

RESEARCH ARTICLE

More than memory: A qualitative analysis of carer-reported psychosocial benefits of Memory Cafés

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Abstract

Issue addressed: Memory Cafés are a psychosocial intervention that aims to provide socialisation and interpersonal support for those living with dementia and their carers. This study explores the Memory Café model and determines the impact of the peer-to-peer Memory Café model on the psychosocial well-being of those living with dementia and their carers.

Methods: Participants were informal carers of those living with dementia, recruited from four Memory Cafés located in metropolitan Perth, Western Australia. Demographic information was collected from participants. Eleven semi-structured interviews were conducted. The data were transcribed and analysed thematically.

Results: The benefits of participation are described under four themes; sharing experiences and reduction of stigma, a place to feel joy and be yourself, a time to socialise and build friendships and improvements in life outside the Memory Café. The positive attributes of the Memory Cafés that contributed to the benefits were also identified. Concerns about Memory Cafés were limited to it becoming a carers-only group.

Conclusions: Memory Cafés contribute significantly to the psychosocial well-being of carers of those living with dementia and provide a positive outlet for carers to build social networks and become active in their community. The effect on the psychosocial well-being of those living with dementia may be more limited but is still described positively.

So what?: Dementia is a condition with significant impacts on carers and families. Successful peer-based social interventions such as Memory Cafés can lead to further development of dementia-friendly communities aimed at providing joy as well as support.

KEYWORDS

Alzheimer's, dementia, evaluation, Memory Café, psychosocial, qualitative

1 | INTRODUCTION

In Australia, it is estimated over 400 000 people are living with dementia.¹ Most live in the community (83% of males, 73% of females) with approximately 46% of those receiving informal care only.² Informal carers of those living with dementia are often family members such as spouses or children, with little or no medical

training or support.² Increasingly, they become responsible for daily care, managing medical appointments and making important financial decisions for the person living with dementia.³ Informal carers frequently give up their paid work or are retired, increasing financial and social pressure.⁴ The dominant discourse is that carers of those living with dementia experience a reduced quality of life and poorer health outcomes than their non-carer counterparts.⁵

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Receiving a diagnosis of dementia, as well as becoming an informal carer, has a significant impact on psychosocial well-being.^{4,6} Psychosocial well-being is defined as the ability and capacity to function socially to receive the psychological benefits of interaction.⁷ Interventions have been developed to address the psychosocial impact of dementia.^{7,8} Interventions include support groups, psycho-education sessions and therapeutic groups.⁹ One such intervention that has gained popularity is Memory Cafés.¹⁰

Memory Cafés provide a social gathering for those living with dementia and their carers at a local café in a supportive environment.¹⁰ Initially developed in the Netherlands in 1997, Memory Cafés aimed to provide a venue for open conversations about dementia to occur, with the intent of reducing social isolation.¹¹ Enthusiasm for Memory Cafés spread globally, and two models began to emerge: formal and informal.¹¹ For example, Memory Cafés in the United States are usually considered formal sessions with planned education and activities.¹¹ Whilst those in Europe and the United Kingdom tend to be informal social gatherings with an occasional activity.¹²

Although Memory Cafés have been operating in Australia since 2002, there has been limited research undertaken in this context with only one qualitative study and one case study identified.^{13,14} The qualitative study was conducted in Victoria. It found that overall, these cafes supported social inclusion, but did not meet the needs of all those who attended.¹³ International qualitative studies, although limited, have shown that Memory Cafés provide a sense of normalcy, social support and consistency to both carers and those living with dementia in carer-reported studies.^{4,10} It is important to expand this research to better understand the impact of Memory Cafés on the psychosocial well-being of those living with dementia and their carers.

Memory Cafés in the Perth Metropolitan Area of Western Australia are mostly run by community members and listed on the Alzheimer's WA website. Alzheimer's WA is an organisation that works with those living with dementia, and their families, to provide education, care and advocacy.¹⁸ Whilst Alzheimer's WA maintains a regular presence at Memory Cafés to facilitate support if needed, they are often organised by carers, sometimes in conjunction with the local council, and have a greater focus on peer-to-peer support. Heisler¹⁵ describes peer-to-peer support as "support from a person who has experiential knowledge of specific behaviours or stressors and similar characteristics as the target population." p. 215. Memory Cafés in Western Australia run informally without an eligibility assessment or fee beyond the cost of refreshments. This makes them more easily accessible without the barriers that formal services may have. Investigating the benefits of Memory Cafés in Perth will provide novel insights into the peer-to-peer model and how it contributes to aspects of psychosocial well-being of attendees, such as the capacity to socialise or gain connection through shared experience.

2 | METHODS

2.1 | Study design

This qualitative study collected data from semi-structured interviews with carers of those living with dementia attending Memory Cafés. The methodology took an interpretive phenomenological

approach to interpret, describe and understand the experiences of the participants through thematic analysis.¹⁶ The consolidated criteria for reporting qualitative research (COREQ) checklist guided the reporting of the findings.¹⁷ The COREQ consists of three domains to be reported in qualitative studies; research team and reflexivity, study design and analysis and findings.¹⁷ A proposal was submitted and accepted by the Human Research Ethics Committee (HREC) at Curtin University (Number 2019-0324). A semi-structured interview schedule was developed by the researchers and assessed by experts from Alzheimer's WA for content validity and trialled for clarity and comprehension (Appendix S1). The schedule contained six general topics: living with dementia, introduction to the café, café environment, carer benefits and benefits for the person living with dementia. Prompts for topics focused on both the well-being of the carer and the person living with dementia.

2.2 | Population and sample recruitment

A list of Memory Cafés located in the Perth Metropolitan area was identified through Alzheimer's WA¹⁸ and four were selected as identified based on the recommendation of Alzheimer's WA as to which cafés were best attended. The managers of the cafés were contacted by telephone to introduce the researcher, establish the time and date the Memory Cafés were held and briefly introduce the research concept. An email was sent to the café managers with an information sheet explaining the research objectives and processes.

The researcher attended the café with an Alzheimer's WA staff member who facilitated introductions to the carers and explained the research. Each Memory Café had 20-25 attendees. Carers who expressed interest in being involved with the research were provided with the information sheet which explained the research objectives and that all information would remain confidential, and that they could withdraw at any time, prior to providing consent. Any carer attending the Memory Café was eligible to participate. Around the same number of participants was recruited from each café.

2.3 | Data collection

One researcher arranged and conducted the carer interviews, which were held in a public location chosen by the carer, such as a library. Prior to the commencement of the interviews, written consent and permission to record the interview were obtained. Demographic information was collected from participants including their age, time as a carer, education level and previous occupation. Similar information was collected about the person living with dementia. These demographic characteristics were taken with the purpose of creating a context of who participants were and to note any relevant patterns of who was represented amongst the participants. The interview schedule was used as a guide to explore the impact of Memory Cafés for the carer and the person living with dementia. At the end

of the interview, participants were free to make any additional comments. The duration of the interviews ranged from 25 to 50 minutes.

2.4 | Data analysis

The interviews were anonymised and transcribed within two weeks of being conducted by three final-year health promotion students at XXXXXX University, supervised by the researchers. Thematic analysis followed Braun & Clark's¹⁹ six steps for thematic analysis. Familiarisation of the data involved reading through the transcripts and highlighting meaningful quotes. These quotes formed initial codes such as "laughter" or "friendship." The program NVivo was used to categorise these codes into potential themes. Quotes taken from the transcriptions were allocated to themes and were further collated until four distinct themes emerged.

Data in each theme were checked to ensure repetition did not occur.⁴ After defining each theme, the researcher identified positive aspects of Memory Cafés, and any reported concerns. The initial coding and thematic analysis were completed by one researcher, with the final themes reviewed for consensus by the research team. After the 11th interview, data saturation was reached with no new codes emerging.²⁰

3 | FINDINGS

3.1 | Demographic characteristics of participants

In total, 11 carers were interviewed, all were family members and only one participant had any formal aged care training. The ages of carers ranged from 54 to 86 years and all spoke English as a first language (Table 1). Although those living with dementia were not interviewed, carers provided their demographic characteristics. The ages of those living with dementia ranged from 61 to 91 (Table 1).

3.2 | Living with dementia

It is important to illustrate the context of living with dementia and the impact the diagnosis has on carers lives to better understand the role of the Memory Cafés.⁴ The diagnosis was consistently described as a lengthy and emotionally exhausting process for both the carer and the person living with dementia.

P10 "... Well, I suppose my attitude would have been that this won't be too difficult. That's probably how I felt for a start. And as time was going on, and as the disease progressed... it has become... to a point which... is extremely stressful. Can be extremely traumatic..."

Further difficulties were identified surrounding the general loss of independence for the person living with dementia. A

TABLE 1 Demographic characteristics

| | |
|---|---|
| Carers (n = 11) | |
| Mean age (years) | 71.1 ($\sigma = 8.29$) |
| % Female | 63.64% |
| Mean time as carer (years) | 2.99 |
| Range of time as carer (years) | 1.5-6 |
| Relationship to person living with dementia | Spouse = 8 Sibling = 2 Son-in-law = 1 |
| Highest education level | Tertiary = 4 Technical and further education (TAFE)/college = 4 High school = 3 |
| Persons living with dementia (n = 10) | |
| Mean age (years) | 75.9 ($\sigma = 10.10$) |
| % Female | 50% |
| Mean time since diagnosis (years) | 3.35 |
| Range of time since diagnosis (years) | 1.5-6 |
| Highest education level | Tertiary = 3 Technical and further education (TAFE)/college = 1 High school = 4 Primary school = 2 |

Note: Characteristics of carers and persons living with dementia taken prior to interview.

common occurrence was the distress experienced when the person lost their drivers licence. This distress associated with driving cessation in the context of a dementia diagnosis is well supported in the literature.²¹ Not only does it have a negative psychosocial impact on the person living with dementia, but it can also affect carers as described by Chacko et al.²¹ Their qualitative research found that whilst carers were negatively impacted by driving cessation, those living with dementia tended to not recognise this impact.²¹

P10 "... I had to hand it in, yeah. And that was a real war that went on for a while. And I wanted her to, I mean... I was much more lenient with her... But the kids would have had her license off a lot sooner than what I did."

A significant impact on socialisation was described by carers after the dementia diagnosis. Isolation was a common issue, as well as the loss of friendships.

P4 "We travelled a lot and then gradually he became more dependent on me. Stop doing, stop being, well, stop being able to go out. He had to give up golf, he

had to give up the rugby club, had to give up going to the bowling club and lots of things.”

The stress on carers was also found in a qualitative study on the significance of Memory Cafés to participants.¹² A strong theme identified was that of social isolation and loss of family networks.¹²

3.3 | Identified themes

Four main themes were identified from interview data: sharing experiences and reduction of stigma; a place to feel joy and be yourself; a time to socialise and build friendships; improvements in life outside the Memory Café.

3.3.1 | Theme 1: Sharing experiences and reduction of stigma

The theme of shared experience and sharing strategies to manage the dementia diagnosis was strongly represented in the data. Feelings of isolation were common amongst carers, with the Memory Café experience making them feel as if they were not alone. Carers described the value of discussing future care planning with other carers whose spouses are at a more advanced stage of dementia.

P2 “...comparing notes with the other carers... It’s nice to chat and have that common bond I suppose... you feel you’re not the only one. You know, you can share your story.”

P7 “I see other people who are a bit more advanced than [partner], I can observe how their carer helps them... And that gives me a kind of a heads up...”

The benefit of this peer support is consistent with the findings in Greenwood et al.⁴ They found that Memory Cafés allowed carers to share with others experiencing the same situation, and the positive impact reported by carers.⁴

Those interviewed discussed carers whose partner had passed away or moved to residential care who had continued to attend Memory Cafés. This was controversial for carers as some believed it reduced the image of Memory Cafés as only for carers and further excluded those living with dementia. However, others felt it enhanced the sharing of experiences and the realities of being a carer.

P4 “With the Memory Café, you can talk to other people... whose spouses are either in care or they’ve died, and you can learn more from them than you can from lots of other places.”

Some carers described how the café enabled the person with dementia to share their experiences. This was also the case in the study conducted by Greenwood et al.⁴

P7 “She likes to talk to people...”

Many of the carers reported that they did not have much personal stigma towards dementia before their partner’s diagnosis, as they had other family and friends living with dementia. However, they did indicate that attending the Memory Café had enabled them to consider the language they used around the dementia diagnosis. This contributed to an environment where people who were living with dementia could share experiences without judgement.

P10 “I don’t like using the word [dementia]... and it’s always been a bit of a slur to say... I don’t know about him; he’s got dementia and there’s nothing wrong with the person they’re talking about.”

P3 “I think it sometimes gives people a better perspective because when they hear dementia, they think locked wards and incontinence and all the nasty stuff that comes to them at the end. But they don’t think about the person.”

The normalisation of dementia and the new understanding of the importance of language contributed to the Memory Café being a welcoming environment for people living with dementia.

3.3.2 | Theme 2: A place to feel joy and be yourself

Many participants expressed a feeling of joyfulness and the ability for both the carer and person living with dementia to be themselves at the Memory Café. It also provided a space for those caring for their spouses to attend as husband and wife, as opposed to the carer/person living with dementia dynamic.

P4 “It’s [Memory Café] something to look forward to that we can do together. It’s like choir, it’s something we can do together and be comfortable.”

When asked in interviews what words came to mind when thinking about the Memory Café, the majority of participants listed variations of happiness, enjoyment, laughter, familiarity, relaxation and friendliness. Participants described the Memory Café as something to look forward to.

P1 “... when you get up in the morning, you’re not thinking oh, no, what’s going on here? What stage are we at? What’s gonna happen today? It’s... let’s go and have some fun. Let’s go and have coffee and cake somewhere and meet other people who want to do the same.”

Participants also reported the joy experienced by newcomers whom they had encouraged to attend the Memory Café. The atmosphere of the Memory Café's created a place to laugh and lessen the stress created by the dementia diagnosis.

P1 "And as she left, she took my arm and said, 'this was the first time I've laughed since being diagnosed and I'm definitely coming back.' And they come every month now. And that makes you realise that... it's working."

Although some participants reported a neutral response from the person living with dementia, others reported very positive effects. Participants also reported a sense of familiarity experienced by those living with dementia in attending the Memory Café, even if they did not remember going.

P1 "He's always happy and if he wasn't happy then maybe then I wouldn't be either. But he enjoys, he loves the interaction. And I mean, he won't always say anything... He's enjoying himself and he's in his happy place which is brilliant."

The benefits of happiness are underexplored in people living with dementia. However, from the responses of the carers in this study and others exploring Memory Cafés, positive benefits are identified.^{4,11}

3.3.3 | Theme 3: A time to socialise and build friendships

The Memory Café is a place to build friendships and a support network. It was described as a place to practice social interaction, which participants felt was important for both themselves and the person living with dementia. Social support ranged from familiarity with acquaintances to very close friendships.

P10 "...familiarity is one. In other words, you know, you're waving to the people up the end that are pleased you've turned up..."

Participants rated their friendships with one another as extremely important and stressed the importance of social connection as a carer of a spouse living with dementia.

P5 "[We] have created a very nice friendship. We've gone away together, we put our husband's into respite. And the three of us go away. Because otherwise you cry. And you weep and you sob because it's a hideous, hideous, hideous condition. It is rather than sob and cry we three laughed and screeched."

Participants described the Memory Café atmosphere itself as welcoming, which fostered a safe environment for social interaction. The

informal process of the Memory Café's was important for facilitating the conversation. It allowed carers to socialise in a way that made them personally comfortable.

P5 "...I create more friendships. I'm a very social outgoing person."

The Memory Cafés helped to create a sense of community and a place to belong in a positive way. Instead of focusing on the negative aspects of the dementia diagnosis, it created a social bond between individuals based on a shared experience and positivity. This finding is in keeping with the research conducted in Victoria, in that Memory Cafés are a space for social inclusion and prevent isolation.¹³

P8 "It was just the fact that there was nobody who said, right, this is what you do, your name badge is here... there was none of that. And I loved the informality of it."

Whilst the benefits for carers in terms of social networking was evident, this was not necessarily the same for those living with dementia. No negative effects on the person living with dementia were reported, but often their ability to socialise was described as very limited. This meant that the opportunity to socialise at Memory Cafés did not provide the benefits to them that were so apparent for carers.

P6 "...but [he] barely speaks, he can but he chooses not to. One-word answers. Sometimes he just plain ignores you."

3.3.4 | Theme 4: Improvements in life outside of the Memory Café

Whilst those living with dementia had a reduced capacity to create long-term friendships, short-term benefits were reported by carers.

P10 "...if that [Memory Café] wasn't there, then, then my wife would probably be... A bit more anxious, yeah. Or nervous or shy. And she's not. She tends to be quite relaxed when she's there and she laughs and jokes and so on with other people."

This led to a discussion about more subtle changes observed by carers in the overall mood of the person living with dementia. This included their participation in their care and general interest in the world around them.

P7 "I noticed for the rest of the day, that she's just that little bit more elevated. She's a little bit more interested in other things."

Benefits are more easily identified by those who know the person living with dementia well, as it does not require verbal communication. Some carers were very clear on the mood improvements outside of the Memory Café as well as the happiness experienced in anticipation of going out somewhere together.

P4 "...my husband enjoys it and when we leave, I say, 'did you enjoy that?' and he says 'yes' even though he might not have engaged in conversation."

Other participants were unsure of any long-term effects for those living with dementia in relation to Memory Cafés. They viewed the Memory Café as mostly having benefits for the carer with no positive or negative effects for their spouse.

P5 "It's quite nice for me. And for [spouse] is no benefit. Going or not going. It's immaterial."

3.4 | Memory Café structure

Carers identified practical characteristics of the Memory Café that supported the positive experience detailed in the four themes.

3.4.1 | Discovery

Carers often found Memory Cafés by searching the Alzheimer's WA website whilst looking for resources and social activities. Other carers found Memory Cafés through other Alzheimer's WA resources such as pamphlets or newsletters. Other discovery methods included word of mouth and media reports.

P3 "I think I looked online at the Alzheimer's Association [Alzheimer's WA], that's the first thing I went to. And found there's all sorts of information."

P7 "That came about by the newsletter we get a e-newsletter from being members of Alzheimer's WA."

The next most frequently reported method of discovery was through a prior support group that some participants had been members of before attending Memory Cafés.

P6 "We started looking for cafés... one of the men said well I'm not leaving here until we organize to get together because we're all good friends."

3.4.2 | Facilities

Due to those living with dementia and their carers occasionally having physical mobility issues, all participants emphasised the

importance of accessibility when attending Memory Cafés. All four cafés had appropriate bathroom facilities and parking.

P4 "You've got to know where disabled toilets are and you go to lots of places... we went to a hotel for breakfast, for someone's birthday... They had disabled toilets within the male and the female but... not the one where the carer could go."

3.4.3 | Café services

The cafés and staff that were responsible for hosting the Memory Cafés were described by participants as very important for supporting the positive atmosphere of Memory Cafés. All carers spoke highly of the cafés at their location as well as the staff.

P10 "Very well mannered, and we couldn't be looked after better as far as I'm concerned."

One of the cafés agreeing to host a Memory Café made the choice to open half an hour earlier than their normal time to create a pleasant atmosphere for those attending and provide table service for attendees. Another location provided a special price deal on coffee.

P4 "...by providing a, a venue that's not open to the public, that they open especially for us. Normally I think its eleven o'clock."

P7 "They've set up a long table for us. They're quite happy for us to grab other tables and extended... Yeah, the more people turn up and just make it longer and them quite happy to do that. They've been very cooperative... And you can order your coffee. And a nibble if you wanted. And then you pay for it later. You don't have to pay up front."

3.4.4 | Informality

Participants described the informality in a positive light, as they felt it allowed them to socialise comfortably without interruption.

P8 "...it's a very unstructured, I would almost say ad hoc kind of process... there's nothing structured about it. There's no kind of speech making or anything, it's just you engage with the person next to you or you can get up and so... I was taken by how informal it was."

Whilst participants expressed enjoyment of the occasional speech or announcement, overall the response was of informality adding to the enjoyment of Memory Cafés.

P5 "I just know occasionally I've been to the [location] Memory Café. And very occasionally... they may have a guest speaker for maybe five minutes of their time. And some of them really enjoy just having someone it's usually someone from [location] City Council because they're very dementia friendly community."

3.5 | Memory Café concerns

One concern was that the Memory Cafés would evolve into a carers support group. Whilst some participants saw carer-only attendance as a positive for those whose partners had passed away or gone into residential care, others were concerned about these minimising opportunities for people living with dementia to socialise.

P1 "...you've got to influence new people to keep coming, keep getting new people coming in. Let us all join in so those carers should be able to share their experiences with other carers and their spouses... Rather than it just becoming a closed carers group."

Participants did not want to make those who came only as carers feel excluded or ask them to leave, particularly in the event of a spouse passing away. However, they did feel that Memory Cafés should not evolve only into a group for carers or past carers.

P1 "...but you don't oust people. That was the one problem with the actual carers group... Is that once their person that they were caring for goes into permanent care, they can't come any longer."

Other concerns were the noise involved in hosting Memory Cafés in shopping centres, difficulty in speaking to everyone due to mobility issues and having a person living with dementia wander off from the café up the main road.

P6 "We looked at so many cafés. You've got to have the right sort of café... in [location]. I found that really noisy. Noise can upset some people with dementia."

One participant felt that Memory Cafés were not an appropriate intervention for themselves and their spouse living with dementia as they did not feel there was anyone they could relate to. The participant felt that their spouse was ignored and expressed sadness at being there.

P9 "...just sat there, she drank her coffee and ate a piece of cake. And then she just sat there, and no one bothered, she may as well have been invisible."

A concern highlighted by a few participants were with the name "Memory Café" itself. Most participants felt the name was suitable

and had fairly neutral connotations. However, other suggestions were changing it to "Forget-Me-Not" similar to the Memory Cafés in the United Kingdom, using the flower as a symbol. These participants felt that the name "Memory Café" was potentially confusing and possibly hurtful for those who did not remember parts of their life.

P1 "...for the partner, it's painful remembering what they were. And I guess we're trying to look forward..."

4 | DISCUSSION

This study aimed to determine the impact of Memory Cafés on the psychosocial well-being of those living with dementia and their carers residing in the Perth Metropolitan area. This is an under-researched area in the Australian context.

We found that Memory Cafés benefit attendees by providing a place to relax, laugh and feel joy. Before finding the Memory Café, carers reported struggling with their partner or family member becoming less able to socialise and enjoy themselves. However, the Memory Café provides something to look forward to for both the carer and person living with dementia. The findings suggest a significant positive psychosocial impact on attendees overall. This is consistent with the similar research on Memory Cafés.^{4,11,13}

We found that the benefits of Memory Cafés extend beyond social interaction. Through the interactions, carers can gain insights from their peers into new approaches to caring for someone living with dementia. This positive regular discourse supports future planning as carers are often at different stages of caring for living with dementia and they can exchange information and provide support. Although not every journey with dementia is the same, access to peer support has a significant impact on psychosocial well-being, demonstrated in the literature. Peer support models have reported benefits in the context of other disease processes such as cancer, diabetes and mental health,^{15,22,23} as they create a greater capacity for empathy and understanding within groups of those affected by similar circumstances.²² In contrast to other interventions such as formal support groups, attending a Memory Café feels like an activity they might do with their spouse or family member for fun as opposed to a necessity as a result of living with dementia. Our findings have shown this improves psychosocial well-being and provides joy in a relaxed, safe environment.

Prior to attending Memory Cafés, carers reported a significant decline in social interaction with friends and family once the diagnosis of dementia was made. Their support network was severely diminished which was detrimental to both the carer and person living with dementia. Memory Cafés provide a place to rebuild a social network with others who understand their situation. Increased social connection in this context is shown to have a positive impact on carers psychosocial well-being by increasing their capacity to receive the benefits of such interaction. This is demonstrated through the themes of joy and the creation of friendships, where the benefits are reflected in their mood and the rebuilding of social networks with

peers who can provide mutual support and understanding. Memory Cafés provide an opportunity to create bonds based on positivity and enjoyment. The Memory Café has a significantly positive impact on the ability of carers to socialise, whilst for those living with dementia, it was perceived as more limited.

The impact of Memory Cafés on those living with dementia was described by carers as being either beneficial or neutral. Some carers reported noticeable elevation in mood, happy to be going out together and short-term positive socialisation experiences with others. These findings suggest some positive impacts on the psychosocial well-being of those living with dementia after attending a Memory Café.

The research highlights the practicalities when establishing a Memory Café, with the need to consider ease of discovery, accessibility, café service and the benefits of the informal peer-to-peer format. Allowing free, informal socialisation is an essential aspect of providing peer support in Memory Cafés, whilst a café manager/owner who is flexible and supportive further enhances the Memory Café experience.

Concerns were raised by some carers, particularly the issue of Memory Cafés evolving into a carers group. Carers did not want to ask people to leave but did want to continue to encourage people living with dementia to attend. Other concerns included finding a non-noisy venue, those living with dementia being ignored socially and the connotations of the name "Memory Café." Whilst these were not found to have a negative impact on psychosocial well-being, they are still issues to be considered when looking to improve the Memory Café experience.

4.1 | Strengths of study

This study adds to the limited body of research surrounding Memory Cafés. Providing unique insights into the context of peer-to-peer interventions in the context of the Perth Metropolitan area. Using a semi-structured interview method, participants were encouraged to engage in a relaxed dialogue with the researcher. This provided a rich set of data. It gathered data from multiple Memory Cafés as opposed to one, as has been the case in previous publications.^{13,14} Our study was also unique in that it included those who were relatively new to Memory Cafés, as opposed to only established participants, to determine if there were difficulties for those newly attending.

4.2 | Limitations of study

The participants were of a similar background and, therefore, the study does not provide information about the experiences of culturally and linguistically diverse populations. Additionally, the research does not address the unique needs of those who live rurally who attend Memory Cafés. Investigation into these areas will provide a more comprehensive picture of the psychosocial impact of Memory Cafés in Western Australia.

Ethical approval was limited to only carers participating in interviews. The results are, therefore, restricted to carer-reported benefits for the person living with dementia. Future studies should include those living with dementia who wish to talk about their experiences.

4.3 | Conclusions

This study has demonstrated that Memory Cafés are a vehicle to support the psychosocial well-being of carers of those living with dementia. Memory Cafés provide a place to socialise, build support networks, become involved in the community and have fun. Memory Cafés provide a place for carers of those living with dementia to experience joy and feel as that they are not alone and that the experience of being a carer can be positive. For some participants, it provided significant long-lasting friendships that have improved their lives outside the Memory Café.

For those living with dementia, the improvement in psychosocial well-being was harder to determine. Nevertheless, carers reported that Memory Cafés seemed to support some improvement in the psychosocial well-being of those living with dementia, either through socialising at the café or mood improvements overall after attending Memory Cafés.

Recommendations for Memory Cafés in Perth involve maintaining the informal atmosphere and facilitation of the peer-to-peer model by organisations such as local councils. Continuing research and evaluation as Memory Cafés grow in popularity will serve to inform community members and organisations as to how to run them successfully. A repeated qualitative study in rural West Australia would demonstrate how this model works in the context of very little medical support, and if it is a feasible way of providing psychosocial joy to those communities. Future research should endeavour to also include those living with dementia as participants²⁴.

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CONFLICT OF INTEREST

The author(s) declare that there is no conflict of interest.

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REFERENCES

1. Australian Institute of Health and Welfare. Australia's Health 2020: Data Insights. 2020; [cited 2021 October 7]. Available from: <https://www.aihw.gov.au/reports/australias-health/australias-health-2020-data-insights/contents/summary>

2. Brown L, Hansnata E, La HA. Economic Cost of Dementia in Australia 2016–2056. Canberra: Alzheimer's Australia; 2017.
3. Whitlatch CJ, Orsulic-Jeras S. Meeting the informal, educational and psychosocial support needs of persons living with dementia and their family caregivers. *Gerontologist*. 2017;58(1):58–73.
4. Greenwood N, Smith R, Akhtar F, Richardson A. A qualitative study of carers' experiences of dementia cafés: a place to feel supported and be yourself. *BMC Geriatrics*. 2017;17(1):4.
5. Goren A, Montgomery W, Kahle-Wroblewski K, Nakamura T, Ueda K. Impact of caring for persons with Alzheimer's disease or dementia on caregivers' health outcomes: findings from a community based survey in Japan. *BMC Geriatrics*. 2016;16(1):122.
6. Hansen A, Solveig H, Bergland A. Meeting psychosocial needs for persons with dementia in home care services – a qualitative study of different perceptions and practices among health care providers. *BMC Geriatrics*. 2017;17(1):211.
7. Brooks D, Fielding E, Beattie E, Edwards H, Hines S. Effectiveness of psychosocial interventions on the psychological health and emotional well-being of family carers of people with dementia following residential care placement: a systematic review. *JBHI Database Syst Rev Implement Rep*. 2018;16(5):1240–68.
8. Cooke DD, McNally L, Mulligan KT, Harrison MJG, Newman SP. Psychosocial interventions for caregivers of people with dementia: a systematic review. *Aging Ment Health*. 2001;5(2):120–35.
9. Toms GR, Clare L, Nixon J, Quinn C. A systematic narrative review of support groups for people with dementia. *Int Psychogeriatr*. 2015;27(9):1439–65.
10. Akhtar F, Greenwood N, Smith R, Richardson A. Dementia cafés: recommendations from interviews with informal carers. *Work Older People*. 2017;21(4):236–42.
11. McFadden S, Koll A. Popular memory cafés in Wisconsin's Fox Valley battle social isolation. *Generations*. 2014;38(1):68–71.
12. Capus J. The Kingston Dementia Café: the benefits of establishing an Alzheimer café for carers and people with dementia. *Dementia*. 2005;4(4):588–91.
13. Dow B, Haralambous B, Hempton C, Hunt S, Calleja D. Evaluation of Alzheimer's Australia Vic Memory Lane Cafés. *Int Psychogeriatr*. 2011;23(2):246–55.
14. Mather L. Memory Lane Café: follow-up support for people with early stage dementia and their families and carers. *Dementia*. 2006;5(2):290–3.
15. Heisler M. Overview of peer support models to improve diabetes self-management and clinical outcomes. *Diabetes Spectrum*. 2007;20(4):214–21.
16. Tuohy D, Cooney A, Dowling M, Murphy K, Sixsmith J. An overview of interpretive phenomenology as a research methodology. *Nurse Res*. 2013;20(6):17–20.
17. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–57.
18. Alzheimer's WA. Memory Cafés. 2019; [cited 2019 Nov 4]. Available from: <https://www.alzheimerswa.org.au/about-dementia/supporting-person-living-dementia/memory-cafes/>
19. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.
20. Guest G, Bunce A, Johnson L. How many interviews are enough?: an experiment with data saturation and variability. *Field Methods*. 2006;18(1):59–82.
21. Chacko EE, Wright WM, Worrall RC, Adamson C, Cheung G. Reactions to driving cessation: a qualitative study of people with dementia and their families. *Australas Psychiatry*. 2015;23(5):496–99.
22. Boyes A, Turon H, Hall A, Watson R, Proietto A, Sanson-Fisher R. Preferences for models of peer support in the digital era: a cross-sectional survey of people with cancer. *Psycho-Oncology*. 2018;27(9):2148–54.
23. Ashing-Giwa K, Tapp C, Rosales M, McDowell K, Martin V, Santifer RH, et al. Peer-based models of supportive care: the impact of peer support groups in African American breast cancer survivors. *Oncol Nurs Forum*. 2012;39(6):585–91.
24. Masoud SS, Meyer KN, Martin Sweet L, Prado PJ, White CL. "We Don't Feel so Alone": a qualitative study of virtual Memory Cafés to support social connectedness among individuals living with dementia and care partners during COVID-19. *Front Public Health*. 2021;9:660144.

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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