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ORIGINAL ARTICLE

Seeking Asylum: The Benefits for Clients, Family Members and Care-givers of Using Music in Hospice Care

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ABSTRACT

The arts are becoming an increasingly important feature of care and their value in promoting increased levels of wellbeing is continually being experienced but not yet well understood. Similarly, the arts, and especially music appear to be able to bring increased levels of wellbeing to clients, family members and nursing staff, when used as an integral part of hospice, or end of life care. This article adopts an expanded definition of the word 'asylum' in order to assess the extent to which a series of musical concerts can contribute to the well being of all those involved in end of life care contexts.

The research involved carrying out observations and interviews with clients, care workers and family members who experienced a musical event. Interviews were carried out with individual participants before and after a one hour concert taking place within an open social space either within a hospice or a care facility. All concerts were given by one or two musicians with significant levels of experience of performing in such concerts. Observations of responses were also carried out during each of the concerts and notes were recorded accordingly. Ethical permission for the work was provided by the lead university. Results suggest that the concert experience provided significant levels of emotional support, was an ideal medium for promoting new and positive memories, and provided brief periods of respite for all those involved.

<Key-words>

music, psychology, hospice care, end of life care services

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I. Background

In a recent publication, Tia DeNora (2015) encourages us to consider the idea of 'musical asylums'. The word 'asylum' has a number of socially and culturally constructed meanings. In the UK, historically the word asylum was frequently used to denote the hospital, the physical institution or the building in which people were placed when suffering from any form of mental illness. Currently, the word is usually reserved for those unfortunate peoples who, for a variety of reasons, are required to leave their usual home environment and move elsewhere, that is to seek 'asylum' in the first place of safety. We consider the term 'asylum seeker' to refer to an individual who has for example, left their home country to seek asylum in another, safe country. The Japanese term for asylum refers to a building, hospital or more recently, a department of psychiatry whilst the term for asylum seeker specifically denotes a political refugee. However, DeNora adopts and defines the term 'asylum' in a different way. Accordingly, she uses the word to denote not just a physical building, institution, country or place but also to represent a mental state or condition; a brief period in space - time that is free from distress and provides a place to enjoy a sense of "... *connection to others, to feel pleasure, perhaps to note the absence, or the temporary abatement of pain*" (p.1).

The Oxford English Dictionary defines the word '*hospice*' as a home for the care of sick or dying people. Yet, at any one time, many of the individuals who are present in any hospice are neither sick, or dying. Some are nursing staff, carers and doctors, others carry out other vital service roles and some are family members wishing to spend time with their loved ones. In this article, we argue that all contexts of care can become 'asylums' by focussing equally on the physical and mental wellbeing but also by focussing equally on all those involved. Second, we will argue that the use of appropriate musical experiences, when included as an important component of palliative care, can make not only a significant contribution, but in some ways a unique contribution to hospice care by facilitating some brief moments of 'asylum' for all.

The role which music plays in dealing with illness is varied and culturally specific (see for example: Mills, 2012; Wolf, 2001) and in most cultures, music frequently plays a significant part in the rituals surrounding illness and death. Societies and cultures themselves, imbue all 'musics' with particular 'values' and strict rules often apply in terms of what types or styles of 'musics' are acceptable in particular social or cultural contexts. For many in the west, music associated with the end of life is often quiet, meditative and some would argue, full of sorrow, whereas other cultures employ joyful and celebratory musics. Individuals and institutions are not immune from such values and they contribute to many facets of our personality, including our musical identity.

The benefits of music on all those involved in the context of health care is well documented (Aldridge, 1996, 1999; Ito and Maruya, 2013; Nuki, 2009). For example, previous studies have frequently reported on the benefits to be gained from employing musical experiences in the management of pain and anxiety, (Krishnaswamy and Nair, 2016; Krout, 2001, 2003; Magill, 2001), the management of grief and depression (Periyakoil and Hallenbeck, 2002) and for decreasing the levels of anxiety and distress during medical treatments and therapies (Clarke et al., 2006; Whitehead-Pleaux, 2006).

More specifically, in terms of palliative and hospice related care, an increasing number of studies, largely grounded in music therapy approaches, have explored the use and benefits of music for those managing long term illness, (see for example Hilliard, 2001, 2003, 2006; Nitta and Kawabata, 2007), those facing terminal illness (Clements-Cortes, 2004; Horne-Thompson, 2007; Kitagawa, Kuwana and Okayasu, 2009; O'Kelly and Koffman, 2007) those people in care and nearing the end of life (Ricciarelli, 2015) and a relatively limited number of studies have explored the effects of musical experiences on care-givers following bereavement (O'Callaghan et al., 2012; Magill, 2009a), suggesting that engagements with music prior to bereavement can facilitate a number of important benefits following the death of a loved one. Knapp et al. (2009) for example, reported that parents were far more likely to report high levels of satisfaction with palliative care programmes following the inclusion of music therapy with terminally ill children.

Similarly, McFerran et al. (2010) reported decreased levels of loneliness and increased levels of emotional expression and willingness to talk amongst recently bereaved teenagers. Magill and Berenson (2007) reported on the benefits of musical experiences with family members of terminally ill people. Their findings suggested that the presence of music assisted in communication between family members and care givers, increased feelings of comfort – especially amongst children, and ‘played a memorable role’ in helping the family to prepare for a forthcoming death. Similarly, Magill (2009a, 2009b) reported on the benefits that musical events prior to bereavement can bring by providing caregivers and family members with positive memories of ‘joy and empowerment’, “rather than with memories of pain and distress” (p.97). Thus, there is a significant body of work suggesting that musical therapies can provide significant positive experiences and benefits for all those involved in hospice and palliative care for those living with long term illness.

It is important to note that whilst many of the benefits reported previously emerge from studies based in music therapy, the current research emerges from the discipline of music psychology. The substantive differences between the two approaches has been commented on previously (see Shibazaki and Marshall, 2016). In this respect, the musical experiences on which the current work is based and those employed in many of the previous studies are not immediately comparable. Most of the previous work has

involved therapy and therefore the musical experiences have been based on *making* music with *clients* and *others*; that is creating, performing, playing, singing and actively joining in. It is also important to note that therapeutic sessions often include the participant in some way having some control over the repertoire, the length of time that they engage with the therapist and these musical experiences often take place in smaller and more individual and personal contexts. In addition, music therapy programmes tend to take place over a prolonged period of time, and during this time, the therapist will become very much connected with not only their client but their family members. One could therefore argue that any emerging benefits are the results of this unique, and prolonged friendship and the deep level of social contact and interaction.

In contrast, the musical experiences in the current study consisted solely of concerts performed by either one or two professional musicians. The musicians came, performed to all who attended and left again with only a limited amount of social interaction. In this respect the main musical activity was therefore passive *listening* and when appropriate, singing and joining in with songs that were familiar. Participants had little or no control over the repertoire, the duration of the musical experience and in all cases the events were made available for all by taking place in communal spaces. It could therefore be argued that those studies reporting from the perspective of music therapy are more conducive to the expression of personal feelings or increased levels of emotion whereas in the current study, the whole context is more public. However, what then becomes interesting are those aspects which are reported as occurring within both contexts and those that do not. Thus, the aim of this study was to identify and to compare those benefits which individuals experienced in both types of musical experience.

Therefore, in order to achieve this aim, the current study had the following two research questions. Within the context of hospice and care for the terminally ill:

- i) To what extent can music concerts contribute to the creation of 'asylum' for the clients, the families, the nursing and care staff?
- ii) What similarities and commonalities exist between the benefits obtained through music therapy and those identified through engagement with music concerts?

Through engaging with these two questions, we expect to better understand how music can contribute to the creation of 'asylum', that is the creation of a brief period in space - time that is free from distress and full of enjoyment, for all those involved.

II. Method

Our current research focussed on the impact that musical experiences reportedly had on the clients, the care staff and the families of those in hospice care or individuals with terminal illness. In terms of hospice care, a total, 9 one hour music concerts took place in 2 institutions (in the greater London area, UK). All musical events were part of a regular day care programme. Clients mainly attended with one or two family members and all concerts took place with a central, communal space within the hospice. The study employed two forms of data collection, namely interviews and observations. Interviews were held with care and nursing staff (n=16), musicians (n=12), clients (n=6) and family members, (n=11). All interviews took place during or immediately after the musical events however, in 3 instances, telephone interviews were held with family members. In the case of the care facilities (n=3), musical concerts were provided according to the same criteria as the hospices. In one instance, the same musician was involved. Observations, focussing on events rather than just on fixed individuals, were carried out before, during and after the musical events. Observations were recorded in field notes. No personal information was collected and no identifying features were recorded.

All concerts were carried out by professional musicians with significant levels of experience of performing in the research contexts. In all cases, performances lasted for approximately one hour and were performed by either one or two professional musicians. No control was possible over the repertoire and therefore overall the concerts represented a variety and range of styles and instrumental combinations. However, all performers followed similar patterns of behaviour including engagement with individuals, asking for individual requests, performing small sections of songs to individual clients or family members and relating interesting stories.

Data collected from interviews were recorded accurately in field note books and analysis of the data followed standard procedures for qualitative data (Robson, 2011). Data from each of the four participant types (client, family member, musician and nursing/care staff) was first recorded onto one summative sheet per participant type. Data was then analysed through the six stage process of template analysis (Brooks, McClusky, Turley and King, 2015). Template analysis follows an iterative process in which initial coding of data is placed into clusters. These clusters are then used to develop an initial template through which all subsequent data can be thematised. The process also allows for the identification of integrative themes; that is, where a lateral relationship is identified between clusters. For example, in our data set, we identified 'Guilt' as an integrative theme across all participant types. One advantage of template analysis is that at stage 2 of the process: "*..... it is permissibleto start with some a priori themes, identified in advance as likely to be helpful and relevant to the analysis.*" (Brooks et al., 2015, p.203).

In view of this, our initial a priori themes were taken from the full definition of asylum, as set down by DeNora (2015), namely:

- Respite from distress
- Feeling in the flow of the moment
- Feeling creative
- Engaging in creative play
- Experiencing a sense of validation or a connection to others
- Feeling pleasure
- Noting the absence of pain.

Appropriate data was assigned first to one of our a priori categories with one further integrative category of 'Guilt'. Data from observations was used to provide additional evidence for the interviews, as and when appropriate.

III. Results

1. Respite from distress

In common with other studies (Krout, 2001; Warth et al., 2014) we witnessed numerous individuals becoming calmer and more relaxed. Observed indicators of decreased levels of distress included increased frequency of smiling, increased singing, relaxed facial expression, quiet, stillness, decreased agitation, increased musical activity or movement and becoming less demanding of staff and / or family members. Amongst the interview data, evidence included:

Client (2) "Everyone here is wonderful – you could not find a better place to be but it is, what it is! but last week I came to the hospice, this week I have been to a concert on a day out –

Family (5) "It changes the place and we go home happy talking about the concert instead of talking about – you know what and how many more times we do this journey"

Staff (12) "You get bad news about somebody you have become attached to but these (concerts) carry you through"

2. Feeling in the flow of the moment and feeling creative

Observations clearly showed almost all individuals 'feeling the flow of the moment'. As evidence for this we took instances where individuals ignored other distracting events taking place within close proximity, ceasing negative, distracting or anti social

behaviours (such as shouting / crying out, trying to leave or rocking), continuous periods of attention to the musician moving around the performance space.

As evidence for creative feelings and engaging in creative play we witnessed, responding musically (conducting /moving / tapping), singing in harmony with the performer, whistling counter melodies, improvising a short tune in between the lines of a song, and in two cases of individuals with significantly reduced movement, changing the pattern of breathing in time with the phrasing of the song.

Client (6) *“I sit and watch the clock but time seems to stand still when they are playing, you have no idea you have been here for over an hour”*

Family (8) *“He was always known for making up funny words to songs – ... and now he does that again – makes us laugh”*

Staff (3) *“Many of them find it hard to concentrate on other things but in the concerts, they just go with it – just sitting quiet listening with their eyes closed and they are still joining in”*

Staff (14) *“It’s the one chance you get to see who they really are”*

Musician (4) *“We had one lady stood up and danced with us ... then afterwards she suddenly said – of dear, where is my walking frame ? – she was so ‘into it’.*

3. Experiencing a sense of validation or a connection to others

Music binds people together and our appreciation of music helps us to express who we are as humans. As evidence of validation and connection, from our observations we would cite taking hold of hands, increased eye contact, demonstrating the need to hold hands, increased social interaction (smiling at people, initiating talk or contact), acknowledging the presence or movements of others and increased levels of talk.

Client (4) *“That song they sang – I knew it, and that style was always ‘me’ - True – I knew every word”*

Client (3) *“You just feel human again, part of the world, listening to music and just doing what everybody else does”*

Family (1) *“Those songs were just about ‘us’, we said we could almost remember where we were when we heard it first – it just takes us back”*

Staff (6) *“Did you see ? – he held her hand – they don’t even know each other !”*

Two further issues of note. We noted that interviews carried out post concert contained significantly more use of the words 'us' and 'we'. Pre-concert interviews more often related to the individual. Partners and family members spoke about themselves or others whereas post – concert talk more frequently related to joint stories, joint memories and stories about each other.

Secondly, two musicians (2 and 6) both commented that during the actual concerts in the day care hospice groups they often found it difficult to identify the client and the family member as both tended behave in very similar ways; there sometimes being no clear indication as to who was ill.

4. Feeling pleasure

Evidence from observation notes relating to feeling a sense of pleasure included increased levels of smiling, singing or humming, increased levels of social interaction, expressions of joy, increased levels of social and musical behaviour. We also suggest that feelings of pleasure were also evidenced by increased periods of calm, silence and neutral facial expressions.

Evidence from interviews included:

Client (1) "I just find it so uplifting and we love every minute of it "

Family (7) "It's a real joy and we just look forward to coming – it really is the highlight of the week"

Staff (10) "We all get so much pleasure out of this, we all talk about it and we do our jobs better"

One further indication of pleasure related to memories and to the creation of new memories. Almost all participants in both the client and the family group spoke about memories and these could be placed into two categories. First, memories associated with a particular piece of music or a song. In such instances, the personal meaning of the music to the individual promoted increased levels of talk and pleasure through reminiscence. Examples included music played at weddings, or related to a parent or an association between the music and a place (e.g. a holiday destination). In the second category, participants referred to the music helping them to create new memories which they could treasure in the future. Examples of this were:

Client (6) "I would rather my grandchildren remembered me being happy and singing along with this than any other memory of me"

Family (4) "These are the moments I will treasure – this is who they are"

Staff (5) "I often remember them in the concerts and how they were - makes me smile and happy they could have this experience - it makes up for everything else they have to go through"

5. Noting the absence of pain.

There is a significant body of evidence to suggest that music can assist in controlling pain (Good et al., 2000; Kahar, 2011; Tabane et al., 2001; Vaajoki et al., 2012). However, neither interviews or observations are sufficiently sensitive instruments to provide evidence for the absence of pain. In addition, pain management is one of the key foci of hospice and care of the terminally ill and therefore this particular study had limited opportunities to explore this particular aspect. When asked about pain, clients and family members reported an absence of pain resulting from their medication and therefore could not comment further. However our observations show significant increases in levels of activity, mobility, calm, engagement and social interaction, an increased ability to focus and concentrate, along with a decrease in behaviours and facial expressions normally associated with pain (e.g. grimace, frowning). Interview data was also inconclusive but 3 staff members with substantial knowledge of individual clients (staff members 1, 9 and 11) did report that in their opinion and through their knowledge of their clients, concerts did improve overall levels of wellbeing as evidenced through increased levels of participation, increased facial 'colour', increased levels of eye contact and social interaction. Pain measures other than this are beyond the scope of this paper.

6. Integrative Theme: Guilt

The notion of feeling guilty appeared as an integrative theme across all participant types. Four clients in our study discussed feeling guilty when family members accompanied them to the hospice or visited them in the care facility. Comments included:

Client (5) "I have to come here but my wife does not and often she just has to sit here with me and you often just focus on why you have to be here – but the music makes such a real difference – it's real day out"

Client (2) "I feel I drag my daughter with me but with the concert, I don't feel quite so bad"

Clients appreciated family members being with them however, there was a sense that partners/ family members had 'better things to do' than to sit in a hospice or a nursing home. However, the presence of the concerts provided clients with a sense of 'giving back' something to their families.

Family members (3 and 6) reported similar feelings of guilt. Comments included, for example:

Family (3) "I always want to come but it is sometimes hard to fill the time, and you feel guilty – you feel you should appreciate this time more but in the concert, you can just appreciate being together"

Family (6) "You feel guilty because there is so little you can do, but this is something we can do together"

IV. Considerations and Conclusions

Collecting data at difficult moments in life is not easy but the current study suggests that musical concerts can achieve similar benefits to those obtained by other therapeutic programmes, although we have no evidence for how long these benefits continue. In common with studies by O'Callaghan and Magill (see also Kitagawa et al., 2009), we found evidence for increased pleasure, increased movement and engagement, increased social contact and improvement in overall levels of wellbeing in staff, clients and their families. We also found evidence for the role that musical events can play in both reminiscence and in creating new memories, supporting the findings of therapy work by authors such as Magill (2009b). In terms of our second research question, we found appropriate levels of evidence for each of the categories identified by DeNora, in her definition of asylum.

Of further interest is the fact that much of the musical repertoire that our participants experienced would not always be considered as being slow, meditative, sad, emotional or even spiritual, and not all the styles were classical, sedate and formal. Instead the musicians provided a wide range of instrumentation, musical style and repertoire of music that reflected the lives of the individuals, their histories and their memories; and it was the fact that the concerts reflected 'life in entirety' that pleased the most. In conclusion, we argue that taken overall, musical concerts can be a major component in creating brief periods in space / time in which all concerned with hospice and end of life care can be free of distress and flourish in a musical asylum.

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