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**Title:** Perspectives of people living with dementia and their care partners about the impact on social health when participating in a co-designed Dementia café

## **Abstract**

Those diagnosed with dementia and those who provide care and support often feel socially isolated with limited opportunities for social engagement, increasing the potential for loneliness and further isolation that is detrimental to social health. This study examined how a co-designed dementia café impacted on the self-reported social health of community dwelling people with dementia and their care partners in the North-West of England. Semi-structured interviews were conducted at two time periods (summer of 2019 and spring of 2020), with 5 people living with dementia and 8 care partners. The key finding was that participating in the cafés led to a sense of belonging and purpose that was beneficial to wellbeing and social health for all participants. Community based initiatives that provide opportunities for peer support for the person with the diagnosis and the care partner are essential so that people living with dementia may rebuild their confidence as well as retaining opportunities to socialise.

**Key words:** community dwelling; wellbeing; social health; dementia; co-designed; care partners; dementia café

**What is known about this topic:**

- Dementia (or Alzheimer) Cafés are a global approach and have been developed and adapted by health and social practitioners in different countries since the 1990's.
- There is limited evidence from the person living with dementia about their experiences of dementia cafés.

**What this paper adds:**

- Creating opportunities for people living with dementia and care partners to interact and participate with people experiencing life in similar ways can enhance their wellbeing and social health.
- Dementia Cafés provide a mechanism to promote self-reported social inclusion and social health for both the person with the diagnosis and care partners.

## **Introduction**

Social networks and informal social support are recognised as important for the wellbeing of both the community dwelling person with dementia and those who provide support (Wiersma and Denton, 2016). However, those diagnosed with dementia and those who provide care and support often feel socially isolated with limited opportunities to engage in social groups increasing the potential for loneliness and further isolation (Alzheimer Society, 2013, Victor et al, 2020) that is detrimental to social health. Supportive social environments focusing on retained abilities and social inclusion are key to balancing out the experienced negative impacts of dementia (Kitwood, 1997, Ray et al, 2017, Lee et al, 2020). Social health is a useful concept (de Vugt and Dröes, 2017) to understand and promote living well with dementia. Vernooij-Dassen et al (2018) have argued that social health offers the opportunity to focus on the social aspects of living with dementia and a way of understanding the opportunities and barriers to living well with dementia and the importance of social networks and engagement with society for the lived experience of the condition. Crucially, it has been argued that facilitating 'social health' may be achieved by enhancing one's sense of active engagement and connectedness (Vernooij-Dassen et al, 2018). Thus, social groups provide a medium to promote Kitwood's (1997) notion of wellbeing via the preservation of social health when neurological health is impaired by dementia.

Alzheimer's or Dementia Cafés are a popular approach to engaging those living with dementia and their care partners in supportive social environments. Dementia cafés stem from Bere Miesen's initiative to address the lack of psychosocial support available around dementia in the 1990s (Miesen and Jones, 2004). Two primary approaches have developed for Dementia or Alzheimer Cafés with either 1) an educational focus (European) or 2) a peer

support/social focus (American). Both approaches reduce social isolation, facilitate social network development and act as useful information sources, most however focus on the impact for care partners or family members (Akhtar et al, 2017, Dow et al, 2011, Fukui et al, 2019, Greenwood et al, 2017, Teahan et al, 2020) with less focus on the benefits to the person living with dementia (Capus, 2005, Merlo et al, 2018). Adaptations to these two primary models have been made to suit the local context (Ney et al, 2015, Takechi et al, 2019).

Based on the Dementia Café approaches, a co-designed café, known as SIDS café, was developed between academics (1 and 5) and community dwelling people living with dementia and those providing care and support. A hybrid model evolved with a focus on learning new skills and having fun, and thus had elements of both American and European approaches. Through co-delivery, that is where participants and staff facilitated sessions together, the café gave individuals living with dementia and care partners the opportunity to show case their talents and hobbies. In addition, a key design element of the café was the opportunity to socialise around refreshments, share experiences and build friendships. The ability to mix with others in a similar situation is a key feature of café research with the benefits of peer support for carers reported (Akhtar et al, 2017). Participating in activities through attending café groups has been reported as important for people living with dementia (Capus, 2005). The co-designed café evolved to become structured sessions where at least one activity was available (such as a speaker on a subject chosen by attendees or a craft based activity) as well as opportunities to talk, share experiences and generally have time to relax with others who also had a diagnosis of dementia or were supporting someone with a diagnosis.

The objective of this study was to examine how this co-designed dementia café impacted on the self-reported wellbeing and social health of both community dwelling people with dementia and their care partners. Groups designed for both the person living with dementia and their family members have been found to promote social wellbeing through social connection with others, reconnection with the Self as well as supporting the carer–cared-for relationship (Lee et al, 2020). The monthly, no-cost to attend, café was run at the authors’ University by academic staff (co-author 5) with sessions developed together, and at times co-facilitated, with participants. This study adds to the growing evidence base on the benefits of café approaches to supporting not just the care partners of those with dementia but the person living with dementia and the care dyad (Merlo et al, 2018). This is important as it builds on a recognition that attending an Alzheimer Café can facilitate relationship building within care dyads and with other attendees and potentially enable wider community awareness and engagement (Teahan et al, 2020).

## **Methods**

This study addressed the research question - How does a co-designed dementia café impact the well-being and social health of community dwelling people with dementia and their care partners?

At two time periods (summer 2019, spring 2020), data were collected using qualitative semi-structured interviews as they can capture rich, detailed, first-person accounts of participants’ experiences and perspectives. Interviews have been successfully used in previous research examining the lived experiences of people living with dementia and family members (Innes et al., 2014) and those attending dementia cafés (Teahan et al, 2020).

The monthly café was open to all those with dementia and their care partners. The mean number of people attending each of the eight cafés running during the research period was 12. Four planned sessions were cancelled due to COVID-19 restrictions. Participants were recruited from locally run groups. Most participants had previously attended an earlier version of the café and wished to be involved in the research as they had co-designed the new café format, however all members became involved in planning future sessions and were therefore ‘co-designers’ of the café. All participants had first-hand experience of living with dementia. All participants were able to give informed consent and we followed the process consent method detailed by Dewing (2007). Thirteen participants gave their written consent to be interviewed; 5 people living with dementia (PLWD) (3 male and 2 female) 3 care partners (CP) (2 female and 1 male) and 5 former care partners (FCP) (all female). Of the 5 participants living with dementia, 3 took part as a dyad and 2 took part independently. The age range for participants was 50- 87 years.

An interview topic guide designed solely for this study facilitated consistency across the interviews and included topics such as motivations for joining the café, experiences of the café, perceived benefits of the café for wellbeing and social health and how this initiative compared to other support available and groups attended. All interviews were digitally recorded and transcribed verbatim. Ethical approval for the study was obtained in May 2018 (HSR1718-062). Due to restrictions imposed in response to the COVID-19 pandemic, follow up interviews were conducted over video and voice calls, rather than in-person following an ethics amendment received in April 2020.

Data from the interviews were audio recorded and transcribed verbatim and analysed using Thematic Analysis (Braun and Clarke, 2006), incorporating inductive and deductive techniques guided by the research questions but also by the information shared by participants, to capture the subjective lived experiences of participants.

Table 1 about here

Using NVivo software, initial codes were identified, with transcripts revisited to identify themes. The advantage in using such software is that it ensures researchers follow a thorough and methodical approach to data analysis, to improve the quality of research (Bazeley, 2007). All initial codes and themes were discussed amongst the researchers and amended until a consensus was reached. The COREQ guidelines (Tong, Sainsbury and Craig, 2007) were consulted for reporting this study.

## **Findings**

The key finding was that participating in the café sessions led to a sense of belonging and purpose that was beneficial to self-reported wellbeing for all participants.

Belonging was underpinned by the café setting that was perceived as a **welcoming and emotionally safe space**. **Perceptions of attendance contributing to wellbeing and social health** was achieved via Kitwood's (1997) elements of personhood of inclusion, attachment, comfort, identity, and occupation. **Peer support and understanding** as well as **friendships** developed through attending the café and contributed strongly to a sense of belonging



promoting perceived wellbeing and social health. We will now discuss each of these key thematic findings.

***The café setting: a welcoming and emotionally safe space***

Participants spoke about the café as somewhere they experienced a welcoming environment, promoting feelings of comfort and safety. The perception that the physical environment allowed them to feel secure was important to participants and as something that set the café location apart from other settings:

*PLWD10: It is close knit here. I mean I like going to [another group] ...but there is some animosity sometimes there... Here it tends to be, you just get round, pop yourself anywhere, nobody says, hey that's my seat, and they just take it.... And it's nice and warm when you come in, you just feel like - it feels like home sort of thing, like you are coming home to your other home.*

This sense of being home, of feeling the metaphorical, emotional and physical warmth of the café provided participants with a sense of wellbeing.

Participants viewed the groups at the café as offering a safe place. The feelings of safety appeared to be derived from the physical environment, the presence of familiar people and the fact that groups were run in a non-threatening manner, observing confidentiality, allowing members to feel safe in sharing their thoughts and feelings. It was important to participants that they could be honest, and share their experiences, giving them the feeling that they were not alone:

FCP03: *You become so isolated and become so fearful, ...and to know that each week you can come to a place where you can bring the person that you're looking after and anything goes, and I mean anything.*

CP06: *You can get things off your chest. You can be open. Because other people are in the same position as you it's fine, so it's like releasing something out of a drawer...*

Participants spoke of their need to have a safe environment, enabling them to share openly, and support one another.

Participants saw the benefit from attending the café as an opportunity to meet people in similar situations. This sense of shared experience, brought with it a feeling of being in a non-judgemental environment, where their feelings would be understood, and their views heard:

FCP05: *...that camaraderie and the amount of respect, the mutual support, the understanding, the empathy, it's massive, and when you're really, really struggling, to have that safety net of knowing that you can walk in there and people in that room truly understand and truly care is priceless.*

Participants perceived that they would be recognised as individuals and not judged by others. Personhood describes the interpersonal processes that occur in social settings, when the person themselves become invisible, and the focus becomes the dementia (Kitwood, 1997, p. 14). This

is described by one care partner, who had experienced her parent being labelled, and stigmatised, and consequently not treated as an individual, with personal needs:

*CP07: They don't see dementia here [SIDS café] they just see the person. And I think that is the most important thing, that you just see the person. And likewise, you don't see me as a carer, you see me as the person. So, I think that's important, because a lot of places you go to, you get tagged with that label, and then that's all people see, and they forget that there is a person...behind the diagnosis of dementia. Here, they get to know that person, and some places they don't.*

Recognising the individual and supporting their sense of self, personhood and identity was key to the positive perceptions of belonging that attending the café engendered.

### ***Perceptions of attending contributing to wellbeing and social health***

Participants reported that attending the café enhanced their feelings of wellbeing by promoting a sense of purpose that is key to social health. Using the working definition of personhood from Kitwood (1997) wellbeing is achieved when the psychological needs of inclusion, attachment, comfort, identity, and occupation are met. These are not mutually exclusive categories, as our participants demonstrate in their reports of the benefits to their wellbeing and social health of participating in the co-designed café:

*PLWD09: We've all got a common purpose to support each other. The staff are very, very supportive. If you were to walk in here not knowing anybody, you wouldn't know*

*who is a member of staff and who isn't, which I think is very, very important.... I mean, like it is, you know, everything that's happened, obviously it's designed for like people with dementia and the carers and that, it's been delivered in a non-patronising way, which is very important, you know.*

*CP06: And it doesn't matter who you are, or what, if you have a diagnosis or not, we're all the same, we're all the same, on a par with each other, and that's what you want.... In a way, because this group gives us the acceptance that we don't get in other groups. Where we are accepted.... But for [Partner living with dementia] to see, and although she doesn't say a lot, granted, but for her to see and be involved, and you can tell just by her expressions that she is happy to do it.*

Inclusion was perceived as belonging, being part of the group, and not feeling different, or disadvantaged because of the diagnosis of dementia. The observation that there was no differentiation made between anyone and being a participant on an equal footing was particularly valued in a world where having dementia often led to feelings of difference.

*PLWD09: Well, first of all, you're with like-minded people. The vast majority of people that I have met have been wonderful people. Without knowing, you don't know how much help you can be giving to other people, just by talking.*

Participants who were living with dementia, described that to feel strong and comfortable, they needed the warmth and support of the group.

PLWD08: *I like coming here because I can talk to people that I wouldn't be able to talk to because I don't know them or I'm busy or whatever... You feel as though you belong*

This also promoted their identity and sense of self:

PLWD08: *Yeah, you trigger my thoughts and we have a good giggle, and then it's all over. Unless somebody says, oh, remember so and so? Oh, yeah, I remember so and so*

PLWD09: *Without knowing, you don't know how much help you can be giving to other people, just by talking.... I mean, the thing is with dementia, it can make you feel isolated and, you know, alienated and disenfranchised from society. And it's a focal point where, you know, you do feel empowered.*

Identity was described by participants indirectly, in terms of the struggles they faced, because of their dementia. They described how the social interactions with others influence their sense of wellbeing and feeling of belonging.

FCP01: *Finding my way again, after losing [name of partner with dementia]*

PLWD10: *And I do miss the company of the people. I do like messing about (with art/craft). I used to be good at cartoons and things like that.*

Identity was described by participants as a way of finding oneself again, being supported to engage in activities that are enjoyed or simply sitting with friends and being able to share

laughter. They described how the social interactions with others influenced their sense of wellbeing and feeling of belonging.

*PLWD10: It makes me feel good wherever I go, because I hate sitting in watching telly... It gives me an incentive to get up and do something. And to meet people that I enjoy being in the company of... I'll have a go at anything... here we've done all sorts of things....I mean it wasn't easy at first. I mean I couldn't do it now, I've forgot how to do it, but I did it on the day and that was an achievement.*

Participant's spoke about the sense of purpose which they felt they derived from the occupation element of attending the café. They reflected upon how attending the group was a focal point within their week, motivating them to leave the house, something that they were very aware of when the second time period interviews took place, during a national lockdown when freedom of movement was curtailed and café attendance was not possible:

*PLWD09: So, you know, it's not only occupying your time but it gives you that sense of purpose, if you like.*

*CP08: And it's become, or up until now, it's been a real, something for us to focus on, it's been a landmark in the week for both of us. PLWD08: .... Uh-huh, but I can't do it alone.*

A sense of purpose achieved via the belonging (inclusion) to the group, and the occupation achieved through participating in activities at the café. Not only did the groups promote a sense of purpose but also a sense of value and retaining a connection with others and the wider world.

The ability to engage with others, or with an activity that demonstrated abilities, promoted a sense of achievement key to the perceived wellbeing benefits for participants.

### ***Peer Support and understanding***

Participants with dementia likened the support they encountered by attending the café as being like a family; this reflects the shared experience and understanding of peer support. Attendance at the group allowed them to share experiences, giving them strength in coping with day-to-day life:

*PLWD09: Shared experience, that's the phrase I'm looking for... Peer support.*

The support and understanding by and from other care partners also led to increased perceptions of ability to cope:

*FCP05: It is peer support, that is what the café is all about, it's about that we all have different journeys, ... but when you get people together, the consensus, the empathy, the level of support, is priceless, and it can make a massive difference.*

*CP07: I like it because of the camaraderie, the peer support, the fact that people are going through exactly what you're going through or have been through it, and also for the fact that you're not judged.*

Peer support gained from attending the café was an important aspect of being a member of this group. Participants spoke about the value of sharing experiences and being understood by people with similar experiences. This shared experience was important to all participants and reflected the support they received from one another that they saw as vital to their individual wellbeing. Peer support was closely linked to friendships formed.

### ***Friendship***

Friendships developed unexpectedly for café attendees. This often began with enjoying sessions together. Participants spoke about the ‘banter’ and interactions within the groups. Participants emphasised that being with other people in a regular group created stimulating conversations that led to strong friendships. These friendships became central to participants’ attendance at the group and was reported as something very valuable impacting positively on other areas of their lives. However, it was acknowledged that friendship was built up over time and was perhaps an unexpected benefit from attending the group. When looking back, many participants had encountered isolation whilst looking after someone who was living with dementia. The group interactions and subsequent friendships they developed were therefore held in high esteem, enabling them to form attachments and connections which extended into their lives outside of the café:

*PLWD09: But I daresay that you don't think about, you know, the strong friendships that are going to be established and the camaraderie.*

*CP07: ...I think if I hadn't have come here, then I wouldn't have had that because the friendships are very strong, and I think that's what you find. So, you still have that*



*connection, or you'll still see people socially after that, because those are the friendships that started from here that carry on... we call them our dementia family.*

One participant spoke about the impact that the unique friendships formed from groups such as SIDS café, had made to her, by recounting the words of another group member:

*FCP05: She turned to me and she said, I truly don't know how I could have got through this without my friends [here], because I can say things to you that I can't say to my children, that I can't say to my friends,*

Whilst talking was an enjoyable part of the session, conversations continued beyond the session, and acted as a catalyst for interactions and discussions after the café finished. The benefit to the relationship for the dyad was evident too as this excerpt from a husband and wife demonstrates:

*CP08: [Directing the question towards her husband] you look forward to it and you'll talk about it afterwards. It keeps your mood up.*

*PLWD08: I'll talk when I'm going home, yeah, but after that it's all gone, the shutters have come down... Yeah, you trigger my thoughts and we have a good giggle, and then it's all over*

*CP08: It's about stimulating rather than saying do you remember so and so, this is something we thought you might be interested in... offering you something that might be the trigger... bringing something to mind that you've not thought of for a long time.*

*And I think that's wonderful, because we can't do that at home and we do the same old, same old.*

Participant's wellbeing and social health was positively impacted by attending groups that went on to improve their lives after the groups had ended and when they returned home. Participants spoke of the difficulties of dealing with the diagnosis of dementia, and the subsequent support they encountered when they attended the café. Having the acceptance via peer support and friendship of others appeared to be crucial to participants perceived wellbeing and sense of belonging. All participants highlighted this need for acceptance, of belonging, and how it motivated them to attend the café. Friendships and peer support were vital to the perceived benefit of attending the café. Participants spoke about not expecting to make such strong connections, and how these had built up overtime. Friendship contributed to feelings of inclusion, belonging and attachment and as such the friendships forged by participation in the café can be clearly seen as part of maintaining personhood and wellbeing (Kitwood, 1997) and social health (de Vugt and Dröes, 2017).

### ***A sense of belonging***

A sense of belonging stemmed from the shared understanding of having first-hand experience of living with dementia and the perceived atmosphere of the café. The experiences of SIDS café presented above reflects the camaraderie and non-judgemental environment they experienced:

CP07: *You feel as though you belong here. Enjoyment and feeling positive was a way of describing how the café made participants feel, about being together and laughing together*

CP06: *But she [person living with dementia] does like the café, yeah. And you can always tell, because if she doesn't want to go she will let me know. You know. It is actually a pity you couldn't capture the smile there actually, because that would answer your question (PLWD 06 smiles broadly)*

Through participation at SIDS café relational and self-identity was maintained. The café served as place to learn from others' experiences with practical tips and emotional support key benefits for both those with the diagnosis and those providing support. In this way attending the café brought social health benefits to both the person living with dementia and their care partners.

## **Discussion**

Our study adds to the growing knowledge base about the potential of belonging to a group to combat loneliness (Tsekleves et al, 2020) and create social reserve that can be associated with social health that enables attendees to have the capacity to better manage the challenges associated with dementia (Teahan et al, 2020). As with other research our findings suggest that belonging to a group like SIDS café can foster peer support, social inclusion and belonging (Lee et al, 2020, Akhtar et al, 2017, Dupuis et al 2012). The importance of peer support and acceptance was a central finding and was interwoven with other perceived experiences such as safety, inclusion and friendship. This reflects evidence that suggests that the opportunity to socialise with others experiencing life in similar ways can reduce social isolation and lead to

informal peer support networks (Dow et al., 2011, Takechi et al, 2019). Study findings support the importance of adopting person-centred approaches in dementia support groups and dementia cafes. SIDS café promotes the ethos of personhood for those living with dementia, where positive relationships were developed and feelings of being valued and empowered were fostered (Alsawy et al, 2020). Participant's narratives demonstrate the importance placed on belonging to the group which gave them the opportunity to positively reflect on their own experiences and laugh with other members, regardless of whether they had a diagnosis of dementia or not, and to maintain their social health. Participants who were living with dementia benefitted from feeling that they were accepted and not judged by others attending SIDS Café.

Within our study, the importance of engaging alongside others in activities that were personally relevant, enjoyable and meaningful, clearly linked with a sense of identity and perceived wellbeing. Our findings demonstrate how participants experienced the co-designed café as a welcoming and safe place promoting wellbeing and social health. Kitwood's notion of personhood was evidenced through participant self-reports of the strong sense of belonging membership of the café engendered, reflecting attachment to the group defined as 'a kind of safety net when the world is full of uncertainty', (Kitwood, 1997, p. 19) supporting the ability to function and maintain identity. Café participation was experienced as a safe and welcoming space where everyone was included, and thus providing what Kitwood termed comfort, 'enabling a person to remain in one piece when they are in danger of falling apart' (1997, p. 19).

The co-designed café supported the personhood of participants, through their ownership of the café at the outset through the co-design process, and also by delivering sessions with staff enabling them to showcase their hobbies and skills. Participating in the café thus helped

participants retain their sense of identity, defined as ‘involves maintaining a sense of continuity with the past, and some kind of consistency in the present life’ (Kitwood, 1997, p. 20). Our findings strongly evidence Kitwood’s (1997) belief in the benefits of maintaining personhood, and we argue that this is closely aligned to preserving social health.

Teahan et al (2020) argue that community engagement activities have the potential to reduce stigma as community members see people living with dementia and their care partners engaging in usual ways. This study supports the need for increased allocation of funding for development of low-cost interventions, such as dementia cafés, to be made accessible to community dwelling individuals living with dementia and care partners wherever they live (Lee et al, 2020). This is important as the issues raised in this study reflect reports in the literature, of how care-partners can experience anxiety and depression (Mahoney et al, 2005), loneliness (Victor et al, 2020) that can in turn affect their ability to provide care (Holst and Edberg, 2011). Dementia support groups and dementia cafés can provide coping strategies and enjoyable/occupying activities, and also offer the social support often associated with subjective wellbeing (Safavi et al, 2017) and social health (Vernooj-Dassen et al, 2018, de Vugt and Dröes, 2017). In addition, partnership working when creating groups also brings benefits of empowerment through the enactment of social citizenship (Dupuis et al, 2012). These issues were clearly represented within this study; with both care partners and people living with dementia describing gaining ways of coping better in their everyday lives and no longer feeling disenfranchised, this was achieved via experiencing peer support and participating in enjoyable activities that promoted personhood and social health.

## **Limitations**

Participants were self-selecting, and as such the generalisability of the findings beyond the sample in this study is limited. It should also be acknowledged that the positive findings reported above, arrived at via the self-reported views of participants on the impact on wellbeing and social health could be influenced by participating in a café participants had a strong sense of ‘ownership’ (due to their involvement in the design of the café). In addition, as participants were known to the authors they could have felt the need to respond in a particular way. To mitigate this risk the authors primarily involved in data collection (2,3 and 4) were different to those involved in co-designing the café with participants (authors 1 and 5). A future study could compare the benefits of new members to a dementia café and members who co-designed the café they attended.

## **Conclusion**

Cafés provide the opportunity to help address increasing loneliness and social isolation that people living with dementia and their care partners commonly face. Community based initiatives that provide opportunities for peer support for the person with the diagnosis and the care partner are essential, so people living with dementia may rebuild their social confidence as well as retain opportunities to socialise. For care partners, the importance of peer support is a way of achieving reciprocal interactions with people experiencing life in similar ways. Opportunities to interact and participate with people experiencing life in similar ways, should be an essential part of everyday life to enhance participation, communication and mood. Creating these opportunities is important, as demonstrated in our findings where, for our participants it led to engagement and belonging, enhanced perhaps by their involvement in the design of the café contributing to ownership of the group.

## References

Akhtar, F., Greenwood, N., Smith, R., & Richardson, A. (2017). Dementia cafés: recommendations from interviews with informal carers. *Working with Older People*, 21(4), 236–242. doi.org/10.1108/WWOP-07-2017-0018

Alsawy, S., Tai, S., McEvoy, P., & Mansell, W. (2020). ‘It’s nice to think somebody’s listening to me instead of saying “oh shut up”’. People with dementia reflect on what makes communication good and meaningful. *Journal of Psychiatric and Mental Health Nursing*, 27(2), 151-161. doi.org/10.1111/jpm.12559

Alzheimer’s Society. (2013). *Dementia 2013: the hidden voice of loneliness*. Retrieved from: [http://www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=1056](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1056)

Bazeley, P. (2007). *Qualitative data analysis with NVivo*. London, 6-15.

Braun, V. & Clarke, V. (2006). Qualitative Research in Psychology Using thematic analysis in psychology Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. DOI: 10.1191/1478088706qp063oa

Capus, J. (2005) The Kingston Dementia Café: The benefits of establishing an Alzheimer café for carers and people with dementia. *Dementia*, 4(4), 588–591. doi:10.1177/1471301205059240

de Vugt, M. & Dröes, R. (2017). Social health in dementia. Towards a positive dementia discourse. *Ageing and Mental Health*, 21(1), 1–3. DOI: 10.1080/13607863.2016.1262822

Dupuis, S.L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L., and Sadler, L. (2012). Moving beyond patient and client approaches: Mobilizing ‘authentic partnerships’ in dementia care, support and services. *Dementia*. 11(4), 427-452. doi:10.1177/1471301211421063

Fukui, C., Fujisaki-Sueda-Sakai, M., Yokouchi, N., Sumikawa, Y., Horinuki, F., Baba, A., Suto, M., Okada, H., Ogino, R., Park, H. & Okata, J. (2019). Needs of persons with dementia and their family caregivers in dementia cafés. *Aging Clinical and Experimental Research*, 31(12), 1807–1816. doi: 10.1007/s40520-019-01129-2

Greenwood, N., Smith, R., Akhtar, F. & Richardson, A. (2017). A qualitative study of carers’ experiences of dementia cafés: a place to feel supported and be yourself. *BMC Geriatrics*, 17(1), 164. doi: 10.1186/s12877-017-0559-4.



Holst, G., & Edberg, A. K. (2011). Wellbeing among people with dementia and their next of kin over a period of 3 years. *Scandinavian Journal of Caring Sciences*, 25(3), 549–557. DOI: 10.1111/j.1471-6712.2010.00863.x

Innes, A., Szymczynska, P. & Stark, C. (2014). Dementia diagnosis and post-diagnostic support in Scottish rural communities: Experiences of people with dementia and their families. *Dementia*, 13(2), 233–247. doi.org/10.1177/1471301212460608

Kitwood, T. (1997) *Dementia Reconsidered: The person comes first*. Buckingham: Open University Press

Lee, S., O'Neill, D. & Moss, H. (2020). Promoting well-being among people with early-stage dementia and their family carers through community-based group singing: a phenomenological study, *Arts & Health*, DOI: 10.1080/17533015.2020.1839776

Mahoney, R., Regan, C., Katona, C., & Livingston, G. (2005). Anxiety and depression in family caregivers of people with Alzheimer's Disease: the LASER- AD study. *The American Journal of Geriatric Psychiatry*, 13(9), 795–801. doi: 10.1176/appi.ajgp.13.9.795

Merlo, P., Devita, M., Mandelli, A., Rusconi, M.L., Taddeucci, R., Terzi, A., Arosio, G., Bellati, M., Gavazzeni, M. & Mondini, S. (2018). Alzheimer Café: an approach focused on

Alzheimer's patients but with remarkable values on the quality of life of their caregivers. *Aging Clinical and Experimental Research*. 30(7), 767–774. doi: 10.1007/s40520-017-0844- 2.

Miesen, B.L., & Jones, G.M.M. (2004). The Alzheimer café concept: A response to the trauma, drama and tragedy of dementia. In G.M.M. Jones & B.L. Miesen (Eds.), *Caregiving in dementia: Research and applications* (Vol. 3; pp. 307–333). Hove: Brunner Routledge .

Nay, R., Bauer, M., Fetherstonhaugh, D., Moyle, W., Tarzia, L. & McAuliffe, L. (2015). Social participation and family carers of people living with dementia in Australia. *Health and Social Care in the Community*, 23(5), 550–558. doi: 10.1111/hsc.12163.

Safavi, R., Berry, K., and Wearden, A. (2017). Expressed Emotion in relatives of persons with dementia: a systematic review and meta-analysis. *Aging & Mental Health*, 21(2), 113– 124. doi: 10.1080/13607863.2015.1111863

Takechi, H., Yabuki, T., Takahashi, M., Osada, H. & Kato, S. (2019). Dementia Cafés as a Community Resource for Persons With Early-Stage Cognitive Disorders: A Nationwide Survey in Japan. *Journal of American Medical Directors Association*. 20(12), 1515–1520. Doi.org/10.1016/j.jamda.2019.04.017

Teahan, Á., Fitzgerald, C. & O'Shea, E. (2020). Family carers' perspectives of the Alzheimer Café in Ireland [version 2; peer review: 4 approved]. *HRB Open Research*, 3(18) doi.org/10.12688/hrbopenres.13040.2

Teahan, Á., Lafferty, A. , McAuliffe, E. , Phelan, A. , O'Sullivan, L. , O'Shea, E., Nicholson, E., & Fealy, G. (2020). Psychosocial interventions for family carers of PLWD: A systematic review and meta-analysis. *Journal of Aging and Health*, 1–16. doi.org/10.1177/0898264319899793

Tong, A., Sainsbury, P. and Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. /doi.org/10.1093/intqhc/mzm042

Tsekleves, E., Bingley, A. F., Luján Escalante, M. A., & Gradinar, A. (2020). Engaging people with dementia in designing playful and creative practices: Co-design or co-creation? *Dementia*, 19(3), 915–931. doi.org/10.1177/1471301218791692

Vernooij-Dassen, M., Moniz-Cook, E., & Jeon, Y. (2018). Social health in dementia care: harnessing an applied research agenda. *International Psychogeriatrics*, 30(6), 775–778. doi.org/10.1017/S1041610217002769.

Victor, C. R. , Rippon, I. , Quinn, C. , Nelis, S. M. , Martyr, A. , Hart, N. , Lamont, R. , & Clare, L. (2020). The prevalence and predictors of loneliness in caregivers of people with dementia: Findings from the IDEAL programme. *Aging & Mental Health*, 1–7. <https://doi.org/10.1080/13607863.2020.1753014>

Wiersma, E. and Denton, A. (2016). From social network to safety net: dementia-friendly communities in rural northern Ontario. *Dementia*, 15(1), 51–68. doi: 10.1177/1471301213516118

**Table 1: Braun and Clarke’s (2006) six-phase approach to thematic analysis; including detail of how this was implemented and by whom.**

Phases	Application of the phases within this study
1. Becoming familiar with the data	<i>Authors 2, 3, 4.</i> conducted the interviews. Transcripts were repeatedly read.
2. Generating initial codes	<i>Authors 2, 3, 4</i> coded the data in a systematic fashion across the entire dataset. All interview data that related to the SIDS were coded.
3. Searching for themes	All significant patterns in the data were noted and initial table of second-order codes and quotes created. Throughout this and subsequent stages, findings were reviewed for coherence and credibility by <i>Author1</i> and the raw data were regularly referred to by authors 2, 3, 4.

4. Reviewing themes From the initial table of significant second-order codes and discussions with authors 1, 2, 3, 4, candidate themes were identified. These were then refined by repeatedly referring back to data and codes, and by creating a detailed thematic map. Candidate themes were examined to establish whether they were coherent, externally heterogeneous, and had explanatory power.
5. Defining and naming themes Through further discussions a more parsimonious list of themes were created. These were refined through peer debriefing and verification.
6. Producing the paper The paper was drafted and feedback obtained from all authors.
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