Australian Journal of DementiaCare

Research Focus

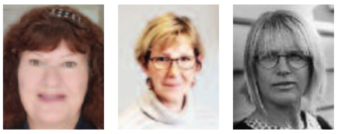
This section aims to provide a channel of two-way communication between researchers and practitioners in the expanding field of social, psychological and nursing research in dementia care, including all aspects of nursing and care practice, communication and the environment.

The Research Focus section of the *Australian Journal of Dementia Care* aims to keep readers up to date with the fast expanding field of social, psychological and nursing research in dementia care. By this we mean every aspect of person-to-person communication, nursing and care practice and organisation, and the influence of all aspects of the environment. The aim is to provide a channel of two-way communication between researchers and practitioners, to ensure that research findings influence practice and that practitioners' concerns are fed into the research agenda. We would like to hear from you, specifically with:

- notice of the publication (recent or imminent) of peer reviewed papers with practical relevance to dementia care;
- research reports available for interested readers;
- requests or offers for sharing information and experience in particular fields of interest.

Fostering community conversations around dementia

University of Tasmania researchers (pictured from left) **Susanne Becker**, **Helen Courtney-Pratt**, and **Pauline Marsh** report on a pilot project exploring how informal community cafés, where all are welcome, might reduce stigma and normalise discussion about dementia in everyday life



The impact of dementia on individuals, families and communities is far-ranging. Stigma and fear can contribute to isolation of those living with the impact of the condition, resulting in subsequent invisibility in the community.

Whilst significant work has been undertaken in the movement toward dementia-friendly communities, where inclusion and respect for the rights of all are central, there is still a way to go before people can comfortably and openly disclose a diagnosis and experience authentic respect for their personhood and rights. Indeed, one of the biggest challenges is to 'get the conversation going'. The pilot project described in this article drew on the example of 'death cafés' to explore how an informal conversation strategy might reduce stigma and normalise open discussion and consideration of dementia in everyday life.

Project aim

The aim of this study was to explore whether café-style conversations around dementia would be welcomed, supported by, and beneficial to a range of people.

Project background

About 70% of people with dementia live in the community (Alzheimer's Australia 2014) and, progressively, the proportion of people living with dementia within their communities will increase. Recent aged care reforms in Australia have sought to strengthen and extend services offered to older people to enable them to remain in their own home and communities (Department of Social Services 2015).

In addition to support for ageing-in-place, further initiatives such as age-friendly cities (World Health Organization 2007) and dementia-friendly communities (Chalk & Page 2016) have emerged (Turner & Morken 2016). Alongside these, there have been moves to decrease the stigma of dementia through education and improved citizenship rights for people living with the condition, nationally and internationally (ADI 2019; Kim *et al* 2019). There is, however, a long way to go.

There is an established recognition of the importance of supporting community conversations about dementia in order to decrease stigma, isolation of those living with the condition, and to understand how people living with the condition can be supported to live well in the community. Fostering conversations at a grassroots level can help to demystify dementia and facilitate those living with dementia to make ongoing contributions to the community (ADI 2019, 2018). Other suggested benefits include delayed entry to residential aged care, and greater support for ageing in place for all (Evans 2018).

The Wicking Dementia Research and Education Centre through its *Dementia friendly communities: prioritising action through community input* research stream (Courtney-Pratt *et al* 2018), discovered a strong need for informal information sessions with the capacity to reach a wide range of community members.

The notion of a community café pilot project was developed, based on the successful death café model. The death café model aims to decrease stigma and societal discomfort about discussing and planning for death (Baldwin 2017) and is an established, albeit grassroots, approach to demystifying often difficult topics in the general community. In the death café model anyone is welcome, sometimes to listen and socialise, but there are other benefits including linkages to information and service providers, and social support (Miles & Corr 2017).

Although dementia cafés have been operating in some communities, their primary purpose has generally been to provide networking and support groups for carers and/or people living with dementia (Dow *et al* 2011). In this pilot study, however, we extended the invitation to the general community and opened the conversations to include those worried about receiving a dementia diagnosis, wanting to seek further information, caring for those living with the impact of dementia, and importantly anyone with a diagnosis or current experience.

What we did

Four cafés were arranged late in 2018, with key community personnel and advertised through one local council's Positive Ageing Network, and posters placed in local shopping and community hubs. Morning tea was provided. Two café sessions partnered with existing community morning tea events at a neighbourhood house and a community garden.

Community members were advised that their normal morning event would host a dementia café instead of usual activities and other participants were invited via advertising through local networks. The other two cafes were standalone events – one in a community hall and the other in a community garden attached to a local school. Representatives who understood the current health provision framework, local community resources, and had knowledge of dementia attended all cafes.

Participants were asked to answer four questions via postcard at completion of the sessions (see images this page). Return of postcards implied consent and all responses were anonymous. Cards contained a small amount of demographic information (suburb, age and gender) and option for free text responses. Attendees were not asked to declare the presence of a dementia diagnosis or carer role, and although several individuals indicated through discussion they were living with dementia or were in a caring role, others may have chosen not to disclose a diagnosis.

Community feedback

Of the 78 people who attended the four cafés, 29 provided feedback via the postcard. Under half of those attending the pilot cafes provided written feedback and responses provide insights into why people attended, what they hoped to gain from a session, and what adaptations may be required to extend the café concept into the broader community. The average age of those providing feedback data was 57 years of age (range 31-83) and respondents were predominantly female (27 females and two males).

HAVE YOUR SAY ON CAFÉ CONVERSATIONS ABOUT DEMENTIA

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WE ARE INTERESTED IN HEARING VIEWS FROM EVERYONE WHO ATTENDED

Please complete the answers on reverse side and post back.

Tell us a little about why you came to the café today?

What did you hope to get out of coming today?

What did you get out of coming today?

What advice would you give us about holding future café conversations about dementia?

Answers to the questions will be used to inform the development of a toolbox that communities can use to enable conversations about dementia. Feedback will also be used in short reports or publications. For more info, please contact Susanne at: s.e.becker@utas.edu.au

AGE
GENDER
SUBURB

Participants were asked to answer four questions via postcard at completion of the sessions, covering the following: (1) Tell us a little about why you attended today?, (2) What did you expect from attendance?, (3) Has attendance met your expectations?, and (4) What feedback do you have to improve the running of future cafés?

Attendance and expectations

Overwhelmingly, feedback identified that people attended the café *"to find out more about dementia and learn" (1 Male)*, a comment reiterated by many participants. Other phrases captured a similar essence, including being *"interested in the subject" (3 Female)*, and *"for information" (25 F & 26 M)*. Other participants provided greater depth as to what type of information they sought, writing that they came *"more to find out about how to deal with or notice changes in people" (22 F)* or *"to learn more about dementia and to be able to tell when one has this disease" (27 F)*. Some individuals were worried about the possibility of their own dementia diagnosis and came because, for example, *"I have a few signs of memory loss that concern me" (19 F)*.

Participants also stated they attended to share experiences, to listen or to assist others. For example, one respondent wrote: *"to help others from my first-hand experience with dementia (mother)" (8 F)*, and *"to listen to other people and learn more about their experiences" (12 F)*. One person attended three of the four cafés as she was motivated to share her experiences and insights with others, writing *"my mum has dementia and she is now in a nursing home. I've done lots of courses about dementia and would like to help others"* (17 F).

A small number of participants came to support the initiative despite not having a connection to someone with dementia, or a specific dementia motivation. For example, a member of the local council's Positive Ageing Network said they wanted *"to learn more about dementia"* and *"add support to the initiative"* (15 F). Other participants had support roles in the community as volunteers or as allied health team members. One participant said they attended because, *"I coordinate volunteers, some of whom spend time with people who have dementia – diagnosed or undiagnosed"* (14 F) and another was a *"…local social worker supporting the local community"* (24 F).

What was helpful?

Most respondents (n = 26) stated that they gained information, which ranged from upcoming dementia education opportunities (three participants), understanding *"where to go or ring up if I have questions"* (5 Not Stated), and *"having general information about what is available in the community"* (6 F).

The opportunity to share stories and make connections with people in their own community was highlighted. One participant responded that *"helping others with advice is most rewarding"* (17 F), while another participant was able to recruit a volunteer for their local community activity (14 F). Attendance at the café provided an opportunity to meet others informally, with comments including: *"nice to talk to like-minded folk"* (2 F), *"pleasant and open conversation"* (19 F), and the *"value of connection and conversation"* (24 F), and a *"relaxing and enjoyable session"* (6 F).

Future café formats

Feedback was overwhelmingly positive with most respondents expressing a variant of "have as many as possible" (17 F) or having "regular meetings in the community" (21 F). The informal format of the sessions was supported with one woman, for example, describing the session as *"casual, informative, helpful, friendly – keep going with this format"* (28 F), and others saying the food and 'cuppa' were great additions (multiple participants).

It was suggested that more pamphlets with information to support verbal discussions would be helpful (11 F, 16 F and 19 F). Others suggested the addition of a *"person at each table to open the conversation about dementia and facilitate discussions and questions"* (14 F).

Increased community involvement could be a future aspiration: *"greater involvement of community members, including youth and intergenerational"* (15 F). Two participants commented on the Neighbourhood House as an ideal venue to have *"informal chats in a relaxed atmosphere"* (20 F), and to reach out to members of a community, for example, *"where people might not have access to doctors as easily"* (3 F).

Two participants felt the café style session was too loud and impacted on their capacity to participate and suggested providing seating away from the main gathering for those who were hard of hearing (9 F and 12 F).

What the feedback tells us

Our findings indicate that the café style is welcome and beneficial, a heartening response when communities are seeking opportunities to improve community awareness and understanding around dementia. Given the push by the *National Framework for Action on Dementia 2015-2019* (AHMAC 2015) to improve communities' understanding, such an 'open-invitation' café concept is a valid option for communities seeking such initiatives.

Information and understanding

All participants who completed feedback indicated they had gained information or understanding around dementia, findings consistent with other café concept studies (Dow *et al* 2011; Kiddle *et al* 2015; Merlo *et al* 2018). Diverging slightly from the more established Memory Lane Café (Dow *et al* 2011) and Alzheimer's or dementia café's concept (Greenwood *et al* 2017; Merlo *et al* 2018) that target people with dementia and their carers, our cafés successfully attracted interest from the wider community.

Decreasing stigma

Providing relaxed, café-style opportunities can decrease stigma, link individuals and improve awareness and create communities that are more inclusive and accepting of the person with dementia. Although stigma wasn't directly addressed in participants' comments, we suggest that informally sharing stories and listening to the stories of others attending the café may assist in decreasing the stigma associated with the media's often homogenous portrayal of those living with dementia (Kilduff 2014). As reported in the *World Alzheimer Report 2019* (p144): "Conversations can change lives. We know that sharing personal stories within communities is vital for ending stigma."

Choice of venue

From this small study it appears the site of the café may have an impact on attendance. It is not always clear whether similar café-style studies are reporting on cafés held in established café businesses or using a public or private space and making it into an improvised café (for example Dow *et al* 2011; Greenwood *et al* 2017). Other studies have used a mixture of established cafés and public places (eg Friedman *et al* 2016) or created a space within an Alzheimer's clinic (eg Merlo *et al* 2018). Kiddle and colleagues (2015) held their sessions in a local youth centre.

Choice and suitability of the venues was not discussed or evaluated further in these above studies.

Nevertheless, the greatest number of people in our study attended the café held in the local neighbourhood house where a fortnightly morning tea event was long established. Members of this community were familiar with the location, space and timetabling, which may have significantly impacted on attendance. Choosing a venue where people usually gather may assist with attendance. This aspect for future cafés demands attention and further evaluation, particularly given the 'all are welcome' concept.

Community partnerships

Working in partnership with key community personnel and a local council, and building on their experiences of holding events and implementing initiatives, assisted in advertising our pilot study's cafés through established avenues such as networks and community hubs.

Collaborating with agencies outside of the health sector, to increase the reach and provide initiatives such as café-style conversations in sites where community members already feel comfortable, may be one way of furthering community members' awareness and understanding of dementia.

Conducted in two local council areas, one of which has an established and active Positive Ageing Network, we were able to value-add onto an existing calendar of events. While this is a strength to build on in these communities, it is acknowledged that not all communities have this foundation and may require significant support to conduct similar sessions.

As a small pilot study, information collected about the café-style conversation approach will add to the toolbox of strategies to increase the awareness and understanding around dementia in the community. The café model successfully stimulated conversations around dementia on a range of topics and catered to the various interests and needs of the attendees.

Conclusion

Feedback from this pilot study suggests that a format based on the death café model of 'all are welcome' and an atmosphere that ignites conversations around dementia can be beneficial to community members.

Holding the cafés in local community hubs where people are already comfortable, such as neighbourhood houses and community gardens, may facilitate attendance. Participants were generous in sharing their own experiences, which others found aided their understanding.

This is a worthwhile and accessible model for communities to consider, to improve awareness and create communities that are more inclusive and accepting of the person with dementia.

There is a need to further evaluate and understand the impact of community-based interventions that intend to get community conversations started, to decrease stigma and promote the citizenship rights of people living with dementia. ■

References

Alzheimer's Australia (2014) *Living With Dementia In The Community: Challenges And Opportunities.* Available at: https://bit.ly/2RFAqBQ.

Alzheimer's Disease International (2019) *World Alzheimer Report 2019: Attitudes To Dementia*. London: Alzheimer's Disease International.

Alzheimer's Disease International (2018) *World Alzheimer Report 2018: The State Of The Art Of Dementia Research: New Frontiers*. London: Alzheimer's Disease International.

Australian Health Ministers Advisory Council (AHMAC) (2015) *National Framework For Action On Dementia 2015-2019.* Available at: https://bit.ly/3hG64cP.

Australian Institute of Health and Welfare (2019) *Deaths In Australia.* Available at: https://bit.ly/33HLSSL.

Baldwin PK (2017) Death Cafes: Death Doulas and Family Communication. *Behavioral Sciences* 7(2) 26.

Chalk A, Page S (2016) Dementia RED (Respect Empathy Dignity): Collaborating To Build Dementia Supportive Communities In North Wales – Reporting On A Pilot Project (Innovative Practice). *Dementia* 15(2) 257-262.

Courtney-Pratt H, Mathison K, Doherty K, (2018) Distilling Authentic Community-Led Strategies To Support People With Dementia To Live Well. *Community Development* 49(4) 432-449.

Dementia Australia (2020) *Transforming Dementia Care*. Available at: https://bit.ly/3hIqq5g.

Department of Social Services (2015)

Living Well At Home: CHSP Good Practice Guide. Available at: https://bit.ly/3iH4TLu.

Dow B, Haralambous B, Hempton C, Hunt S, Calleja D (2011) Evaluation Of Alzheimer's Australia Vic Memory Lane Cafés. *International Psychogeriatrics* 23(2) 246-255.

Evans, S (2018) *Ageism and Dementia*. In: Ayalon L, Tesch-Römer C (Eds) Contemporary Perspectives on Ageism. *International Perspectives On Aging* 19 263-275. Cham, Switzerland: Springer.

Friedman DB, Gibson A, Torres W, Irizarry J, Rodriguez J, Tang W, Kannaley K (2016) Increasing Community Awareness About Alzheimer's Disease In Puerto Rico Through Coffee Shop Education And Social Media. *Journal of Community Health* 41(5) 1006-1012.

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(164).

Kiddle H, Drew N, Crabbe P, Wigmore J (2015) A Pilot Memory Café For People With Learning Disabilities And Memory Difficulties. *British Journal of Learning Disabilities* 44 175-181.

Kilduff A (2014) Dementia and Stigma: A Review Of The Literature On The Reality Of Living With Dementia. *Mental Health Nursing* 34(5) 7-11.

Kim S, Werner P, Richardson A, Anstey KJ (2019) Dementia Stigma Reduction (DESeRvE): Study Protocol For A Randomized Controlled Trial Of An Online Intervention Program To Reduce Dementia-Related Public Stigma. *Contemporary Clinical Trials Communications* 14 1-5.

Merlo P, Devita M, *et al*. (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* 30 767-774.

Miles L, Corr C (2017) Death Café: What Is It And What We Can Learn From It. *OMEGA – Journal of Death and Dying* 75(2) 151-165.

Nelson R (2017) Discussing Death Over Coffee And Cake: The Emergence Of The Death Café. *American Journal of Nursing* 117(2) 8-9.

Turner N, Morken L (2016) *Better Together: A Comparative Analysis Of Age-Friendly And Dementia Friendly Communities*. Available at: https://bit.ly/3iHVG5R.

World Health Organization (2007) *Global Age-Friendly Cities: A Guide*. Geneva: WHO Press.