

“Now he sings”. The My Musical Memories Reminiscence Programme: personalised interactive reminiscence sessions for people living with dementia.

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Acknowledgements

The authors are very grateful to all of the people living with dementia and their carers who took part in the evaluation.

We would also like to thank the regional Alzheimer’s Society staff and volunteers who delivered the My Musical Memories Programme and took part in the evaluation, and the national office who commissioned our evaluation as part of an Innovation Grant.

Abstract

This paper explores the impact of the My Musical Memories Reminiscence Programme (MMMRP), an innovative intervention that adopts a music-based reminiscence approach. MMMRP builds on the format of the popular Singing for the Brain sessions with the aim of increasing opportunities for interaction and reminiscence among people living with dementia. Data were collected pre- and post-intervention and three months later using structured observation, interviews and focus groups. Results suggest that that programme had a positive impact on participants by promoting engagement, reminiscence and social interaction. For some individuals the impacts continued beyond their participation in the programme. A range of key facilitators for successful implementation of this approach were identified including the Session Leader role, the involvement of informal carers and the input of volunteers.

Keywords

Interaction; Music; Personalisation; Reminiscence;

Introduction

Growing recognition of the physical, mental and emotional pain experienced by people with dementia has precipitated increasing interest in discovering effective non-pharmaceutical palliative approaches based on acupuncture, massage and music (Witzke *et al.*, 2008; Cohen-Mansfield, 2013). This is partly due to the limited effectiveness of drug treatments in ameliorating the symptoms of dementia (Park and Specht, 2009), but also as a response to the wide range of negative side effects that are frequently experienced (Nair *et al.*, 2013). Creative arts (music, visual arts, poetry, dance, drama, etc.) are increasingly recognised for their perceived ability to foster engagement and communication for most people living with all levels and forms of dementia, thus improving their wellbeing (Fraser *et al.*, 2014; Zeilig *et al.*, 2014; Cowl and Gaugler, 2014).

Within the creative arts diaspora, music in particular is widely recognised as a powerful form of non-verbal communication because of its ability to surpass communication barriers common to dementia (Blackburn and Bradshaw, 2014; Gerdner and McBride, 2015; Vleuten *et al.*, 2012), and is considered to be *“a unique stimulus, because it can induce both physiological and psychological responses in the listener”* (Chlan and Tracy, 1999:35). Music has been shown to reduce many forms of pain (Krout, 2003), while also effectively distracting listeners from their experienced pain (Gerdner and Schoenfelder, 2010). Music interventions generally cost less than pharmacological interventions, and do not involve side-effects common to some of the latter types of interventions (Archie *et al.*, 2013).

Music can also provide points of reference for the phases and important events in one’s life, thus helping people with dementia to reconnect with past memories (Cuddy *et al.*, 2015; Dempsy *et al.*, 2012; DeNora, 2015). This is thought to be primarily due to the potential for

music to reach uninjured parts of the brain, which enables people living with dementia to improve how they interact with people within their environment, and helps alleviate the isolation often attributed to dementia (Hubbard *et al.*, 2002; Sorrell, 2008; Gerdner, 2009). A recent review of the literature concluded that music can benefit people with dementia by reducing agitation, improving cognition and enhancing social wellbeing (Elliott and Gardner, 2016). The authors also noted that most of the evidence for the impact of music on people with dementia comes from quantitative research designs, and suggested that a qualitative approach may be more appropriate.

Reminiscence and Dementia

Accessing and connecting with past memories has been found to be an effective means of engaging with people who are living with dementia (Dempsey *et al.*, 2012; Woods *et al.*, 2005). One approach to working with people living with dementia is known as 'Reminiscence Therapy (RT), which "...involves the discussion of past activities, events and experiences, with another person or group of people...often assisted by aids such as videos, pictures, archives and life story book" (Woods *et al.*, 2005:1).

Although RT has been found to have positive benefits (Gonzalez *et al.*, 2015), reminiscence need not be undertaken with regard to specific therapeutic goals. Researchers have found that simply sharing the activity of reminiscing with people living with dementia can reap numerous benefits including improving communication and social engagement, and fostering interaction (Dempsey *et al.*, 2012), as well as "...reminiscence and individuality" (Dempsey *et al.*, 2012:11).

The intervention described in this paper employed familiar personalised music as the primary vehicle towards shared reminiscence. The mid-range theory of Individualized Music Intervention for Agitation (IMIA) developed and pioneered by Gerdner (2000) remains a relevant underpinning for this approach, notwithstanding that the reduction of agitation for people living with dementia was not a specific goal in this project. The relevance of IMIA lies in the idea that because music must be personalised in order to elicit memories in the listener, considerable care should be taken to determine what specific musical preferences a prospective listener has prior to conducting an effective individualised music intervention (Gerdner, 2000).

The My Musical Memories Reminiscence Programme

This paper explores the impacts of an innovative intervention for people living with dementia based on music-based reminiscence sessions. It provides the background for the My Musical Memories Reminiscence Programme (MMMRP), describes the evaluation methods and findings, and offers recommendations for future implementation and evaluation of this type of approach.

The MMMRP was devised by the Alzheimer's Society in England with the aim of improving the wellbeing of people living with dementia and their family carers. Crucially, it adopted a personalised approach to reminiscence-based interventions. This acknowledges the limitations of previous approaches that is highlighted in the literature and the need to take into account individual preferences and life histories. The MMMRP comprised an initial 'taster' session followed by a series of six weekly one-hour sessions for four groups of up to six people living with dementia. The pilot programme ran during 2014/15 and comprised four series of six sessions each in the county of Worcestershire. Each session focused on a

different theme such as 'work', or 'weddings and courting'. A trained Session Leader from the Alzheimer's Society facilitated the sessions, encouraging interaction and engagement amongst the participants by playing music that was familiar and meaningful to them, and providing relevant visual aids such as album covers, books, magazines and photographs. These were supplemented with personal photos supplied by the participants. The MMMRP sessions required a relatively high ratio of experienced volunteers to participants. These volunteers supported the participants, actively participated in the sessions and completed observation forms that focused on participant responses to each musical track being played. During each session the participants' family carers were invited to share experiences and information with one another in an adjacent room.

At the conclusion of each series of six MMMRP sessions, personalised CDs and booklets were produced based on observations and documentation made by volunteers and the Session Leader. These were taken away by each participant and their informal carer to use however they wished.

This pilot programme differed from previous interventions in three main ways. Firstly, the membership of each cohort consisted solely of people living with dementia, who were joined by trained volunteers (with a ratio of approximately 1 volunteer to every two people living with dementia). Secondly, preparation included gathering information regarding not only the preferred musical genres and wherever possible specific favourite pieces of each group member, but also in accruing pertinent visual artefacts (photos, record covers, etc.) with the aim of enriching each group member's experience. Thirdly, a personalised CD containing each group member's favourite pieces, accompanied by a personalised booklet

including the words to these pieces and relevant anecdotes and photos, were created for use by the families within their daily lives.

Methods

The Association for Dementia Studies (ADS) at the University of Worcester was commissioned by the Alzheimer's Society to carry out an external evaluation of the pilot programme. The main aims of the evaluation were twofold: to explore the potential of the programme to improve quality of life for people living with dementia and their family carers; and to document the key elements of the programme and make recommendations for best practice.

All participants in the pilot programme were invited to take part in the evaluation: people living with dementia, family carers, volunteers and Alzheimer's Society staff. In accordance with guidance for researchers based on the Mental Capacity Act and established best practice in this field (Killick and Allan, 2001), a process approach was adopted whereby the researchers assessed capacity to consent at each point of contact. Approval for the evaluation was given by an Ethics Committee at the University of Worcester.

A mixed method, pre- and post-intervention methodology was adopted for this evaluation. Sixteen of the MMMRP sessions were attended by members of the ADS evaluation team in order to become familiar with this new intervention. In addition, the Alzheimer's Society provided a range of documentation that had been developed during their programme planning and delivery process, including musical history forms completed by participants and their carers prior to the sessions and information on the audio equipment used, group

size and the frequency and structure of sessions. With the aim of exploring the impact of the programme on participants with dementia, the 'Creative Expressive Activities observation tool (CEAA) (Gottlieb-Tanaka *et al.*, 2008) was completed by the evaluation team during the 16 observed sessions. CEAA is one of the few observational tools designed specifically for people with dementia and has been reviewed as suitable for evaluating quality of life during creative activity sessions (Algar *et al.*, 2016). The CEAA Client Observation Form consists of 27 items grouped under the headings, 'memory'; 'attention'; 'language'; 'psychosocial'; 'reasoning/problem solving'; 'emotions'; 'culture'. Several people can be observed simultaneously, using a rating scale to capture the frequency for each item (0=no observation; 1=never; 2=rarely; 3=sometimes; 4=(nearly) always) for the entire observation period – during MMMRP, each observation period was as session that lasted for approximately one-hour. The total score from each session is then entered onto a 'Client Progress Summary' sheet. Figure 1 shows these totals for each participant over the entire number of sessions observed.

In addition, the volunteers who supported the participants during the sessions provided brief written feedback at the end of each session (n = 28) regarding their observations of the participants they were supporting. These observations focused on levels and types of engagement, triggers for engagement, barriers to engaging in the sessions, and the impact of participant's engagement.

Focus groups were held with informal carers at the start (n = 17) and end (n = 18) of each series of sessions and with the volunteers at the end of each series of sessions (n = 12).

These explored expectations and experiences of the programme and its possible impacts on the participants in terms of, for example, changes in their emotional wellbeing, relationships, self-esteem and levels of agitation.

It was originally the intention of the research team to carry out short 'go along' interviews with the participants with dementia at the end of each session, in order to explore their experiences of taking part. However, it soon became evident that this was not possible for two main reasons. First, the way that the sessions were structured during the pilot meant that the family carers joined the group for the final ten minutes, making it difficult for the researchers to have any time alone with the participants with dementia. Second, the limited communication skills of the people with dementia were a barrier to conducting a meaningful conversation in what had become a very busy and noisy room. While we recognise this as a limitation of the research, it does also highlight the challenges of including the direct views of participants with advanced dementia in 'real life' intervention research settings.

Individual interviews were carried out with the Session Leader twice during the programme, exploring their views about what worked well and what could be improved. Finally, interviews were carried out with 19 dyads (participant with dementia and their carer) three months after the end of their involvement in the MMMRP programme. These interviews explored the extent to which the personalised CDs and booklets were being used, their broad impact, any barriers and facilitators to their use, and any other lasting effects that may have resulted from participating in the MMMRP. A dyadic approach was adopted to these interviews to capture the views of both the person with dementia and their carer, and to facilitate discussion between them, thus enhancing the value of the data collected.

All focus groups and interviews were audio-recorded, transcribed and thematically coded, using a specialist software package. Thematic coding is a recognised analytical method

common to ethnographic and other qualitative research. It begins with the researcher searching for and consolidating key words or strings of words into one document in order to review them for similarities and contexts (Fetterman, 1998). The scores from the observations made using the CEAA tool were entered into an Excel spreadsheet for analysis. Due to the small group sizes and obtaining one overall score per participant per session, a limited amount of statistical analysis was required. Apart from looking at the scores for each participant across sessions to identify potential trends, the analysis consisted of calculating the minimum, maximum and mean scores for each group in each session to gain an overview of the range of scores recorded.

Findings

This section presents details of the participants in the My Musical Memories Reminiscence Programme, followed by the analysis of data from the sources described above to inform a discussion of the impact of the pilot programme on participants with dementia, their family carers, the Session Leader and the volunteers.

A total of 20 people with dementia took part in the programme across four phases, as shown in Table 1 along with the number of staff and volunteers. Six were male and 14 were female, and the mean age of the participants was 79.6 years, with an age range of 64-95 years.

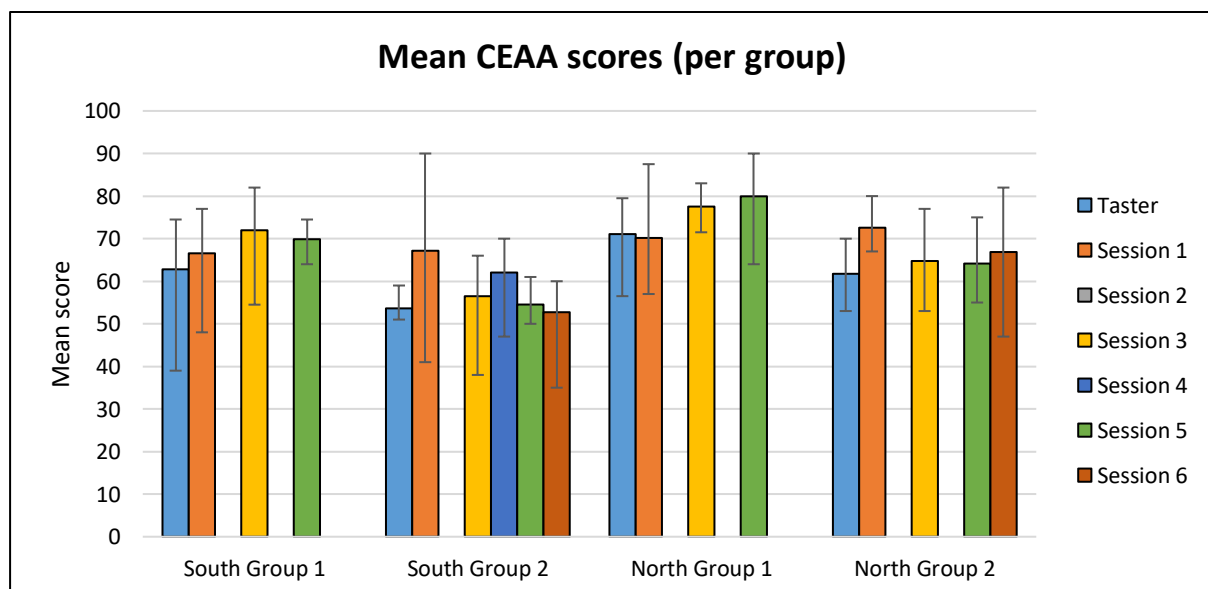
Table 1: Summary of attendance at sessions

	North Worcestershire		South Worcestershire	
	Phase 1	Phase 2	Phase 3	Phase 4
Total number of sessions	7	7	7	7
Number of participants	5 (3 male 2 female)	5 (2 male 3 female)	5 (5 male)	5 (4 male, 1 female)
Number of volunteers	3	3	4	4
Number of Alzheimer's Society staff (excluding Session Leader)	2	1	2	1

Impacts on participants with dementia

Error! Reference source not found. Figure 1 below shows the mean total score obtained by all participants within each group from the CEEA observations. These scores indicate the overall level of engagement for each group during an MMMRP session. Missing columns occur when observations were not carried out in a session.

Figure 1: Mean observation scores by group.



This suggests that for most of the groups the CEEA scores tended to increase over the course of the sessions, or at least were maintained. There was some variability between the

minimum and maximum scores within each group as shown by the bars in Figure 1, but overall the level of engagement was quite high throughout. Although the South Group 2 scores were lower than the other groups, they still showed good results. Due to the different composition of the groups, caution is required when trying to compare scores between groups. Additionally, it is important to recognise that there are several potential confounding factors which can make comparing participant scores across MMMRP sessions less reliable. These include an individual's current overall mood, the specific theme of each session, the affinity that each participant had to the specific music played on any given day, the number of volunteers in attendance and the level of interaction between a volunteer and each participant.

Analysis of data from the focus groups with carers and volunteers identified a range of themes. Carers suggested that despite their initial doubts about the value of the programme, they had noticed positive impacts on the mood and levels of engagement of the person with dementia. Some felt that this was limited to the sessions themselves, while for others the impacts continued for some time afterwards. They also mentioned the positive impact of the CD after the programme had ended. The volunteers highlighted their enjoyment of the sessions and the development of relationships with participants. They also recognised the challenges of catering for diverse musical experiences and preferences, particularly in relation to the younger participants. This paper now explores these themes in detail.

For the carers, an important indicator that the person with dementia was enjoying the MMMRP sessions was their attitude towards attending:

“...mum suffers with pain in her leg... but I said to her last time, ‘do you really want to go?’ ‘Cause she was, we’d got out the door and she was in pain and she says, ‘no, I want to go!’” (Carer)

“...every time he didn’t want to miss a session at all. No, he’d say; ‘I can’t miss it’. So it went very well...” (Carer)

Another frequently noted indicator of the positive impact that the MMRP sessions were having on participants was visible changes in their mood. Firstly, the following comments suggest the improved mood of participants during a single session:

“Today [participant] said to me ‘this is really nice, I’m enjoying this’. I mean it didn’t come out quite like that, but you know I got the idea, and he said ‘this is really nice’ he said, ‘it’s good, it’s good’ he said, ‘laughing and talking’.” (Volunteer)

“Oh yes, oh yes, we all noticed it. He was on top of the world, and you could see he got the interest back, he didn’t just sit down and look into space...” (Carer)

In addition, the volunteers observed changes in the participants over the span of their series of MMRP sessions:

“...when he [participant] first started off he didn’t open his mouth, now he sings...” (Volunteer)

“He [participant] was quite reluctant to talk before, but now, he’s quite funny as well...” (Volunteer)

Increased engagement with the music played and the various visual aids supplied were additional signs that the MMRP sessions were having a positive impact on participants:

“They’re clapping, on their feet...talking...singing...foot tapping...facial expressions...smiling...laughing...” (Volunteer)

Some family carers also noticed a range of longer term impacts of the MMRP for the person with dementia that was evident outside of the sessions themselves, including increased levels of engagement with music since participating in the programme:

“[Mum’s] come out with songs from the past. She comes out with more songs a bit more than before...It’s jogged her memory for songs even my dad hasn’t heard before – from early childhood and teenage years.” (Carer)

“Mum would normally fall asleep, she sleeps a lot in the day, but when we’ve been to a session, she doesn’t sleep at all, she’s quite...alert the rest of the afternoon. And she’s following what’s going on, you know, it sort of wakes her up.” (Carer)

Another carer spoke about the ongoing impact of the programme on his wife in terms of promoting reminiscence:

“Because it’s stimulated [wife] into other things...like [participants] talk about things from the past, like, the one week we had the cinemas in Birmingham which they’d been talking about so she continued to reel that off when she thought about it which was surprising, the rest of the afternoon and when I got, we got in the car she continued it...” (Carer)

This had led to increased interaction at home and within the wider family:

“I think it does trigger memories in mum that she does talk about at lunch time after, when we get back on the day. And that involves dad as well, and all of a sudden they’re interacting, mum and dad, which they don’t do very often, which is good.

She talked about the whist drive and the dances that they went to when they were teenagers, and dad said 'Oh, I've got a ticket, an old ticket from that'. (Carer)

"Well it's done, well brought things about work and all kinds of stuff really, and it actually 'do you remember this, do you remember that?' Whereas it's sometimes difficult to think of things that might spark a memory. But this has given me ideas."
(Carer)

However, other carers reported that the impact of the programme was limited to within the actual sessions:

"He's [husband] probably saying more in there [during MMMRP session] now and doing more, 'cause he seems to go into himself when we go home." (Carer)

"While they were there they enjoyed it... but as soon as you take them away, it's gone...we can't generate it back – it needs to be back in the group." (Carer)

As would be expected within any group, participants expressed varying degrees of engagement while listening to diverse genres of music being played:

"...some of the music didn't have any effect at all on some of them because they weren't interested in that sort of music..." (Volunteer)

"...a lot of the music is very familiar to most people, but then there are specific types of music that appeal to some, maybe not to others." (Volunteer)

Some volunteers noted the challenge of catering for potentially diverse musical experiences and preferences:

"...it's so difficult isn't it, cause some people have quite an eclectic mixture of musical, you know you could play hymns which would mean nothing to somebody,

but for a lot of people hymns would be good, even if they're not churchgoers."

(Volunteer)

This was felt to be a particular problem for the small number of participants who were considerably younger than the rest of their group:

"I've felt occasionally that [participant]'s missed out because they're playing music that went really, that was before his time and he couldn't, there's no recognition for him at all. And he does sort of go, I thought he's shutting himself off a little because he just, it doesn't mean anything to him this music that's being played." (Volunteer)

One unanticipated impact of the programme arose as a result of the inclusive approach that was adopted, whereby participants were at different stages of their dementia trajectory.

This inclusivity can potentially cause some distress for those participants at the beginning of their dementia journey:

"...once in a while when we get home, [wife]'s really depressed, because we've been with somebody who is in quite a bad way and an advanced condition and it kind of reminds her, you know, she takes it as a prognosis." (Carer)

The impact on informal carers

The programme was positively received by all of the carers involved, as the following quotes demonstrate:

"I think it's been brilliant, as far as I'm concerned, can't fault it." (Carer)

"We were really, really sad when it stopped..." (Carer)

An element of their satisfaction was derived from the fact that their family member enjoyed taking part:

“I think we all feel that if the husband’s happy, we feel really satisfied it’s been a good day. It makes our life easier.” (Carer)

This was despite the fact that some carers initially expressed low expectations regarding how the person with dementia would respond:

“I think...that [husband] won’t be able to participate in and, and they [organisers] are aware of that because he can’t... really relate to...songs from the shows and that sort of thing, he hasn’t got a clue about that and he never did have, so they’re sort of talking about things that he never related to anyway, because he...really he had no happy musical experience that I know of.” (Carer)

Impacts and experiences for staff and volunteers

All of the volunteers were enthusiastic in their praise for the programme and many described their enjoyment at taking part, as the following quote demonstrates:

“Best day of the week for me. So for the last seven weeks I’ve looked forward to it so much. All my other work, I just go ‘oh, if I get through this I’ll get to Thursday’.”

(Volunteer)

Volunteers also valued the personal relationships they made with the participants over the course of the seven sessions of each phase of MMRP:

“That’s what’s been so revelatory, because [participant] seems so quiet and wasn’t going to share...and you’re finding out more and more about her.”

(Volunteer)

“I say you become quite attached to them and you get to know what they like and what they don’t like, and they will open up to you, don’t they?” (Volunteer)

Some volunteers were uncertain about how much to engage with the participants during the sessions:

“I get a lot from [MMMRP], but sometimes it’s difficult to know boundaries, that’s what I find, how far do you prompt? Do you sit back and let them not get it? You know it’s difficult, that’s what I find quite difficult, I, I don’t like to see somebody wracking their brains for something, but do you give them a clue? I don’t know...”

(Volunteer)

Several suggestions for addressing this were made, including having the opportunity to meet the participants and their carers prior to their first session and speaking with the carers at the end of each series of sessions:

“I think [a fellow volunteer] and I’ve said that...it would’ve been nice to know a little bit of the background of the people we’re sitting with, because some of them, well you know you’re just grasping a word here and there and then trying to make some sense of it.” (Volunteer)

When asked how they felt the first phase of the sessions had gone, the Session Leader was very positive:

“On the whole, brilliant. How I feel myself before during and after the sessions, but also spontaneous feedback from the people, the folks attending and the families...”

(Session Leader)

She also described how she felt about the responses to MMRP that she overheard or directly received:

“...hearing the people just spontaneously ‘oh that was good’ without being asked ‘did you enjoy that?’ then you’re teasing it out and your expectation is they’re going to say, ‘yes!’ But if we have quite a few just spontaneously say, ‘that was really good’, ‘oh is this the last one?’ - speaks for itself really.” (Session Leader)

The impacts of the personalised CD

As described above, a key element of the programme was a personalised CD and booklet based on the observed reactions of each individual participant during their MMRP sessions. When interviewed three months after the end of each series of sessions, most participants and carers reported that they continued to use the CD:

“[Husband] absolutely loves it [personalised CD] and we do talk about it...We play it at least once a week...I’m usually round about during the CD and [he] is singing loudly to it.” (Carer)

“...as soon as...I put the CD on and [husband] hears ‘Desert Island Discs’, he’s there. Now, as soon as I put George Hornby and Spike Milligan on, which he never took interest in, he’s joining in.” (Carer)

Overall, playing the personalised CD seemed to promote the continuation of those positive effects that were experienced during the actual MMRP sessions. For example, some carers reported that listening to the personalised CD triggered memories for both their family member with dementia and themselves:

“[The personalised CD] in the player and if it’s on she’ll say, something – makes her smile...reminds her of stories...two songs on disc always remind them of two very good friends – ignited long story from them...” (Carer)

“It was good that there is a variety of songs on the CD that were not necessarily [his] favourites because it triggers memories because we both knew these songs too.”
(Carer)

It also seemed that listening to the personalised CD improved the mood of their family member living with dementia, as the following comments suggest:

“I enjoy [the personalised CD], and when I put it on it calms [wife] down and she listens to it; she doesn't talk...we listen to it together...” (Carer)

“When [husband] gets agitated we put on the music and it relaxes him.” (Carer)

Carers also reported that they often listened to the personalised CD together, which seemed to increase opportunities for interaction between them:

“...some of [wife's] favourite songs are on there, which I wouldn’t know. So I’m able to sing with her when it’s on.” (Carer)

“Sometimes [we listen to the CD together], because it is quite fun, and it is nice to hear [husband] chuckling you know?” (Carer)

One carer mentioned how this also extended to other family members:

“...we’ve listened to [the personalised CD] together, and whenever anybody comes, like the son lives in Turkey...and...the daughter, now she sat down and listened to it with him and listened to it. But when [son] came over in March, he was listening, he shared it with him and sharing it all with him...” (Carer)

The booklet that accompanied the CD was used less frequently, but was also beneficial in various ways for the participants and more widely. For example, looking at the personalised booklet helped to trigger memories associated with the songs:

“Yes, yes! I’ve got it right here!...it gives you wider thoughts...this is something that sort of jogs your memory, and once it gets you going...” (Participant)

“[Husband's] looked at the booklet yes...I’ve just listening, or I’ve just sat here and gone through the booklet...and like when we went to see Bill Haley, and that was in there – that was just before he went to the National Service, so it’s all memories...” (Carer)

In addition, looking at the personalised booklet sometimes fostered greater interaction the person with dementia and others:

“Yes [husband] does [look at the personalised booklet] and whenever anybody comes over he shows it to them...” (Carer)

Several carers also spoke of the value of the personalised booklet in providing paid carers with information about the person with dementia:

“I’ve looked at [the personalised booklet] but no I don’t look at it with [husband]...it’s helpful for carers because they don’t know him. But I have found that

there's some useful information in it about the performers...I've gone onto YouTube on the iPad to see what other tunes some performers have done..." (Carer)

Key features and challenges of the My Musical Memories Reminiscence Programme

Several features of the programme were highlighted by carers and volunteers as particularly important contributors to the positive effects that were observed for the people with dementia who took part.

Separate sessions

There is no clear evidence regarding whether including a person closely connected with a person with dementia in creative arts interventions enhances or detracts from the impact. These MMRP sessions were conducted solely for people living with dementia, whilst the carers were invited to convene in an adjacent room for informal conversation. Although some participants initially demonstrated some anxiety about this arrangement, this quickly changed:

"The first week [husband] asked where I was all the time, but he doesn't now. He did, he came out to see where I was when I was talking to [volunteer], but he went back in. And he went by himself, I didn't take him back, so that by itself shows that he's enjoying it..." (Carer)

Many volunteers and carers felt that this approach worked particularly well. For example, one volunteer noted the benefit of carers not being in the room:

“I think that it allows them the opportunity to actually express themselves, which I think often they don’t necessarily have because a lot of people, often their partners will speak for them in social situations...” (Volunteer)

Several carers also appreciated the value of separating them from the person they cared for in this situation, as the following quote demonstrates:

“It’s got to be a separate thing, because it’s so easy for them just to sit back and not say anything and us to do the talking... ‘Cause you do tend to speak for them, don’t you...” (Carer)

However, others voiced frustration at not being able to directly observe how their family member was getting on:

“I know it is difficult to have the carer there, but I didn’t actually know...I didn’t know myself what sparked his memory...Because we didn’t see, I didn’t know what sparked [husband]...” (Carer)

To help remedy this, some volunteers and carers made suggestions including video-recording the sessions – with prior consent – for those who wished to view at a later time, or inviting carers to observe the end of the final MMRP session of each series:

“I’m just wondering whether there might be a possibility of, of having it very slightly shorter and inviting carers to come in.” (Volunteer)

Carer sessions

Rather than joining the MMRP sessions, carers were invited to meet together in an adjacent room over refreshments, or were free to leave and use the time as they wished.

Most carers chose to stay at the venue and spoke of this time as a positive experience:

“The thing is we pass each other like ships in the night we carers, so to have that opportunity to sit-down with a cup of coffee with normal people...” (Carer)

“...what it did with us all sitting together, which we don’t get to do at [other activities], was give us a chance to actually sit together and talk about what we think about the person who’s got dementia and what they do, so that we related to each other and it was interesting to see how one got on with her husband and what he did, and...’ah that’s funny because mum does that occasionally’...” (Carer)

Support

A notable feature of the programme was the high level of attention and support that each participant received from experienced and skilled staff. This included the role of the volunteers, who were able to pick up detailed information about the responses of participants to each piece of music, as noted by the Session Leader:

“The volunteers are absolutely vital...the little asides where someone could just make that quiet comment that the facilitator can’t hear or the Session Leader can’t hear, is just vital. Good team work. It is team work...’that was well planned and’ and all the rest of it; yeah well, I just can’t say how vital and integral it is to have those volunteers dotted about within that little circle.” (Session Leader)

Similarly, the volunteers and carers spoke highly of the contribution of the Session Leader and the importance of her input to the positive experiences of the participants:

“...she initiates the different, yes, a song coming on or a memory or a date, and that’ll trigger, and she’s very good at singling the different ones out isn’t she. She’s

obviously done a lot of homework! She's very good, and she will get them talking..."

(Volunteer)

"...I know that [Session Leader], as things come up in a session she will respond to that. If it goes off on a completely different tangent from what she had planned, she just goes with it..." (Carer)

Session design

Certain elements of the MMMRP format were felt to have especially contributed to the participants' positive responses. These included the relatively small size of the groups and the use of themes for each session:

"I liked the way they got, they had different things each week, like the cinema, talking about the dance venues, whereas [name] didn't really go to the pictures that much, but she was always at a dance venue, 'cause she'd dance and sing. So she knew the cinemas..." (Carer)

Perhaps not surprisingly, the music that the Session Leader chose to play in each session was crucial to the success of the programme. This was carefully planned, based initially on the information provided in advance and subsequently on the responses of every individual as observed during each session. Sharing the activity of listening to music was the 'glue' which held these MMMRP sessions together, as well as being the prime driver for engagement and interaction:

"...it two or three sessions back...[participant] got on to...he even became quite lucid, I mean stringing sentences together that made sense where because he was so

caught up in telling us all about some piece of music that [the Session Leader] had played, yes it does need the music.” (Volunteer)

“Because [participant’s] got a background of playing with brass bands and jazz, well last week he really became quite animated when we...had ‘16 Tons’ and then we had some jazz things, he just was in there, he really loved it. It was, he’d been quietly listening and saying some words before, but he suddenly got much more involved in it. I think it must stir memories.” (Volunteer)

It was also suggested that having a Session Leader and volunteers who were familiar with the local area enhanced the participants’ experience of the MMMRP sessions:

“She knew lots of areas in Birmingham that I knew, and her brother worked in a coal mine near where we used to live, so it’s all these little things, and I think that’s, being a local, well Birmingham born and bred almost, I think that was really great for me and the participant.” (Carer)

“Even for the Kidderminster, you see [leader] knows Kidderminster, so when they talked about the dance halls in Kidderminster they were able to recall that as well. So its little things like that, it just sparks so much interaction.” (Volunteer)

However, this also meant that any participants who didn’t have that level of local knowledge, perhaps because they hadn’t lived in the area for so long, might feel disconnected with the conversation taking place during the sessions, as one volunteer noted:

“...because you know [participants] were talking a lot about [the local town] and I think she just kind of switched off a little bit because she didn’t relate to it.”

(Volunteer)

Prior information capture

Another important feature of the programme was the advance collection of information about the musical preferences of those people with dementia who were going to take part. This was crucial for the Session Leader in planning the first session in particular, and was achieved through the completion of a questionnaire by the person with dementia with the help of their carer. However, some carers spoke of finding it quite difficult to answer the initial musical preference questionnaire on their own, with a number of carers receiving assistance from the coordinator with this task:

“ ...and the questions I could ask [husband], well you know I just felt awkward doing that...The problem was...I actually had [coordinator] do it with me over the phone because I actually don’t know what songs would have sparked memories from his childhood or... there were some things I couldn’t really, and I’ve not got a good memory myself... I’m not a musical person...” (Carer)

The Session Leader suggested that the questionnaire might benefit from the addition of more contextual information, including personal anecdotes from different eras of each participant's life, such as school, sports, jobs, performers, concerts, and courting.

Discussion

The findings of this study confirm the potential of non-pharmaceutical interventions to counter some of the symptoms of dementia, as suggested by previous research (Witzke *et al.*, 2008; Cohen-Mansfield, 2013). We have identified a range of positive impacts of the programme, which support the potential for approaches based on the creative arts to promote engagement and social interaction for people with dementia, thus increasing levels of wellbeing (Elliott and Gardner, 2016). This was augmented by evidence from unpaid carers and volunteers of participants' enjoyment of the intervention, including a strong desire not to miss any sessions as demonstrated by the following quote: "Mum suffers with pain in her leg, but I said to her last time, 'do you really want to go?' 'Cause she was, we'd got out the door and she was in pain and she says, 'no, I want to go!'" (Carer)

Our findings also suggest the ability of this music based reminiscence intervention to encourage non-verbal communication, which has been shown as importance for people with advanced dementia (Blackburn and Bradshaw, 2014; Gerdner and McBride, 2015), and to support reconnection with past memories (Cuddy *et al.*, 2015; Dempsey *et al.*, 2012; DeNora, 2015). Similarly, this study supports previous evidence that sharing the activity of reminiscing with people living with dementia can improve communication and social engagement, and foster interaction (Dempsey *et al.*, 2012). The following quote provides a good example of this effect: "I think it does trigger memories in mum that she does talk about at lunch time after, when we get back on the day. And that involves dad as well, and all of a sudden they're interacting, mum and dad, which they don't do very often, which is good."

Our study offers new evidence regarding the longer-term impacts of a music based reminiscence programme. This was demonstrated at three levels:

- after individual sessions - “Mum would normally fall asleep, she sleeps a lot in the day, but when we’ve been to a session, she doesn’t sleep at all, she’s quite...alert the rest of the afternoon.” (Carer);
- across each series of sessions - “When he [participant] first started off he didn’t open his mouth, now he sings” (Volunteer);
- and three months later, after the continued use of a personalised CD - “[The personalised CD] in the player and if it’s on she’ll say, something – makes her smile...reminds her of stories...two songs on disc always remind them of two very good friends” (Carer).

Our findings also suggest benefits for unpaid carers, partly because of the pleasure of seeing the person they care for enjoying the sessions, but also because of the respite that the programme offered and the opportunity to talk to other carers while the sessions were taking place. This is an area where more research is required.

Identified key elements – venue, planning, local knowledge, high levels of support - and areas for improvement – how to cater for diverse musical interests and experiences

Overall, this study lends support for the theory of Individualized Music Intervention for Agitation, which highlights the need for effective music interventions to take an individualised approach (Gerdner, 2000).

This study has highlighted the value of using qualitative approaches to explore the social and contextual factors of music based interventions for people with dementia, such as

engagement and wellbeing (Elliot and Gardner, 2016). However, we also found support for the findings of a review of observational measures for assessing the quality of life and wellbeing of people with dementia, which highlighted the challenges of choosing the correct tool for specific psychosocial interventions (Algar *et al.*, 2016). Our use of the CEAA tool did not allow us to identify the subtle details of the experiences and reactions of participants. This is in part due to its requirement that only one measurement be taken for each participant across an entire, in this instance hour-long, intervention.

Conclusion

The evaluation found that there had been a positive impact for all of those involved in the MMMRP, participants with dementia, unpaid carers and Alzheimer's Society staff and volunteers. For the participants with dementia this was not just during the sessions, but in many cases during the hours and days that followed. The longer term impact was enhanced by the provision of the personalised CD and booklet, although it was recognised that the CD was broadly the more important of these two elements.

The impact of the MMMRP sessions differed for each individual and tended to depend on many factors including the mood of the participants, the session theme, the participants' affinity for the musical choices, and their interaction with volunteers.

Although personalising the choice of music made the sessions more meaningful to participants and triggered more targeted reminiscence, the approach for obtaining information from carers prior to sessions needs greater consideration, as some carers struggled with this aspect. The workload for the Session Leader should also not be

underestimated. Planning the MMMRP sessions required additional preparation time and a not inconsiderable amount of effort, especially when visual artefacts and related materials were required. From a wider planning perspective, the group composition can affect levels of engagement and group dynamics, with group size, ages of participants and stages of dementia being the main factors to bear in mind.

Working with people with dementia separately from their carers appeared to be a key element in the success of the programme, partly because it gave the participants the opportunity to actively engage as individuals. To ensure that the carers appreciate the full impact of the sessions, consideration should be given to devising a means of enabling carers to see what takes place during a session. This could help them to understand how the person with dementia is engaging and what they are capable of doing in a specific environment. However, procedures would be needed to ensure that this does not have an adverse impact for the participants.

This study has also highlighted some of the challenges of evaluating arts-based interventions, which have been well-documented (see for example Vink *et al.*, 2004; McDermott *et al.*, 2014). This study adds evidence of these challenges and supports calls for further research into the most appropriate methodological approaches. It also raises questions about how to fully involve participants with dementia in the evaluation of complex interventions.

Declaration of Conflicting Interests

The Authors declares that there is no conflict of interest.

References

Archie, P., Bruera, E. and Cohen, L. (2013). Music-based interventions in palliative cancer care: a review of quantitative studies and neurobiological literature. *Supportive Care in Cancer*, 21(9), 2609-2624.

Algar, K., Woods, R.T. and Windle, G. (2016). Measuring the quality of life and well-being of people with dementia: A review of observational measures. *Dementia*, 15(4), 832-857.

Blackburn, R. and Bradshaw, T. (2014). Music therapy for service users with dementia: a critical review of the literature. *Journal of psychiatric and mental health nursing*, 21(10), 879-888.

Chlan, L. and Tracy, M.F. (1999). Music Therapy in Critical Care: indications and guidelines for intervention. *Critical Care Nurse*, 19(3), 35-41.

Cohen-Mansfield, J. (2013). Nonpharmacologic treatment of behavioral disorders in dementia. *Current treatment options in neurology*, 15(6), 765-785.

Cowl, A.L. and Gaugler, J.E. (2014). Efficacy of creative arts therapy in treatment of Alzheimer's Disease and dementia: a systematic literature review. *Activities, Adaptation & Aging*, 38(4), 281-330.

Cuddy, L.L., Sikka, R. and Vanstone, A. (2015). Preservation of musical memory and engagement in healthy aging and Alzheimer's disease. *Annals of the New York Academy of Sciences*, 1337(1), 223-231.

Dempsey, L., Murphy, K., Cooney, A., Casey, D., O'Shea, E., Devane, D., Jordan, F. and Hunter, A. (2012). Reminiscence in dementia: A concept analysis. *Dementia*, 13(2), 176-192.

DeNora, T. (2015). *Music Asylums: Wellbeing through music in everyday life*. Ashgate Publishing, Ltd.

Elliott, M. and Gardner, P. (2016). The role of music in the lives of older adults with dementia ageing in place: A scoping review. *Dementia*, online first 1471301216639424.

Fetterman, David M. Ethnography, in Bickman, Leonard (Ed); Rog, Debra J. (Ed). (1998). *Handbook of applied social research methods*, (pp. 473-504). Thousand Oaks, CA, US: Sage Publications

Fraser, A., Bungay, H. and Munn-Giddings, C. (2014). The value of the use of participatory arts activities in residential care settings to enhance the well-being and quality of life of older people: A rapid review of the literature. *Arts & Health*, 6(3), 266-278.

Gerdner, L.A. (2000). Effects of individualized versus classical “relaxation” music on the frequency of agitation in elderly persons with Alzheimer's disease and related disorders. *International Psychogeriatrics*, 12(1), 49-65.

Gerdner, L.A. (2009). Top cited papers in international psychogeriatrics: 4. Effects of individualized vs. Classical “relaxation” music on the frequency of agitation in elderly persons with Alzheimer’s disease and related disorders. *International Psychogeriatrics*, 21(4), 667-671.

Gerdner, L.A. and McBride, M.R. (2015). Individualized Music Intervention for Agitation in Dementia Care and Disaster Preparedness. *Journal of Gerontology and Geriatric Medicine*, 1(5).

Gerdner, L.A. and Schoenfelder, D.P. (2010). Evidence-based guideline, Individualized music for elders with dementia. *Journal of gerontological nursing*, 36(6), 7-15.

Gonzalez, J., Mayordomo, T., Torres, M., Sales, A. and Meléndez, J.C. (2015). Reminiscence and dementia: a therapeutic intervention. *International psychogeriatrics/IPA*, 27(10), 1731-1737.

Gottlieb-Tanaka, D., Lee, H., and Graf, P. (2008). Creative-Expressive Abilities Assessment (CEAA). Vancouver, British Columbia: ArtScience Press.

Hubbard, G., Cook, A., Tester, S. and Downs, M. (2002). Beyond words: Older people with dementia using and interpreting nonverbal behaviour. *Journal of Aging Studies*, 16(2), 155-167.

Killick, J. and Allan, K. (2001). Communication and the Care of People with Dementia, Open University Press: London

Krout, R.E. (2003). Music Therapy with imminently dying hospice patients and their families: Facilitating release near the time of death. *American Journal of Hospice and Palliative Care*, 20(2), 129-134.

McDermott, O., Orrell, M. and Ridder, H.M. (2014). The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists. *Aging & Mental Health*, 18(6), 706-716.

Nair, B., Browne, W., Marley, J., and Heim, C. (2013). Music and dementia. *Degenerative Neurological and Neuromuscular Disease*, 3, 47-51. <http://doi.org/10.2147/DNND.S35762>.

Park, H. and Specht, J.K.P. (2009). Effect of individualized music on agitation in individuals with dementia who live at home. *Journal of Gerontological Nursing*, 35(8), 47-55.

Sorrell, J. (2008). Aging Matters. *Journal of Psychosocial Nursing*, 46(3), 22-24.

van der Vleuten, M., Visser, A. and Meeuwesen, L. (2012). The contribution of intimate live music performances to the quality of life for persons with dementia. *Patient education and counseling*, 89(3), 484-488.

Vink, A.C., Bruinsma, M.S. and Scholten, R.J.P.M. (2003). Music therapy for people with dementia. *The Cochrane Library*.

Witzke, J., Rhone, R.A., Backhaus, D. and Shaver, N.A. (2008). How sweet the sound: Research evidence for the use of music in Alzheimer's dementia. *Journal of Gerontological Nursing*, 34(10), 45-52.

Woods, B., Spector, A., Jones, C., Orrell, M. and Davies, S. (2005). Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews*, 2.

Zeilig, H., Killick, J. and Fox, C. (2014). The participative arts for people living with a dementia: a critical review. *International Journal of Ageing and Later Life*, 9(1), 7-34.