

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

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

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

# Raising awareness of dementia in urban Aboriginal Australians

There is widespread awareness of the deplorable gap in life expectancy for Indigenous compared to non-Indigenous Australians, and considerable public resources rightly devoted to Closing the Gap initiatives. However, this often overshadows the fact that many Aboriginal people live to old ages (well past the current 67-73 year average life expectancy) and that the number of older Aboriginal Australians is set to increase dramatically in coming decades. Until recently, the issue of dementia in Aboriginal and Torres Strait Islander communities was rarely considered or, where it was, it was assumed that dementia was typically a direct consequence of alcohol abuse, with limited evidence to support this view (Arkles *et al* 2010; Pollitt 1997).

In 2008, the first rigorous study of dementia prevalence in Aboriginal people was

“Healthy ageing is your mind staying young.”

– Participant in the Koori Growing Old Well Study

The number of older Aboriginal Australians is set to increase dramatically, yet until now little has been known about their health and dementia rates. This is the first of two articles in which **Kylie Radford, Holly Mack, Sharon Wall** and **Tony Broe** discuss the results of the Koori Growing Old Well Study, which set out to determine the prevalence and potential risk factors for dementia in urban Aboriginal settings, valid screening and diagnostic tools, service use and needs, and how to improve dementia knowledge in Aboriginal communities and researchers

published by the research team at the Western Australian Centre for Health and Ageing (WACHA) (Smith *et al* 2008). This study showed that the prevalence of dementia in the remote Kimberley region of Western Australia was around five times higher than in mainstream Australia, at ages 45 years and older. The causes of dementia in this population were not always clear, but Alzheimer's-type dementia was frequently diagnosed. In general, dementia diagnosis was associated with a history of stroke, head injury or epilepsy. Older age, male gender, lack of formal education and current smoking were also linked to dementia, but current alcohol use was not.

This study was extremely important in providing the first reliable data on dementia in Aboriginal communities and in

beginning to demystify this issue. However, an important question remained: does this high prevalence of dementia also apply to the majority of Aboriginal Australians who live in non-remote settings? That is, people living in regional towns and major cities, largely in NSW and QLD, who tend to have different experiences in terms of greater access to formal education and health services, and less traditional lifestyles.

## Dementia prevalence

Between 2010 and 2012, the Koori Growing Old Well Study (KGOWS) conducted a comprehensive survey of all Aboriginal men and women aged 60 years and over residing in five NSW Aboriginal communities (Radford *et al* 2014a). This research was a partnership between academics

at Neuroscience Research Australia (NeuRA) and local Aboriginal community-controlled organisations. A total of 336 people aged 60-92 years old participated in the study, with 42 per cent from two communities in Sydney and 58 per cent from the three mid-North Coast regions of NSW. Study participants had been born and raised all over NSW and other parts of Australia (including remote areas), but the large majority had been living in their current community for more than 20 years. All participants spoke English, primarily as a first language, and some also spoke their traditional Indigenous language.

This study found that the prevalence of dementia in older Aboriginal people from urban and regional areas was three times higher than the rate of

## “The next generation can learn from older people.”

– Participant in the Koori Growing Old Well Study

dementia in non-Indigenous Australians (Radford *et al* 2014b). The most common type of dementia diagnosed was Alzheimer’s dementia, followed by vascular dementia and dementia due to head trauma. About one in three cases received a mixed dementia diagnosis (ie, two or three types of dementia identified). Alcohol abuse contributed to some mixed dementia cases, but this was much less common than these other main types of dementia. As would be expected, the prevalence of dementia increased with age, but many were diagnosed relatively young (ie, two in every five cases had dementia onset before age 65). There was no difference in the rates of dementia between urban Sydney, and regional cities, towns and rural areas. Further exploration of other factors associated with dementia in this population is currently under way.

Thus, urban and regional Aboriginal Australians share similarly high rates of dementia as remote Aboriginal peoples, and some of the highest rates observed worldwide. Our collective challenge now that we are beginning to understand the importance of this issue is raising awareness about dementia in Aboriginal communities and improving dementia assessment and care for Aboriginal people in urban and regional areas, as is currently under way in remote areas.

### Dementia assessment

A formal assessment of cognitive function is central to

a diagnosis of dementia, especially in the early/mild stages of the disease process. However, the appropriateness and validity of many cognitive assessment tools for Aboriginal people is unknown. To address this problem in remote Aboriginal Australians, the Kimberley Indigenous Cognitive Assessment (KICA; <http://www.wacha.org.au/kica.html>) was developed (LoGiudice *et al* 2006).

Clinicians and researchers in this remote population required a tool that would be suitable for assessing cognitive decline in a culturally sensitive manner, in a population with low rates of education and literacy, and one that could be translated into many different Indigenous languages, as well as used in English.

The KICA tool (more specifically the KICA-Cog; maximum score 39; dementia screening cut-off 33/34; Smith *et al* 2009) has successfully fulfilled its purpose, with good sensitivity (ie, it is able to detect dementia) and specificity (ie, it avoids too many false alarms) demonstrated. It consists of 16 items assessing aspects of cognitive function that typically deteriorate in dementia (eg, orientation, memory, naming) and, in this regard, has many similarities with other dementia assessment tools.

However, likely owing to the dearth of alternatives, the KICA has been used beyond its intended and validated purpose (eg, with young people or in non-remote settings). At face value, the appropriateness of the KICA for many urban Aboriginal people is questionable. Urban Aboriginal people are more likely to speak English, be literate with at least basic schooling and to have been exposed to non-Indigenous cultures, as we have found in KGOWS. As such, in planning KGOWS, we worked with the KICA developers to modify this tool in a way that would be more appropriate for urban/regional Aboriginal



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## “[Healthy ageing means] being well and fit like my mother who lived to 110 years.”

– Participant in the Koori Growing Old Well Study

populations. A summary of these modifications is available in a report of our successful pilot study completed in 2009 (Radford & Mack 2012; <http://bit.ly/1hUtvZy>).

We also acknowledge another study, currently in progress in Victoria, to validate a modified version of the KICA suitable for regional and urban Aboriginal Australians (<http://www.wacha.org.au/kica.html>).

In KGOWS, we evaluated the modified KICA (mKICA; Radford *et al* 2014a; Radford & Mack 2012; <http://bit.ly/1hUtvZy>) in urban/regional Aboriginal Australians and directly compared it to other cognitive

assessment tools, namely the Mini Mental State Examination (MMSE) and the Rowland Universal Dementia Assessment Scale (RUDAS; [bit.ly/R24LbK](http://bit.ly/R24LbK)). The MMSE (maximum score 30; dementia screening cut-off 23/24; Folstein *et al* 1975) is probably the most common cognitive screening tool used in dementia assessment around the world, and will be familiar to many health professionals. It is also globally used in research with many different cultural groups, although some have questioned its appropriateness in populations other than white English-speaking Westerners, particularly where low levels of education are common.

The RUDAS (maximum score 30; dementia screening cut-off 22/23; Storey *et al* 2004) was developed to address some of the limitations of tools like the MMSE for culturally and linguistically diverse populations in Australia. Similar to the MMSE, it assesses memory, language and visuospatial skills, but in contrast, does not require any literacy skills and is less influenced by education or language background. In our study, the tests were given by trained research assistants (with qualifications in

“My aim is to watch my great grandkids grow up. I want to live to 127 years old.”

– Participant in the Koori Growing Old Well Study

psychology or related fields) working alongside local Aboriginal researchers [see Aunty Margaret’s story, right].

### Which test is best?

All three tests were widely acceptable in an urban/regional Aboriginal population, confirming the findings of our pilot study. Not surprisingly, given some overlap in the cognitive skills assessed, the scores on all three tests were highly correlated. Each test performed adequately in distinguishing between people with dementia and those without (referenced against an independent, detailed clinical assessment and consensus diagnosis).

However, in our community-based study, the MMSE and mKICA performed better than the RUDAS in flagging dementia cases. In terms of overall accuracy at the recommended cut-off scores, the MMSE was the most accurate, followed by the mKICA and then the RUDAS. (A detailed report comparing these tools is currently in preparation; please contact the authors for further inquiries). In a small number of cases (five), poor literacy interfered with assessment on some MMSE items. In such cases, a pro-rated total score can be calculated or the mKICA used as an alternative.

For the mKICA and RUDAS, sensory impairments were more likely to limit the administration of some items (four cases), given the increased visual and motor

demands of these tests. This tended to be apparent in those who suffered from other age-related problems, such as previous stroke or severe arthritis.

In summary, we recommend the MMSE as a useful screening tool for dementia in most urban and regional Aboriginal Australians, based on current research. Its present widespread use and familiarity should expedite better dementia assessment for Aboriginal people, now that there is evidence of validity in this population. It is also more sensitive to subtle cognitive decline associated with mild cognitive impairment or early dementia than the mKICA. Clinicians and health workers should be mindful of the usual caveats that go with its administration, including floor and ceiling effects in certain

clinical presentations, along with the confounding effects of very low or very high levels of education.

The mKICA is a good alternative to the MMSE where it is judged to be more culturally appropriate – on the grounds of language, literacy, community or personal choice. Some older Aboriginal people may be more comfortable being assessed with the KICA, and some may not. We had instances where people (albeit cognitively intact) were put off by being given an “Aboriginal test”, which was perceived as too easy.

As with all screening tools, the MMSE or mKICA should be used in conjunction with a good history (including from family) of any cognitive problems and followed up with more detailed neuropsychological

assessment if the results are not entirely clear. Although these findings are from a NSW study, they should generalise to many urban and regional settings across Australia.

### Summary

The number of older Aboriginal Australians is increasing rapidly, yet little has been known about their health and dementia rates. The KGOWS takes a life-cycle approach, examining both early-life and mid-life risk factors for later cognitive decline through an extensive survey of personal history, health, and well-being across the lifespan.

KGOWS has shown that urban/regional Aboriginal people in NSW have a dementia prevalence that is three times higher than the general Australian population,

## Aunty Margaret’s story

Aunty Margaret Anderson grew up on the Moree mission in NSW and has lived in the Campbelltown (NSW) area since 1978. She is the matriarch of her family, which includes 15 children and step-children, 50 grandchildren, 53 great-grandchildren, and she has also been ‘mum’ to many other children she helped bring up over the years. Aunty Margaret is a well-respected Tharawal community Elder where she volunteers for several community groups, including involvement with the Tharawal Aboriginal Corporation and as a founding member of the Tharawal Local Aboriginal Land Council. She gained a wealth of experience in delivering services working as an Aboriginal health worker with various community health organisations.



KGOWS researcher Dr Kylie Radford (left) with research assistant and Tharawal Aboriginal community Elder Aunty Margaret Anderson

We first met Aunty Margaret when she agreed to participate in the Koori Growing Old Well Study (KGOWS) in 2011. She was interested in finding out more about dementia and the help that is available for families since her husband, John, had been experiencing memory problems for several years and was eventually diagnosed with dementia. Her passion for helping others, especially the older people in her community, led Aunty Margaret to join KGOWS as a research assistant where she fostered relationships between the study team and the Tharawal community, and greatly assisted in the recruitment of community members to take part in KGOWS.

Having Aboriginal research assistants who were similar in age to our study cohort and personally identified with community health concerns was integral to people feeling comfortable and willing to participate in our projects.

Very sadly, John passed away last year, but Aunty Margaret continues in her important liaison role through the Koori Dementia Care Project by putting people in touch with resources and services for aged care and dementia. She also encourages community members to take part in activities provided by local services, such as Northcott Disability Services and MacArthur Disability Services, and she is now helping set up a Tharawal Elders group.

which is consistent with previous findings in a study carried out in the remote Kimberley region.

After assessing three cognitive screening tools, KGOWS data indicate that the MMSE, followed by the mKICA were the most accurate and reliable screening tests for use in our partner Aboriginal NSW communities, and should be appropriate in other urban/regional Aboriginal areas as well.

Our future plans are to conduct a KGOWS follow-up study with the aim to find the risk factors that predict or are causing these high rates of dementia and compare this with known risk factors for non-Indigenous ageing and dementia. ■

Visit our website for more information about KGOWS, including a YouTube film clip discussing Aboriginal health, ageing and dementia: <http://www.neura.edu.au/research/themes/broe-group>.

In the next issue of AJDC (August/September 2014), we will be highlighting our Koori Dementia Care Project (KDCP) which translates the research findings from KGOWS into sustainable practice and capacity about the effects of dementia on older Aboriginal people and their carers and families within our partner communities.

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## Dementia rate higher among Indigenous people in NT

The estimated prevalence of dementia is three times higher in the Northern Territory's Indigenous population than among their non-Indigenous counterparts, according to new research.

In 2011, the estimated prevalence in the NT Indigenous population aged 45 years and over was 3.7 per 100, compared with 1.1 per 100 in the non-Indigenous population, according to the study published in the *Medical Journal of Australia* (5 May, 2014). It also found Indigenous people with dementia were generally younger, with a median age of 72 years, compared with 79 years for non-Indigenous Territorians.

The researchers, led by Dr Shu Qin Li from NT Department of Health, analysed 784 diagnosed dementia cases in the NT, identified from four data sources from 2008 to 2011.

The high prevalence of dementia was consistent with the high prevalence of well-known risk factors for dementia such as stroke, epilepsy, brain injury, smoking and alcohol-related problems.

The researchers say the results highlight the urgent need for interventions to moderate the emerging impact of dementia in the Australian Indigenous population.

The findings are consistent with the Koori Growing Old Well Study of NSW Indigenous communities, reported in this issue, which found dementia prevalence was three times higher than in non-Indigenous Australians, and a 2008 study from the Kimberley, WA, showing the dementia prevalence rate among the Indigenous population was five times higher than in the non-Indigenous population and occurred at an earlier age.