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Understanding the experience of group singing for couples where one partner has a diagnosis of dementia

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Abstract

Purpose of Study: There is a continuing interest around the use of group singing in dementia care. Although studies generally indicate positive outcomes, limited research has been carried out from a relational perspective, which places the couple relationship in a central position. This study aimed to better understand how group singing benefits people with dementia and their partners. **Design and Methods:** Interview data from 17 couples (N = 34) with one member having dementia, who participated in a range of different types of singing groups, were analysed using grounded theory methodology. **Results:** Five key areas were identified, resulting in the development of the *group singing model in dementia for couple dyads*. Group singing was experienced as being both joyful and accessible. The accessibility of singing, combined with effective facilitation, created an environment for active participation and enjoyment. The group effect mediated further benefits for the person with dementia and for the caregiver which, when combined, increased benefits for the couple through participation in new experiences. **Implications:** An opportunity for couples to share in-the-moment creative expression and the positive affect of artistic creation circumventing cognitive

impairment is likely to contribute positively to the experience of the relationship. A more refined understanding of shared creative processes in relationship-centred models of care could inform dementia support services. Future research would benefit from longitudinally exploring the links between creativity in couples and relationship resilience.

Key words: group singing, couples, relational perspective, dementia care, creativity

Introduction

The majority of recommended interventions for people with dementia are pharmacological, however treatment guidelines recognise the need for non-pharmacological, 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 (1997) 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. Considering the wider system around the person with dementia could arguably be seen as central to future dementia care research.

Many caregivers are partners or spouses (NICE, 2006), and spousal relationships often 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). Given the value of these relationships in dementia care it is essential to consider ways in which to support this relationship by helping couples manage connectedness and separateness, working together, maintaining involvement and retaining couple identity (Keady & Nolan, 2003; Merrick, Camic, & O’Shaughnessy, 2013). 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).

Singing and Dementia

A review of participative arts and dementia care (Zeilig, Killik & Fox, 2014) suggested that the literature around arts-based activities for dementia is in an early stage and that musical activities were the only ones to have been explored in a Cochrane review (Vink, Bruinsma, & Scholten, 2003). 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. During the past two decades there has been a growing interest in the experience of group singing for people with dementia. Some research has suggested that musical memory is preserved above other types of memory in dementia (Baird & Samson, 2009). Positive benefits have been highlighted by the Alzheimer's Society's Singing for the Brain model, and the Silver Song Club project (Skingley & Vella Burrows, 2010). A randomised controlled trial by Särkämö et al. (2013) found that group singing enhanced or maintained areas of cognition (such as attention, executive function, short term memory and orientation) and improved mood when compared with usual care at 6-month follow up, while also decreasing caregiver burden. A further study, which compared group singing to a community quiz social activity control (Davidson & Almeida, 2014) found significant improvements in lucidity, focus, mood and relaxation for people with dementia, and a significant improvement in caregiver mood.

Several studies have reported positive feelings of achievement, belonging, and decreased social isolation for group singing (Osman, Tischler & Schneider, 2014). Camic, Williams and Meeten (2013) used a mixed methodology and while standardised measures did not yield significant results, thematic analysis found a strong sense of enjoyment, new learning, social inclusion, and enhanced emotions. McCabe, Greaseley-Adams & Goodson (2013) described positive views of a creative group singing project, noting themes such as joy, increased confidence and changing perception of self. Both studies highlighted 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). A recent study theorising about the impact of art gallery experiences on people with dementia and caregivers in group programmes found that the gallery was seen as a physically valued place providing intellectual stimulation and opportunities for social inclusion, which came together to create

strong positive emotional and relational effects for both the person with dementia and caregiver (Camic, Baker & Tischler, 2015). As with the art gallery experience, the present study seeks to explore the experience of singing within the couple dyad.

The Present Study

Whilst the studies reported above provide promising initial evidence for the positive benefits of group singing, the process through which group singing may bring about change remains unclear. In order to advance our understanding of singing groups in dementia care a systematic exploration of the experience of singing is warranted. The present study aimed to develop an understanding of how group singing affects the couple dyad where one person of the couple has a diagnosis of dementia. The following broad research questions acted as a guide:

- 1) How does the group singing experience impact the relationship between the person with dementia and their spouse?
- 2) What are the key factors involved in this experience for the couple?

Design and Methods

A qualitative design using semi-structured interviews developed in accordance with grounded theory methodology (Glaser & Strauss, 1967; Urquhart, 2013) was employed. Grounded theory was chosen in order to help build a theoretical understanding of how singing might psychologically and socially impact people with a dementia and their partners when they sing together in a group. Whilst the term “theory” can be interpreted differently across disciplines, within grounded theory it is used to represent the relationship between key factors, the effect they have on one another, and the variables that affect them (Urquhart, 2013). Whilst this study follows the Glaserian method of data analysis (Glaser, 1996), the researchers can be said to hold a “critical realist” epistemological position (Collier, 1994) in which awareness of

the researcher's impact on the research process has been considered alongside positivist assumptions.

Participants

Participants included 17 heterosexual couples (n = 34) that had taken part in various forms of group singing. Mean age for those with dementia was 72.2 years (range 66 -87) and for caregivers 70.3 years (range 61 – 89). Inclusion criteria consisted of any dementia diagnosis, the couple residing together at home and the ability to give informed consent or consent by proxy; two people participated through proxy consent by their caregiver. Dementia impairment was determined using the clinical dementia rating scale (CDR) (Morris, 1993) (Table 1). An ethics panel at Canterbury Christ Church University granted approval for the overall study and a National Health Service ethics committee granted approval for those referred through the NHS. Couples were interviewed together (35 - 70 minutes), which were audio-recorded and transcribed. Recruitment was carried out through theoretical sampling by contacting different types of singing groups in England and Wales. Participants were selected for interview to fulfil theoretical sampling assumptions (coming from different: types of singing groups, impairment and ability levels, socioeconomic areas) in the order shown in Figure 1.

Table 1 here

Procedure

Theoretical sampling. The process of recruitment was influenced by the grounded theory concept of theoretical sampling, where concepts identified from initial coding influenced future recruitment and theory development (Glaser & Strauss, 1967, p. 112). In order to develop a more nuanced understanding of the potential for greater generalizability

(Urquhart, 2013), participants from a heterogeneous sample of singing groups were selected (Figure 1).

Figure 1 here

Interviews. Initial interview questions were developed under three broad topics: (a) history and experience together as a couple, (b) responses to dementia and (c), the experience of group singing. Questions were kept purposefully open during interviews to allow for a wide range of responses

Data analysis. Concurrent data collection and analysis was carried out in order to allow for the initial codes to direct sampling (Glaser & Strauss, 1967). The process followed several phases:

1. Initial line by line/open coding of the first five transcripts followed by
2. Selective coding of these transcripts using the constant comparative method to begin developing core categories. New instances of data and codes were 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.
4. Four additional interviews to further develop findings from initial analysis were analysed using selective coding and constant comparison. Categories and conceptual relationships were refined with the aid of theoretical memos and early theoretical diagrams.
5. A further dataset of eight couple transcripts were analysed in order to refine and validate the theory against individual cases and to test theoretical sufficiency.

Theoretical sufficiency. The concept of “theoretical sufficiency” guided data collection and analysis (Dey, 1999, p. 257) because it offered a more flexible approach than

“theoretical saturation” (Glaser & Strauss, 1967, p. 61) and was a better fit for the critical realist epistemological approach taken by the authors. Sufficient data was thought to have been collected when the relationships between categories (constructs) were theoretically explored and formed a coherent and plausible theoretical understanding.

Quality assurance. Bracketing interviews to examine assumptions held by the authors about dementia, singing, wellbeing and other areas were held at three points during the study based on procedures laid out by Ahern (1999). The interviews were carried out by two colleagues and a reflective diary was kept throughout the research process. In order to ensure the quality and rigour of grounded theory Chiovitti and Piran’s (2003) methods of practice that focused on demonstrating credibility, auditability and fittingness were followed. Additionally, about 30 per cent of the data analysis was scrutinised by the second author and a research 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 determined by consensus of the authors.

Results

Five key areas were identified, which were conceptualized as the *group singing model in dementia for couple dyads* (Figure 2). The central bold arrows in the diagram represent the movement of the main process whilst further factors are represented by the side arrows. The singing experience was described by couples as being both joyful and accessible. The accessibility of singing, combined with effective facilitation, created an environment for active participation and enjoyment. This appeared to enhance the positive effects of belonging to a social group and sharing a valuable 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 was part of a singing group, themes of new experiences, excitement about building something and anticipation of looking forward emerged that was not as often 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 singing was an activity easily carried out by both partners at home together.

Figure 2 here

Singing Experience

This overarching category captures the two main elements of the singing experience: the joy of singing 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” (C4¹). The four main elements of this category were enjoyment, uplifting, stimulating and therapeutic.

Enjoyment. 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” (C5). 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” (C7). Participants also appeared to enjoy singing regardless of the individual’s previous singing ability or history. Many had never sung with a group before.

¹ C refers to the caregiver and D to the person with dementia

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. (D9)

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. (C11)

Stimulating. The experience of singing in the various groups was described as stimulating by a number of participants. This aspect of singing was mostly reported by caregivers.

The singing 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. (C4)

Therapeutic. The combined effects of singing on mood were often described as therapeutic. One participant noted, “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.” (C11) Couples also noted the therapeutic effect of being fully engaged in singing.

Everyone in that room has got a problem, whatever it may be, but when you are singing...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. (C15)

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. (C16)

Accessibility of singing. When exploring what factors enabled 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.” (C16) 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, not like with a game where you have to know the rules and understand how to move things. It’s innate; you can soon pick it up if it’s a song, like automatically you can hear it in your head. It’s inside us all. (C13)

This accessibility appeared to be especially important to some 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.” (D8)

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 a participant with dementia, "...it's for everybody, not just some people, and everyone can take part and probably has at some point." (D12) Some described how this universality helped them access the singing group, and for one participant with dementia it felt "...less daunting than maybe going to other things." (D15). 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." (D28)

Effective group facilitation. Whilst most attributed positive feelings to the act of singing itself, it became clear that some people 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 was recognized as a vital component of this process, without which further benefits of group singing were not experienced. Encouraging participation, person-centeredness and equality were identified as part of the role of an effective group facilitator.

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

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. (C5)

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." (C2)

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." (C4)

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 soloists and spending less time on the whole group. They described feeling left out of the process of song selection, felt that many members could not relate to the songs chosen, and that the facilitator did not focus on equality of participation. Although the couple reported enjoying singing itself, the caregiver described feeling that they had missed out on the other benefits of group singing.

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. (C18).

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" (D6), 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 enjoyment, as highlighted by this person with dementia: “I can join in, it’s a good experience to be able to join...and you can!” (D9) The equality of participation between different types of people was highlighted as an important facet of the group experience. It was noted 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. (C11)

Nearly all participants reiterated that participation in these particular singing groups was not dependent on singing ability, and that being encouraged to participate equally as part of a group enabled expression: “I can’t sing, but I enjoy the singing.” (C16)

Group effect. Where people felt able to fully participate in group singing, there was a beneficial sense of belonging to a social group, sharing an experience, and forming a group identity. 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 different backgrounds...but as it went on we became a real group” (C7). 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.” (C2)

New experiences.

Whilst singing together in a group did feed directly into benefits for the individual and the couple across all groups, an alternative narrative developed from the groups that incorporated attending a singing group for the first time, performing, learning new songs and partaking in a compositional element. The participants in these groups tended to report a stronger sense of positive experience and 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." (C2) 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." (C4) Participants involved in performances also described an "excitement about doing that, getting up and showing everyone what you have created." (C7) A few participants who were involved in reminiscence based singing groups 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." (C18)

Individual and couple benefits.

Person with dementia. A number of those with dementia described increased confidence both for themselves and other members of the group: "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" (D34), while another commented, "Sharing in a creative artistic project helped our general confidence too." (D6) 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. The sense of equality within the group whilst singing 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 sing...I think we all felt then that we could do something. (C2)

Some participants 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 his old self really, it gave the confidence to get that back.” (C5) 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.” (D6)

Caregiver benefit. Caregivers in particular reiterated the importance of effective facilitation, which enabled a “release” from caring responsibilities. 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.” (C2) Caregivers also reported that this combined with the equality of a group setting allowed for equal participation between themselves and their partners.

I used to take [name] along to day care and leave...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. (C7)

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!” (C16)

Couple benefits. 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

together to create a 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, “Well, I can’t sing, you always sang didn’t you? Yes, I have to teach you! I didn’t half laugh at your efforts, it’s very funny, you are getting better though.” (C7, D8) One couple reported that they argued less whilst being involved in the group (P17, P18), 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 singing releases energy so the dynamic is lighter and brighter.” (C4)

Some couples joined other activities or groups after the singing groups. A caregiver stated, “I suppose it made me a bit readier 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.” (C5)

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 mostly lost the capacity for speech. 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 she is still in there, we do everything together anyway but this is a way I get answered back, she is still there inside, I believe in that.” (C13)

Discussion

This study sought to contribute to the development of a greater 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 value of this activity. A wide range of positive themes around the enjoyment and therapeutic effects of singing were conveyed, which appeared relevant across severity of dementia and type of singing group and was not dissimilar to studies of older adults without dementia (Clift et al., 2010). 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 of enjoyment was the perceived accessibility of singing as an activity regardless of ability level or singing history. Enjoyment was also dependent on the effectiveness of group facilitation. The importance of facilitation is a novel finding, as previous studies have not focused on the relationship between facilitator and singers in this context. 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 wellbeing (Anshel & Kipper, 1988), which may point to singing as a particularly good tool for group development. As people with dementia are often excluded from traditional social activities (Batsch & Mittelman, 2012), the present study suggests that using group singing can be a useful tool to aid social inclusion.

Experiencing a new activity and being creative were both shown to be important components of the singing groups, especially for caregivers and people with mild to moderate dementia. Whilst some recent studies have also suggested this (Camic et al., 2013; McCabe et al., 2013), previous research has often focused on the reminiscence aspects of singing rather than on creativity and learning (Ashida, 2000). Although reminiscence can sometimes be enjoyable, a large scale RCT has cast doubt on some forms of reminiscence therapy-focused

group 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. The present study is in line with research supporting the desire for learning into older age (Fernández-Ballesteros, Molina, Schettini, & del Rey, 2012).

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 preserve the identity of a person regardless of their cognitive ability, suggesting that singing may be a good intervention for maintaining personhood. Caregivers reported that the release of caregiver burden and liberation was a key benefit. 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 et al., 2005; 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

Although the present study aimed to capture the couple's experience through 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. The couples discussed their journey through the dementia diagnosis and their relationship histories in some depth. However, as the focus of the study

primarily looked at how singing in a group impacted the couple dyad, previous relationship quality, couple interpersonal style, resilience and general coping strategies were not addressed. The findings are specific to the participants who took part in this study despite the attempts to obtain a heterogeneous sample. The researchers' preconceptions were reflected upon through the use of bracketing interviews, a research diary and analytic memos; however the potential effect of researcher assumptions cannot be completely eliminated. The study is also vulnerable to a self-selection bias as participants volunteered for group singing. And lastly, the sample was entirely heterosexual and the emerging theory may not fully capture experiences and interactions for same-sex couples.

Future Research

Various components found in this study, which we see as a work in progress, need to be tested in future research. How on-going group singing might be used to support couple relationships would be useful to explore longitudinally as a part of non-clinical, community-based care. An exploration into whether longer term or existing creativity in couples is linked to relationship quality and resilience in dementia could deepen the understanding of singing together. When considering the reported interest in new experiences and learning, a comparison study between reminiscence singing interventions and singing that includes new learning experiences may yield valuable results for public health policy and clinical practice. This would be supported by a number of studies that have shown musical cognition in people with dementia is preserved (Cuddy & Duffin, 2005; Hailstone, Omar, & Warren, 2009; Van de Winckel, Feys, De Weerd, & Dom, 2004). Key theoretical constructs were established in the present study from which standardised measures could be developed, such as equality in groups, participation and facilitation factors. As highlighted by one participant, a broader range of people from different ethnic groups needs to be sampled to both broaden and deepen the findings in order to better appreciate that diverse cultural groups may have distinctive

ideas and perspectives about singing and music. In addition, there is also the need to compare other meaningful couple activities in order to delineate unspecific as well as specific values. Dancing, writing poetry and reading books together, for example, may offer similar or different types of benefits as compared to singing.

Practice Implications

Community organisations and dementia care practitioners may want to consider making singing groups a part of their programming. Singing or music based interventions that involve learning new songs may prove highly suitable as they do not rely on traditional cognitive skills and can provide a socially-inclusive, creative activity for people with dementia and their caregivers to engage in. In addition, in multi-cultural societies and across different socioeconomic groups, what is shared remembrance is likely to vary. The ability of group facilitators to engender a sense of equality and inclusion appears to be a vital component in the proposed model. Therefore, facilitators need to encourage group formation and parity; for example those with dementia and caregivers can be helped to participate *as singers* as opposed to patients and caregivers. This blurring of role identity poses a benefit to the couple but also to the wider community, in which the person with dementia's abilities can be passed onto others.

References

- Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research*, 9, 407-411. <http://dx.doi.org/10.1177/104973239900900309>
- Anshel, A., & Kipper, D. A. (1988). The influence of group singing on trust and cooperation. *Journal of Music Therapy*, 25, 145-155. <http://dx.doi.org/10.1093/jmt/25.3.145>

- Ashida, S. (2000). The effect of reminiscence music therapy sessions on changes in depressive symptoms in elderly persons with dementia. *Journal of Music Therapy*, 37, 170-182. <http://dx.doi.org/10.1093/jmt/37.3.170>
- Baikie, E. (2002). The impact of dementia on marital relationships. *Sexual and Relationship Therapy*, 17, 289-299. <http://dx.doi.org/10.1080/14681990220149095>
- Baird, A., & Samson, S. (2009). Memory for music in alzheimer's disease: unforgettable?. *Neuropsychology review*, 19, 85-101. <http://dx.doi.org/10.1007/s11065-009-9085-2>
- Batsch, N. L. & Mittelman, M. S. (2012). *World Alzheimer report 2012: Overcoming stigma of dementia*. New York & London: Alzheimer's Disease International. Accessed from: <http://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>
- Brooker, D., & Duce, L. (2000). Wellbeing and activity in dementia: A comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time. *Aging & Mental Health*, 4, 354-358. <http://dx.doi.org/10.1080/713649967>
- Camic, P.M., Baker, E. & Tischler, V. (2015). Theorising how art gallery interventions impact people with dementia and their caregivers. *The Gerontologist*. <http://gerontologist.oxfordjournals.org/cgi/content/full/gnv063?ijkey=e9cuXXuz8FD2xJB&keytype=ref>
- Camic, P. M., Williams, C. M., & Meeten, F. (2013). Does a 'Singing together group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*, 12, 157-176. <http://dx.doi.org/10.1177/1471301211422761>

- Chiovitti, R. F., & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing*, 44, 427-435. <http://dx.doi.org/10.1046/j.0309-2402.2003.02822.x>
- Chen, L. K., Kim, Y. S., Moon, P., & Merriam, S. B. (2008). A review and critique of the portrayal of older adult learners in adult education journals, 1980-2006. *Adult Education Quarterly*, 59, 3-21. <http://dx.doi.org/10.1177/0741713608325169>
- Collier, A. (1994). *Critical realism: An introduction to Roy Bhaskar's philosophy*. Brooklyn, NY: Verso.
- Clift, S., Hancox, G., Morrison, I., Hess, B., Kreutz, G., & Stewart, D. (2010). Choral singing and psychological wellbeing: Quantitative and qualitative findings from English choirs in a cross-national survey. *Journal of Applied Arts & Health*, 1(1),19-34. <http://dx.doi.org/10.1386/jaah.1.1.19/1>
- Cuddy, L. L., & Duffin, J. (2005). Music, memory, and Alzheimer's disease: is music recognition spared in dementia, and how can it be assessed?. *Medical hypotheses*, 64, 229-235. <http://dx.doi.org/10.1016/j.mehy.2004.09.005>
- Davidson, J. W., & Almeida, R. A. (2014). An exploratory study of the impact of group singing activities on lucidity, energy, focus, mood and relaxation for persons with dementia and their caregivers. *Psychology of Well-Being*, 4, 1-13. <http://dx.doi.org/10.1186/s13612-014-0024-5>
- Dey, I. (1999). *Grounding grounded theory: Guidelines for qualitative inquiry*. Bingley, UK: Emerald Group.
- Fernández-Ballesteros, R., Molina, M. Á., Schettini, R., & del Rey, Á. L. (2012). Promoting active aging through university programs for older adults: An evaluation

- study. *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry*, 25, 145.
- Glaser, B. G. (1996). *Theoretical sensitivity*. San Francisco: Sociology Press
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New Jersey: Transaction Publishers.
- Hailstone, J. C., Omar, R., & Warren, J. D. (2009). Relatively preserved knowledge of music in semantic dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, 80, 808-809. <http://dx.doi.org/10.1136/jnnp.2008.153130>
- Hellström, I., Nolan, M., & Lundh, U. (2005). 'We do things together' 'A case study of 'couplehood' in dementia. *Dementia*, 4, 7-22.
<http://dx.doi.org/10.1177/1471301205049188>
- Innes, A., Archibald, C., & Murphy, C. (Eds.) (2004). *Dementia and social inclusion: Marginalised groups and marginalised areas of dementia research, care and practice*. London: Jessica Kingsley.
- Keady, J., & Nolan, M. (2003). The dynamics of dementia: Working together, working separately, or working alone? In M. Nolan, U. Lundh, G. Grant, & J. Keady (Eds.) *Partnerships in family care* (pp. 15-32). Maidenhead: Open University Press.
- Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health*, 1, 13-22.
<http://dx.doi.org/10.1080/13607869757344>
- McCabe, L., Greasley-Adams, C., & Goodson, K. (2013). 'What I want to do is get half a dozen of them and go and see Simon Cowell' reflecting on participation and outcomes for people with dementia taking part in a creative musical project. *Dementia*. Advance online publication. <http://dx.doi.org/10.1177/1471301213508128>

- McDermott, O., Crellin, N., Ridder, H. M., & Orrell, M. (2013). Music therapy in dementia: A narrative synthesis systematic review. *International Journal of Geriatric Psychiatry, 28*, 781-794. <http://dx.doi.org/10.1002/gps.3895>
- Merrick, K., Camic, P. M., & O'Shaughnessy, M. (2013). Couples constructing their experiences of dementia: A relational perspective. *Dementia*. Advance online publication. <http://dx.doi.org/10.1177/1471301213513029>
- Molyneaux, V. J., Butchard, S., Simpson, J., & Murray, C. (2012). The co-construction of couplehood in dementia. *Dementia, 11*, 483-502. <http://dx.doi.org/10.1177/1471301211421070>
- Morris, J. C. (1993). The clinical dementia rating (CDR): Current vision and scoring rules *Neurology, 19*, 2412-2414. doi: 10.1212/WNL.43.11.2412-a
- National Institute for Health and Care Excellence. (2006). *Supporting people with dementia and their carers in health and social care*. Manchester: NICE
- Osman, S. E., Tischler, V., & Schneider, J. (2014). 'Singing for the Brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers. *Dementia*. Advance online publication. <http://dx.doi.org/10.1177/1471301214556291>
- Ryan, T., Nolan, M., Reid, D., & Enderby, P. (2008). Using the senses framework to achieve relationship-centred dementia care services: A case example. *Dementia, 7*, 71-93. <http://dx.doi.org/10.1177/1471301207085368>
- Särkämö, T., Tervaniemi, M., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K., & Rantanen, P. (2014). Cognitive, emotional, and social benefits of regular musical

- activities in early dementia: Randomized controlled study. *The Gerontologist*, 54, 634-650. <http://dx.doi.org/10.1093/geront/gnt100>
- Skingley, A., & Vella-Burrows, T. (2010). Therapeutic effects of music and singing for older people. *Nursing Standard*, 24(19), 35-41.
<http://dx.doi.org/10.7748/ns2010.01.24.19.35.c7446>
- Urquhart, C. (2013) *Grounded theory for qualitative research: A practical guide*. London: Sage.
- Van de Winckel, A., Feys, H., De Weerd, W., & Dom, R. (2004). Cognitive and behavioural effects of music-based exercises in patients with dementia. *Clinical rehabilitation*, 18, 253-260. <http://dx.doi.org/10.1191/0269215504cr750oa>
- Vink, A. C., Bruinsma, M. S., & Scholten, R. J. (2003). Music therapy for people with dementia. *Cochrane Database of Systematic Reviews* 2003 (4), 1-46.
<http://dx.doi.org/10.1002/14651858.CD003477.pub2>.
- Woods, R.T., Bruce E., Edwards, R.T., Elvish, R., Hoare Z...Russell, I. T. (2012). REMCARE: Reminiscence groups for people with dementia and their family caregivers – effectiveness and cost-effectiveness pragmatic multicentre randomised trial. *Health Technology Assessment*, 16, 1-117. <http://dx.doi.org/10.3310/hta16480>
- Wright, S. D., Lund, D. A., Pett, M. A., & Caserta, M. S. (1987). The assessment of support group experiences by caregivers of dementia patients. *Clinical Gerontologist*, 6(4), 35-60. http://dx.doi.org/10.1300/j018v06n04_05
- Zeilig, H., Killick, J., & Fox, C. (2014). The participative arts for people living with a dementia: a critical review. *International Journal of Ageing and Later Life*, 9, 7-34.
<http://dx.doi.org/10.3384/ijal.1652-8670.14238>

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Table 1. *Participant details*

Participant number	Sex and age	Impairment Level*	Diagnosis**	Group type
1	M (87)	2	C/M	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 in the gallery. Ended in a choral performance and a follow up reunion.
2	F (76)			
3	M (74)	2	F	
4	F (61)			
5	M (82)			
6	F (82)	1	A	
7	M (72)			
8	F (70)	0.5	A	
9	M (82)	2	V	
10	F (77)			
11	M (89)			Ongoing group singing involving music, movement and percussion for people with dementia and their caregivers.
12	F (87)	2	U	
13	M (71)			
14	F (68)	3	C	
15	M (71)	2	F	Ongoing choir for people with dementia and their caregivers. Regular performances and a CD recording.
16	F (67)			
17	M (86)	2	A	Ongoing group singing hosted by a national charity involving reminiscence singing and movement.
18	F (77)			
19	M (66)	2	A	10 session group singing and music making programme for people with dementia and their caregivers.
20	F (66)			
21	M (77)			
22	F (77)	2	A	
23	M (81)			
24	F (79)	0.5	V	
25	M (73)	1	A	
26	F (69)			
27	M (80)	2	M	
28	F (79)			
29	M (72)	0.5	MCI	
30	F (73)			
31	M (74)			
32	F (70)	1	V	
33	M (87)			
34	F (86)	1	A	

Key: *CDR impairment levels: .5 (questionable), 1.0 (mild), 2.0 (moderate), 3.0 (severe). ** Diagnosis: Alzheimer's (A), frontotemporal (F), vascular (V), Cadasil (C), mixed (M), mild cognitive impairment (MCI) and unspecified (U)

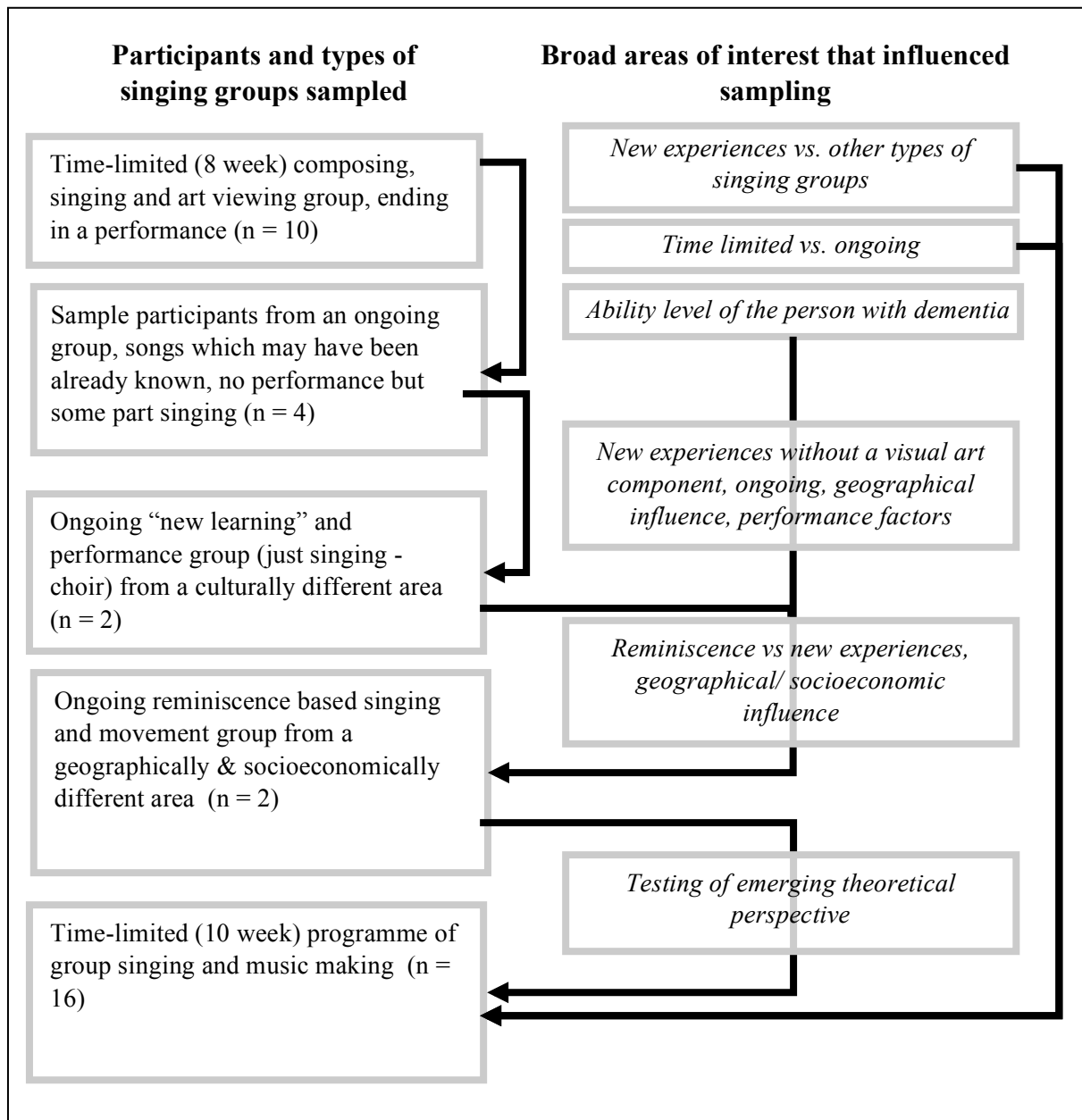


Figure 1. Theoretical sampling process

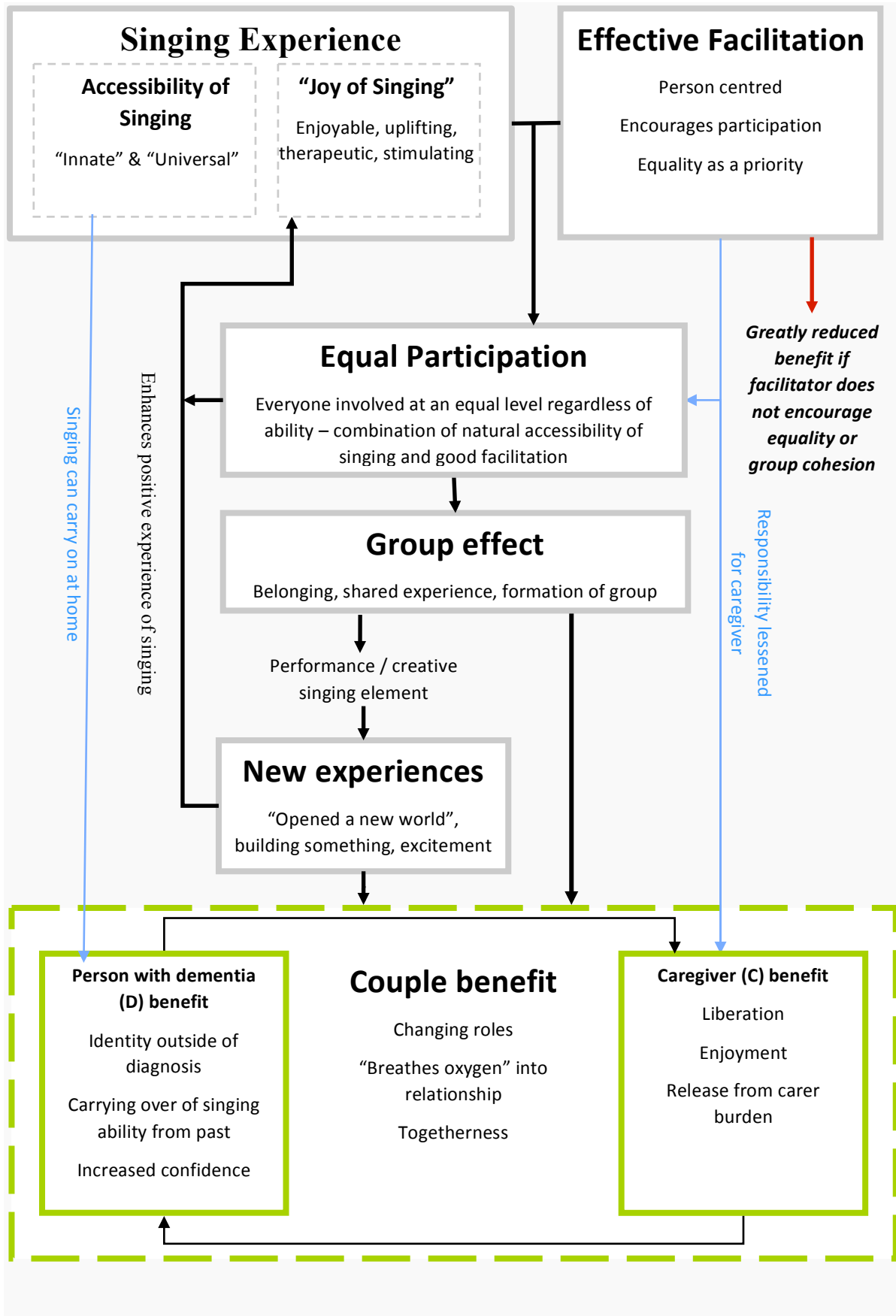


Figure 2. The group singing model in dementia for couple dyads