

Making sense of dementia: understanding amongst Indigenous Australians[†]

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Introduction: Dementia is a growing health and social concern for all Australians. Whilst the prevalence of dementia amongst Australia's Indigenous people is unclear, there is some evidence that dementia rates are five times that of the general Australian population. To date no studies have examined dementia knowledge levels in Indigenous communities.

Purpose of the study: This paper aims to explore Indigenous Australians' understanding, knowledge and misconceptions of dementia.

Design and methods: Hundered and seventy-four Indigenous adults participated in a cross-sectional survey using a modified version of the Alzheimer's Disease Knowledge Test (ADK). The survey included demographic information, two open-ended questions and 20 multiple choice questions. Each ADK item was examined to identify responses that revealed commonly held correct beliefs, knowledge gaps and misconceptions.

Results: The overall level of understanding of dementia was poor. Younger participants were significantly more likely to have no knowledge of Alzheimer's Disease, whereas the other age groups were most likely to have at least some knowledge. It was also revealed that there are common misconceptions about Alzheimer's Disease held by both Indigenous and non-Indigenous communities.

Implications: Culturally appropriate awareness campaigns and targeted educational interventions need to be implemented to improve the general level of understanding of dementia in Indigenous communities. Copyright © 2010 John Wiley & Sons, Ltd.

Key words: disparities; Alzheimer's disease; survey design

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INTRODUCTION

Dementia is a growing health and social concern for all Australians. The prevalence of dementia in Australia is predicted to rise significantly as the proportion of older

people in the population increases, and by the year 2016 it is expected to be the major cause of disability in Australia (Australian Institute of Health and Welfare, 2006). To date, very few studies have investigated the general public awareness of dementia (Steckenrider,

1993; Werner, 2003; Arai *et al.*, 2008) and only a small proportion of these studies have been conducted in Australia (Sullivan *et al.*, 2003; Low and Anstey, 2007; Sullivan, 2008). Fewer studies have included samples from different nationalities or cultural groups (Ayalon and Arian, 2004; Purandare *et al.*, 2007; Arai *et al.*, 2008). In general these studies report similar findings about specific cultural interpretations of dementia. Dementia is not widely known about or understood amongst the general public or specific cultural groups and its impact on health and social concerns in these latter populations is most likely under-considered.

Studies investigating the general public's awareness of dementia have mainly used structured questionnaires to elicit this information (Laforce and McLean, 2005; Arai *et al.*, 2008; Sullivan, 2008). Most studies have included the Alzheimer's Disease Knowledge Test (ADK) (Dieckmann *et al.*, 1988) or selected items (Sullivan and O'conor, 2001; Sullivan *et al.*, 2003; Arai *et al.*, 2008; Sullivan, 2008). The ADK items include questions on general and biomedical information about Alzheimer's Disease (AD). Findings from such studies indicated poor levels of AD knowledge exist within the general community (Laforce and McLean, 2005; Arai *et al.*, 2008; Sullivan, 2008).

Sullivan *et al.* (2007) modified the ADK for use in an Australian context. They also compared the misconceptions, knowledge gaps and commonly held correct beliefs amongst dementia patients, carers and non-carer adults and reported that the overall knowledge of AD amongst participants was poor. However the carers group had significantly greater AD knowledge compared to other participants, yet they only correctly answered 50% of the items (Sullivan *et al.*, 2007). All participants held some misconceptions about AD (Sullivan *et al.*, 2007). Sullivan (2008) confirmed the lack of knowledge about AD amongst the general community, despite the sample being relatively educated and most knowing someone with dementia.

With the life expectancy of Indigenous Australians documented as 17 years lower than their non-Indigenous counterparts (ABS and AIHW, 2008), dementia has not been considered a health or social priority for Indigenous Australians in the recent past (Pollitt, 1997; Australian Institute of Health and Welfare, 2007). It was thought that Indigenous Australians did not live long enough to get dementia (Pollitt, 1997). Indigenous Australians report 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). As Indigenous people grow older and life expectancy

increases they will encounter causes of death and disability not unlike their non-Indigenous counterparts, including increased presentations of dementia (Arabena, 2007).

From the evidence provided to date we do know that there is a lack of comprehensive statistical information from which the prevalence of dementia amongst Indigenous people can be determined. Although there have been some recent attempts to clarify the prevalence of dementia in Indigenous Australian communities (Smith *et al.*, 2008), the entire national picture remains unclear. In one of the few studies reported, evidence indicates dementia is an 'epidemic' in some Indigenous Australian communities (Arehart-Treichel, 2008) with 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 *et al.*, 2008). As Indigenous life expectancy increases, appropriate diagnostic tools become more readily available, data sets are reported and community awareness increases, it is possible that these prevalence rates may be reflected across Australia.

Given the growing concern about dementia and the relevance of this to Indigenous Australians, it is timely that culturally appropriate health promotion strategies are developed. To enable Indigenous people and communities to recognise the signs of dementia and to seek professional assistance early there needs to be greater public awareness of this condition amongst these communities. However, before such strategies can be implemented, a greater understanding of Indigenous communities' perceptions, understanding and awareness of dementia is required, as health promotion strategies are more successful if they are based on pre-existing beliefs (Donovan, 2004). This paper aims to explore Indigenous Australians' knowledge, understanding and misconceptions of dementia.

Design and methods

Ethics approval was obtained from the Queensland Institute of Medical Research and the Queensland University of Technology Human Research Ethics Committees.

Design and setting

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

the largest Indigenous sporting event in Australia. Sports and cultural teams travelled from around Australia, New Zealand and Papua New Guinea to compete. A number of health promotion, food, art and craft and community awareness stalls were present during the 3-day event. Data for this study was collected at one such stall.

Participants

The sample ($n = 174$) consisted of festival attendees who identified as Indigenous Australians aged 18 years and over and who consented to completing the modified Alzheimer's Disease Knowledge Test (ADKT) and additional items. Those not of Indigenous Australian descent were excluded from the analysis.

Procedure

The project team trained and employed five local Indigenous people to recruit participants to the study. The participants either approached or were approached by one of the trained Indigenous interviewers. Potential participants were then invited to complete the survey after reading the participant information sheet. Those who gave informed consent to participate were offered assistance (reading the questions out aloud and writing down the participants response) to complete the questionnaire, if required. Completed surveys were placed in a clearly marked collection box by participants.

Measures

The Sullivan *et al.* (2007) modified ADK was initially used. It consists of 20 questions and all questions require a multiple choice response (a single correct response from a choice of five answers, including an 'I don't know' option). Scoring was simply summing the number of correct responses (one point for a correct response; zero for an incorrect response). The modified ADK had been tested for reliability and validity and it had good psychometric properties (Sullivan *et al.*, 2007).

Pilot study

The modified ADK (Sullivan *et al.*, 2007) was piloted with a convenience sample of three males and two females of Aboriginal and Torres Strait Islander descent from a range of employment backgrounds,

aged between 21 and 57 years. Participants were asked to complete the modified ADK (Sullivan *et al.*, 2007) and then to answer a number of questions regarding the content validity of the survey.

As a result of the pilot study, the main changes to the modified ADK (Sullivan *et al.*, 2007) were English-language variations and to separate the more 'biomedical' questions from the more 'general' ones. Some words were changed and some sentence structures altered. For example, an original-modified ADK question was *The percentage of people over 65 who have Alzheimer's Disease is estimated to be*, which became *How many people over 65 do you think have Alzheimer's?* (Modified ADK for Indigenous Australians).

For operational efficiency, the 20 questions from the modified ADK (Sullivan *et al.*, 2007) were re-ordered and grouped into two parts (Part 1 being 'general' items and Part 2 'biomedical' items), each containing 10 questions. For example, a 'general' question in Part 1 was: *Which of the following do you always have when you have Alzheimer's?* and a more 'biomedical' question in Part 2 was *How do you find out that the symptoms you have are because you have Alzheimer's?* Part 1 was designed to more closely represent the main focus of this study that is eliciting Aboriginal and Torres Strait Islander's general understanding of perceptions of dementia.

Final study survey (modified ADK for Indigenous Australians)

The final survey included demographic information (age group, gender, state, postcode of usual residence, education level and indigeneity), two open-ended questions about the participants' understanding of AD and dementia and 20 multiple choice questions, divided into two parts (each containing 10 questions). All participants were asked to complete the demographic information, the two open-ended questions, Part 1 of the multiple choice questions and, if they had time, Part 2. The survey took approximately 15 min to complete.

Data analysis

Statistical Package for the Social Sciences (Version 15.0) was used to calculate frequency of responses and to compare results and demographics using cross tabulations. Statistical significance was set at $\alpha = 0.05$. Means and standard deviations were used for normally

distributed data, proportions and chi-squared test were used to compare categorical variables.

Understanding of AD and dementia

Based on the written responses to the open-ended questions, no participants were able to differentiate between dementia and AD. Therefore the responses were pooled and graded as though they were defining dementia alone.

To enable analysis of the open-ended questions, the study team agreed on a four point definition of dementia (based on that from the Alzheimer's Australia website www.alzheimers.org.au on 25 February 2009). Allowance was made for the participants' use of Aboriginal English and layman terms (indicated in italics). Our teams agreed that important aspects of dementia are:

- A. Alzheimer's is the most common (or a) form of dementia (*dementia*).
- B. Dementia is a progressive, degenerative disease that attacks the brain (*affects the brain; gets worse over time*).
- C. It results in impaired memory, thinking and behaviour (memory loss; little bit womba; losing the plot; forget things).
- D. Dementia is most common amongst older people but not normal (*some older people get it*).

Participant responses were coded by assigning a score of one for each substantially correct response for each of the four points (A, B, C and D). Answers were independently coded by two operators, discrepancies were resolved by mutual discussion, and final coding was checked by a third party.

Modified ADK for Indigenous Australians

Of the 174 participants who completed the survey, 17 did not attempt to answer Part 2. Given that non-response to Part 2 did not necessarily equate to a lack of knowledge, those 17 participants were excluded from analysis pertaining to Part 2 and overall totals. Consequently, 157 participants were included for analysis of Part 2 and overall totals.

The participant responses to the 20 questions in the survey were analysed by first comparing knowledge levels with five demographic variables (gender, state, regionality (as per Australian Standard Geographical Classification (ASGC) Remoteness classification), age

group and education level) for Part 1 ($n = 174$), Part 2 ($n = 157$) and overall totals ($n = 157$). For this comparison, the totals were categorised. For Part 1, it was considered that 'no knowledge' was equivalent to a score of two or lower out of ten as that score could be achieved by chance using five level multiple-choice questions. Scores of five or higher were considered to be 'good' levels of knowledge. The same principles of chance were applied to Part 2 totals. However these biomedical type questions in Part 2 scored lower results. As a consequence, we categorised scores of two or lower as 'no knowledge', and three or higher as 'some/good knowledge' for Part 2 since only eight participants scored higher than four. By summing the components 'no knowledge' and 'some/good knowledge' scores, we allocated overall totals of four or lower as 'no knowledge', and five or higher as 'some/good knowledge'.

Second, an analysis was conducted replicating the process previously established by Sullivan *et al.* (2007). This analysis examined each question independently, identifying responses that revealed commonly held correct beliefs, knowledge gaps and misconceptions. Misconceptions were defined as endorsement of a particular 'incorrect' response by 25% or more of the sample; knowledge gaps were considered to have occurred 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.

Results

Sample

Hundred and seventy-four Aboriginal and Torres Strait Islander people completed the survey. The participants were mainly from Queensland (87.9%), female (60.3%) and aged between 25 and 44 years (49.4%). Most commonly, the participants had education levels of year 10 or lower (42%) and lived in a major city (71.8%).

Understanding of AD and dementia

Fewer than half the sample ($n = 64$, 36%) did not respond to the open-ended questions. Of the 110 participants who provided a response to the open-ended questions, none were able to clearly differentiate between dementia and AD. Most participants provided one word or short phrase answers. Only 9.1% of participants provided answers to two of the four parts

Table 1. Mean totals for Part 1, Part 2 and Overall in modified ADK for Indigenous Australians

	Number of correct responses	
	<i>n</i>	Mean (SD)
Part 1 (max = 10)	174	3.13 (1.9)
Part 2 (max = 10)	157	1.60 (1.6)
Overall total (max = 20)	157	(3.1)

Note: Part 1 included more 'general' knowledge questions; Part 2 included more 'biomedical' questions; Overall is Part 1 and 2 combined.

of the definition of dementia. No participants provided three or more parts of the definition.

In relation to the definition of dementia 88.2% (*n* = 97) defined AD/dementia as memory loss or forgetfulness and 11.8% (*n* = 13) mentioned that the disease affected the brain or was progressive. A low proportion of participants (4.5%, *n* = 5) linked AD/dementia with older age. Only 0.9% (*n* = 1) of participants associated AD with dementia.

Of the 97 participants who defined AD/dementia as memory loss, only five also mentioned that the disease involved the brain and/or was progressive. Statistically significant was the prediction that if a participant provided a response (correct or incorrect) to the open-ended question, they were more likely to score higher overall in the ADK (*p* = < 0.0001).

Modified ADK for Indigenous Australians

The mean numbers of correct responses are presented in Table 1 where the mean overall total (out of twenty) was 4.76.

Initial analysis of correct responses after categorisation found that Part 2 totals yielded no statistically significant differences for any of the demographic variables (gender, age, education, state or regionality) thus we limited our analysis to Part 1 and overall totals. Education level was confounded by age (*p* < 0.001), whereby older participants (45 and older) were more likely to have completed formal education to year 10 only, and younger participants (under 25) were more likely to have completed year 12. Consequently, education was excluded from further analysis. There was no significant difference in results based on state. There were no significant gender differences in either Part 1 (*p* = 0.27) or in the overall total (*p* = 0.25). Nor were there any significant differences between city dwellers and those who lived in regional or remote areas (Part 1 *p* = 0.18; overall total *p* = 0.29).

As outlined in Table 2, age was highly significant in the analysis. For Part 1 and Overall, the younger participants were more likely to have only some or no knowledge of AD, whereas the other age groups were most likely to have at least some knowledge (*p* = 0.001 and *p* = 0.007, respectively).

Modified ADK for Indigenous Australians response classification

Eight misconceptions, four knowledge gaps and just one commonly held correct belief were identified (see Table 3). 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

Table 2 Cross tabulations for Part 1 total and overall total compared with age

			For Part 1 total			<i>p</i> -value
Explanatory variables			Knowledge level			
Variable	Category	<i>N</i>	None (%)	Some (%)	Good (%)	
Age	< 25 years	39	66.7	25.6	7.7	0.001
	25–44 years	86	31.4	45.3	23.3	
	45+ years	49	26.5	51.0	22.4	
For overall total (Part 1 and Part 2 combined)						
Explanatory variables			Knowledge level			<i>p</i> -value
Variable	Category	<i>n</i>	None (%)	Some/Good (%)		
Age	< 25 years	33	69.7	30.3		0.007
	25–44 years	82	47.6	52.4		
	45+ years	42	33.3	66.7		

Table 3 ADK response classifications by Indigenous community sample compared to non-Indigenous community (Sullivan, 2008) sample

Modified Alzheimer's disease knowledge response classification	n	% of sample	Sullivan (2008)	
			n = 114	% of non-Indigenous sample
Misconceptions				
That prompt treatment of Alzheimer's disease may prevent worsening of symptoms	172	51.7	114	57
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	n/a	n/a
Over-estimated the prevalence of Alzheimer's disease	171	38.0	114	29
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	n/a	n/a
That patients react to their diagnosis with a lack of awareness of their symptoms	173	26.6	114	35
That treating depression will alleviate depressive symptoms and prevent further intellectual decline	152	26.3	114	42
Confirmation of diagnosis can be achieved via mental status testing ^c	157	26.1	114	41
Confirmation of diagnosis can be achieved via CT scan ^c	157	26.1	n/a	n/a
Knowledge gaps				
A person is expected to live 6–12 years after first getting Alzheimer's disease ^d	153	64.7	n/a	n/a
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	n/a	n/a
Aluminium may or may not be the reason why people get Alzheimer's disease ^e	157	57.3	n/a	n/a
Poor nutrition can make symptoms of Alzheimer's worse	154	51.3	n/a	n/a
Commonly held correct beliefs				
When self-care becomes impaired, assistance to help the patient remain as independent as possible is advised	172	51.7	114	86

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)

n/a = not applicable.

^aAs opposed to simply locking doors.

^bAs opposed to the first point alone.

^cTwo misconceptions within the one question/item were revealed by participants.

^dHeld as a misconception for Sullivan sample (Sullivan, 2008) by underestimating post-diagnosis life expectancy.

^eHeld as a misconception for Sullivan sample (Sullivan, 2008) by attributing role of aluminium in onset of Alzheimer's.

revealed in the areas of life expectancy, patient memory and the roles of aluminium and nutrition in AD. 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 AD prevalence and treatment, management of wandering and depression, personality changes and patient's reaction to diagnosis.

Discussion

A limitation of our study was the use of a convenience sample. Participants were all attendees of a Sports and Cultural Festival and may have had an underlying interest in health and as a result may have biased the results. The effect of this bias may be that Indigenous community knowledge of AD is lower than that reported in this study. A further limitation is that the results of this study were compared with a sample that had previously completed surveys.

Notwithstanding the limitation of using a convenience sample, this study is significant in that it is the first study to have investigated the awareness of dementia amongst a sample of Indigenous Australians. It revealed gaps in knowledge and common misconceptions about dementia. 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 Indigenous communities, as other Australian studies (Sullivan *et al.*, 2003; Low and 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). The non-Indigenous comparison sample ($n = 114$) were mostly female (68%), middle aged ($M = 46$ years $SD = 15$ years), had tertiary qualifications (51%) and were general community members. Eighty percent of this sample also knew someone with dementia, yet this latter factor did not affect results (Sullivan, 2008).

Indigenous participants in this study scored lower in Part 2 of the ADK which included more 'biomedical' questions about AD (mean 1.6 out of 10). This is also consistent with other studies (Prohaska *et al.*, 1987; Boise *et al.*, 1999; Bond *et al.*, 2005).

In the present study, there were group differences in the ADK categorical scores (Table 2) where the older age groups had greater levels of knowledge than younger participants. This was despite the younger participants (<25 years) having completed more formal education. 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. Sullivan (2008) also found that older participants scored higher than younger participants.

The Indigenous sample in this study revealed only one commonly held correct belief (51.7%) (Table 3). This was also held as a correct belief in Sullivan's (2008), albeit by a greater percentage of participants (86%). Sullivan (2008) reported a larger number (seven) of commonly held correct beliefs giving a higher mean ADK total score than participants in this study.

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 (see Sullivan, 2008, Table 3). The majority (62.5%) of misconceptions in this study were reported in Part 1 ('general' knowledge questions). 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 of which came from items in Part 2 of the survey. As reported in studies involving non-Indigenous groups (Purandare *et al.*, 2007; Arai *et al.*, 2008; Sullivan, 2008), this study also found that Indigenous participants had a lack of knowledge in the prognosis of dementia.

Whilst the Indigenous sample indicated a general lack of understanding about AD, there is a need to consider specifically developed and targeted education programmes for those groups (for example young Indigenous people) who have greater knowledge gaps about AD. This issue of targeted programmes has been previously raised by Sullivan (2008) and Arai *et al.* (2008). In so doing, it may also be important to consider the way in which information is prioritised, to ensure that the key issues are covered. If there is a risk that educational programmes that include content related to biomedical information, conflicts with the illness conceptualisations of individuals or groups, then priority may be given to covering those issues that would support early dementia recognition and help-seeking. We suggest careful negotiation of these aspects of programme development as part of an approach that would facilitate tailored information, maximise participation and engagement, and assist people to understand more about dementia.

Conflicts of interest

None declared.

Disclaimer

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Key Points

- Indigenous peoples understanding of dementia was poor particularly for younger participants
- Some of the misconceptions held by Indigenous people about dementia were also the same as what had previously been reported for non-Indigenous people.
- Culturally appropriate awareness campaigns and targeted educational interventions on understanding dementia are needed in Indigenous communities

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