the past. These conflicting emotions were often characterised by feelings of guilt, frustration and anxiety, which she found difficult to discuss with others; however, she expressed a sense of relief in 'being given the permission' to confide these issues with me. I encouraged Sarah to write down some of her feelings over the next week, in a reflexive diary, with a view to collaborating in songwriting in the second session.

Clinicians have proposed a variety of techniques for producing songs in music therapy (Baker and Wigram, 2005). One of the most detailed descriptions of technique is provided by Krout's ten-stage process, or 'Ten steps in the song writing process' (Krout, 2005). Krout recommends that the therapist and client begin the process by determining the focus of a song, through identification of a clinical need. In Sarah's case, this centred on her need to express her conflicting emotions, and access her creativity and sense of self, which had been lost through the demands of caring. We decided together that Sarah would produce the lyrics for a song, and that I would help her craft a melody from her vocal or instrumental improvisations on the variety of accessible instruments in the music room. *Box 1* details Krout's ten-step therapeutic songwriting process.

The clinical needs of the client(s) should drive the songwriting process. The client may be involved in this process of determining if songwriting is an experience in which they would like to be involved. Sarah's clinical needs centred on her need to express her conflicting emotions, and access her creativity and sense of self, which had been lost through the demands of caring. Songwriting was a natural choice given her skills as a writer.

Here, the therapist needs to determine if the song will be written with the client or by the therapist for use clinically with the client. Sarah was very capable of writing the basic structure and lyrical content of a song.

We agreed on lyrics first, to be distilled from Sarah's reflexive diary. Sarah achieved this by

writing a reflexive diary covering her thoughts and feelings over one week. The style of a folk ballad was chosen, as this was felt as an appropriate genre for capturing Sarah's story of her sometimes turbulent relationship with Alan.

The material from Sarah's diary lent itself to a description of the 'ups and downs' of her relationship with Alan. Her words seemed to flow without the need for rhyming, providing lyrical material for a verse, and which centred on a refrain, 'Because of the way we are', which summed up the strength of their relationship. The rhythm of this refrain when spoken inspired a chorus melody composed by Sarah in free vocal improvisation.

I suggested a number of different chord progressions to suit the chorus melody. Once the chord changes were selected, steps six to eight were repeated with the verse lyrics, and a bridge section was composed using metaphor to describe the difficult times in Sarah's relationship with Alan.

The final structure and order of verses, chorus and bridge were agreed, and a rough audio recording was made, and converted to CD.

We decided to arrange the song for voice, piano and flute. The flute part would provide melodic embellishments suggested by Sarah in vocal improvisations which emerged from listening to the rough recording of the song.

The final song (*Box 2*) was recorded with the assistance of a local community musician who played the flute part. Sarah continued to write songs with me covering a variety of aspects of her life, and has been inspired to produce a collection of poems on her own, highlighting the plight of carers. Sarah described her experience of songwriting in music therapy during one session:


'Without realising it, someone can become so serious in their caring role, that the sun can no longer find its way in. For me the combination of music and words in song opened up a whole new world for me, and gave me back the fun, creative element that was missing.'

With Sarah's permission, the song was played to Alan, in a very emotional joint session. Both Alan and Sarah were keen for the song to be heard by a wider audience, and it has since been used both as part of my educational presentations to carers and palliative care professionals, and in a concert celebrating the work of the Towersey Foundation (a UK charity dedicated to promoting music therapy in palliative care). In this sense, the song developed a 'song

history'. Initially, the song creation reinforced a more creative, holistic sense of self for Sarah, and also provided her with a timely opportunity to acknowledge the difficulties in her relationship with Alan, while expressing the deep bond of love between them. Through performances of the song to a wider audience of carers and palliative care professionals, the song may also be considered as fostering what Aasgaard describes as an 'ecology of love', operating within the 'interplay between individual health and the health of the ecological context within which the individual lives' (Aasgaard, 2001).

Discussion

Caregiver burden will increasingly pose challenges to palliative and other statutory services caring for those with chronic, long-term illnesses, as our life expectancy increases and as health care policy is targeted towards encouraging home-based care. As life expectancy in the UK and other developed countries continues to increase by an estimated two years per decade (Wellcome Trust, 2006), these issues are likely to pose difficult political, moral and economic challenges for the statutory services. For these services to continue to benefit from the contribution made by informal carers, it is arguably an imperative that a whole systems approach is adopted, which incorporates effective means of supporting and protecting carers from stress related illness.

My experience of working with carers, from a wide variety of backgrounds, suggests music therapy may offer a flexible, effective emotional support, which may alleviate caregiver burden, and enhance wellness. In addition to providing this support, the songs written by carers provide a unique and authentic insight into the lived experience of carers, in a manner which may be used to amplify the relatively dry reading common to some research literature. As such, it is an area which merits further attention from campaigners, researchers and clinicians alike. 

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Key words

- Music therapy
- Palliative care
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