

**Dementia Collaborative Research Centre
Assessment and Better Care Outcomes**

Summary

Project Title: Cognition, Ageing and Dementia in Australian Aboriginal and Torres Strait Islander Peoples: A Review of the Literature

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Main Messages

A number of Indigenous communities in rural and remote regions of Western Australia and the Northern Territory have almost five times as much dementia as the general Australian population but we don't know if this is the same for Indigenous people in cities and country towns.

Many Indigenous Australians may be at greater risk of developing dementia because more Aboriginal and Torres Strait Islanders are starting to live longer; there are still very high rates of chronic diseases like diabetes and stroke; the burden of childhood infections including periodontal disease, is higher in Indigenous communities; many younger Indigenous people are at high risk of head injuries and cognitive damage due to drugs and alcohol, all factors that may increase the chances of getting dementia in later life.

Very few Indigenous people with dementia access mainstream government community programs in comparison to the rest of the population. There is insufficient information about how big the problem of dementia is in Indigenous people and what types of dementia affect different people in diverse communities across the country. Therefore we are unable to assess whether existing services are meeting the needs of this population or the real extent to which people are able to access programs.

There is a strong Aboriginal belief that a life 'out of balance', having lost the connection to the land and to traditional relationships causes sickness; some have described dementia as a 'sick spirit'. Our solutions to the problem of dementia need to take account of cultural perspectives and approaches to wellness.

¹ This summary report presents some key findings of a review of the literature into ageing and dementia in people of Aboriginal and Torres Strait Islander background. It tells us what we do and don't know about cognitive decline and dementia amongst Indigenous Australians and makes some recommendations about future research and service gaps. The full report, with references, will be made available as a pdf document on the DCRC website. Watch this space!

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What do studies tell us about dementia rates in Australian Aboriginal populations?

Rural and remote communities in WA show that dementia affects around 12.4 percent of Indigenous people compared to around 2.6 percent in the general population.

Local customs, language and way of life were taken into account when diagnosing dementia in these communities and this approach was successfully used in communities in the Northern Territory.

The current picture is that Indigenous males seem to be more greatly affected by dementia than Indigenous females; and Indigenous people get dementia at an earlier age than other Australians.

Acquired brain injury is most prevalent in the Northern Territory and Indigenous Australians are 21 times more likely to suffer a head injury with serious implications for cognitive and behavioural changes.

What do studies tell us about systems of care and support for Indigenous people?

Indigenous people experience ongoing challenges finding services that are appropriate to their needs and circumstances; and often have problems accessing services, where they exist.

In rural and remote areas, Indigenous people need transport to services, need actual facilities such as respite and Home and Community Care services (HACC), and need staff and services capable of delivering care adapted to their language, culture and local circumstances.

In urban areas, many Indigenous people have problems accessing services because they are socially isolated and have personal and health problems affecting their ability to use services.

Relatively few Indigenous clients (0 to 3 percent) with dementia use the following government community programs: Aged Care Assessment Program (ACAP), National Respite for Carers Program (NCRP), Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH) and the Commonwealth Carer Respite Centre Programs (CCRC). While 2.5 percent of Australians are Indigenous, we have no data on dementia prevalence in non-remote Aboriginal communities.

Small numbers of Indigenous clients also use a variety of Aged Care Programs, but it is not known if these are for dementia related problems. The most noticeable difference between Indigenous and non-Indigenous clients is that far greater percentages of Indigenous clients need dementia and aged care services before age 55 years.

Aboriginal elders wish to be cared for in their communities where they are close to family and kin and where they can die on their land; Older Indigenous people are greatly concerned about the erosion of their local culture and wish to reverse this trend. We know little about the impact of this on families and their care arrangements.

What do studies tell us about the dementia experience in Indigenous populations?

Dementia is perceived and experienced in many different ways but is often not recognised as a medical condition.

Many Indigenous carers and families lack understanding of what causes dementia and are fearful of the medical system. These as well as language and cultural differences prevent many from using early intervention services.

Some experience the behavioural changes of dementia as “childlike” or “sickness” or “madness” but communities become very distressed and often call for help when the person with dementia breaks cultural taboos and norms.

What do studies tell us about the life experiences of older Indigenous Australians?

Ageing successfully for Indigenous Australians is tied up with important roles and responsibilities in community such as, passing on knowledge, traditional languages and customs, participating in decision making and ceremonies and ‘Looking after country’.

Indigenous Elders pass on education in traditional law, land and language through their reliance on memory and therefore the impact of a dementia diagnosis can be devastating not just for immediate family but for community.

What do studies tell us about changes occurring in the Indigenous population?

Indigenous Australians still die on average 17 years earlier than other Australians and there are far fewer Indigenous people older than 45 compared to the rest of the Australian community.

However, changes within the Indigenous population over the last decade - more people between 45 and 64 years, fewer people dying from chronic diseases in some parts of the country and fewer babies being born - suggest that the Indigenous population is starting to age in a similar way to the rest of Australia.

The social and health profile of Indigenous Australians show many of the risks associated with a greater chance of developing dementia in later life in non-Indigenous populations and this is cause for concern.

Major Knowledge Gaps & Research Recommendations

Gaps	Recommendations
<p>What understanding do Indigenous people in different parts of Australia have about dementia?</p>	<p>We recommend that research be undertaken about Indigenous understandings of ageing well, spirituality and dementia in traditional and non-traditional living Indigenous populations.</p>
<p>How do Indigenous people in different parts of Australia experience caring for a person with dementia? How are Indigenous families and the broader community affected by dementia?</p>	<p>We recommend research examining the extent and type of dementia in urban and regional areas as well as in under-researched Indigenous populations such as Torres Strait Islanders.</p>
<p>What are the best ways to identify and assess dementia in diverse Indigenous communities?</p>	<p>We recommend research into the acceptability, use and reliability of (modified) screening tools for identifying dementia in diverse Indigenous populations.</p>
<p>What screening tools are best used in urban Indigenous populations?</p>	<p>We recommend that research be undertaken to examine the role and impact of being a dementia carer; and how 'culture' influences the experience of care and the use of both formal and informal care and support services.</p>

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