Prevalence of Dementia in Torres Strait Islander Communities

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Welcome

I would like to start by thanking everyone who took part in the study including our older community members, health centre staff, and other community organisations, without whom this study could not have been completed.

I have worked as an Aged Care Assessment Team (ACAT) assessor and coordinator for the Torres Strait and Northern Peninsula Area (NPA) for many years. During this time, I have had many conversations with older community members and their families around the difficulties they face as they grow old. When working with Dr Eddy Strivens (aged care doctor from Cairns) who regularly visits older adults in the region, community members often told us they had concerns about memory problems and other health problems of ageing.

After many conversations like this, myself, along with Dr Eddy, Dr Sarah and the rest of the research team (known as HART), partnered with Diai Luffman and the PARAC team on Thursday Island to see if we could understand how common some of these issues of ageing were in the region. During the study, we went to every island community in the Torres Strait and those in the Northern Peninsula Area where the team completed health and memory assessments with adults in the community. This report talks about the findings of that study, which showed there were more people with memory problems and dementia than found in the wider Australian population. You may have taken part in this yourself and may remember there were lots of morning teas and homemade cakes shared along the way.

This study is only the beginning our understanding ageing in Torres Strait and NPA communities and there is more work to be done. Moving forward, we will be working with communities and health centres to support people to age well in the Torres Strait & NPA.

Many thanks for taking the time to read this report.

Esso

Betty Sagigi

Acknowledgement

We acknowledge Aboriginal and Torres Strait Islander people as the custodians of Country throughout Australia, and continuing connections to land, sea and community. We pay respects to our cultures, and to Elders past, present, and emerging.

The Healthy Ageing Research Team

Members of the Healthy Ageing Research Team have been working up in the Torres Strait clinically providing services to older people over the past 20 years. The team is led by Adjunct Professor Eddy Strivens who is a Regional Geriatrician and Clinical Director for Older Persons, Subacute and Rehabilitation (OPSAR) based in Cairns.

The Healthy Ageing Research Team:
L-R: Gavin Miller, Rachel Quigley, Sarah Russell, Eddy Strivens, Fintan Thompson, Diane Cadet-James & Jenny Mann, based in Cairns with Betty Sagigi, based in the Torres Strait.

We would like to thank the wider HART team and Queensland Health clinicians for their contributions to the study and final report.

Thank you from the team

The Healthy Ageing Research Team (HART) wish to thank the residents of the Torres Strait and Northern Peninsula Area who participated in this study and the staff at the primary health centres who made this study possible.

Dementia Rates in the Torres Strait

What is dementia?

Dementia affects thinking and memory over time. It affects older people but is not part of healthy ageing.
Dementia rates in 18 islands of the Torres Strait and 5 NPA communities were looked at between 2015 - 18.

What was found?

39 out of 274 people between 45 - 93 years old had dementia. This means that 14 people out of 100 (14%) had dementia.

Rates of dementia in Torres Strait communities were 3 times higher that in people elsewhere in Australia of the same age.

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What makes dementia more frequent in Torres communities?

History of diseases of the heart or kidneys, such as high blood pressure, stroke and diabetes.

How can we change this?

By staying healthy, being active, connecting with community and learning new things you may be able to reduce the risk of dementia.

For more information contact hart@jcu.edu.au

Background

What is Dementia?

Dementia is the term used to describe a range of conditions affecting the brain that leads to progressive decline in thinking and memory that increasingly interferes with the ability to complete daily tasks[1]. Dementia usually affects older people but is not a normal part of ageing.

The main causes of dementia in older people include Alzheimer's disease, Vascular dementia, and Dementia with Lewy Bodies[1]. Initially, symptoms may differ across different types of dementia depending up which areas of the brain are affected, but eventually all brain functions are impacted by dementia.

- Alzheimer's disease is the most common cause of dementia in older adults. It develops due to a build-up of abnormal proteins in the brain, known as plaques and tangles, which destroy brain cells. Memory loss is a very common early symptom, along with language problems, before wider thinking and memory problems emerge[2].
- Vascular dementia arises from damage to the blood supply to the brain. This can occur due to a sudden blockage or bleed in the brain (a stroke) or more slowly through gradual damage to the blood vessels carrying blood to, and around, the brain. People with Vascular dementia often have problems with attention, speed of processing, and thinking flexibly before memory loss becomes noticeable [1]. They may also have early physical changes to how they walk and continence issues. It is possible to have a mixed Alzheimer's and vascular dementia, particularly in the oldest old[2].
- People with Dementia with Lewy Bodies have noticeable problems with attention and falls and often develop visual hallucinations, where they see things that are not there. Their attention and thinking may vary quite a lot during the day and they may be restless and thrash around in their sleep[2].

Sometimes people start to have memory and thinking problems but these issues do not have too much impact on daily tasks. This is known as Mild Cognitive Impairment and it is often a risk factor for dementia[2].

Dementia in Australia

In 2021, there are approximately 500,000 people living with dementia in Australia, with the number expected to increase to one million by 2058[3]. Dementia is now the second leading cause of death in Australia overall and the main cause of death in women[4]. There is no cure for dementia and the very few treatments available help to reduce symptoms for a while. There are some risk factors for dementia that cannot be changed including getting old and having certain genes (such as the APOE ε4 gene)[1]. However, studies have found that up to 40% of dementia risk is associated with lifestyle-related factors such as midlife chronic disease (high blood pressure, high cholesterol, and diabetes), smoking, obesity, and late life depression that may possibly be prevented[5]. Many of these conditions are risk factors for vascular disease because they damage blood vessels supplying the brain, which is known to increase the risk of vascular dementia and Alzheimer's disease[6]. There are also factors that seem to protect against dementia including higher levels of education, regular physical activity, and being socially connected[5]. These findings suggest that promoting protective factors across the lifespan and targeting lifestyle risk factors in mid-life may help reduce the development of dementia in late life[5].

Dementia in Aboriginal Communities

Two recent studies have shown the risk of developing dementia is three to five times higher in Australian Aboriginal communities than the general population and occurring at an earlier age of 45 years and over[7,8]. The most commonly diagnosed type of dementia in both studies was Alzheimer's disease. In remote Aboriginal communities in the Kimberley region of Western Australia, dementia risk was associated with older age, being male, not having any education, smoking, and brain injury (stroke, epilepsy, and head injury). People with dementia were also more likely to have problems seen with ageing such as poor mobility, incontinence, and have a higher risk of falls[9]. In a study in urban and regional Aboriginal communities in NSW, age, head injury and stroke were also significant dementia risk factors, as well as social and life span risk factors such as unskilled work and childhood psychological trauma[10].

Torres Strait Islander people and Dementia

Before the current study, there had not been any largescale investigation of rates of dementia in the Torres Strait, so it was not known if Torres Strait communities shared the

increased risk of dementia seen in Aboriginal communities. Risk factors may differ across the country and in different communities due to differences in diet, health, access to medical and health services, and other cultural, social, and geographical reasons. As previous studies had shown that there are high rates of midlife chronic disease such as hypertension and diabetes in the Torres Strait[11,12] , it was possible that rates of dementia were high as well.

Aim of the study

The aim of the study was to establish rates of dementia in the Torres Strait and identify factors associated with dementia risk.

Ethical Considerations

Ethics approval was obtained from Queensland Health (HREC/13/QCH/129-878) and James Cook University (H5495) Human Research Ethics Committees. Before starting the study, we consulted with community members living in the Torres Strait to make sure this research was needed and supported by the community. The study was developed and run in partnership with Diai Luffman, Victor Nona and the team at the Post Acute, Rehabilitation, and Aged Care (PARAC) service based on Thursday Island. Betty Sagigi, the area coordinator for the Aged Care Assessment Team, also joined our team as a researcher and worked on the project with us. We also set up a committee of local Torres Strait Islander community members to provide advice and guidance throughout the study.

Methods

Study Design

We visited all 18 Island communities in the Torres Strait and 5 Northern Peninsula Area communities between May 2015 and February 2018 to investigate rates of dementia in the region. We invited anyone aged 45 and over to take part in the study, as the aim was to recruit as many residents as possible.

Each participant was given a comprehensive health assessment known as the Kimberley Indigenous Cognitive Assessment (KICA), administered by members of the research team. Information was collected about participants' age, education, past work, medical issues, smoking and drinking history, depression and anxiety, how they were managing at home and what services they received. Participants were also given a memory test developed

specifically for Aboriginal people that we adapted for the Torres Strait (KICA-cog). If a person attended the appointment with a family member or carer, they were also interviewed with permission, about the participant's functioning and memory. Participants also agreed to have a medical assessment for dementia with a Geriatrician, who is a doctor who specialises in looking after older people. Assessments were completed at the local primary health service or community hall depending upon community preference, with some participants choosing to be seen at home. Betty Sagigi provided cultural and language support throughout. Another two Geriatricians and an Older Persons' Psychiatrist later reviewed the de-identified medical information so that everyone agreed that the correct diagnosis had been made for each participant. Diagnoses were made according to standard criteria outlined in the Diagnostic Statistical and Manual of Mental Disorders, 4th Edition (DSM IV-TR)[13]. No names were collected, so no participants could be identified and results were reported based on the group as a whole.

Recruitment

Local primary health centre staff invited known clients and other community members to participate. Other people were recruited through dementia education sessions, local radio talks, and other community events conducted by the team as part of the community consultation process; flyers placed on the local radio Facebook page; community noticeboards; local council newsletters and the local paper; and from word of mouth. Residents of the residential aged care facility located on Thursday Island were also invited to participate in the study and were assessed at the facility. If a person had dementia and they were no longer able to consent to take part but wanted to be involved, we contacted their next of kin or guardian to obtain consent.

Results

Participants

A total of 276 people aged between 45 years and 93 years took part in the study. Not enough information was available for two participants to make a dementia diagnosis, which reduced the sample to 274 people.

Of these, 88% were of Torres Strait Islander descent, 4% were of Aboriginal descent and 8% were of Aboriginal and Torres Strait Islander descent. The average age was 65 years and 34.3% were male. Everyone had some formal education, with nearly half (45%) having completed Grade 11/12 or post school education. Torres Strait Kriol was the primary language spoken by 45.8% of people, but 95% of participants spoke English as either a primary or a secondary language.

Based on Government information from the Australian Bureau of Statistics, we estimated that we recruited around 16.5% of Aboriginal and/or Torres Strait Islander resident living in the region aged 45 and over.

Dementia Prevalence

Within the sample, 39 people were diagnosed with dementia and 60 people were diagnosed with Mild Cognitive Impairment. Based on the number of people diagnosed with dementia, the prevalence of dementia in the sample was 14.1%. After we accounted for the age of our participants, this was nearly three times higher than the 3.6% seen in wider community aged 45 and older.

The risk was much higher (4.23 times higher) for people aged 60-69-year, and narrowed with age, to a 2.28 times higher risk in those aged 80 and over.

The types of dementia diagnosed are shown in Table 1 below. The most common diagnosis was *Dementia, Not Otherwise Specified*, seen in 38.5% of cases. This means that there was not enough clinical information to diagnose a subtype of dementia. The most commonly diagnosed subtype of dementia was Alzheimer's disease (30.7%) followed by Vascular dementia (20.5%).

Table 1: Dementia subtypes in 39 participants diagnosed with dementia

DSM IV Diagnosis	Number of people (%)
Dementia, not otherwise specified	15 (38.5)
Alzheimer's Disease	12 (30.7)
Vascular Dementia	8 (20.5)
Dementia due to other general medical condition	3 (7.7)
Dementia due to multiple etiologies	1 (2.6)

Characteristics of the sample

There were high rates of chronic disease within the sample as a whole, as over 64% of people had high blood pressure, 62% had diabetes, and 42% had high cholesterol. Problems associated with ageing were also high including over 40% of people reporting pain, 30% low mood, 28% difficulty walking, 24% incontinence, and 17% having had a recent fall. Table 2 compares background, self-reported health issues and medical conditions for people with and without a diagnosis of dementia. People with dementia were significantly older (average age 74.9) than those without dementia (average age 63.4) and were more likely to have less education. This is not surprising because age and lack of education are strong risk factors for dementia.

Table 2: Comparison of background, self-reported health issues and medical conditions in people with and without dementia (N=274)

	Dementia n=39 n (%)	No Dementia n= 235 n (%)
Demographics		
Male	14 (35.9)	80 (34.8)
Female	25 (64.1)	155 (66.0)
Education		
Primary	13 (48.1)	69 (30.7)
Year 10	8 (29.6)	48 (21.3)
Year 12	2 (7.4)	16 (7.1)
Post school	4 (14.8)	92 (40.9)
Self-reported health		
Current smoker	4 (11.1)	37 (16.2)
Past smoker	19 (65.5)	161 (71.9)
Poor mobility	17 (54.8)	61 (27.4)
Recent Falls	4 (13.3)	43 (19.4)
Pain	10 (32.3)	101 (45.3)
Incontinence	10 (32.3)	57 (25.6)
Low mood	7 (24.1)	77 (35)
Medical Conditions		
Hearing impairment	12 (31.6)	34 (14.6)
Head Injury	4 (15.4)	40 (18.3)
Epilepsy	2 (5.1)	1 (0.4)
Diabetes	30 (76.9)	141 (60.0)
High Cholesterol	23 (59.0)	94 (40.0)
Chronic Kidney Disease	15 (38.5)	40 (17.0)
Heart disease	10 (25.6)	39 (16.6)
Cerebrovascular Disease	12 (30.8)	7 (3.0)
High Blood Pressure	28 (71.8)	149 (63.4)
Number of medications	5.18 (2.3)	4.22 (2.96)
Takes 5 or more medications	24 (63.2)	100 (46.9)

Risk and Protective Factors for Dementia

People with dementia were significantly more likely to have the following problems than those without dementia:

- Hearing impairment
- Chronic kidney disease
- High Cholesterol
- Past stroke
- Poor mobility
- Increased pain
- Risk of falls
- More medications

As people in the study with dementia were older, they may be having more problems with these aspects of their health because of their age. We therefore used statistical techniques to remove the effect of ageing (and education, which also affects scores) to see what other factors increased the risk of dementia.

In particular, we were interested to see if dementia risk was related to having vascular risk factors such as being a past or current smoker, or having diabetes, high blood pressure, high cholesterol, heart disease, stroke or chronic kidney disease.

We found that people with dementia had significantly more vascular risk factors (average 3.65) compared to those without dementia (average 2.7) but numbers were high for everyone, with at least one risk factor seen in 95.6% of all participants.

Overall, our results showed that a history of past stroke or chronic kidney disease was significantly associated with an increased risk of dementia regardless of a person's age or education. Although other vascular risk factors were not significant in this study, they were still important contributors to dementia in Torres communities.

Key Points

- The prevalence of dementia in the Torres Strait was almost three times higher than the general population, consistent with previous research with Aboriginal Australians
- The most significant risk factors for dementia in the Torres Strait were a history of stroke or chronic kidney disease, and older age
- Having more education was protective against dementia
- Several risk factors identified in this study (e.g. stroke, older age, lower education) and associated problems of ageing (e.g. mobility and incontinence) were consistent with findings in Aboriginal communities

    - ❖ Similarities between studies likely reflect the impact of health inequalities and socioeconomic disadvantage across the lifespan that contribute to development of midlife chronic diseases that in turn, increases dementia risk

- Unlike the Kimberley and NSW studies, head injury and epilepsy were not significant risk factors, possibly because less people in the Torres study had a history of either condition.

    - ❖ Differences between studies show how exposure to specific risk factors leads to distinct patterns of risk within communities

- Rates of chronic disease and vascular risk factors for dementia were high across the sample, highlighting that many adults may be at risk of developing dementia. Problems of ageing, associated with ageing such as falls risk, poor mobility, and incontinence were also high and can significantly affect health and quality of life
- Many of these issues are amenable to intervention, highlighting the importance of:

    - ❖ Dementia awareness programs
    - ❖ Primary and community care identifying people with dementia
    - ❖ Developing culturally appropriate screening and interventions to address the high rates of chronic disease, problems of ageing, and dementia risk
    - ❖ Documentation of cognitive status in medical records, so adequate and appropriate services can be delivered to enable independence and to support carers

Future Directions

During our study, we met many older adults living in the Torres Strait who were ageing well. When discussing the results of our study, we received requests from Torres Strait communities to continue to collaborate with local partners and work with health centres to develop a framework for ageing well for older adults in the Torres Strait. Our collaborative work will adopt a strengths-based approach looking at how people age well. As 40% (or more) of dementia risk may be lifestyle-related, there are positive things that can be done now to improve the health and wellbeing of older adults living in the Torres Strait. These include:

The Healthy Ageing Research Team is committed to continuing to partner with PARAC, primary health centres, community organisations and community members to collaborate on projects with the aim of improving the health and wellbeing of people living in the Torres Strait.

References

1. LoGiudice D, Watson R. Dementia in older people: an update. *Intern Med J.* 2014;44(11):1066-1073.
2. Arvanitakis Z, Shah RC, Bennett DA. Diagnosis and Management of Dementia: Review. *JAMA.* 2019;322(16):1589-1599.
3. Dementia Australia. Dementia: Key facts and statistics 2018. https://www.dementia.org.au/files/documents/2018_Dementia_Key_facts%2526stats.pdf. Published 2018. Accessed 01/03/20.
4. Australian Bureau of Statistics. *Causes of Death, Australia, 2019. Cat. no. 3303.0.* Canberra: ABS;2020.
5. Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet.* 2020;396(10248):413-446.
6. Australian Institute of Health and Welfare. *Contribution of vascular diseases and risk factors to the burden of dementia in Australia: Australian Burden of Disease Study 2011. Australian Burden of Disease Study series no. 9. Cat. no. BOD 10.* Canberra: AIHW;2016.
7. Radford K, Mack HA, Draper B, et al. Prevalence of dementia in urban and regional Aboriginal Australians. *Alzheimer's & dementia : the journal of the Alzheimer's Association.* 2015;11(3):271-279.
8. Smith K, Flicker L, Lautenschlager NT, et al. High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology.* 2008;71(19):1470-1473.
9. Smith K, Flicker L, Dwyer A, et al. Factors associated with dementia in Aboriginal Australians. *Aust N Z J Psychiatry.* 2010;44(10):888-893.
10. Radford K, Lavrencic LM, Delbaere K, et al. Factors Associated with the High Prevalence of Dementia in Older Aboriginal Australians. *J Alzheimers Dis.* 2019;70(s1):S75-S85.
11. O'Dea K. Preventable chronic diseases among indigenous australians: the need for a comprehensive national approach. *Heart Lung Circ.* 2005;14(3):167-171.
12. Leonard D, McDermott R, Odea K, et al. Obesity, diabetes and associated cardiovascular risk factors among Torres Strait Islander people. *Aust N Z J Public Health.* 2002;26(2):144-149.
13. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (4th Ed., Text Revision).* Washington, DC: Author; 2000.

14. Kuzma E, Lourida I, Moore SF, Levine DA, Ukoumunne OC, Llewellyn DJ. Stroke and dementia risk: A systematic review and meta-analysis. *Alzheimer's & dementia : the journal of the Alzheimer's Association.* 2018;14(11):1416-1426.
15. Savva GM, Stephan BCM. Epidemiological Studies of the Effect of Stroke on Incident Dementia. *Stroke.* 2010;41(1):e41-e46.
16. Australian Institute of Health and Welfare. Australia's Health 2020. https://www.aihw.gov.au/reports-data/australias-health. Published 2020. Accessed 14 September, 2020, 2020.
17. LoGiudice D, Smith K, Thomas J, et al. Kimberley Indigenous Cognitive Assessment tool (KICA): development of a cognitive assessment tool for older indigenous Australians. *International psychogeriatrics.* 2006;18(2):269-280.
18. Cwikel JG, Fried AV, Biderman A, Galinsky D. Validation of a fall-risk screening test, the Elderly Fall Screening Test (EFST), for community-dwelling elderly. *Disabil Rehabil.* 1998;20(5):161-167.
19. Cleeland CS. *The Brief Pain Inventory: User Guide.* Texas: Department of Symptom Research, The University of Texas M. D. Anderson Cancer Centre,;1991.
20. Avery K, Donovan J, Peters TJ, Shaw C, Gotoh M, Abrams P. ICIQ: a brief and robust measure for evaluating the symptoms and impact of urinary incontinence. *Neurourol Urodyn.* 2004;23(4):322-330.
21. Almeida OP, Flicker L, Fenner S, et al. The Kimberley assessment of depression of older Indigenous Australians: prevalence of depressive disorders, risk factors and validation of the KICA-dep scale. *PloS one.* 2014;9(4):e94983.
22. Byrne GJ, Pachana NA. Development and validation of a short form of the Geriatric Anxiety Inventory--the GAI-SF. *International psychogeriatrics.* 2011;23(1):125-131.