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Shreena Unadkat BSc

**GROUP SINGING FOR COUPLES WHERE
ONE PARTNER HAS A DIAGNOSIS OF DEMENTIA**

Section A: The experience of group singing for people with dementia and their
caregivers: A review of the psychological evidence and underlying theories

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Section B: Theorising the experience of group singing for heterosexual couples where
one partner has a diagnosis of dementia

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SALOMONS

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Summary of Portfolio of Work

This work considers the experience of group singing for couples where one partner has a diagnosis of dementia, and explores the underlying theoretical mechanisms of the experience

Section A is a literature review exploring the psychological theories behind the experience of singing and providing an overview of the evidence to support the use of group singing in dementia care. The literature indicated positive outcomes for group singing for people with dementia and their caregivers. A need for further research is highlighted, particularly from a relational context as current research explores the separate experiences of people with dementia and their caregivers and not the relationship between them.

Section B aims to theorise the experience of group singing for couples where one person has a diagnosis of dementia. A qualitative grounded theory study is presented in which couples carry out in depth interviews. The theory that emerged showed the act of singing combined with effective group facilitation enabled equal participation and a group effect. A further benefit of new learning and creativity was identified, and these factors were linked with benefits for both the individual and the couple.

Section C offers support for the review and study, alongside reflections on the research process.

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Section A: The experience of group singing for people with dementia and their caregivers: A
review of the psychological evidence and underlying theories

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Psychology

Abstract

This paper evaluates the existing literature base regarding the experience of group singing in dementia care. Theoretical perspectives and empirical research are presented, followed by a discussion of the findings, implications for clinical practice and recommendations for future research. The current findings indicate initial positive experiences for people with dementia and their caregivers who take part in group singing. Initial studies used observational methods, with a more recent move to including the perspectives of participants. Standardised measures yielded limited significant results, with qualitative data proving to be the main medium through which benefits are reported. Questions around the suitability of standardised measures in this field are discussed, along with a recommendation for clinical and research practice to be grounded in participant experience.

Introduction

Dementia

Dementia is defined as a chronic and progressive clinical syndrome in which the affected person experiences a widespread deterioration of cognitive function, beyond what may be expected from normal ageing. The symptoms of dementia are varied and are one of the major causes of disability and dependency amongst older people globally. Whilst symptoms are varied and will be experienced differently by all people affected, common symptoms can include impairments in memory, planning, concentration, organisation, language, visuospatial skills, learning capacity, judgement, and mood. In the later stages of dementia, a person may also experience appetite disturbance, muscle loss, and weight changes (World Health Organisation (WHO), 2012).

Dementia can be caused by diseases in which the development of proteins or abnormal structures within brain cells damage their structure or chemistry (Alzheimer's disease, Dementia with Lewy bodies, Frontotemporal dementia), or by the narrowing or blockage of blood vessels to the brain (Vascular dementia), leading to cell death. Rarer causes of dementia include alcohol-related brain damage, corticobasal degeneration, progressive supranuclear palsy, Niemann-Pick disease, HIV infection and Creutzfeldt-Jakob disease (Alzheimer's Society, 2014a).

It is estimated that there will be over 850,000 people with dementia (PWD) in the UK in 2015 (or one in every 79 (1.3%) of the entire population and 1 in every 14 of the population aged 65 years and over) cared for by a further 670,000 people. This represents a cost of £26.3m billion (Alzheimer's Society, 2014b). The most recent global prevalence rates show there are 35.6 million people suffering with dementia worldwide, with this set to double every 20 years at the current rate of growth (Prince et al., 2010).

Emotional and Social Impact of Dementia

Alongside the cognitive and medical impact of dementia, the emotional and social impact is far reaching, affecting the individual diagnosed as well as the individual's social network. The journey from noticing initial symptoms through diagnosis and to adaptation and adjustment has historically been supported by family members (Chenoweth & Spencer, 1986). Symptoms are often noticed gradually and brought to the attention of health professionals by the surrounding network (Teel & Carson, 2003). It is estimated that many people with dementia live at home with partners or other family members who become the main source of care as the syndrome progresses, and who save an estimated £11billion in care costs each year (Alzheimer's Society, 2014b).

The emotional impact of dementia has been well documented, showing an increased prevalence of depression, anxiety, and other emotional conditions (Ballard et al., 2000; Cuijpers, 2005; Ritchie & Lovestone, 2002). These cognitive, emotional and behavioural changes occur within the context of existing social relationships and can therefore have an impact on carers and the nature of supportive relationships. Whilst it is important to note that many caregivers report positive aspects of caring (Cohen, Colantonio & Vernich, 2002) the experience is also linked with adverse effects in multiple areas of life. Dementia carers experience a higher level of distress and strain than other carers of older people (Moise, Schwarzingler, Um, 2004) and report anticipatory grief, loss and changing of roles in their relationships (Alzheimer's Society, 2014c). Carers also show increased symptoms of depression and anxiety when compared to age and gender norms (Cuijpers, 2005) and report a higher incidence of physical ailments such as infections (Kiecolt-Glaser, Dura, Speicher, Trask, O. J., & Glaser 1991).

Relationships and Personhood

Research has historically focused on the separate experiences of the carer and person with dementia. Some studies have begun to explore the effect of dementia on the relationship between the two: especially on couple relationships, as many PWD live at home with their spouse. Research suggests that the impact on marital relationships may be significant, with couples experiencing reduced shared activities, loss of emotional support, loss of intimacy, decreased verbal communication and a decrease in relationship quality (Baikie, 2002; Garand et al., 2007; Morris, Morris & Briton, 1988). There is small but growing body of evidence exploring how couples manage the challenges to their relationship, noting the importance of concepts such as connectedness and separateness, working together, maintaining involvement and retaining couple identity (O'Shaughnessy, Lee, & Lintern, 2010; Keady & Nolan, 2003; Merrick, Camic, & O'Shaughnessy, 2012;). Nonetheless, research that explores the person with dementia as part of a relationship or that combines the perspectives of both partners is limited. It has been argued that a move towards a wider understanding of the impact of dementia on relationships, not just individuals, is needed (Prakke, 2011).

The situating of people with dementia within a social and relational context is a key aspect of the concept of 'personhood', as suggested by Kitwood (1997). Kitwood calls for both research and interventions in dementia care to preserve the person behind the diagnosis. Dementia has been described as being a prominent modern cultural image of ageing, in which notions of hopelessness, loss of identity and depersonalisation are dominant (Stoddart, 1998). Interventions based on personhood would ideally be placed within a psychosocial context in order to recognise the person with dementia as a part of interconnected, supportive relationships. This view has been supported in recent research, which shows that psychosocial interventions can reduce caregiver burden, delay nursing home admission, reduce behavioural symptoms, improve cognitive abilities, and promote everyday functioning (Brodaty, Green, &

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Koschera 2003; Brodarty & Donkin, 2009; Vernooij-Dassen, Vasse, Zuidema, Cohen-Mansfield, & Moyle, 2010). However, as many people with dementia struggle to access traditional social activities due to cognitive impairment or loss of confidence (Frank et al., 2006), the need to explore alternative activities which can be accessible to both the person with dementia and their caregiver is indicated.

Arts and Health in Dementia

A growing area of interest for people with dementia and their carers are arts-based interventions. Arts based activities appear to have a number of strengths when choosing an intervention including the accessible opportunity for expression, play, creativity (all of which are also highlighted by Kitwood's (1997) model of personhood). A recent study reported that involvement in arts based activities help to preventatively reduce the risk of dementia (Roberts et al., 2015). A review into the participative arts for dementia noted that although the research base in this area is relatively sparse, initial findings report positive outcomes in various arts interventions (Zeilig, Killik & Fox, 2014). The review also noted that musical activities were the only ones to have been explored in a Cochrane review (Vink, Bruinsma, & Scholten, 2003). This Cochrane review reported that whilst all studies included identified positive effects of music therapy in dementia care, robust conclusions could not be drawn due to small sample sizes, an inability to compare across studies due to differing measures, and poor reporting of methodological processes. A narrative synthesis review of music therapy further reported group singing as a particularly effective medium for benefits for people with dementia (McDermott, Crellin, Ridder, & Orrell, 2013). Given the recent increase in group singing activities for people with dementia nationally (Alzheimer's Society, 2010d), exploring the impact and experience of group singing may be of particular importance to researchers interested in arts-based interventions for dementia.

Singing as an Intervention

The singing of songs as a social vehicle is a long standing part of human history across cultures, ages, races and genders. Accounts of people singing together to celebrate, pray, mourn and entertain have been noted across the world throughout history (Koopman, 1999). Whilst the evolutionary origins and purposes of singing are debated, there seems to be a consensus around its universality and early acquisition into human behaviour as a possible form of communication (Mithien, 2005). Research indicates that singing activities can still be accessible to PWD with language impairments. Findings from cognitive neuropsychology point towards the idea that the processing of singing (melody & lyrics) is a separate cognitive system to that of language recall. This was first hypothesised by Broca in 1861 who found that an aphasia patient who could not pronounce words in speech was able to produce intelligible words when singing (Peretz, Gagnon, Hébert, & Macoir, 2004). This has been demonstrated in a number of dementia cases (Cuddy & Duffin, 2005; Kerer et al., 2008) and is partially evidenced in neuroimaging studies (Jeffries, Fritz & Braun, 2003; Özdemir, Norton, & Schlaug, 2006; Peretz, Gagnon, Hébert & Macoir, 2004).

Additionally, singing has been shown to have perceived physiological, emotional, cognitive and behavioural benefits (Clift, Hancox, Staricoff & Whitmore, 2008; Clift et al., 2010; Hillman, 2002). Specifically it has been shown to increase positive affect when compared to listening to choral music (Kreutz, Bongard, Rohrman, Hodapp & Grebe, 2004), suggesting that a significant aspect of the emotional benefit comes from active engagement.

Theoretical perspectives. The positive effect of singing on wellbeing can be thought about from two theoretical perspectives: the first exploring the strong link between music and emotional state, and the second linking these emotional states to the concept of wellbeing. Thompson and Quinto (2011) draw on multiple neuropsychological and cognitive theories of

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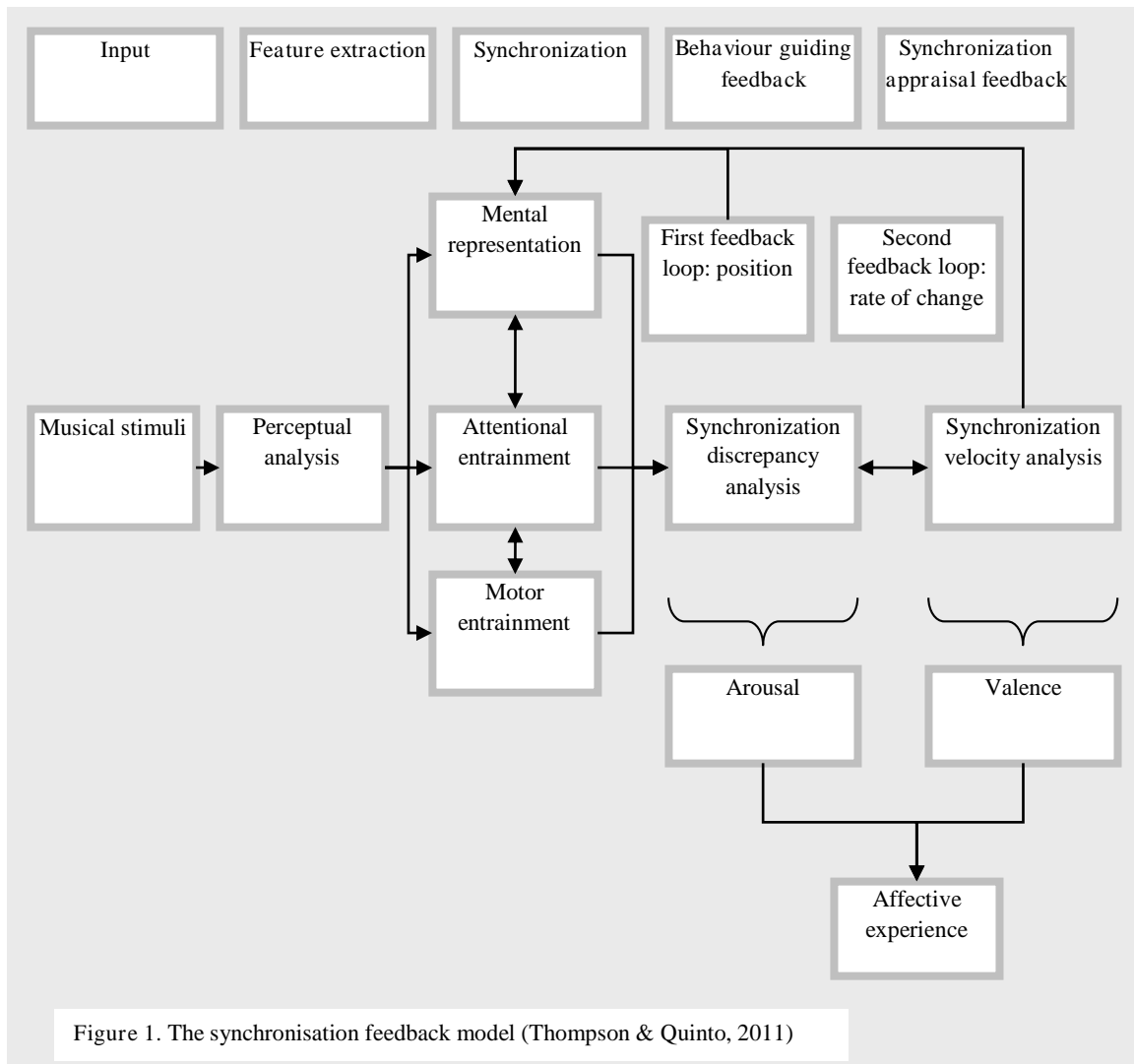
attention, expectation and association to suggest that the power of music on emotion occurs due to our ability to synchronise at multiple levels (attention, imagination and action). Neuroimaging studies have shown that the mirror neuron system activates motor areas of the brain when shown images of a person under threat (Nummenmaa, Hirvonen, Parkkola, & Hietanen, 2008). This can be seen as a hard-wired tendency to synchronise between perception and action which may have served as a useful social tool historically. Music is then described as building upon the capacity and tendency of human beings to synchronise.

The model states that as music is heard, our mental perception of the music will induce a synchronisation between attention and motor systems and the tempo, rhythm and tone of the music. Any discrepancies in synchronisation produce a greater effort to synchronise in an initial feedback loop (leading to arousal). An analysis of the velocity of the music then gives rise to a positive or negative valence. The effect of this feedback loop combined with arousal and valence leads to a powerful affective experience (Figure 1).

Whilst this model goes some way to explain the relationship between music and emotions, it offers little explanation regarding the link between the synchronisation and the varied affective experiences induced by music. Following this model, one may expect that the same tempo and rhythm will produce the same affective experience across populations; however different people respond differently to similar pieces of music. Some room is given to “mental representation” in the model, and more detail around this may be needed to account for the subjective human response to music.

Although we can link music to strong emotional responses, simply doing so does not demonstrate a link to wellbeing. In the second theoretical perspective, Lamont (2011) uses the positive psychology framework (Seligman, 2002) to demonstrate how the experience of music

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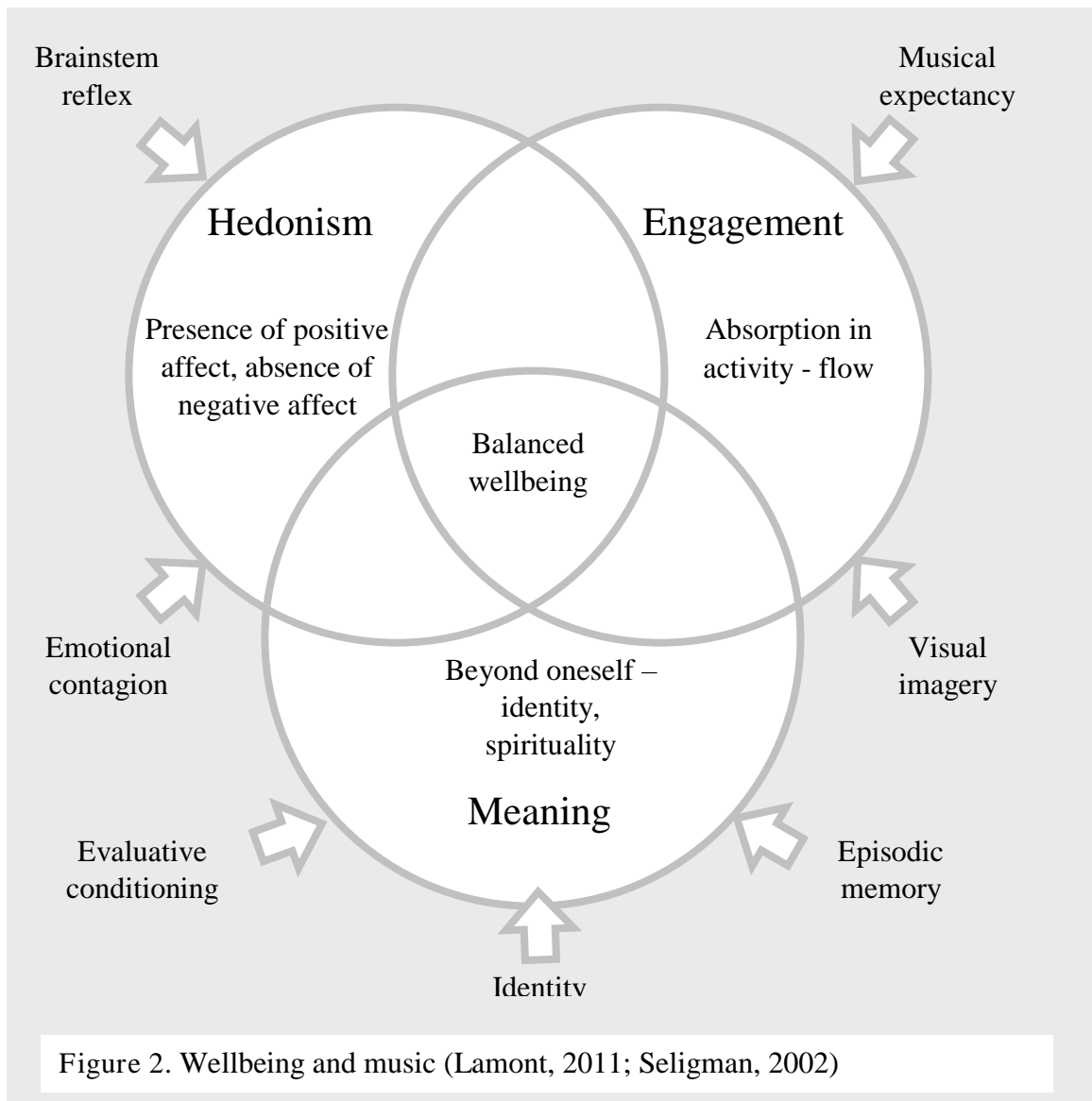


incorporates all the components for balanced wellbeing (i.e. pleasure, engagement and meaning) (Figure 2).

Drawing on similar cognitive theories of expectancy, memory, and brain activation as Thompson and Quinto (2011) above, Lamont demonstrates how the experience of music activates reward systems in the brain and can evoke pleasurable feelings without conscious attention. The theory goes on to state that although there is a general lack of research into the concept of meaning, music can accompany meaningful activities (such as spiritual worship, or social celebration) and can be associated with meaningful memories. Finally, Lamont explores how the act of listening to music provides a means to engage with activities such as

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reminiscence, catharsis, and calming. Additionally the model links music listening to the concept of ‘flow’; namely the act of being fully absorbed in an activity.



This model relies strongly on the presence of a positive affect and the absence of negative for wellbeing, however sad or poignant music can enhance negative mood. Additionally little attention is paid to the social element of music, which may be a significant factor in engagement. It is worth noting that both models focus on the act of music listening and not singing as the main source of emotional response/wellbeing. Group singing, may build upon musical experiences by providing further opportunities for social synchronisation and

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meaning through the membership of a group (Anshel & Kipper, 1988). Additionally singing can be seen to be a more active method of engaging with music than simply music listening, furthering the effect of engagement on wellbeing (Stacy, Brittain, & Kerr, 2002).

Empirical research. Having explored the underlying theoretical perspectives for the use of singing as an intervention, attention can now turn to the empirical literature base for its use in dementia care. Studies using singing during caregiving have shown benefits for ease of transfer, expressed emotions, communication, mood and resistance (Götell, Brown, & Ekman, 2009; Götell, Thunborg, Söderlund, & Wågert, 2012; Hammar, Emami, Engström, & Götell, 2011). Whilst these results indicate positive benefits of singing in dementia care, this review will focus on the use of group singing as opposed to individual singing due to the potential benefits of group membership, engagement, and social inclusion detailed above.

Research reviews. Three recent reviews into this broad area that include group singing have looked at a mixture of interventions such as group singing, individual singing, music therapy, music listening, and other participatory arts in dementia; however none identified have focused solely on group singing. The detailed findings and critique of these reviews is beyond the scope of this paper, however brief findings are presented.

McDermott, Crellin, Ridder, & Orrell's (2013) narrative synthesis of music therapy in dementia highlighted the use of group singing as an important medium for change amongst varied music therapy interventions. Skingley & Vella Burrows (2010) carried out a review into therapeutic singing and music for older people, citing positive effects of music listening, touch, and group singing on enjoyment, social interaction, physiology, memory and cognitive stimulation. The authors note the limitation of carrying out a 'mini' review in order to appeal to busy nursing practitioners, and recommend a fuller review be carried out for depth. In a critical review of the participative arts for dementia, Zeilig, Killick and Fox (2014) find similar

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positive outcomes in singing groups for people with dementia, noting an enhancement of mood, quality of life (QOL), and cognitive ability in the few studies explored. However methodological weaknesses and the paucity of research was also highlighted, making it difficult to draw conclusions in this case.

Rationale for current review. The literature broadly supports the view that group singing can be beneficial for people with dementia and their caregivers. Given the initial benefits found by reviews in group singing, and that some reviews indicate a difference between the act of singing and other musical interventions, it is surprising that all reviews thus far have explored music listening, instrument playing, group singing and caregiver singing under the same umbrella. Additionally, little information is paid to the difference between music therapy interventions and group singing interventions that are not grounded in music therapy theory. While the reviews hold some strength in their methodology (providing clear exclusion and inclusion criteria, systematic search methods, and clear critique of the surrounding literature), the lack of distinction between types of music intervention causes some confusion as to where the positive benefit lies. It may be that in some cases singing interventions are unable to be individuated from other types of music; however the need for a more focused review to explore the experience of group singing for people with dementia and their carers is clear.

In order to focus on personhood this review will aim to explore not only ‘objective’ outcomes (such as health, wellbeing, cognitive ability and quality of life) of group singing, but also the subjective experiences as reported by people with dementia and carers. The review will be structured around the two research questions:

- 1) What health, wellbeing, QoL and cognitive outcomes are reported for people with dementia and their carers who take part in group singing?

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- 2) What do people with dementia and their carers report about the experience of group singing?

Methodology

A systematic literature review was conducted to synthesise findings around the experience of group singing for people with dementia and their carers. Findings are reviewed and critiqued in a traditional review structure (i.e. presentation of findings and critical review of methodology).

Search Strategy

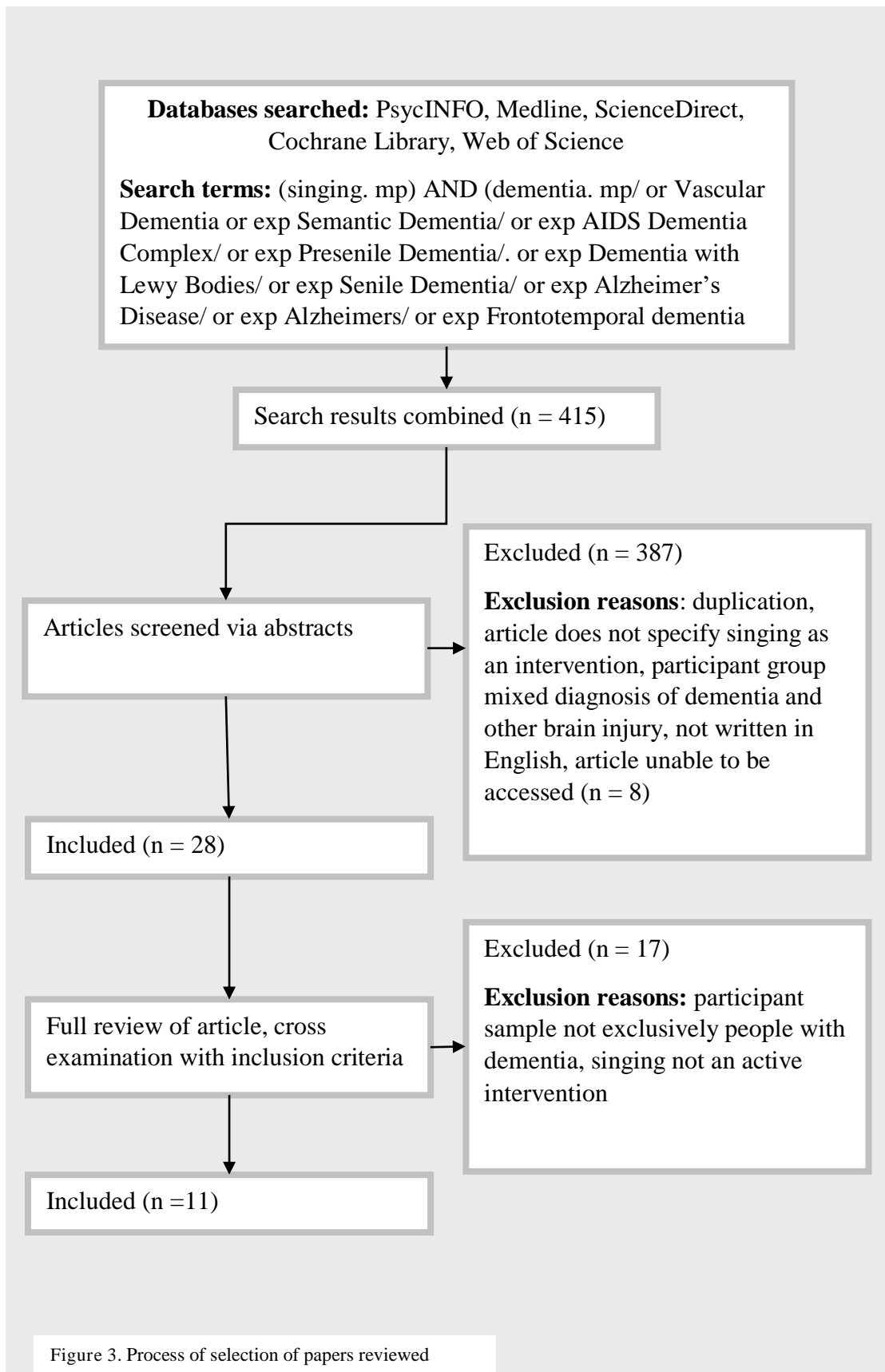
The following electronic search engines were used to identify research papers: PsycINFO, Medline, ScienceDirect, Cochrane Library and Web of Science. References were hand searched for additional material, and any papers deemed relevant were obtained in full where possible. Articles were restricted to English language articles. No parameters were set around date as no previous reviews had been identified. Full search terms and strategy can be seen in Figure 3.

Selection Criteria

Papers were selected for review if:

- They included group singing as an active intervention, and specified the details of this intervention (in both music therapy and non music therapy settings)
- This intervention was empirically evaluated
- The intervention was carried out with a participants with a diagnosis of dementia (and their carer where specified, although this was not necessary for inclusion in the review)
- They were published in a peer reviewed journal
- They were written in English

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Data Extraction and Analysis

Data was synthesised from the selected papers with the aid of a specially constructed 'data extraction' form (Appendix A). This form considered the type of intervention, the training of the facilitator, sample size and characteristics, design, analysis and main findings. Eleven papers are presented and critically evaluated in accordance with the Critical Skills Appraisal Programme (CASP) guidelines (1999) (Appendix B). For each study an overall percentage on the relevant CASP guideline checklist was calculated by going through each category to decide whether studies met standards fully, partially or not at all. Mixed method studies also have individual qualitative and quantitative scores reported. Details of papers, including rating on quality criteria items, are presented in Table 1.

Results

Studies which explore group singing for people with dementia and their caregivers are discussed below, along with an individual methodological critique. Following this, a brief summary of all the research findings are presented in order to indicate overall trends.

Quantitative Studies

Four of the noted studies used solely quantitative research designs. Of these, two were the earliest studies in the field (Olderog-Milliard & Smith, 1989; Hanson, Gfeller, Woodworth, Swanson, & Garand, 1996) and two were recent randomised control trials (RCT)(Cooke, Moyle, Shum, Harrison, & Murfield, 2010; Särkämö et al., 2013). The earliest study of those examined in this review carried out by Olderog-Millard & Smith (1989) explored group singing and behavioural changes in Alzheimer's patients from a specialist Alzheimer's disease (AD) residential unit. Behaviour was recorded by two observers using an adapted 'behavioural mapping' tool. The study shows a significant increase in verbal/vocal participation during singing sessions when compared to discussion control.

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Table 1 Papers reviewed

Author and date	Location	Intervention	Sample size and characteristics	Design, methodology and analysis	CASP quality score	Effect size	Main results and effect sizes (if applicable)
Dassa, A. & Amir, D. (2014)	Israel	Music therapy intervention: Group singing 8 session programme - sang familiar and national identity songs. Discussion regarding topics and feelings after each song. Facilitated by a music therapist.	6 PWD (n = 6) Mid-late stage AD (defined by MMSE) Randomly selected from 3 larger groups	Randomly assigned to singing groups as part of a larger study Content analysis	70%	N/A	Songs from the past (especially songs related to national identity) elicited memories. Group singing encouraged spontaneous responses in conversation. Group members expressed positive feelings, a sense of accomplishment and belonging.
Davidson, J. W. & Almeida, R. A. (2014)	Australia	Group singing compared to a control (verbal quiz): one off session and 6 week programme	Group A formed from community members of Alzheimer's charity and family carers, 6 PWD 6 carers (n = 12) and Group B formed from residential facility and professional carers (n = 15, 11 PWD 4 carers) 1. Control PWD group (n=8)	Mixed methods Group A + B: Pre – post questionnaire of one off session analysed with a paired sample t-test Group B: questionnaire as above and interviews at weeks 2,4,6 of group.	59.5% (Quantitative: 54% Qualitative: 65%)	Not reported	One off session: quantitative positive changes in PWD found (pre-post) when compared to control (verbal quiz): lucidity (p < 0.05), agitation (p < 0.05), focus (p < 0.01). Caregiver energy, mood and focus improved (pre-post) (p < 0.05) Six week singing: Quantitative data only shows improvement on PWD focus on week 2 (p<0.05) Qualitative data supports these improvements, and also shows positive identity construction elicited by singing (which in turn appears to facilitate socio-emotional connection between carer and PWD. Reminiscence singing valued.

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Harris, P. B. & Caporella, C. A. 2014	USA	Group choral singing constructed to decrease stigma and reduce isolation. Weekly rehearsals for 8 weeks culminating in a concert.	6 PWD (Alzheimer's diagnosis), 7 family members, 13 undergraduate college students) (n =26). Recruited through local Alzheimer's charity and local college	Mixed methods Repeated measures with pre, midway and post-test rating data regarding stigma from college students, reported using descriptive statistics. Focus group for PWD and family members, analysed with thematic analysis.	70% (Quantitative: 55% Qualitative: 85%)	N/A	Quantitative data show a decrease in negative responses and an increases in positive responses when students had a higher knowledge level about PWD. Qualitative data from students also showed increased recognition of capabilities, lessened social discomfort, and reduced stigma. Two major themes from focus groups with PWD and family members: Decreased social isolation and enjoyment of time spent together.
Osman, S. E., Tischler, V. & Schneider, J. 2014	UK	Group singing (familiar songs) with movement: ongoing sessions (Singing for the Brain model)	PWD-carer dyads 10 PWD 10 carers, 3 mother daughter dyads and 7 marital dyads (n=20) Attended a minimum of 2 SftB groups	Qualitative – semi structured interviews analysed using thematic analysis	55%	N/A	Positive feedback noted from participants with 6 main themes identified: 1) Social inclusion and support, 2) Shared experience, 3) Positive impact on relationships, 4)Positive impact on memory, 5) Lifting the spirits, 6) Acceptance of the diagnosis
Särkämö, T. et al, 2013	Finland	Group singing with exercises 10 week programme (compared to group music listening)	89 PWD-carer dyads (n=89) (PWD with mild-moderate dementia) randomised to 10 week singing group, music listening group, or usual care control group	RCT single blind Pre, post and 6 month follow up standardised neuropsychological and QOL measures (valid and reliable)	90%	Where reported, med-large effect (r=.33-.50)	Compared with usual care, singing and music listening improved mood, orientation, memory, executive function, general cognition. Singing also enhanced short term and working memory and caregiver wellbeing.
McCabe, L., Greaseley-Adams, C. & Goodson, K. 2013	UK	Group creative singing: development, writing, design and performance of a musical production about experiences of love (1 year project)	9 PWD, 3 carers (n = 12) who had all participated in the year long programme	Qualitative – semi structured interviews (individual and group) analysed using thematic analysis	75%	N/A	Positive outcomes found include new learning, joy, increased confidence and changing perception of self. Performances were highlighted positively. The opportunity for PWD and carers to learn new skills as equals was highlighted. The difficulty of time limited interventions was noted as participants experienced much sadness at the close of the programme.

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Camic, P. M., Williams, M. W. & Mceteen, F. 2013	UK	Group singing and movement for 10 weekly sessions	10 PWD 10 family carers (n = 20) Mixed diagnoses	Mixed (pre, post, 10 week follow up) Repeated measures standardised cognitive and QOL measures (valid and reliable) Specially constructed engagement measure during sessions Semi structured interviews	77.5% (Quantitative: 70% Qualitative: 85%)	N/A	PWD deteriorating throughout 10 week programme however QOL stayed the same. Other standardised measures show inconclusive results. Engagement and attendance high throughout the programme. Qualitative data indicates a promotion of wellbeing of all participants with many positive themes covering (but not exclusive to) enjoyment, social inclusion, new learning, challenged beliefs and attitudes, enhanced emotions and impact outside of the group)
Davidson, J. W. & Fedele, J. 2011	Australia	Group singing programme (x2) developed for older people. 6 weeks, facilitated in a community and residential setting	42 into 2 groups. Group 1: 11 PWD, advanced range, 11 carers, 1 carer who attended alone (n = 23) recruited through Alzheimer's charity and Group 2: 18 residential PWD, mild-moderate range and 7 volunteer support workers (n = 25)	Mixed quantitative and qualitative. Standardised measures (QoL, HDS (mental decline), Likert scale) at pre and post (valid and reliable) Anecdotal feedback, observational data by facilitator, videotaped sessions to observe interactions	59% (Quantitative: 68% Qualitative: 50%)	N/A	No significant effect found on standardised outcome measures. Study specific measures and qualitative analyses indicate that participants showed increased lucidity, improved social interaction, enjoyment of singing, singing engagement and carry over recall from one week to the next.
Cooke, M. L. et al 2010	Australia	Group singing: Live music programme with facilitated singing and listening (3/week x 8 weeks) compared to reading control	47 PWD (mild-moderate, no significant difference in MMSE scores) residing in a nursing home with a history of aggression/agitation	RCT cross over design. Participants allocated to each group with 5 week period between activities. CMAI-SF (agitated behaviours) and RAID (anxiety) measures(valid and reliable) at pre, post 1 st group, post 2 nd group.	75%	N/A	No significant effect of music programme on anxiety or agitation when compared to reading control group. Sub analysis of 24 participants attending ≥50% of both groups showed increases in verbal aggression over time. T55

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Hanson, N., Gfeller, K., Woodworth, G., Swanson, E. A. & Garand, L. 1996	USA	Music therapy intervention comparing group singing, movement and rhythm exercises at high and low demand. Developed and facilitated by music therapists in 5 different facilities. Delivered bi-weekly to groups of 4-6 participants over 12 weeks.	51 PWD (Alzheimer's) of high, mid and low cognitive functioning. Recruited from adult day program, residential care facility, general nursing home, Alzheimer's units within a hospital and a long term care facility	3 levels of IV: level of cognitive functioning, type of musical activity, difficulty of activity. DV: Trained observers rated quality of participation using a time sampling sheet. Analysed 3x2x3 ANOVA. Likert scale evaluation of programme collected from facility directors.	58%	N/A	Participants at all three stages of cognitive functioning showed greater amount of participation during movement activities than signing activities. Significantly greater amount of passivity occurred during singing. Participants showed more participation in rhythm and singing when presented at low demand. Randomised by site?
Olderog- Millard, K. & Smith, J. M. 1989	USA	Group (therapeutic) singing condition compared to baseline condition discussion with visual prompts group. Familiar songs sung over bi weekly sessions for 5 weeks	10 PWD (diagnosed Alzheimer's/organic brain syndrome/probable AD)	ABABA design (with participants serving as their own controls). Direct observation of physical and social behaviour frequencies using "behaviour mapping" over a specified time. Analysed using a two way within subjects ANOVA	54%	N/A	Results show significant difference ($p < 0.05$) between baselines (discussion) and treatment (singing) in a) Sitting and Walking with Others behaviours during or immediately after sessions, b) a higher level of vocal/verbal participation in treatment sessions, b) increased social behaviour (Walking with Others) post treatment session. Additionally, researchers note significant increase in many physical and social behaviours after both baseline and treatment sessions.

PWD = person with dementia

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The study showed some considerable strengths considering it was one of the first in this area: high inter-rater reliability, a clearly described intervention and replicable analysis. The study's main weakness occurred in the quality of the "behaviour mapping tool" which is not well described. Little description is given to how the two observers recorded behaviours for all 10 participants during the sessions. Potential confounding variables (such as usual treatment for patients or membership in other groups) were not considered. Additionally, whilst the ABABA design holds strengths in attributing the change found to the intervention, it has been historically used for single subject studies so that behaviours can be fully observed. As an interesting comment on the process of dementia care research, the authors noted that "behaviour mapping is one of the few feasible ways to measure changes objectively in patients with AD as verbal information from demented patients is not reliable" (p.63). The lack of attention paid to the perspective of the person with dementia is common in other studies; this early study may have unintentionally demonstrated this view explicitly by not considering other ways in which to incorporate the person.

A later and larger study carried out by Hanson, Gfeller, Woodworth, Swanson and Garand (1996) focused on levels of participation in activities by comparing group singing with group movement and group rhythm sessions (each activity carried out by each group over 12 weeks). This study presented these activities at two levels of difficulty (high and low) to people with dementia at three stages of functioning (high, medium and low), and measured purposeful participation in these exercises. This study is one of two found that explicitly describe the intervention as a 'music therapy' intervention: in this case, the interventions were designed, checked and validated for difficulty levels by panels of music therapists with expertise in the field.

The findings showed significantly higher levels of participation for all participants in movement activities than singing, and significantly higher levels of passivity during singing

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when compared to both other activities. The authors hypothesised that singing requires a greater cognitive ability (as verbal abilities decline prior to gross motor skills) than non-verbal activities, resulting in passivity. Participation was rated by two observers using a scale from “low response” to “active disruption”; authors noted that all activities resulted in low levels of disruption.

A key strength of this study was seen in the thorough development of the interventions evaluated. Activities were independently examined by panels of seven music therapists for suitability and levels of difficulty. Furthermore, the distinction of participants’ different levels of cognitive functioning and the testing across outpatient, residential and community settings added to the breadth of the study. The use of a greater statistically sensitive level ($p > 0.01$) is appropriate due to the number of t-tests used in analysis.

Some key aspects were missing from the reporting within this study, such as any power calculations, the order in which the interventions were carried out over the 12-week programme, and any description of any counterbalancing attempt. The authors appeared to link participation with observed low or high responses. Although these responses were externally observed there is no discussion of how the observer may have interpreted responses in a different way to the participant, or of the individual differences between participants (who may not have been expressive either naturally or as part of the deterioration). Nonetheless, the findings of this study should be noted as they go against the general preference for singing activities in the literature, and make the important argument for tailored interventions for levels of difficulty.

A more recent RCT addresses some of the methodological issues in the above studies. Cooke et al. (2010) report on part of an RCT using a cross over design to study the effects of music singing and listening on agitation, aggression and emotion compared to reading group

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control. Standardised measures of agitation and aggression were used (completed by care staff), alongside assisted self-report anxiety and QoL standardised measures. Findings show no significant effects of the music intervention on any of the measures; however one interesting finding showed a significant increase in verbalisation from participation in both groups.

This rigorous design benefited from the use of valid and reliable standardised measures, the measurement and adjustment for confounding variables, largely similar groups in cognitive ability and demographics, and staff being blind to the interventions. The authors' also included self-report measures for the participants with dementia. The music intervention did not separate singing and music listening, so we are unable to determine their individual effects. Although participant inclusion in the programme was dependent on a history of aggression or agitation, standardised scores on these measures were initially low. It may be that any other effects of the groups were missed as the main research questions were based around aggression, agitation and anxiety. Additionally, the authors noted that had the person with dementia and carers/proxies been used to measure both agitation and anxiety the results may have been vastly different, and recommend that all perspectives be included in future research.

An RCT study that also resolved many of the methodological issues of the field was carried out by Särkämö et al. (2013). That study adopted a single blind approach and randomised 89 dyads to three groups: a singing coaching group, a music listening and discussion group, and care as usual. A comprehensive battery of neuropsychological tests were carried out with people with dementia at pre, post and 6 month follow up. Additionally, QoL and mood measures were carried out with people with dementia and wellbeing, carer burden, and semi structured telephone interviews between post and follow up testing were completed with family caregivers. Findings show that both music interventions maintained or improved cognition for the people with dementia post intervention, with some areas of cognition still improved at follow-up for the singing group. Caregiver wellbeing was also improved. The

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long-term effects on cognition were marginally statistically significant, however, they do provide support for that singing activities are cognitively stimulating. The study showed a number of assets, which included the use of conservative statistics to strengthen findings (namely Tukey's honest significance test), well validated measures, detailed intervention planning, and the consideration given to confounding variables. Where effect sizes are reported they fall within the medium to large range, however they are not consistently reported throughout the study. The findings add a great deal to the literature around the impact of group singing for people with dementia and caregivers; they may indicate that other studies (below) that have had difficulties finding significant results on standardised measures may be due to small sample sizes or methodological weaknesses reported, rather than singing as an intervention.

Mixed Methods Studies

Four studies reviewed employed a mixed methods approach (Davidson & Almeida, 2014; Davidson & Fedele, 2011; Harris & Caporella, 2014; Camic, Williams, & Meeten, 2013). The study carried out by Davidson & Fedele (2011) explored the impact of a six-week group singing programme for people with dementia and their family caregivers. Originally developed by music therapists and educators for older adults mainly without dementia (based on a UK model, (Clift, Hancox, Staricoff, & Witmore, 2008), the intervention incorporated new and familiar songs, rhythmic movement, harmonisation, encouragement of reflective listening and a strong emphasis on tailoring the intervention to the ability of the group. The intervention was trialled on two groups; one community group of people with dementia accompanied by family carers, and one residential group accompanied by volunteer support workers. A number of standardised measures and Likert scales were carried out pre and post intervention on wellbeing, QoL, cognitive decline, mood, social contact, and programme experience. The study also employed a qualitative element. No significant effects was found on standardised

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measures, however the qualitative data showed increased social interaction, enjoyment, engagement and lucidity for people with dementia rated on an observed checklist over the 6 week singing programme.

This study's main strengths were in the varied nature of its sample and its detailed descriptions of demographic breakdown, as these provide information that other studies neglect. The report did not provide power calculations, and therefore it was uncertain whether the sample size was enough for quantitative analysis. Additionally, non parametric statistics were used as the sample did not meet assumptions for parametric testing, further weakening the power of the quantitative element. The qualitative element of this study appeared to detect change in response to the intervention, and this is clearly reported in the text. However, there was no description of how representative quotes were chosen to map onto the concepts measured quantitatively (for example lucidity or energy), making the study difficult to replicate. Although the facilitator of the groups was involved in analysing videos of session for the study, there is no discussion in the text of how potential bias was mediated.

The findings from this study were further developed in a later study involving the lead author (Davidson & Almeida, 2014), in which the same singing programme was used. This was a mixed methods exploratory study looking at the impact of the group singing intervention for people with dementia and caregivers compared to a verbal quiz control. In stage one (quantitative) of this study, all carers (group A = family caregivers, group B = professional carers) gave proxy responses and self-assessments at pre and post session. People with dementia were informally interviewed immediately following the singing session. Findings show significant improvements on lucidity, energy, focus, mood and relaxation for people with dementia as reported by family caregivers on five bi-polar scales (i.e. Confused – Lucid, Agitated-Relaxed), which were not found in the quiz control. Additionally, caregiver mood showed significant improvement pre-post session. Qualitative analysis described participant

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enjoyment, feeling a sense of connection with others, and the development of positive identity construction through the process of singing (i.e. some participants commented on seeing parts of the person with dementia's identity come to the forefront ahead of the diagnosis).

This later study benefited from the use of an active control, however the control groups were only matched for age (and not cognitive ability, which could have been a confounding variable). Quantitative analysis proved difficult in this study due to the high attrition rate from the groups. The researchers stated that the goal of ecological validity was sought in using real life, on-going cohort groups; however, the lack of randomisation to groups limited the generalisability and replicability of the quantitative findings. The study arranges the qualitative data into themes, however the researchers do not give any indication as to how the analysis was carried out. Representative quotes are published in the text alongside themes, but no quality assurance is reported. Although both studies show significant methodological concerns, taken together as exploratory studies they show some initial positive findings in the qualitative data.

A similar mixed methods study (Camic, Williams & Meeten, 2013) found a further lack of significant findings on standardised measures. This 10-week singing group contained familiar and new songs facilitated by an experienced musician. Although this was a smaller scale study of 10 people with dementia and their family carers, it also contained a 10-week follow-up. Standardised measures were carried out at pre, post, and 10-week follow up with people with dementia and carers. Participant dyads were also interviewed and data thematically analysed.

Quantitative results found no significant changes. Although those with dementia had deteriorating scores on all measures over the 10-week period; self-rated and carer measures of QoL remained stable. Engagement and participation was rated as high across the group, with a

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small level of attrition. The results may suggest some stabilising or even positive effect of the group. Qualitative findings showed a number of emerging positive themes such as enjoyment, an appreciation of social inclusion, enhanced emotional life outside of the group, and new learning. The engagement in musical activities was still present in both carer and people with dementia at follow up.

This study resolved some of the methodological issues above by revisiting participants at follow-up, providing clear description of analysis procedures, and by using appropriate measures. However the lack of a control group led to difficulties in drawing firm conclusions about the link between the intervention and the effect. Additionally, the study experienced some attrition at follow up. As with studies above, it is unclear if the sample size of the group met power for the statistical tests chosen. Whilst the qualitative methodology is well described, no interview schedule was provided, which would have added to the quality of this study.

A novel intervention was undertaken by Harris & Caporella (2014). An intergenerational choir was formed with university students, people with dementia, and carers. Although the main aim of the study was to lessen stigmatisation for students around Alzheimer's disease, benefits were also noted for the person with dementia and carers. Participants attended an 8-week choir group in which a university student spent time with a person with dementia. Semi-structured, open-ended questions were gathered from students at three time points over rehearsals, and a focus group was carried out with people with dementia and carers. Data was analysed using thematic analysis.

Findings show that through social contact positive attitudes towards dementia increased, with university students recognising capabilities and experiencing less social discomfort. Findings from the focus group also show less social isolation and enjoyment for people with dementia and carers. The findings from the study are seen as an attempt to view

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the people with dementia and carers as part of a wider context, and is the first study found to acknowledge the effect of attitudes and social stigma on dementia health and wellbeing.

Several methodological issues arose from this study. The recruitment process inclusion criteria stated that people who already enjoy singing were approached. It appeared that the main aim of the study was to test out the use of singing in a group as a medium for social diversity, however this inclusion criteria means any positive effect cannot be attributed to singing as an activity. Similar effects could be found in other groups where members enjoy the activity, and so the study would have benefitted from a control group. Quantitative data was reported descriptively; whilst overall trends are indicated we cannot be sure of their significance. This study (similar to previous studies) would have benefitted from a more rigorous approach to its thematic analysis, as no theme development or quality assurance was reported. The main strength of this study was its aim to work with people with dementia and the surrounding non family network, which is novel, and therefore adds a systemic element to the literature base.

Qualitative studies

Three of the eleven studies reviewed employed a qualitative analysis (Dassa & Amir, 2014; Osman, Tischler, & Schneider, 2014; McCabe; Greaseley-Adams, & Goodson, 2013). The most recent of these was carried out in Israel (Dassa & Amir, 2014), and is the second in this review to actively describe the intervention given as a music therapy intervention. As part of a larger quantitative study examining speech quality (currently unpublished), participants with middle to late stage AD took part in an eight session group singing programme. The programme was developed and led by an experienced music therapist with the aim of eliciting emotions and emotional conversation through the use of themed (e.g. patriotic, love) songs. Six participants were randomly selected from the wider three groups to take part in singing

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sessions (that were video recorded and analysed). The findings showed that songs elicited spontaneous conversation tied to the themes of the music about the past. The authors noted that failures in spontaneous speech are common in middle to late stage AD, and that speech around this subject may have been easier as group singing is rooted in Jewish culture.

This small-scale study stated that content analysis was its primary methodology (which is sometimes viewed as a quantitative analysis), however aside from the use of themes and categories, little other information about the analytical process is given. The researchers state that the themes were independently reviewed and that a researcher log was kept. Naming of the intervention as music therapy may indicate a different cultural use of the term, as the intervention appears similar to interventions classed as social singing in the UK. Additionally, the music therapist took a double role as the main researcher, but no discussion of this possible conflict or its impact on data analysis is in the paper. A discussion around cultural identity and its relationship to music is detailed, which brings a cross cultural perspective into the literature base.

Osman et al. (2014) evaluated an Alzheimer's Society 'Singing for the Brain' group, and built on previous findings by interviewing person with dementia-carer dyads together. Semi-structured interviews were analysed using thematic analysis and six main themes were identified: social inclusion and support, a shared experience, positive impact on relationships, positive impact on memory, lifting the spirits, and acceptance of the diagnosis.

Although this study indicates positive outcomes for people with dementia and their carers, the reporting of the procedures in the study is brief. Recruitment and sampling are discussed briefly, however the selection of participants is not detailed. Thematic analysis and quality assurance procedures are also briefly described, however one is unable to ascertain the quality of these from the text. The literature review in this study focused mainly on music

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therapy which is not the basis for Singing for the Brain groups, omitting to mention findings from other significant group singing studies. Further detail in the reporting of all areas in this study would have added to the quality, and would have helped to highlight its contributions to furthering understanding in this field (one of which is the reporting of the joint perspective of a dyad).

The final study utilised a very different type of singing group from those described above. McCabe et al. (2013) involved 9 PWD and 3 carers in a project of developing an operatic production on the subject of love. Alongside the Scottish Opera Company, participants were involved in the writing and development of the production for one year (ending with a performance). Six interviews were carried out in groups with a mixture of carers alone, carers with PWD and PWD in groups. Interview data was analysed using thematic analysis (carried out by two researchers). The findings showed a number of positive themes emerging from the data, such as increased confidence, positive social involvement, being seen in a new way, and an improvement of physical strength. The study also noted the welcoming of new learning, similar to Camic et al. (2013) above, which builds on the idea that creativity and new learning are welcomed by those with early to middle stage dementia.

A strength of the study lies in the thorough planning of the intervention, and the gathering of many viewpoints (both individual and relational). The methodology of the study was not presented in great detail. For instance, it is unclear how the data presented was selected from the sample. Recruitment processes are also not detailed, which means it is unclear whether participants were selected or sampled through opportunity. Whilst the planning and execution of this intervention is a strength, the novelty of the intervention means that findings are very limited to this particular type of intervention.

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Summary of Research

Initial quantitative studies in this area failed to find significant outcomes for the impact of singing groups for people with dementia on both standardised and observed measures. Many of the quantitative studies reviewed showed significant methodological and reporting weaknesses, such as small sample sizes, a lack of reported effect sizes or power calculations, and a lack of generalisability of findings. One RCT attempted to resolve these issues and found significant positive outcomes on standardised measures. Mixed methods studies point to the qualitative data as the carrier of positive outcomes. In contrast to the quantitative data, the qualitative studies have shown a clear positive benefit for people with dementia and carers from the experience of group singing over a variety of interventions. The social aspect of group singing is often commented upon, along with enjoyment, engagement with music, and an increase in wellbeing. Additionally, some studies have noted a positive experience of new learning. The use of thematic analysis was a popular choice in the studies reviewed, however a more thorough description of the process of analysis was missing in the majority of studies. The qualitative studies showed a greater use of the people with dementia and carer's own views and experiences, indicating a move away from the rating of observed behaviours, and adding a richness and representation of the PWD's inner world around group singing. Nonetheless, the majority of studies focus on the separate experiences of the person with dementia and the caregiver, neglecting the relationship between the two.

Discussion

This review aimed to address two questions. The first explored the health, wellbeing, QoL and cognitive outcomes that are reported for people with dementia and their carers who take part in group singing. The review shows largely inconclusive results on standardised measures, however larger studies yielded some positive cognitive and wellbeing results. However when

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considering the second question, which explored what people with dementia and their carers report about the experience of group singing, we can see that strong positive experiences were reported across the large majority of studies that incorporated the subjective views of participants.

The literature reviewed in this paper generally supports the use of group singing as a part of dementia care for people with dementia and carers. Initial studies in this field employed the use of observational data as a way of exploring experience, however this neglected the person with dementia's own perspective. When considering current research guidelines in dementia care (Association of Medical Research Charities, 2002) which call for an inclusion of the person with dementia in the research process, it is perhaps unsurprising that these early studies did not concur with later studies (that were conducted from a more person centred perspective). The use of standardised measures in the research base also struggled to detect the positive experience that was reported in the qualitative data. The stark contrast between standardised measures and qualitative data often occurred within the same studies, prompting questions around the suitability of such measures in this field. Although the majority of the measures used in this study have been shown to be both reliable and valid in the literature, the difficulty in measuring psychosocial concepts with them has been explored (Banerjee, 2009).

Qualitative findings showed a stronger indication that people with dementia and carers gain benefit from singing in groups. The majority of studies reported these findings but had not considered them in the light of theoretical or explanatory models, leading to a lack of clarity about why benefits are reported so strongly by participants. Additionally, although studies have begun to consider people with dementia as a part of their social context very little is reported of the relational aspect of singing together. NICE guidelines (2006) currently indicate the need for relational research and interventions in dementia care; the results of this review further highlight the paucity of relational research in this area.

Clinical Implications

When considering interventions for people with dementia and their carers, this review highlights the potential use of group singing as an activity for both. Of particular importance are the benefits reported by both caregiver and person with dementia. When considering Kitwood's (1997) model of personhood, it appears that the results fulfil many of the criteria suggested for preserving personal identity (such as social inclusion, enjoyment, expression and play). Practitioners could keep in mind the accessibility of this intervention for service users. Many current interventions for people with dementia focus on reminiscence activities (Schweitzer & Bruce, 2008). Whilst this is still indicated as a positive experience in this review, the theme of new learning has also emerged for people with early to mid-stage dementia in some studies. This may be tentatively useful for some services when planning interventions for people with dementia, in terms of exploring the preferences of the service users between reminiscence therapy and other therapies.

Research Recommendations

The findings from current studies have shown the potential benefit of the use of group singing for people with dementia. However, the ongoing questions about how these benefits are conceptualised and measured requires some additional thought. Standardised measures were often developed outside of dementia care and so their applicability to people with dementia and carers may be limited. Although qualitative data has reported strong benefits, these have not been thought about theoretically. Nonetheless, the need for further studies to be grounded in the participant experience is indicated. This would align with a move towards user focused dementia care research (Cantley, 2001).

Further studies could therefore explore the theoretical underlying mechanisms of change in group singing in dementia care. An additional benefit would be the exploration of

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the relational perspective through the use of joint interviews. Theories and concepts from these initial studies may emerged from which accurate, sensitive and specific measures could be developed.

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Section B: Theorising the experience of group singing for heterosexual couples where
one partner has a diagnosis of dementia

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Abstract

There is an emerging interest in the literature base around the use of group singing in dementia care. Although studies indicate positive outcomes, limited research has been carried out from a relational perspective. Additionally, theoretical underpinnings of the reported benefits have yet to be explored. This study aims to investigate the key theoretical mechanisms underlying the experience of group singing. Interview data from seventeen couples who sing together in a group is analysed using grounded theory method. Several key aspects of group singing are presented, namely that the positive experience of the act of singing combined with effective group facilitation enables equal participation and a powerful group effect. A further benefit of new learning and creativity is explored. Implications for clinical practice include recommendations for singing as an accessible activity for all levels of dementia, the need for effective facilitation, and the inclusion of new learning elements. Suggestions for future research are stated, such as studies to test key theoretical constructs, larger scale studies, and the development of standardised measures from these.

Introduction

Dementia is a progressive condition characterised by a widespread impairment in mental function accompanied by cognitive decline. Symptoms can consist of difficulties in memory, planning, communication, reasoning, mood and motor skills (World Health Organisation (WHO, 2012). A diagnosis of dementia has also been shown to have a significant impact in emotional and social domains, with people living with dementia showing an increased prevalence for mood disorders and relationship disruption (Ballard et al., 2000; Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; De Vugt et al., 2003). Consequently, dementia can be seen to be a major cause of disability for older people worldwide (WHO, 2012). In 2013 the number of people with dementia in the UK was estimated at 800,000 with a further 670,000 people caring for them. This number is set to double every twenty years at the current rate of growth (Alzheimer's Society, 2013; Prince et al., 2013). Dementia therefore poses an ongoing challenge for health services, currently representing an annual cost of £26.3 billion to the UK (Alzheimer's Society, 2014).

The majority of recommended interventions for people with dementia are pharmacological, however treatment guidelines recognise the need for psychosocial interventions and acknowledge the importance of "relationships and interactions with others to the person with dementia" (National Institute for Health and Care Excellence (NICE), 2006, p. 6). Kitwood's psychosocial construct of "personhood" also calls for high quality interventions that place the person with dementia in a relational context, arguing that social interconnectedness is a key element to supporting the core essence of the person throughout cognitive decline (Kitwood, 1997). Therefore considering the wider system around the person with dementia could arguably be seen as central to future dementia care research.

Two thirds of people with dementia currently live in the community; many of these with family caregivers who save the UK government £11 billion each year in care costs

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(Alzheimer's Society, 2013). However, this saving is not without cost to caregivers themselves, as caregivers of people with dementia experience a higher prevalence of physical ailments, depression and anxiety when compared to age and gender norms (Cuijpers, 2005; Kasuya, Polgar-Bailey, & Takeuchi, 2000; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). The majority of caregivers are partners or spouses (NICE, 2006), and research shows that spousal relationships suffer from loss of emotional intimacy, reduced relationship quality, loss of communication and other consequences due to the impact of dementia and caring responsibilities (Baikie, 2002; Garand et al., 2007; Morris, Morris & Briton, 1988). Given the value of these relationships in dementia care it is important for to consider ways in which to support the person with dementia, the caregiver, and the quality of the relationship between the two. Prakke (2011) argues that a wider understanding of the impact that dementia has on couple relationships is needed as research has historically focused on the separate experiences of the person with dementia and the caregiver. There is an emerging body of evidence exploring how couples manage the challenges to their relationship, noting the importance of concepts such as connectedness and separateness, working together, maintaining involvement and retaining couple identity (Keady & Nolan, 2003; Merrick, Camic, & O'Shaughnessy, 2013; Shaughnessy, Lee, & Lintern, 2010). An important aspect in the preservation of the couple relationship in dementia is the idea of doing things together, especially within a social context (Hellström, Nolan & Lundh, 2005).

The Department of Health (DoH) has highlighted the importance of community engagement and access to social activities for this client group (DoH, 2009). However many current interventions are geared solely towards the person with dementia which potentially exclude the carer, and the person with dementia may struggle to access traditional social activities through loss of understanding or confidence (Frank et al., 2006). Therefore, there are a restricted number of activities that the couple can meaningfully engage in. One emerging

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field of research, which may arguably be accessible to both members of the couple, is arts-based interventions for dementia. Additionally, these interventions may further align with Kitwood's (1997) personhood model, which highlights play (the encouragement of expressions of spontaneity), stimulation (interacting through use of the senses), creation (contribution to creative activities) and facilitation (enabling participation of activities) as key elements of person-centred care.

Arts Based Healthcare

There is a growing interest in the use of arts for various healthcare benefits. The National Alliance for Arts, Health and Wellbeing (2012) argue that active engagement in the creative arts can improve healthcare, promote the prevention of disease, and build wellbeing for both individuals and communities. A recent review of the participative arts and dementia care (Zeilig, Killik & Fox, 2014) suggested that the literature base around arts-based activities for dementia is in its infancy. Nonetheless, the review indicated positive outcomes in poetry, theatre, dance, art and singing interventions. The review also noted that of all the possible art practices, it is only music therapy that has been examined in a Cochrane review. A further narrative synthesis review of music therapy for dementia (McDermott, Crellin, Ridder, & Orrell, 2013) highlighted group singing to be an important medium for beneficial change. Although both of these reviews focus on music therapy and not community-based arts interventions, they nonetheless point towards music and group singing in particular as a potential arts activity that can aid wellbeing, be accessed by both the person with dementia and caregiver, and therefore may be of particular interest to researchers and practitioners.

Group Singing and Dementia

During the past two decades there has been a growing interest in the effects and experience of group singing for people with dementia. Positive benefits have been highlighted by the development of the Alzheimer's Society's Singing for the Brain model, and the

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development of the Silver Song Club project (Skingley & Vella Burrows, 2010). As highlighted by Zeilig, Killick & Fox (2014) the research base is still young and relatively sparse, but nonetheless contains good quality studies that show positive outcomes. A randomised controlled trial by Särkämö et al. (2013) found that a group singing intervention enhanced or maintained areas of cognition (such as attention, executive function, short term memory and orientation) and improved mood when compared with usual care. Some areas of cognition were still improved at 6-month follow up when paired with continued musical activities at home. A significant decrease in caregiver burden was also shown at follow up. This robust study was the first in the field to yield multiple, statistically significant quality of life and cognitive findings using standardised measures, and suggested that some benefits are maintained in the longer term. A further study which compared group singing to a quiz control (Davidson & Almeida, 2014) found significant improvements in lucidity, focus, mood and relaxation for people with dementia, and a significant improvement in caregiver mood post session.

Furthermore, a growing body of evidence is emerging which takes a person-centred stance, using qualitative and quantitative methodology to bring in participant views. Many studies report positive feelings of achievement, belonging, decreased social isolation, and engagement in group singing (Dassa & Amir, 2014; Harris & Caporella, 2014; Osman, Tischler & Schneider, 2014). Camic, Williams and Meeten (2013) used a mixed methodology and while standardised measures yielded inconclusive results, thematic analysis found a strong sense of enjoyment, new learning, social inclusion, and enhanced emotions. McCabe, Greaseley-Adams & Goodson (2013) describe strong positive views of a creative group singing project, noting themes such as joy, increased confidence and changing perception of self. Both studies highlight opportunities for new learning as an important benefit, providing evidence against a common assumption in older adult literature that older adults are not interested in or capable of learning new skills (Chen, Kim, Moon & Merriam, 2008).

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Whilst these studies provide promising initial evidence for the positive benefits of group singing, the process through which group singing may bring about change remains unstudied in the literature. Understanding theoretical change processes is a key element when seeking to implement treatment (Kazdin, 2007). It is clear that whilst the participants report strong positive benefits from group singing, the majority of standardised measures do not represent the nuances of these changes. Capturing such changes is an ongoing challenge for quantitative research measures (Banerjee et al, 2009). In order to develop more sensitive tools specific to this population and intervention a theoretical understanding of the possible mechanisms of change is first needed. As the majority of benefit arises in the qualitative data, developing a theoretical base grounded in participant experience may be an appropriate step forward for the research base. This will also continue the aim of giving voice to a marginalised group in line with previous research. Additionally, the majority of the previous studies focus on the individual experiences of the person with dementia and the caregiver. Given the recommendations in treatment guidelines for the consideration of relationships, and the high number of people with dementia living at home with a spouse or partner as the main caregiver, addressing the relational aspects of the potential benefits of group singing may prove valuable.

The Present Study

The present study aimed to develop a theoretical understanding of how group singing affects the couple dyad where one person of the couple has a diagnosis of dementia. In order to adopt a relational stance to the investigation both people with dementia and their spousal caregivers' perspectives were included, with a specific focus on psychological and social aspects of the joint singing experience. In developing the theory the following broad research questions acted as a guide:

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- 1) How does the group singing experience impact the relationship between the person with dementia and their spouse?
- 2) What are the key mechanisms of change of group singing for couples where one partner has a diagnosis of dementia?

Method

Design

The study employed a qualitative non-experimental design, using a semi structured interview schedule developed in accordance with grounded theory methodology (Glaser & Strauss, 1967; Urquhart, 2013). Grounded theory was chosen in order to help build a theoretical understanding of how singing psychologically and socially impacts people with a dementia and their caregiver partners when they sing together in a group. A qualitative approach seemed most appropriate to explore the richness, depth and subtlety of these experiences. The principal aim was to build on previous findings by developing a theoretical framework by investigating the potential underlying mechanisms of change in group singing for couples. Grounded theory is a method that helps to iteratively and systematically develop new theoretical models that are grounded in participant social experiences (Glaser & Strauss, 1967; Urquhart, 2013), and so was chosen over other qualitative methodologies that focus only on subjective experiences such as IPA (Smith & Shinebourne, 2012), do not seek to theorise as part of theme development as claimed by Braun and Clarke (2006) in thematic analysis, or that primarily aim to discover semantic and contextual meaning behind language use such as discourse analysis (Potter, 2012).

Epistemological position. The original ground theory methodology held a positivist epistemological position, with definitive facts and resulting theories seen to “emerge” from the

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data (Glaser, 1992). Whilst this study follows the Glaserian method of data analysis the researcher can be said to hold a ‘critical realist’ position (Collier, 1994), in which some awareness of the self’s impact on emerging categories and theories has been considered alongside positivist assumptions.

Participants

Participants included 17 couples (n=34) who had taken part in various forms of group singing. Demographic, area and group singing details are presented in Table 2. The researcher introduced the study via information leaflets and by attending the first two group singing programmes for people with dementia and their caregivers which were found through the supervisors of the study. Recruitment posters were then posted to choirs around the country, leading to the researcher interviewing one couple from a third group. Recruitment posters were then given to colleagues in the field to give to participants of their studies, via which a final couple attending a reminiscence singing and movement group were found. Participants interviewed by the researcher were drawn from four different groups in total.

Consent was then sought to sample anonymous data from a study previously completed by a supervisor of the project in order to aid theoretical development (Camic et al., 2013). Participants from this study attended a group singing programme for people with dementia and their caregivers, and both caregiver and person with dementia transcripts from post and follow up evaluation interviews were obtained. Overall demographics for this study are also reported in Table 2.

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Table 2

Participant demographics and singing group details			
Participant number	Demographic details	Stage of dementia	Group type
1	Male (87)	Moderately Severe	
2	Female (76)	-	
3	Male (74)	Moderate	7 session singing and composing group held by art gallery and opera company in which people with dementia and their caregivers composed an opera based on art around the gallery. Ended in a performance and a follow up reunion.
4	Female (61)	-	
5	Male (82)	-	
6	Female (82)	Mild	
7	Male (72)	-	
8	Female (70)	Mild	
9	Male (82)	Moderate	
10	Female (77)	-	
11	Male (89)	-	Ongoing group singing involving music, movement and percussion for people with dementia and their caregivers.
12	Female (87)	Moderate	
13	Male (71)	-	
14	Female (68)	Severe	Area demographics: low socioeconomic rural area
15	Male (71)	Moderately Severe	Ongoing choir for people with dementia and their caregivers. Regular performances and a CD recording. Area demographics: high socioeconomic rural area
16	Female (67)	-	
17	Male (86)	Moderate	Ongoing group singing hosted by a national charity involving reminiscence singing and movement Area demographics: low socioeconomic urban area
18	Female (77)	-	
19-34	68-88 (mean = 75, SD 6.70)	Alzheimer's Disease, Vascular Dementia, Mild Cognitive Impairment and Mixed diagnosis	10 session group singing and music making programme for people with dementia and their carers, facilitated by community musician. Area demographics: high socioeconomic coastal area

Procedure

Ethical considerations. Ethics approval was granted for the study by an ethics panel at Canterbury Christ Church University (Appendix D). For the first 10 participants ethics approval was obtained from Canterbury Christ Church University as part of a larger study (Appendix E). Permission was also obtained from the holder of ethics approval for access to the anonymous transcripts from a previously completed study, and can be found along with ethical approval in Appendix F. The researcher followed the British Psychological Society's Code of Ethics (2009) throughout research.

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Informed consent. The study aimed to approach the manner of informed consent in a thorough and respectful manner. The barriers to consent in dementia research are well documented (Warner, McCarney, Griffin, Hill, & Fisher, 2008; Baskin, Morris, Ahronheim, Meier, & Morrison, 1998), and so guidance was sought prior to interviewing through discussion with a regional Alzheimer’s society office, and by consulting published guidelines (Association of Medical Research Charities, 2002). All couples interviewed were supplied information and consent forms (Appendix G) prior to interviewing which included study details, contact numbers and complaints procedures. Full discussions were had with all participants about the purpose of the study before consent was obtained.

Theoretical and heterogeneous sampling. The process of recruitment was influenced by the grounded theory concept of “theoretical sampling” where concepts identified from initial coding influenced future recruitment in order to attempt to “saturate” categories (Glaser & Strauss, 1967, p. 112) in the emerging theory. In order to develop a more nuanced understanding of when the theory may or may not be applicable (Urquhart, 2013) participants from a heterogeneous sample were selected. The initial line of questioning that emerged in this study led the researcher to sample a range of ability levels in dementia and various types of singing groups nationally. A flowchart of the theoretical sampling process can be found in Figure 4.

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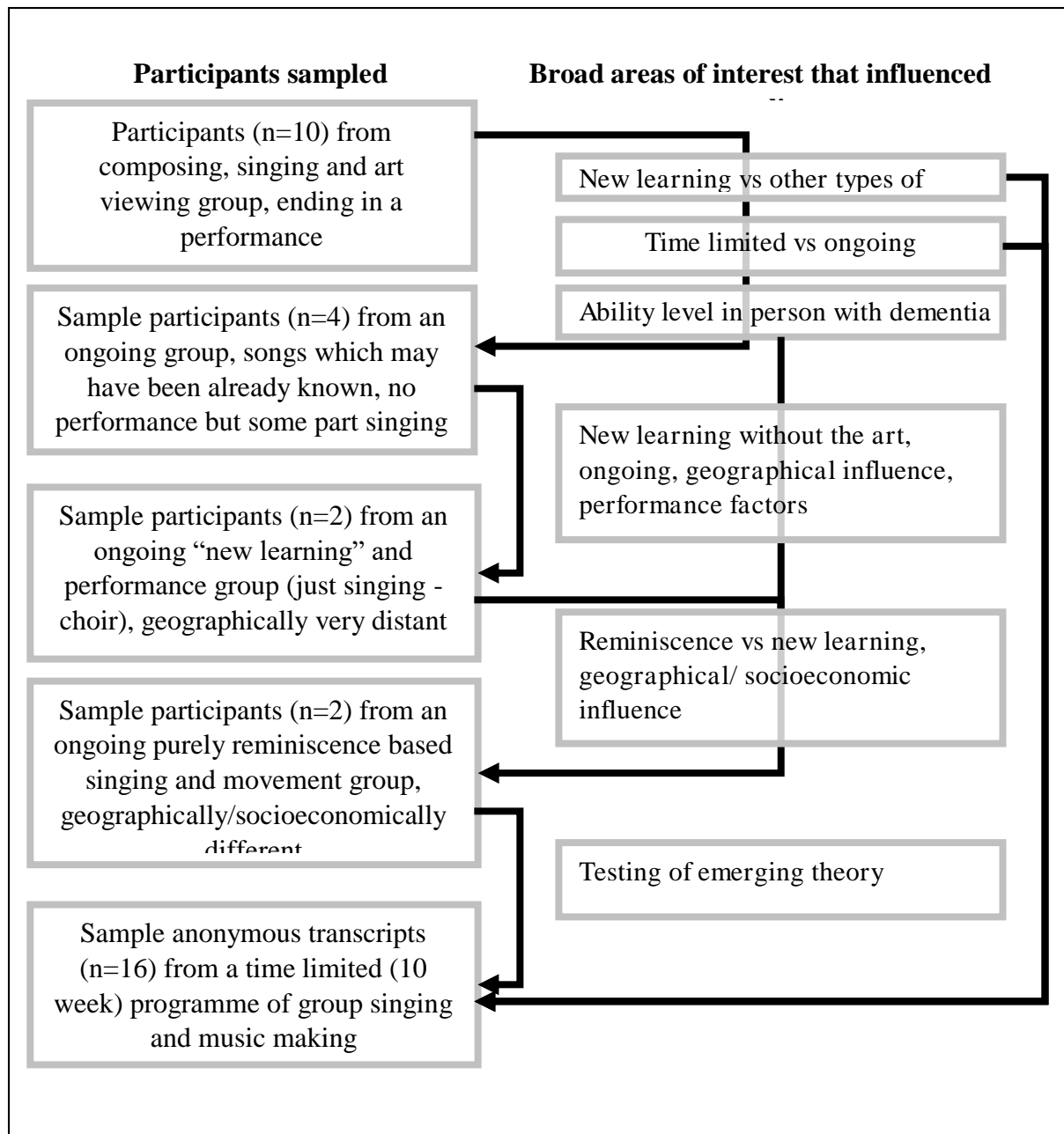


Figure 4. Theoretical sampling process

Interviews. Initial interview questions were developed under three broad topic umbrellas: (a) the relationship experience and history (for context) (b) the journey through diagnosis and (c) the experience of group singing. Existing research literature was not consulted by the researcher at this point as doing so may have unconsciously influenced the direction of questioning (Glaser, 1978). Interview topics and questions were kept purposefully

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open in this first stage to allow for complex and varied responses, in the hope of facilitating “rich and sufficient” data (Charmaz, 2006, p.18). Couples carried out semi structured interviews together in order to gain an idea of the joint experience of the relationship and the group singing. Interviews were recorded and transcribed for the purposes of analysis. Details of interview questions can be found in Appendix H.

Data collection consisted of three stages: The first two stages involved interviewing nine couples. Firstly, five couples were interviewed. Detailed theoretical memos (Urquhart, 2013) were kept and following initial coding a line of enquiry for a second stage of interviewing was developed where a further four couples were recruited; the interviews all lasted between 35 - 70 minutes. In order to aid the development of theory, a further eight couple interviews from a previous evaluation dataset (exploring the experience of group singing) were analysed. This is a process in line with Glaser’s concept in grounded theory that “all is data” (Glaser, 1978). Although the interviews were not carried out by the researcher, full transcripts were obtained and a detailed discussion about the evaluation was carried out with the lead researcher.

Data analysis. Transcripts were analysed using procedures from Glaser & Strauss (1967) and Urquhart (2013). Concurrent data collection and analysis was carried out in order to allow for the initial codes to direct sampling. The process followed several stages:

- 1) Line by line/open coding of initial 5 transcripts by hand: allowed the researcher to immerse themselves in the data.
- 2) Selective coding: coding relevant core categories. At this stage, ‘constant comparison’ of the data was employed (where new instances of data and code are compared to previous data to support the direction of analysis)
- 3) Theoretical coding: substantive codes were ‘scaled up’ into conceptual categories, and relationships between codes were explored.

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- 4) Four further interviews were then carried out to develop findings from initial analysis. They were transcribed and analysed using selective coding and constant comparison. Categories and conceptual relationships were refined with the aid of theoretical memos (Appendix I) and early theoretical diagrams (Appendix J).
- 5) A further dataset of 7 couple interviews were sampled from a previously completed study by the supervisor of the current project.

The decision to sample 7 couple interviews from a previous study completed by a different researcher was taken in order to test emerging key constructs against individual cases so as to add weight to theoretical sufficiency (see below). Additionally, using transcripts from a different interviewer enabled the researcher to understand their own influence over the data at an open coding level, and allowed for further nuanced theory building by prompting the comparison between subtleties between the different interviews. Discussions with the lead researcher of the completed project (and the supervisor of the current project) added to the detailed thinking behind emerging constructs.

Theoretical sufficiency. Within grounded theory tradition the notion of “theoretical saturation” is defined as “...when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories.”(Charmaz, 2006, p. 113). Dey (1999, p. 257) challenges the concept of saturation stating that conjecture is required to claim that no further properties are being generated. Dey suggests that the term “theoretical sufficiency” is a more precise description of the process whereby categories are being suggested by the data. The concept of theoretical sufficiency guided data collection and recruitment, which ceased when this was deemed to have been achieved. Sufficient data was thought to have been collected when categories arose from identified codes that allowed the relationships between them to be theoretically explored. Through peer group review, supervisor

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discussion and constant comparison, theoretical sufficiency was deemed to have been met at the end of this study.

Quality assurance. As previously stated, the researcher held a ‘critical realist’ position in data analysis, and as such a number of quality assurance methods were undertaken in order to raise awareness of how the researcher’s motivations and preconceptions may have been shaping the data analysis. Three bracketing interviews were held at various points of the study based on procedure laid out by Ahern (1999). The interviews were carried out by two colleagues and reflective notes were made after each interview (Appendix K). A reflective diary (Appendix L) was kept to keep a running focus on self-awareness throughout the research process. In order to ensure the quality and rigour of grounded theory studies, Chiovitti and Piran (2003) developed 8 criteria to apply to the process (Figure 5). The researcher referred to these methods at each stage of the research in order to increase the credibility of findings. Additionally a portion of data analysis was scrutinised by a research supervisor and a peer group at three stages during the process, at which point codes were checked and compared. Disagreements prompted discussions that were resolved in these meetings. Cases which disconfirmed direction of analysis were sought during coding and the emerging theoretical model was verified by a research supervisor before finalising.

Standards of rigour	Suggested methods of research practice
Credibility	<ol style="list-style-type: none"> 1. Let participants guide the inquiry process 2. Check the theoretical construction generated against participants’ meanings of the phenomenon 3. Use participants’ actual words in the theory 4. Articulate the researcher’s personal views and insights about the phenomenon explored by means of <ol style="list-style-type: none"> (a) Postcomment interview sheets used as a tool (b) A personal journal (c) Monitoring how the literature was used
Auditability	<ol style="list-style-type: none"> 5. Specify the criteria built into the researcher’s thinking 6. Specify how and why participants in the study were selected
Fittingness	<ol style="list-style-type: none"> 7. Delineate the scope of the research in terms of the sample, setting, and the level of the theory generated 8. Describe how the literature relates to each category which emerged in the theory

Figure 5. Grounded theory quality assurance guidelines (Chiovitti & Piran, 2003)

Results

Five key areas emerged from the data analysis that contribute to the benefit of group singing for both the individual and the couple, and are depicted visually in the model below (Figure 6). The areas are not separate processes through which change occurs but are linked. The movement of the main process is represented by the central bold arrows in the diagram, whilst further factors that are implicated in the change processes and areas where there is a reduction in benefit are represented by the side arrows. The singing experience was described by couples as being both a joyful experience and an accessible one. The combination of the accessibility of singing and effective facilitation enabled an ability to fully participate in the singing group. This appeared to enhance the positive effects of belonging to a social group and truly sharing an experience. The group effect mediated further benefits for the person with dementia and for the caregiver which, when combined increased benefits for the couple. Furthermore, where a performance or creative singing element was included in the intervention a strong theme of new learning, an excitement about building something and an appreciation of looking forward emerged that was not present in other groups. This was seen to enhance the overall positive experience of singing. The model portrays that effective group facilitation is key to the other processes that emerged with a reduced benefit reported where this did not occur. Additionally couples noted that that singing was an activity that was easily carried out by both partners at home together.

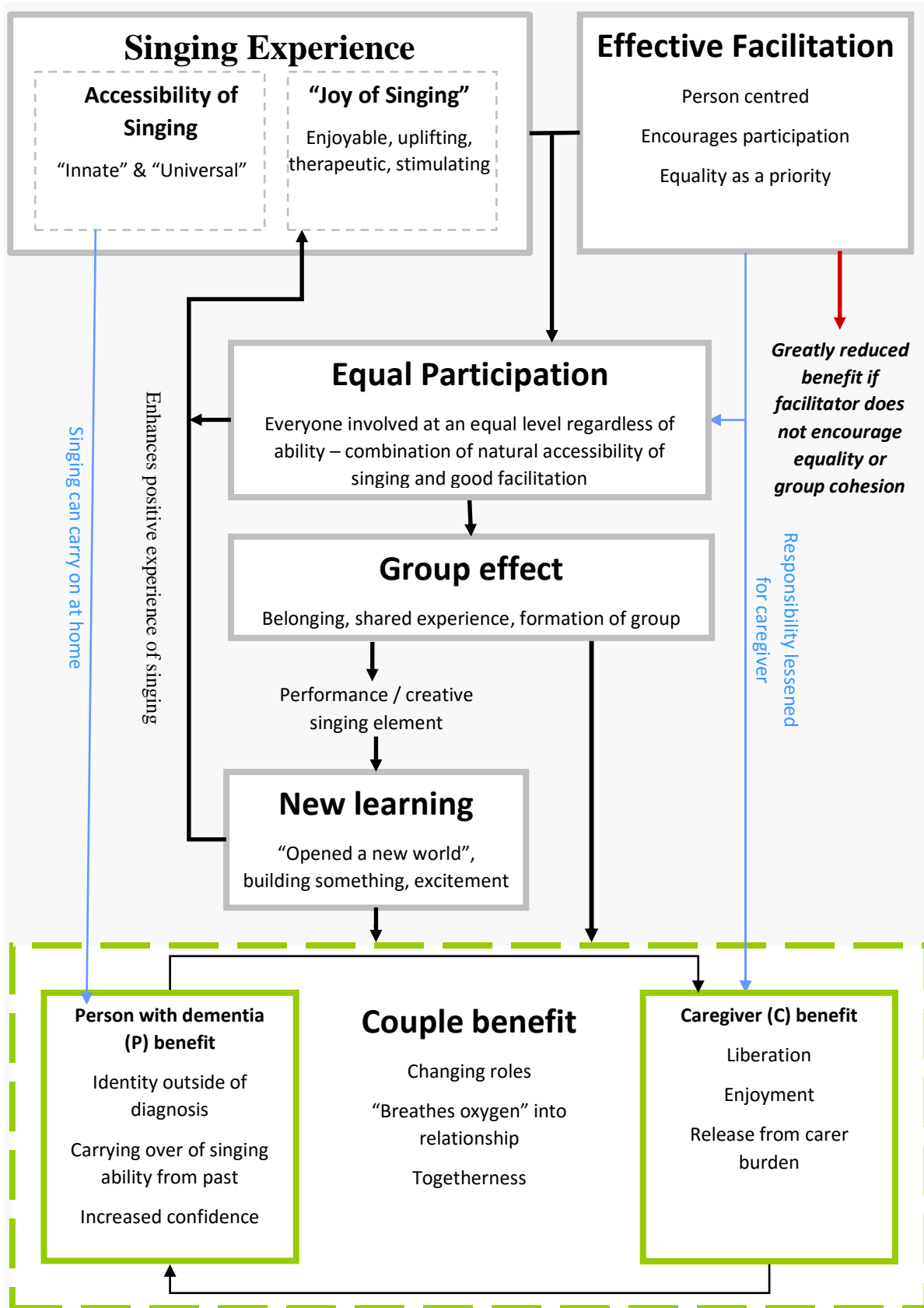


Figure 6. Potential mechanisms of change in group singing as reported by participants

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Below is a fuller account of each category. Participants with dementia are referred to as PD and caregivers as PC within the text. Further details of categories and codes can be found in Appendix M.

Singing Experience

This overarching category captures the two main elements of the singing experience: the joy of the singing act and the accessibility of singing as an activity.

The “joy of singing”. Participants often spontaneously stated positive feelings about the pleasure and enjoyment derived from singing, even in cases where the overall group singing experience was not enjoyed. As one participant stated, the “act of singing is just joyful in itself, it’s the joy of singing which makes us feel so good” (PC4). The four main elements of this category that emerged from the data were enjoyment, uplifting, stimulating and therapeutic

Enjoyment. The enjoyment derived from the act of singing was the most common theme reported by participants in this category. As one caregiver described, “The singing was one of the most enjoyable experiences I have had in later life” (PC5). Couples often described in detail how living with dementia can be limiting for both partners, and so the enjoyment of activities was noted as an important facet of coping. As highlighted by this caregiver, “...its enjoyment. I think that Alzheimer’s is not an enjoyable thing in anyone’s life, so it brings a bit of light.” (PC7). Participants also appeared to enjoy singing regardless of the individual’s previous history with singing. Many had never sung with a group before. One person with dementia noted the difference between uncomfortable childhood experiences of singing and his current feelings.

When I went to school... if you couldn't sing they just said get out... but it is horrible how teachers were horrible to children who couldn't sing. But it's better now, yes it's different, I like singing, enjoyment and singing. (PD9)

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Many participants also commented that the enjoyment was independent of singing ability. One caregiver also felt surprised by the satisfaction they received from the singing: “It’s a pleasurable thing to do, even if you don’t do it well its enjoyment.”(PD8)

Uplifting. Many participants went further to describe the experience of singing as uplifting. When explored in interviews this was deemed to be conceptually different to the enjoyment of singing as the “lifting of the spirits” continued after the act of singing had ceased.

We go away feeling uplifted, the lightness and brightness follows us home. I mean joining in with the singing in the moment lifts us too, think about in the First World War, or marching in the Air Force, what did they do? They sang to lift the spirits to take them into battle, well that lifting follows us home. (PC11)

Stimulating. The experience of singing in the various groups was described as stimulating for by a number of participants. This aspect of singing was mostly reported on by caregivers who described the stimulation as a benefit for themselves as well as their partner.

I think singing of itself was stimulating, you know, your pheromones or whatever, feel good chemicals, I think that's noticeable. I think the combination because you are stimulated on so many levels, I think it does make a difference. (PC4)

Therapeutic. The combined effects of singing on mood was often described as therapeutic. As one participant described, “I don’t care what people say, singing is a therapy, in my book. You know, because, you know, if you’re feeling fed up, have a song, you know. And if you’re feeling down, sing.” (PC11). Couples also noted the therapeutic effect of being fully engaged in singing, commonly stating that it encouraged focus away from the self and into the present moment.

[Caregiver] Everyone in that room has got a problem, whatever it may be, but when you are singing...[Person with dementia]: It goes...[Caregiver]: It goes...I’m not

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thinking about, you know, the next problem we may have, and all the rest of it, we're outside of ourselves (PC11, PD12).

Occasionally participants favourably compared singing to other therapeutic activities or treatments, with one caregiver stating that singing provided a good alternative to medication for mood.

It makes one feel more cheerful and happy, yes it gets one out of oneself. I think it is a very positive thing. I can imagine people do get depressed, they have a lot of stress, and that sort of thing I think is better, far better, than relying on pills" (PC16)

Accessibility of singing. When exploring the factors that enabled the positive experiences of singing, the accessibility of singing regardless of age, culture, gender or cognitive ability was often described. The descriptions of this accessibility mainly fell into two categories named by participants as "Innate" and "Universal".

Innate. The term "innate" was often used in interviews, with one participant stating "I wonder if it's an innate thing that humans have, you know, to want to have a sing" (PC16). Many participants remarked on human ability to make sounds and recognise melodies as young children, and commented on how people living with dementia are able to draw on this ability throughout the progression of the condition.

You know the people who aren't even speaking anymore, they were singing, maybe not well but wholeheartedly singing along sometimes, not like with a game where you have to know the rules and understand how to move the counters and hold that, you just know. It's innate, you can soon pick it up if it's a song, like automatically you can hear it in your head even if you aren't singing out loud, see? It is, you know, it's inside us all. (PC13)

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This accessibility appeared to be especially important to some participants who described a benefit in being able to carry on the singing activity together at home "...because we can just pick it up again instantly, without needing any props or equipment or things". (PD8)

Universal. Singing was frequently perceived to be a common activity that had often been experienced in one form or another for most people interviewed. As highlighted by this participant with dementia, "...singing is universal, it's for everybody, not just some people, and everyone can take part and probably has at some point."(PD12) Some participants described how this universality helped them access the singing group, and for one participant with dementia it felt "...less daunting yes, daunting, than maybe going to other things" (PD15). Many participants described how singing ability was not necessary for participation in the group. One person with dementia discussed participation, "...even if you can't sing. Other people do that and even if they're very old or young they can still do something like that." (PD28)

Effective group facilitation. Whilst the majority of participants attributed positive feelings to the act of singing itself, it became clear that some participants experienced singing as more positive than others. On further investigation, a key element that emerged was the importance of being an active part of the singing group. The role of an effective group facilitator emerged as a vital component of this process, without which the further benefits of group singing were not experienced. A number of factors were identified as part of the role of an effective group facilitator.

Encourages participation. The participants who experienced positive group singing noted that the facilitators of the group encouraged both members of the dyad to get involved in group singing, often drawing members into the activity who may have otherwise been reluctant to join.

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I mean the staff straight off weren't going to let anybody stand against the wall, you know, one was always greeted most warmly, and several people concerned with the project would come up in succession and talk to us...so there wasn't any chance for anybody to be like me to stand in the corner. (PC5)

Many commented on the enthusiasm or talent of the facilitators involved, with one person describing the facilitator's use of humour in "getting us all going" (PC2).

Person centred. Facilitators who based the development of the group around the needs of the participants were especially valued, with many people spontaneously acknowledging the thought and effort taken to tailor the song selection, development, or group pace to the needs of the group: "...they have structured the whole thing around the needs of these people, very much with them as the centre and the focus. That is lovely, that is lovely." (PC4)

Equality as a priority. The importance of this category became most apparent when interviewing a couple who felt that their facilitator did not provide equal attention to group members by picking out the same soloists and spending less time on the group as a whole. They described feeling left out of the process of song selection, and felt that many members could not relate to the songs chosen, and that the focus from the facilitator was not on equality or participation. Although the couple reported enjoying singing in itself, the caregiver described feeling as though they had missed out on the other benefits of group singing because of their experience.

But we can't all take part. He'll pick [X] and say "we'll have some real singing now", well that's not right, is it? Maybe we'd all be able to get to the stage where we could sing it properly, then we would get these benefits that you would hear about of singing together, doing something together, feeling invigorated, feeling better because we've all done something together. But we don't. (PC18).

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Couples had also highlighted the importance of equality, with one person with dementia describing how “no one had to, no one was asked to...sing a solo” (PD6), adding strength to this category as an important part of the facilitator’s role.

Equal participation. The combination of the joyful and accessible experience of singing and an effective group facilitator were identified as enabling full participation in group singing. This ability to fully participate was the most common factor associated with the enjoyment of singing, as highlighted by this person with dementia: “I can join in, it’s a good experience to be able to join...and you can!” (PD9). Within this category, the equality of participation between different types of people was highlighted as an important facet of the group experience. Participants stated that whilst singing, differences between the people with dementia, facilitators and caregivers became less important. One caregiver attributed this to the act of singing, stating:

Even high executives...you get the managing director singing with the man that ties up the parcels that go out, you know. I think it brings a lot of people to a same level, you know, so that everyone’s the same. We’re all singing. (PC11).

Additionally, the majority of participants reiterated that participation in these particular singing groups was not dependent on singing performance ability, and that being encouraged to participate equally as part of a group enable expression: “I like the singing. As I say, I enjoy singing. I can’t sing, but I enjoy the singing” (PC16).

Group effect. Where participants felt able to fully participate in group singing, an overall group effect was observed in which the majority of participants identified belonging to a social group, sharing an experience, and forming a group identity as a major benefit. Many couples stated that they formed strong relationships with the people with whom they shared the singing experience: “But I think, the joy of it was that we were all completely different, from

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different backgrounds...but as it went on we became a real group” (PC7). Also valued was a sense of sharing an experience with others that they may have otherwise had difficulty accessing. One participant highlighted the ease with which music lends itself to shared experiences, stating that “...music and singing especially, brings people together, if you are singing then you are sharing in something no matter who you are beforehand because you are all going for it together” (PC2)

New learning. Whilst the above pathway of singing together in a group did feed directly into benefits for the individual and the couple for all types of singing group, an alternative narrative developed from the singing groups that incorporated a performance or creative singing element. The participants in these groups tended to report a more positive experience of singing and a stronger sense of participation in the activity. Participants also valued the creative act of “...building something together, seeing something develop, and being left with something that came out of it” (PC2). One caregiver described the experience as “...opening your mind to new experiences, using your brain, in something that you never thought of using it in before. It’s a bit like a steamed window where you can’t see outside and you clean it then see a new world.” (PC4). Participants involved in performances also described an “excitement about doing that, getting up and showing everyone what you have created” (PC7). A few participants who were involved in reminiscence based singing groups also wondered about the value of creating and looking forward, with one participant stating “all that looking back, it can be a bit mindless maybe, possibly if we were being active and creating something it would be more beneficial, like a sort of new learning for us” (PC18).

Individual and couple benefits. A number of benefits were reported individually and as a couple. These benefits appeared to be mediated by the pathway leading to participation in a group, as individuals who were not able to participate equally described fewer, if any, benefits.

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Person with dementia benefit. A number of those with dementia described a sense of increased confidence, both for themselves and other members of the group. One person with dementia noticed this in a fellow group member, stating, “And you know the chap who was with me, he was a very quiet man and he’s sort of come out since that’s been going” (PD34). Sharing in a creative artistic project helped our general confidence too.” (PD6). Another strong narrative that emerged from the data was an increased awareness of the person with dementia’s identity outside of the diagnosis. This was attributed to a number of factors in the data. The sense of equality within the group whilst singing was appeared to blur the lines between those with dementia and those without.

I was very surprised to learn that she was the cared for person, because before she seemed very outgoing in herself...she had the confidence to come forward and walk across and sing with other people in front of a crowd, you know, so I think it was a can do thing, I think we all felt then that we could do something. (PC2)

Some participants also reported a ‘carrying over’ of singing ability from premorbid days that helped to tap into memories of previous times and identity. One caregiver described how their partner “...was always the singer, used to sing, it was like [name’s] old self really, it gave the confidence to get that back” (PC5). Lastly, a sense of being seen and valued within the group setting was noted, “...it made you feel that you were important, which is important in itself” (PD6).

Caregiver benefit. Caregivers in particular reiterated the importance of facilitation, and some expressed a “release” from caring responsibilities with effective facilitation. One caregiver described how “it was something we could do together, where I wasn’t responsible...I was relieved of any responsibility as it was all taken care of” (PC2). Caregivers also reported that this combined with the equality of a group setting allowed for equal participation between themselves and their partners. Caregivers reported a surprising sense of

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enjoyment as historically they may have found other activities for people with dementia less relevant to themselves.

I used to take [name] along sometimes and leave...I would depart and do other things.

I thought it was going to be similar to that...with singing I didn't even think I would be involved. But what I thought I would do, to be fair, I would stay the first day to see what was going on and whether [name] was comfortable and whatever was going on.

And what developed I thought oh, I quite enjoy this. (PC7)

One caregiver experienced frustration in the role of caring, a sense of freeing from this frustration was found in the act of singing. As they described, "...it's like liberation, well like I said I haven't got a cat, I can't kick the cat, but I can go and sing it all out!" (PC16).

Couple benefit. The benefits of the increased awareness of the person with dementia's identity outside the diagnosis and the release of caregiver burden appeared to link into one another to create a couple benefit of changing roles. Some couples talked about a feeling of equality, and several couples described the person with dementia as the one with singing ability, having to lead the caregiver in learning this new skill. As one couple stated "[Caregiver] Well, I can't sing, [name] always sang didn't you? [Person with dementia] Yes, I have to teach you! I didn't half laugh at your efforts, it's very funny, you are getting better though." (PC7, PD8). One couple reported that they fought less whilst being involved in the group (P7, P8), whilst another caregiver summarised their feelings by stating "I think it's like breathing oxygen into us, it is a stimulant, you know, it's not that you hadn't oxygen all around you all day, but it's like an extra puff...that releases energy so the dynamic is lighter and brighter" (PC4).

Some couples increased doing other activities together/joining other groups together after a positive group singing experience. One caregiver stated "I suppose it made me a bit ready-er to be helped. Really, it's not that I fight off, far from it, but it made me realise that

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things like group experiences have things to offer that I might perhaps need now, that we can both go to now. So I learnt that.” (PC5).

In a poignant example of togetherness one caregiver began singing a familiar tune from the group setting to their partner, a person with advanced dementia who had lost the vast majority of speech ability. Whilst the person with dementia had not spoken throughout the interview, she audibly attempted to join in with the final words of sentences in the singing. The caregiver expressed a sense of feeling togetherness during this interaction, stating “...see, it’s obviously gone in...I know that [name] is still in there, we do everything together anyway but this is a way I get answered back, [name] is still there inside, I believe in that.” (PC13)

Discussion

This study sought to develop a theoretical understanding of how group singing affects the couple dyad where one person of the couple has a diagnosis of dementia. In doing so it attempted to specifically draw out psychological and social components of group singing in order to gain a more nuanced appreciation for the mechanisms of this activity, which can later be tested and evaluated in future research. The main components of the theory are discussed below.

A wide range of positive themes around the enjoyment and therapeutic effects of singing were conveyed in this study, which appears to hold for the majority of people with dementia and caregivers across severity of condition and type of singing group. This is in line with previous research findings, which have also described enjoyment as a primary experience of group singing. (Camic et al., 2013; McCabe et al., 2013; Osman et al., 2014; Särkämö et al., 2013). A key factor in the reported enjoyment was the perceived accessibility of singing as an activity regardless of ability level or singing history. This was also dependent on the effectiveness of group facilitation in a group setting. The importance of facilitation is a novel

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finding as previous studies have not focused on the relationship between facilitator and singers. An appreciation of belonging and participating equally to a group was mediated by good facilitation. Social inclusion has been highlighted as an important aspect of dementia care (Innes, Archibald, & Murphy, 2004) and feelings of belonging to a group are associated with wellbeing in caregivers and people with dementia (Brooker & Duce, 2000; Wright, Lund, Pett & Caserta, 1987). Group singing research outside of dementia care has highlighted the positive impact of singing on trust, co-operation and feelings of belonging to a group (Anshel & Kipper, 1988; Bailey & Davidson, 2003), which may point to singing as a particularly good tool for group formation. As people with dementia are often excluded from traditional social activities (Frank et. Al, 2006), the above may indicate that using group singing may be a useful tool to aid social inclusion.

Experiences of learning something new and being creative were both shown to be important components of the singing groups (especially for caregivers and people with mild-moderate dementia). Whilst some recent studies have also suggested this (Camic et al., 2013; McCabe et al., 2013), many singing groups and previous research have focused on the reminiscence aspects of singing rather than on creativity and learning (Ashida, 2000; Watt & Cappeliez, 2000). Although reminiscence can sometimes be enjoyable, a large scale RCT has cast doubt on reminiscence-focused activities showing them to be stressful for some caregivers and not necessarily beneficial for people with dementia (Woods et al., 2012). In contrast, those participating in singing groups described a sense of excitement, a desire to look forward and an appreciation of learning a new skill. A commonly held cultural belief that older adults are unable or unwilling to learn new skills (Rodin & Langer, 1980) is not supported by the present study.

For people with dementia, a sense of being seen outside of their diagnosis was a particular benefit. This aligns with Kitwood's (1997) personhood model, which aims to

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preserve the identity of a person regardless of their cognitive ability, suggesting that singing may be a good intervention for maintaining personhood. For caregivers, a major benefit reported was the release of caregiver burden and liberation through singing. Group singing has been shown to increase caregiver wellbeing even in the longer term (Särkämö, 2013), and the current study may therefore go further to explain the nuances of this effect by suggesting that when both members of the couple are able to equally take part in group singing, a number of positive benefits for the relationship are stated. Previous studies have shown that the maintenance of social activities is important for relationship preservation (Hellström, Nolan, & Lundh, 2007; Molyneaux, Butchard, Simpson & Murray, 2012). The current study builds on these findings by acknowledging the importance of social activities in which a sense of equality can be aimed for even if not achieved.

Limitations of the Current Study

Although the present study aimed to capture the couple experience by carrying out joint interviews and attempted to bring in the person with dementia's point of view wherever possible, it may be that the caregivers' views are overly represented due to their better cognitive agility and verbal ability. On reflection, the researcher could have carried out separate interviews on top of the couple interview in order to overcome these difficulties. Language or other communication aids could have been used to mediate potential communication barriers. Finally, the interviewer could have pre-sent some already known questions to the couples for the person with dementia to answer at their own pace.

The couples discussed their journey through the dementia diagnosis and their relationship histories in some depth, however as the focus of the study was primarily singing the effect of current relationship quality, couple style and coping strategies were not linked to the benefits felt. The theory is specific to the participants who took part in this study despite

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the attempts at a truly heterogeneous sample. While theoretical sampling techniques guided recruitment throughout, time constraints meant that a larger scale grounded theory study may have been more able to broaden out and test concepts with further participants from different ethnic and socioeconomic backgrounds. The researchers own preconceptions were reflected upon through the use of a research diary, supervision, and analytic memos; however the potential effect of the researcher assumptions cannot be completely ruled out. The study is also vulnerable to a self-selection bias as participants volunteered for group singing and for the study.

Future Research

Future research could include studies to test various aspects of the theory. A study exploring the use of facilitation in group singing may wish to test the specific elements of good facilitation noted by this study against group satisfaction or individual outcomes. Studies may also measure participation in group singing and couple relationship quality or satisfaction by using standardised relationship satisfaction measures. When considering the reported interest in new learning, a larger scale comparison study between reminiscence singing interventions and singing that includes new learning and creativity may yield valuable results for clinical practice. Key theoretical constructs were established from which standardised measures may be developed, such as equality in groups, participation and facilitation factors. As highlighted by one participant, further ethnic groups could be sampled to strengthen the findings as different cultures have a different idea about singing and music.

Practice Implications

The theory developed in this study may have indications for dementia care practice. Group singing has been described to be an accessible way to encourage social inclusion that could be incorporated into residential or home settings that is both cost effective and has

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positive benefits for service users. As noted in this study the access to musical sounds may be preserved in cases where speech is lost, suggesting that people with advanced dementia can still participate. Group singing may also be useful where a primary aim is to conserve personhood; health practitioners could be aware of the reported usefulness of singing in acknowledging the person with dementia's identity outside of the diagnosis. The effective facilitation of groups is a key component of this theory. In particular, the equality that is brought to a group by facilitators appears to be vital. Therefore the need for facilitators to encourage group formation and equality is highly indicated, along with the inclusion of caregivers as an equal (as opposed to simply supporting) role within group settings. This blurring of role identity poses a benefit to both the person with dementia and the caregiver, and wider dementia care interventions may consider activities in which the person with dementia's enduring skills can be passed onto group members or caregivers.

Dementia care practitioners may also benefit from bringing a new learning or creative element into their interventions given the enthusiasm demonstrated by participants in this study. Singing or music based interventions may prove more suitable for this purpose as they do not rely as heavily on traditional cognitive skills (such as planning, speech, writing, executive function), and may provide a forward-looking activity for people with dementia and their caregivers to enjoy.

Conclusion

The current study aimed to build a theoretical understanding grounded in participant data of the benefits of group singing for couples where one partner has a diagnosis of dementia. Several key aspects of group singing were identified, namely that the positive experience of the act of singing combined with effective group facilitation enables equal participation and a powerful group effect. A further benefit of new learning and creativity was identified, and these

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factors were linked with benefits for both the individual and the couple. Implications for clinical practice and possible directions for future research have been outlined.

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Section C: Appendices and Supporting Material

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APRIL 2015

A thesis submitted in partial fulfilment of the
requirements of Canterbury Christ Church
University for the degree of Doctor of Clinical
Psychology

Appendix A
Data Extraction Form

Authors, year and title:	
Country:	
Design:	
Theoretical basis:	
Facilitator type/training:	
Sample Size:	
Analysis:	
Main findings:	
CASP score and comments	

Appendix B

Critical Skills Appraisal Checklists (case control, RCT, cohort study, qualitative)

Critical skills appraisal programme: Case control study checklist

Are the results of the trial valid? (Section A)
<p>1. Did the study address a clearly focused issue?</p> <p>HINT: A question can be focused in terms of:</p> <ul style="list-style-type: none"> • The population studied • The risk factors studied • Whether the study tried to detect a beneficial or harmful effect?
<p>2. Did the authors use an appropriate method answer their question?</p> <p>HINT: Consider:</p> <ul style="list-style-type: none"> • Is a case control study an appropriate way of answering the question under the circumstances? (Is the outcome rare or harmful) • Did it address the study question?
<p>3. Were the cases recruited in an acceptable way?</p> <p>HINT: We are looking for selection bias which might compromise validity of the findings:</p> <ul style="list-style-type: none"> • Were the cases representative of a defined population (geographically and/or temporally?) • Was there an established reliable system for selecting all the cases? • Are the cases defined precisely? • Are they incident or prevalent? • Is there something special about the cases? • Is the time frame of the study relevant to disease/exposure? • Was there a sufficient number of cases selected? • Was there a power calculation?

4. Were the controls selected in an acceptable way?

HINT: We are looking for selection bias which might compromise the generalisibility of the findings:

- Were the controls representative of defined population (geographically and/or temporally)
- Was there something special about the controls?
- Was the non-response high? Could non-respondents be different in any way?
- Are they matched, population based or randomly selected?
- Was there a sufficient number of controls selected?

5. Was the exposure accurately measured to minimise bias?

HINT: We are looking for measurement, recall or classification bias:

- Was the exposure clearly defined and accurately measured?
- Did the authors use subjective or objective measurements?
- Do the measures truly reflect what they are supposed to measure? (Have they been validated?)
- Were the measurement methods similar in the cases and controls?
- Did the study incorporate blinding where feasible?
- Is the temporal relation correct? (Does the exposure of interest precede the outcome?)

6a. What confounding factors have the authors accounted for?

HINT:

- Genetic
- Environmental
- Socio-economic

6b. Have the authors taken account of the potential confounding factors in the design and/or in their analysis?

HINT: Look for:

- Restriction in design, and techniques e.g. modelling stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors

What are the results? (Section B)

7. What are the results of this study?

- What are the bottom line results?
- Is the analysis appropriate to the design?
- How strong is the association between exposure and outcome (look at the odds ratio)?
- Are the results adjusted for confounding, and might confounding still explain the association?

8. How precise are the results?

- How precise is the estimate of risk?
- Size of the P-value
- Size of the confidence intervals
- Have the authors considered all the important variables?
- How was the effect of subjects refusing to participate evaluated?

9. Do you believe the results?

- Big effect is hard to ignore!
- Can it be due to chance, bias or confounding?
- Are the design and methods of this study sufficiently flawed to make the results unreliable?
- Consider Bradford Hills criteria (e.g. time sequence, dose-response gradient, strength, biological plausibility)

Will the results help locally? (Section C)

10. Can the results be applied to the local population?

HINT: Consider whether

- The subjects covered in the study could be sufficiently different from your population to cause concern
- Your local setting is likely to differ much from that of the study
- Can you quantify the local benefits and harms?

11. Do the results of this study fit with other available evidence?

HINT: Consider:

- All the available evidence from RCT's, systematic reviews, cohort studies and case-control studies as well for consistency.

Critical skills appraisal programme: Randomised control trial checklist

Are the results of the trial valid? (Section A)
<p>1. Did the trial address a clearly focused issue?</p> <p>Consider: An issue can be focused in terms of:</p> <ul style="list-style-type: none"> • The population studied • The intervention given • The comparator given • The outcomes considered
<p>2. Was the assignment of patients to treatments randomised?</p> <p>Consider:</p> <ul style="list-style-type: none"> • How was this carried out, some methods may produce broken allocation concealment • Was the allocation concealed from researchers?
<p>3. Were patients, health workers and study personnel blinded?</p> <p>Consider:</p> <ul style="list-style-type: none"> • Health workers could be; clinicians, nurses etc • Study personnel – especially outcome assessors
<p>4. Were the groups similar at the start of the trial?</p> <p>Consider: Look at</p> <ul style="list-style-type: none"> • Other factors that might affect the outcome such as age, sex, social class, these may be called baseline characteristics
<p>5. Aside from the experimental intervention were the groups treated equally?</p>
<p>6. Were all of the patients who entered the trial properly accounted for at its conclusion?</p> <p>Consider:</p> <ul style="list-style-type: none"> • Was the trial stopped early? • Were patients analysed in the groups to which they were randomised?
What are the results? (Section B)
<p>7. How large was the treatment effect?</p> <p>Consider:</p> <ul style="list-style-type: none"> • What outcomes were measured? • Is the primary outcome clearly specified?

- What results were found for each outcome? Is there evidence of selective reporting of outcomes?

8. How precise was the estimate of the treatment effect?

Consider:

- What are the confidence limits?
- Were they statistically significant?

Will the results help locally? (Section C)

9. Can the results be applied in your context?

Consider:

- Do you have reason to believe that your population of interest is different to that in the trial?
- If so, in what way?

10. Were all clinically important outcomes considered?

Consider:

- Is there other information you would like to have seen?
- Was the need for this trial clearly described?

11. Are the benefits worth the harms and costs?

Consider:

- Even if this is not addressed by the trial, what do you think?

Critical skills appraisal checklist: Cohort studies

Are the results of the study valid? (Section A)
<p>1. Did the study address a clearly focused issue?</p> <p>HINT: A question can be ‘focused’ in terms of</p> <ul style="list-style-type: none"> • The population studied • The risk factors studied • The outcomes considered • Is it clear whether the study tried to detect a beneficial or harmful effect?
<p>2. Was the cohort recruited in an acceptable way?</p> <p>HINT: Look for selection bias which might compromise the generalisability of the findings:</p> <ul style="list-style-type: none"> • Was the cohort representative of a defined population? • Was there something special about the cohort? • Was everybody included who should have been included?
<p>3. Was the exposure accurately measured to minimise bias?</p> <p>HINT: Look for measurement or classification bias:</p> <ul style="list-style-type: none"> • Did they use subjective or objective measurements? • Do the measurements truly reflect what you want them to (have they been validated)? • Were all the subjects classified into exposure groups using the same procedure
<p>4. Was the outcome accurately measured to minimise bias?</p> <p>HINT: Look for measurement or classification bias:</p> <ul style="list-style-type: none"> • Did they use subjective or objective measurements? • Do the measures truly reflect what you want them to (have they been validated)? • Has a reliable system been established for detecting all the cases (for measuring disease occurrence)? • Were the measurement methods similar in the different groups? • Were the subjects and/or the outcome assessor blinded to exposure (does this matter)?

5a. Have the authors identified all important confounding factors?

5b. Have they taken account of the confounding factors in the design and/or analysis?

HINT: Look for restriction in design, and techniques e.g. modelling, stratified-, regression-, or sensitivity analysis to correct, control or adjust for confounding factors

6a. Was the follow up of subjects complete enough?

6b. Was the follow up of subjects long enough?

HINT: Consider:

- The good or bad effects should have had long enough to reveal themselves
- The persons that are lost to follow-up may have different outcomes than those available for assessment
- In an open or dynamic cohort, was there anything special about the outcome of the people leaving, or the exposure of the people entering the cohort?

What are the results? (Section B)

7. What are the results of this study?

HINT: Consider

- What are the bottom line results?
- Have they reported the rate or the proportion between the exposed/unexposed, the ratio/the rate difference?
- How strong is the association between exposure and outcome?
- What is the absolute risk reduction?

8. How precise are the results?

HINT: Look for the range of the confidence intervals, if given.

9. Do you believe the results?

HINT: Consider

- Big effect is hard to ignore!
- Can it be due to bias, chance or confounding?
- Are the design and methods of this study sufficiently flawed to make the results unreliable?
- Bradford Hills criteria (e.g. time sequence, dose-response gradient, biological plausibility, consistency)

Will the results help locally? (Section C)

10. Can the results be applied to the local population?

HINT: Consider whether

- A cohort study was the appropriate method to answer this question
- The subjects covered in this study could be sufficiently different from your population to cause concern
- Your local setting is likely to differ much from that of the study
- You can quantify the local benefits and harms

11. Do the results of this study fit with other available evidence?

12. What are the implications of this study for practice?

HINT: Consider

- One observational study rarely provides sufficiently robust evidence to recommend changes to clinical practice or within health policy decision making
- For certain questions observational studies provide the only evidence
- Recommendations from observational studies are always stronger when supported by other evidence

Critical skills appraisal programme checklist: Qualitative Studies

Are the results of the review valid? (Section A)
<p>1. Was there a clear statement of the of the research?</p> <p>HINT: Consider</p> <ul style="list-style-type: none"> • What was the goal of the research? • Why it was thought important? • Its relevance
<p>2. Is a qualitative methodology appropriate?</p> <p>HINT: Consider</p> <ul style="list-style-type: none"> • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the right methodology for addressing the research goal?
<p>3) Was the research design appropriate to address the aims of the research?</p> <p>HINT: Consider</p> <ul style="list-style-type: none"> • If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?
<p>4. Was the recruitment strategy appropriate to the aims of the research?</p> <p>HINT: Consider</p> <ul style="list-style-type: none"> • If the researcher has explained how the participants were selected • If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study • If there are any discussions around recruitment (e.g. why some people chose not to take part)
<p>5. Was the data collected in a way that addressed the research issue?</p> <ul style="list-style-type: none"> • HINT: Consider • If the setting for data collection was justified • If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) • If the researcher has justified the methods chosen • If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? • If methods were modified during the study. If so, has the researcher explained how and why? • If the form of data is clear (e.g. tape recordings, video material, notes etc) • If the researcher has discussed saturation of data
<p>6. Has the relationship between researcher and participants been adequately considered?</p>

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?

HINT: Consider

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

10. How valuable is the research?

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy? or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix C

The Global Deterioration Scale for Assessment of Primary Degenerative Dementia

The Global Deterioration Scale for Assessment of Primary Degenerative Dementia

The Global Deterioration Scale (GDS), developed by Dr. Barry Reisberg, provides caregivers an overview of the stages of cognitive function for those suffering from a primary degenerative dementia such as Alzheimer's disease. It is broken down into 7 different stages. Stages 1-3 are the pre-dementia stages. Stages 4-7 are the dementia stages. Beginning in stage 5, an individual can no longer survive without assistance. Within the GDS, each stage is numbered (1-7), given a short title (i.e., Forgetfulness, Early Confusional, etc. followed by a brief listing of the characteristics for that stage. Caregivers can get a rough idea of where an individual is at in the disease process by observing that individual's behavioral characteristics and comparing them to the GDS. For more specific assessments, use the accompanying [Brief Cognitive Rating Scale \(BCRS\)](#) and the [Functional Assessment Staging \(FAST\)](#) measures.

Level	Clinical Characteristics
1 No cognitive decline	No subjective complaints of memory deficit. No memory deficit evident on clinical interview.
2 Very mild cognitive decline (Age Associated Memory Impairment)	Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.
3 Mild cognitive decline (Mild Cognitive Impairment)	Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word and name finding deficit becomes evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.
4 Moderate cognitive decline (Mild Dementia)	Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of one's personal history; (c) concentration deficit elicited on serial subtractions; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and place; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations frequently occur.

<p style="text-align: center;">5 Moderately severe cognitive decline (Moderate Dementia)</p>	<p>Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives, e.g., an address or telephone number of many years, the names of close family members (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses' and children's names. They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.</p>
<p style="text-align: center;">6 Severe cognitive decline (Moderately Severe Dementia)</p>	<p>May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and, sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will be able to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.</p>
<p style="text-align: center;">7 Very severe cognitive decline (Severe Dementia)</p>	<p>All verbal abilities are lost over the course of this stage. Frequently there is no speech at all -only unintelligible utterances and rare emergence of seemingly forgotten words and phrases. Incontinent of urine, requires assistance toileting and feeding. Basic psychomotor skills, e.g., ability to walk, are lost with the progression of this stage. The brain appears to no longer be able to tell the body what to do. Generalized rigidity and developmental neurologic reflexes are frequently present.</p>

Reisberg, B., Ferris, S.H., de Leon, M.J., and Crook, T. The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, 1982, 139: 1136-1139.

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Appendix D

Ethical approval and insurance cover for current study

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Appendix F

Ethical approval for larger study

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Appendix F

Written permission and ethical approval for anonymous dataset


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Appendix G Information and consent forms for current study



****Research project: Couples' experiences of singing together when one partner has memory difficulties****



Do you and your spouse/partner sing together?

Do either of you live with memory difficulties/a diagnosis of dementia?

If so, I would like to hear from you!

My name is Shreena Unadkat and I am conducting research into the experience of singing together on couples who are living with dementia. Singing has been shown to be beneficial for a number of health conditions, and through the research I hope to gain some insight into the impact it has, if any, on quality of life and on relationships. I am hoping to interview couples who attend singing groups together. These can be any type of singing group: choirs, informal groups, or groups specifically designed for people with memory difficulties (such as Singing for the Brain by the Alzheimer's Society).

Participation in the research involves meeting with me for an interview where I will speak to you both together to discuss your experience of singing together in the group, at a location of your choice. The total time involved should not exceed 2 hours. I hope that this research will help to influence and support the current provisions for singing in healthcare.

All information shared in the interviews will be kept anonymous. The study is being completed as part of a doctoral qualification in clinical psychology awarded by Canterbury Christ Church University.

If you are interested in taking part, or would just like more information, please do call, email or write to me at:

07882766501

s.unadkat25@canterbury.ac.uk

Shreena Unadkat, Trainee Clinical Psychologist, Runcie Court, Salcey, Canterbury Christ Church University, Broomhill Road, Tunbridge Wells, Kent, TN3 0TG

Thank you for taking the time to read this advert, and I hope to hear from you soon! Shreena



**Information sheet for both participants
(to be gone through with the researcher)**

My name is Shreena Unadkat, and I am conducting a research study with Canterbury Christ Church University. I would like to invite you to take part in this study. Please read the information below so that you are fully aware of what they study entails before you decide to take part. If you have any questions at all, please do not hesitate to contact me on [REDACTED]

What is this research study about?

Previous research has shown that singing has a beneficial effect on general wellbeing. Other research has also looked at couples where one partner has dementia, and the ways in which that couple manages the difficulties.

This research study will be looking to explore the effects that singing together in a group has on couple relationships where one partner has dementia.

Why have I been invited?

You have been invited to take part in this study because you and your partner have attended singing groups together. You may have attended in the past, or may still currently be attending now. You do not have to take part in this study, it is completely voluntary. Your decision to take part or not will not affect your membership of the singing group.

What will I be asked to do, if I decide to participate?

In this study I will be interviewing both you and your spouse/partner together. The interview will take between 30 and 90 minutes, and will be recorded so that it can be transcribed. They will take place in a private place, and no one else will be present but the researcher. Any transcripts will be made anonymous, so no one will know your name or identity from the final write up. Anonymous quotes will be used in the final reports.



Potential advantages and disadvantages of taking part:

Although this study may not directly benefit your singing group, we hope that it will give us some further information about the effects of singing, which may help organisations in the UK decide which aspects of this group to develop.

I may be asking some questions about you, your relationship with your spouse/partner and how you are currently feeling. If you find that this is distressing in any way, please do let me know. You will have the option to stop the interview at any point during the process, and will also be able to withdraw from the study at any time with any consequences to you whatsoever.

Whatever you say in the interview will remain confidential, and will not affect your continued participation in the singing group. The only reason that confidentiality would be broken is if I feel that you, your partner, or someone else is at serious risk from something that is disclosed. In this situation, I will consult you before contacting your GP or other relevant agencies.

What if there is a problem with the study, or if I have a complaint?

If you have any questions or concerns about the study, please do not hesitate to contact me and I will try and answer your questions for you to the best of my ability. If for any reason you do not feel able to do this, or if you wish to complain formally, you can do this by contacting the Research Department at Applied Psychology, David Salomons Estate, Broomhill Rd, Royal Tunbridge Wells, Kent TN3 0TG

What will happen with the results of the study?

The results of this study will be written up in the year following your interview. They will be available to view at Canterbury Christ Church University, and I will be more than happy to let you know of the outcome after the study has been written up.



Participant Consent Form



If you wish to participate in this study, please tick the relevant boxes below, and sign. If you wish to ask any further questions before doing so, please do not hesitate to contact me on



Please tick:

I confirm that I have read the information sheet above, and have been given the opportunity to ask questions about the study

I understand that the research study will contain interviews that will be recorded

I have been informed that I am volunteering for this study, and have the right to withdraw my consent with no consequences to me whatsoever

If you wish to take part in the study, please sign below:

Name _____

Signature _____

Date _____

Researcher Name _____

Signature _____

Date _____

Appendix H

Interview schedule

Grounded theory method guidelines state that initial interviews should be as open as possible, so that participants can fully express all of their views on the topics discussed, and in order not to close down potential theoretical avenues. Questions were tailored for stage of study, communicative ability and type of singing group. Questions may have been simplified if communication became too difficult or distressing. Three broad areas were covered: 1) the relationship history 2) the journey through diagnosis and 3) the experience of the singing group. Please find some examples of general questions below.

Relationship history:

- How long have you been together?
- Tell me about some things you have enjoyed doing together?
- What do you currently enjoy doing together?
- Where have you lived?
- Do you have family? Are they close by?
- Tell me a little about when you first met
- What was your wedding day like?
- What was your first home together like?
- What is your favourite part of your home at the moment?

Journey through diagnosis:

- What was life like before the diagnosis?
- How long has it been since the diagnosis? What has that journey been like for both of you?
- What has changed since the diagnosis?
- What services are you involved with since the diagnosis?
- Are things different between you since the diagnosis? How?

The experience of the singing group:

- How do you find coming to singing group/ what is it like coming to singing group?
- What do you sing about?
- Have you met many new people here?
- Do you sing outside of the group sessions?
- Did you sing previously? If so, who was the singer?
- What impact does coming to the singing group have on your life?

For later stages of interviewing:

- What, if anything, do you feel is the difference between singing and other activities?
- What does your facilitator bring to your group?
- How does singing feel? Does this carry on after the group?
- Some people have talked about new learning. Do you feel like you have learnt anything new in your group, and what has this been like for you both?
- What don't you like about your singing group? What could be improved?
- Describe your experience of being part of a group with all the different people.
- Has coming to the group affected your relationship?

Appendix I: Example theoretical memos

MRP - Theoretical Memos

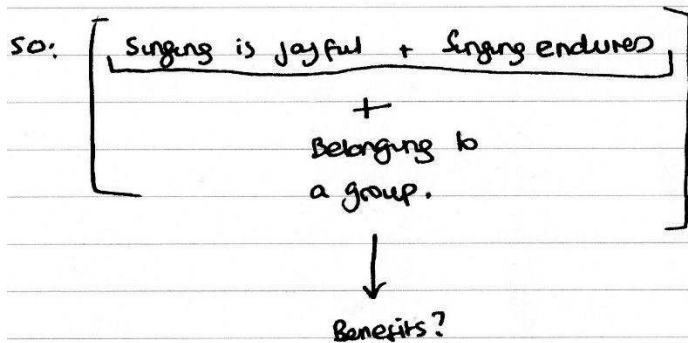
29.08.2014

Singing as an activity →

So far people have talked about this as 'Universal' quite a lot. I am wondering if it is easier to get involved in as it is a non 'cognitive' activity (No planning needed, or language in some cases).

For people with dementia → activities are restricted, decrease in activities and loss of previous roles / interests

↳ Does music and singing endure?

MRP - Theoretical Memos

05.09.2014

A note about singing ability

Singing ability and singing participation are distinct entities in this study.

Many people report:

"I can't sing but I like singing".

Therefore, joyfulness, togetherness and participation are NOT dependent on talent in these cases.

MRP - Theoretical memos. 10.09.2014

Caregiver and person with dementia benefit and how it differs:

↳ Caregivers seem to be reporting a sense of release

↳ PwD reporting being seen

Do these feed into one another?

Remembering a quote from an interview:

"like breathing oxygen into our relationship"

So: $\underbrace{[\text{Caregiver benefit}] + [\text{PwD benefit}]}$
couple benefit?

Also: Lightening of "seriousness" and enjoyment is a good thing for couples in dark times.

12.09.2014

Dementia and its impact on couples = lessening / decreasing activity and intimacy. Changing roles. So: music as an equalizer?

MRP Theoretical memos

30.11.2014

Facilitators and their importance

DISCONFIRMING CASE → very few benefits reported as the facilitator set up a [HIERARCHY OF TALENT]

Therefore - facilitators play VITAL role in helping people participate. Good facilitation must happen in order for people to feel like they don't have to be able to sing well to enjoy the group singing

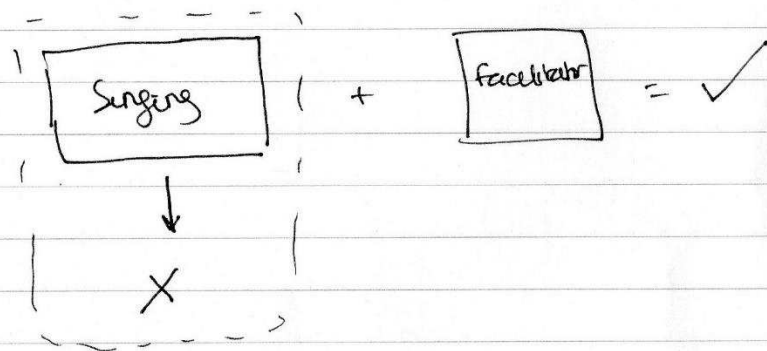
MRP Theoretical memo: later some day

Equality → maybe people feel like a proper group if they can participate equally?

MRP Theoretical Memos 10.01.2015

Singing ability 2:

Many individuals have pointed out that people in their group have 'good / beautiful' voices. So it's not that people don't recognize ability, but if their facilitator helps them to feel part of it then they can experience the benefits.



SINGING ABILITY NOT MECHANISM
OF CHANGE

SINGING PARTICIPATION VITAL FOR
CHANGE

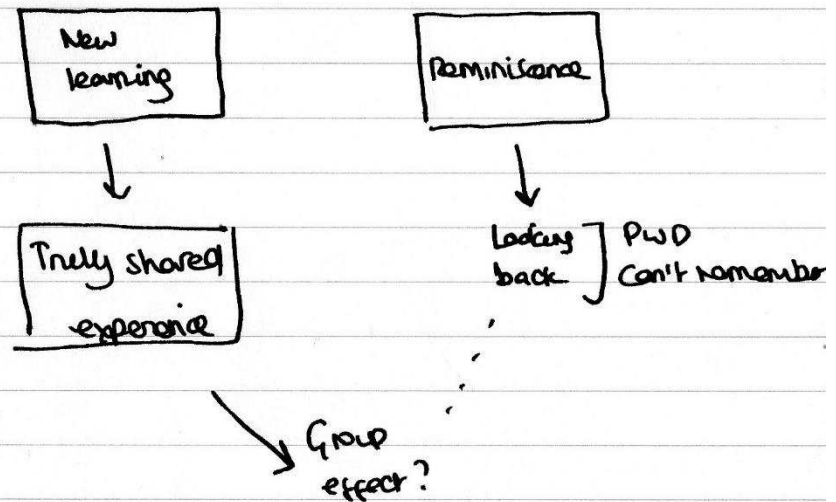
MRP Theoretical Memos : 11.01.2015

New learning and ageing

People in composing, creating and performing groups report more positive statements about singing.

Added element of excitement, goes against regular ageing culture

Report of building something and looking forward



MRP Theoretical Memos 25.01.2015

Creativity vs. Reminiscence

Creator of something new \Rightarrow end up
with a feeling of having produced
something

Reminiscence \Rightarrow Good memories of
the past (what if you have bad
memories of the past?)

Reminiscence dependent on memory
Creativity dependent on ability to learn.



Singing is not 'cognitive' as such so
maybe easier to learn/pick up than
other skills? : "Better than a game"

Participant 13

MRP - Theoretical Memos: 30.02.2014

Noted that participants positive experiences
appeared to be tied to group belonging
so far, although no disconfirming cases
as of yet. So - questions:

\rightarrow Can singing by yourself be as
powerful as singing in a group?

\rightarrow Group singing is enabled by something

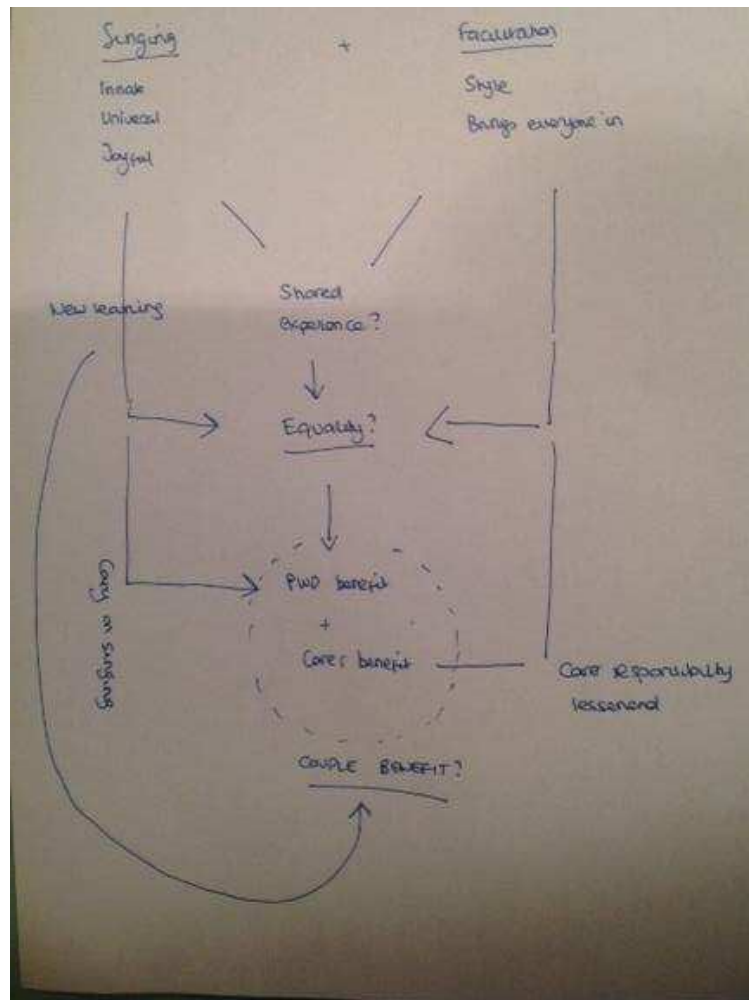
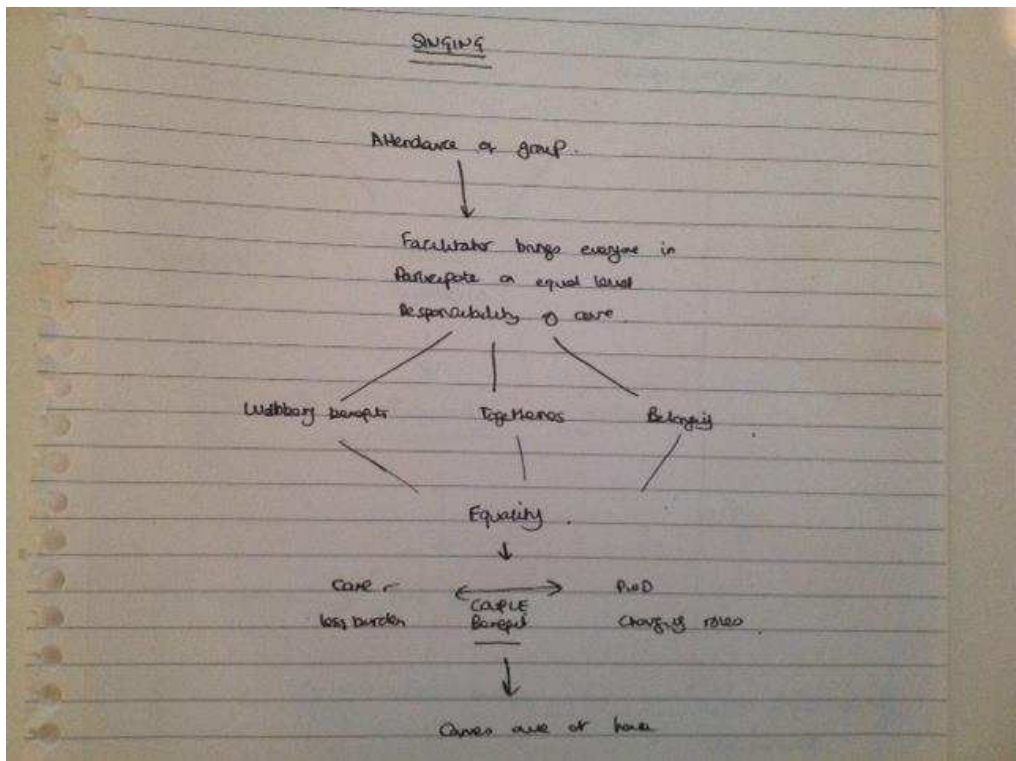
31.02.2014

Additionally positive experiences are described
as joyful as opposed to just pleasant.

[Powerful emotions reported + group effect.]

Appendix J

Example theoretical diagrams



Appendix K

Bracketing interview summaries

Bracketing interview 1

Singing: my own experience of singing. Moving to a new place, joining the local choir whilst unemployed. Gave us a social life and a presence in the community, let me take advantage of my singing ability (at a time where I perhaps had no other abilities on show). This meant that the singing group meant a lot to me and was a) validating of my ability b) a social connection. The singing group was full of lots of older people, giving me the idea for this study.

It's possible I may feel like I have something in common with people with dementia, at that time I was disempowered and it gave me a voice or a purpose. It's possible that I am looking for this.

Just because I have a good experience of singing, doesn't mean that everyone will. What about the people who don't actually enjoy singing groups? Will they be disconfirming my beliefs and therefore will I attend to these voices less?

Couples: In my last relationship I was in a disempowered position (financially) and therefore took the social and family role on as a major task. Was a caregiver as my job, and my individual ambitions were really only being met by the choir.

What will I be looking for from caregivers? Is it possible that I really identify with the caregiver role and am searching for something for them over and above something for the person with dementia? Or possibly identify with the PWD role as disempowered? I imagine this will bring up strong emotions. How will this affect my questioning? I could focus on role empowerment and shut down other lines of questioning if not careful.

Bracketing interview 2: summary

Cultural issues with speaking to older people: In my cultural upbringing, one does not ask elders about the intimate details of their relationships. Was feeling stuck in certain interviews and by the end of this bracketing interview (and questioning) we had figured out that this is the reason why. This may be closing down areas of questioning (as well as increasing my anxiety in interview situations).

Cultural ideas about marriage: Arranged marriage, not currently married myself. Underlying beliefs that couples stay together out of 'duty' – discussed how this plays into the caregiver role (if at all). There is a possible assumption of a lack of happiness/love and a presence of regret or hopelessness. Also ideas about family and a close family support network not necessarily being a good thing (having come from a particularly hierarchical background myself).

Class issues: Have interviewed in various socioeconomic areas. Currently from a mixed area myself, there is also an assumption that wealth = happiness and security in older life (L pointed out I may not be wrong here). I could be directing questioning to confirm or deny this (by emphasising the good parts of the wealthier lifestyle and emphasising the negative parts of a not so wealthy one).

Appendix L

Abridged Research Diary

Below are selected entries from a research diary spanning the length of the project (approximately 24 months)

07.02.2013. Met with Paul to discuss the design of the project, he seemed fine with the idea that we look at the couples' experience of singing. Explained to him about my connections with singing groups where I used to live and how I came up with the idea, and felt a bit worried that it would influence my analysis in one way or another; after all, I do think that singing is a good thing. Had a good discussion about subjectivity and objectivity, and Paul helped me to realise that it is not a bad thing to have a passion for something that you are researching – it might actually be a good thing in the end as it motivates you. Talked a lot about how to keep an eye on how I may be influencing the process.

12. 04. 2013 Met with second supervisor Trish today to discuss how the project might run – really interesting conversation about how to possibly bring health economics into the study. Might be worth looking at although I don't know how realistic it is, given the timescales that we have to do this in. Would be worth thinking about the added value of singing as an intervention, after all times are more and more stretched. Thought again about what kind of methodology to use – my background is quantitative and I am a quantitative thinker really. But thinking back to the singing groups I've been a part of – what measures are there out there that would capture this experience? Personally, it would be safer ground for me to stick with numbers. Also really aware that I have had a positive experience of singing, this might not be the case for everyone.

26.04.2013. Met with Paul today to discuss design. Am starting to move towards a more mixed methods sort of study. The only problem with this is thinking about how to make power. However, on reflection now I am wondering if me sticking to what I know is just a move towards 'safe certainty'. This might not be the best way to open up the research, and this is an area I feel very strongly about – I want to do the best I can for this population. I am noting here that my 'advocate' voice is very strong in my discussions with supervisors and others about this project (wanting to speak up for a population with little voice). This was a strong reason for me wanting to get into clinical psychology in the first place, and I might need to think more about whether this is limiting me somehow.

16. 05. 2013. Decided on grounded theory as a methodology after some consideration and discussions with supervisors. It's a terrifying step as I've never done qualitative methodology before,

but it does seem like the most suitable approach considering what I am looking for in a study. I'm really interested in trying to understand things theoretically and want to look at people's experiences. So much reflection and time has already gone into this process and I haven't even started the study, so the scale of it feels overwhelming. How will my background in quantitative work have an effect on this study? Reading up on grounded theory – it seems like a very thorough process, which I like the idea of. My assumptions about qualitative work are already starting to get in the way though, I assumed it would not be as 'scientific' as quantitative studies are.

18.05.2013. Good conversation with G (who knows me and knows my interest in this area very well) today about why I am looking at couples specifically. He made some insightful points (as usual, will try and remember to consult him as a non-psychology viewpoint). I have been focusing my attention on how my experience of singing groups (choirs etc) is influencing this project, and he reminded me to be aware of my experience of couples also. What is it that I am looking for from these couples? How has my recent experience of being in a couple been affecting my thinking about this? I have made a note of this to include in a bracketing interview with a colleague soon.

24.05.2013. A meeting with both Paul and Trish has left me both full of excitement and anxious about what is to come. Some good ideas from them both about using questionnaires to situate the sample, and we talked a lot about how to ask questions in interviews. I realised how much of this research will draw upon my 'therapy' skills in order to keep it open. I arrived very well prepared for the meeting, and realised that is not a very "grounded theory" thing to do. I have decided to try and stay with the methodology as much as I can (despite it being slightly counter intuitive to me) and focus on my participants and the data before I look into literature and theory. This way I can approach the interviews fresh without letting too many preconceived ideas shape the questioning.

12.12.2013. Went along to a rehearsal last week and then the ending performance today at the picture gallery and felt overcome with emotion. The music was beautiful and many people seemed to be really participating and taking part. Went round and spoke to some potential participants and was warmly welcomed by them all. Everyone seemed very enthusiastic about the programme, and lots of couples were willing to take part in the research. It all feels very positive and I got completely caught up in people's stories and how well everyone seemed. It was an affluent area however, and I should keep this in mind for theoretical sampling. Found myself thinking about the caregivers and their experiences of the group – they seemed to be really enjoying themselves too. I wonder if this means something for them as a couple? I am also rethinking my idea of using standardised measures in the interview at all. Discussed with Paul, and have decided not to use them as I really feel that this will impact the flow of

the interviews. I will instead be looking at the range of dementia. This does feel more in keeping with the philosophy that I am trying to get at with grounded theory!

30.01.2014. Carried out first interview from the picture gallery group this week. Left the interview feeling very sad, and wrote down the following words in the car: loss, grief, decline, not the person they know, marriage, long term partners, hard work. None of these things were explicitly said in the interview, but we did talk about their marriage and how things have changed for them since the diagnosis. A lot, it would seem. Bringing in the person with dementia's voice is very important as in this interview very little was said by him. They were very hopeful and positive about the group overall though. Initial ideas from the interview have been jotted down, but I need to do some line by line coding before I change the questioning at this stage, it's too early.

28.02.2014. Carried out two more interviews this week. It is really tempting to go to the literature at this point to see where I'm at but with all the reading I've been doing about the method I am resisting for now. I was apprehensive about both of these interviews as I left the last one feeling such sadness, but I actually found that both of these had a different feel to them. Overall the comments have been positive, and I am pleased that they will also be helping with the evaluation for the gallery – I tried as hard as I could to allow for negative responses to happen but unfortunately there don't seem to be many at the moment. Initial themes have definitely started developing in my mind, and although I am trying not to let these guide the process. I am struck by how much I want to understand how these couples cope with this diagnosis.

07.03.2014. Meeting with Paul. He suggests that now I have done the first lot of interviewing I do some thorough line by line coding to inform where I am going next. I did develop the questions from the first three interviews to the last two of this set, but it's important to formalise this for the next stage of recruitment. Initial themes have led me to an idea about where to sample next, but how will this work with the practicalities of the project? I am left wondering about grounded theory studies as a whole, so I have been looking at other studies. Brene Brown's research is grounded theory based which I am thrilled to find out (less thrilled when I realised the scope of her project).

22.04.2014. I have just finished my first attempt at line by line coding of a transcript. It took much, much longer than expected and I was not able to do it all in one sitting. I found myself struggling with trying to find the "right" answer with the coding, and ended up just paraphrasing each sentence for a while. Have read up a little bit more about analytical versus descriptive coding but the data isn't there yet. I already have so many initial codes from this one interview, I wonder how it is all going to look

when I have coded the rest of the interviews? I am considering moving over to NVivo as it's too hard to manage all the coding on paper.

02.06.2014. After the first lot of initial coding is done, I am starting to get an idea of the shape of the answers. I've been introduced to the idea of diagramming and it is making it much easier to think about how concepts might tentatively link at this point (although I keep going back to the transcripts to try and understand if it is coming from the data or just from my own ideas). Still struggling with the idea of things being "right" or "wrong" – it's brought up some epistemological questions for me. I have realised that although clinically and in conversation I tend towards the social constructionist viewpoint, actually in this research I am taking a more positivist standpoint. Not completely though as I feel acutely aware of how my ideas, preconceptions and previous experience are shaping things. Critical realist, perhaps.

18.07.2014. Organised and had my first bracketing interview today with a peer from my cohort (as I am going to be going into the second round of recruitment soon). It brought up some unexpected idea and emotions, such as the role of power in a relationship, the role conflicts I have experienced in my past relationships, and the drive I have to speak up for those without a voice. It also brought up how much value I place in cognitive intellect as a method of connection or communication. There have been lots of examples of nonverbal communication (or even musical communication) in the interviews so far. Something to keep in mind for the next round of recruitment.

22.08.2014. Went along today to a very different type of singing group – reminiscence based, in a less affluent area, run by Trish. Good to talk to her and see her leading the group reminds me of the actual reality of how this is applied therapeutically. A bigger mix of people at this group, being led in songs they might know (but still learning a few new ones occasionally). There was a different flavour to this, and I began wondering if all the people from this group would be able to access the art gallery group in the same way. There appeared to be a sense of community at this group which tapped into a memory in me about belonging to a singing group. This was a theme in the coding and is something I want to keep in mind if I interview here.

29.08.2014. Carried out an interview today after the reminiscence group session with a very welcoming couple. We focused a lot in this interview on the singing process, although I did get to hear about their history and marriage for context. Theoretically this interview does help to move the theory along – themes such as togetherness and belonging are a big part of things. I left feeling very hopeful

and enthused by their comments. I am really aware that people are being very positive no matter how hard I am trying to allow negative aspects of the group singing experience to come out.

01.09.2014. Carried out an interview today with the second couple from the reminiscence based singing group. This is the first interview where one member of the couple has been profoundly disabled. My own assumptions about the value of singing for this lady were really challenged – although she had not moved or said anything for the whole interview, when her husband sang to her a song from the group, she began mouthing the words. It was a very powerful interview. I hope to be able to capture the richness of this in the write up. It is once again a really positive interview, and I'm overwhelmed with the bravery of this couple over the years. In terms of the research, I'm aware that I am focusing very much on what the singing experience brings. Whilst it is a powerful thing, I'm realising it is only one part of a much bigger picture. There are many ways I could look at this theoretically, and I have to be careful not to confuse the benefits with the general coping style of the couple. Or perhaps that is another study?

28.10.2014. Meeting with C and L (peers) to check over my coding so far. Have put in a big effort this month with coding and feel like I know the data backwards - but they did have lots of questions about my decisions with the coding! I may not be being analytical enough in the coding. We talked through discrepancies which felt uncomfortable as I had started to just take ownership of the direction of the study, and I feel a little less confident now. Discrepancies were resolved however, and I have to stop looking for the 'ultimate truth' of the matter or trying to 'get it right' It's always going to be slightly subjective because it is my perspective! Evidence, not proof.

10.09.2014. Managed to recruit from a really unique group very far away from here – which follows several branches of my theoretical sampling tree at once. It was a really interesting interview, especially as it is the first one where I felt some less than positive sides were being talked about. Mostly they were not about the singing but about the general burden for the couple of the diagnosis. Spent a lot of time talking about the individual benefits and how these feed into the life at home. Was really struck by the changes in role that occur - there is something here about equality in a partnership. Again I can see that there are a thousand different ways I could take this model, but I have to think about what is best from a theoretical point of view. The way that the couples relate to each other is important, but I don't think I'll be able to really think about the premorbid relationship quality as that is a whole different study. I do have a big interest in the changing nature of relationships though, so I don't want to totally ignore it.

11.11.2014. The constant comparison process of coding is really different to what I have done before with thematic analysis. It is actually starting to feel like categories are building on one another and I am really surprised at how thorough the process is. I am feeling disappointed that I am having to let go of some of the codes in order to pull out the main themes. I'm also surprised at how often I am going back to the original interviews and how much strength there is behind the main categories. I think I assumed that I would have to search hard to find support for the emerging theory, and although it's time consuming, the data is definitely there. Why am I surprised? I wonder if it is something to do with my worries that I will be 'directing' the data.

27.11.2014. Really very satisfying interview today from a couple who took part in another reminiscence group. Caregiver was very dismissive of the group - the first disconfirming case! Everything they were saying has taken the theory on leaps and bounds - they talked a lot about what would have enabled their enjoyment. Interesting that it was so satisfying even though they didn't enjoy the singing group - in some ways it is the most important interview as it shows where the theory doesn't really hold up. Need to have a rethink about how I am drawing the diagrams about this. I thought I would not like hearing from people who didn't enjoy singing as much as I do, but I spent nearly 75 minutes taking about it with them.

11.12.2014. Meeting with Paul to check over my coding. Showed him selections of transcripts, and my coding tables, and the spider diagrams of how the codes fit together. I was worried about including things that did have many instances in the text, but actually that is me thinking quantitatively again. For instance, the last interview is highly significant, even if it is just one interview, because it is a disconfirming case. Talked through discrepancies and Paul started talking to me about how things apply in my theory. Got really stuck because I was overthinking it. Sometimes it can be simple that is ok.

12.12.2014. Another note on simplicity: clarity and the participants stories are more important than anything else. Therefore use client words and make it as simple as possible for people to understand.

08.01.2014. Now that I have started putting the theory together, I have spent a week in Section A and looking at the literature. Really starting to understand some of the basis for why music is such a powerful thing now, neurologically and psychologically. However, I am feeling challenged by the scale of it all. I'm just not able to put everything in that I want to, and it's demoralising in a way. The theoretical coding goes on, and makes sense but is also vast. I've spent some time reflecting on what the aims of this study are, and it's difficult to remember that I can't encapsulate everything about this whole experience. Is this an egocentric drive? Can't really put my finger on it.

06.03.2014. Meeting with Paul to go over my first draft of the diagrammed theory. He picked up that I had tried to make it very simple. Also picked up that it was too positive and I really need to remember to include where the theory doesn't hold in the diagram. I had a really emotional reaction to our discussion about 'carer burden'. I have not used this phrase up to now because I feel like it is somehow distressing for the PWD. Talked through how the distress and burden if caregiving is a real thing, and how not paying attention to it because it is uncomfortable is unfair to carers.

Appendix M

High level categories and example quotes

Appendix (?)

High level categories, example selective codes, example associated quotes

Overarching Category	Sub category	Example Quote
Joy of singing	Enjoyment	<p>Oh yes definitely, I think we both enjoyed it enormously. (P2)</p> <p>It's wonderful. We thoroughly, thoroughly enjoyed it. (P4)</p> <p>I had no sort of negative feelings about any of it. The singing was one of the most enjoyable experiences I have had in later life (PC5)</p> <p>...its enjoyment. I think that Alzheimer's is not an enjoyable thing in anyone's life, so it brings a bit of light. (PC7)</p> <p>It's a pleasurable thing to do, even if you don't do it well its enjoyment.(PD8)</p>

		<p>When I went to school... if you couldn't sing they just said get out... but it is horrible how teachers were horrible to children who couldn't sing. But it's better now, yes it's different, I like singing, enjoyment and singing. (PD9)</p> <p>Exactly. It's a lovely experience. A very good experience. (PC10)</p> <p>Yes that, and just the enjoyment of singing (PD12)</p> <p>To me, it's a God send, you know, I say it's a God send, I enjoy going, sort of thing, you know. (PC13)</p> <p>She said, yeah, she said you seemed to be enjoying yourself on Monday night (P16)</p> <p>It was a very enjoyable thing to do and we all enjoyed it (PC20)</p> <p>It was fun, for a start. You know when things don't get off on a real scale, but it just sort of seemed to gel all the time and it was just lovely (PC22)</p> <p>I enjoyed all the singing (PD24)</p> <p>We just enjoyed it so much, yes (PD30)</p> <p>I thought it was wonderful, and you and your comrades had got it all together and we just enjoyed it...once she's there (partners name) she's enjoying it, that's the main thing you know, it's the enjoyment. (PD34)</p>
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		<p>The singing group, yer, I thoroughly enjoyed that. I enjoy it. I enjoyed being in the singing group. (PD34)</p>
	Uplifting	<p>I think it's amazing. It's very uplifting, you leave there feeling a great deal better about life in general. Things are very stimulating. Very uplifting. (PC4)</p> <p>And I think singing is in a way. Music is very, very uplifting. (PC7)</p> <p>Yes it gets one out of oneself. (PC10)</p> <p>We go away feeling uplifted, the lightness and brightness follows us home. I mean joining in with the singing in the moment lifts us too, think about in the First World War, or marching in the Air Force, what did they do? They sang to lift the spirits to take them into battle, well that lifting follows us home. (PC11)</p> <p>I like to think of people being lifted up with the singing. (PC17)</p> <p>Yes, yes. It's very uplifting (PD24)</p> <p>I think mainly what helps you is when you're actually singing, when you're joining in with a group singing it lifts your spirits and makes you feel really good. (PC33)</p>
	Stimulating	<p>I think singing of itself was stimulating, you know, your pheromones or whatever, feel good chemicals, I think that's noticeable. I think the combination because you are stimulated on so many levels, I think it does make a difference. (PC4)</p>

		<p>It was going to be a good stimulus. A mental stimulus, you know. I think singing of itself was stimulating, you know, your pheromones or whatever, feel good chemicals, I think that's noticeable. I think the combination because you are stimulated on so many levels, I think it does make a difference. (PC4)</p> <p>You had to use your grey matter, which sometimes that's the biggest problem when you're not using your grey matter, so it was stimulating for us all.(PC7)</p> <p>With the singing, I think it all stimulates the brain, and the more stimulation the brain gets the more active, or the longer, it's going to sort of remain able to be stimulated. (PC13)</p> <p>And who was it, V commented on Monday night that she'd never seen you so animated at the recording (PC16)</p> <p>Yeah. It sort of stimulates people. It stimulates them. (PC17)</p> <p>It was lovely you know, it did make people focused. Instead of just sitting there and looking at other people, you were focused on what was coming up (PC34)</p>
	Therapeutic	<p>You come away feeling lighter and brighter and happier, you know... And also in some ways to forget about ourselves. You get lost in the process and that gives you space you know. (PC4)</p> <p>And who knows that being happy the body reacts, everyone reacts differently when they are happy then when they are sad or depressed. With anybody. (PC7)</p>

	<p>Well it lightens one, you feel less.... I feel it makes one feel a lot more positive and happy. Yes it makes one feel more cheerful and happy, yes it gets one out of oneself. (PC10)</p> <p>I don't care what people say, singing is a therapy, in my book. You know, because, you know, if you're feeling fed up, have a song, you know. And if you're feeling down, sing. (PC11).</p> <p>[Caregiver] Everyone in that room has got a problem, whatever it may be, but when you are singing...[Person with dementia]: It goes...[Caregiver]: It goes...I'm not thinking about, you know, the next problem we may have, and all the rest of it, we're outside of ourselves (PC11, PD12).</p> <p>It makes one feel more cheerful and happy, yes it gets one out of oneself. I think it is a very positive thing. I can imagine people do get depressed, they have a lot of stress, and that sort of thing I think is better, far better, than relying on pills. (PC16)</p> <p>When I get involved in that I can forget about other things and other things that might be bothering me, or I just get involved in the here and now. So for that couple of hours a week I'm sort of up there rather than down there. (PC16)</p> <p>You leave your problems behind because you're in the singing. (P19)</p> <p>Yes, it seems to reach parts that you can't reach sometimes with people with AZ. That's what it seemed to do with (x). (PC22)</p>
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<p>Accessibility of singing</p>	<p>Innate</p>	<p>You don't need to know how to sing, you just sing and that is that (PC4)</p> <p>Babies respond to singing and I think in some places they actually make sounds like melodies, it's natural (PC4)</p> <p>...because we can just pick it up again instantly, without needing any props or equipment or things. (PD8)</p> <p>Well I guess you just don't need to learn it, exactly, do you, singing? Not a skill like that, just something you do. (PC11)</p> <p>You know the people who aren't even speaking anymore, they were singing, maybe not well but wholeheartedly singing along sometimes, not like with a game where you have to know the rules and understand how to move the counters and hold that, you just know. It's innate, you can soon pick it up if it's a song, like automatically you can hear it in your head even if you aren't singing out loud, see? It is, you know, it's inside us all. (PC13)</p> <p>I wonder if it's an innate thing that humans have, you know, to want to have a sing (PC16)</p>
	<p>Universal</p>	<p>Whichever way you look at it, just think of the First World War, which we're thinking a lot of at the moment. What did the soldiers do when they were marching? Singing. (PC11)</p> <p>...singing is universal, it's for everybody, not just some people, and everyone can take part and probably has at some point. (PD12)</p>

		<p>They sing all over the world don't they, at weddings and funerals and everything. (PC13)</p> <p>...less daunting yes, daunting, than maybe going to other things (PD15).</p> <p>Even if you can't sing. Other people do that and even if they're very old or young they can still do something like that. (PD28)</p> <p>Everybody can sing, and they should sing. (PD17)</p> <p>You see it's not like some things which are just for one person and not for another, or rely on you to hold a paintbrush or anything like that stuff, it should be something for everyone really (PC17)</p>
<p>Effective facilitation</p>	<p>Encourages participation</p>	<p>...getting us all going (PC2).</p> <p>R was quite clear that it was for Carers as well. Despite of the fact that I am a dreadful singer....I mean the staff straight off weren't going to let anybody stand against the wall, you know, one was always greeted most warmly, and several people concerned with the project would come up in succession and talk to us...so there wasn't any chance for anybody to be like me to stand in the corner. (PC5)</p> <p>Well I think they were extremely welcoming. We had a wonderful time that first session, you know. We were introduced, and there was a bit if singing going on. And it was very relaxed and easy (PC10)</p> <p>I found the leadership very positive and very energised. (PC23)</p>

		<p>[Facilitator] puts you at ease and you don't feel as if you are constantly, even if the music is new, you don't feel sort of bewildered. (PD24)</p> <p>Exception: I think he doesn't really try to get people involved, I mean he does with some things but mostly not. We can't really all participate in it. (PC17)</p>
	<p>Person centred</p>	<p>...they have structured the whole thing around the needs of these people, very much with them as the centre and the focus. That is lovely, that is lovely. (PC4)</p> <p>...immediately greeted by people and made you feel you were important, which is important in itself, you know. (PC10)</p> <p>[Caregiver]: And, of course, [facilitator] is very good, isn't she, the way she puts it over, you know, in her manner, she tailors it all around us [Person with dementia]: Oh yes lovely, she's lovely (PC11. PD12)</p> <p>Rather than thinking, you have to go there and hope something, they made sure that it came from us, it was focused on us. (PD8)</p> <p>Exception: But I personally – it's difficult really without mentioning individuals, but I will, the leader – I don't have to say who he is, he's very much a sort of performer himself. Do you know what I mean? (PC17)</p>

	Equality as a priority	<p>Exception: But we can't all take part. He'll pick [X] and say we'll have some real singing now, well that's not right, is it? Maybe we'd all be able to get to the stage where we could sing it properly, then we would get these benefits that you would hear about of singing together, doing something together, feeling invigorated, feeling better because we've all done something together. But we don't. (PC18).</p> <p>Exception: And I get the impression that he tends to favour people, unlike me I suppose, who like his type of music, you see. (PC18)</p> <p>...no one had to, no one was asked to...sing a solo (PD6)</p> <p>You're part of it all, you are singing together, [facilitator] helps you to do that (PC11)</p> <p>I think they made sure that everyone was getting involved all at the same sort of pace (PC16)</p>
Equal participation	Equal participation	<p>I can join in, it's a good experience to be able to join...and you can! (PD9).</p> <p>Even high executives...you get the managing director singing with the man that ties up the parcels that go out, you know. I think it brings a lot of people to a same level, you know, so that everyone's the same. We're all singing. (PC11).</p> <p>Yes, yes, I think it's marvellous because most people wouldn't sing normally and they would never thought to be able to sing, but it doesn't matter, if you're not so bad it doesn't matter at all. (PD28)</p>

		<p>And it was nice to see that we were all equal there, that came across really well. There wasn't anybody that looked any different to anyone else, we were all equal which I thought was really good for all of us. (PC19)</p> <p>It's a great leveller you see, music and singing, everyone comes to the same level, even if you can't sing you can take part and that is because you are doing it together (PC13)</p>
	Group effect	<p>...feel that we belonged...yes definitely, laughing with friends. (PC2)</p> <p>...a good group experience. Again both of us recognised the value of the groups. But neither of us is really a group person. You aren't either really; you used to flinch at the prospect of joining a group....The group experience here was a real development for you, and experience for X, and it was for me. (PC6)</p> <p>But I think, the joy of it was that we were all completely different, from different backgrounds...but as it went on we became a real group. (PC7).</p> <p>You're joining a group and you're going to come out of it a better person than when you're going in. (PC11)</p> <p>And meeting the other people there – and the big thing about this is that the people who come, sometimes their partner moves on, dies, goes into, whatever, but they still keep coming because they feel comfortable and, you know, you make friends there (PC16)</p>

		<p>What I liked about the group was that it wasn't an individual singing group, it was a collective group and I liked that. I think (x) liked that, I don't think she would have been impressed to go to singing as an individual. (PC29)</p> <p>I thought it was wonderful, and you and your comrades had got it all together and we just enjoyed it. (PD34)</p>
New learning	New experiences	<p>Lots of things going on for people with dementia and carers, and a lot of it is based on reminiscence. But you don't always want to be reminiscing you want to be doing things now and looking forward. (PC2)</p> <p>... just opened up this whole world for us (PC4)</p> <p>It's opening your mind to new experiences, using your brain, in something that you never thought of using it in before. It's a bit like a steamed window where you can't see outside and you clean it then see a new world. (PC7)</p> <p>It's something that has probably happened which wouldn't have happened otherwise, because I don't think we would have gone along to a mixed choir together. (PC16)</p> <p>Yes, yes, I think it's marvellous because most people wouldn't sing normally and they would never thought to be able to sing, but it doesn't matter, if you're not so bad it doesn't matter at all. (PD28)</p>

		[Interviewer]: What did you like best? [Participant with dementia]: Learning new songs (PD30)
	Excitement/Building something	<p>And it's the excitement of being involved in something creative with other people right now. Not always thinking about the past (PC2)</p> <p>Oh the excitement of doing something new. (PC4)</p> <p>...so it has excited my love of the arts (PC7)</p> <p>...excitement about doing that, getting up and showing everyone what you have created (PC16)</p> <p>[Caregiver]: ...the performing and recording, well it's really exciting at our age, isn't it X? [Person with dementia]: Hmm, oh yes, exciting, well I used to be in a choir and it was called half tidy, and we used to performances. Very exciting. (PC16, PD17)</p> <p>of ...building something together, seeing something develop, being left with something that came out of it (PC2).</p> <p>Exception: Well everyone is hung up on music. I mean wherever you go there's music...well it's very boring, isn't it, really? (PC18)</p> <p>Exception: all that looking back, it can be a bit mindless maybe, possibly if we were being active and creating something it would be more beneficial, like a sort of new learning for us (PC18).</p>

<p>Person with dementia benefit</p>	<p>Increased confidence</p>	<p>And then I think she must of said that she knew the bit of music, but clearly she wasn't, when it came to it, she was not very confident in it. But she had the confidence to come forward and walk across and sing with other people in front of a crowd, you know, so I think it was a can do thing, I think we all felt we could do something. (PC2)</p> <p>I feel more confident about joining group activities of any kind, as a result my husband does too. Sharing in a creative artistic project helped our general confidence too. (PD6)</p> <p>At the end I never thought I would sing on my own...I surprised myself. (PD8)</p> <p>Because it's given them confidence, you see. (PC11)</p> <p>He looks forward to going to the other groups now, it's just given him a bit more confidence I think. (PC19)</p> <p>...that's been the single event where (x) has become animated and confident. (PC21)</p> <p>And you know the chap who was with me, he was a very quiet man and he's sort of come out since that's been going (PD34)</p>
	<p>Being seen</p>	<p>A full, range of people watching us. Full, full. (PD3)</p> <p>But they do that, and it is good for them to, because its education for these young ones, people who are otherwise unseen in society. (PC4)</p> <p>...it made you feel that you were important, which is important in itself (PD6).</p>

		Yeah, he does like it. He likes to be the centre of attraction, you see, and so he sort of fools around and everything. (PC18)
	Carrying over of singing ability	<p>Oh gosh he reads music. You know and understands music, the theory of music as well. You know, and can often ask very pertinent questions, you know (PC4)</p> <p>...was always the singer, used to sing, it was like [name's] old self really, it gave the confidence to get that back (PC5).</p> <p>It gave W the opportunity in sharing in an activity that I had greatly enjoyed in our early married life (PD6)</p> <p>But I mean A was much better at singing than I was, because he has been brought up to sing in a choir, you know, from a child, you know doing part singing and all sort of thing, so I mean he really does like traditional church music, don't you? That's what he really likes. (PC18)</p>
	Identity outside of diagnosis	<p>I was very surprised to learn that she was the cared for person, because before she seemed very outgoing in herself...she had the confidence to come forward and walk across and sing with other people in front of a crowd, you know, so I think it was a can do thing, I think we all felt then that we could do something. (PC2)</p> <p>And you know we are very vocal, [person with dementia] is particularly vocal in telling everyone about [singing group] (PC4)</p>

		<p>...see, it's obviously gone in...I know that [name] is still in there, we do everything together anyway but this is a way I get answered back, [name] is still there inside, I believe in that. (PC13)</p> <p>...that lady over there, it was the first time we'd seen her smile you know (PD34)</p>
<p>Caregiver benefit</p>	<p>Release from carer burden</p>	<p>it was something we could do together, where I wasn't responsible...I was relieved of any responsibility as it was all taken care of (PC2).</p> <p>I think, and I have found, that sometimes, like you can see how her hands all – well, when I wash her, sometimes it's really hard to get the fingers out to wash in between, you know. But if I sort of sing it to a little tune, whether it's my imagination or not, I don't know, but I believe it helps. (PC11)</p> <p>...it's like liberation, well like I said I haven't got a cat, I can't kick the cat, but I can go and sing it all out! Because I don't feel that I'm doing everything that I could be doing. So perhaps I'm putting all my energy in to shouting very loud to music (PC16)</p> <p>Exception: I'd be very happy if somebody else would take you. But I'm not able to find anybody. (PC18)</p>
	<p>Enjoyment</p>	<p>I am not musical, and I have no musical background, so you know, to be able to sing together with other people, not very loudly, just keeping my voice down, you know I was learning how to sing with other people (PC2)</p>

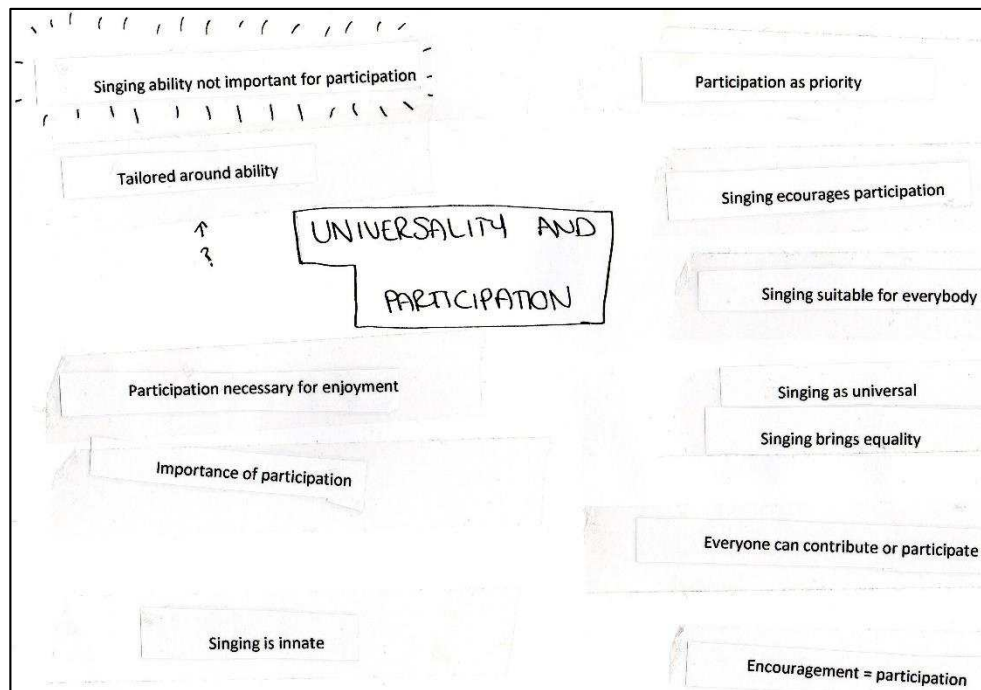
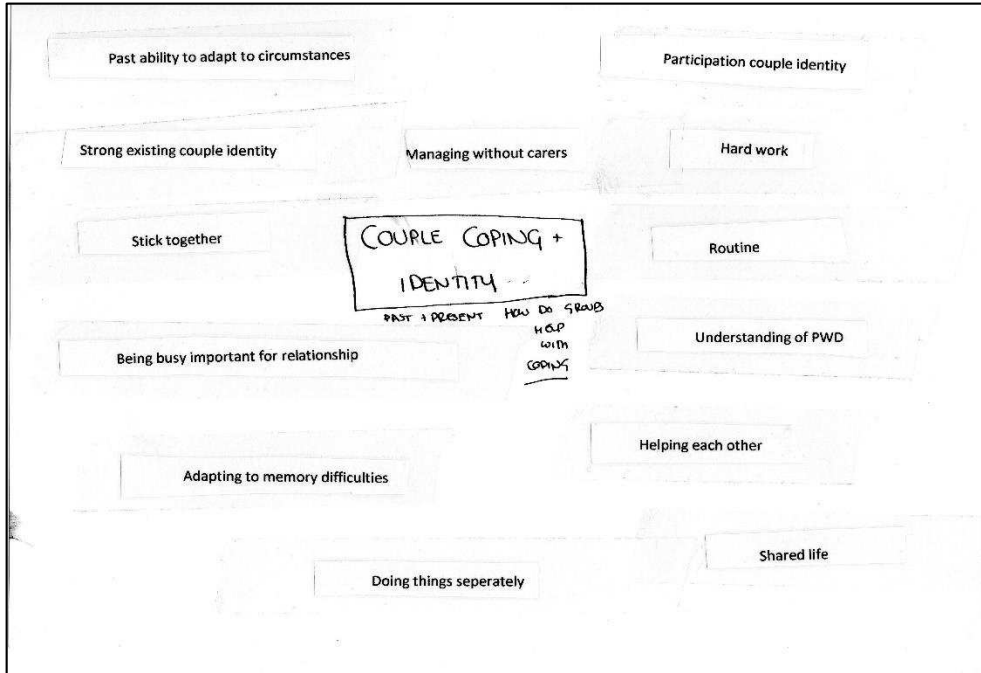
		<p>I used to take [name] along sometimes and leave...I would depart and do other things. I thought it was going to be similar to that...with singing I didn't even think I would be involved. But what I thought I would do, to be fair, I would stay the first day to see what was going on and whether [name] was comfortable and whatever was going on. And what developed I thought oh, I quite enjoy this. (PC7)</p> <p>But when we went there I was surprised at, you know, the satisfaction you do get from it. (PC18)</p> <p>I think I said previously, what I liked about the group was that it wasn't focused on AZ as such it was focused on an activity, for carers and people with AZ and I found that very enjoyable, it was straight forward unadulterated pleasure if you like. (PC23)</p>
Couple benefit	Changing roles	<p>[Caregiver] Despite of the fact that I am a dreadful singer. [Person with dementia] It's not dreadful but it's not good. [Caregiver] Well I have obviously improved then. (PC5, PD6)</p> <p>[Caregiver] Well, I can't sing, [name] always sang didn't you? [Person with dementia] Yes, I have to teach you! I didn't half laugh at your efforts, it's very funny, you are getting better though. (PC7, PD8).</p> <p>We're more equal in that group you see, and I can sing and she can sing just the same (PC11)</p> <p>I really just followed in your trail, didn't I, well I guess I still do at the group because you quite can do it all well (PC18)</p>

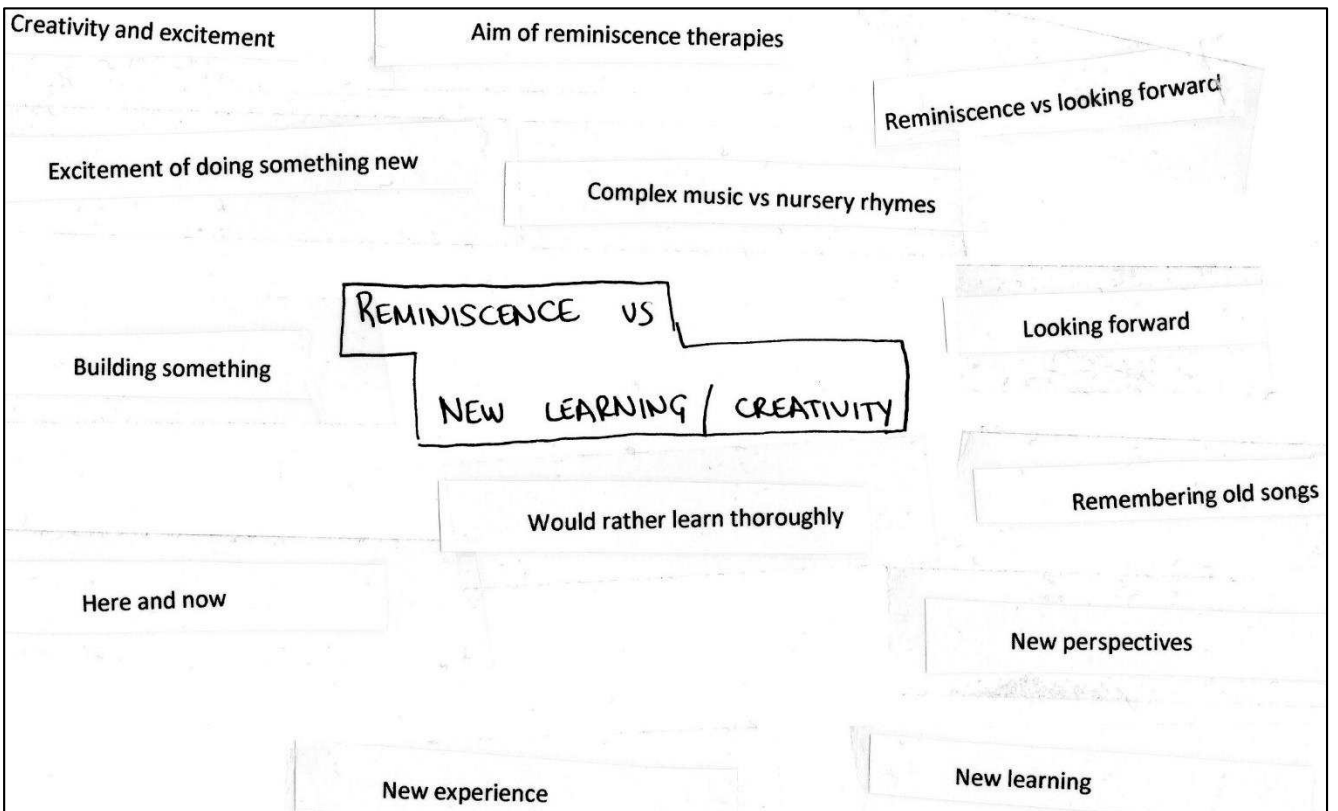
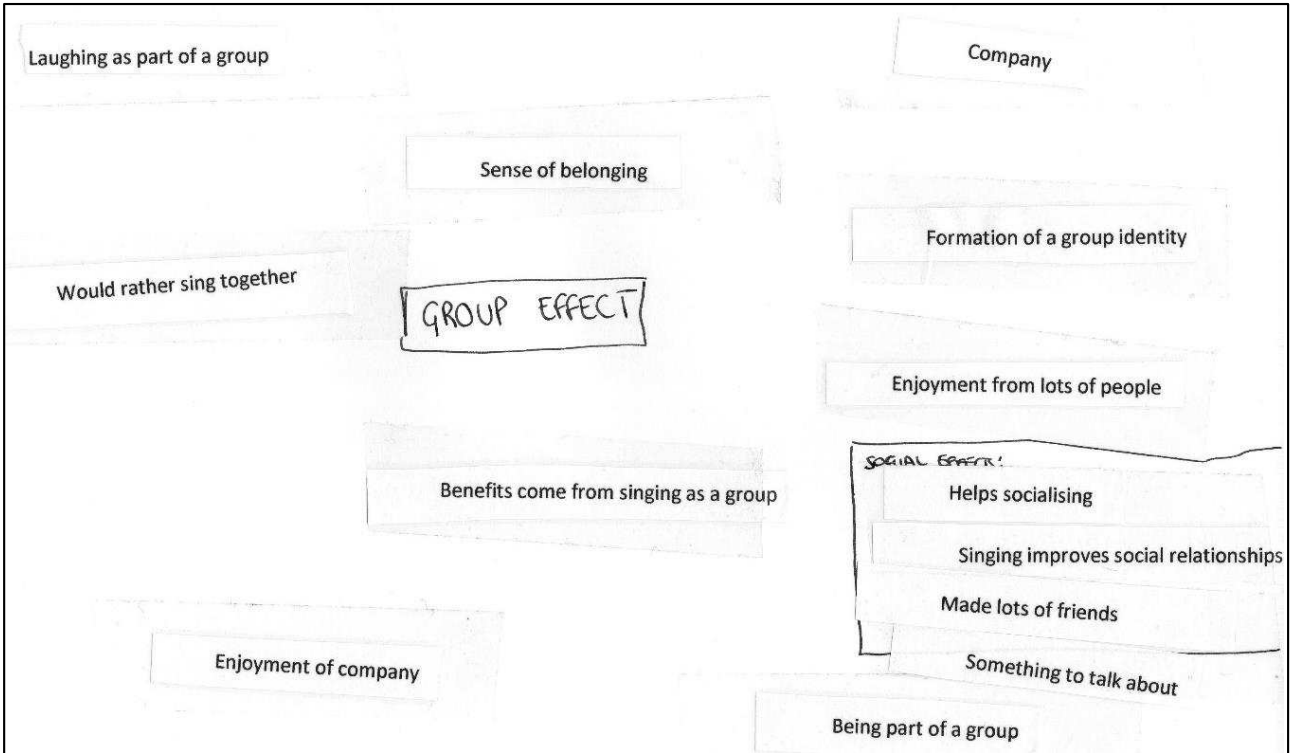
	Direct benefit	<p>So we could laugh about things together, couldn't we X, on that course. (PC2)</p> <p>I think it enriches. Individually and collectively, but the sum of that is greater than the sum of its parts. It's greater than one plus one in my opinion... It's a very precious part of our life because it has been so enriching for us. (PC4)</p> <p>His attempts at singing gave me much amusement, and we had fun together. (PD6)</p> <p>[Caregiver] While we were there we didn't fight and argue did we? [Person with dementia] Not very much, unusual. No. (P7, P8)</p> <p>I think it's like breathing oxygen into us, it is a stimulant, you know, it's not that you hadn't oxygen all around you all day, but it's like an extra puff...that releases energy so the dynamic is lighter and brighter (PC4).</p>
	Increase in activity	<p>I suppose it made me a bit ready-er to be helped. Really, it's not that I fight off, far from it, but it made me realise that things like group experiences have things to offer that I might perhaps need now, that we can both go to now. So I learnt that. (PC5).</p> <p>I feel more confident about joining group activities of any kind (PC6)</p> <p>Yes, it does, the more they are encouraged, and enveloped in it, the more, they will respond to it. (PC4)</p> <p>He looks forward to going to the other groups now (PC19)</p>

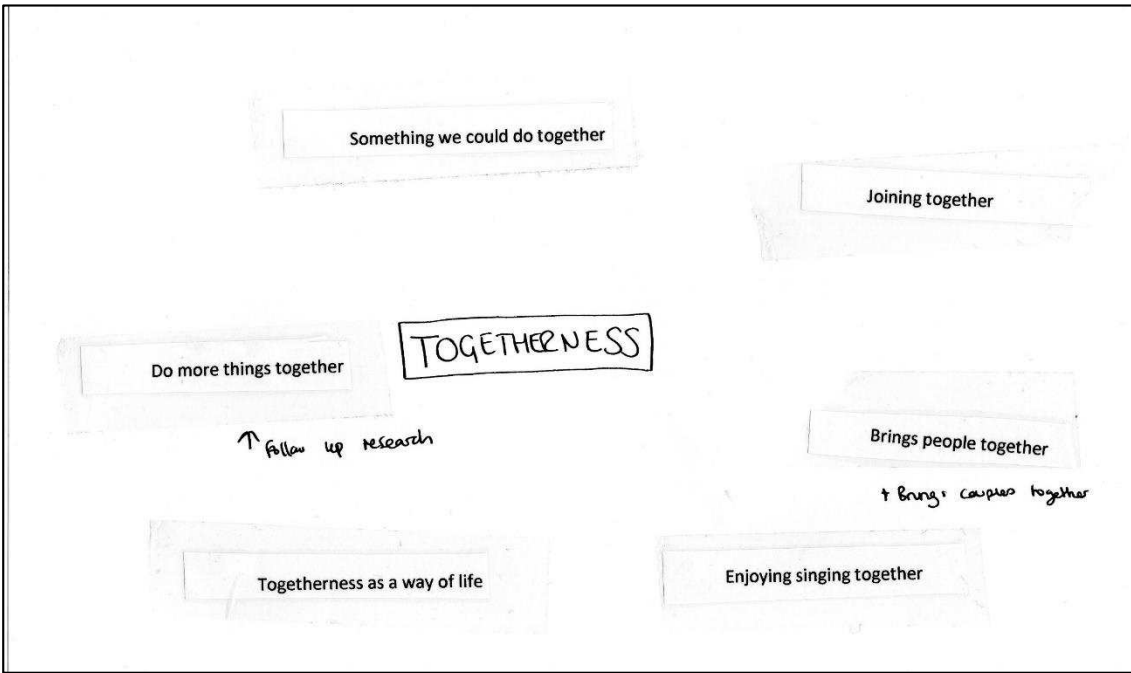
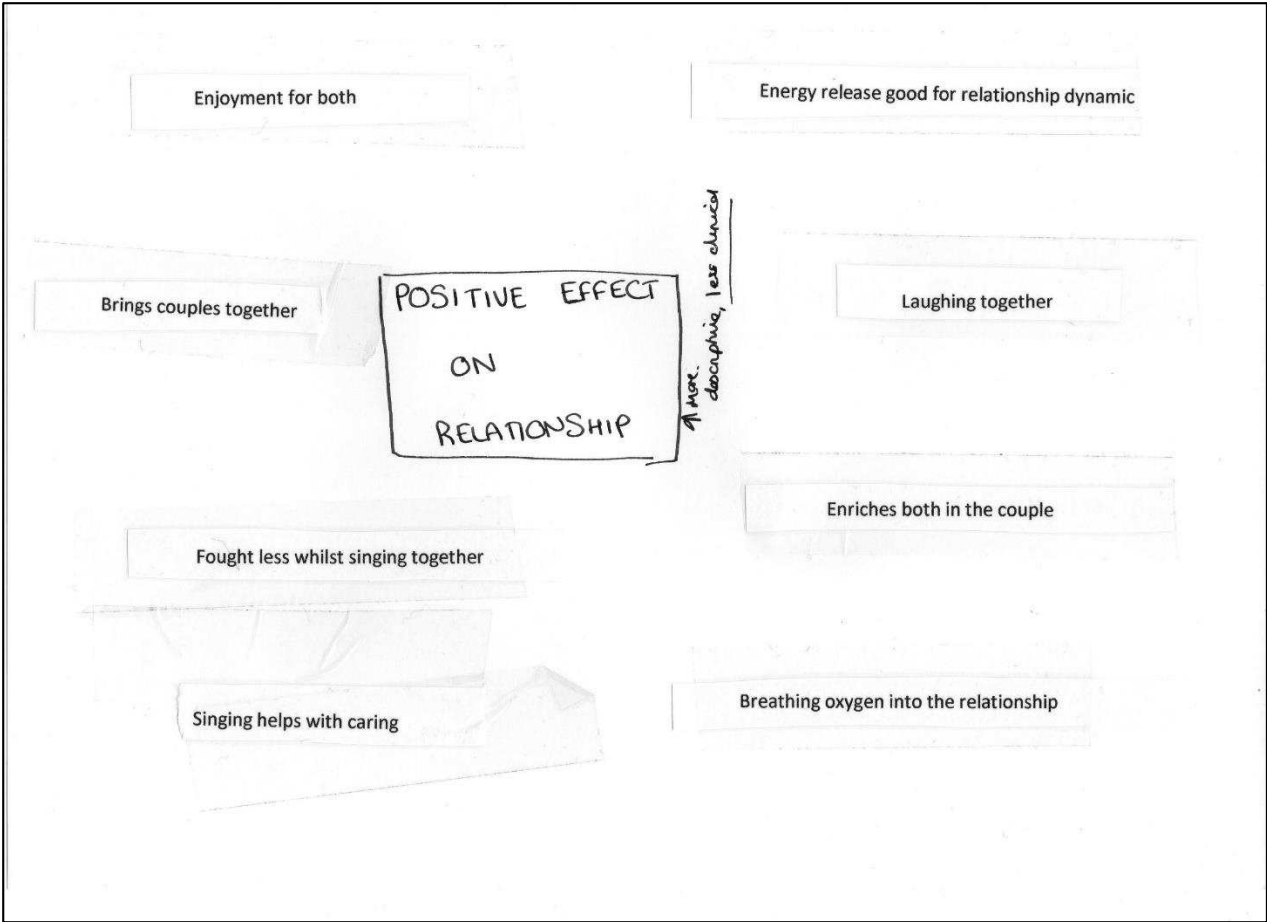
		<p>I just couldn't believe it, within a couple of days we were doing things that I never thought I would do (PD20)</p>
	<p>Together</p>	<p>Because we do things together in the past and it may well be that I am doing it, because B wants to do, and that if I want to do it B has done the opposite. So it was something that's equally enjoyable. So whether that improved our relationship, probably. (PC7)</p> <p>But this I think that we both had pleasure together, to me that was the major for us that we did something together. (PD8)</p> <p>Yes its very nice to do something together because sometimes [person with dementia] will be going to something that's fine, because he enjoys painting up at the gallery, but sometimes I'll go to things, so its quite nice to sometimes have things that we both do, its not so easy nowadays. (PC10)</p> <p>I think it brings couples together, because they're doing something together which they normally wouldn't think of doing. (PC11)</p> <p>...see, it's obviously gone in...I know that [name] is still in there, we do everything together anyway but this is a way I get answered back, [name] is still there inside, I believe in that. (PC13)</p> <p>Yeah, I sing, yeah, make up words and that, you know, and to get a tune and make up different words to it and that, and she laughs away, you know, well that's what I call laughing, like that. (PC13)</p>

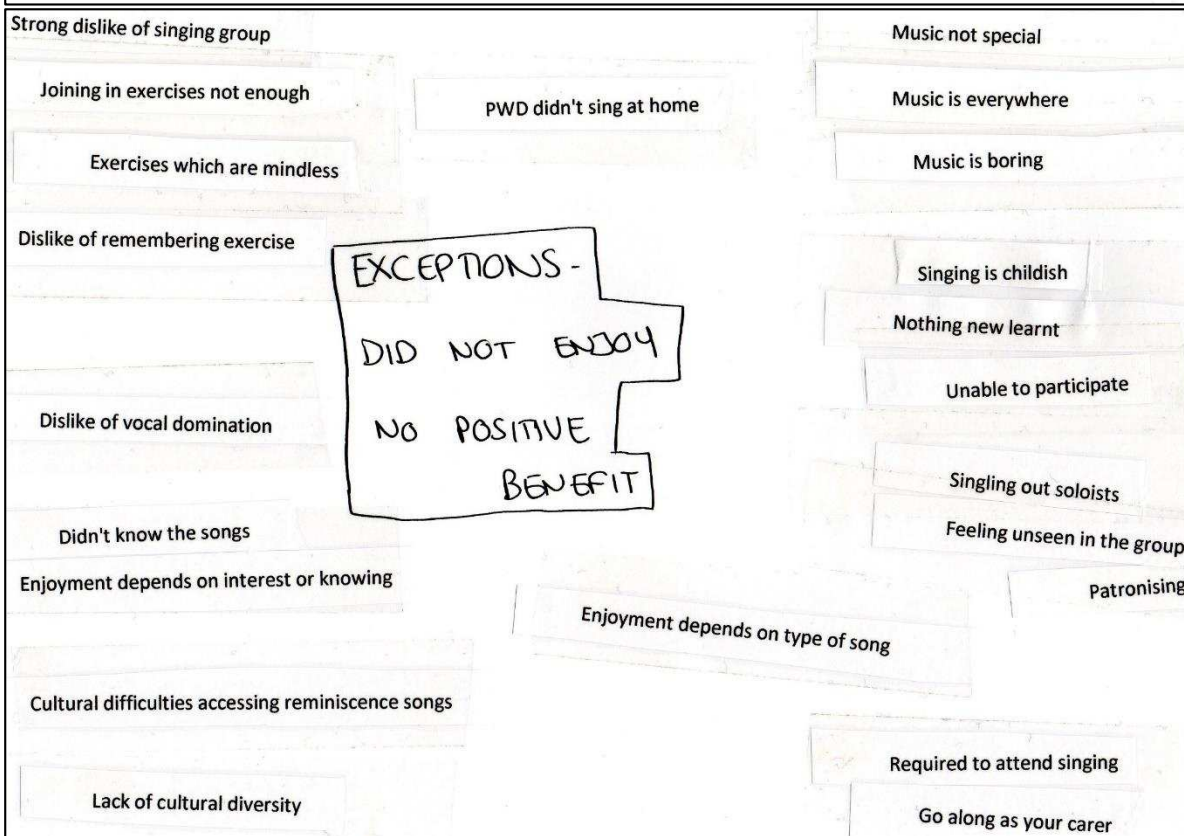
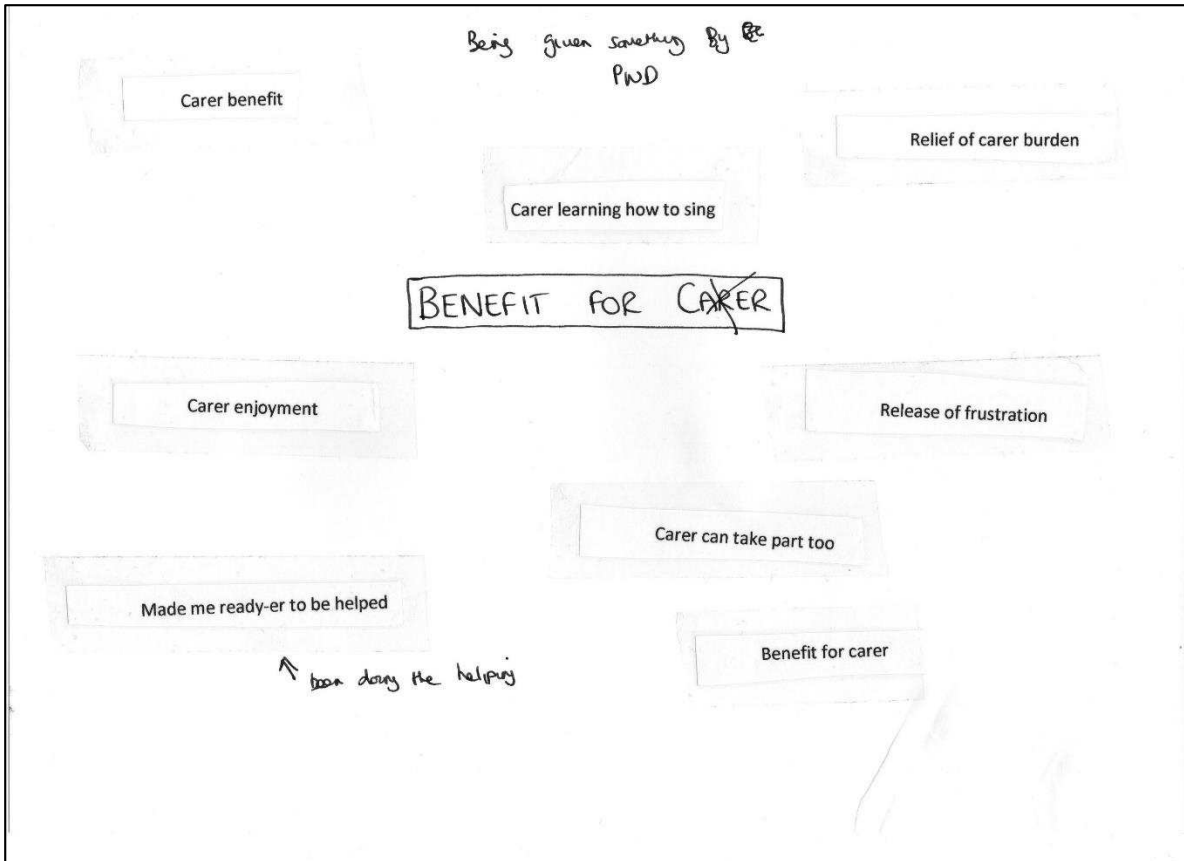
Appendix M

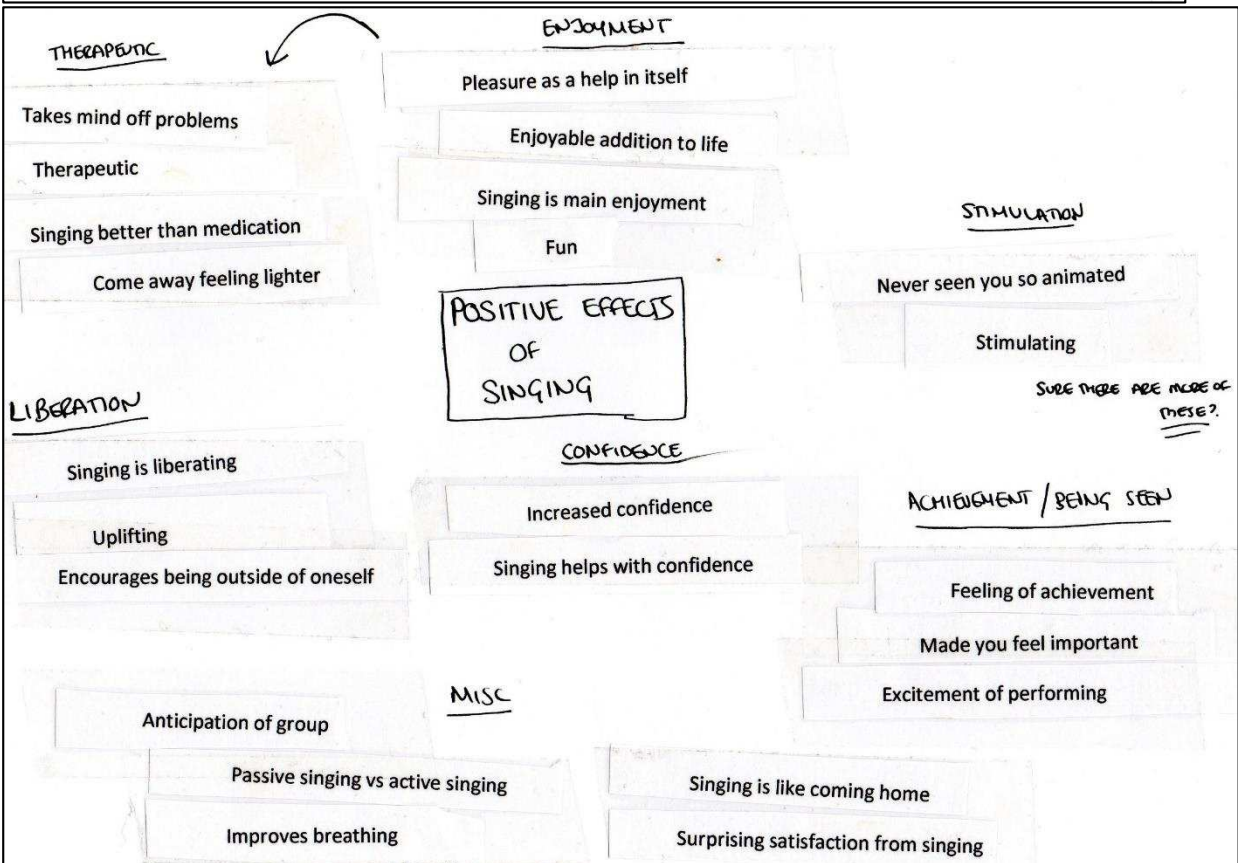
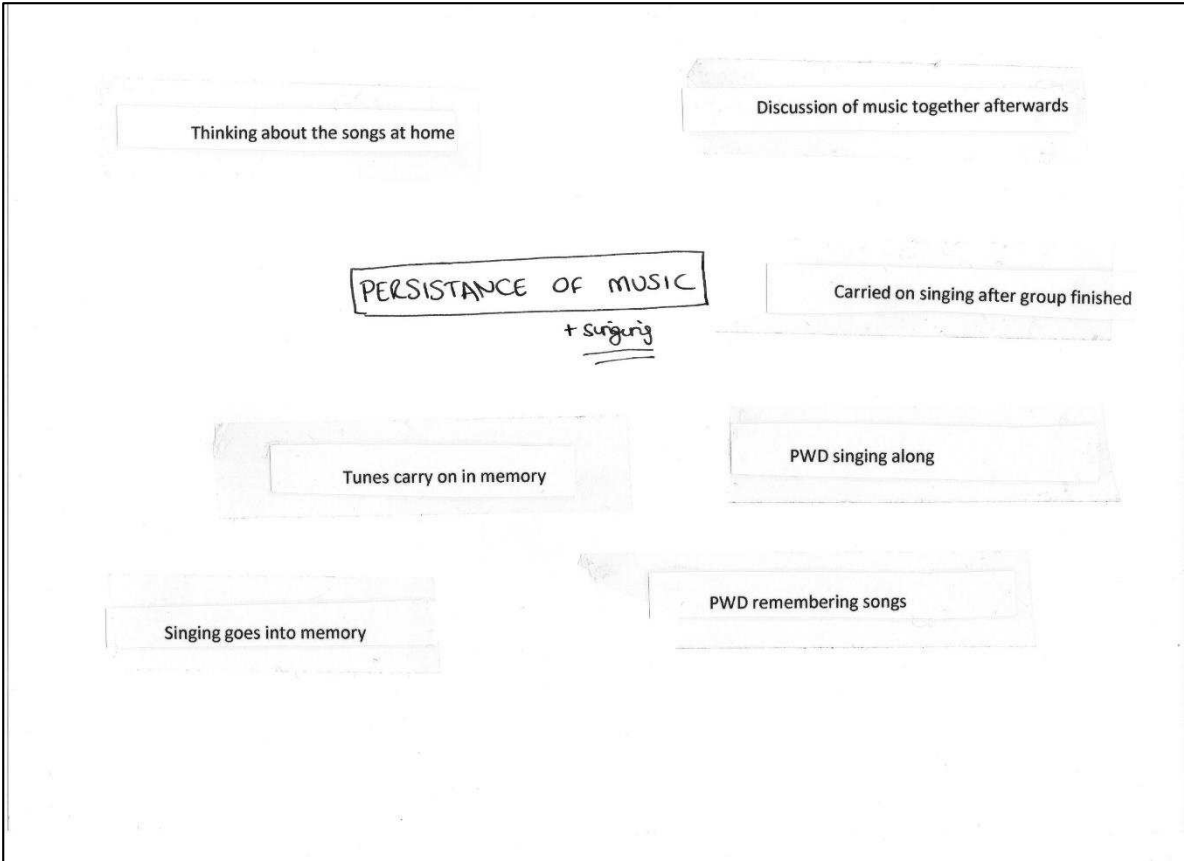
Example diagrams showing initial code organisation

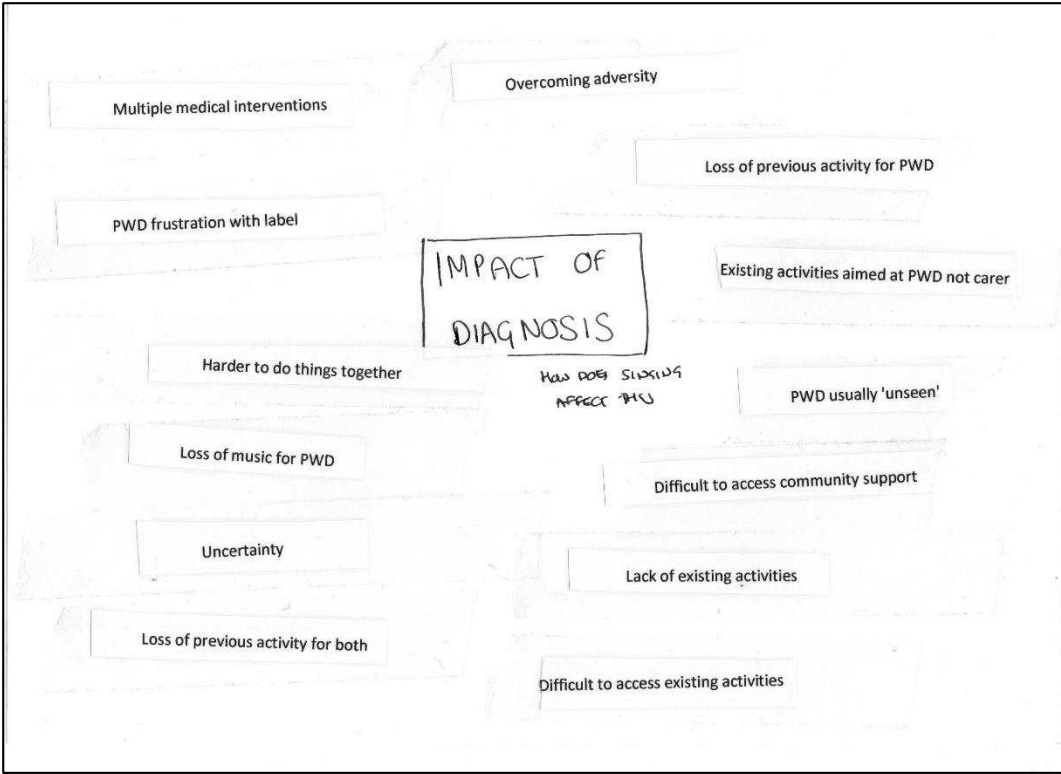












Appendix O
Selection for 3 coded transcripts

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Appendix P

End of study summary for ethics committee

Background: There is a growing interest in the use of singing in dementia care. The research base reports positive outcomes for group singing for people with dementia and their caregivers. A need for further research is highlighted, particularly from a relational context as current research explores the separate experiences of people with dementia and their caregivers and not the relationship between them

Summary of results: The couples involved in the study described singing as joyful and accessible. Another theme that came up was the importance of good facilitation in which the person running the group encouraged participation, treated everyone equally and tailored the singing to the individual needs in the group. All of these things combined helped people to participate fully in the group singing. Participation was particularly important as those who weren't able to participate didn't report as many benefits of the singing group as others.

Belonging to the singing group had benefits for the person with dementia and for the caregiver which, when combined increased benefits for the couple. For the person with dementia, being seen as someone with an identity outside of dementia, increased confidence, and an idea that singing ability hadn't changed much were important benefits. For caregivers, liberation, enjoyment and a release from responsibility were common themes. Together, these led to a sense of togetherness and other benefits for some couples. Additionally couples noted that that singing was an activity that was easily carried out by both partners at home together.

Furthermore, where a performance or creative singing element was included in the intervention a strong theme of new learning, an excitement about building something and an appreciation of looking forward emerged that was not present in other groups. This was seen to enhance the overall positive experience of singing.

Clinical Implications: Group singing may be an accessible and cost effective way to encourage social inclusion. As noted in this study the access to musical sounds may be preserved in cases where speech is lost, suggesting that people with advanced dementia can participate. The effective facilitation of groups is a key component of this theory. In particular, the equality that is brought to a group by facilitators appears to be vital. Dementia care practitioners may also benefit from bringing a new learning or creative element into their interventions given the enthusiasm demonstrated by participants in this study. Singing or music based interventions may prove more suitable for this purpose as they do not rely as heavily on traditional cognitive skills (such as planning, speech, writing, executive function), and may provide a forward-looking activity for people with dementia and their caregivers to enjoy.

Shreena Unadkat

Trainee Clinical Psychologist

Salomons Centre for Applied Psychology

Canterbury Christ Church University

Appendix Q
End of study participant letter



**The experience of group singing for couples where one partner has a diagnosis of dementia:
study results**

Dear [participant] and [participant]

Thank you both for taking part in my study, and for telling me your experiences of group singing together. The study has now come to an end, and I have spent some time putting together my findings. I have included a brief summary along with a diagram overleaf. I would be very grateful if you have any feedback at all about the findings, as I can carry on adapting them to your comments if necessary. If you have any comments about the findings, or would like to ask me any questions, please do contact me on the following:

Telephone: 07882766501

Email address: s.unadkat25@canterbury.ac.uk

Address: Shreena Unadkat, Trainee Clinical Psychologist, Runcie Court, Salomons Campus,
Canterbury Christ Church University, Broomhill Road, Tunbridge Wells, Kent, TN3 0TG

Many Thanks,

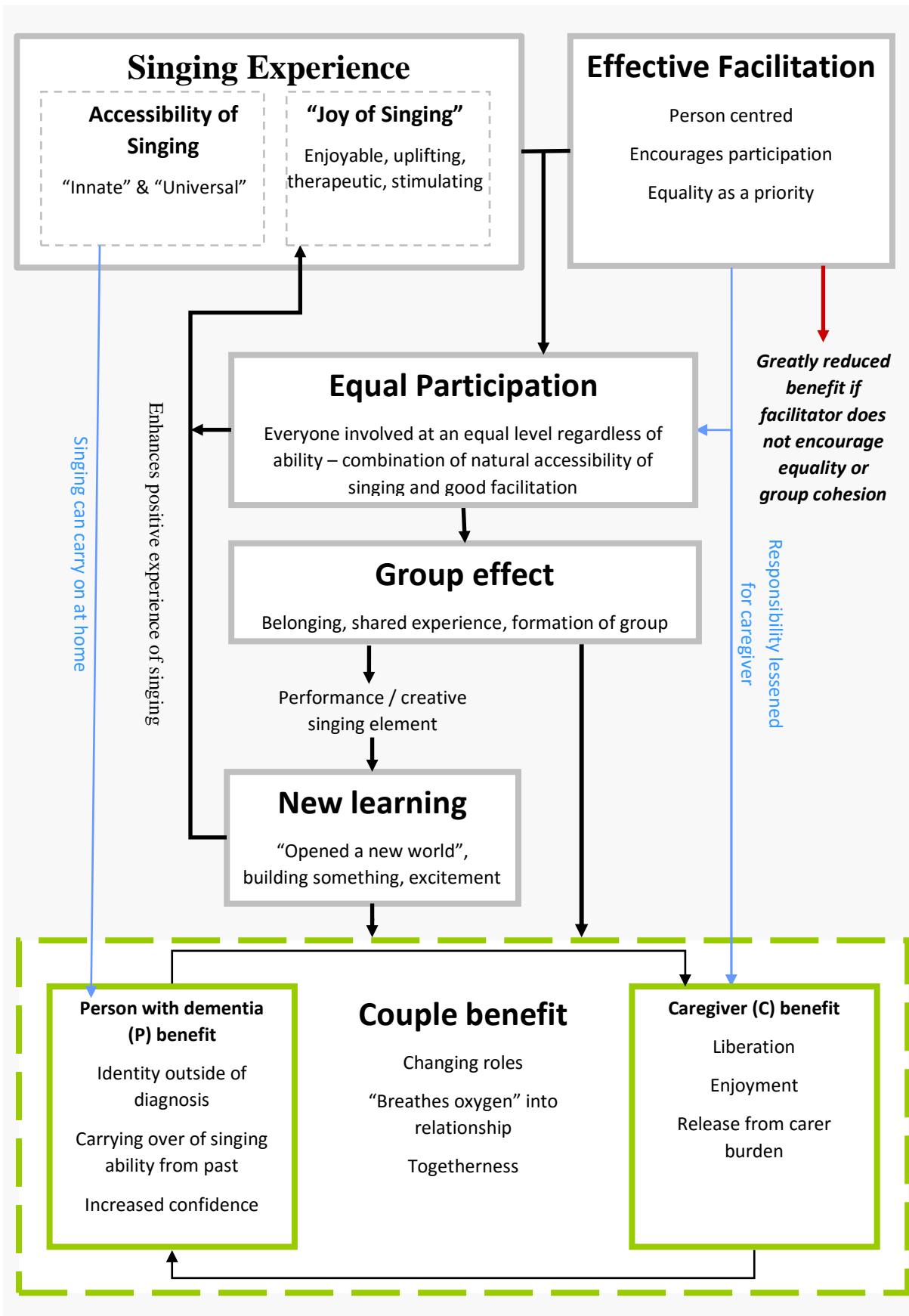
Shreena Unadkat – Trainee Clinical Psychologist

Summary of results: The couples involved in the study described singing as joyful and accessible. Another theme that came up was the importance of good facilitation in which the person running the group encouraged participation, treated everyone equally and tailored the singing to the individual needs in the group. All of these things combined helped people to participate fully in the group singing. Participation was particularly important as those who weren't able to participate didn't report as many benefits of the singing group as others.

Belonging to the singing group had benefits for the person with dementia and for the caregiver which, when combined increased benefits for the couple. For the person with dementia, being seen as someone with an identity outside of dementia, increased confidence, and an idea that singing ability hadn't changed much were important benefits. For caregivers, liberation, enjoyment and a release from responsibility were common themes. Together, these led to a sense of togetherness and other benefits for some couples. Additionally couples noted that that singing was an activity that was easily carried out by both partners at home together.

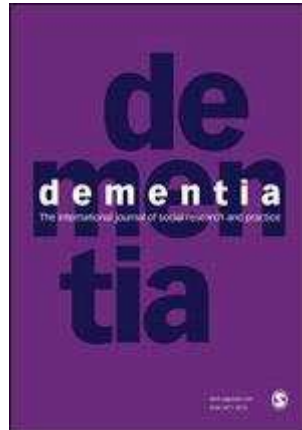
Furthermore, where a performance or creative singing element was included in the intervention a strong theme of new learning, an excitement about building something and an appreciation of looking forward emerged that was not present in other groups. This was seen to enhance the overall positive experience of singing.

Please find all this in a diagram overleaf.



Appendix R

Journal submission guidelines



Dementia publishes original research or original contributions to the existing literature on social research and dementia. The journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.

1. Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

2. Article types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Dementia also welcomes papers on various aspects of innovative practice in dementia care. Submissions for this part of the journal should be between 750-1500 words.

The journal also publishes book reviews.

3. How to submit your manuscript

Before submitting your manuscript, please ensure you carefully read and adhere to all the guidelines and instructions to authors provided below. Manuscripts not conforming to these guidelines may be returned.

Dementia is hosted on SAGE track a web based online submission and peer review system powered by ScholarOne[®] Manuscripts. Please read the Manuscript Submission guidelines below, and then simply visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

IMPORTANT: If you are a new user, you will first need to create an account. Submissions should be made by logging in and selecting the Author Center and the 'Click here to Submit a New Manuscript' option. Follow the instructions on each page, clicking the 'Next' button on each screen to save your work and advance to the next screen. If at any stage you have any questions or require the user guide, please use the 'Online Help' button at the top right of every screen.

All original papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please refer to the contact details below.

Innovative Practice papers must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Jo Moriarty jo.moriarty@kcl.ac.uk.

4. Journal contributor's publishing agreement

Before publication SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. For more information please visit our Frequently Asked Questions on the SAGE Journal Author Gateway.

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of articles published in the journal. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked using duplication-checking software. Where an article is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article (removing it from the journal); taking up the matter with the head of department or dean of the author's institution and/or relevant

academic bodies or societies; banning the author from publication in the journal or all SAGE journals, or appropriate legal action.

4.1 SAGE Choice and Open Access

If you or your funder wish your article to be freely available online to non subscribers immediately upon publication (gold open access), you can opt for it to be included in SAGE Choice, subject to payment of a publication fee. The manuscript submission and peer review procedure is unchanged. On acceptance of your article, you will be asked to let SAGE know directly if you are choosing SAGE Choice. To check journal eligibility and the publication fee, please visit SAGE Choice. For more information on open access options and compliance at SAGE, including self author archiving deposits (green open access) visit SAGE Publishing Policies on our Journal Author Gateway.

5. Declaration of conflicting interests

Within your Journal Contributor's Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please include any declaration at the end of your manuscript after any acknowledgements and prior to the references, under a heading 'Declaration of Conflicting Interests'. If no declaration is made the following will be printed under this heading in your article: 'None Declared'.

Alternatively, you may wish to state that 'The Author(s) declare(s) that there is no conflict of interest'.

When making a declaration the disclosure information must be specific and include any financial relationship that all authors of the article has with any sponsoring organization and the for-profit interests the organization represents, and with any for-profit product discussed or implied in the text of the article.

Any commercial or financial involvements that might represent an appearance of a conflict of interest need to be additionally disclosed in the covering letter accompanying your article to assist the Editor in evaluating whether sufficient disclosure has been made within the Declaration of Conflicting Interests provided in the article.

Please acknowledge the name(s) of any medical writers who contributed to your article. With multiple authors, please indicate whether contributions were equal, or indicate who contributed what to the article.

For more information please visit the SAGE Journal Author Gateway.

6. Other conventions

6.1 Informed consent

Submitted manuscripts should be arranged according to the "Uniform Requirements for Manuscripts Submitted to Biomedical Journals". The full document is available at <http://icmje.org>. When submitting a paper, the author should always make a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work.

Ethical considerations: All research on human subjects must have been approved by the appropriate research body in accordance with national requirements and must conform to the principles embodied in the Declaration of Helsinki (<http://www.wma.net>) as well as to the International Ethical Guidelines for Biomedical Research Involving Human Subjects and the International Guidelines for Ethical Review for Epidemiological Studies (<http://www.cioms.ch>). An appropriate statement about ethical considerations, if applicable, should be included in the methods section of the paper.

6.2 Ethics

When reporting experiments on human subjects, indicate whether the procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional or regional) or with the Declaration of Helsinki 1975, revised Hong Kong 1989. Do not use patients' names, initials or hospital numbers, especially in illustrative material. When reporting experiments on animals, indicate which guideline/law on the care and use of laboratory animals was followed.

7. Acknowledgements

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

7.1 Funding Acknowledgement

To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), Dementia additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit Funding Acknowledgement on the SAGE Journal Author Gateway for funding acknowledgement guidelines.

8. Permissions

Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our Frequently Asked Questions on the SAGE Journal Author Gateway.

9. Manuscript style

9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, DOCX, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork [and supplemental files] below.

9.2 Journal Style

Dementia conforms to the SAGE house style. [Click here to review guidelines on SAGE UK House Style.](#)

Lengthy quotations (over 40 words) should be displayed and indented in the text.

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of

nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used.

Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

9.3 Reference Style

Dementia adheres to the APA reference style. [Click here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

9.4. Manuscript Preparation

The text should be double-spaced throughout with generous left and right-hand margins. Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Innovative practice papers should be between 750-1500 words.

9.4.1 Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online. The abstract should be 100-150 words, and up to five keywords should be supplied in alphabetical order.

9.4.2 Corresponding Author Contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

9.4.3 Guidelines for submitting artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

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This journal is able to host approved supplemental materials online, alongside the full-text of articles. Supplemental files will be subjected to peer-review alongside the article. For more information please refer to SAGE's Guidelines for Authors on Supplemental Files.

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Non-English speaking authors who would like to refine their use of language in their manuscripts might consider using a professional editing service. Visit English Language Editing Services for further information.

10. After acceptance

10.1 Proofs

We will email a PDF of the proofs to the corresponding author.

10.2 E-Prints

SAGE provides authors with access to a PDF of their final article. For further information please visit <http://www.sagepub.co.uk/authors/journal/reprint.sp>.

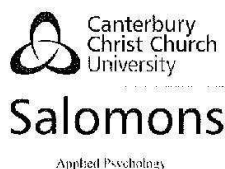
10.3 SAGE Production

At SAGE we work to the highest production standards. We attach great importance to our quality service levels in copy-editing, typesetting, printing, and online publication (<http://online.sagepub.com/>). We also seek to uphold excellent author relations throughout the publication process.

We value your feedback to ensure we continue to improve our author service levels. On publication all corresponding authors will receive a brief survey questionnaire on your experience of publishing in Dementia with SAGE.

Appendix S

Transcribing agreement



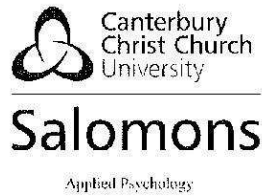
Confidentiality Statement for Persons Undertaking Transcription of Research Project Interviews

Project title THESIS

Researcher's name SHREENNA UNADKAT

The tape/s or recording/s you are transcribing have been created as part of a research project. Tapes may contain information of a very personal nature, which should be kept confidential and not disclosed to others. Maintaining this confidentiality is of utmost importance to the University. Signing this form means you agree not to disclose any information you may hear on the recording to others, and not to reveal any identifying names, place-names or other information on the recording to any person other than the researcher/s named above. You agree to keep the recording in a secure place where it cannot be accessed or heard by other people, and to show your transcription only to the relevant individual/s who is involved in the research project, i.e. the researcher/s named above.

You will also follow any instructions given to you by the researcher about how to disguise the names of people and places talked about on



any recordings as you transcribe them, so that the written transcript will not contain such names of people and places.

Following completion of the transcription work you will not retain any recordings or transcript material, in any form. You will pass all tapes back to the researcher and erase any material remaining on your computer hard drive or other electronic medium on which it has been held.

You agree that if you find that anyone speaking on a tape is known to you, you will stop transcription work on that tape immediately and pass it back to the researcher.

Declaration

I agree that:

1. I will discuss the content of the recording/s only with the researcher/s named on the previous page.
2. I will keep all recordings in a secure place where they cannot be found or heard by others.
3. I will treat the transcripts of the recordings as confidential information.



Salomons

Applied Psychology

4. I will agree with the researcher how to disguise names of people and places on the recordings.
5. I will not retain any material following completion of transcription.
6. If the person being interviewed on a recording is known to me I will undertake no further transcription work on the recording and will return it to the researcher as soon as is possible.

I agree to act according to the above constraints

Your name AJ BANFIELD

Signature AJ Banfield

Date 13/11/14

Occasionally, the conversations on recordings can be distressing to hear. If you should find it upsetting, please speak to the researcher.