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## **Dementia in Aboriginal people in Residential Aged Care Facilities in Alice Springs – A Descriptive Study**

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## Abstract

### Background

A high prevalence of dementia among Aboriginal and Torres Strait Islanders has been reported but knowledge of underlying causes and associations remains limited.

### Objective

To identify the prevalence of factors that may be associated with the categories of Major neurocognitive disorders (Major NCDs) in Aboriginal people living in residential aged care facilities in Alice Springs in the Northern Territory (NT).

### Design and Setting

This descriptive cross-sectional study analysed clinical file and cognitive assessment data of participants who were identified as having cognitive impairment between January and June 2016

### Method

Screening for the presence of cognitive impairment using the Kimberley Indigenous Cognitive Assessment (KICA) was undertaken and 58 of 84 Aboriginal people were admitted to the study. Using a clinical file audit, diagnoses of Major NCDs consistent with the DSM-5 classification were made and the prevalence of factors possibly associated with these diagnoses described.

### Results

Fifty of the 58 participants were diagnosed with a Major NCD. The most frequent diagnoses were Major NCD due to vascular disease (30%), Major NCD due to Alzheimer's Disease (26%) and Major NCD due to brain injury (20%). Hypertension, Type 2 Diabetes Mellitus

and alcohol misuse were commonly reported together with hypothyroidism, hypoglycaemia and vitamin D deficiency.

### **Conclusion(s)**

This study identified possible associations with Major NCDs in this population as well as a different spread of Major NCD diagnoses to previous studies in Aboriginal populations.

There is a need for further research to understand the causes of dementia in Australian Aboriginal people and to use this information to appropriately tailor treatment and prevention programs.

## Introduction

Dementia is three to five times more prevalent in Aboriginal people than in other Australians. (Smith et al., 2008; Radford et al., 2015; Li et al., 2014; Pollitt, 1997) To develop effective prevention programs, it is important to understand the reasons for this difference.

In this paper the term ‘Aboriginal’ is used respectfully as the preferred term used by Central Australian Aboriginal people. The terms ‘dementia’ and ‘Major Neurocognitive Disorder’ (Major NCD) are used synonymously, to describe the syndrome of decline in one or more cognitive domains and described in the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> edition (DSM-5). (American Psychiatric Association, 2013) This is consistent with Dementia Australia recommendations. (Dementia Australia, 2018) NCD may be divided into either Mild or Major categories, depending largely on a person’s ability to function independently. Since all participants in this study are dependent upon their Residential Aged Care Facility (RACF) for their activities of daily living, all those found to have an NCD were categorized as having ‘Major NCD’.

Dementia diagnosis in Aboriginal people has been greatly helped by the development of the Kimberley Indigenous Cognitive Assessment (KICA), a validated tool for use with Aboriginal people in Western Australia, the NT and Queensland. (LoGiudice et al., 2006; Smith et al., 2009) Unfortunately, the identification of causes of dementia in Aboriginal people remains poorly understood, with Smith (2008) and Li (2014) citing frequencies of above 50% for dementia of ‘unspecified’ cause.

This study also seeks to identify the prevalence of factors that may be associated with categories of dementia found in Aboriginal people living in RACFs in Alice Springs, the major town in Central Australia.

Ethics approval was granted by the Human Research Ethics Committee for NT Department of Health and Menzies School of Health Research (HREC 2015-2462 on 6/1/2016) and the Central Australian Human Research Ethics Committee (HREC-15-336 on 7/12/2015)

## **Methods**

### **Participants and setting**

Eighty-four potential Aboriginal participants aged 45 years or greater were identified in the three RACFS in Alice Springs. Consent was obtained from the individual (n=40) or legal guardian (n=35). Nine residents with no legal guardian refused or were unable to consent. (Figure 1.) The Aboriginality of participants was determined from RACF records and confirmed with participants and/or carers prior to recruitment.

### **Data collection**

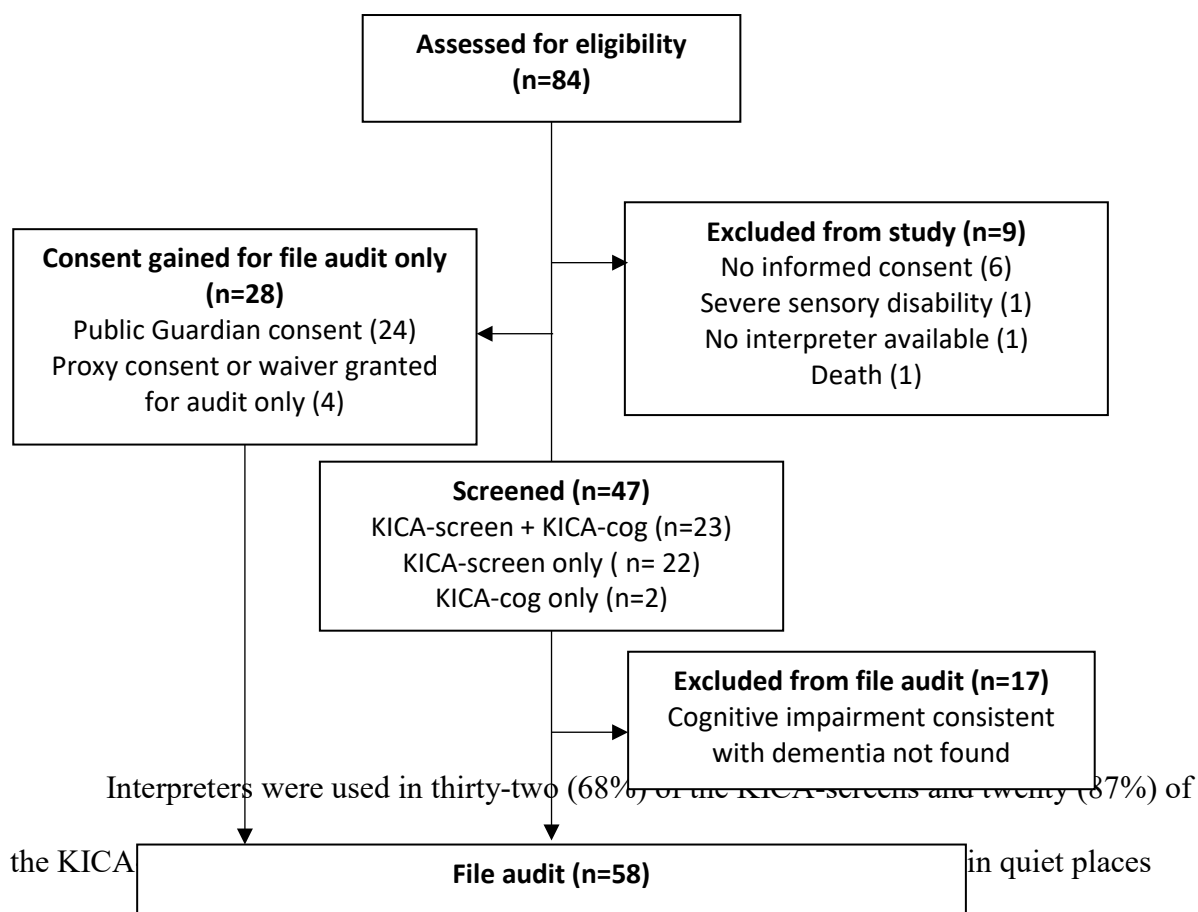
The research team included an experienced NT general practitioner, geriatrician; senior nurse; four senior researchers with psychiatric, aged care and physician expertise; two allied health academics and representatives from Australian Regional and Remote Community Services who manage the residential facilities and Dementia Australia.

Interpreters for six different Central Australian languages worked with guidelines adapted from the Aboriginal Interpreter Service. Team members provided training to interpreters in the appropriate use of the KICA. Culturally adapted consent forms, study information sheets and a pictorial flip chart were developed using pictures, plain English and minimal text. All screening was performed by an experienced NT general practitioner. Hospital file audits were conducted by an experienced NT geriatrician.

### **Cognitive screening and assessment**

Of the 84 participants assessed for eligibility, 9 were excluded due to lack of informed consent or inability to be assessed; 28 proceeded straight to file audit with guardian or proxy consent or a waiver of consent, leaving 47 people screened. (Figure 1) Of the participants screened, 30 proceeded to file audit with 58 participants audited in total. The KICA screen (n=47) was used to identify cognitive impairment with a follow-up KICA-cog (n=25) wherever possible. The shorter screening test was used to permit consent for entry into the study while the longer form of the KICA was used to confirm cognitive impairment (Figure 1) Two residents who were unavailable for KICA-screen testing were later tested using only the KICA-cog. Those scoring above the cut off [21/22 for KICA-screen and 33/34 for KICA-cog (LoGiudice et al., 2011)] were excluded from the study. If an initial assessment was incomplete, data was included for those who had attempted 80% or more of the items.

**Figure 1.** Participant flow through the study





within the RACFs. KICA-screens were completed in January and March and the KICA-cogs in April and June 2016. In recognition of the potential for practice effects it is noted that no participants were found to have an improved KICA-cog score following a KICA-screen and all twenty-three participants assessed with the KICA-cog had an abnormal result.

### **File audit**

The electronic NT hospital records of the 58 participants were reviewed. Most of these records went back to the early 2000s. All records were reviewed for clinical assessments of cognitive capacity and diagnoses; brain imaging and reports; pathology reports, and prescriptions of relevant medications. CT images, or reports of images, were available for almost all (93%) of the participants in this study. The median age of the most recent imaging was two years. RACF files were also reviewed for current medication and current diagnoses. These files also contained detail of assessments, doctors' letters and opinions.

DSM-5 criteria for sub-types of Major NCD guided each diagnosis, which was based upon KICA-cog and screen results and analysis of file audit data. Many participants had extensive case notes over many years, allowing a timeline of cognitive deterioration to be obtained. When this information was not available an assumption was made that participants had functioned at a higher level prior to admission to the nursing home review, unless there was a known diagnosis such as developmental delay.

A likely causal link between key events was assumed where other evidence was lacking. For example, a participant with a history of head injury and extensive encephalomalacia and previous craniotomy visible on CT scan, was diagnosed with Major NCD due to traumatic brain injury (TBI). The assumption was made that the impairment of cognition occurred following the injury. While we recognize that TBI is also a risk factor for

Alzheimer's Disease, we classified people as having NCD due to TBI only when file audit and imaging supported brain injury itself as the primary cause of cognitive loss.

Clinical examination of participants was not conducted because of difficulties with obtaining assent in all participants, and the likelihood that examination would cause discomfort and distress in this highly vulnerable population. Most participants had records of multiple previous assessments available and the geriatrician in the study had assessed almost half of the participants previously. Personal, clinical and historical information about participants were also sought from a senior clinician (GP, nurse) or carer working in the RACFs. Many of the interpreters also had a prior knowledge of participants even though they might not have seen them for many years (and often expressed sadness at the deterioration in participants when compared to their memories).

## Results

### Diagnoses

Fifty of the 58 participants were diagnosed as having a Major NCD. Thirty-nine (67%) participant files had a diagnosis of 'dementia' already documented, 85% of which were of unspecified cause. (Table 1)

Diagnoses were divided into five groupings: Major NCD due to vascular disease (VaD) (30%), Major NCD due to Alzheimer's Disease (AD) (26%), Major NCD due to Brain Injury (BI) (20%); a fourth group (Major NCD-Other) containing the less frequent diagnoses and a fifth group of participants without Major NCD. (Table 2)

The group of Major NCD due to Brain injury included both the DSM-5 classification of Major NCD due to TBI and the group with Major NCD due to neurosurgery – a group that is not classified separately in DSM-5. This is because many participants had both TBI and subsequent or related surgery, either of which could have been the cause of cognitive

impairment. In addition, both groups of participants had similar long-term concerns such as epilepsy. The Major NCD-other group contained participants with Major NCD due to mixed Alzheimer's Disease and vascular disease (10%); Major NCD of unspecified cause (4%); Major NCD due to substance misuse (4%) – both patients with Wernicke/Korsakoff syndrome; Major NCD due to another medical condition (4%) and one diagnosis of Major NCD due to Frontotemporal Dementia.

**Table 1:** Demographics of residents enrolled after initial KICA screening (N = 58)

		n (%)
Gender	Female:Male	39:19
Age	45-59 yrs	6 (10)
	60-69 yrs	16 (28)
	70-79 yrs	14 (24)
	80+ yrs	22 (38)
Mean age	74.3 years	
Language group	Central Arrernte	9 (15.5)
	Western Arrernte	5 (8.5)
	Eastern Arrernte	4 (7)
	Luritja	9 (15.5)
	Pitinjinjarra	7 (12)
	Warlpiri	5 (8.5)
	Anmatjerre	3 (5)
	Others	4 (7)
	English	4 (7)
	Not recorded	8 (14)
	Residency in RACF	< 1 years
1-5 years		22 (38)
5+ years		14 (24)
Consent	Self or proxy sought	23 (40)
	Public guardian	35 (60)
Recorded Dementia Diagnosis*	Dementia	39 (67)
Recorded Dementia Type	Vascular	2 (5)
	Alzheimer's	2 (5)
	Substance misuse	2 (5)
	Unspecified	33 (85)

\*Diagnosis recorded in NT public hospital case notes and/or in aged care facility files

No participants were classified as Mild NCD. This assessment took into account the KICA results, clinical file review and the evidence that admission to the residential facility resulted from the need for significant support in Activities of Daily Living.

### **Associations**

The prevalence of a variety of associated factors were reviewed for each of the diagnostic groups. (Table 2) Hypertension was recorded in 59% of participants, a prevalence that was spread relatively evenly across all diagnoses. Type 2 Diabetes Mellitus (T2DM) was diagnosed in 60% of participants, four of whom had previous hypoglycaemic episodes recorded, and 23 (74%) had a lowest HbA1c recording of less than 6.5%, suggesting the possibility of undiagnosed hypoglycaemic events. The highest prevalence of T2DM was found in those with Major NCD due to AD and Major NCD due to VaD

Twelve participants (24%) diagnosed with Major NCD had hypothyroidism, either as a recorded diagnosis (9) or with a record of at least one high TSH level ( $> 5.5\text{mIU/L}$ ) and regular treatment with Thyroxine (3). Seven of these twelve (58%) had Major NCD due to AD.

Twenty-four of all participants (41%) had a history of alcohol misuse documented in their hospital files, most commonly in with the group with Major NCD due to BI (70%).

Twenty-six percent had seizures recorded, also most commonly in with the group of Major NCD due to BI (60%). Of those with seizures, 71.5% had a documented history of alcohol misuse.

Records of 17 of the 18 people for whom tobacco use was documented showed they chewed rather than smoked tobacco; however, many of these participants were also observed smoking.

Low vitamin D levels (<50 nmol/L) were recorded in 68% of the 25 residents with documented levels. Most were recorded prior to admission to the facility suggesting that vitamin D deficiency was a pre-existing condition.

Of the 19 diagnosed with Major NCD who were tested for HTLV-1, 13 (68%) were positive for the disease.

No active syphilis infection was found in any participants.

**Table 2: Associations with Major Neurocognitive Disorders (Major NCD)**

	NCD-AD	NCD-VD	NCD-BI	NCD-Other	Total with NCD	Nil NCD	Total Study pop
N	13	15	10	12	50	8	58
Median age (range)	81 (69-96)	78 (60-96)	66 (53-78)	76 (53-88)	76	67 (56-85)	75
Diabetes Mellitus	10 (77%)	10 (67%)	5 (50%)	6 (50%)	31 (62%)	4 (50%)	35 (60%)
Hypertension	7 (54%)	9 (60%)	3 (30%)	9 (75%)	17 (34%)	6 (75%)	23 (40%)
Thyroid Disease	7/12 (58%)	2/14 (14%)	0/2	3/12 (25%)	12/40 (30%)	3 (37.5%)	15 (26%)
History of Alcohol	4 (31%)	5 (33%)	7 (70%)	6 (50%)	22 (44%)	2 (25%)	24 (41%)
Seizures	1 (8%)	3 (20%)	6 (60%)	3 (25%)	13 (26%)	4 (50%)	17 (29%)
Tobacco	5 (38%)	5(33%)	2 (20%)	3 (25%)	15 (30%)	4 (50%)	19 (33%)
Vit D <50	5/6 (83%)	6/8 (75%)	1/3 (33%)	2/3 (67%)	14/20 (70%)	3/6 (50%)	17/26(65%)
HTLV-1	2/3 (67%)	3/4 (75%)	4/5 (80%)	4/7 (57%)	13/19 (68%)	2/4 (50%)	15/23(65%)
CKD (eGFR<60)	5 (38%)	7(47%)	2 (20%)	3 (25%)	17 (34%)	5 (62.5%)	22 (38%)
History of CVA	1 (8%)	7 (47%)	3 (30%)	3 (25%)	14 (28%)	2(25%)	26 (45%)
Pos Syphilis ser.	4/6 (66%)	3/5 (60%)	4/4(100%)	4/9 (44%)	15/24 (62%)	1/3 (30%)	16/27(59%)

VaD: Vascular disease; AD: Alzheimer's Disease; TBI: Traumatic Brain Injury. T2DM: Type 2 Diabetes Mellitus

Denominators in rows labelled 'Thyroid Disease', 'Vit D', 'HTLV-1' and 'Pos Syphilis serology' are the total numbers with test results documented for each group.

Positive Syphilis serology: all results reflect previously treated infection. No active disease documented.

## Discussion

Understanding the reasons for the high prevalence of dementia in Aboriginal people is a prerequisite to developing effective prevention programs. While diagnosis was difficult at times, the availability of imaging and/or imaging results in this study led to greater

confidence of diagnosis and improved ability to understand some of the underlying causes of dementia.

DSM-5 uses a syndromic approach to diagnosis and it can be hard to fit pathological diagnoses into this framework. For example, it is not clear how to classify impairment due to neurosurgery. Similarly, Korsakoff's syndrome was classified as Major NCD due to substance abuse, where more properly it is due to thiamine deficiency.

Compared to similar studies, this study found higher rates of Major NCD due to VaD and TBI and lower rates of major Neuro-cognitive Disorders due to AD and unspecified causes. It is important to note, however, distinct differences in methodology and the study population limit direct comparison between studies. For example, the NSW community study by Radford et al (2015) found higher rates of Alzheimer's disease, which may perhaps be explained by the insidious onset and progress of Alzheimer's Disease leading to a higher number of cases in the community.

Studies of Aboriginal populations undertaken prior to the introduction of the DSM-5 have reported few diagnoses of dementia due to brain injury, despite finding high rates of head injury in their populations. High levels of head injury in Aboriginal people with dementia have been previously reported by Smith et al. (2008), LoGiudice et al (2016) and Radford et al. (2015), but only Radford et al. diagnosed dementia due to brain injury in a small proportion of their dementia group.

Twenty years ago, Pollitt suggested that alcohol misuse was the major cause of dementia in Aboriginal people (Pollitt, 1997). Only two participants (4%) in this study were diagnosed with Major NCD due to substance misuse (in both cases, Korsakoff syndrome). Alcohol misuse, however, continues to be commonly associated with dementia (Radford et al. 2015; LoGiudice et al. 2016; Smith et al. 2018) and with physical trauma such as motor

vehicle accidents and assaults. (AIC, 2009) In the clinical file audit, it was common to find patients had been reported as heavy drinkers or as misusing alcohol. This data was included in the audit and, like other missing data, was assumed to be absent when it was not documented. Alcohol misuse was noted in 80% of those with a history of a head injury requiring hospital involvement and in 70% of those diagnosed with Major NCD due to BI.

Aboriginal people are reported to have a younger onset of dementia than non-Indigenous Australians, (Li et al., 2014) however this study did not confirm this finding. The difference is unlikely to be attributable only to the age of our study population, as RACFs may accommodate Aboriginal people from the age of 50 years. Of the six people under 60 years of age in this study, none had Alzheimer's disease; three had histories of major head injuries, one a history of Korsakoff's syndrome, one a history of congenital intellectual impairment and one had suffered a cerebral tumour.

Smith et al. (2010) identified factors associated with dementia in Aboriginal people, including advanced age, current smoking, previous CVA, epilepsy, head injury and a lack of formal education. Our study identified further possible associations. As expected, there was a high frequency of T2DM across the study population and the possibility of undiagnosed hypoglycaemia in many of these people. Even with improved chronic disease care in the NT, food security remains a concern in the elderly, and hypoglycaemia may be an underlying factor in diabetics with Major NCD. (Schillinger et.al. 2010)

The prevalence of hypertension was high and spread across the whole study group. Hypertension is a known risk factor for dementia (Hughes and Sink, 2016). These findings suggest that better management of cardiovascular risk factors may lower the incidence of Major NCD.

Hypothyroidism was most commonly found in participants diagnosed with Major NCD due to AD (58%). Clinical hypothyroidism is now recognised as a cause of both reversible and irreversible cognitive impairment. (Tan et al., 2008; Harper and Roe, 2010; Breteler et al., 1991; Yeap et al., 2012) There is also growing literature about the role of subclinical hypothyroidism in the cognitive dysfunction of elderly people. (Pasqualetti et al., 2015)

Previous research suggests that low Vitamin D levels may be associated with cognitive decline. (Balion et al., 2012) Vitamin D deficiency (defined as a blood level less than 50nmol/L) is common (38.7%) in Aboriginal people living in remote areas. (ABS, 2016) The high frequency of vitamin D deficiency found in this study (62% of those with Major NCD) may reflect inadequate sun exposure in an elderly population both in their home communities and in the aged care facilities. Its role, if any, in Major NCD in this population needs to be clarified.

HTLV-1 seropositivity is common in Central Australian Aboriginal people. (Gordon, 2012) and varies by geographical region. Amongst the twenty-three study participants tested, 65% were positive and in 68% of those with Major NCD. In a cross-sectional study of 104 participants in Brazil, HTLV-1 sero-positivity was linked to cognitive impairment. (Gascon et al., 2017) Whether HTLV-1 has a causal role in the development of Major NCD in Aboriginal people is currently unknown.

Twenty-one participants had both a KICA-screen and a KICA-cog, using interpreters and conducted by the same investigator. The correlation coefficient between the two sets of results was only 0.31. This underlines the importance of repeating cognitive tests with Aboriginal people.

#### [Limitations of this study](#)



This is a small, cross-sectional study in which causal inference cannot be derived with any certainty. A key limitation was the lack of systematic clinical interview of participants and/or their carers. We acknowledge resource limitations as the major reason for our choice of methodology. Our participants, resident in remote Alice Springs in Central Australia, were usually far from home and family and spoke English as a second or third language. These challenges to the research setting rendered comprehensive individual assessments beyond scope. This gap was filled to some extent by the rich detail obtained from the medical records. Additionally, the specific study setting of RACFs in Alice Springs limits the generalisability of the findings to wider populations and does not reflect the spectrum of severity of NCDs in the community.

While imaging is an important aid in classifying categories of Major NCD, our images were not all current, and imaging diagnoses were often not clear cut. Clinical and historical factors remain essential to confident diagnosis of cognitive impairment diseases. Addition of carer interviews with interpreter support, and review of case records by a panel of experts rather than a single clinician would have potentially strengthened our diagnostic certainty.

Further, only 58 of the original 84 potential participants were included in the file audit which may have introduced bias to the results

## **Conclusions**

This study of Aboriginal people living in RACFs in Central Australia reveals a different dementia profile to community-based studies, with higher rates of Major NCD due to VaD and BI and lower rates of Major NCD due to AD and unspecified cause disease. It demonstrates a link between alcohol, traumatic brain injury and Major NCD. The different findings suggest that services and preventative strategies may need adaptation for different

populations. The study also identifies several factors that might be associated with cognitive impairment, and that warrant further investigation, including hypothyroidism, hypoglycaemia, HTLV-1 and Vitamin D deficiency.

Finally, while observing the often-animated interactions between interpreters and previously withdrawn residents, the potential benefit of employing Aboriginal carers in these RACFs became evident, especially for those residents who are a long way from family and country.

### **Acknowledgments**

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### **Conflict of Interest**

**Nil**

### **Ethical Standards**

Ethics approval was granted by the Human Research Ethics Committee for NT Department of Health and Menzies School of Health Research (HREC 2015-2462 on 6/1/2016) and the Central Australian Human Research Ethics Committee (HREC-15-336 on 7/12/2015). The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

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