

## RESEARCH ARTICLE

# Perspectives, understandings of dementia and lived experiences from Australian Aboriginal people in Western Australia

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## Abstract

**Objective:** We explored understandings about dementia and lived experiences from carers among community-dwelling Aboriginal people in Western Australia (WA).

**Methods:** In partnership with Aboriginal medical services in WA, we conducted semi-structured interviews with Aboriginal people in Perth and Bunbury. All interviews were transcribed verbatim and coded thematically.

**Results:** We conducted 39 interviews. Dementia was associated with 'losing your memory', a 'change in behaviour' and unhealthy lifestyles. Increasing awareness about dementia in the community was noted particularly to enable people to recognise the early signs, feel safe to ask for help and know how to best support families. Families were primarily responsible for caring for people with dementia and were finding it difficult to manage. They expressed negative experiences with currently available aged care facilities.

**Conclusions:** Increased awareness of dementia in the community through public health messaging and by health professionals and culturally secure services focussing on dementia care is required.

## KEYWORDS

Aboriginal health, aged-care, cognitive function, dementia, qualitative study

## 1 | INTRODUCTION

In Australia, it is projected that the number of Aboriginal and/or Torres Strait Islander (henceforth referred to as 'Aboriginal') people aged 55 years and over will be

between 124,900 and 130,800 by 2026 (more than double the number from 2011).<sup>1</sup> Given the increase in the ageing population among Aboriginal communities, age-related disorders such as dementia are expected to rise. Australian Aboriginal people have a dementia prevalence 3–5 times

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higher than the general Australian population.<sup>2-4</sup> The age-standardised prevalence for dementia ranges from 21 to 28% among those 60 years and older,<sup>5</sup> and a longitudinal study in WA reported an incidence rate of 21 per 1000 person-years for those over 60 years of age, which is significantly higher compared to other Western populations.<sup>6</sup>

Dementia impacts on memory, thinking, behaviour and the ability to perform everyday activities.<sup>7</sup> Along with lifestyle factors,<sup>6,8-10</sup> co-morbidities such as hypertension, diabetes, hypercholesterolemia, obesity and depression are also associated with an increased risk of cognitive decline and dementia among Aboriginal and non-Aboriginal people.<sup>6,9,11</sup> Longitudinal risk factors for cognitive impairment and dementia are age and head injury.<sup>6</sup>

Previous studies suggest that Australian Aboriginal people have a limited understanding of the biomedical definition of dementia.<sup>12-14</sup> As there is no traditional explanation for dementia, it has been defined as a 'sick spirit', 'childlike' and 'madness'.<sup>14,15,16</sup> Due to lower life expectancy among Aboriginal populations and common misconceptions that Aboriginal people do not live long enough to experience 'geriatric syndromes', little evidence exists regarding the health status and literacy of older Aboriginal people, particularly for dementia, in comparison with the general population.<sup>17</sup> Appropriate support services need to be based on the specific capabilities and cultural perspectives of families caring for someone living with dementia; key attributes of effective communication with Aboriginal people living remotely about dementia include skilled facilitation, a clear implementation strategy, a culturally safe process and the use of local and culturally appropriate languages and images to develop health literacy.<sup>15</sup> A review of the literature also shows an under-representation of Indigenous people using government services.<sup>18</sup>

To date, there have been few studies that have explored the 'lived experience' from people with dementia or providing care for someone with dementia; these have been mainly among remote/regional areas.<sup>19</sup> A study conducted in the Kimberley region of WA found a general lack of awareness among Aboriginal people of services, and the importance and need for community-based culturally safe services. A recent study provided insights from staff at Aboriginal community-controlled health services (ACCHOs) about community needs for dementia care.<sup>20</sup>

We explored the way Australian Aboriginal people in the community and staff from Aboriginal community-controlled health services (ACCHOs), in an urban/regional setting in WA, understand and define dementia, their knowledge of ways that dementia can be prevented or slowed down, their experiences of living with or caring for someone living with dementia and their awareness of the types of local support services available.

### Practice Impact

This research shows the need for increased awareness of dementia in the community through culturally appropriate public health messaging and appropriate advice from health professionals. There is also an urgent need for culturally secure services focussing on dementia care for Aboriginal people.

## 2 | METHODS

### 2.1 | Setting

We conducted this study in metropolitan Perth and a regional town, Bunbury, located in Southwest WA. We partnered with ACCHOs established by local Aboriginal Noongar leaders, which included The South West Aboriginal Medical Service (SWAMS) in Bunbury and Derbarl Yerrigan Health Service (DYHS) in Perth.

### 2.2 | Data collection

This study was informed by a participatory action approach with co-design<sup>21</sup> and data collection shared by University, Aboriginal and non-Aboriginal health service staff.

Aboriginal (SE, KT) and non-Aboriginal (LG, RC) researchers along with Aboriginal health practitioners and nurses in Perth and Bunbury (EP, SC, KH, FE and SD) led the data collection, analysis and interpretation of findings. SE, an Aboriginal researcher from WA with close links with Aboriginal services and expertise in Aboriginal research design and methods, lead the project. KT is an Aboriginal researcher with skills and experience in conducting community lead research. LG and RC are non-Aboriginal researchers with experience working with Aboriginal communities in the region. Aboriginal health service staff led the identification of appropriate recruitment strategies, interview and distress protocols and recruitment. This leadership was vital in ensuring that the project was Indigenous lead and feedback to service improvement. Reflexivity was important for both Aboriginal and non-Aboriginal investigators and was supported by workshops held at the health services to discuss research findings.

Aboriginal health service staff (EP, SC, KH, FE and SD) were provided with training on qualitative research, led the recruitment of participants and conducted the semi-structured interviews. All interviewers

were females. The methodological approach of semi-structured interviews was used in this project to capture the views and perspectives of dementia by community participants and staff themselves. Given that we were asking participants to draw on their personal and professional experiences of dementia, interviews were deemed appropriate in discussing potentially sensitive issues.<sup>22</sup> The theoretical framework of constructivism supported this methodological approach as we were interested in the social and cultural meanings that participants ascribed to dementia.<sup>23</sup>

Our semi-structured interview guide, developed in consultation with the research team, included questions about the participant's knowledge and understanding of dementia, dementia prevention, experiences caring for someone living with dementia and local available support services. Health service staff were also asked whether they were aware of any guidelines or frameworks and/or received any specific training to help them care for older people or people with dementia. The interview guide was piloted with a convenience sample of four Indigenous health service staff and two community members. Slight modifications were made to the interview guide: (1) the interview was split into clearly defined sections, (2) there was further clarification and simplification of the language used, and (3) prompts were added to aid the interviewer.

We recruited through purposive and convenience sampling. Participants included male and female staff from SWAMS and DYHS and Aboriginal male and females residing in the community, aged 18 years and above. We consulted senior staff at the health services to identify staff to be interviewed. Community participants were invited mainly through the clinic waiting rooms (with permission from respective health services) and through community networks. Community participants received a \$50 gift voucher for their time. Interviews were conducted after the participants had read, understood and signed the consent forms in the clinic rooms, and they took place between April 2019 and June 2019.

### 2.3 | Data analysis

All interviews were digitally recorded, independently transcribed verbatim and analysed thematically by two researchers (KT and LG) using NVivo 12. A coding framework was used to code all transcripts. Some themes were identified in advance using the interview guide, and new themes were also derived from the data.

This study received ethics approvals from the Western Australia Aboriginal Health Ethics Committee (WAAHEC#863) and the University of Melbourne Human

Research Ethics Committee (HREC#1852484). We also received approvals from the research subcommittees of our partner Aboriginal health services.

## 3 | RESULTS

We conducted 39 semi-structured interviews until data saturation was reached (duration ranged from 5 to 30 minutes). Twenty-three participants were Aboriginal people from the local community (8 from the Bunbury area [C1] and 15 from the Perth area [C2]) and 16 participants were staff from SWAMS (HS1) (n = 10) and DHYS (HS2) (n = 6).

### 3.1 | Understandings of dementia

Overall, some staff had greater awareness and understanding of the biomedical basis of dementia compared to community participants; given these small differences, responses from all participants have been combined. The most common theme amongst participants was the association dementia had with memory loss and forgetfulness, particularly with long-term memory.

So, it's not knowing possibly who you are or who family members are, or anybody. Where you are, what you're doing, walk into one room and "what am I here for?" You might not remember what day of the week it is.

[HS1 Participant 2]

Some participants related memory loss to lack of ability to carry out activities of daily living:

It takes over control of the brain, the memory loss. They forget to take their tablets, they forget about their hygiene, going to the toilet, showering, eating, everything like that.

[C1 Participant 9]

Participants also noticed a change in behaviour with increased aggression frequently mentioned.

She talks about how she would all of a sudden just going off saying "I'm going to kill you," and then an hour later it's like "oh, what are you doing my son."

[C2 Participant 3]

Participants spoke about dementia being related to drug/alcohol use and mental health and trauma:

I think it can be drug induced, or alcohol induced. And that like with alcohol, the onset can come earlier.

[C2 Participant 16]

We have been deprived from birth, in a lot of circumstances. And I think that has got to do a lot with mental health and the way that that is managed in our lifetime. And I think that if that is managed, your outcome is looking a lot rosier. [

C2 Participant 8]

### 3.2 | Community awareness of dementia

There was little discussion or understanding of the onset of dementia in the community explaining that this could be due to feelings of shame.

‘I think with Aboriginal people, I think that there’s a lot of dementia that does start and people don’t understand what are the signs or symptoms of dementia.’

[C2 Participant 1]

‘We don’t see it; we don’t hear about it. And people don’t actually talk about dementia enough. You know, to look out for the warning signs...A lot more education needs to be put into it. Is it shame? Or admittance, no one wants to admit that they’re getting dementia...But if we all knew about it, you know, is it a fearful conversation that you want to have with someone? Does it look like “oh, I’m going to die, now that I’ve got dementia. Or do I need to go into a home, because I’ve got dementia?”’

[HS1 Participant 2]

People would feel shameful if they said they or someone else they knew may have dementia.

Well, they have, but people are usually in denial, and they say “no, we’re not, no we’re not, we don’t,” you know, but they reckon that’s a “senior’s moment.” [

C2 Participant 7]

Well, with the Aboriginal people in general, they don’t understand you know. And especially with the younger ones, it’ll be like a shame thing. You never tell a Noongar fella

that they can’t, they’ll think like this. That’s how they’ll probably think about it.

[HS2 Participant 1]

Participants expressed the need for more education and awareness of how to recognise dementia and what to do when family members go through it.

Also, with education, it’s important that Noongars get educated about this here so they can probably keep their loved ones at home longer.

[DYHS Community 9]

So, they just accepted that was the norm for them, and that’s how mum was, but they had no idea what she was going through, so they couldn’t provide any support to help, or anything. All the kids thought that she was just, I don’t know, going off I suppose, and had no real understanding of what to do about it.

[C2 Participant 3]

#### 3.2.1 | Caring for family with dementia

Participants shared experiences where they had previously either cared for a person or engaged with a family member living with dementia, and expressed how difficult it can be for the family to provide the required care without some support.

It generates a lot of issues within families about who’s responsible to look after that person. The impact it has on others in the family, and the household, around that constant monitoring.

[HS1 Participant 3]

Participants spoke about how it was culturally the norm to keep families at home and taking elders to aged care facilities is a challenging experience with some having negative experiences and a fear of ‘losing their elders’.

We grew up with that, keeping people, family at home. We saw that because my great grandmother was over a hundred and she stayed at home. So, it was something we thought, well that was what you gotta do. That’s why it’s a big challenge today with people going into residential facilities. You know that’s a

discussion that isn't done well. Or prepared families for. And then all of a sudden it happens and they've got to make decisions, and it creates lots of issues.

[HS1 Participant 3]

She didn't like that there, and there was big family arguments about putting her in a home. And her daughter got her out, and she needed full time care but no one would, was taking the full-time care, wasn't doing a proper job. And that's why her grand-daughter put her in the home, and her mother put her in a home in the first place, and then got her out, wasn't giving her proper care, and was neglecting her, taking advantage of her, taking her money off her.

[C1 Participant 9]

### 3.2.2 | Reducing the risk of acquiring dementia

Participants thought that dementia could not be prevented or cured, and suggested some potential strategies to reduce the risk, such as keeping the mind active and socially/culturally engaged, avoiding stress and adopting healthy behaviours (good diet, physical activity, avoiding alcohol, drugs and cigarettes).

Active as in being engaged in activities with family members. Like, going bush, and reconnecting with country. And even doing simple things during the day such as puzzles, to keep the mind active.

[C2 Participant 14]

Just taking her [mother] round as she got older, and making sure she was able to you know, visit family, and see her family members. That she could sit on Country and do those sorts of things.

[HS1 Participant 3]

### 3.2.3 | Support services for dementia

Participants spoke about lack of culturally appropriate support services available for people with dementia and their family members. A few previously available 'home care programs' for older people were mentioned, but nothing specific to dementia.

...there is a big gap with aged care, isn't there? There's a lot of oldies out there that are being cared by the younger generation, the grannies are coming through. They're being cared for by their children, and they're not going into the aged care homes or anything. I don't even know if there's actually an aged care that is, actually, no Harvey Lodge has a dementia unit, so that's good to know. I don't think they've got Aboriginal specific beds allocated. You know, that cultural appropriateness needs to be embedded in those environments.

[HS1 Participant 2]

There also needs to be more appropriate care that does not cause confusion. An example was given where someone was confused as to why a mental health nurse was coming to see him:

And when we told Dad that it was a mental health nurse coming in cos it was a part of dementia, he turned around and told him he wasn't even mad.

[C2 Participant 1]

## 4 | DISCUSSION

We examined the lived experiences of Aboriginal people and staff from ACCHOs in WA about dementia and caring for people with dementia. Further education and awareness are required in the community around the early signs and symptoms to help family members identify it within their families, get appropriate support and to remove the shame and stigma associated with dementia. Importantly, it was evident that families were finding it very difficult to care for family members with dementia and many had negative experiences with 'aged care homes and facilities' that were not culturally appropriate. The findings from this study are in accordance with a similar qualitative study undertaken recently among ACCHO staff across Australia.<sup>20</sup>

There was a general understanding by participants that dementia was related to 'losing your memory' and a 'change in behaviour'. Participants identified risk factors (alcohol, drug use, smoking and stress) and potential protective factors (good diet, exercise and social support). Two previous studies have assessed knowledge about dementia among Aboriginal people using a scale Dementia Knowledge Assessment Scale (DKAS).<sup>12,13</sup> Has four domains (causes and characteristics; communication; care needs; risk factors and health promotion).

Knowledge gaps have been identified among Aboriginal community members in Tasmania in 'identifying early symptoms, risk factors and the progressive nature of dementia'.<sup>12</sup> Using a convenience sample of people attending a Sports and Cultural Festival, a study showed that Indigenous participants scored lower on the 'biomedical' questions and about the prognosis of dementia.<sup>13</sup> Older participants also showed greater knowledge than younger participants.

We found participants had confusion around the impact of drugs, alcohol and mental trauma on memory loss and whether that is associated with dementia or not. Recent evidence has shown the impact of harmful alcohol use and dementia.<sup>8</sup> However, further educating the community on knowing the difference between the short-term memory loss related to alcohol/drug use and dementia-related symptoms is critical. Interestingly, there were a couple of examples related to dementia onset following trauma. In relation to this, a study among urban/regional communities in New South Wales demonstrated the association between childhood adversity (separation from family, poor childhood health, frequent relocation and growing up in a major city) and diagnosis of Alzheimer's disease in late life even after controlling for depression and anxiety.<sup>24</sup> Further work is required to explore whether trauma during the life course (not just restricted to childhood) has an impact on dementia risk and ways of mitigating the impact.

We found agreement among participants that there was not enough education and awareness in the community around dementia and that this was something that would benefit the community. These findings are in accordance to previous studies conducted across Australia, which have reported a lack of community awareness about dementia and the need for education programs to ensure carers of Aboriginal people living with dementia are well informed and to provide culturally appropriate care.<sup>12,20</sup> Our study also shows that there needs to be more awareness so that people do not feel shameful about it and deny that they are experiencing symptoms. There is a need for a more systematic approach to informing people about dementia in the community. A previous qualitative evaluation undertaken in the Northern Territory among health-care professionals and aged care workers found that effective resources for community and staff need to take into account the target audience and that dementia awareness must be a 'whole of system' responsibility and not just restricted to the aged care services.<sup>25</sup> Thus, people will not associate dementia with shame and stigma and will also be able to find ways of managing it effectively if it is promoted more widely through community organisations.

Participants with a lived experience about dementia spoke about the significant impact it has on families;

similar findings have also been reported in a study from the Kimberley region of WA.<sup>19</sup> Although it was difficult, families preferred to care for their elders at home rather than have them in aged care facilities where they were not receiving culturally secure care. Similarly, another study reported that aged care organisations were the '*least preferred dementia care option*'.<sup>12</sup> A recent study by Bryant et al (2021) also emphasised the lack of culturally appropriate dementia care for Aboriginal people.<sup>20</sup> Indigenous communities in New Zealand, Canada and Norway are also facing similar issues in delivering culturally safe aged care services.<sup>26</sup> Our participants also noted that '*fear of losing them*' was another reason Aboriginal people chose to keep their elders at home. These findings suggest that 'in the home' support services would be more beneficial to families. Only one health service staff member reported having had undertaken training in aged care. Having more Aboriginal health service staff trained in aged care, and particularly dementia care, would alleviate the situation; this has recently been acknowledged in a research paper and through the Royal Commission report on Aged Care Services.<sup>20,27</sup> The report has outlined some key recommendations: appointing an Aboriginal aged care commissioner, prioritising Aboriginal organisations in providing aged care services in partnership with other services, improving employment and training in cultural safety and trauma-informed service delivery.

We explored knowledge and understanding of dementia and the lived experience of caring for family members with dementia among both community participants and staff from ACCHOs in a predominantly urban area of WA. Hence, it adds to the knowledge base from previous studies that have used surveys and qualitative data from lived experiences.<sup>12,13,20</sup> Although our participants were mostly from urban areas of WA, a few participants mentioned services located in more regional/rural areas. Given the similarities between our study and previous ones, it appears that the issues with service access are similar across different geographical areas.

## 5 | CONCLUSIONS

In conclusion, there is an urgent need to implement health promotion programs through ACCHOs to raise community awareness about dementia. The benefits of healthy lifestyles on dementia must be reinforced. Importantly, families need support when caring for family members with dementia and current aged care facilities are inappropriate. Aged care and dementia-specific services must integrate family, culture and community into their service delivery model.

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## CONFLICTS OF INTEREST

No conflicts of interest declared.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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