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Does a ‘Singing Together Group’ improve the quality of life of people with a dementia and their carers? A pilot evaluation study

Paul M Camic
Canterbury Christ Church University, UK

Caroline Myferi Williams
Sussex Partnership NHS Foundation Trust, UK

Frances Meeten
University of Sussex, UK

Abstract
Ten people with dementia (PWD) and their family carers participated in a Singing Together Group for 10 weeks and measures of mood, quality of life, PWD's behavioural and psychological problems, activities of daily living and cognitive status were measured at pre, post and 10-week follow-up. Engagement levels were monitored during the sessions and care partners asked to rate each session. Additional qualitative information was obtained through interview pre-post and at follow-up and subjected to thematic analysis. The results showed that PWD were deteriorating slowly over the course of the study on all measures but that they and their carers’ quality of life remained relatively stable. Engagement levels during the group were very high and attendance excellent. Qualitative data gave strong support to the group having promoted wellbeing of all participants and Nolan’s ‘Senses Framework’ was used to explore this further. Future research directions are suggested.

Keywords
dementia, quality of life, Senses Framework, singing group, wellbeing

Corresponding author:
Paul M Camic, Canterbury Christ Church University, UK
Email: paul.camic@canterbury.ac.uk
Introduction

Older people with a dementia (PWD) are often doubly disadvantaged due to widespread ageism in society combined with the stigma associated with mental health problems. Positive wellbeing (i.e. happiness and life satisfaction) in later life is thought to be derived from being involved in activities that are personally meaningful and valued, especially informal social activities (Adams, Leibbrandt, & Moon, 2011). PWD may find they are excluded from many of these activities or lose confidence in their abilities themselves and withdraw socially. Due to the caring commitments and concern about leaving the PWD unattended, carers may lose contact with family and friends and be unable to engage in social activities on their own; they may also find social activities that both of them could enjoy together more difficult to identify as the condition progresses. Group singing as an intervention is an example of a positive approach to mental health; it is an activity that can be enjoyed by both the carer and the PWD and can be seen as a normalising one, which recognises the importance of relationships in dementia care and inspires and validates hope in living well together with a dementia.

In selecting a suitable social activity, music and especially singing appear to have a number of strengths. There is a developing literature on the benefits of music (Clift, et al., 2010; Cohen, 2009; Sixsmith & Gibson, 2007) and particularly singing in dementia care (e.g. Gotell, Brown, & Ekman, 2009; Hays & Minichillo, 2005; Holmes, Knights, Dean, Hodkinson, & Hopkins, 2006; Kneafsey, 1997; Staricoff, 2004; Sung & Chang, 2005). Evidence for the beneficial effects of singing in groups also comes from the ‘Singing for the Brain’ model, which was devised by the West Berkshire Branch of the Alzheimer’s Society\(^1\) and the Silver Song Club Project (Skingley & Vella-Burrows, 2010). Bannan and Mongomery-Smith’s (2008) evaluation of a three-session singing group demonstrated singing was an enjoyable activity for PWD and had the potential to enhance wellbeing and quality of life for them and their carers. Hammar, Emami, Engstrom, and Gotell (2010) successfully used ‘Music Therapeutic Caregiving’, which is music in residential settings in caregiving situations, to reduce behavioural and psychological problems of people with moderate to severe dementia.

Measuring the quality of life (QoL) for PWD has proven to be quite challenging (Banerjee, et al., 2009), with no one standardised measure being preferable. Major concepts have been identified which are related to quality of life for PWD and include ‘emotional states, activities of daily living, communication, cognitive functioning, and caregiver perception of the PWD’ (Kwasky, Harrison, & Whall, 2010, p. 186). These authors determined, as did Banerjee et al. (2006), that QoL was not statistically significantly associated with the degree of cognitive functioning or the carer’s age but that the greater the behavioural and psychological symptoms of the PWD, the lower the QoL for the PWD.

A related psychosocial construct is that of wellbeing; this can pertain to the PWD or the carer. For the PWD, a key component contained within wellbeing is thought to be ‘personhood’ (Kitwood, 1997), which has been difficult to define but is essentially the idea there is a core essence of the person, no matter how severe the dementia, which can be nourished by a supportive environment and diminished by what has been termed a ‘malignant social environment’. This concept has been further developed by Snyder (2006) who also incorporates some of Sabat’s work (2001) to propose a ‘sense of selfhood’; this is seen as a compelling and central aspect of being a person with a dementia and is

\(^1\)Please note that the page references may not correlate with the actual page numbers in the original text.
co-constructed by the PWD and those around him/her and, as with all people, is formed in part by the interdependence and interconnectedness of human beings (Kelley, 2007). Failure to support the selfhood of the PWD is thought to add to the difficulties already experienced due to cognitive impairment and may lead to a further reduction in self-confidence and increased social exclusion. In relation to carers, there is a vast literature on carer burden and stress and a range of interventions that provide support or training for carers in managing the PWD (Brodady & Berman, 2008). However, reducing carer burden may not be the same as increasing carer wellbeing and improving quality of life and different interventions may be needed. Although a great deal of attention has been given to the selfhood of the PWD, less focus has been given to that of the carer’s sense of self; carers often report feelings of isolation and loneliness, especially when their relative’s communication skills are affected, and find there are less opportunities to engage with others in a socially meaningful way.

The project was therefore interested in both the PWD and their carers’ wellbeing and is based on a relationship model that is being developed within dementia services and which takes a more systemic perspective (Adams & Gardiner, 2005; Nolan, Ryan, Enderby, & Reid 2002; Yarry, Judge, & Orsulic-Jeras, 2010). Nolan et al. (2002) propose that good care requires that everyone involved in the caring situation needs to have a sense of security (feeling safe and delivering or receiving competent and sensitive care), continuity (recognition of biography, using the past to contextualise the present), belonging (opportunities to form meaningful relationships or feel part of a team), purpose (opportunities to engage in purposeful activities), fulfilment (achieving meaningful or valued goals and feeling satisfied with one’s efforts) and significance (feeling you matter and are valued as a person) and collectively term these the ‘Senses Framework’.

The ‘Singing Together Group’ is aimed at developing activities which bring a positive experience to the PWD and their carer and, unlike many other interventions in dementia care, does not focus on the PWD’s weakness (i.e. cognitive impairment). In relation to the Senses Framework, it is anticipated that singing old songs may provide continuity with the past and may increase a sense of personal history between the PWD and their carer, thereby supporting their relationship. Singing in a group may give a sense of belonging, and learning new songs may give a sense of achievement, fulfilment and significance. The group potentially offers an activity that both sets of participants can engage in as equals and provides an opportunity for peer support. It is also consistent with the approach taken by Yarry et al. (2010), which targets the caregiving dyad rather than providing separate interventions for the care partners.

**The present study**

The present study seeks to determine if participation in a community singing group had a positive impact on both people with a dementia (PWD) and their carers by increasing wellbeing, improving day-to-day functioning and reducing social exclusion. We anticipated that this would be evidenced by decreased levels of psychological distress, increased quality of life and an increase in social inclusion. By including the carers in the singing group, we were also interested in supporting the relationship between a family carer (partner or offspring) and PWD and exploring how music and singing is used outside the singing session.
The UK Medical Research Council (Craig et al., 2008) provide a useful framework and guidelines for some of the methodological issues involved in evaluating complex interventions such as a community singing group. Their framework consists of ‘a sequential series of phases of investigation which sets out the objectives to be met at each stage prior to moving forward to the next stage’. The present project is a Phase I exploratory study where initial hypotheses and propositions were formulated and explored in order to develop a future Phase II study that would involve a control group and randomisation procedures.

**Method**

**Participants**

Ten people with a dementia and their main carer (family member/partner) were recruited from an older people’s community mental health service in England (20 participants in total) to take part in a ‘Singing Together Group’. Inclusion criteria: a diagnosis of dementia or Mild Cognitive Impairment (MCI), aged 65 and over, able to come to a disability-accessible venue for weekly singing groups with their carer who is willing to participate in the singing. Exclusion criteria: not being able to give consent at the beginning of the study or currently experiencing a psychotic disorder.

For the 10 participants with dementia or MCI (for ease of reference both are to be referred to as PWD) the mean age was 75 years (SD 6.70) with a range of 68–88 years. There were five men and five women; nine participants were accompanied by their spouse and one by their daughter. Six participants had a diagnosis of Alzheimer’s Disease, two with Vascular Dementia, one with Mixed Dementia and one with Mild Cognitive Impairment. All except the latter were on anti-dementia medication. Pre-group scores on the Addenbrooke Cognitive Examination–Revised (ACE-R) (Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006) ranged from 14–77 (cut-off point of 82) showed a wide range of abilities but that everyone was in the impaired range, suggestive of dementia. At baseline assessment, Mini Mental Status Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) scores ranged from 5–28 ($m = 19$). Some people with low scores were included as their language difficulties overestimated their cognitive impairment. The ACE-R was used, which incorporates the MMSE, because it is a more reliable measure of impairment than the MMSE alone.

Neuropsychiatric Inventory (NPI) (Cummings, Mega, Gray, Rosemberg-Thompson, & Gornbein, 1994), scores ranged from 0–33/144 ($m = 14.8$) showing only a low level of behavioural and psychological problems. All participants were ambulatory throughout the singing groups. There was 85% attendance over the 10 weeks.

Attrition during the singing group was low, as evidenced by high attendance rates. However, only seven of the 10 dyads were available for 10-week follow-up due to dementia-related health deterioration in two cases and recuperation from an unrelated accident in one case. There were some cases where a PWD was able to complete only one of the two questionnaires due to fatigue or difficulties coping with different scales.

**Procedure**

The study was approved by a local UK National Health Service ethics panel and followed appropriate Department of Health ethical guidelines for research with participants who may lose the capacity to consent during the course of the study. Data collection followed a mixed
methodological repeated measures design with data collected pre, during, post and at 10-week follow-up.

After explaining the study and taking consent, both members of the dyad were interviewed separately for approximately 30 minutes and then administered several standardised questionnaires. Dyads were subsequently interviewed at the end of the group and at 10 weeks post-group; questionnaires were also re-administered at these times. In addition, behavioural observations were undertaken during each singing group session.

The singing group was facilitated by a qualified community musician with expertise in facilitating group music-making and singing (professional choir leader) and met weekly, during late afternoon, over a period of 10 weeks for 90 minutes, including a break for refreshments. The musician used a portable electronic keyboard during all sessions and some recorded music. Percussion instruments were also available to use and songs were sung sitting or standing in a circle with opportunities to move to the music. In a pre-group meeting, participants were asked about their interests and music preferences and requests were then incorporated in the programme (e.g. an ex-miner asked for songs he used to sing down the coal mine and another for New Zealand songs). Groups always started with vocal warm-ups and then a mixture of well-known, new and requested songs gradually introduced; some of these were performed in rounds. All the song lyrics were printed out on sheets and the facilitator would also shout out the line prior to singing it for those who had lost the ability to read. Participants were encouraged to reminisce about the songs and to mix with each other during the tea break. The sessions therefore provided the opportunity for mild respiratory and physical exercise, cognitive stimulation, new learning, reminiscence and social interaction.

Measures

**Semi-structured interviews.** The 10 carers and PWD were interviewed separately prior to the beginning of the group, immediately at post-group (9 carers and 8 PWD) and at 10-week follow-up (8 carers and 7 PWD); all interviews were audio recorded and transcribed with the participants’ consent. The pre-group semi-structured interview sought information about activities undertaken by each individual and done as a dyad, currently and in the past. It solicited information about routine household activities, hobbies, cultural and sports events, and music and singing. Subsequent interviews sought information about their experience in the singing group, their post-group use of singing and music, as well information about the activities cited above.

**Standardised measures.** The PWD’s cognitive abilities were assessed at baseline with the Addenbrooke Cognitive Examination (ACE-R) (Mioshi et al., 2006) (which incorporates the MMSE) and subsequently at post-group and 10-week follow-up with the much briefer Folstein Mini Mental Status Exam (MMSE) (Folstein et al., 1975). Their mood was assessed with the Geriatric Depression Scale (GDS) (Sheikh & Yesavage, 1986) and their quality of life was assessed with the Dementia Quality of Life (Dem-QoL-4) scale (Smith et al, 2005); carers then rated the PWD’s quality of life with the Dem-QoL-proxy (Brod, Stewart, Sands, & Walton, 1999), their behavioural and psychological problems with the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994), and their activities of daily living with the Bristol Activities of Daily Living Scale (BADLS) (Andersen, Wittrup-Jensen, Lolk, Andersen, & Kragh-Sorensen, 2004).
Carers completed standardised measures of their own anxiety, stress, and depression (DASS) (Crawford & Henry, 2003; Lovibond & Lovibond, 1995) and quality of life (WHO-QoL BREF) (Skevington, Lofty, & O’Connell, 2004) pre-group, post-group, and at 10-week follow-up.

All of the above quantitative measures are frequently used in clinical environments and have good test-retest reliability and acceptable levels of validity.

Other measures. In addition to these standardised measures, levels of engagement and participation were measured using a specially constructed observational scale, which involved observing each participant for 30 seconds and noting their predominant behaviour; this was repeated five times during each session and inter-rater reliability data collected.

Subjective evaluation of participant experiences is an important and often overlooked part of healthcare research (Kazdin, 1977). Carers were asked for feedback after each session. Anonymous evaluation cards were given to each dyad at the end of each session and dyads were asked to rate on a five-point scale (ranging from ‘strongly disagree’ to ‘strongly agree’) four statements: The group was enjoyable; Songs sung included ones we liked; We joined in most of the time; and We enjoyed talking to other group members.

Carers were also asked to keep a weekly diary of the dyad’s singing and music-listening activities throughout the intervention. This was to explore whether they increased their use of singing or music outside the group and to see if they spontaneously reported using singing to help with activities of daily living.

Results

Interview data, behavioural observations and weekly session ratings showed that PWD were able to participate in the singing groups and they and their carers expressed considerable enthusiasm for this activity with excellent attendance rates (only one dyad missed one session due to weather conditions). However, standardised measures were inconclusive and may reflect the ongoing difficulty in adequately measuring quality of life (Banerjee et al, 2009) and other non-cognitive indicators for someone with a dementia who is likely to deteriorate over time by virtue of the nature of the illness. The quantitative and qualitative measures will be examined separately below.

Standardised measures

People with a dementia. The PWD’s mean ratings of depression (GDS), self-rated quality of life (DEM-QoL), the carers’ mean ratings of the PWD’s quality of life (DEM-QoL Proxy) and the carers’ mean ratings of the PWD’s ability to carry out activities of daily living (BADL) and their behavioural and psychological problems (NPI) are detailed in Table 1. This suggests that there is slight deterioration in PWD’s cognitive abilities, activities of daily living skills and their behavioural and psychological problems over the course of the study consistent with a progressive disorder such as dementia.

Due to a decrease in sample size at follow-up, only the pre-post measures were subjected to further analysis. Repeated measures t-tests were performed examining pre-and post-group ratings, and mean values are shown in Tables 2 & 3. There were no significant differences in quality of life as rated by PWD themselves or as rated by their carer. Pre and post scores on
the GDS were compared using data from the six participants who completed measures at both time points (pre $M = 2.50$ (2.43) and post $M = 4.17$ (3.13), $t(5) = 3.37$, $p = .02$, $d = 0.60$). This shows an increase in depression scores post-group, bringing some participants from a non-clinically depressed score to just in the depressed range.

The Dem-QoL and Dem-QoL-Proxy both include a snapshot overall rating of quality of life on a four-point scale from 0 = ‘Poor’ to 4 = ‘Very Good’ and answers to this question are scored independently from the rest of the measure. This QoL rating for the PWD (measured by Dem-QoL-Proxy) did not change significantly over the course of the study. Mean ratings with standard deviations at pre, post, and follow-up data collection points respectively were 2.60 (.70), 2.67 (.70), 2.43 (.98). This shows little change over time in PWD QoL ratings and is a potentially important finding considering that there was a gradual reduction in cognitive abilities, a slight increase in impairment in the ability to perform activities of daily living and some increase in behavioural and psychological problems. To follow up on findings by Banerjee et al. (2006), correlations between PWD QoL as rated by the carer and measures of behavioural and psychological symptoms (measured by the NPI) were examined. There was a marginal negative correlation between QoL and NPI ratings pre-group ($r = -.54$,}

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-group</th>
<th>Post-group</th>
<th>10-week follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>MMSE</td>
<td>19 (7.9) ($N = 9$)</td>
<td>16.5 (8.5) ($N = 8$)</td>
<td>16.1 (7.2) ($N = 7$)</td>
</tr>
<tr>
<td>DEM-QoL</td>
<td>90.67 (13.28) ($N = 9$)</td>
<td>92.71 (18.31) ($N = 7$)</td>
<td>84.80 (20.75) ($N = 5$)</td>
</tr>
<tr>
<td>DEM-QoL PROXY</td>
<td>85.66 (8.99) ($N = 10$)</td>
<td>80.27 (8.17) ($N = 9$)</td>
<td>81.95 (16.70) ($N = 7$)</td>
</tr>
<tr>
<td>GDS</td>
<td>2.71 (2.30) ($N = 7$)</td>
<td>4.17 (3.31) ($N = 6$)</td>
<td>3.34 (3.50) ($N = 7$)</td>
</tr>
<tr>
<td>BADL</td>
<td>13.00 (7.76) ($N = 10$)</td>
<td>17.00 (6.62) ($N = 9$)</td>
<td>19.00 (5.66) ($N = 7$)</td>
</tr>
<tr>
<td>NPI</td>
<td>14.8 (9.3) ($N = 10$)</td>
<td>16 (10.9) ($N = 8$)</td>
<td>20.1 (13.7) ($N = 7$)</td>
</tr>
</tbody>
</table>

MMSE: Lower scores indicate greater impairment.
GDS: Higher scores show higher levels of depression (norms) with 4/5 being the cut-off point for clinical depression.
BADL: Higher scores represent increased difficulties with ADLS.
NPI: Higher scores show greater impairment in behavioural and psychological problems.

<table>
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</tr>
</tbody>
</table>

GDS: Higher scores show higher levels of depression (norms).
BADL: Higher scores represent increased dependency on a carer.

Table 1. Mean measures (+ standard deviation) of cognitive ability (MMSE), quality of life as rated by PWD (DEM-QoL) and carer (DEM-QoL proxy), depression, behavioural and psychological problems (NPI) and activities of daily living (BADL) before and after the group, and at 10-week follow-up

Table 2. Mean measures (+ standard deviation) of quality of life as rated by PWD (DEM-QoL) and partner (DEM-QoL proxy), depression, and activities of daily living before and after the group, and at 10-week follow-up
Table 3. Carer mean (+ standard deviation) quality of life scores pre- and post-group, and at 10-week follow-up

<table>
<thead>
<tr>
<th>WHOQoL-BREF</th>
<th>Pre-group</th>
<th>Post-group</th>
<th>10-week follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>13.96 (1.88) $^{(N=10)}$</td>
<td>14.03 (1.07) $^{(N=9)}$</td>
<td>14.12 (1.13) $^{(N=7)}$</td>
</tr>
<tr>
<td>Psychological</td>
<td>14.36 (2.17)</td>
<td>14.59 (1.22)</td>
<td>14.48 (1.53)</td>
</tr>
<tr>
<td>Social</td>
<td>14.67 (4.17)</td>
<td>15.63 (2.36)</td>
<td>15.50 (3.56)</td>
</tr>
<tr>
<td>Environmental</td>
<td>16.76 (1.96)</td>
<td>17.11 (1.56)</td>
<td>16.50 (2.16)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DASS</th>
<th>Pre-group</th>
<th>Post-group</th>
<th>10-week follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>1.70 (1.64) $^{(N=10)}$</td>
<td>1.00 (1.20) $^{(N=8)}$</td>
<td>3.00 (3.16) $^{(N=7)}$</td>
</tr>
<tr>
<td>Depression</td>
<td>5.60 (4.50)</td>
<td>4.63 (3.16)</td>
<td>4.43 (1.40)</td>
</tr>
<tr>
<td>Stress</td>
<td>8.90 (4.70)</td>
<td>10.13 (5.64)</td>
<td>9.43 (2.94)</td>
</tr>
</tbody>
</table>

$p = 0.06$, one tailed (and follow-up $r = -.62$, $p = 0.07$, one tailed), but not at post-group ratings ($r = -.40$, $p = 0.14$, one tailed). As expected, in accordance with findings by Banerjee at al., this indicates that at pre-group and follow-up, as scores on the NPI increased, QoL ratings for the PWD decreased. However, this was not found at all three time points and correlations were marginal; furthermore, there was no significant correlation between QoL as reported by the PWD and carers’ QoL and NPI scores, thus findings would need to be replicated with a larger sample.

Although MMSE scores showed some variation at post-group and follow-up (see Figure 1), most scores fluctuated over the course of the study with some people improving and others deteriorating (participant 5 did not wish to complete any cognitive assessments). One carer reported that the PWD’s anti-dementia medication had been stopped and had contributed to deterioration in mood and cognitive abilities towards the end of the singing group and which was then restarted with subsequent improvement. None of the others had any significant change in their medication.

Carers. For the WHOQoL-BREF used to measure the carers’ quality of life, the international protocol for handling and scoring missing data was followed (WHOQoL-BREF Group, 1996). Question 1 of this scale is examined as a standalone question and asks about the individual’s overall perception of quality of life; ratings are on a five-point scale where $1 = ‘very poor’, 3 = ‘neither poor nor good’ and $5 = ‘very good’. Mean ratings with standard deviations at pre, post, and follow-up data collection points respectively were $3.70 (.82), 3.78 (.97), 3.57 (.53)$, showing little change over the course of the study. This scale is divided up into different domains and the mean score of items within each BREF domain were used to calculate the domain score. Carers’ pre, post, and follow-up scores are shown in Table 3. Repeated measures t-tests were used to compare carers’ pre- and post-group data on the WHOQoL-BREF and on the DASS mood scale. The results showed that there were no significant differences in any of the four quality of life domains, or on measures of anxiety,
depression, and stress (carers showed a slight decrease in anxiety and depression and slightly higher overall stress levels). Carers rated themselves as having a relatively good quality of life throughout the study and so it may be that a change in scores was not found as the project sample included people who were already coping well. However, the fact that they maintained their wellbeing even though their relative was slowly deteriorating could be used to support the use of community singing in preventing loss of quality of life.

Engagement in singing sessions. Inter-rater reliability on the specially constructed engagement scale was high (90%). Mean engagement in the singing sessions across the group was 9.85 (range 5–10, with 10 being highest). These high engagement levels were remarkable especially for the participants with more moderate to severe impairment, and suggest that this is an enjoyable activity even for those with moderate levels of dementia.

Post-group evaluations
The dyads’ ratings of each singing session were averaged over the 10 sessions and show extremely high satisfaction ratings (see Figure 2).
Thematic analysis

Interview data were analysed using thematic analysis (Boyatzis, 1998), which is a qualitative methodology to help focus what is meaningful across a data set by helping the researcher make sense of shared meanings and experiences (Braun & Clarke, 2006); qualitative methods can often help to assess trends and subtle differences in ways that quantitative methods cannot (Camic, Rhodes, & Yardley, 2003). For the purposes of this paper we would like to focus on the themes that were identified post-intervention and at 10-week follow-up for the PWD (P) and family carer (C). Themes were iteratively coded by the first and third authors and were further examined for consistency by an independent reviewer. Few inconsistencies were identified but, for those that were, further discussion and re-examination of transcripts resolved them.

Post-intervention themes for PWD. Six themes were identified at the end of the intervention for people with a dementia. Themes will be presented here with illustrative quotes for each theme and, where appropriate, related back to the Nolan’s Senses Framework (2002).

![Figure 2. Responses to session evaluation cards over 10 sessions.](image-url)
Challenged beliefs and attitudes. Developing both an ability to sing in the group and an enjoyment of the processes really surprised people and seemed to give them a ‘sense of fulfilment’: ‘I couldn’t believe it. Within a couple of days we were doing things I never thought I would do’ (P1); ‘It takes you out of yourself. You can get on with your life without worrying what’s behind’ (P11); ‘I thought I probably can’t sing but when you do it with others it makes a tremendous difference’ (P8).

Enjoyment. There was an enthusiastic and positive response to the group as participants described how much pleasure they experienced and their ‘sense of belonging’ from the shared experience: ‘I thought it was super, it was fun’ (P2); ‘I thought it was wonderful... we just enjoyed it and by the look of the faces on the others they did too’ (P11); ‘I had never sung before and I enjoyed it’ (P1); ‘I liked the variety of songs’ (P9); ‘I think singing is a lovely way of relaxing... everybody joined in’ (P10).

Opportunity. It was seen as something new and unexpected that everyone could be involved in and feel that they had achieved something (sense of fulfilment): ‘It was a tremendous opportunity to do what we did’ (P1); ‘One lady, who had never smiled, smiled when we got up and sang and moved about. That was what it was all about’ (P11).

Singing facilitator. The person who conducted the group was seen as someone competent and also as someone who supported and positively challenged: ‘She was nice’ (P1); ‘She was fantastic, splendid’ (P2); ‘She was marvellous’ (P8); ‘She got on to what you were doing and enjoyed it’ (P11). This may have contributed to a ‘sense of security’, which was experienced by all participants.

Welcomed new learning. New learning, as used by participants, is a controversial issue in dementia research and care but one that has recently received cautious attention (Bier et al., 2008; Blessing et al., 2010). In the context of this study, positive affect and an increased sense of stimulation during group sessions may have led PWD to recognise known songs and enjoy being able to: ‘Still learn something new’ (P8); ‘It’s all new work, a little more each week’ (P3); ‘I liked learning new songs best’ (P9); ‘If songs came along [that he didn’t know] I sang them, it’s as simple as that’ (P10). This may have helped them feel a ‘sense of purpose’ and a ‘sense of fulfilment’.

Personal changes. It was important to hear directly from PWD what, if any, changes occurred as the result of attending the singing group. These were reported enthusiastically, generally without hesitation, with some also overlapping the theme, welcomed new learning: ‘I play a lot now, I listen to more music’ (P1); ‘I sing at home what we’ve sung in the group’ (P3); ‘I listen to CDs quite a lot now’ (P9); ‘We’re meeting up with another couple to go to a concert’ (P11). PWD participants also commented on changes they noticed in their carer: ‘My husband is now teaching himself to play piano’ (P3); ‘My husband now puts on the radio (he didn’t do that before)’ (P9).

Post-intervention themes for carers. Themes in this section were taken from interviews with carers and classified into three overarching categories and include, Carer response to the group, From the carer’s perspective: PWD response to group and Impact outside the group,
the latter category referring to reports of changes that occurred in the day today lives of participants that were attributed to participation in the singing group.

**Carer response to the group**

**Pre-group deliberation.** Carers reported a range of responses about initially contemplating the group: ‘We were very apprehensive’ (C1); ‘We wondered if it would be therapeutic and enjoyable’ (C2); ‘I don’t sing and if it hadn’t been for my husband I would not have dreamed of going’ (C10); ‘It was a surprise to actually be in a choir and sing, knowing full well that neither of us could’ (C7).

**Ambience and environment.** The carer, like their co-participant, enthusiastically reported enjoying the atmosphere of the group often for the same reasons (indicating a sense of security and belonging) but also included additional ones. They also described how much they enjoyed the venue, the music facilitator and other participants: ‘It was very relaxing, no one was left out. We were all taking part, no matter if we could sing or not’ (C1); ‘I was not naturally good at music, I’ve always been somewhat humiliated at school for my lack of musical ability but there was no question of that with the facilitator’ (C5); ‘The room was appropriately sized, there was parking, it was on a bus route’ (C11). One particularly poignant comment echoed how the group helped normalise PWD and reduce the sense of challenge and social isolation dementia can cause families, ‘You couldn’t tell who was the carer or who was the patient. It was good to see other people to talk and to sing’ (C9).

**Structure.** A pragmatic but important part of the intervention was to ensure that it was an easily accessible and welcoming environment: ‘The length was just right’ (C2); ‘The songs were well chosen and allowed everyone to participate’ (C5); ‘I liked that we sung as a group and not individually’ (C9); ‘I appreciated the time to socialise at tea’ (C1). Two comments suggested changes to be made for future groups: ‘I would have preferred it in the morning’ (C10); ‘Would have preferred it to be a bit longer’ (C11).

**Social inclusion.** A strongly articulated theme for carers was how important it was for them to be able to meet other people in the same situation, going through the same life experiences but not focus on illness, doctor visits or diagnosis. Even if they were unsure how they benefited, all identified benefits for their care partner: ‘It did us really both good to go and mix with other people, and sing and talk with others, which we wouldn’t do at home. It was nice to know other people going through the same thing’ (C2); ‘We go out a little more’ (C3); ‘The other thing I liked about the group was that it was a group of people with dementia and carers but the dementia was not the focus. It enabled me to see people in a sort of natural setting that were clearly involved, engaged, coping and comfortable with each other’ (C5); ‘It gives you a kind of backing, others going through the same thing as you’ (C7); ‘It was beneficial to meet with other couples to chat and sing with them’ (C8); ‘It’s difficult to say how if it helped me at all but my wife is so much better when she’s doing something worthwhile’ (indicating sense of purpose and fulfilment). The more things she can do the better’ (C9); ‘I didn’t dis-enjoy it, but I didn’t enjoy it because I can’t sing. It was all very nice and sociable though, and he enjoyed it’ (C11).
The experience of singing. ‘It’s a pleasure. I just liked it. I think it’s nice to be able to sing with other people. It’s a community feeling perhaps’ (C5); ‘I think it takes you out of yourself and you tend to forget what’s happening or what’s happening with her’ (C8).

From the carer’s perspective: PWD response to group. Carers were asked about their observations of their family member’s response to the group. Three themes were identified based on responses that were nearly always positive and consisted of some of the most important and lengthy responses during interviews.

Social inclusion. As with carers, PWD also benefited from the socially inclusive aspects that group singing offered: ‘It was the highlight of his day. He had not sung since he was a kid’ (C1); ‘She enjoyed doing something normal with other people. We both did. She has become more engaged with other activities’ (C9); ‘He liked singing in a group but would not have liked singing individually’ (C1); ‘He comes to life when he is in company. He seemed to enjoy all of it. It helped him to talk and be with others in the same situation’ (C11); ‘She got something back again. It was sad seeing how much she had lost, but how nice to see some of it back again’ (C3).

New learning. Carers substantiated PWD assertions that they were learning new songs: ‘She found it difficult to assimilate anything new but once she sang it a few times I could see her rocking and rolling like she use to’ (C2); He was surprisingly quite good in learning new songs. He had to work his way into it each time’ (C5); ‘She engaged well [with new songs] and enjoyed using her brain’ (C9); ‘He was quite happy to learn new songs and took part in that, and I thought he might not, but he did’ (C1).

Enhanced emotions. Group singing was described as benefiting the emotional life of PWD in several ways: ‘Her confidence was so shattered by her inability to speak but the singing was helpful in that respect because she didn’t seem to have the problem then. It’s nice to see a smile on her face’ (C8); ‘She was very animated, much more animated than she normally had been and that lasted until the evening and the next... she was enthused by it. It’s by far the most positive thing we’ve done in years’ (C3); ‘She got a lot out of it, she was having to engage with singing of a type she normally doesn’t’ (C5); ‘There were songs that he sang that he thoroughly enjoyed... he actually did blossom’ (C7); ‘It helps her to relax. It was pleasurable’ (C9).

Impact outside the group. From the above reports it appears that engagement in music-related activities did increase outside of the group and that these activities were jointly shared and enjoyed by both the carer and PWD through providing an activity both participated in together, but carers did not report using music or singing during care giving activities.

As researchers we were surprised at both the level of activities conveyed and the enthusiasm for those activities: ‘He really looked forward to it and when he went home he kept reading his sheets, he was very into it. He used Monday morning to listen and play music’ (C1); ‘At home there is now much more, much more music listening and enjoying it. It relaxes him and allows me to attend to other work at home’ (C2); ‘A neighbour mentioned that he likes jazz and he made a compilation tape for him’ (C2); ‘The breathing and warm up exercises were very good. We now know the exercise you can do each day’ (C3); ‘She has
started playing the piano a bit more. It is something we’ll be pursuing. I’d like to keep up this interest, which we’ve both got now in piano playing. That was a very positive outcome’ (C5); ‘We now use our CD player and I bought some discs. We never used it before but now we put music on in the kitchen that he listens to and if it’s catchy we jig along and the dogs come in and bark and jump around’ (C8); ‘We use CDs and listen to the wireless. She sings to the songs’ (C9).

The carers did not mention that they had used music or singing to help manage any behavioural problems during care giving but this may be due to the relatively high levels of functioning in the non-cognitive domains.

Ten week follow-up: PWD and carers

Both PWD and carers were interviewed 10 weeks after the conclusion of the singing group. For the participants with a dementia, interviews at this point in time were briefer and mostly sought information about music and singing activities since the previous interview.

Themes from PWD. Two primary themes and one secondary theme were identified by the seven remaining PWD participants: the themes of music engagement and enjoyment were clearly evident across responses as was the secondary theme of wanting to join another singing group. In regard to another singing group, all seven respondents expressed a desire to join one.

Music engagement. There was a sense of active and involved engagement in music listening, which was linked to the singing group, but less evidence of continued singing activity: ‘I listen to more music. Since the group I’ve done more listening’ (P1); ‘I like listening to music, it makes me feel real good’ (P2); ‘I find it miraculous that I can read complex music’ (P3); ‘I think it’s marvellous. It’s lovely even if we can’t sing’ (P8); ‘If I’m doing the dusting I’ll put on a CD while dusting. I put on more CDs now’ (P9); ‘I don’t listen to a lot of music. I watch TV, sometimes listen to Radio 3 or Radio 2’ (P10); ‘It was quite nice going and participating in the group’ (P11).

Enjoyment. At this point in the study it was more difficult for several PWD participants to clearly articulate their responses, yet when asked about the group, there were a range of enthusiastic answers which indicated a sense of belonging, fulfilment, purpose and value: ‘You can’t put a value on it. It’s wonderful and I enjoy it and I’m not saying that because you’re sitting here... it’s like meeting an old friend that you haven’t seen in years’ (P11); ‘We enjoyed it so much’ (P9); ‘I think it was very successful’ (P3); ‘I thought it was really well done, thoroughly fun’ (P2); ‘I think it is very important for the really older people’ (P8).

Themes from carers. Responses from carers corroborated PWD responses cited above and led to similar themes from carers. Four carers reported cognitive deterioration over the previous 10 weeks that included memory difficulties and fearful thoughts. The most salient theme, in addition to wanting to attend another singing group, was the importance of musical engagement.

Music engagement. As with PWD, music remained important to carers in their own lives but also in their relationship with their relative: ‘Music helps a great deal. He has always
been very keen on all sorts of music so it does work very well. When I put the rubbish out and get the chores done he’ll sit and relax with a tape or the radio on. He particularly likes jazz and songs of praise choirs. It gives both of us such a good feeling factor and you leave your problems behind because you’re in the singing’ (C1); ‘She has very clear memories of the singing group. . . Although she likes classical music you cannot sing to it so she’s been watching the search for the new Dorothy, she loves it because she can sing along with it. When she was attending the singing group she was confident she could remember the words and she was singing them afterwards’ (C2); ‘She now attends a choir and enjoys it very much, it’s very central in her life and I’ve made a commitment to make sure she gets there every week’ (C3); ‘She does sing a bit more to herself’ (C8); ‘The singing group did help and she looked forward to it. I put on CDs at home now’ (C9); ‘Singing and music is a source of relaxation. He likes to sing’ (C10); ‘He loves the music, it helps him relax’ (C11).

Discussion

Although designed as a mixed methodological study, standardised measures appeared less successful in detecting change over the course of this intervention for both PWD and family carers. If results were only based on standardised measures it could be argued that the singing group had relatively no impact on PWD or carers. However, this is a relatively small-scale study and the intervention was run for a very short time in the context of the length of time the dyads had been living with a dementia; longer-established groups with more participants may show more positive results. It may also be that as the Singing Together Group was only one afternoon a week it may not have been sufficient to improve wellbeing and was outweighed by the stress of caring throughout the week, 24 hours a day. Singing groups may therefore need to be introduced as part of a whole package of care that is available to support the wellbeing of the care dyad.

In relation to measures with PWD, except for a slight increase in depression scores, QoL, stress and anxiety remained relatively stable pre- and post-group; it is feasible the group helped to stabilise stress, anxiety and quality of life for PWD, as increases in anxiety and stress and a decrease in quality of life would not have been unexpected for people with this condition. Building on these results, future research utilising a comparison group could provide more conclusive support for this supposition.

Another prevailing issue is the difficulty in obtaining reliable standardised scores on QoL and other psychosocial constructs from PWD with moderate to moderate/severe levels of cognitive impairment even though a European consensus (Moniz-Cook et al., 2008) on these measures is emerging.

Similarly, carers’ scores on anxiety, depression, stress and QoL measures remained stable at pre, post and follow-up points. This also suggests that participating in a singing group may have acted as a buffer for the carer during a time when increases in depression, anxiety and stress, even if not at clinical levels, might have been expected. Additionally, the study sample included carers who were coping well with their role and who were reporting good quality of life at the beginning of the study. It may be that greater changes would be seen with this intervention with carers who were reporting poorer mood and less sense of wellbeing. In a future larger-scale study, it would be useful to examine how the constructs of carer burden (Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006; Volicer, 2005; Zarit, Reever, & Bach-Peterson, 1980) and resiliency (Gaugler, Kane, & Newcomer, 2007) respond to a singing group intervention as well as looking at changes in wellbeing. As is
apparent in positive psychology literature, a reduction in negative mood or experiences may not be the same as an increase in wellbeing or happiness.

Information from participant observations made during group sessions and subsequent interviews provided a different perspective than the quantitative data about the impact of the singing group on carers and their family member with a dementia. Many entered the study hesitant and cautious about participating in a singing group. Some had embarrassing or even humiliating childhood memories of music and singing experiences in school; others claimed no interest or ability in singing, while some had interest and ability but were unsure if this type of group would be helpful. The range of initial responses to the intervention was not unanticipated and likely reflects the range of opinions about singing held across the general population.

Although beginning a new group activity during a vulnerable time in one’s life can be difficult, both PWD and carers quickly developed rapport with other group members and began to easily participate in singing from the start of the group. The commonly held belief that people with a dementia are either not interested in or incapable of taking on new activities was not supported. In particular for the PWD, being able to participate in a singing group challenged their own beliefs about not being able to sing and no longer fitting into ‘normal’ activities. Through a supportive and engaging process PWD participants were able to take risks of learning new songs, rhythms and movements in a socially inclusive environment.

As the group progressed, observations of foot-tapping, smiling, nodding and attention directed toward the facilitator, in addition to high levels of singing participation, provided a strong indication that the intervention stimulated a great deal of interest and enthusiasm. This was further supported by interviews at end of group and 10-week follow-up when both carers and PWD reported high levels of enjoyment in the experience of group singing.

The intervention benefited carers in important ways; they reported feeling socially included in a non-medical activity (Hulme et al, 2009) with their relative where the focus was on each other, other group members and singing and not on neuropathological processes, medication or symptoms. Carers also reported that experiencing glimpses of their family member’s ‘old self’, although transitory, helped them recognise the person behind the dementia, potentially strengthening the relationship and commitment to caring.

Of particular note was how enthusiastically both carers and PWD described their positive experiences of the group; we were repeatedly told how enjoyable this was and how they wished it could continue. The social experience of group singing with people experiencing similar problems should not be underestimated. The level of enthusiasm was surprising to us and seemed to reflect the few opportunities for non-stigmatised socially inclusive activities available for this population.

In relation to Nolan’s Senses Framework, it is clear from the interview responses that many of the ‘senses’ were met with the community singing group. The atmosphere of the group and personal characteristics of the music facilitator made people feel safe (sense of security) and ‘valued’. Participants were immediately able to have a ‘sense of purpose’ and ‘belonging’ and the opportunity for new learning gave them a ‘sense of fulfilment’. By connecting to old familiar songs, people were able to reminisce about their past working lives and relationships, giving people ‘a sense of continuity’ and ‘a sense of being valued’. This framework seems to be a useful one against which other psychosocial interventions could be evaluated as a way of promoting a more positive approach to living with dementia.
In regards to future research, considering the results of this study and other small-scale quantitative and qualitative studies that have shown benefits of singing for the PWD and for the PWD-FC dyad (e.g. better concentration, reduction in problematic behaviours, reduced anxiety, increased quality of life and wellbeing), there is now sufficient evidence to warrant larger-scale studies, preferably RCT designs, to assess the impact of group singing compared to other group activities (e.g. relaxation training, visual art-making) and treatment as usual. In addition to examining clinical effectiveness (e.g. quality of life, wellbeing, reduction in psychological distress), health economic analysis should also be part of future studies. In relation to improving dementia care, it seems prudent to examine a large range of possible activities and interventions (e.g. art-making, cultural activities such as art gallery and museum programmes, physical activity, relaxation and mindfulness) that might help engage Nolan’s Senses Framework for both the PWD and their caregivers.

**Conclusion**

This pilot project found that the Singing Together Group was a very positive experience for people with a dementia and their carers and further research into the benefits is indicated with a controlled trial. Future studies could also consider whether open-ended singing groups would provide longer-term support for participants as well as immediate benefits of singing (Von Lob, Camic, & Clift, 2010). The study has demonstrated the importance of considering the dyad of care partners in dementia care and the need to provide opportunities for people to do informal social activities together which focus on the PWD’s strengths rather than their weaknesses and which support the relationship as well as promoting the wellbeing of both care partners. Carers seeing their relative able to behave normally in a social situation may help them retain a sense of the PWD’s selfhood and, by providing the opportunity for peer support, help reduce their own isolation. Indications are that a good experience in a singing group might give PWD the confidence to try out and engage in other social activities that they have discontinued and so this may pave the way back into social integration. In designing future dementia services, it would be important to be able to offer people a number of activities that could help them manage this condition together with an emphasis on improving wellbeing using the Senses Framework as a guide.

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**Notes**

1. See www.singingforthebrain.org/.
2. Referring to the number of sessions.
3. Carer 5 took up piano playing for the first time during the group and continued it after its completion.
References


Paul M Camic is professor of psychology and a consultant clinical health psychologist, Department of Applied Psychology, Canterbury Christ Church University, Salomons Campus, Tunbridge Wells, Kent, UK.

Caroline Myferi Williams is a consultant clinical psychologist, Older People’s Community Mental Health Services, Sussex Partnership NHS Foundation Trust, Hove, East Sussex, UK

Frances Meeten is a Research Fellow, School of Psychology, University of Sussex, Brighton, East Sussex, UK