

Carers Create: carer perspectives of a creative programme for people with dementia and their carers on the relationship within the (carer and cared for) dyad.

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Abstract

Introduction

Relationships between people with dementia and their carers can prove challenging over the trajectory of the disease. Interventions with a potential to address this include arts and music-based activities. This research project aimed to evaluate a community engagement programme (Carers Create) where both people with dementia and their carers participate together in singing and other activities. A specific focus was on the impact of the sessions on the dyadic relationship.

Methods

A grounded theory approach involved conducting three focus group interviews with carers of people with dementia (n=16) facilitated by members of a local U3A (University of the Third Age) who were trained and supported by university researchers. Recorded conversations were transcribed and analysed using a three-stage coding and thematic development technique.

Results

Four overarching themes were identified from the discourse: remembering the positive qualities of the cared-for; the physical and emotional demands of caring; Carers Create as a shared, beneficial activity; the enduring value of Carers Create.

Conclusion

Carers found the sessions to positively influence the relationship with the person they cared for through offering some relief from the day-to-day pressures of caring and in some cases restoring elements of a previously strong relationship. Crucial to the experience was the fact that the sessions included both carer and cared-for, offering activities to do together, and that they took place within a group, thereby offering a degree of mutual support. In addition, some carers were able to build on learning which had taken place and use certain techniques, such as singing, to help manage care, thus extending the improved relationship.

Keywords: Carers, creative, dementia, music, singing, relationships

Background

The costs of caring for the 885,000 people living with dementia in the UK are currently estimated to be £34.7bn (Wittenberg et al., 2019), with over 40% of this amount attributable to unpaid care. In recognition of these high costs, at the G8 Dementia Summit in 2013, senior heads of state called for 'greater innovation to improve the quality of life for people with dementia and their carers while reducing emotional and financial burden' (G8UK, 2013). Among the various policy-related initiatives subsequent to this has been the provision of an online training programme for carers of people living with dementia (World Health Organization, 2017) and, more recently in the UK, a promise to strengthen support to address the individual health care needs of carers in the Long Term Plan for the National Health Service (NHS, 2019).

Research evidence

Much research focusing on carers of people with dementia emphasises significant unmet need. Aoun et al. (2018), using a support needs assessment tool, identified the top five support needs of family carers to be: having time to yourself during the day; knowing what to expect in the future; practical help in the home; looking after your own health; and dealing with feelings and worries. In addition, carers appreciated the opportunity to be heard. Stirling et al. (2010), however, suggested that this 'normative' approach may not adequately reflect the carer's felt needs, elicited through more qualitative approaches, which may be perceived as greater than assessed need identifies. Nor are these needs static or similar across all carer dyad relationships. Research by the Carers Trust (2013) identified several critical points along the dementia journey, from diagnosis to end of life care, where needs are different. Tatangelo (2018), by way of example, found a need for emotional support to be more prominent for spouses at a time when partners with dementia were no longer able to provide this.

Initiatives set up to meet these carer needs have included a range of psycho-social interventions. A review by La Fontaine et al. (2016) concluded that the most effective of these involved the person with dementia as well as the carer and comprised a range of strategies. Group-based interventions also appear to be successful (Barnes et al., 2013; Milne et al., 2014), particularly where they involved continued contact with others in the group after it had ended. Milne et al. (2014) further reported in their research that a carers' course was felt to have therapeutic value, being a safe and supportive place where carers could speak openly. However, most studies were derived from the USA, were short in duration and had questionable transferability to real-life practice.

Although some of these evaluation studies mention improved relationships between carer and cared-for, this is often of secondary importance and is not seen within the context of relationship theory in general. The evidence suggests that the most valued qualities, across different types of relationships, are intimacy, dependability, achievement and kindness (Cann, 2004). Relationship theory holds that the degree to which these are present may depend on the power balance within a relationship, with satisfaction being greater for both partners who are relatively equal in power (Dunbar, 2004). Clearly, when these findings are applied to relationships where one partner has dementia, this can be problematic.

The review by La Fontaine et al. (2016) found that maintaining relationships becomes more difficult as deterioration occurs in the individual with dementia as there are changes to reciprocity and commitment, although maintaining affection is possible. Robinson (2019) also found that the effects of caring can change the relational dynamics, with one of the pair often becoming a manager, rather than a partner and this, in turn, can give rise to feelings of distress and loneliness. Other research reinforces this emphasis on the emotional effects of relationship destabilisation in such dyads (Riley et al., 2018). On the other hand, Featherstonhaugh et al. (2019) noted that emotional connection,

built up over many years, continued despite a diagnosis of dementia, while O'Rourke et al. (2011) suggested that a buffer to carer distress might be attributed to marital idealisation – a propensity to idealise one's spouse and relationship by carers of individuals with Alzheimer's disease.

There is now a large body of evidence linking arts engagement with health and wellbeing across a range of social and age groups and health conditions, including dementia (Gordon-Nesbitt & Howarth, 2019). One example of this is the potential for music and related interventions to improve the ability of carers to relate to their person with dementia. Camic et al. (2013) evaluated a 'Singing Together' group for people with dementia and their carers. While the condition of the dementia participants continued to deteriorate, interview data with carers suggested that the experience led to reduced feelings of isolation. Also there were glimpses of a previous self in those they cared for, potentially improving family relationships. The positive effects of singing together on relationships is supported in an evaluation of the Alzheimer's Society's 'Singing for the Brain' intervention (Osman et al., 2016). A further study using museum visits rather than singing was also found to enhance the caring relationship (Camic et al., 2014).

Two studies which do specifically focus on the effect of music on the relationship between the person with dementia and their carer have been undertaken by Baker et al. (2012) and Unadkat et al. (2017). The first of these recruited five couples, where the carer was trained to introduce a music intervention designed to stimulate meaningful interaction with the person with dementia. Data collection before and after the six-week intervention comprised a number of quantitative scales, a semi-structured interview and a carer diary. Quantitative findings were inconclusive but the themes developed from the interviews and diary indicated: enjoyment and relaxation; enhanced spousal relationships; strengthened reciprocity; and an increase in satisfaction with the caregiving role.

Unadkat et al. (2017) interviewed 17 couples (n=34) where one of the couple had dementia and where both attended a singing group and placed the couple's relationship in a central position. Data were analysed using grounded theory and five key areas were identified: the groups were found to be joyful and accessible; the environment was conducive to equal participation; the group effect was beneficial; new experiences took place; there was benefit for the couple promoting togetherness. The authors commented that further studies are needed to confirm these findings.

In summary, research to date suggests that the arts, and particularly music and singing, can be beneficial for the carer-cared for relationship. However, in many cases neither the intervention nor the research focus is aimed at the relationship *per se*. Where this is a focus sample sizes are often small, making quantitative data unlikely to achieve statistical significance. In addition, some interventions may be considered costly, for example where administered one-to-one, or problematical to access, for example where a music therapist is required. There is a need to fill some of these gaps in the evidence and at the same time address the need for further evaluation as Unadkat et al. (2017) suggested.

The Carers Create project is an arts-centred community engagement project for carers of people with dementia and their cared-for. The project, delivered by Music for Wellbeing (M4W) ran from 2015, though a precursor (a singing group) was established some time before this and formed one of the four Carers Create groups. Further details of the project's activities can be found in an evaluation report (Vella-Burrows, 2017). Two structured wellbeing scales were used in the evaluation, plus other less formal methods such as gathering quotations and participant observation. Although the quantitative data revealed a positive trend in nearly all aspects of wellbeing, there was only a narrow floor to ceiling change in overall responses in before-after session measures, in comparison to the very positive self-reported perceptions of wellbeing expressed in comments.

This gave rise to questions about the sensitivity of scales in general and their inability to ‘get into the shoes’ of participants in a study (Lacey & Luff, 2009). It was decided that the best way to explore experiences was to adopt a qualitative approach and, through the Carers Create groups, to address the potential for the arts to affect wellbeing and, in particular, to positively influence the relationship between carer and cared for. The present research focused on the perspectives of the carers only, unlike that of Unadkat et al. (2017), who involved both partners of the dyads. This was because it seemed likely that carers would be less constrained, when talking about their relationship with the person with dementia, without the latter being present. With these principles in mind, our research aim became ‘to explore carer perspectives of a creative programme for people with dementia and their carers on the relationship within the (carer and cared for) dyad’.

Research design

A grounded theory approach was adopted, which provides ‘systematic, yet flexible, guidelines for collecting and analysing qualitative data to construct theories grounded in the data themselves’ (Charmaz, 2006 p.2). Our epistemological approach aligned more closely with the Strausserian interpretation of this method, since it allowed for a prior review of relevant literature, a structured approach to analysis and the active role of the researcher in the interpretation of data (Corbin & Strauss, 1990). A novel feature of this research was its collaborative approach between researchers from a university and members of a local University of the Third Age (U3A) group, who represented a non-hierarchical presence (including a current carer) with whom research participants might feel more comfortable than with academics.

Focus groups, (discussion-type interviews that produce a particular type of qualitative data generated via group interaction – Breakwell et al. 2006) were used as a vehicle through which to capture the experiences of carers. The method helps people explore views and experiences in ways

that are less easily achieved using one-to-one interviews (Traynor, 2015). This is helpful for researchers seeking to understand the breadth of shared experiences within a group, without necessarily trying to come to any consensus. The conduct of a focus group includes the setting of ground rules, construction of a questionnaire schedule which structures the discussion and the presence of a moderator to pose questions and ensure participants are all able to contribute. Training in running focus groups was provided to U3A members by a research professor at the university.

Sample

A convenience sample (n=16) of self-selecting carer volunteers was recruited from the four existing Carers Create groups. Each had attended their group for at least a year. Publicity was provided by U3A researchers visiting the group sessions to explain about the project, aided by further input from the group facilitators (leaders). In addition, invitations were extended to ex-carers (where the cared-for no longer attended due to admission to a care home or death) who still attended themselves. Two further carers, who were unable to attend the groups, submitted unsolicited narratives instead.

Data collection

Four U3A members working in pairs took the focus groups forward. Two discussions were held in the usual Carers Create activity venues, and one in a local Age UK centre. Each took place at a mutually convenient time while an alternative activity, in a separate room, was organised for the related people with dementia. Carers were given time to ensure their cared-for was settled and reassured that they would be alerted if there were any concerns. The focus groups corresponded to two of the Carers Create groups, with a further focus group combining the two remaining ones. Participants completed a demographic profile and, following an explanation of the format and introductions,

were invited to discuss issues around: the activities of the group, the programme and facilitation, accessibility and participation, the group format and their relationship with their cared-for. These topic areas were derived from the findings of Unadkat et al. (2017) as described above. Discussions were digitally recorded with permission and co-moderators took notes and made observations which were incorporated into the data analysis.

Ethics

Compliance with ethical procedures was granted by the Faculty of Medicine, Health and Social Care at Canterbury Christ Church University. Participants were asked to read an information sheet and sign to signify informed consent. Confidentiality was assured and no individuals were identified in data analysis or reports. Digital data were held on password protected computers and paperwork holding personal data kept in locked filing cabinets within the university.

Data analysis

Recordings were transcribed and uploaded to a password protected Google Drive, set up by one of the U3A group, to enable sharing of data and other materials. Further U3A members, who had not been involved in the focus groups, were invited at this point to read the anonymised transcripts and feedback initial impressions. This was in order to minimise bias in the analysis. For more in-depth analysis, we considered a number of approaches consistent with our research method (Braun & Clarke, 2006; Wirihana et al., 2018; Twiddy et al., 2017), before adopting the three stage model developed by Twiddy et al. (2017) as this also drew on focus group data and aligns closely with a grounded theory approach as interpreted by Corbin and Strauss (1990).

Each focus group transcript was assigned to a pair or trio of U3A researchers, who worked in parallel and then together with any disagreements resolved by discussion. The first stage (open coding) identified small chunks of relevant text which conveyed something meaningful in the context of the research aim. The second stage (axial coding) grouped conceptually similar codes into categories which were labelled. The third stage (thematic development) was concerned with the overall meaning contained within a group of categories. We then performed a cross-group analysis so that final themes reflected the experiences of all focus groups equally.

We felt it was important to be able to trace how we had developed our final themes from the original data and so, like Twiddy et al. (2017), made use of letters to link codes to themes. This is what Yin (2009) refers to as a 'chain of evidence' and acts as a means to maximising reliability. The principle is to allow an external observer/reader to follow the derivation of any evidence from the initial research data to the conclusions. As an added dimension, the data were reviewed within three time frames which covered discussion relating to (i) past (pre Carers Create) events and time, (ii) observations within a Carers Create session and (iii) anything subsequent to or outside of these sessions. Finally the pairs and trios brought their findings to the plenary meeting to fine tune the overall themes identified.

Findings

The demographic profile of focus group participants is outlined in tables 1, 2 and 3 which show that, of the 16 carers taking part, ages ranged from 59 to 86 years and the male:female ratio was 4:12. Thirteen carers were caring for spouses, two were caring for friends and one caring for a mother. All except one had attended the Carers Create groups for over a year but the caring responsibilities were all considerably longer. We were not able to collect demographic data from the two submitting

a written response, however they volunteered that one was a husband and the other a daughter of an individual with dementia.

Four overarching themes were identified across all three Carers Create groups: remembering positive qualities of the cared-for (focusing on the pre-dementia relationship within the dyad); the physical and emotional demands of caring (focusing on the changed relationship post-dementia diagnosis); Carers Create as a shared, beneficial activity (focusing on the relationship within a session); and the enduring value of Carers Create (focusing on any continuation of the session experiences outside and beyond the groups). These themes will be addressed in turn.

Remembering the positive qualities of the cared-for

Carers talked about the pre-dementia person they cared for in almost universally positive terms, describing them as able and strong:

'I was a teacher, mainly juniors. A lot of time she was head of maths in the school. She got an advanced diploma in maths, a very intelligent person'.

'I've never seen her bitter about anything, she's always been strong in that way. I think her mind is good'.

They were also seen as dependable (indicating perhaps where the power balance had been), with an attractive personality:

'I've known her for a long, long time. She's such a lovely lady. She's still the same I I knew'

'D would have been my rock'.

Such language tends to suggest a positive relationship in the past based on a reciprocity that results from an assumption of equality, or even conferring a higher status to the other person ('my rock'). It also suggests, to a certain extent, the ability to see through the dementia to the person the carer once knew and the continuation of the personality, if not the ability.

The physical and emotional demands of caring

Caring for the person with dementia was seen as hard work which often led to feelings of isolation and coping alone.

But I was a wreck. It's really hard, hard work. It really is.

it's isolating, the disease is isolating, isn't it, when you are home all the time...

There was evidence in the discussions of a certain consensus as participants signified agreement with comments and indicated an empathy arising from experience:

Carer 1: I'm in that sort of emotional middle stage if you know what I mean ...

Carer 2: That's hard [sounds of agreement].

Carer 3: It's the worst, worst disease, the opposite to what they were as a person.

Carer 4: That's right yes. That's the trouble, they're not what they was (sic).

Challenges included finding time for oneself, guilt (for example when thinking about admission to residential care), emotional volatility and frustration:

that's the biggest problem, trying to fit everything in – and sometimes finding time for myself.

... you do feel wicked. I feel really wicked putting him in a home. I really do, because you feel guilty.

Carers often felt resigned to their situation while others were willing to try anything that might have an effect on the dementia. It was felt that there was nothing for the carer and cared-for to do together outside of the home:

I just have to get on with it

we clutch at straws, we see something in the paper, we try it and try it

Yes there isn't many other activities are there? ... there's nothing you can do together, much.

It's either one thing or the other

Here, the carers were probably referring to the Day Centres (for people with dementia) run by Age UK, or carers' courses (for carers only) also provided by Age UK and other organizations such as the Carers Trust. Although such provision may have done something to ameliorate the sentiments expressed about 'getting on with it' and 'clutching at straws' these were obviously not seen as the answer by participants.

Of note is the way that a previous relationship had changed with the onset of the dementia, such that the carer role becomes the dominant one:

I can't be the wife, I've got to be the carer

I am different people, so I don't know who I am half the time when he is asking me questions

This reflects the re-ordering of social relationships which is a common theme in the broader literature on the assumption of a caring role (Moral-Fernández et al., 2018), and this is perhaps magnified where one of the pair has dementia.

Another positive, though unrelated, issue to emerge was the benefit which some carers ascribed to the very act of taking part in the focus group discussion itself:

Well we never talk about it do we? I've never spoken to anyone about it. And it's been good, just talking.

This was noted by one of the moderators, who observed in notes: 'a number of the focus group participants spoke at the end about how useful it had been to have had the discussion'. Other researchers have also noted this to be a potential feature of the qualitative research interview as opposed to the clinical interview (Rossetto, 2014) and, while perhaps unavoidable, should be acknowledged.

Carers Create as a shared, beneficial activity

One of the most frequent expressions emerging from the focus groups was one of enjoyment and fun experienced during a Carers Create session, with carers often interpreting their cared-for's reactions through facial expressions and anecdotes relating particular moments of enjoyment:

not many, especially older people, experience the joy and the fun we have at that event

to see J enjoying, yes enjoying herself for want of a better word. She couldn't um, the only sort of reaction I could get were with the facial expressions you know, but saying that, her favourite song was 'I'll buy a teapot big enough for two'. And I used to sing ...

For some the sessions provided a distraction and means of escape from the overwhelming caring responsibilities described above:

for me it's just an escape from the pressure cooker environment at home

Gets you out of the house, and meet other peopleso it's an activity getting out of the house, which I think is important for both of us really

It stops the endless questions, you don't have this every two minutes

There was also discussion around the physical and mental wellbeing impact of the experience in terms of improved relaxation, counteracting the stress normally felt, or more physical effects, such as better breathing. For the people with dementia, the feeling was that the music and singing in particular helped to improve cognition:

Well I do know it's relaxing for me, I feel tired when I walk away and that's because I've got oxygen into my lung and you relax when normally you're on edge all the time.

the main thing for the singing, from my point of view, it's helping with memory and it's helping with breathing.

Some participants spoke directly about how their relationship with the cared-for had improved, ascribing this to the fact that the sessions provided an opportunity to do things together, making up for the dearth of such opportunities alluded to above:

I enjoy it, we laugh, it's good for our relationship, we come out of it, you know, on a high.

it is an activity that we can do together and that is so critical for me, because he doesn't then feel like he's being farmed out, and I don't feel like I'm being turfed out my home

to come along, it was one of the oases that we found, or I found, you know, so from my point of view it was brilliant, to actually have something we could do together,

'Doing things together' was obviously seen by these respondents as foundational to their relationship and to what Hellstrom et al. (2005) have termed 'couplehood', a concept which the presence of dementia in one of a pair does not necessarily negate.

Crucially, Carers Create groups were seen as safe and welcoming places, where the people with dementia were valued, even though for some this was only an 'in the moment' experience, lost after the session ended. The enjoyment of company extended to the relationships built up within the group as well as within the dyad:

We both look forward to it. It is something when I say that we're going to the music, there is some recognition there and it's relaxing because I'm not leaving him anywhere, there's not that stress, we're both together and it's a safe environment and we can both enjoy ourselves in our own ways, can't we?

but there we've got an hour, an hour and a half if you stay for coffee where we're both enjoying ourselves, enjoying each other's company as well as everyone else's so you come away quite buoyed up.

I think it has changed my relationship with P because it enhances her as a person

it's all in the moment, once that moment is over, its over

The enduring value of Carers Create

Despite the 'all in the moment' experience expressed by some participants, it is also clear that learning took place within the Carers Create sessions which were then applied by carers at home. In most cases this took the form of activities used instrumentally to manage aspects of care, meaning that carers and others benefitted too:

I find the singing really calms him down. Like, getting him here, we weren't going to get off that table and so we have a little song, hold my hands and then he'll start to sing it and I think that relaxes him and he forgets. And so we have these little songs and people think I'm mad...

The most recent example is in persuading her to let me help her bathing. Initially she resisted every step of the way, every time. Now I find that humming/singing even a few lines of a song with relevant words or implication gets us happily where we need to be. 'The stripper' tune always gets a laugh; 'Pretty woman' by Roy Orbison (her heart throb) seems to encourage her to want to look her best: 'I'm gonna wash that man right out of my hair' from South Pacific is good for hair wash time.

it [Carers Create] had an equally positive effect on mum, dad, myself and our ability to manage mum at home with the help of song

There was evidence that, although those with dementia often failed to remember where they had been, the emotion, the feeling of having experienced something enjoyable, remained:

In her mind she associates singing and Skylarks – ‘oh they’re a lovely group’. So she is remembering to some extent. So from my point of view it’s a very positive outing

It is notable that the discussions frequently involved the reference to ‘we’ or ‘us’, signifying mutual engagement and being enabled to do things together:

I put the music on for G and he has his favourites, he likes Roy Orbison and we have that on in the week. And sometimes we have a dance, he likes to dance.

The impact of enabling mum and I to sing uninhibited has been priceless. As soon as mum starts to get anxious or angry I hum or sing and soon she starts to join in and forgets feeling bad. Now unable to maintain a conversation or discussion as we used to we can punctuate quiet times with singing together those songs which we like or evoke happy memories for us, we always end up laughing and hugging

This extract illustrates how the arts can be more than a way to manage care, but rather, as noted by Jeong (2019), can also enhance remaining artistic capacity in people living with dementia, and so enhance the affective experience of both carer and cared-for.

Finally, many expressed the way that Carers Create was a highlight of the week as something to look forward to and therefore saw it as essential that such initiatives continued:

that would make the week, that was our life

I think it's so important that these groups continue to give the support to the carers plus to the person that has the terrible disease. If they stop they don't realise whether the family they are helping what damage it can do. They do really need to come along and see what pleasure it gives to the people in the group .

Discussion

In this research we aimed to explore carer perspectives of the value of Carers Create sessions, in particular with regard to the impact on their relationship with the person they care for. The focus group discussions we held were wide-ranging and gave the impression of previously strong relationships, fractured in many ways with the onset of dementia and the caring responsibilities. Carers Create offered a temporary escape from the carer role and into a shared experience of enjoyment and wellbeing which, to a certain extent, countered the negativity of their daily lives. Although this was often a fleeting moment only, it was still worth that moment, especially if something of the experience could be re-created through activities such as singing in other settings.

Much of the data supports existing research evidence. The needs expressed by our carers echo those found by Aoun et al. (2018), notably the need for 'me time' and the opportunity to be heard. It was interesting, if perhaps of some concern, that, for one group of carers, the focus group itself, as well as the Carers Create sessions, provided for that need for the first time. This does raise issues - and ethical questions - about the fine line between interactions as sources of research data and as 'therapy' for research subjects. Certainly our findings suggest the need for more psychological support for carers.

Carers talked about different stages of dementia, as noted in the research by the Carers Trust (2013). Although they suggested that all stages are hard to deal with, the identification of an 'emotional

middle stage' supports the findings of Tatangelo et al. (2018) and the attendant need for emotional support for carers, also going through different stages.

The most valued qualities in relationships, as described in the research by Cann (2004) were referred to in carer narratives relating to the cared-for's past, with examples of dependability ('my rock') achievement ('a teacher') and kindness ('a lovely lady'). Although often lost in the dementia, along with the equality in the power balance which Dunbar (2004) talked about, the Carers Create sessions appeared to go some way to restoring the balance with talk of 'something we can do together' and 'enjoying each other's company'.

A related issue, arguably addressed through the same processes, is that of role change. One participant commented that she could 'no longer be the wife' as everything was subsumed within the carer role, while others noted that they became 'different people' at different times. This resonates with Riley et al's (2018) findings that the carer often becomes a manager, in place of the previous relationship. In Carers Create sessions the 'management', in part at least, is taken on by the facilitators, enabling the carers to revert to their original role, even if temporarily, and enjoy themselves with their relative or friend.

Of course, not all the discussion about caring was negative in tone. The positive references to the personality of the person with dementia when recalling the past, often voiced in present tense, would seem to support the work of O'Rourke et al. (2011), who wrote about the tendency of carers to idealise the relationship with individuals with Alzheimer's and the way this acted to buffer the distress felt. This suggests that interventions which maximise the existing abilities and personality of the person with dementia should be prioritised. Such comments as 'it enhances her as a person' indicates that Carers Create may be achieving this.

Maximising existing skills and abilities of people with dementia through music and singing in particular is well documented, not only in the research cited above (Camic et al., 2013; Osman et al., 2016; Baker et al., 2012; Unadkat et al., 2017) but also in the physiological explanations of what happens in the brain with these stimuli. For example, it is known that regions of the brain associated with musical memory may overlap with regions relatively spared in Alzheimer's disease (Bowell & Bamford, 2018). This may explain why singing, of all the Carers Create activities, was most focused on and used subsequently by carers in the home and other situations.

But our research findings go further than providing support for existing research evidence. Most of the research we found on carers of people with dementia does not place the relationship within the dyad centrally; work that does note improved relationships as an outcome tends to mention this only incidentally. Further, the fact that the intervention was delivered in a group situation seemed to be crucial, with carers talking about meeting other people and enjoying other people's company in positive ways.

Our work most closely replicates that of Unadkat et al. (2017), however the intervention in that research was based on singing and with spousal couples only. As it happened most dyads were spouses in our research and also the singing component of the Carers Create sessions was the most frequently referred to and certainly appeared to be the most easily transferable to a different session. Finally, because we heard from carers only, it is likely that they reported more honestly on the challenges of caring than if they were accompanied by the person with dementia. In this way we were able in the analysis to identify more readily whether the Carers Create sessions had addressed their needs effectively.

Methodological critique

This research was based on a small, self-selecting sample of carers, therefore transferability to other groups may be limited. However, details of context and participant characteristics have been provided in order that readers can make a transferability judgement themselves.

Focus group discussions worked well as a data collection method, allowing participants to freely express their views and enabling the collection of rich data. The contribution of trained U3A members in a collaborative research exercise appeared to assist this, as carers viewed them as 'on their wavelength'.

Although the groups were different sizes and dynamics, this is arguably a strength in design since the data capture a wide range of opinions.

Data collected retrospectively entails dependence on participant memory, in recalling both a time predating dementia diagnosis, but also the more recent experiences of caring and participating in Carers Create sessions. These memories are, however, very much part of the carer experience and, as such, are critical to answering the research question.

Finally, there are, as always, inferences to be made in all data analysis, allowing for a degree of subjectivity. This was to some extent offset by the detailed account of data analysis procedure, demonstrating transparency in the pathway between data via coding to themes.

Recommendations

Since Carers Create offers benefits to carers, we would like to see such schemes, involving both carers and cared-for, funded and extended in number. This would be a means to facilitate the

promise in the government's Long Term Plan (NHS, 2019) to strengthen support of, and address health needs of carers.

Further investment in research into dementia care, also featured in the Long Term Plan, could facilitate larger studies into this model of care.

In view of the expressed benefit for carers of meeting in a group, also supported in the literature, consideration should be given where feasible to dedicated time set aside within sessions for carers to feel free to debrief with co-carers, while their cared-for are occupied separately but nearby.

Conclusions

Carers Create is an arts-centred community engagement project for carers of people with dementia and those they care for. Our research shows that carers have found the sessions to positively influence their relationship with their cared-for through offering some relief from the day to day pressures of caring and in some cases restoring something of a previously strong relationship.

Crucial to the experience was the fact that the sessions included both carer and cared-for, offering something to do together, and that they took place within a group, thereby offering a degree of mutual support. In addition, some carers were able to build on learning which had taken place and use certain techniques, such as singing, to help manage care, thus extending the improved relationship.

References

Aoun, S., Toye, C., Slatyer, S., Robinson, A. & Beattie, W. (2018). A person-centred approach to family carer needs assessment and support in dementia community care in Western Australia. *Health & Social Care in the Community* 26, 578-586.

Baker, F., Grocke, D. & Pachana, N. (2012). Connecting through music: a study of a spousal caregiver-directed music intervention designed to prolong fulfilling relationships in couples where one person has dementia. *Australian Journal of Music Therapy* 23, 4-19.

Barnes, M., Henwood, F., Smith, N. & Waller, D (2013). External evaluation of the Alzheimer's Society Carer Information & Support Programme (CrISP). University of Brighton. Available at:

https://www.brighton.ac.uk/_pdf/research/ssparc/alzheimers-society-crisp-findings.pdf

Bowell, S. & Bamford, S. (2018). 'What would life be – without a song or a dance what are we?' A report from the Commission on Dementia and Music. London, UK; ILC-UK. Available at:

<https://ilcuk.org.uk/wp-content/uploads/2018/10/Commission-on-Dementia-and-Music-report.pdf>

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 77-101.

Breakwell, G., Hammond, S., Fife-Shaw, C. & Smith, J. (Eds) (2006). Research methods in psychology, 3rd edition. London, UK: Sage.

Camic, C., Tischler, V. & Pearman, H. (2014). Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers. *Aging and Mental Health* 18, 161-168

Camic, P., Williams, C. & 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.

Cann, A. (2004). Rated importance of personal qualities across four relationships. *Journal of Social Psychology* 144, 3, 322-334.

Carers Trust (2013). A road less rocky: supporting carers of people with dementia. Carers Trust/SPRU. Available at: <https://carers.org/resources/all-resources/84-a-road-less-rocky-a-supporting-carers-of-people-with-dementia>

Charmaz, K. (2006). Constructing grounded theory: a practical guide through qualitative analysis. London: Sage

Corbin, J. & Strauss, S.A. (1990). Grounded theory research; procedures, canons and evaluative criteria. *Qualitative Sociology* 13, 1, 3-21.

Dunbar, N. (2004). Theory in progress: dyadic power theory: constructing a communication-based theory of relational power. *Journal of Family Communication* 4, 3-4, 235-248.

Featherstonhaugh, D., Rayner, J-A & Tarzia, L (2019). Hanging on to some autonomy in decision-making: how do spouse carers support this? *Dementia* 18, 1219-1236.

Gordon-Nesbitt, R. & Howarth, A. (2019) The arts and social determinants of health: findings from an enquiry conducted by the United Kingdom All-Party Parliamentary Group on Arts, Health and Wellbeing. *Arts and Health* DOI: 10.1080/17533015.2019.1567563

G8UK (2013). Dementia Summit Declaration (p.1). Available online at:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/265869/2901668_G8_DementiaSummitDeclaration_acc.pdf

Hellstrom, I., Nolan, M. & Lundh, U. (2005). 'We do things together': a case study of 'couplehood' in dementia. *Dementia* 4 (1) 7-22.

Jeong, J. (2019). The affective creativity of a couple in dementia care. *Culture, Medicine and Psychiatry*. Available online at: <https://link.springer.com/article/10.1007/s11013-019-09662-5>

Lacey, A. & Luff, D. (2009). Qualitative data analysis. Nottingham & Sheffield, UK: NIHR Research Design Service for the East Midlands/Yorkshire and the Humber.

La Fontaine, J., Jutla, K., Read, K, Brooker, D. & Evans, S. (2016). The experiences, needs and outcomes for carers of people with dementia: literature review. London, UK: RSAS. Available at: <https://dementiacarers.org.uk/wp-content/uploads/2018/11/RSAS-ADS-Experiences-needs-outcomes-for-carers-of-people-with-dementia-Lit-review-2016.pdf>

Moral-Fernández , L., Frías-Osuna, A., Moreno-Cámara, S., Palomino-Moral, P.A. & Del-Pino-Casado, R. (2018). The start of caring for an elderly dependent family member: a qualitative metasynthesis. *BMC Geriatrics* 18:22. Doi.org/10.1186/s12877-018-0922-0. Available at:

<https://bmgeriatr.biomedcentral.com/articles/10.1186/s12877-018-0922-0>

Milne, A., Guss, R. & Russ, A. (2014). Psycho-educational support for relatives of people with a recent diagnosis of mild to moderate dementia: an evaluation of a 'Course for Carers'. *Dementia* 13, 768-787.

NHS (2019). The NHS long term plan. Available at: <https://www.england.nhs.uk/long-term-plan/>

O'Rourke, N., Claxton, A., Kupferschmidt, A., Smith, J. & Beattie, B. (2011) Marital idealization as an enduring buffer to distress among spouses of persons with Alzheimer disease. *Journal of Social and Personal Relationships* 28, 117-133.

Osman, S., Tischler, V. & Schneider, J. (2016). 'Singing for the Brain': a qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers. *Dementia* 15, 1326-1339

Riley, G., Evans, L & Oyeboode. J. (2018). Relationship continuity and emotional well-being in spouses of people with dementia. *Aging and Mental Health* 22, 299-305.

Robinson, G (2019) Supporting carers of people with dementia. *Nursing Standard* 34, 1, 44-49.

Rossetto, K.R. (2014). Qualitative research interviews: assessing the therapeutic value and challenges. *Journal of Social and Personal Relationships* 31(4) 482-489. Doi: 10.1177/0265407514522892.

Stirling, C., Andrews, S., Croft, T., Vickers, J, Turner, P.& Robinson, A. (2010). Measuring dementia carers' unmet need for services – an exploratory mixed method study. *BMC Health Services Research* 10:122. Available at:

<https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-10-122>

Tatangelo, G., McCabe, M., Macleod, A. & You, E. (2018). 'I just don't focus on my needs'. The unmet health needs of partner and offspring caregivers of people with dementia. *International Journal of Nursing Studies* 77, 8-14.

Traynor, M. (2015). Focus group research. *Nursing Standard* 29, 37, 44-48.

Twiddy, H., Hanna, J. & Haynes, L. (2017). Growing pains: understanding the needs of emerging adults with chronic pain. *British Journal of Pain* 113, 108-118.

Unadkat, S., Camic, P. & Vella-Burrows, T. (2017). Understanding the experiences of group singing for couples where one partner has a diagnosis of dementia. *The Gerontologist* 57, 469-478.

Vella-Burrows, T. (2017). Carers Create 2015-2017: Report on activities and evaluation of effect. Canterbury Christ Church University. Available at:

<http://www.artshealthresources.org.uk/docs/carers-create-2015-2017-report-on-activities-and-evaluation-of-effect/>

Wittenberg, R., Hu, B., Barraza-Araiza, L. & Rehill, A. (2019). *Projections of Older People Living with Dementia and Costs of Dementia Care in the United Kingdom, 2019–2040*, Care Policy and Evaluation Centre Working Paper 5. Available at:

lse.ac.uk/cpec/assets/documents/Working-paper-5-Wittenberg-et-al-dementia.pdf _

World Health Organization (WHO) (2017). iSupport: online training programme for carers of people with dementia. Available at:

https://www.youtube.com/watch?v=_g2KMgjukzs&feature=youtu.be

Wirihana, L., Welch, A., Williamson, M, Christensen, M., Bakon, S., Craft, J. (2018). Using Colaizzi's method of data analysis to explore the experiences of nurse academics teaching on satellite campuses. *Nurse Researcher* 25, 4, 30-34.

Yin, R. (2009). Case study research: design and methods 4th ed. Los Angeles, USA: Sage

Table 1: Focus group A

Participant	A1	A2	A3	A4	A5	A6
Age	86	68	79	59	78	73
M/F	F	F	F	F	M	F
Relationship	Wife	Spouse	Spouse	Wife	Husband	Wife
Length caring	7 yrs	6 yrs 2 mo	25 yrs 6 mo	4 yrs	7 yrs	15 yrs
Time attending CC	3 yrs	2 yrs	-	2 yrs	3 yrs	3 yrs

Table 2: Focus group B

Participant	B1	B2	B3	B4	B5	B6	B7
Age	68	69	67	77	84	75	-
M/F	M	F	F	F	F	F	F
Relationship	Husband	Wife	Wife	Wife	Wife	Friend	Wife
Length caring	8 yrs	7 yrs	8 yrs	4 yrs 6 mo	4 yrs 6 mo	4 yrs	6 yrs
Time attending CC	6-8 mo	1 yr	1 yr	4 yrs	4 yrs	4 yrs	3.5-4 yrs

Table 3: Focus group C

Participant	C1	C2	C3
Age	64	74	67
M/F	F	M	M
Relationship	Daughter	Husband	Friend
Length caring	4 yrs	22 yrs	4 yrs
Time attending CC	2 yrs	2 yrs??	3 yrs

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