

'Singing for the Brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers

Dementia

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dem.sagepub.com**Sara Eldirdiry Osman**

The Institute of Mental Health, University of Nottingham, Nottingham, UK

Victoria Tischler

University of the Arts, London College of Fashion, London UK

Justine Schneider

The Institute of Mental Health, University of Nottingham, Nottingham, UK

Abstract

Dementia has detrimental effects on cognitive, psychological and behavioural functioning, as well as significant impact on those who provide care. There is a need to find suitable psychosocial interventions to help manage the condition, enhance well-being, and to provide support for caregivers. This study explored the impact of Singing for the Brain™, an intervention based on group singing activities developed by The Alzheimer's Society for people with dementia and their carers. This qualitative study used semi-structured interviews with people with dementia and their carers. Ten interviews involving 20 participants were analysed thematically. Social inclusiveness and improvements in relationships, memory and mood were found to be especially important to participants. As well as enjoying the sessions, participants found that attending Singing for the Brain™ helped in accepting and coping with dementia.

Keywords

dementia, music therapy, Singing for the Brain, psychosocial care

Corresponding author:

Victoria Tischler, London College of Fashion University of the Arts London 20 John Prince's St, W1G 0BJ London, UK.
Email: v.tischler@arts.ac.uk

Introduction

Dementia is an illness that presents significant challenges to our society in the 21st century: it can reduce an independent, healthy individual to one who struggles in most aspects of life and who must rely heavily on the care provided by others. Understanding the experience of dementia from the perspectives of those diagnosed with the condition and measuring the needs of their carers is of increasing concern to healthcare providers and policy makers (Wimo & Prince, 2010).

Alongside deterioration in cognitive functioning, many difficult behavioural and psychological changes may occur, including aggression, anxiety, hallucinations and culturally inappropriate behaviours. Taken together, the physiological changes and the social correlates threaten quality of life for the patient and relatives (Hurt, 2008; Jones & Meisen, 1992; Kuhlman, Wilson, Hutchinson, & Wallhagen, 1991; Ryu et al., 2011; Woods, 1995; Zarit, Reever, & Bach-Peterson, 1980). Carers, even when highly motivated, can find it hard to establish their role and fulfil their capability as a carer without training and support. Family carer stress is directly correlated with behavioural and psychological symptoms of dementia (Bradshaw, Goldberg, Schneider, & Harwood, 2013; Finkel, Costa e Silva, Cohen, Miller, & Sartorius, 1996; Woods, 2001).

The limited benefit of pharmacological interventions for behavioural symptoms in dementia (O'Neil, Freeman, & Portland, 2011) presents a potential role for non-pharmacological interventions which have been advocated and developed for people with dementia (Gitlin, Kales, & Lyketsos, 2012). Such therapies include reality orientation, validation, reminiscence, art, occupational therapy, complementary and multi-sensory approaches as well as interventions that utilise expressive and receptive music as therapy (Douglas, James, & Ballard, 2004). O'Neil et al. (2011) state that although the body of evidence to support these non-pharmacological interventions is somewhat limited, some beneficial effects have been seen warranting further research into these methods for the management of dementia.

Music and dementia

Music as therapy refers to the impact of music upon the psychological aspect of an individual; it can be used to improve mood, regulate emotion and relieve stress (Clair & Memmott, 2008). Sacks (2008) states that the aims of music therapy are 'to address the emotions, cognitive powers, thoughts and memories, the surviving "self" of the patient, to stimulate these and bring them to the fore. It aims to enrich existence, to give freedom, stability, organisation, and focus' (p. 336). Music can arouse and provide pleasure (Matarasso, 2014). Emerging before evidence supports the benefits of music for people with dementia (Aldridge, 2000). Indeed, music therapy is now a valid treatment option (Han et al., 2010; Raglio et al., 2010; Sung, Chang, & Lee, 2010; Sung, Lee, Li, & Watson, 2012). Music activities also appear to have promising beneficial effects for carers. Gotell, Brown, and Ekman (2000) concluded that music events for people with dementia in which the carers provided assistance are a way to improve the relationship between the person with dementia and carer, and hence ease carer burden.

While formal music therapy is applied by professionals with the appropriate qualifications who work within a largely medical paradigm, alternative approaches to music in dementia care are also of increasing interest, for example the film 'Alive Inside' about the use of music

delivered by iPods in nursing homes was premiered at the 2014 Sundance film festival (Murray, 2014). Such approaches emphasise the intrinsic value of music and its 'in the moment' benefits and may have wide applicability although there is a limited body of research to support them.

A review by Hulme, Wright, Crocker, Oluboyede, and House (2010) concluded that although many studies had weak designs or small sample sizes, the therapeutic application of music does seem to be effective in reducing the behavioural and psychological symptoms associated with dementia. A Cochrane review of this type of intervention suggested inconclusively that 'there is no substantial evidence to support, nor discourage the use of music therapy in the care of older people with dementia' (Vink, Bruinsma, & Scholten, 2003, p. 2). This was based largely upon poor study designs which made it difficult to obtain useful evidence. Since then, new studies have been carried out that add to the evolving evidence base (Chou & Lin, 2012; Raglio et al., 2008, 2010; Vink et al., 2013, 2014).

A recent report by Cameron and Sosinowicz (2014) suggests that music has multiple benefits; for people with dementia, their carers, staff working with them and for the musicians involved.

Music appears to benefit individuals through the nuanced, yet significant connection between brain, ear and instrument. These links produce a positive effect on all of those involved in the care, management or experience of dementia (Wall & Duffy, 2010). Singing, as one aspect of music, combines language, music and instinctive human behaviour to enhance neurological stimulation (Jeffries, Fritz, & Braun, 2003). Group music interventions may help to improve social interaction between people with dementia, promoting relaxation and reducing levels of agitation (Lin et al., 2011).

The current study aims to explore the experiences of people with dementia and their carers attending a group singing activity.

Method

Design

A qualitative study with semi-structured interviews was used to gather in-depth information about the experiences of people with dementia and their carers.

Singing for the BrainTM

Singing for the Brain (SftB) was established by The Alzheimer's Society in 2003. Its characteristics were described by Montgomery-Smith (2006), and Bannan and Montgomery-Smith (2008) undertook a pilot study which suggested that the activity encouraged participation and facilitated the learning of new songs. It combines aspects of reminiscence therapy and music. SftB is a standardised service that follows a specific model that is adhered to across the UK. It aims to incorporate social interaction, peer support, engagement and active participation to improve quality of life, communication and social engagement and to enhance the relationship between the person with dementia and the caregiver. The group activity involves a musician, people with dementia and their caregivers. During a session, carer-patient pairs gather in a large circle and follow instruction from the musician. The session starts with warm-up exercises for voice and body before moving on to singing familiar songs that follow a different theme each week for example 'the weather' or 'places'. Attendees are provided with song sheets including the lyrics for each song. Songs are sung in unison accompanied by the musician or in rounds

with harmonies. Depending on access to equipment, attendees can use percussive instruments during the session. At the beginning and end of each session, there is an opportunity for refreshments and time to socialise.

Participants

The participants were recruited in the East Midlands area of the UK. Participants were patient–carer pairs attending at least two sessions of SftB in this region. A total of 10 patient–carer pairs were recruited and interviewed (20 participants in total). There were three mother–daughter couples and seven husband–wife pairs. In the marital pairs, five were men with dementia cared for by their wives and two were women with dementia cared for by their husbands. Two carers were male and the rest female. No other demographic data were collected about participants. One of the participants ‘Linda’ may be considered a key informant, as she was particularly knowledgeable about the SftB group (Mays & Pope, 1995).

Ethical issues

Ethical approval for the study was granted by the University of Nottingham Medical School Research Ethics committee (2012-F13092012 IMH). Local Research Ethics approval was not required, as participants were recruited via a non-clinical community setting. All participants were given information about the study and invited to participate at an initial session of the SftB group. Capacity to take part was not formally assessed; however, participation was entirely voluntary, and two versions of the information sheet were prepared: one for participants with dementia and another for carers. Written consent was provided by participants prior to interviews taking place.

Interviews

Interviews were semi-structured and included topics identified from the literature and in discussion with the research team. The topics included the experience of attending and participating in the group, impact on communication and relationships, and changes in health and behaviour during and after the sessions. Interviews ranged from 37 to 85 minutes in length and took place in the home of the carer and the participant with dementia during a two-month period in which they were attending SftB sessions. Interviews were digitally recorded and transcribed by the lead author. The lead author participated in the SftB sessions prior to and throughout the data collection period which ensured that she was familiar with interviewees (Shenton, 2004). Every effort was taken to engage both parties in each interview, as this has been reported as beneficial, particularly for those with dementia who may be excluded from research (Clark & Keady, 2002).

Analysis

Transcripts were subjected to thematic analysis (Braun & Clarke, 2006) which involves examining the text in detail to identify recurring patterns (open coding) which are refined into ‘themes’. Thematic analysis facilitates production of both inductive and deductive findings. That is, those that arise directly from the data and those which relate to theory and previous findings, respectively. The process was undertaken iteratively, with open codes

identified by the lead author and ongoing discussion between all authors throughout analysis to ensure reliability of the findings.

Results

The following six themes were identified from the data:

- (1) Social inclusion and support
- (2) A shared experience
- (3) Positive impact on relationships
- (4) Positive impact on memory
- (5) Lifting the spirits
- (6) Acceptance of the diagnosis

Social inclusion and support

SftB supports social inclusiveness, as it enables all participants to get involved, regardless of the stage of dementia.

I see people there that are very, very 'far gone', and yet I see them participating, which I think is wonderful. (Robert, Carer)

That is the greatness about the group, it doesn't matter what stage you're at, you can enjoy it... and as I say the delight I get in seeing them doing things, there's one guy there and I know he's really bad and I know, you can see him, normally he would go to sleep but he's there, he's awake and you can see that he's enjoying it. (Ellen, Carer)

As noted, loss of function and the deterioration associated with dementia can cause great anxiety for the people affected. Even when many daily activities are no longer possible for people with dementia, the interviews show that participating in SftB appears to be something that remains achievable and enjoyable. If the person with dementia experiences apathy, this can lead to deterioration in their relationships (De Vugt et al., 2003); therefore, SftB has the potential to stimulate physical and emotional participation that appear to have beneficial effects for both the person with dementia and the carer.

People attending the sessions felt that SftB allowed them to form bonds with people to whom they could relate thus nurturing supportive networks.

I have appreciated that the whole concept of Singing for the Brain... Wherever you go and whatever group of people you're in singing seems to break down barriers and to open up sort of, not only companionship, but a sense of belonging, and that's great. (George, PWD)

Being a carer is very lonely because you've got a social life but it's not the social life you thought you were going to have when you're first retiring, it's totally different, and it is a very lonely existence, and it's nice to have all these people that you meet to talk to who are going through the same thing so... it's much better. (Julia, Carer)

The importance of feeling part of a group is particularly salient in dementia care because of the negative impact of isolation which compounds disease burden. The burden of caregiving on carers means they often become socially isolated (Taylor et al., 1998). A paper by Haley, Levine, Brown, and Bartolucci (1987) reported that those caregivers with a larger number of friends and social contacts, as well as those carers who attended more

social activities with friends had an increased overall life satisfaction. A more recent study conducted by Daly, McCarron, Higgins, and McCallion (2013) demonstrates how informal carers use social networks as a way to manage and sustain their changing role as carer.

It was suggested that SftB was an opportunity for carers to share information and form supportive networks. Beard and Fox (2008) note that groups such as these nurture a sense of solidarity and collectivity.

From a carer's point of view I think it is fantastic, it is really, that they can get together and understand the varying stages of dementia, you get to know an awful lot you know, mixing together, of what is available for you, more so than someone coming along and trying to give you a talk, you know, you get to know from other people that have experienced it... people relax and mix, we are joined together and help one another, and you get to know these people, and as you go along the line you help them you know, and I think that's the beauty of something like this, is being there for one another you know. (Ellen, Carer)

SftB is a service where carers can discuss topics of concern in a relaxed, informal environment. Studies have shown that lower levels of informal support are linked to increased carer burden and increased depression (Coen, O'Boyle, Swanwick, & Coakley, 1999; Coen, Swanwick, O'Boyle, & Coakley, 1997; Gold et al., 1995). Increased social support is related to positive carer outcomes (Shaw et al., 1997). Despite the obvious solution to reduce this aspect of carer burden, it can be difficult for carers to interact in a social environment for example due to time constraints (Haley et al., 1995). SftB provides a platform for these interactions to take place. The fact that people can share information and support one another at these sessions may mean that less support is required from health and social care services.

A shared experience

SftB provides a mutual, shared, enjoyable experience for the person with dementia and their carer.

This is one of the great sadnesses and I get quite emotional about this, there is so much we can't share anymore and this, I should say that this, the Singing for the Brain is one thing that has benefitted me because it's one thing that we can do together for an hour or two and get equal pleasure from and equal meaning. (Robert, Carer)

If activities that were done together in the past become no longer possible, it can contribute to a sense of loss for both parties (Purves & Phinney, 2013). This seems to be especially important in marital pairs (De Vugt et al., 2003; Wright, 1991). Issues such as less intimacy, reduced enjoyment of companionship and less reciprocity may result in a reduced quality of the marital relationship (Wright, 1991). SftB provides a mutually enjoyable activity that should have a positive impact on care and well-being for the person with dementia and their carer, in keeping with reports about other psychosocial interventions (e.g. Melunsky et al., 2013). This can be seen as an antidote to the sense of loss experienced in many spousal relationships when one partner has dementia.

Positive impact on relationships

SftB has a positive impact on the relationship between the person with dementia and carer, and their relationship with others. The activity is seen as an enjoyable topic of

conversation, as a way to improve relationships and adds another dimension to the relationship.

We've talked about that as an extra kind of thing...and it's given something for you (refers to PWD) and dad to talk about...you've had much more to talk about with Dad. (Linda, Carer)

The importance of a meaningful interaction between the person with dementia and their carer that was not focussed on the clinical aspects of care; one that allows communication and connection at a different level, is especially important in the care of those with dementia where communication has deteriorated and has been advocated (e.g. Basting, 2009).

Well like I said when I turn round and see you (PWD) smiling as you're singing and there's definitely, I mean it's pure pleasure for me but it's nice for us to look at each other while we're singing...it's like we understand what we're both experiencing you know, so you don't need to say it, it's just there...and that's lovely isn't it, really lovely. (Linda, Carer)

The nature of dementia means that, for those with the condition, the benefit of the sessions is somewhat short-lived as the activity is forgotten in some cases; therefore, the intrinsic value of the sessions becomes most important. Studies by Bruer, Spitznagel, and Cloninger (2007) and Svansdottir and Snaedal (2006) support this, as does work by Basting (2005). However, longer lasting benefits were reported by carers, who indicate that the sessions have an enduring positive effect on their sense of well-being and their capacity to provide care.

SftB acts as a platform to stimulate memories and reminiscence. The songs that are sung at the session provide topics on which to reminisce.

It was nice doing some of those old ones you haven't heard for a long time, and often you find yourselves singing them, and 'oh this is great'. And does it make you think about things from years and years ago. (Linda, Carer)

I think it reminds you of some songs that you've not sung for a while so it sort of brings back things. (Mark, PWD)

It is also beneficial for the person with dementia to realise that some aspects of their memory are still intact as they remember the lyrics to some of the familiar songs. For the person with dementia, the realisation that their ability to remember remains helps to give them a feeling of hope and positivity. Such benefits support Kitwood's (1997) theory of person-centred care, by promoting agency and reducing 'malignant social psychology', and concur with reviews of similar interventions, e.g. Beard (2012). The positive impact of reminiscence on psychological well-being has been backed up in a meta-analysis conducted by Bohlmeijer, Roemer, Cuijpers, and Smit (2007).

I was looking at you when you were singing and you didn't have to look at the lyrics for a lot of it cause you remembered it, and that's great isn't it, cause it's nice to actually remember something. (Linda, Carer)

A study by El Haj, Fasotti, and Allain (2012) proposed that music has the ability to enhance autobiographical memory-recall in Alzheimer's patients. It was found that, compared to memories evoked in 'silence', those memories evoked in the presence of music were more specific, with more emotional substance and were recalled faster. However, the direct mechanism by which this is achieved remains unclear. It may be that the familiar music

utilised at SftB somehow unlocks these memories in the participants. The music acts as a cue to stimulate involuntary autobiographical memories (Johannessen & Berntsen, 2010).

When presented with sung versus spoken lyrics, it was found that patients with Alzheimer's disease had increased accuracy for remembering sung lyrics, whereas healthy adults showed no significant difference. By observing these differences, it was suggested that the music-processing areas of the brain may be spared in Alzheimer's disease and also that music enhances arousal, and therefore better attention and improved memory (Simmons-Stern, Budson, & Ally, 2010). These findings support the observations that were made during a SftB session, namely that lyrics of songs can be recalled when many other memories cannot.

Lifting the spirits

Attendance at SftB was reported to have a positive impact on mood and well-being.

To go to something you enjoy you overcome what is wrong with you. I mean I know George wasn't feeling well on Tuesday but we came and we enjoyed it and we were rejoicing thinking, man weren't that wonderful. (Karen, Carer)

I feel better when I come home, I mean I enjoy going. (Mary, PWD)

Respondents suggest that SftB makes them feel better. It offers an enjoyable activity that helps improve people's sense of well-being that can have a lasting effect on some.

I've certainly noticed a huge difference in mum since she's been coming . . . You're brighter, more alert, more like your old self. (Diana, Carer)

You can feel quite low, quite sad and then we've sat there and we've been singing and I've turned round and looked at you and you've had this big smile on your face and that's what's been the lovely thing for me, to see this difference and this weight being lifted just for that little bit of time and then it just seems to keep you going for a little bit afterwards. (Linda, Carer)

Music has been found to stimulate and regulate emotions, provide enjoyment and relieve stress (Juslin & Laukka, 2005). It induces emotions that can lead to changes in heart rate, respiration, skin temperature and hormone secretion, including endorphins (Khalfa, Dalla Bella, Roy, Peretz, & Lupien, 2003; Lundqvist, Carlson, Hilmersson, & Juslin, 2009; Suda, Morimoto, Obata, Koizumi, & Maki, 2008). These effects are likely to contribute to the enhanced mood reported by attendees at SftB.

The point is that I think that music, irrespective of what you may be suffering from, is uplifting for just everybody really. (Roger, Carer)

Everybody has just got so much pleasure on their faces, and that's uplifting in itself, when you see other people really enjoying something. (Linda, Carer)

Acceptance of the diagnosis

Another reported benefit of SftB was in helping people come to terms with the diagnosis of dementia.

It can be very frightening, when they tell you you've got it, it can be very frightening . . . I think in a nutshell, I think those meetings up there are good for everybody . . . whether you have got the

Alzheimer's or whether you're just a supporter, I think it's good for everybody, to come to terms and accept it... and try and continue on as long as you can. (Gary, PWD)

The impact of diagnosis on patient–carer couples has been discussed in many papers (e.g. Beard, Sakhtah, Imse, & Galvin, 2011; Davies, 2011; Hayes, Boylstein, & Zimmerman, 2009; Keady & Nolan, 2003; Nolan, Lundh, Keady, & Grant, 2003; Robinson, Clare, & Evans, 2005; Searson, Hendry, Ramachandran, Burns, & Purandare, 2008.) Finding ways to cope or finding acceptance of the diagnosis will help people adjust to their life-changing situation. The development of ways to cope with the diagnosis on the part of the person with dementia and the carer is crucial to finding a sense of well-being and minimising excess disability (Clare, 2002, 2003; Pearce, Clare, & Pistrang, 2002). Robinson et al. (2005) suggested that couples who understood and accepted the diagnosis were better able to adapt to their changed circumstances.

SftB is a targeted activity that can be incorporated into the routine of those living with dementia. It thus indirectly acts as a means to help with the acceptance of the diagnosis and facilitates contact with individuals in a similar situation with whom they can identify.

Conclusions

The findings add to a growing literature on the utility of arts-based interventions in the care of people with dementia. The qualitative approach generated in-depth accounts of people's opinions and feelings related to the activity. This study supports the now well-documented claims that the perspectives of people with dementia can and should be included in research (Alzheimer Europe, 2012) and contributes to the burgeoning body of literature that focuses on meaning – rather than outcome-based programmes by demonstrating the intrinsic value of music for people with dementia and their carers alike.

Although participant numbers were relatively low, this is acceptable in qualitative research which focuses on in-depth understanding from a homogenous group selected for their knowledge and experience of a particular phenomenon. Despite rich and detailed accounts of the activity from both the perspective of the carer and the person with dementia, in some instances the participant with dementia was unable to recall the SftB sessions and therefore carers tended to dominate the discussion.

The positive response to SftB from people with dementia and carers suggests that the programme has potential to be offered to a wider range of people. Since 2003, access to the service across the UK has grown and there are currently 101 SftB services available, many of which have long waiting lists. As a growing service for which there is has been relatively little research, this study has generated evidence for its value in this population. As it is a standardised service model, it can easily be replicated. SftB is a relatively low-cost activity and does not require specialist resources aside from the musician leading the sessions. Its potential cost effectiveness should therefore be explored in detail in future studies.

Future studies could look in more detail at the improvements reported in the sessions, for example enhanced memory could be measured using standardised tests. The SftB sessions were led by one musician. It is therefore important to look at SftB sessions led by different musicians to see whether this affects the results. The way in which music interventions are delivered has been noted to be important (Vella-Burrows, 2012). As all participants in the study were White British it is important for the activity to be evaluated in different regions to capture a more diverse population.

A musical activity such as SftB has multiple health and well-being benefits for people with dementia and their carers. In addition, the group setting facilitates a sense of belonging and provides much needed social support. As well as improvements in mood which outlast the sessions, and enhanced relationships, the activity facilitated acceptance of the diagnosis of dementia which may help promote longer term well-being for people with dementia and their carers and enable earlier access to appropriate support. The ability of singing to stimulate memory and its mutually beneficial impact on people with dementia and carers are unique features of this activity but support promising findings from studies using other modalities, for example visual art (Camic, Tischler, & Pearman, 2014; MacPherson, Bird, Anderson, Davis, & Blair, 2009) and thus should be the subject of further research.

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Sara Eldirdiry Osman is a final year medical student at the University of Nottingham. She has research interests in old age psychiatry and in the use of music in dementia care.

Victoria Tischler is a chartered psychologist and senior lecturer in psychology at University of the Arts London – London College of Fashion. Her research interests concern the development, use and evaluation of creative approaches to enhance mental health and well-being. She is a curator with interests in the socio-cultural and historical significance of artwork made by people with mental illness.

Justine Schneider is a social worker and social researcher, with expertise in many aspects of applied health research using a wide range of methodologies and approaches. She has experience of research in mental health service evaluation, carers, care homes, costs and supported employment. Her current work focuses primarily on dementia and staff development, and she is exploring innovative approaches to knowledge exchange in dementia care using the arts.