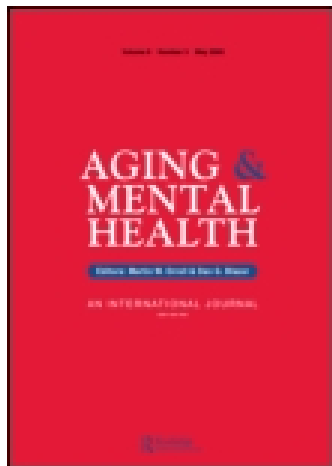


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The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists

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The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists

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Objectives: Despite the popularity of music-based interventions in dementia care, there is a limited knowledge of how and why people with dementia find music beneficial for their well-being. A qualitative study was conducted to develop further insights into the musical experiences of people with dementia and explore the meaning of music in their lives.

Method: Separate focus groups and interviews with (1) care home residents with dementia and their families, (2) day hospital clients with dementia, (3) care home staff, and (4) music therapists, were conducted. The findings of the thematic analysis were investigated further in the light of psychosocial factors with the aim of developing a theoretical model on music in dementia.

Results: Six key themes were identified. The accessibility of music for people at all stages of dementia, close links between music, personal identity and life events, the importance of relationship-building through music making were particularly highlighted as valuable. The *psychosocial model of music in dementia* was developed. The model revealed the importance of music to support the personal psychology of people with dementia and the social psychology of the care home environment.

Conclusion: The effects of music go beyond the reduction of behavioural and psychological symptoms. Individual preference of music is preserved throughout the process of dementia. Sustaining musical and interpersonal *connectedness* would help value *who the person is* and maintain the quality of their life.

Keywords: music; dementia; personal psychology; social psychology; psychosocial model

Introduction

Music-based interventions including music therapy, community singing groups and music listening are widely accepted as beneficial for the psychological well-being of people with dementia. Music may be valued as an easily accessible and stimulating medium, which can be enjoyed alone or with others even in the context of severe dementia. Care home residents with dementia and families have highlighted music listening, singing and dancing as particularly meaningful amongst all care home activities (Harmer & Orrell, 2008). Sixsmith and Gibson (2007) conducted interviews with 26 people with dementia and their carers and found that music was not only enjoyed in its own right, but was also valued as a social activity. The ability to appreciate and engage with music remained intact even as cognitive functions deteriorated. A disadvantage of their study may be that it made a limited attempt to link the study findings with a theoretical framework of dementia care, other than mentioning that the study was ‘guided by the ecological model of well-being’ (Sixsmith & Gibson, 2007, p. 129). A recent narrative synthesis systematic review on music therapy in dementia also identified a limited use of relevant theoretical frameworks (McDermott, Crellin, Ridder, & Orrell, 2013). To understand how and why music interventions may be beneficial for the

psychological well-being of people with dementia, it is necessary to go beyond summarising the study findings and contextualise the study outcome with the aim of developing a theoretical model for music in dementia.

The centrality of engaging directly with the experience of people with dementia and trying to understand the viewpoint of the person with dementia became prominent in the 1990s (Brooker, 2007). Kitwood is particularly known for establishing the concept of person-centred care in dementia where the personhood of an individual with dementia forms the basis of care (Brooker, 2007; Kitwood, 1993a, 1997; Kitwood & Bredin, 1992). Kitwood (1997) defined *personhood* as: ‘a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust’ (Kitwood, 1997, p. 8). He argued how the personal psychology of the person with dementia is affected by the social psychology of the care culture and debated how the clinical manifestation of a dementia may arise from a complex interaction between *personality, biography, physical health, neurological impairment, and social psychology* (Kitwood, 1993b). The quality and sensitivity of the interpersonal process between a person with dementia and a carer is one of the key components of person-centred care. This has a

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particular relevance to music therapy where relationship-building through musical interactions is the core of the therapeutic intervention. Trevarthen and Malloch (2008) argued that music making was a human activity that communicates motives. The theory of *communicative musicality* (Trevarthen & Malloch, 2008) also resonates with Kitwood's argument on understanding the *communicative attempt* made by people with dementia.

Spector and Orrell (2010) proposed an updated biopsychosocial model of dementia that 'disaggregates psychosocial and biological processes, with the aim of understanding the inter-relationship between the two' (p. 959). The biopsychosocial model also disaggregates tractable factors ('aspects which may be amenable to change') and fixed factors ('aspects which relate to history or risk factors and therefore may not be amenable to change'). Examples of tractable psychosocial factors include mental stimulation, mood, coping strategies, personal psychology and social environment, whereas fixed psychosocial factors are closely linked to the person's personality traits, previous life events and education. The biopsychosocial model urges clinicians and researchers to view dementia as 'something which is malleable and where change, adaptation and improvement is possible' (Spector & Orrell, 2010, p. 959). Although the model has not been empirically tested yet, it provides a comprehensive framework where the impact of dementia is presented as a process, rather than just as an end-product, thus allowing an intervention to influence its process.

Some aspects of musical experiences may influence a person's psychosocial tractable factors, or may be linked with the person's psychosocial fixed factors. This paper does not explore the effects of music on the biological aspects of the biopsychosocial model, even though the effects of music therapy on physiological changes in people with dementia have been discussed (McDermott et al., 2013). The investigation of the effects of music on the psychosocial factors may help us understand how and why music impacts on people with dementia and guide the development of a theoretical model.

Aims

- To explore the meaning and value of music from the perspective of people with dementia.
- To investigate how families, care home staff and music therapists perceive the effects of music on people with moderate to severe dementia.
- To explore a link between psychosocial factors and the study findings in order to develop a theoretical model of music in dementia.

Methods

This study was part of a research project on the development of a music therapy outcome measure. To obtain the qualitative data of the importance of music for people with dementia, separate focus groups and interviews with: (1) care home residents with dementia and their families,

(2) care home staff, (3) day hospital clients with dementia living in the community and (4) music therapists, were conducted. All focus groups and interviews were conducted by the lead researcher Orii McDermott (OM).

Study sample

Two National Health Service (NHS) care homes (Home A and Home B hereafter) that are primarily for people with moderate to severe dementia, and where OM also worked as a music therapist, agreed to take part in the research project. The majority of the residents in Home A ($n = 45$) and Home B ($n = 24$) had a diagnosis of dementia recorded in their medical files. All the residents were informed of the project and OM also spoke to the residents individually. Since many residents had moderate to severe cognitive impairment and their speech was often unclear or were easily misinterpreted, it was decided to hold joint focus groups for the residents and their family members who could help interpreting residents' speech as well as provide additional information on the musical experiences of the residents. Invitation letters for focus groups and research information sheets with a self-addressed envelope were sent to the next of kin of the residents who had a diagnosis of dementia and who lived within a reasonable travelling distance from the care homes. The researchers did not invite those families that care home staff judged had very little contact with the residents and potentially not clinically appropriate to approach for a research purpose. Family members of the residents who did not have dementia were not directly invited to focus groups but were informed of the project. Focus groups with the residents and their families took place in Home A and Home B.

Focus groups with staff who provide day-to-day care to the residents (e.g. assisting the residents during meal time, helping with their personal care) were organised in consultation with the managers to minimise disruptions to the daily routine of the homes. Staff members who were not involved in day-to-day care of the residents (e.g. managers, domestic workers, therapists) were excluded from the study but were informed of the project and the reason for their exclusion. Home A had a high percentage of temporary staff members who had a limited knowledge of the residents. A senior nurse suggested health care assistants (HCAs) and nurses who had sufficient knowledge of the residents and sufficient experience of working in Home A, and organised their shift work so that they could attend the focus groups. For Home B staff focus groups, it was agreed with the unit manager that OM sent invitation letters to all HCAs and nurses on the Home B staff list and arrange the focus groups according to staff responses. In addition, day hospital clients who attended music therapy group run by OM's colleague were invited for individual interviews. The decision to conduct individual interviews and not a focus group was made based on the variations of the severity of their dementia and their ability to articulate their thoughts. Music therapists were recruited through OM's professional network. All therapists were qualified from a recognised postgraduate music therapy programme and were registered with Health Professional Council in

the UK or a Board Certified Music Therapist in the USA. All therapists had a minimum of four years' experience of working with clients with dementia in residential settings. The majority of music therapists used an active music therapy model where clients were encouraged to explore musical instruments and/or their voice with the therapist. The method of facilitation and clinical intervention varied, and was determined by the clinical needs of each client and were shaped by the theoretical orientations and experiences of the music therapists. However, the use of well-known songs combined with exploratory improvisation was common. Recruitment of music therapists was terminated when saturation in collecting raw data appeared to have been achieved.

Key questions for focus groups and interviews

The main aim of the focus groups and interviews was to engage directly with the musical experience of people with dementia. The key questions asked were:

What does music mean to you? What do you think of your music therapy/music activities? If music is important to you, in what way? (People with dementia)

What changes and responses do you observe in your family members/clients following music therapy or music activities? How do you know when music is meaningful to the person? (Families, staff and music therapists)

Ethics procedure

Ethics approval from the National Research Ethics Service (NRES Committee London East, REC reference 11/LO/0596) was granted in June 2011. Whenever possible, consent for participation in the study was sought from the residents themselves, but many residents needed the second consent from family members or from key nurses on behalf of the residents in order to adhere to the Mental Capacity Act (2005). Some residents in the study had no next of kin or no contact with their families. In these cases, assent or consent was sought from their key nurses and residents' involvement in the study was discussed and monitored in the care home multi-disciplinary team meetings. The day hospital clients with dementia were able to provide their own written consent. Consent was also obtained from all staff, families and music therapists.

Procedure for data analysis

Focus groups and interviews were audio recorded whenever possible with consent from the participants. If participants declined the audio recording, OM asked if it was possible to take notes during the interviews. OM listened back to the recordings several times until she was familiar with their content and gained an understanding of emerging themes. The main purpose of this process was to retrieve reoccurring themes and identify key comments particularly for the outcome measure development.

Comments that were potentially relevant were transcribed for further analysis.

The general inductive approach was chosen to analyse the qualitative data. The general inductive approach is a 'systematic procedure for analysing qualitative data in which the analysis is likely to be guided by specific evaluation objectives' (Thomas, 2006, p. 238). This is similar to the grounded theory, but the main purpose of the inductive approach is the rigorous systematic extraction of data and description of themes and categories that are most relevant to research objectives; not necessarily an in-depth theory generating process which is typically applied in the grounded theory. The analysis of the key comments aimed to identify emerging themes for scale development, not theory generating at this point; hence the general inductive approach was applied. The general inductive approach can be seen as simpler than other analysis methods but still involves a systematic analysis of raw data in order to achieve qualitative research trustworthiness described by Lincoln and Guba (1985): credibility (internal validity), transferability (external validity), dependability (reliability) and confirmability (objectivity).

To increase the transparency of analysis, the long-table approach (Krueger & Casey, 2000) was utilised. The transcripts were printed and cut into individual quotes to produce transcription cards of the key comments. This allowed the qualitative data to be quantified and facilitate merging and comparison of data, as discussed by Bazeley (2010). The result of the preliminary analysis was discussed with Martin Orrell (MO) and Hanne Mette Ridder (HMR) until consensus on the key themes was achieved. These themes were reduced further to key points to develop scale items. The data analysis was also presented to the professors and the doctoral researchers at the Doctoral Programme in Music Therapy, Aalborg University for further discussion and scrutiny. OM then reviewed each card again against the previous categories by re-applying the long-table approach. The transcription cards were re-grouped and discussed further with MO and HMR.

Once all the authors agreed upon the re-grouping of the transcription cards, the emerged themes were explored further in the context of the psychosocial factors of the biopsychosocial model (Spector & Orrell, 2010). A theoretical framework for *the psychosocial model of music in dementia* began to emerge. OM and HMR conducted consistency checks (Thomas, 2006) in order to establish credibility of the interpretations of the transcription cards for theory development.

Results

Table 1 shows the constitution of the study participants. Out of the 44 families contacted, 19 sent a reply slip back. Fifteen family carers agreed to attend the focus groups or interviews, four indicated they were unable to attend due to family and work commitments. Care home residents with dementia were approached individually for informal discussion about the project. Though many expressed their interest in discussing music, it was often unclear whether they agreed to take part in research due to their

Table 1. Constitution of the study participants.

Study participants	Inclusion criteria	Recruitment method	Response rate	Data collection method	Number of participants
People with dementia living in care homes	Care home residents with dementia	Face-to-face talk with OM and liaison with family	N/A	Residents attended either: (1) joint focus groups with carers or (2) joint interviews with carers*	Total $n = 12$ (Home A $n = 6$, Home B $n = 6$)
People with dementia living in the community	Day hospital clients with dementia who are able to provide own consent	Recruited by a music therapist working in the day hospital	4/4 (100%)	Four individual interviews	$n = 4$
Family carers	Family carers of the residents with dementia	Invitation letters sent to the next of kin	15/44 (34%)	Families attended either: (1) joint focus groups with residents or (2) joint interviews with residents*	Total $n = 15$ (Home A $n = 7$, Home B $n = 8$)
Care home staff	Staff who provide day-to-day care to the residents	Home A: senior nurse suggested who would be suitable participants based on their knowledge and experience with the residents Home B: OM sent invitation letters to all nurses and health care assistants Through OM's professional network	Home A: 9/9 (100%) Home B: 5/49 (10%)	Focus groups (2 groups in Home A) (1 group in Home B)	Total $n = 14$ (Home A $n = 9$) (Home B $n = 5$)
Music therapists	With minimum of 4 years' experience with clients with dementia and have worked in residential settings		8/8 (100%)	Eight individual interviews	$n = 8$ (6 full-time, 2 part-time). 1 therapist worked solely in one home, others worked in several homes or on inpatient wards

*In total, three joint focus groups for residents and families (two in Home A, one in Home B) and five joint interviews for residents and families (two in Home A, three in Home B) were conducted.

severity of dementia. At the end, the three authors agreed OM to conduct joint focus groups and interviews with residents and his/her family members. Day hospital clients were at an earlier stage of dementia and were able to give full consent to take part in research. All were under the care of the NHS Trust where the ethics approval was granted. All staff members approached in Home A showed their willingness to participate in the project. Out of the 49 Home B staff that the invitation letter was sent to, only 16 replied. Out of the 16 respondents, 5 agreed to participate, 8 indicated they were not interested, 3 returned blank forms. All the music therapists OM contacted agreed to take part in the project. At the end, the total of 53 participants comprising of: care home residents with dementia ($n = 12$), day hospital clients with dementia (4), family carers (15), care home staff (14) and music therapists (8), attended a focus group or were interviewed individually. In total, 6 focus groups and 17 interviews were conducted. Each focus group consisted of between 4 and 7 participants. Interviews were conducted either on an individual basis for the day hospital clients or in the care homes where the residents had more severe dementia, interviews were conducted with the resident with dementia and one or more family members.

Arranging a mutually convenient time for family carers to attend focus groups proved to be more challenging than initially anticipated due to the participants' family and work commitments and also due to time constraints of this project. As a result, a larger number of interviews were held. One advantage of conducting interviews was that observing direct interactions between the residents and family carers was easier in individual interviews and small cues from the residents (e.g. subtle nodding or shaking their head in response to what their families said) were also easier to pick up. The length of the interviews and focus groups varied greatly from 15 minutes (day hospital clients) to an hour and a half interview with one family. An average focus group with staff and interviews with residents and families lasted 1 hour; an average interview with music therapists lasted 1 hour and 15 minutes. The majority of the participants gave permission to be audio recorded. Two day hospital clients requested not to record their interviews but allowed OM to make notes during their interviews.

Following the identification and transcription of the key comments and the initial analysis of the data with the general inductive approach, 270 transcription cards were produced to be analysed further using the long-table approach.

Qualitative data analysis utilising the general inductive approach and the long-table approach

Initial categorisation of the themes for scale development and revision of the categories for this study resulted in identifying six themes. Themes 1–3 were linked to musical experiences of people with dementia; Themes 4 and 5 were the effects of such musical experiences and Theme 6 focused on the evaluation and communication of music therapy clinical work. Some cards covered more than

one theme. In such cases, OM, MO and HMR discussed which theme should be regarded as the most prominent one for the purpose of categorisation. All the names of the participants used in the quotes have been anonymised.

Theme 1. 'Here and Now' (number of transcription cards = 61)

Music as a readily accessible medium. The most common theme was the importance of 'Here and Now' musical experiences for people at all stages of dementia. All participants discussed the stimulating effect of music and how playing instruments or listening to music instantly caught the attention of many residents who often appeared less aware or disinterested in other people or activities around them. Residents typically responded to familiar music by feet tapping, hand clapping, whistling, singing along or dancing. Many discussed the flexibility of music activities that allow different levels of participation:

A lot of the times, people's eyes are closed, activities have been found for them, music is very good, a bit of this, a bit of that, everyone enjoys. . . there is a region of the brain. . . seems less affected by dementia, accessibility of music is so important. (Sandra: spouse)

(I get easily confused, but) Everything is simple in music therapy group, that's what I like. (Ahmed: day hospital client)

Music as mental stimulation. Stimulating and energising effects of music were particularly emphasised by day hospital clients, residents and families:

I often think it's very hard to imagine how it feels (to be a resident), we don't know but there may be an awful lot of things going on, but (they) can't explain. . . anything stimulating, uplifting, anything that changes the tempo of the day is a good thing. Music is great for that. (Carol: daughter)

After lunch, feels a bit tired. . . but playing music, tapping feet, stimulates brains. Music is such a diverse. . . forms, drums, guitar, all these things. . . therapeutic if you are coping or not coping. . . everyone gets depressed, tired, lazy, but music stimulates you. (Peter: day hospital client)

Immediate and short-term musical engagement. All participants agreed music was one of the few mediums people at all stages of dementia immediately responded to. However, some family members voiced their doubt if musical experiences had a long-term effect on residents' mood and behavioural changes:

I think music therapy is good for her, but I don't think she is going to change. If she is happy, she will take part, but there is nothing you can do when she is angry, so I don't think music therapy (or any therapeutic activities) will calm her down. (Isabella: niece)

He says he enjoyed every time he comes out of your (music therapy) session. He said: "it lifts my spirit, the

music”, that’s what he tells me. I usually ask him immediately... if you ask him in the evening how the session went, he might have forgotten it. (Rebecca: spouse)

Emotionally meaningful experience. Residents and day hospital clients explained playing, singing and listening to music was an emotionally meaningful experience for them. Families and therapists acknowledged they were often surprised by emotional responses to music by people at late stages of dementia:

(Music making is) Totally different... mixture of... great sound... excluding everything else, great picture of sound... that is dynamic, series of sound... flowing through. (James: resident)

There is a particular song we still sing together, and I changed the lyrics to “mum”, sometimes she gets quite emotional, she will go “ah”... there is still a lot of emotion there, whereas you might think she has not understood or messages cannot be relayed. She will sometimes cry when I change the words or she remembers something. (Claire: daughter)

Theme 2. ‘Who you are’ (number of transcription cards = 48)

Retained memory of song lyrics linked to personal history. Many residents explained music has always been part of their daily life, and families and staff acknowledged the residents’ recognition of familiar music and retained memory of well-known songs. A number of therapists also identified the use of songs as a crucial component when working with people with dementia:

I think music always brings back their memory. Remembering old songs...you can see changes (in residents). Resident E starts dancing...once he told me “that’s not the way you dance” so he started teaching me how to dance. (Susan: staff)

Resident A whistles...legs going, waving her hands...her knowledge of music is incredible, because she can whistle anything, even though her memory is poor, she can even whistle the Blaydon races that I hadn’t played (a CD)... she remembers. (Stephen: staff)

(I) forget things... but when I make a cup of tea standing in the kitchen, I sing what I remember. Music when I was a child, I am old now, but music (stays). (Peter: day hospital client)

Music as personal and cultural identity. Music was closely related to personal history and life events, and there was often a particular type of music that was linked to personal and cultural identity. Many had a Christian background and going to church and singing hymns have been part of upbringings.

Religion was so important to her, she used to go to church all the time so I know church music and hymns mean a lot to her. It’s linked to her life and history. (Jane: niece)

Music gives him a kind of wholeness, of a person, of his spirituality, life generally. Probably connects him with some of his earlier life in a way of how he saw life. Music takes him back to the times he was able to be himself. (Teresa: guardian)

At the same time, listening to music from one’s cultural background was sometimes a reminder of a severe reality:

I put jig-like Scottish music on, then she was tearful...I thought she was upset, something definitely going on there. Then she turned around, and said clearly: “I was young once – I was a young lady once”, she says “I wasn’t always like this”. I had to take that music off, because she was getting really upset, because she was listening to Scottish music. (Gary: staff)

‘Who you are’ now. Musical identity and individualities also emerged through music making with therapists and other group members. A number of therapists stated their clinical focus was to give value to whatever their clients express in a session by improvising music with them, often incorporating the musical style of clients’ cultural background. The need to accept the impact of dementia as part of the individuality of each person (*‘Who you are’ now*) and the importance of trying to understand the underlying causes of what may be perceived as challenging behaviour were highlighted by staff and therapists. In the case of music therapy, therapists often tried to match qualities of their clients’ shouting or screaming by improvising music with them in order to give the clients an experience of being heard.

To categorise these crucial connections between music, cultural identity, individual history and the associated memories as *‘Who you are’* may come across as an over-simplification. It can be argued this theme is more accurately described as *Personal Identity*. The limitation, however, is that *Personal Identity* does not cover the full spectrum of who one is. Other elements such as personal and historical life events and personal psychology (e.g. how the person reacts to life events) may influence *‘Who you are’* as well as the process of dementia. A broad term to cover the whole spectrum was necessary, thus the term *‘Who you are’* was chosen for this theme.

Theme 3. ‘Connectedness’ (number of transcription cards = 40)

New experience of music making. Playing instruments was a new experience for many people. Some explained they were interested in learning an instrument when they were young, but did not have an opportunity. Day hospital clients acknowledged that learning how to play together as a group was not always easy since everyone had different musical opinions but all were in agreement the new experience of exploring various instruments as a group was enjoyable and they valued their weekly session:

I wanted to play the drum when I was young... I used to listen to the drum in a dance hall... *How does it feel*

playing the drum in the music therapy group? I am old now... but it gives me a bit of life (when we are) playing together. (Charles: day hospital client)

(The client was) ...still quite articulate, not a native English speaker but could speak some English, an educated gentleman in his native country... his status in the group is good, people say "listen to him", fascinated by him leading the group (music). When he came to the day hospital, people were not aware what he could do, but affirmation in music therapy... capable, able leader... it gave him confidence. (Ruth: therapist)

Building and sustaining relationships with others.

Development of a relationship through musical connectedness took many forms. Ahmed (day hospital client) explained that he valued having a space to talk about issues that were affecting him, and found sharing his feelings through music with other group members helpful. For people at later stages of dementia, the development of a relationship was often indicated by prolonged eye contact, head turning, reaching out for instruments or changes in facial expression during music making. Claire (daughter) reported how her mother learned and began to recognise the therapist's voice even though she wouldn't visually recognise the therapist straight away.

Families and therapists also acknowledged familiarity of musical connectedness: for example, singing favorite songs together or continuing with music therapy sessions with the same therapist as dementia progressed was often crucial for people at late stages of dementia. All emphasised that music and its familiarity was one of the few accessible mediums that facilitated human connectedness:

She (client) would be much stiller (than how she was on the ward), she would look at me, would make an attempt to communicate with me, she would engage with songs and instruments... as she deteriorated, these pockets of connection would become smaller and less, but I do think towards the later stage of us working together, music was one of the only things she was engaging with. (Emma: therapist)

Sustainability of musical connectedness. How long the connectedness with other residents or group members was sustained after music therapy or music activities was unclear. Several staff members reported residents were more sociable and communicative immediately after music activities. Many therapists acknowledged they did not know how much staff or family carers noticed sustained communicability following music therapy sessions. Therapists generally seemed to regard meaningful connection with others and normal togetherness that happened during a session more crucial for the well-being of people with dementia than potential long-term effects of therapy:

He (client in music therapy group) had a stuck rhythm and we had to make music around him... strong rhythm, he couldn't adjust first... but gradually became more aware of the group music... if I am trying to end (improvising) music, he is the one ends... there is a connection in

music, but not socially (outside of the session). (Ruth: therapist)

I have anecdotal feedback (from staff) ... for example, they (clients) carried on singing together when they went back to the lounge, and their "better, communicative mood" stayed for a while... less, withdrawn, more able to say what they wanted... for how long, I do not know. (Hannah: therapist)

Theme 4. Effects of music on mood (number of transcription cards = 30)

Immediate effects on mood. It was frequently reported that music helped improve the mood of people with dementia, and its effects were often immediate and observable. Many staff identified how listening to music and singing decreased agitation levels in residents, which had beneficial effects for the residents themselves and others around them. Brighter mood and increased alertness immediately after participating in music therapy was also observed:

T (resident) seemed brighter when he came out (of Music Therapy room) and looked brighter for a while afterwards. He was more alert, more conversational – for one hour or something, a bit more spark – he seemed more animated. (Gary: staff)

M (resident) was so agitated, wandering, shouting, but when Christmas carols were playing yesterday, she started singing carols as if she was in choir... Music calms her down. If M is happy, everyone around her is settled. (Susan: staff)

I used to have (my own) business, but had to close it down... I often feel sad, I might feel like crying but music makes me forget. (Victor: day hospital client)

Short-term effects on improved mood. Notable improvements in the residents' mood following music therapy and music activities were frequently reported. However, the effect of music on their mood tended to be short-term. Staff, families and therapists all recognised residents' mood changes were often unpredictable as so many variables in the care homes affected their mood. They also acknowledged the nature of advanced stages of their dementia and added they were unsure how long the residents would retain the musical experience. Nevertheless, all emphasised that the *Here and Now* mood enhancement was still beneficial for the well-being of residents and stressed the importance of taking individual musical taste into account.

Theme 5. Effects of music on care home environment (number of transcription cards = 21)

Staff stated music had positive effects not only on residents, but also on visiting family members and on the unit as a whole. Many residents became restless in early evenings, but several staff members reported that playing a good CD had a major relaxing effect in the care home environment, which was also noted by visiting families.

Some staff seemed to appreciate the fact music listening was an easy-to-deliver therapeutic activity to implement while they carried on their daily tasks. Residents' families seem to value the social aspects of music activities in care homes:

Social interaction is so important...so little left for them (residents) but they still respond to music. When a young violinist came to play at Christmas party their response was amazing. Even M and R (whose emotional responses tend to be minimum) were almost tearful, E was tapping his fingers, everyone was so engaged... music is social and that's really meaningful to them. (Karen: daughter)

On the other hand, some families stated there were some challenges in meeting individual musical preferences in care home settings. The lounge area was a focal point for many residents, but each resident had their own taste in music and it was not an easy task for carers to balance between individually meaningful music and more generic well-known music. In addition, the majority of residents in the two care homes were of white British origin and spent most of their adult life in relatively well-to-do inner London areas. Many residents had regularly attended classical concerts or had professional musician friends/colleagues. Most nurses and HCAs in the two homes had Afro-Caribbean or east European background, and were not necessarily familiar with western classical music. Some families felt classical music was not the preference of staff and added it would be helpful if staff were more sensitive to individual musical preferences when they chose radio stations for residents who spent most of time in their bedrooms.

Theme 6. Evaluation and communication of music therapy clinical work (number of transcription cards = 34)

Evaluation of music therapy and use of outcome measures. Opinions on how to evaluate music therapy were divided. Some therapists were cautious of over-interpreting clients' body language or facial expression, and wondered whether it is ever possible to evaluate the instinctive feeling that the therapist made an emotionally meaningful connection with a person at late stage of dementia. Others stated they struggled to find clinically appropriate outcome measures and often devised their own questionnaires. One therapist felt implementation of standardised outcome measures was problematic because it creates standardised inputs. Staff also acknowledged the difficulty of using standardised outcome measures:

...a behavioural scale can be a good measuring tool to notice changes you might not notice otherwise... but there are little (important) things you can't put on a form...(such as) acknowledging, warmth, difference in responses in different people...you notice only if you know someone well. (Tom: staff)

Challenges and benefits of communicating music therapy process with other professionals. All participants spoke of beneficial effects of music therapy and music activities

in care homes. At the same time, music therapists and staff acknowledged implementing music therapy in care home settings was not always straightforward. Most therapists worked part-time. Finding a suitable time and space for sessions within the care home daily routine required careful planning and negotiation with care home staff. Finding a time for hand over and feedback on sessions was often challenging due to time constraints and sometimes due to perceived limited interest in therapy from front-line staff. A staff member cautioned music therapy could be perceived as a bit of mystery. For instance, some staff wondered why some clients were invited for music therapy but not others and why they could not casually observe sessions.

On the other hand, there were examples where music therapy helped to bond nursing staff and residents and promoted caregivers' communication with clients after staff participated in music therapy sessions. Therapists who worked on inpatient wards generally appeared to find communicating with ward staff a little easier. They reported many ward staff welcomed to hear how patients engaged with therapeutic activities that were not part of routine daily care.

Discussion

Of the six distinctive themes, the nature of the six themes may be broadly described as: the impact of music on the individual (Themes 1–3), the effect of the impact of music (Theme 4 and 5) and evaluating and communicating the impact of music (Theme 6). The analysis suggests that music taps into an individual's sense of self in relation to their personal preferences and life history, and it goes beyond the idea of music as a tool to fix a behavioural problem (e.g. agitation) suggesting that it is part of a wider appreciation of life. This is in line with the notion of *self-actualisation* and *self-transcendence*: the highest levels of Maslow's (1943, 1998) Hierarchy of Needs.

The majority of studies on music therapy in dementia have focused on the effect of music on behavioural and psychological symptoms (e.g. Ledger & Baker, 2007; Raglio et al., 2008) or the effect of music therapy on physiological changes such as an improvement in heart rate variability (e.g. Okada et al., 2009) and increased melatonin concentration in serum associated with a 'calmer mood' (Kumar et al., 1999). There were no high-quality longitudinal studies that investigated *how* and *why* music might have worked (McDermott et al., 2013). To investigate the impact of music on a person with dementia, the findings of this study have been explored in relation to a psychosocial fixed factor (life events) and psychosocial tractable factors (mood, mental stimulation, personal and social psychology, and environment) (Spector & Orrell, 2010). The *Psychosocial Model of Music in Dementia* emerged. (Figure 1).

Families, staff and therapists frequently highlighted the immediacy of residents' responses to musical stimuli (*Here and Now*). Families particularly seemed to welcome the visible uplifting effect of music on residents' mood, an increased alertness and interest in their surroundings,

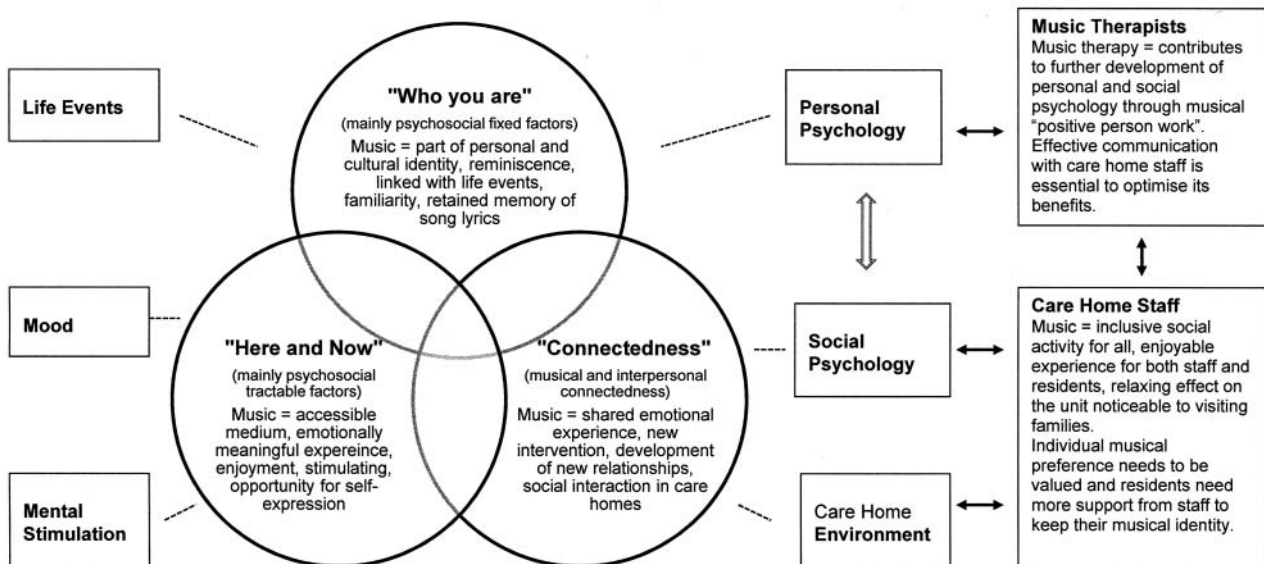


Figure 1. Psychosocial model of music in dementia.

suggesting music has a stimulating effect. Staff emphasised the relaxing effect of music on residents' mood and its consequent effect on their care home environment. Therapists highlighted the importance of musically matching whatever clients expressed here and now, including repetitive vocalisation, crying or wandering which can be perceived as challenging behaviour in other circumstances. The importance of mental stimulation for the prevention of dementia is well known, and the study outcomes of other therapies (e.g. Cognitive Stimulation Therapy) suggest that engaging in mental activities at earlier stages of dementia can improve memory, cognition, and quality of life of people with dementia. Although it will be unrealistic to expect much cognitive or memory improvements in care home residents with moderate to severe dementia, music seems accessible to people at all stages of dementia, has a stimulating effect and improves mood.

It was evident that the choice of music was highly personal. Each individual had a musical identity that was often closely linked to life events, personal and cultural identity and a particular era (e.g. post-war). Recognition of familiar music was considered emotionally meaningful particularly for people at late stages of dementia. *Who you are* as a person was predominantly influenced by psychosocial fixed factors such as previous life events and personality traits but was also influenced by personal psychology of the person and the severity of the person's dementia. For the day hospital client who acknowledged he could still remember songs from childhood even though he 'often forgets things', songs seemed to help support his personal identity. For another resident, listening to music from her cultural background reminded her of the devastating effect of dementia on herself.

Spector (2001) discussed an example of a person who 'used to be a lawyer' and highlights the challenge every person with dementia faces: '...this deconstruction, from a successful lawyer into a dependent person with a terminal illness or disease might not only be emotionally damaging for the person with dementia, but redefine the way

they see themselves and hence relate to, and are interpreted by others' (p. 44). The process of deconstruction and reconstruction of identity has a huge impact on personal psychology. Music may help protect the identity of a person or support the process of redefining identity through *positive person work* (Kitwood, 1997) but the potential emotional impact of music on each person needs to be remembered.

Meaningful musical experiences often resulted in experiences of emotional *connectedness* with other people. Music therapy seemed to encourage day hospital clients to share the challenges of living with dementia verbally and non-verbally during group music making. Residents at mid to late stages of dementia were still able to sustain and develop musical relationships with therapists even when their physical and cognitive functions became more limited. The uniqueness of the person (*Who you are*) came through musical interactions, allowing the therapist to contribute to *positive person work* through musical *Recognition, Negotiation, Collaboration* and *Facilitation* (Kitwood, 1997).

Music activities in care homes offered opportunities for social interactions between residents and staff, which made a positive impact on care home environment and social psychology. Social psychology (Kitwood, 1990, 1993a; Sabat, 1994) is strongly influenced by care home culture and staff morale. The dialectics of dementia that Kitwood (1990) debated may happen less frequently in current dementia care. On the other hand, a lack of understanding of the optimum capacities of each resident can still lead to institutionalisation and cause *excess disability* (Sabat, 1994) without the presence of *malignant social psychology* (Kitwood, 1990, 1997). Equally, a lack of sensitivity towards individual psychosocial needs can influence the personal psychology of the residents. Some families emphasised that not everyone enjoyed old time music, and requested staff to be more aware of the musical preferences of individual residents so that they can still maintain their *connectedness* with *who they are*,

particularly when other mediums become less accessible due to dementia.

The need for a stronger *connectedness* between professionals, in this case, more unified approaches and better communications between music therapists and care home staff, was also highlighted. The differences in their roles sometimes caused friction; part-time music therapists and staff working on shifts did not always have enough time or opportunities to build professional relationships. Therapists working on inpatient wards appeared to find it easier to become part of a multi-disciplinary team. This may be due to the length of time these therapists spent on the wards or their regular presence at ward rounds and meetings. Overall, there was a consensus that both music therapists and care home staff could take a more unifying approach in order to provide holistic care for their residents.

The three components: *Who you are*, *Here and Now* and *Connectedness* are closely related. Some factors may also overlap depending on individual circumstances and separating each factor may not always be helpful. Nevertheless, the model highlights the diversity of the meanings of music in the lives of people with dementia. Both the psychosocial fixed factors and tractable factors are incorporated in music-based interventions. Carefully planned music interventions will provide opportunities to support the personal psychology of the person with dementia and help sustain a good social psychology in their care settings. It may be possible to conclude that a successful *Here and Now* intervention allows each person with dementia to be *Who You Are*, which in turn leads to meaningful *Connectedness* with other people and with their environment.

The findings of this study have strong similarities to the results of two studies by Hays and Minichiello (2005a, 2005b). They conducted interviews and focus groups with older people living in Australia examining the experience, the meaning and the role of music. These studies found that music had a positive impact on a sense of self, helped to protect self-identity, lessened feelings of isolations and loneliness, helped the development of connecting with other people and provided an experience of spirituality. Although it is not explicitly stated that none of the study participants had any forms of cognitive impairment, all lived independently in the community. The fact that the findings of our study with people with dementia have strong similarities to the outcome of the studies with independent older people (Hays & Minichiello, 2005a, 2005b), highlight that the musical identity of an individual and the need for shared meaningful musical experiences is retained through the ageing process even in the context of dementia.

Limitations of the study and future recommendations

There are some limitations to this study. The focus groups and interviews were conducted and analysed with a specific aim of developing a quantitative music therapy outcome measure for people with moderate to severe dementia. Therefore, it is possible that some aspects of meaningfulness of music to the lives of people with dementia were not picked up during the data collection

and during the data analysis. Most of the residents, families and staff had known OM as a clinician and this would have affected how study participants responded during the focus groups and interviews. The initial extraction of the key comments and recurring themes was conducted by OM but not all the recordings were transcribed for analysis. This is an acknowledged limitation of this study.

Apart from the four day hospital clients, people at early to mid-stages of dementia were not included in the study due to the restrictions of the ethics approval and the time limitation of the project. Therefore, it is possible the importance of music for people with dementia with mild to moderate dementia may be under-represented. Future studies may benefit from focusing on people with moderate dementia whose language may be easier to understand and whose comments can be taken at face value without risking over-interpretation. Feinberg and Whitlatch (2001) found people with 'mild to moderate cognitive impairment' were able to provide consistent answers to questions about 'preferences, choices, and their involvement in decision about daily living' (Feinberg & Whitlatch, 2001, p. 374). Mozley et al. (1999) also found that over 77% of care home residents with an MMSE score of 10 or more were able to express their views. However, the comments from the majority of the residents with dementia in this study were not concrete enough to be used as the quotes in the article, even though they were able to indicate when they agreed with their families' comments by nodding their head or with simple phrases (e.g. 'that's right, I always liked music'). Additionally, our recent systematic review (McDermott et al., 2013) found few high-quality RCTs with people with mild or moderate dementia living in the communities have been conducted to date. Following this, it is evident that there is a need to conduct a study on the meaning and the value of music incorporating the view of people with early to moderate dementia.

Finally, the *psychosocial model of music in dementia* has not been empirically tested. The model needs to be presented to music therapists, families, and a wide range of professionals involved in dementia care to evaluate its usefulness as a theoretical model for music therapy in dementia using a consensus method.

Conclusion

The study explored the experience, the meaning and value of music for people with dementia from the perspectives of family carers, staff, music therapists and people with dementia themselves. It is the first in-depth study on the meaning and value of music for people with dementia from the perspectives of these four groups. The study findings demonstrated that the effects of music go beyond the reduction of behavioural and psychological symptoms. Not withholding the limitations, the study highlights how music is closely linked to personal identity and life history of an individual, how people at all stages of dementia can access music and how music can help improve social psychology of care home environment. Moreover, it is evident individual preference of music was preserved

throughout the process of dementia. Thus, the importance of learning each person's musical history for those involved in dementia care cannot be overestimated. Sustaining musical and interpersonal connectedness particularly when the progress of dementia becomes more prominent would help value *who the person is* and maintain the person's quality of life.

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