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A Pilot Study to Estimate the Prevalence of Dementia in Torres Strait Islander Communities



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Translating Dementia Research Into Practice

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Abstract

Objective To estimate the prevalence of dementia in one Torres Strait Islander community and test the appropriateness of the research methodology for a future larger prevalence study.

Method Twenty residents from Hammond Island in the Torres Strait aged 45 years and over participated in a comprehensive health assessment using the Kimberley Indigenous Cognitive Assessment tool and Geriatrician review.

Results The prevalence of dementia, at 5%, was lower than previous research with Aboriginal Australians but still higher than found in the general population.

Conclusion(s) The methodology was shown to be appropriate for use in the Torres Strait with results identifying an increased risk of dementia. High rates of vascular risk factors were identified and may contribute to this increased risk of dementia. Further research is required to establish the prevalence of dementia within the wider Torres Strait region.

Introduction

In 2011, the number of Australians diagnosed with dementia was estimated to be around 298,000 with rates expected to rise to 900,000 by 2050 (1). Given the expected increase in demand on health and aged care services, accurate prevalence figures are critical for future planning and provision of appropriate care for people with dementia. Until recently, establishing the prevalence of dementia in Indigenous Australians has been hampered by the lack of culturally appropriate cognitive screening tools. To address this gap, the Kimberley Indigenous Cognitive Assessment (KICA) was developed for older Indigenous Australians living in rural and remote regions of Australia (2) with a shortened version, the KICA screen, recently validated in seven Aboriginal and Torres Strait Islander communities in Far North Queensland (3).

Using the KICA, the prevalence of dementia in Aboriginal Australians living in the Kimberley region of Western Australia aged 45 years and over was found to be 12.4% (4), which was more than 5.2 times higher than the population rate of 2.4% (5). The prevalence of cognitive impairment not fulfilling the criteria for dementia (CIND) was 8% (4). Within the sample, 40% of participants had no formal education, there were more than 20 first languages spoken and high rates of vascular risk factors were found. Demographic variables such as older age, male gender and no formal education were significantly associated with dementia. Once these were controlled, current smoking, previous stroke, epilepsy and head injury were significantly associated with dementia (6).

The Torres Strait comprises 18 island and 2 Northern Peninsula Area communities, located between the tip of Cape York in Queensland and Papua New Guinea and Indonesia (7). According to the 2011 census, 52,616 people in Australia identified as being of Torres Strait Islander origin, 5,787 of whom were living in the Torres Strait region (8). Torres Strait Islanders experience similar socioeconomic disadvantage and poorer health outcomes as Aboriginal Australians in general, with those living in the Torres Strait having similar levels of disadvantage as remote Aboriginal communities. The age distribution is also similar to Aboriginal Australians, with only 10% of the Torres Strait Islander population aged 55 years or over compared with 24% of non-Indigenous Australians (9).

It is not known if Torres Strait Islander communities share the increased risk of dementia seen in remote Aboriginal communities, although high rates of cardiovascular risk factors such as

hypertension and diabetes, which may all contribute to increase the risk of dementia, are found in the Torres Strait (10). Rates of dementia may vary between Aboriginal and Torres Strait communities in different areas of Australia due to diversity in lifestyles, health factors, access to medical and health services and other demographic differences (11).

The aim of this pilot study was to assess the prevalence of dementia in individuals aged 45 and over living on Hammond Island in the Torres Strait and to test the appropriateness of the research methodology for a future larger prevalence study. The research design was similar to the Kimberley prevalence study and involved a comprehensive health assessment using the KICA and Geriatrician review (2). Several additional questionnaires were included to obtain more information about conditions commonly seen in older adults including falls risk, pain, incontinence and depression.

Hammond Island (Keriri) has a population of approximately 242 people and is accessible by water taxi in a 15-minute trip from Thursday Island (12). The island has a small shop, primary school and council offices and receives monthly outreach health services from Thursday Island. It was selected for the study due to its close proximity to Thursday Island and already established links between the community and the Post Acute, Rehabilitation and Aged Care (PARAC) team from the Primary Health Care Centre on Thursday Island.

Method

Participants

A total of 20 out of a possible 28 residents of Hammond Island aged 45 and over participated in the study (9 males) resulting in a participation rate of 71%. Reasons given for not participating included working or visiting family on other islands. Eighteen participants were of Torres Strait Islander descent, one participant was of Aboriginal descent and one participant was born in Fiji. Enquiries failed to identify any residents who had recently left the island due to poor health or had been relocated to the nursing home on Thursday Island. The average age of the sample was 65.8 years (*SD* 9.46, range 45-85 years). Eighteen of the participants had seven years or more education (mean=7.45 years (*SD* 1.67, range 3-10 years). All participants spoke English as their primary language or co-language.

Materials

The KICA was administered together with five screening questionnaires assessing falls risk, pain, incontinence, depression and carer burden. A separate Falls Risk for Older People in the Community (FROP-Com) screening tool (13) and the Mini Mental State Examination (14) were administered as part of the Geriatrician assessment.

The Kimberley Indigenous Cognitive Assessment (KICA). The KICA collects information from the patient and an informant about relevant medical history, smoking and alcohol history, mood and functional abilities (2). The cognitive component of the tool (KICA-Cog) assesses orientation and memory, comprehension, language and executive functioning using simple English and culture fair test items including culturally appropriate pictures and commonly used objects. A total score between 0 and 39 is calculated with scores of 33 or below indicating possible dementia (15). An eight item informant report, the KICA-Carer, is embedded in the tool to obtain information from the informant about recent changes they may have observed in the patient's cognitive status and the frequency of such behaviours. A total score between 0 and 16 is calculated, with scores of 3 or higher indicating further investigation is required.

In response to community feedback during the validation of the KICA screen in Far North Queensland, several stimulus pictures from the memory recall and recognition task were modified to reflect local Torres Strait culture (Figure 1). A Torres Strait Islander drum replaced the boomerang as the initial sample item with a spear and headdress used as foils on the sample recognition trial. The Aboriginal people were redrawn as Torres Strait Islander people and the turtle, bird and emu were redrawn as a Green Turtle, Torres Strait pigeon and Cassowary respectively. All original KICA pictures were also redrawn to maintain consistency and quality of the images. On the advice of local Torres Strait health workers, several words were changed from Aboriginal language to Torres Strait Islander Creole. For example, mungari (food) was changed to kaikai and gumbu (urine) was changed to pipi.

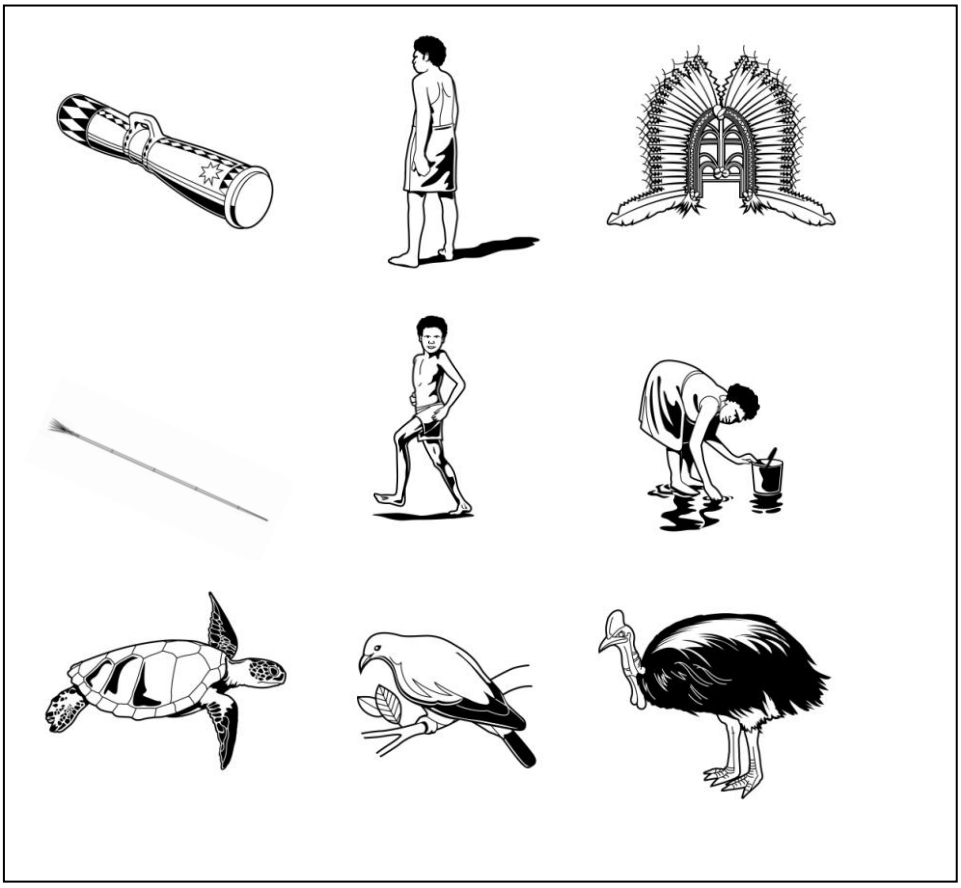


Figure 1. Revised stimulus pictures used in the study

Elderly Falls Screening Test. This questionnaire comprises five items assessing the frequency and nature of falls over the past year together with an assessment of the patient's ability to walk at normal speed over a 5m distance and gait (16). Scores of 2 and above trigger a referral for further assessment. An additional question was included from the FROP-Com (13) to identify the reason for the most recent fall.

Pain Scale. This seven item questionnaire was adapted from the Brief Pain Inventory (17) to assess the presence and severity of pain and its functional impact. Pictorial representations of the front and back of the body were included to identify the location of any pain and six targets of increasing size ranging from 0 (no pain) to 5 (as bad as you can imagine/big mob pain) were included to identify pain severity. Referral to a Geriatrician was indicated if the patient reports being in pain all the time, for more than one week AND if the pain is greater than 2/5 on targets and /or interfering with activities.

Modified ICIQ Continence Questionnaire. The modified ICIQ comprises four questions assessing the presence and severity of urinary incontinence with scores of two and above triggering a referral for a continence assessment (18).

Modified PHQ-9 Depression Scale. The PHQ-9 is a widely used tool for depression that has been modified recently for use with Aboriginal and Torres Strait Islander people (19). The questionnaire comprises 11 questions assessing the presence and severity of symptoms of depression experienced in the past week, ranging from never (0) to all the time (3), with scores of 9 or above indicating a referral for further assessment was required. The modified version included an additional item directly assessing feelings of anger, which had been identified as a common symptom of depression in Aboriginal and Torres Strait Islander people (19).

Adapted Zarit-6 Carer Burden Interview. A modified 6-item version of the Zarit Burden Interview (20) was included to measure subjective burden among caregivers. Scores range from 0-24, with higher scores indicating a higher level of perceived burden.

The Falls Risk for Older People in the Community (FROP-Com) screening tool. This tool comprises 26 questions assessing 13 risk factors for falls and was developed to identify people at risk of falls in the community (21). Scores range from 0-63, with scores of 15 and below indicating a low falls risk, 16-24 a moderate falls risk, and over 24 indicating a high falls risk.

The Mini Mental State Examination (MMSE). The MMSE is a widely used brief screening tool for cognitive impairment assessing orientation, attention and calculation, registration and recall, language and visuoconstructional abilities (14). A total score between 0 and 30 can be calculated with scores of 23 or less indicative of cognitive impairment (14). As MMSE scores are influenced by demographic variables such as age, education, ethnicity and socioeconomic status, this tool has been recommended for use with people who have a minimum grade eight education and are fluent in English.

Procedure

Residents aged 45 and over living on Hammond Island in the Torres Strait were approached by Primary Health Care staff from the Post Acute, Rehabilitation and Aged Care service on

Thursday Island and invited to participate in the study. Names of those who consented to participate were forwarded to the researchers who arranged for assessments to be conducted in the participant's home or at the local council office, depending upon the participant's preference. A Torres Strait Islander health worker, Betty Sagigi, who is the ACAT coordinator for Thursday Island, accompanied the researchers on the field trip to provide introductions as well as translation services as required. The project officer, Dr Sarah Russell, administered the KICA and additional questionnaires to all participants and obtained an informant history from a family member. Participants also underwent a comprehensive geriatric assessment conducted by the principal investigator and Regional Geriatrician, Dr Eddy Strivens, who was blinded to the KICA-cog scores. Participants were classified as having dementia, CIND or normal cognition according to DSM IV diagnostic criteria (22).

Local government, council and community members were consulted during the development of the project and the project was supported by the community of Hammond Island. Ethics approval was obtained from the Cairns and Hinterland Health Service District and James Cook University Human Research Ethics Committees. Consent to conduct the research was also obtained from the Torres Strait and Northern Peninsula Area Health Service District, Queensland Health.

Results

Data Analysis

All data were analysed using SPSS version 20.0.0. Due to the small sample size and lack of statistical power, only descriptive analyses were conducted on the data set.

Geriatrician Diagnosis

One person was diagnosed with *Dementia of the Alzheimer's type,* four with *Cognitive Impairment No Dementia (CIND)* and 15 had normal cognition. Based on these figures, the prevalence of dementia in the sample was 5% and the prevalence of CIND was 20%. Cognitive impairment was found in 55.5% of males and 0% of females. The distribution of diagnosis by age is shown in Table 1. On average, those with impaired cognition were older (mean age = 71.4 years, range 66-75) than those with normal cognition (mean age = 63.9 years, range 45-85). Both groups had an average of seven years education.

Table 1

DSM IV Diagnosis according to Age Group

	Geriatrician Diagnosis		
AGE	**Normal**	**CIND**	**Dementia**
<65	6	0	0
65-69	6	2	0
70-74	1	1	1
75-79	1	1	0
80+	1	0	0
TOTAL	15	4	1

Cognitive Assessment

KICA-cog scores. KICA-Cog scores for the sample are shown in Figure 2. The average score was 36.95 (*SD*1.32, range 34-39) and all participants scored above the cut off score of 33.

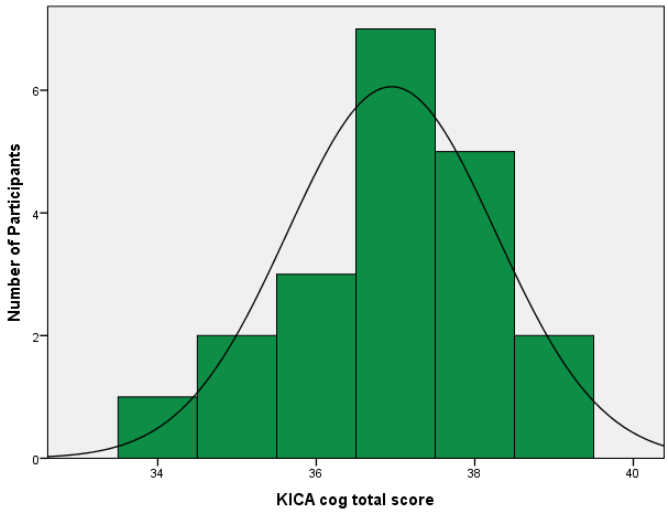


Figure 2. Distribution of KICA-Cog scores within sample.

KICA-cog scores for the sample are shown in Table 2 according to Geriatrician diagnosis.

Table 2

Distribution of KICA-Cog Scores according to Geriatrician Diagnosis

KICA SCORE	Geriatrician Diagnosis			TOTAL
	Normal	CIND	Dementia	
34-36	3	3	0	6
37	5	1	1	7
38-39	7	0	0	7
TOTAL	15	4	1	**20**

Mini Mental State Examination (MMSE) Scores. MMSE scores for the sample are shown in Figure 3. The average MMSE score for the sample was 26.2 (SD3.04, range 15-29) and all but one participant scored above the cut off score of 23. The participant diagnosed with dementia obtained a MMSE score of 15 and a KICA-cog score of 37.

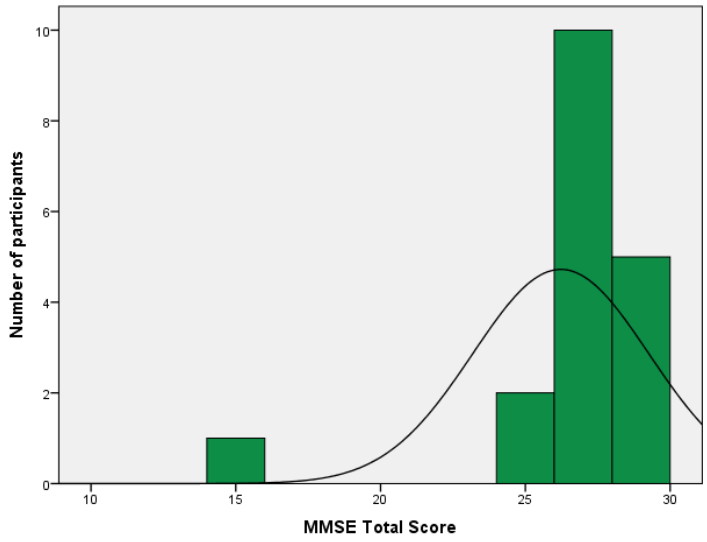


Figure 3. Distribution of MMSE scores obtained for the sample.

Lifestyle/Medical Characteristics

Lifestyle and medical factors for the sample are shown in Table 3. Where possible comparisons have been made to the data published about the Kimberley studies (4). None of the participants in the current study had a history of stroke or epilepsy. Three participants, all

with normal cognition, had a positive family history of dementia. Consistent with previous studies, rates of vascular risk factors were high, seen in 100% of those with cognitive impairment and 73% of those with normal cognition.

Table 3

Lifestyle/Medical Characteristics of Sample and Comparisons to the Kimberley Study

Condition	CIND/Dementia (n=5)	Normal Cognition (n=15)	% of Total Sample (N=20)	% of Kimberley Sample (N=363)
Poor Vision	2	0	10%	59%
Poor Hearing	1	0	5%	18%
Prior Head Injury	2	3	25%	51%
Diabetes	2	4	30%	42%
Hypertension	2	8	50%	43%
Heart problems	2	2	20%	20%
Consumes alcohol	3	7	50%	37%
Drinks every day	1	0	5%	11%
Drinks until drunk	1	1	10%	30%
Currently smoking	2	4	30%	35%
Vascular risk factors present*	5	11	80%	
2 or more	3	8	55%	
Both DM and HTN	1	4	25%	

*Vascular risk determined by presence of any of the following: Diabetes Mellitus (DM), Hypertension (HTN), Heart problems, High Cholesterol, or currently smoking.

Functional Status

All participants identified an informant to provide collateral information. Of these, eight lived with the participant. Six informants were a son or daughter, seven were partners, two were siblings or nieces or nephews and one was a mother, grandchild or cousin.

Level of independence in activities of daily living was assessed via self and informant report with a high level of correspondence found between the two sources of information. Within the

sample, 65% were independent, 20% required partial assistance and 15% were dependent in some activities of daily living. All participants could complete some tasks independently. Of those requiring assistance, all used informal rather than formal sources of support.

Informant and Self Report

Scores from the KICA-Carer, Adapted Zarit Burden Interview and the other questionnaires are shown in Table 4.

Table 4.

Scores on Informant and Self Report Questionnaires

	Mean (SD)	**Range**	**Number above cut off for further investigation**
KICA-CARER	1.89 (1.78)	0-5	6
ZARIT BURDEN SCALE	1.33 (2.6)	0-10	NA
Elderly Falls Screening Test (EF)	1.7 (1.87)	0-6	8
FROP COM	9.84 (6.3)	1-22	5
Pain Score	5.4 (4.75)	0-14	3
Modified ICIQ	0.65 (1.22)	0-4	5
Modified PHQ9 Depression Scale	4.25 (3.14)	0-10	2

There was a lack of correspondence between those identified through informant report on the KICA-Carer as having memory problems and those diagnosed with cognitive impairment on Geriatrician assessment. Of the six people identified by the KICA-Carer as requiring follow up for their memory problems, four were assessed as having normal cognition, one was diagnosed with CIND and one was diagnosed with dementia on Geriatrician review. All had KICA-cog scores of 36 or above. Scores on the Adapted Zarit Burden Interview were generally low, reflecting a low level of perceived burden associated with caring within the informants. The questionnaires assessing associated geriatric conditions all identified some participants as requiring further investigation. Even though only two participants were flagged as requiring further evaluation for depression, over 73% of the sample positively endorsed the additional item on the PHQ item directly assessing feelings of anger.

Discussion

One of the main aims of the study was to test the appropriateness of the research methodology for a future larger prevalence study. Results suggested that the methods used in the pilot study were appropriate for use in Torres Strait Islander communities. The participation rate was high and the modified pictures and language changes were well received by participants and local health workers.

A second aim of the study was to assess the prevalence of dementia in one Torres Strait Islander community. The prevalence of dementia on Hammond Island was 5%, which was lower than the previous research with Aboriginal Australians but still higher than found in the general population. In contrast, rates of CIND, at 20%, were higher than the Kimberley studies. This study therefore provides preliminary objective evidence of an increased risk of dementia and cognitive impairment in Torres Strait communities, with the high rates of vascular risk factors also identified in this study possibly contributing to this risk. However, results are limited due to small sample size and may not be generalisable due to the diversity in lifestyle in the Torres Strait. It is therefore recommended that further research investigating the prevalence across different island communities includes an assessment of potential protective lifestyle factors such as diet and physical exercise as well as evaluation of risk factors for dementia.

Consistent with the Kimberley studies, cognitive impairment was associated with demographic variables such as older age and male gender. Although the statistical significance of these findings was not tested due to the small sample size, these findings highlight the importance of identifying demographic variables that help to predict those at greater risk of developing dementia in Torres Strait communities.

The results suggest that a KICA-cog cut-off score of 33 was not sufficiently sensitive to detect cognitive impairment in this study. All participants scored above the cut off, despite cognitive impairment being diagnosed in 25% of the sample and the participant diagnosed with dementia obtained a KICA-cog score of 37. This may reflect the influence of education and language on test performances, as the current sample had higher levels of education than the Kimberley study and all participants spoke English as their first language or co-language. These preliminary results suggest that the KICA-cog may need to be revalidated for use in the Torres Strait.

Collateral history from a close relative or other informant is an important component of a dementia assessment as it provides the clinician with independent information about the nature and severity of the patient's cognitive concerns. This becomes even more important when a cognitively impaired patient cannot reliably provide this information themselves. In this study, there was a discrepancy between those identified as requiring follow up by the KICA-Carer and those diagnosed with cognitive impairment by the Geriatrician. Only two out of the six participants identified on the KICA-carer as requiring follow up for their memory problems were later assessed as having cognitive impairment or dementia by the Geriatrician, and the KICA-carer failed to identify three participants with CIND. It is possible that informants were unaware that their family member was having memory difficulties, as most were living independently and may have been able to compensate for any functional impact of their memory problems. Alternatively, responses may reflect a more general lack of understanding about symptoms of memory loss and dementia. Further evaluation of the effectiveness of the KICA-Carer in identifying those with symptoms of memory loss based on informant report is recommended in future studies. Evaluation of cultural perceptions and knowledge about memory loss and dementia may also provide a better understanding of how such conditions are understood in Torres Strait Islander communities.

Scores from the Adapted Zarit Burden Interview were low indicating a low level of perceived carer stress in those informants interviewed in the study, which may also reflect the relatively high level of functional independence within the sample. However, all of those who were dependent for some activities of daily living were relying on informal supports, highlighting the potential for carer stress to develop. This emphasises the importance of evaluating what supports are currently available within communities and what needs are not currently been met, as well as to what degree such support is being accessed given the potential impact on carer stress.

The addition of the questionnaires assessing conditions commonly seen in older adults such as falls risk, pain, depression and incontinence were extremely useful, as each scale identified some participants in need of further assessment and intervention. These problems can significantly impact on health and quality of life but may be amenable to intervention, yet many of these issues may not have been identified if the questions had not been asked. These

results highlight the importance of screening for such conditions as people may be reticent to seek help themselves for these problems or not realise that assistance is available.

In conclusion, the main aim of the study was achieved as the methodology used in the current study was shown to be appropriate for use in future prevalence studies in the Torres Strait. The increased risk of dementia found in this study highlights the need for further research to establish the prevalence of dementia within the wider Torres Strait region to assist the future planning and provision of appropriate care for people with dementia. The identification of demographic, medical and lifestyle risk and protective factors for dementia is also important given than some of these factors may be modifiable, can improve health outcomes and quality of life.

Key Points

- The prevalence of dementia in one Torres Strait Island community, at 5%, was lower than previous research with Aboriginal Australians but still higher than found in the general population.

- High rates of vascular risk factors identified in the sample may contribute to this increased risk of dementia

- Certain demographic differences were noted between studies that may account for differences in scores on the KICA-Cog that warrant further investigation in a larger sample

- As results may not be generalisable to other islands due to the diversity in lifestyle in the Torres Strait, further research is required to establish the prevalence of dementia within the wider Torres Strait region

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