

ORIGINAL RESEARCH

‘Gotta be sit down and worked out together’: views of Aboriginal caregivers and service providers on ways to improve dementia care for Aboriginal Australians

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ABSTRACT

Introduction: Dementia is five-fold more prevalent among Aboriginal than non-Aboriginal Australians. Despite this, the quality of care available to people living with dementia in remote Aboriginal communities is poor. The objective of this study was to determine ways to overcome factors affecting the successful delivery of services to Aboriginal people with dementia living in remote communities, and to their families and communities.



Methods: This qualitative research took place in the Kimberley Region of Western Australia. Data collection occurred in three stages: (1) interviews with service providers to identify the services available; (2) interviews with the caregivers of Aboriginal people living with dementia and community-based care workers; and (3) focus groups with community representatives and community care staff. Each stage was concluded when no new themes emerged. At each stage the transcribed information was analysed and joint interpretation identified common themes.

Results: In total, 42 service providers, 31 caregivers and community-based care workers were interviewed and 3 focus groups were conducted. Obstacles to accessing quality care were mentioned and recommendations on ways to improve care were made. The key themes that emerged were caregiver role, perspectives of dementia, community and culturally-appropriate care, workforce, education and training, issues affecting remote communities and service issues. Detailed information on how each theme affects the successful delivery of dementia care is provided.

Conclusions: These research findings indicate that people living with dementia and their caregivers in remote Aboriginal communities are struggling to cope. They are requesting and require better community care. Implementing a culturally safe model of dementia care for remote Aboriginal communities that encompasses the recommendations made and builds on the strengths of the communities could potentially deliver the required improvements to dementia care for this population.

Key words: Aboriginal, Australia, caregivers, community care, dementia, Indigenous.

Introduction

The nature of dementia, which often includes behavioural and psychiatric symptoms, loss of functional independence and the need for constant supervision, presents many challenges for people with dementia, their caregivers and health professionals. International data, including those from developing countries, estimates that the number of people with dementia is expected to double every 20 years and will reach 81 million by 2040¹. Higher rates of dementia are reported in countries of poorer socioeconomic conditions². Rural populations are ageing at a faster rate than urban populations³ and their health is often poorer due to lower socioeconomic status, levels of education, higher environmental risks and decreased access to services⁴.

International systematic approaches to dementia research and interventions in regions with lower socioeconomic conditions have been described⁵. The prevalence of dementia in the Aboriginal population of the Kimberley Region has recently been given as 12.4%, approximately fivefold that of the Australian population⁶. The key to improving Aboriginal and Torres Strait Islander health is ensuring effective and

equitable access to quality health care⁷. It is generally accepted that the development and provision of care for elderly Aboriginal people should reflect their holistic needs, including their spiritual, emotional, cultural, physical and mental wellbeing^{8,9}. There is a paucity of information on the perceived unmet need of Australian Aboriginal people with dementia and their carers, and ways to improve service delivery in remote communities⁷.

The need for research into best practice for Aboriginal and Torres Strait Islander community care has been identified previously^{10,11}. At a national Indigenous dementia workshop run by Alzheimer's Australia¹⁰ participants identified that innovative solutions are required to improve dementia care in Aboriginal and Torres Strait Islander communities and to enhance the ability of community members to age 'successfully'. The respondents called for action on the following issues: community awareness and prevention, care and support, research, diagnosis, referrals and treatment, workforce issues, and partnerships and collaborations.

These issues are not confined to the Australian Indigenous community. In the USA, Jervis et al¹² emphasised the need for improvements to community care and caregiver support



services for Indigenous Americans living with dementia. The authors reported that, as in remote Aboriginal Australian communities, many community care services are not delivered at all on reservations, and that available services are delivered from a range of different sources with no central coordination¹².

The objectives of this study were to describe the unmet needs of those with dementia living in remote communities of the Kimberley, perceived by service providers and caregivers. A further objective was to explore ways to facilitate improved care in this setting.

Methods

Research context

The Kimberley spans 421 451 km² in the north of Western Australia and contains over 200 remote Indigenous communities and 6 towns. Indigenous people comprise 47% of the population with approximately 2100 being over the age of 45 years.

A steering committee consisting of Kimberley-based Aboriginal caregivers, community care workers, key service providers and remote Aboriginal community council members was formed at the outset of the study to guide research staff and provide advice. This committee provided guidance and support to the project team, and approved all research methods, including interview schedules.

Data collection

This was a qualitative study with data collection occurring in three distinct stages.

Data collection stage 1: A scoping study was performed of key service providers of Aboriginal people living with dementia. Forty-two people were interviewed (either face-to-face or by telephone) from a range of services across the Kimberley, including aged care, allied health, mental health,

population health, Aboriginal health services, hospital, dialysis centre, palliative care and disability services. Open-ended questions aimed to determine what services are available for older people with dementia and their caregivers, the strengths or difficulties experienced by service providers, and suggestions about how to improve dementia care.

Data collection stage 2: In the second stage, face-to-face in-depth interviews (using open-ended questions on a semi-structured interview schedule) were conducted with Aboriginal caregivers and remote Aboriginal community care staff. Consent was gained from 6 community councils to interview caregivers and care workers living in their community. Caregivers were then approached individually and recruited through purposive sampling. An information sheet was read out and left with the participants. This gave details of the research to participants and informed them that participation was voluntary. In the majority of cases the individual interviews occurred at the time information was provided and consent was given.

A total of 32 interviews were conducted at this stage with Aboriginal informal caregivers of people with dementia, community care workers and service providers. All interviews lasted 30–60 min and were taped and transcribed. An Aboriginal researcher was involved in the majority of these interviews, in both the interviewing and transcribing process.

Preliminary analysis of these interview transcripts, as well as feedback from the steering committee, informed the development of the next stage of data collection.

Data collection stage 3: Three focus groups were held (two in remote communities with community representatives and community care staff and one in Broome with aged care service providers) drawing on previously determined themes to discuss ways to improve community care. The focus group discussions were transcribed for further analysis.



Data analysis

Transcribed information was entered into NVivo 8 (www.qsrinternational.com), and joint interpretation occurred to identify common themes. Initial data analysis occurred following each stage of data collection. This involved cross-case analysis where data from all interviews were assembled under common categories, usually those that had been determined by the interview questions and other categories that arose during the interviews. This analysis provided broad categories to be compared with emergent themes from the next stages of analysis and to inform other stages of data collection. Each data analysis stage involved several of the authors as well as Aboriginal research assistants, and was concluded when the themes were saturated.

A final and more detailed thematic analysis involved four authors independently reading through interview notes and transcripts and identifying themes. This provided a fuller reading of the texts while searching for other new data categories. Themes were then grouped, compared with the original cross-case results and a consensus reached as to the major themes from the combined data to be presented in the findings

Feedback on the progress of the study was provided through the Kimberley steering committee and a semi-annual newsletter that was distributed to remote Aboriginal communities, relevant service providers and organisations Australia-wide.

Ethics approval

Ethics approval was obtained from the Western Australian Aboriginal Health Information and Ethics Committee and the University of Western Australia Ethics Committee for Human Research.

Results

The information extracted from the research process on potential facilitators and obstacles to the delivery of care to people living with dementia was grouped into 7 broad themes (Table 1):

1. Caregiver role
2. Perspectives of dementia
3. Community and culturally appropriate care
4. Workforce
5. Education and training
6. Issues affecting remote communities
7. Service issues.

Caregiver role

Caregivers undertake the caring role for multiple reasons and have a range of other responsibilities as outlined below.

Reasons for being a caregiver: The key reasons given by caregivers for how they came to be caring for a person with dementia were: cultural and family responsibilities, out of necessity to keep the older person in their community, and the important role that the older person has in keeping the family together and in passing on cultural knowledge and language to family members.

I was married to her son. Mmmm, and she was looking after me when I had my first child, she was always caring for me...that's why I am looking after her. (Carer 1)

Even for the little kids they learn a lot of her as well... She teaches in languages. Words 'right' and 'wrong', how to respect others, she does a lot of things... Yeah um yeah I'm happy keeping her for now 'cause she when she does go away she, she worries she worries about the little ones and she worries about me so she end up coming, she end up coming back and you know she's more happier at home. (Carer 4)



Table 1: Themes and sub-themes of factors impacting on the delivery of quality services to Aboriginal people living with dementia

Theme	Sub-themes
Caregiver role	Reasons for being a caregiver; additional care-giving responsibilities; sharing care-giving roles
Perspectives of dementia	Causes of dementia; signs and symptoms of dementia
Community and culturally appropriate care	Community engagement; community based care; culturally appropriate activities
Workforce	Aboriginal staff; staff who are trusted and accepted; local support and guidance; accommodation; low pay and undervalued; domestic issues
Training and development	Cultural; dementia and elder abuse training
Issues affecting remote communities	Overcrowding; financial burden; transport; elder abuse
Service issues	Communication and co-ordination; intolerant attitudes of staff and general community; flexibility; distance of services from community; interpreter use; clinical pathways and protocols; lack of services

Additional care giving responsibilities: Many caregivers look after other people in addition to their family member with dementia, including children and extended family members, increasing the carer burden.

Yeah I've got four kids of my own plus um one of my sister's child I'm looking after as well. It's a big job, it is yeah trying to work and juggle family at the same time...all of them at school, ahem, one's at home and looking after her is like four kids in one because she's like a big kid herself. Um and it's very hard. (Carer 1)

Sharing care giving role: Sharing the caregiver role may take some of the burden from primary caregivers.

Countrymen could support those people in their community by offering support to other family members and sharing caring roles. (Community worker 10)

There was, however, evidence that some caregivers have this family support.

Well he got my other grandmother and grandfather that lives in that house...we just all take turns helping

out... but, um, I do the main things like doing all the ringing up. (Carer 11)

Perspectives of dementia

Caregivers and community workers view dementia and its signs and symptoms in different ways. This knowledge may assist in improving quality of care, and in the delivery of appropriate education and training.

Causes of dementia: People attributed dementia to a variety of causes including old age, head injury, lack of family visits and brain changes.

When you get to that certain age they accept it, ah, finish, you know...err, there'll be one to say oh I fell off the horse long time. (Carer 9)

Signs and symptoms: Caregivers spoke about how they first noticed that their family member had dementia, such as forgetting where things are kept and people's names, behavioural changes and daily fluctuations in cognition.

...um, she's always arguing and forgetting people...forgetting where she puts things...and she



can't find it she'll start growling at grandchildren.
(Carer 10)

Community and culturally appropriate care

Community engagement: Caregivers, service providers and community workers alike felt strongly that dementia initiatives must be driven by the community and that the community must be engaged at all levels to be successful. The importance of the service provider and community working together was also mentioned.

They should be working in closer like, err, well it should be a two-way thing: community and the service provider and the carer and the person that's being cared for and the whole family in general, that sort of thing gotta be sit down and worked out together. (Carer 14)

Community-based care: The importance of the person with dementia being able to stay in the community close to family and country was discussed, and the benefits this has on their memory and general health.

Keep them home with their own mob families you know... Close where they can remember things every time we repeat things to them you know... They start remembering things then... Properly you know but when they go with kartiyas [non-Indigenous people] they just... Forget. (Carer 8)

Well I am just saying like that's another reason for this thing I think with elderly people is keeping them in Country. You know even though they are losing their mind in terms of their memory and lose concept of who's who and whatever, it is still important for them to feel connected to their country and taking them away like, I am sure that they want to die and pass in their country. You know that's their spirituality that's their connection. (Community worker 5)

Service providers and caregivers also recognised that community members are reluctant to go to town-based residential care because it is regarded as a place where people are sent to die.

Because she said to me 'they want to just drop me off there so I can die', so she has a fear of Numbala Nunga and Frail Aged [residential care facility] she says she just likes to visit... but she will never stay there. She says 'if I go to them places I'll die'. So I think with the family environment, the old girl loved it. (Carer 5)

Culturally appropriate activities: The need for culturally safe activities was discussed.

But for activities and that, it should be something that should be worked out between the person and the carer and the community where they ever looking at the environment on where they live. (Carer 14)

Workforce

Aboriginal staff: Carers and service providers stated that employing more Aboriginal community-based staff was the best way to improve the quality of care for Aboriginal people with dementia.

They need some Aboriginal people working in HACC [Home and Community Care program] to show them where the places are to take out for activities. Yeah no aboriginal people which is funny, not funny but I think it's really silly because the majority of clients is Aboriginal people. (Carer 4)

Staff that are trusted and accepted: Caregivers stated that they need time to trust someone before they feel comfortable leaving them to care for their relative.

It's getting the appropriate person or persons to take on that type of role you know. That's right then you'd



have sort of have a little trial run through the day. Not that I don't think that they'd be capable because I mean they wouldn't just go and recommend just anybody willy nilly. (Carer 6)

Local support and guidance: The shortage of community-based support, regular guidance and feedback for community-based staff was discussed. This issue was mostly attributed to the problems of staff shortages and high turnover, which negatively impacts the level of care provided. One participant who deals most with older people, said she would like to be able to spend more time with the carers in community, but is limited by time and staffing (Service provider 27). Others said:

Oh, well, sometimes we have no, not enough help. That's all just no help. You know the workers. Sometimes be too hard for me. You know. (Community worker 1)

They have problems with staff too, see it keeps changing you know... so I guess you train them up and then, um, they go... (Carer 7)

Accommodation: A lack of housing in the region, particularly in remote towns and communities, was seen by many as a barrier to finding and retaining staff. The inequity of only higher paid staff receiving an accommodation allowance was also discussed.

Noted that housing is an issue and that there is a lack of equity with level 3 Aboriginal staff not qualifying for accommodation. (Service provider 2)

Low pay and undervalued positions: People stated that community care workers needed to be better paid and their roles more highly valued. One service provider indicated that:

... people don't want to be care workers because it is only a part time, occasional position and people can't

afford to live in the Kimberley on a part time wages. The positions are also generally low paid and are not valued. (Service provider 5)

Domestic issues: Domestic issues such as jealousy can also impact on community members' ability to work in community care.

... the young woman did not turn up, as there were issues with her partner jealousying her. (Service provider 9)

Education and training

Cultural training: The importance of cultural training for service providers and external community care staff was discussed by many people.

They should have some basic understanding of Aboriginal culture and respect the way they live and not be judgmental. Respect areas that have cultural significance, Law grounds men and women. (Community worker 10)

Dementia training: It was noted that service providers, caregivers and community workers would benefit from dementia training and education regarding the availability of services to support a person with dementia and their family.

Well there should be more information given out to the families and that because not too many people know that there is help available, they just government mob just keep it all within the office, I don't know who they get as field staff and that to take the information out to, um, educate the people on just awareness of what support is there available for people. (Carer 14)

Elder abuse training: Training on how to recognise elder abuse and how to help people who are being abused was requested.



The other thing that we also see is elder abuse.... In the community. So just making people more aware that that does go on and that does happen and how we can you know recognise it because a lot of people don't talk about it... And it happens in Aboriginal families and non-Aboriginal families... And that may simply be neglect, not changing their nappy, not making sure they are showered, not giving them a good feed. So they're all forms of elder abuse and it can be emotions as well so it... and demanding money, taking the nanna key card. I mean that's all forms of elder abuse. So, I think more community awareness about how can we look after our grannies better, and how can we prevent them from been abused. (Community worker 5)

Issues affecting remote communities

Overcrowding: Overcrowded housing is impacting on the health and welfare of older people living in remote communities. A lack of community housing can lead to caregivers being unable to continue to care for a person with dementia, resulting in admissions to town-based residential care.

All the kids and we bin bring them back here so we've bin all living at camp but it was too much crowded you know... it was crowded so we couldn't stay there. (Community worker 8)

Interviewer: *So now she's over there in that frail aged?*

Yeah. (Community worker 8)

Overcrowding also affects the success of health professionals' recommendations. Service provider 14 gave an example of trying to give practical support. He had recommended keeping the floor surface dry in:

...an 'overcrowded house, big mob of people showering all the time and kids etc – very difficult to

maintain), trying to keep the floors free of obstacles at night time to avoid falls or tripping when wandering (people sleeping on floor – this was not often possible).

Financial burden: Living costs are very high in remote areas, particularly for food and transport, which affects the ability of families to care for a person with dementia. Service provider 25 noted the financial hardship of clients, commenting '...everything is so expensive in the Kimberley and pensions are inadequate. Particularly for people who struggle to budget and get by'.

Transport : A lack of public transport, access to vehicles and the high cost of fuel affect the ability of older people in remote communities to access health and community services, to take part in activities and to visit family and friends.

A lot of people don't have transport, their own transport. (Carer 14)

Service issues

Communication and coordination: A key service issue emphasised by caregivers, service providers and community workers was the need for improved communication and coordination among service providers, and among service providers, communities and caregivers.

...people [service providers] visiting the community and not informing the clinic – if we can't work with each other than how are we going to work with the community? Agencies in...[this community] don't communicate very well – and there are only five main services. Have tried to have regular meeting etc, but never works out. (Service provider 31)

There is also difficulty in communication between service providers and family carers. Service providers have a lack of awareness of what the family carers needs are. (Service provider 3)



There was some evidence that this lack of coordination and lack of client advocacy is preventing services from being delivered and impacting on the ability of the person with dementia to remain living in the community safely.

I was waiting on Homeswest to install some bars since last year. So they still haven't done it I'd be ringing them up boy or getting HACC and aged care mob to do it to ring up about it and the OT and the physio. They find it really hard they reckon and then it would take 18 months. (Carer 4)

For people to stay for longer in community there needs to be better liaison, which would result in a smoother ride for the client and more of an understanding. (Service provider 16)

Intolerant attitudes of staff and general community: Some of the attitudes portrayed by service providers and the general community interviewed were discriminatory or defeatist, which may affect the quality of services that they are delivering to people living in remote Aboriginal communities.

There are huge weaknesses in community...how do you pass on the values of empowerment, responsibility if you can't give people a book. Have to use incidental chances... (Service provider 2)

Flexibility: Service providers reported that a key strength of their service was the flexibility of their service provision in order to meet the needs of the community. Service provider 8 noted strengths during conversation in relation to the flexibility of the program, enabling it to be tailored to remote needs. However, the need for generalist health service to be less discriminatory about aged people and more actively involved in providing quality services to this group was also discussed.

Health care services in general need to consider aged care to be the norm and not a specialist field or someone else's responsibility. Should be a part of

standard, normal practice. Health care services need to change their focus from age, to that of function, to not discriminate against older persons or young people with disability. (Service provider 3)

Distance of services from communities: The large distance between towns (where the majority of health and community service providers are located) and remote communities affects the ability of service providers to provide quality care to people living in these regions.

Geographic sparseness, which has an effect on having to establish rapport with people in remote communities. (Service provider 19)

The services are delivered so infrequently that it is hard to say what is done well. (Service provider 41)

Interpreter use: Service providers stated that interpreter use was lacking in the health and community care setting.

The Anunga rules which bind police / lawyers etc to ensure that interpreters are available, so that the person can understand questions. There should be a similar set of laws for health settings, for example for people in hospital not understanding medications. Without interpreters there is seldom informed consent. (Service provider 20)

Clinical pathways and protocols: The need for clinical pathways and protocols for dementia in the Kimberley Region was emphasised by clinicians. The lack of dementia guidelines has led to inappropriate referrals.

There are currently no agreed upon best care practices that all health professionals at all services use (for dementia). There are no clear pathways for best care leads to inappropriate referrals, or missed referrals. (Service provider 3)



It was also stated that the absence of guidelines has meant that people with dementia were not diagnosed and so missed out on support services.

They probably die before being diagnosed or accessing services. (Service provider 20)

Lack of services: People spoke about a lack of services for Aboriginal people with dementia and their families. The key services unavailable in the region were specialist, community care and caregiver support services.

Specialist services: Service providers were concerned about the lack of aged care specialists in the region and the infrequency of geriatrician and psycho-geriatrician visits to the Kimberley from Perth.

More geriatrician/ psycho-geriatrician visits [are needed]. (Service provider 1)

However it was also thought that remote practitioners should be more proactive in utilising telehealth.

Some talk on absence of psycho geriatrician, and how there could be increased access to these specialists if people (eg nurse in remote clinic) were more assertive in identifying that is what is needed, and that they can use the videoconferencing facility (eg in Balgo) to link up with specialists based in Perth or metro areas. (Service provider 7)

Community care services: Community care services for people with dementia were either not functioning in the remote communities or, when mentioned, were seen as a meal service only.

Noted that the community HACC used to provide meals but that this no longer happens. (Service provider 28)

The paucity of functioning community care services has led to poor outcomes for people with dementia living in remote communities.

Case from community, an older demented lady living very happily at home, immobile, in bed, surrounded by 4/5 dogs, shit, rubbish. People let her stay in pigsty as to take her out would have caused immense unhappiness. Until finally, health services had to step in. This could have been eased if there had of been someone there earlier on in the older ladies life to encourage her to get out of bed each day etc, and this would have eased the pace of the deterioration. (Service provider 30)

Caregiver support services: Caregivers of people with dementia were vocal about their need for more information and support.

Nothing, we don't get help from nobody, we just help each other I suppose because we still have that independence as well but, but that's not the point, sometimes it's good to have that little bit of help even if it's moral support. (Carer 14)

A lack of activities and respite time were key issues for caregivers.

The carer and the family in who they caring for to, um, assist them just by little day or overnight activities camping trips or, like, take them down the beach fishing or camp out overnight, that sort of thing those old people love that kind. They mightn't be able to walk, but even just to sit down on the beach some of them just love it, it builds their morale up too make them feel good and gives that bit of, but even though when you do that you still need someone to give that extra support to the carer as well because, so that there's a bit of balance for the time for the person, the client having their own time as well as the carer having a little bit of time out for themselves as well. (Carer 14)



Discussion

These research findings indicate that people living with dementia and their caregivers in remote Aboriginal communities in Australia are struggling, and the themes raised may contribute to improvement in community care. Many issues described are not unique to Indigenous Australians and have been documented for other Indigenous populations and rural communities^{13,14} and are common to many caregivers of those with dementia. However this is the first study reported undertaking in depth interviews with caregivers and service providers living in remote Aboriginal communities, and as such it forms the basis for potential development of models of care. The main principles considered important by the participants are summarised.

Genuine community engagement

A recurrent theme was the need for remote communities and service providers to work in a cooperative manner, with community representatives involved in the service from the planning stage and formally represented at all levels, including management, to provide necessary expertise and guidance. In addition, service providers and organisations with specific beneficial skills should be engaged to work cooperatively with the community to provide expertise as needed. The need for genuine collaborative partnership is often documented in government policy, and this arises from the knowledge that current western frameworks may be in conflict with Aboriginal beliefs concerning health care¹⁵. Research has strongly linked community development approaches with positive health outcomes, increased access to services and patient satisfaction^{16,17}.

Communication and coordination

It was identified that communication and cooperation among services, and between individual services and the community could be greatly improved. The number of external services working separately leads to poor case management, which is also hindered by distance and inflexible care options¹⁸.

Formal structures must be developed to ensure cooperation and regular communication among services, and between services and the community. Community members were often unaware of the function of services or what services were available; they did not know how to access services nor to contact them to follow up care that was promised. This is common to the carers of those with dementia and those who lack education^{18,19}, and it is compounded by language barriers and stigmatisation²⁰. Inherent differences in and poor coordination of services leads to poor continuity of care²¹. The vast number of remote communities, for example there are over 200 in the Kimberley Region, compounds these issues.

The availability of a community-based advocate who is trusted and easily accessed by both community members and external service providers would be beneficial. In addition, service provision could be streamlined if external services co-funded a community-based service with the community, or with an existing community-owned service (eg a community-run health service).

Community-based and culturally appropriate care

The benefits of community-based care were regularly highlighted by participants. The importance of staying on Land, and of Law and language to the health and wellbeing of Aboriginal community members has been thoroughly documented^{22,23}. The development of community-based services not only improves the health and wellbeing of the people receiving care, but may also improve the health of the whole community by offering employment and training to other community members.

A community-based, culturally safe service would facilitate access to care. ('Cultural safety' places the onus for change on the service provider, rather than the client. The care provider undertakes to consider the things that make clients unique, and to provide care that takes account of differences. This requires care providers to reflect on their own cultural identity and on their relative power as providers of care.



Cultural safety is achieved when the recipients of care deem the care to be meeting their cultural needs²⁴).

Valued and supported Aboriginal workforce

To improve cultural safety and access to care, participants recommended the employment and training of community-based Aboriginal staff. The literature shows that high staff turnover, lack of professional support, reduced opportunities for training and development, and lack of professional supervision results in the short tenures of health and community carers^{17,25}. In the present study, community workers identified that they lacked day-to-day management and support, and external service providers stated that they did not have time to provide the necessary support. Therefore, a community-based manager is essential, with the role to provide regular staff management, feedback, assistance with day-to-day planning and service provision, and to access training for staff. Support and guidance from the community council is also recommended.

Education and training

Community, caregiver and client education, and staff and external service provider training are needed. Participants recommended that all these groups have dementia and elder abuse education and training. Culturally specific training would also benefit external service providers as it would improve service provision. Community members require education about the services available to them and ways to access these services.

Workforce and caregiver education and training is often limited in rural areas due to the high costs of provision and limited providers¹⁸; however, even limited interventions have been shown to improve outcomes in dementia care²⁶. Culturally specific educational material for health workers is currently under development and evaluation²⁷.

Issues affecting remote communities

The high cost of living in a remote community, overcrowding, transport and elder abuse were identified as

issues that are affecting the health and wellbeing of people living with dementia and their caregivers. Accessible housing and other infrastructure are key requirements in providing successful long-term care in remote communities²⁸.

Service provision issues

The availability of community care was often limited and a wider range of flexible, culturally safe services was requested. Also identified were the need for interpreters, cultural education for service providers, specialist services and dementia guidelines and protocols. Although many of these issues are common to the non-Aboriginal rural and remote population, the specific cultural needs of this population needs further exploration.

Information about the model of care developed from this study is available online at the Western Australian Institute for Medical Research website www.wacha.org.au/projects.htm (*Indigenous Services Study: Lungurra Ngoora Community Care Final Report*). However, it is acknowledged that in the present study, information was gathered from only one remote region of Australia. Any subsequent model must be adapted to the unique needs of individual communities, and this can only be done with genuine community involvement.

Conclusion

This article described the unmet need of Aboriginal people living with dementia in remote and rural Australia. The in-depth nature of the interviews provided an important reference for those working with this population. Many of the issues discussed are similar for other populations living in disadvantaged socioeconomic circumstances, remote areas and those from diverse cultural backgrounds. However, the documentation of individuals' thoughts and opinions offers a framework for the improvement of care delivery to this population. In particular, issues relating to cultural safety, the improvement of the local Aboriginal workforce,



giving consideration to the unique concept of health and strong desire for ownership and coordination of services that are strongly based in the community were emphasised in this research.

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