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Original Research

Aboriginal community understandings of dementia and responses to dementia care

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ABSTRACT

Objective: Aboriginal people and Torres Strait Islanders are impacted by dementia at higher rates and at a younger age of onset than the broader Australia population. Public health strategies to support this population require a thorough understanding of how Aboriginal people perceive dementia and dementia care support needs. The aim of this study was to investigate Aboriginal community understandings of dementia and their responses to dementia care.

Study design: This study is a community participatory action research partnership.

Methods: The mixed method study was undertaken in 2017 with members of a discrete Aboriginal community from rural Tasmania, Australia. Participants were older than 18 years, self-identified as an Aboriginal person and were living or had lived in the community studied. Data were derived from 50 participants who completed the 27-item Dementia Knowledge Assessment Scale (DKAS). Twelve of these participants also shared their dementia care experiences in individual interviews.

Results: The DKAS results showed a low overall level of dementia knowledge, with a total mean score of 27.73 (scoring 51% on average) of a possible score of 54. The salient interview theme was the cultural obligation to care for family members living with dementia. Dementia care metaphors represented ways to protect family members living with dementia and maintain their ongoing connections to home and community. However, limited understandings of dementia affected their capacity to provide quality care.

Conclusion: The findings contribute to public health scholarship involving Aboriginal community responses to dementia care. The study has resulted in important initiatives including a community-based dementia education program to ensure Aboriginal people impacted by dementia are provided with effective and culturally appropriate care.

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Introduction

Dementia is a neurodegenerative condition with progressive cognitive decline, reduced independence and lower life expectancy.[1] It is a major public health issue and leading cause of death and disability among the ageing population. However, research has yet to fully examine the impact of dementia among Aboriginal people and Torres Strait Islanders (hereafter, Aboriginal people).[2] The prevalence of dementia among Aboriginal people is excessive, with rates three to five times higher than the Australian population and with a younger age of onset.[3,4] Dementia across urban, regional and remote Aboriginal communities is associated with multiple risk factors, including type 2 diabetes, renal impairment, midlife hypertension, cardiovascular disease, substance abuse, obesity, dietary factors, depression, smoking, physical inactivity and lower levels of education. Maternal health, early childhood development, trauma and obstetric complications also increase the risk for developing dementia later in life.[5] The well-being of Aboriginal people is further impacted by ongoing historical and contemporary factors associated with colonisztion, dispossession, racism, intergenerational trauma and marginalisztion.[6] Aboriginal communities also contend with multiple public health issues associated with housing stress, poverty, water and food security and limited access to affordable primary health care. The rates of dementia rates among Aboriginal people can be notably underreported or not recognised due to cultural norms associated with ageing or overlooked by clinicians due to more immediate health concerns.[6,7]

Historically, low life expectancies among Aboriginal people meant that growing old enough to develop dementia was ‘considered a luxury’.[8] Although evidence now suggests a subtle shift with Aboriginal people ageing at increasing rates, ‘old age’ for Aboriginal people is still substantially below that of other Australians.[4] Research thus needs to focus on Aboriginal understandings of ageing, dementia and appropriate family and community care provisions.[9] Although research has drawn attention to dementia prevalence rates among numerous Aboriginal communities, few studies have examined how Aboriginal people experience dementia and their perspective on dementia care needs.[4,8] Previous research has documented Aboriginal cultural understanding of dementia in terms of ‘a western sickness, a form of tiredness, childlike behaviour or a lost spirit’.[4,5] There remains a need to examine how Aboriginal people give cultural meaning to the care of family and community members with dementia.[8,9] The aim of this article is to contribute to public health discourse by illustrating Aboriginal understandings of dementia and responses to dementia care from the perspective of an Aboriginal community in rural Tasmania, an island state of Australia.

Methods

The study was undertaken in 2017 after Aboriginal leaders approached the first author with concerns of increasing prevalence of dementia and care needs in the community. The author has an established relationship with community members.[10] Consultation with other community members and coauthors resulted in the project progressing as a community participatory action research (CPAR) methodology.[11] CPAR is a culturally appropriate and respectful approach for undertaking research in partnership with Aboriginal communities.[12] The methodology involves Aboriginal people identifying the need to undertake research, maintaining control, prioritising their own community health objectives and contributing through active involvement in all aspects of the research process.[13,14]

Our study used a two-stage mixed methods approach with a validated survey to gather community-level understanding of dementia, and individual interviews to gain qualitative insights into the experiences and needs of carers of family and community members living with dementia. Inclusion criteria required participants to be over 18 years of age, self-identified as Aboriginal people and were living or had lived in the community. Convenience sampling was used to recruit participants through established community kinship networks. Information sheets were made available at community forums, the registered Aboriginal Community Controlled Health Organization and the community centre. Researchers (T.C. and L.G.) were invited to attend two community cultural events to discuss the study with potential participants. Through this community engagement, fifty adult Aboriginal community members gave their informed consent to participate and complete the survey.

The study used the Dementia Knowledge Assessment Scale (DKAS) survey. The survey provided a valid and reliable psychometric assessment of dementia knowledge based on testing with multiple cohorts. It included pathological and psychosocial enquiries of dementia across four domains: causes and characteristics, communication, care needs, risk factors and health promotion.[15–17] The 27-item Likert-style survey questionnaire had options for participants to respond with either false, probably false, probably true, true or I don't know answers. Correct responses received a score of two, whereas probably false and probably true responses received a score of one. Incorrect and don't know responses received a score of zero. DKAS data were entered into a SPSS (version 22.0) program for analysis. Participants provided basic demographic information and responded to all DKAS questions. The DKAS responses were ranked from most accurate to least accurate and examined to determine trends in dementia knowledge across the four domains.

Survey participants with first-hand dementia care experiences were asked to indicate their interest in undertaking an interview by leaving their names and contact details on a separate sheet of the survey. Twelve survey participants expressed their interest in participating in interviews. They were contacted by the first author who then arranged and conducted each individual semi-structured interview.[18,19] Participants discussed their experiences and challenges of caring for family and community member living with dementia, as well as their own needs and expectations of service providers. The digitally recorded interviews were de-identified and transcribed verbatim. Participants had the opportunity to comment on the accuracy of their own transcripts. Interview data were thematically coded and analysed independently to ensure the validity and rigour of the findings.[20] The DKAS results and interview themes were developed into a community-based report. Community leaders reviewed and endorsed the report before its distribution to all participants. The report was also made available to all community members.[21]

Results

Survey participants included 38 women and 12 men with a diverse age range (22–85 years, mean = 46.44 years). Most participants had completed high-school education, and four had undertaken some form of dementia education. Thirteen participants reported having a family member with dementia, and five were providing regular dementia care (Table 1).

The DKAS results represent a total mean score of 27.73 from a maximum score of 54 (Table 2). The more accurate responses (1.6-1.2 out of a maximum score of 2) illustrated greater knowledge in everyday care provision, including communication, comfort and safely, and an awareness that dementia causes difficulties with eating, drinking and learning. Participants also associated dementia with physical changes in the brain, depression and increased dependence. The mid-range results (1.2-0.84) indicated some understanding of care needs and communication and how people living with dementia engage through body language and respond to change, distress or pain. Participants reported some awareness of different forms of dementia and discerning dementia from ‘normal’ ageing. The less accurate responses (0.8-0.32) portrayed minimal knowledge of dementia risk factors, early diagnosis, effects on quality of life and life expectancy. Participants also had difficulty distinguishing acute onset cognitive or behavioural changes from dementia symptoms. Overall, the more accurate results indicated higher levels of understanding the care needs of people living with dementia, whereas the less accurate responses represented lower understandings of dementia risk factors and progressive dementia impairments.

Table 1 – Participant characteristics n=50.

Characteristic	Value
Age in years, mean ± standard deviation	46.44 ± 16
Age in years, range	22–85
Gender, n (%)	
Male	12 (24%)
Female	38 (76%)
Dementia education experience, n (%)	
Yes	4 (8%)
No	46 (92%)
Family member with dementia, n (%)	
Yes	13 (26%)
No	37 (74%)
Provided regular care for a family member with dementia, n (%)	
Yes	5 (38.5%)
No	8 (61.5%)
Provided professional health care for people experiencing dementia, n (%)	
Yes	8 (16%)
No	42 (84%)
Highest level of completed education, n (%)	
Primary/elementary school	6 (12.5%)
High-school graduate	18 (37.5%)
Certificate or apprenticeship	14 (29.2%)
University	5 (10.4%)
Other	5 (10.4%)

Community understandings of dementia

The interview results represented the qualitative ‘voice’ of community members discussing their first-hand dementia care experiences and needs. Participants portrayed dementia as the progressive decline of the person living with the condition. They associated dementia with ageing, memory loss or stress:

> I think people label dementia as part of getting older and memory loss (Jane).

> … a lot of people put it [dementia] down to old age or stress (Toby).

Some participants discussed a dementia diagnosis as a confronting process of moving from denial and acceptance:

> I think it is a denial thing, like to say the word dementia is probably a bit confronting to people. When someone says, ‘they're having a senior moment’, or they're ‘she's just a bit forgetful’ or ‘having a brain fade’ or whatever, I think that when you have a diagnosis and you need to say ‘that word’ it's probably confronting and scary and … you actually have to accept it (Lillian).

Dementia care as a cultural obligation

Participants described dementia care as an obligation to both protect the identities of family members and maintain their connections to home and community. Protection metaphors emerged as ‘hiding’ or ‘covering up’ dementia symptoms:

> I think you can hide it [dementia] for a while, but its debilitating … you might hide it for a couple of years (Fred).

> A lot of the time they will stay at home until it becomes a point where their partner or carer can no longer manage or continue to cover up what they think is just getting old. I've seen a lot of that, partners covering up, they don't see that they might have dementia and it takes quite a while, its fairly late before they're diagnosed (Jane).

Rather than seeing cognitive decline in terms of loss of identity, family members living with dementia were described in transition, of becoming another self with dementia:

> You see someone you love, fade away into this other person (Cath).

Caregivers nevertheless discussed the physical and emotional burdens of dementia care:

> I've seen her [family member] getting worse and worse, not in herself, just her memory is so bad now and getting worse and worse … it is really hard and sad (Lee).

Table 2 – Response scores on the 27-item DKAS ($n = 50$).

Question	Correct response	Mean item score/2
Daily care for a person with advanced dementia is effective when it focuses on providing comfort and making sure the person is safe.	True	1.6
It is important to correct a person with dementia when they are confused.	False	1.44
People with advanced dementia may have difficulty speaking.	True	1.44
People can recover from the most common forms of dementia.	False	1.39
People experiencing dementia do not generally have problems making decisions.	False	1.35
People with dementia are unlikely to experience depression.	False	1.3
Difficulty eating and drinking generally occurs in the later stages of dementia.	True	1.27
Dementia does not result from physical changes in the brain.	False	1.26
People experiencing dementia often have difficulty learning new skills.	True	1.26
It is impossible to communicate with a person who has advanced dementia.	False	1.22
People experiencing advanced dementia often communicate through body language.	True	1.2
Planning for end of life care is generally not necessary following a diagnosis of dementia.	False	1.14
Changed behaviours in a person with dementia can indicate distress or pain.	True	1.12
Exercise is generally beneficial for people experiencing dementia.	True	1.08
The ability to move is generally affected in the later stages of dementia.	True	1.08
Dementia is a normal part of the ageing process.	False	1.04
Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia.	False	0.92
Alzheimer's disease is the most common form of dementia.	True	0.9
Medications are the most effective way of treating behavioural symptoms of dementia.	False	0.84
An early diagnosis of dementia does not generally improve quality of life for people experiencing the condition.	False	0.8
Symptoms of depression can be mistaken for symptoms of dementia.	True	0.79
Most forms of dementia reduce the length of a person's life.	True	0.74
A person experiencing advanced dementia will not generally respond to changes in their physical environment.	False	0.71
Most forms of dementia do not generally shorten a person's life.	False	0.66
Blood vessel disease (vascular dementia) is the most common form of dementia.	False	0.45
Having high blood pressure increases a person's risk of developing dementia.	True	0.41
The sudden onset of cognitive problems is characteristic of common forms of dementia.	False	0.32
Total mean score (51%)		27.73/54

DKAS, Dementia Knowledge Assessment Scale.

They also described underlying stigma experienced by Aboriginal community members that impacted on their capacity to access to dementia support services:

> Well it is a bit of an issue with identification sometimes in a small area, whether people want to share that they are Aboriginal, there's a bit of stigma (Jane).

> Not every family, especially Aboriginal families will fit into a box, we're just too diverse. Some are missing out on support that they're entitled to because they don't know how or where to seek that support (Toby).

However, participants felt well positioned to provide appropriate dementia care because they had a shared understanding of family, history culture, kinship and connection to country:

> In approaching dementia we're an ageing population … with Aboriginal people its about knowing our background and what is most important to us, obviously culture, lifestyle, living on the land … (Annie).

The participants also emphasised that dementia care required skills and strategies with everyday routines and communication:

> I lived with my Nan for 6 months. Routine was a very important part of living with her. Anything outside the normal needed a lot of extra communication. You had to explain extra activities and have a lot of structure and routine and patience (Dean).

> I had a couple of family members with dementia, people make the mistake of arguing with them or correcting them, you never do that, you always go with them (Ty'hana).

Dementia care support

Safety, comfort and quality of life were essential attributes to care for family and community members living with dementia:

> We have to keep them comfortable and feeling safe and give them what they need (Lillian).

Aged care organisations were considered a least preferred dementia care option. As such, participants saw much value in supporting carers with pragmatic, home-based respite:

> I know there is respite and most people I know don't want to go into an aged care home, but to have someone come into

> your home and give you respite care would be awesome, because it keeps them comfortable in their home (Eve).

The obligation to support people living with dementia in their own homes required skilled and supportive family members. Participants stressed the need to support family members with dementia so they remain socially connected:

> We are trying really hard to keep people at home, that's the whole thing nowadays, where they want to be. … I guess it's just trying to get people to understand the condition better, … because the way they do things and the way they see things is so different … the family need to be able to understand that and so does the community, so these people can still actually semi-function in society (Jane).

Participants noted the vulnerability of having dementia and no immediate family support. Institutional dementia care was seen with trepidation:

> Some [community members] don't have extended family and you're on your own …. If you can't get family support, you're stuffed aren't you. You will be in and out of hospital or just dumped in aged care (Eve).

A central concern was the need for education programs to ensure Aboriginal people living with dementia are provided with culturally appropriate family and community-based care:

> I honestly believe there should be something offered in the [Aboriginal] community around dementia training … we're an ageing population (Elizabeth).

> We need experienced carers. A lot of times they [carers] don't understand how the disease works either so … knowing how to help without them getting too frustrated. Without training, carers won't know how best to care for them (Nick).

The participants raised several challenges and strategies associated with dementia care. However, their paramount obligation was to care and protect family members in ways that maintained their social and community connectedness. Dementia education and training was necessary to adequately meet their care obligation.

Discussion

Our mixed methods study drew on survey and interviews to examine one Tasmanian Aboriginal community's understandings of dementia and their responses to dementia care. Based on the available literature, this was the first dementia research undertaken at the request of Aboriginal community leaders in Tasmania, the first to use the DKAS survey instrument with Aboriginal people and the first to combine DKAS and interview methods. The findings illustrate that dementia and dementia care is a priority public health issue in this Aboriginal community, with prevalence rates similar to reports from other Aboriginal communities.[3,22–24] The DKAS results indicate limited understandings of dementia among the community participants. Our findings illustrated knowledge gaps with identifying early dementia symptoms, risk factors associated with developing dementia and the progressive nature of dementia impairment. The primary concern among the Aboriginal participants was to care for their own family and community members while at the same time frustrated with limited understandings of this neurodegenerative disease. Further research and policy responses are recommended to address these dementia care concerns, as well as the socio-economic, education and public health inequalities facing Aboriginal people in Tasmania and Australia.[4,25]

While community members associated dementia with ageing, progressive memory loss and increased dependence, the salient finding stemming from this study was the cultural obligation to care for family and community members living with dementia. This obligation incorporated protecting the identities of family members and helping them to maintain their connections to home, family and community. Identity protection incorporated ‘covering up and hiding’ or de-emphasising dementia symptoms and recognising the transitional cognitive decline of family members as ‘fading away into this other person’. This form of protection had unintended consequences of isolating carers and causing delays with accessing dementia support and carer respite. Participants also noted underlying stigma influenced the capacity of some community members to seek support. Dementia care as a cultural obligation nevertheless represents an important finding. The concept recognises the valuable role of carers in protecting the identity of those living with dementia and their efforts to ensure their family and community relationships are maintained. For these Aboriginal participants, dementia care incorporates the continuity of family and community relationships, despite the neurodegenerative effects of the disease. Cultural obligations of dementia care provide an important public health concept for Aboriginal people and healthcare providers to develop appropriate clinical and community models of support. Such a model requires carers to have appropriate education and training, pragmatic respite support and self-care strategies to increase their capacity to provide effective care.

Our community participatory action research (CPAR) approach has initiated four community development outcomes. First, the project report informs the Aboriginal community with evidence-based knowledge of dementia and dementia care needs.[26] Second, community leaders and researchers have liaised with staff from Dementia Australia to establish a series of dementia education forums for all community members. Third, community leaders, researchers and education providers have developed a dementia education program designed to improve the community's capacity to care for Aboriginal people living with dementia. The program supports ten community members to undertake both on-line tertiary education (Bachelor of Dementia Care) and vocational training in individual care. The fourth outcome incorporates dementia care into existing community health programs to ensure that carers have essential resources, respite and practical support. This whole-of-community approach maintains an ongoing collaborative network involving Aboriginal people and dementia education stakeholders.

While meeting our agreed research aims, we acknowledge both strengths and limitations within our study. The CPAR approach was a strength of the study, involving close collaboration between Aboriginal community leaders and researchers. This provided a culturally safe environment and allowed for rich and culturally meaningful understandings of dementia and dementia care to emerge. The mixed methods design was a further strength in generating qualitative and quantitative data that were both appropriate and useful for the community. However, the modest number of research participants from a discrete Tasmanian Aboriginal community means that caution is required when considering the implications of the results beyond this population. The recruitment process may have attracted an Aboriginal cohort caring for family members living with dementia over a more general community sample. Although the DKAS survey results provided an important community overview of dementia knowledge, further research is required to gain a more nuanced understanding of dementia and dementia care among diverse Aboriginal communities.

In summary, our study contributes to public health scholarship by illustrating Aboriginal people's understandings of dementia and the meanings and cultural obligations they ascribe to dementia care. The needs of carers of people living with dementia were also identified, particularly with dementia education, training, respite support and self-care. The findings can inform public health stakeholders and policy makers to consider strategies that support the growing population of older Aboriginal people living with dementia and their carers across national and international communities.

Author statements

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Ethical approval

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Competing interests

None declared.

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