

Title: *Understanding Dementia amongst Indigenous Australians*

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Introduction

Dementia is a growing health and social concern for all Australians. It has been previously thought that Indigenous Australians did not live long enough to get dementia (Pollitt 1997). Interestingly, Indigenous Australians have reported dementia as being a 'whitefella sickness' (Woenne-Green 1995) as 'the word dementia has no meaning' in Indigenous terms (Fox 1994; Zann 1994). More recently dementia has been described as a 'sick spirit' (Arabena 2007). However, as the life expectancy of Indigenous people increases, and they grow older they will encounter causes of death and disability not unlike their non-Indigenous counterparts, including increased presentations of dementia (Arabena 2007).

Commonly dementia is used to describe the symptoms of a group of illnesses (including Alzheimer's Disease) which causes a progressive decline in how a person functions. This may include loss of memory, intellect, social skills and rationality, and 'norm' emotional reactions. (Alzheimer's Australia website www.alzheimers.org.au). There have been some recent attempts to determine the prevalence of dementia in Indigenous Australian communities (Smith, Flicker et al. 2008), but despite this, the national picture remains unclear. In one of the few studies reported, prevalence rates estimated to be five times that of the general Australian population, which would make it the highest known prevalence rate of dementia in the world. (Smith, Flicker et al. 2008).

Few studies have investigated the general public awareness of dementia (Steckenrider 1993; Werner 2003; Arai, Arai et al. 2008) and even less have been conducted in Australia. (Sullivan, Finch et al. 2003; Low and Anstey 2007; Sullivan 2008). Only a small amount of studies have included samples from different nationalities or cultural groups. (Ayalon and Arean 2004; Purandare, Luthra et al. 2007; Arai, Arai et al. 2008). These studies generally report similar findings about specific or cultural interpretations of dementia, and thus dementia is not widely known about or understood amongst the general public or specific cultural groups. The impact and social concerns in specific cultural groups is most likely not considered.

There is a need to explore and understand the Indigenous communities' perceptions, understanding and awareness of dementia prior to implementing much needed health

promotion strategies. This study aimed to explore Indigenous Australians' knowledge, understanding and misconceptions of dementia.

Methods

A cross-sectional study was conducted in November 2008 during the 15th Annual First Contact Sports and Cultural Festival, Whites Hill, Queensland, Australia.

A modified version of the Alzheimer's Disease Knowledge Survey (Sullivan, Muscat and Mulgrew, 2007) was further adapted for use for Indigenous Australians. Our adapted survey (ADK for Indigenous Australians) included information about the participant (age group, gender, state, postcode of usual residence, education level and Indigeneity), two open ended questions about the participants' understanding of Alzheimer's Disease and dementia and 20 multiple choice questions (about general understanding and perceptions about dementia). The survey took approximately 15 minutes to complete. We trained and employed five local Indigenous people to help recruit participants (who were festival attendees, 18 year and over) and assist in the completion of the survey if needed.

Results

174 Aboriginal and Torres Strait Islander people completed the survey. Most were from Queensland (87.9%), female (60.3%), aged between 25 and 44 years (49.4%), had completed Year 10 education or lower (42%) and lived in a major city (71.8%).

In relation to the definition of dementia 88.2% (n=97) of participants defined Alzheimer's Disease/Dementia as memory loss or forgetfulness and 11.8% (n=13) of them mentioned that the disease affected the brain or was progressive. A lower proportion of participants (4.5%, n=5) linked Alzheimer's Disease/Dementia with older age. Statistically significant was the prediction that if a participant provided a response (correct or incorrect) to the open ended questions, they were more likely to score higher overall in the ADK ($p < 0.0001$).

The mean overall total (out of ~~twenty~~20) of correct responses to the multiple choice questions about Alzheimer's Disease/Dementia was 4.76. The participants level of education was associated with age ($p < 0.001$), whereby older participants (45 and older) were more likely to have completed formal education up to Year 10, and younger participants (under 25) were more likely to have completed Year 12. There was no significant difference in results based on State, gender differences or between Indigenous city dwellers and those who lived in regional or remote areas (Overall total $p = 0.29$). Overall, the younger participants were more likely to have only some or no knowledge of Alzheimer's Disease, whereas the other age groups were most likely to have at least some knowledge ($p = 0.007$).

Eight misconceptions, four knowledge gaps and just one commonly held correct belief were identified (see Table 1). The correct belief of *When self-care becomes impaired, assistance to help the patient remain as independent as possible is advised* was held by just over half (51.7%) of the participants. Knowledge gaps were revealed in the areas of life expectancy, patient memory and the roles of aluminium and nutrition in Alzheimer's Disease. The question, *How do you find out that the symptoms you have are because you have Alzheimer's Disease?* revealed two separate misconceptions; that is that confirmation of diagnosis could be achieved by mental status testing or by CT scan. Other misconceptions were in the areas of Alzheimer's Disease prevalence and treatment, management of wandering and depression, personality changes, and patient reaction to diagnosis.

Discussion

Although there are limitations to our study, this study revealed gaps in knowledge and common misconceptions about dementia held by Indigenous people. Further, this study has highlighted the need for interventions to improve the general level of understanding of dementia in Indigenous communities.

This gap in knowledge is not specific to just Indigenous communities, as other Australian studies (Sullivan, Finch and O'Connor, 2003; Low & Anstey 2007; Sullivan, 2008) have shown the need for further public education about dementia. However, the gap is somewhat greater

for Indigenous communities. This is evidenced by participants in this study who scored a mean of 4.76 ADK items correct out of a possible 20 questions whereas non-Indigenous people scored a mean of 8.2 (Sullivan, 2008).

In the present study, despite the younger participants (< 25years) having completed more formal education, the older age groups had greater levels of knowledge than younger participants. This finding has potential importance for Indigenous communities as there is a strong likelihood that young people will care for someone in their family or community with dementia in the future. The Indigenous sample in this study revealed only one commonly held correct belief (51.7%).

When teasing out the particular responses to the ADK items, Indigenous participants reported a lower number (eight) of misconceptions in comparison to the reports for non-Indigenous participants (10) (Sullivan, 2008). Five of the same misconceptions were reported by both the Indigenous and non-Indigenous participants.⁵ This reinforces the need for greater public awareness of dementia, particularly in Indigenous communities.

Sullivan (2008) found no knowledge gaps in those she surveyed whereas the Indigenous sample in this study reported four (all biomedical related). As reported in studies involving non-Indigenous groups, (Purandare, Luthra et al. 2007; Arai, Arai et al. 2008; Sullivan 2008) this study also found that Indigenous participants had a lack of knowledge in the prognosis of dementia.

Conclusion

Whilst the Indigenous sample indicated a general lack of understanding about Alzheimer's Disease, there is a need to consider specifically developed and targeted education programs for those groups (for example young Indigenous people) who have greater knowledge gaps about Alzheimer's Disease. Further, we recommend the focus of educational programs be directed towards enabling the participants to understand the signs and symptoms of dementia and to know where to seek help and guidance when required.

References

- Arabena, K. (2007). "'Before I forget'; dementia in Aboriginal and Torres Strait Islander communities." *Ngoonjook: a Journal of Australian Indigenous Issues* **30**: 41-49.
- Arai, Y., A. Arai, et al. (2008). "What do we know about dementia?: a survey on knowledge about dementia in the general public of Japan." *Int J Geriatr Psychiatry* **23**(4): 433-438.
- Ayalon, L. and P. A. Arean (2004). "Knowledge of Alzheimer's disease in four ethnic groups of older adults." *Int J Geriatr Psychiatry* **19**(1): 51-57.
- Fox, D. (1994). How can the family help itself alleviate the crisis in the Aboriginal and Torres Strait Islander community? In *A Family Crisis? 4th National Conference Alzheimer's Association Australia*. Sydney.
- Low, L. F. and K. J. Anstey (2007). "The public's perception of the plausibility of dementia risk factors is not influenced by scientific evidence." *Dement Geriatr Cogn Disord* **23**(3): 202-206.
- Pollitt, P. A. (1997). "The problem of dementia in Australian aboriginal and Torres Strait Islander communities: an overview." *Int J Geriatr Psychiatry* **12**(2): 155-163.
- Purandare, N., V. Luthra, et al. (2007). "Knowledge of dementia among South Asian (Indian) older people in Manchester, UK." *Int J Geriatr Psychiatry* **22**(8): 777-781.
- Smith, K., L. Flicker, et al. (2008). "High prevalence of dementia and cognitive impairment in Indigenous Australians." *Neurology* **71**(19): 1470-1473.
- Steckenrider, J. S. (1993). "What people know about Alzheimer's disease: a study of public knowledge." *Am J Alzheimers Dis Other Demen* **8**: 6-14.
- Sullivan, K. (2008). "A survey of community awareness of Alzheimer's disease: what are the common misconceptions?" *Int J Geriatr Psychiatry* **23**(12): 1320-1322.
- Sullivan, K., S. Finch, et al. (2003). "A confidence interval analysis of three studies using the Alzheimer's disease knowledge test." *Aging Ment Health* **7**(3): 176-181.
- Werner, P. (2003). "Knowledge about symptoms of Alzheimer's disease: correlates and relationship to help-seeking behavior." *Int J Geriatr Psychiatry* **18**(11): 1029-1036.
- Woenne-Green, S. (1995). *They Might Have to Drag Me Like a Bullock*. Canberra, Aged and Community Care: 5.

Zann, S. (1994). Identification of Support, Education and Training Needs of Rural/Remote Health Care Service providers Involved in Dementia care, Northern Regional Health Authority, Queensland: 4.

Table 1. Response Classifications by Indigenous Community Sample to modified ADK Survey

Modified Alzheimer's Disease Knowledge response classification	n	% of sample
<i>Misconceptions</i>		
That prompt treatment of Alzheimer's Disease may prevent worsening of symptoms	172	51.7
That sharing feelings about wandering with the patient as well as practical solutions such as locked doors is the best way to manage wandering ^a	172	40.7
Over-estimated the prevalence of Alzheimer's Disease	171	38.0
That personality changes were due to damage to the brain and usually beyond control of the person, as well as deliberate attempts by the patient to lash out due to frustration ^b	170	28.8
That patients react to their diagnosis with a lack of awareness of their symptoms	173	26.6
That treating depression will alleviate depressive symptoms and prevent further intellectual decline	152	26.3
Confirmation of diagnosis can be achieved via mental status testing ^c	157	26.1
Confirmation of diagnosis can be achieved via CT scan ^c	157	26.1
<i>Knowledge Gaps</i>		
A person is expected to live 6-12 years after first getting Alzheimer's Disease	153	64.7
Helping Alzheimer's Disease patients with things like reminding them of time and date/place has no lasting effect on patient's memory	152	57.9
Aluminium may or may not be the reason why people get Alzheimer's Disease	157	57.3
Poor nutrition can make symptoms of Alzheimer's worse	154	51.3
<i>Commonly held correct beliefs</i>		
When self-care becomes impaired, assistance to help the patient remain as independent as possible is advised	172	51.7
<i>Notes:</i> Misconceptions were defined as endorsement of an "incorrect" response by 25% or more of the sample; Knowledge gaps were defined as when more than 50% of the sample chose the "I don't know" response; Commonly held correct beliefs were defined as endorsement of the correct response by 50% or more of the sample (n=varies)		
<i>Key:</i>		
^a as opposed to simply locking doors		
^b as opposed to the first point alone		
^c two misconceptions within the one question/item were revealed by participants		