Culturally safe, trauma-informed approach to cognitive impairment and dementia in older Aboriginal and Torres Strait Islander people

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Background
The population of older (age ≥50 years) Aboriginal and Torres Strait Islander people is increasing, and the rate of dementia in this group is three to fivefold higher than in the general population. A high prevalence of risk factors across the life course likely contributes to these rates.

Objective
This paper highlights practical ways to apply best practice principles when addressing the detection of cognitive impairment and dementia in older Aboriginal and Torres Strait Islander people and its management in the context of a person's family, carers and community.

Discussion
Recognising culture, the collective nature of family and community decision making for a person, the ways to uphold respect for Elders and a trauma-informed approach are fundamental to the care of older Aboriginal and Torres Strait Islander people with cognitive impairment and dementia.

OLDER (AGE ≥50 YEARS) Aboriginal and Torres Strait Islander people (hereafter respectfully referred to as First Nations people) and Elders are deeply respected as cultural custodians and hold important roles in families, communities and on Country. The First Nations population is ageing, with many living well into older age,[1] yet a substantial number continue to experience poor health outcomes and reduced quality of life due the effects of historical and continued colonisation policies on the social determinants of health.[2] Conditions such as dementia are emerging as important public health issues, with rates documented in the First Nations population between three- and five-fold higher than those of the general population, along with a younger age of onset.[3] These high rates of dementia and cognitive impairment in the First Nations population have been found in urban, regional and remote areas,[4,5] and projections estimate that the number of individuals with dementia will reach four- to five-fold current numbers by 2051.[6]

Dementia is a chronic, progressive condition, with the most common causes, generally and in First Nations populations, being Alzheimer's disease and vascular.[3–5] Recent research has dispelled myths that First Nations people do not live long enough to develop dementia and that alcohol is a predominant cause; both statements are unfounded.[3–5] Clinical and cultural recommendations to consider when addressing the needs of First Nations people at risk of or living with dementia have been developed through a Delphi-based consensus process with clinicians and non-clinicians experienced in primary healthcare, and with strong engagement from First Nations people. This best practice guide is available as a clinical resource on The Royal Australian College of General Practitioners (RACGP) website and is endorsed by the National Aboriginal Community Controlled Health Organisation (NACCHO).[7]

Aim

The purpose of this article, using practical examples in the form of a case study, is to highlight how the clinical and cultural recommendations may be applied in practice in the detection and management of cognitive impairment or dementia in a First Nations older person attending primary care. Because many First Nations people of middle and older age have been directly affected by historical forced removal from family, Country and culture, identified now as the Stolen Generations,

a trauma-informed approach to dementia care is imperative.[8]

In this paper we use a fictional case study of Aunty Joy and her son Fred to highlight the clinical aspects of the culturally safe, trauma-informed approach to an older person with cognitive impairment (Box 1).

Detection of cognitive impairment or dementia

Dementia and cognitive impairment are widely under-recognised in healthcare settings despite potential benefits of the timely recognition of cognitive impairment.[9]

Population screening for dementia is not recommended.[9] However, given the high prevalence of risk factors and rates of cognitive impairment and dementia in First Nations populations, a case-finding approach is recommended from the age of 50 years.[7,10] Case finding is commonly used in response to concerns raised by patients themselves, family members and health professionals, including Aboriginal and Torres Strait Islander health workers and health practitioners (ATSIHWP) and community members.

Case finding also includes assessing those at higher risk (ie people with risk factors for dementia;[3,10–12] Table 1) and/or asking questions about memory or thinking. This approach aligns with current recommendations for the inclusion of questions about cognition in the Medicare Benefits Schedule (MBS) annual health check for older (age >50 years) people (Item 715 and associated items).[13] The questions include:

1. Do you have any worries about your memory or thinking?
2. Does anyone in your family have any worries about your memory or thinking?

Cognitive screening tools are indicative but not diagnostic of cognitive impairment and the results need to be interpreted in the context of the person's life experience (eg cultural factors, language, education level) and other clinical findings.

Which cognitive assessment screening tool to use will vary on the older person's education and cultural preference. The Kimberley Indigenous Cognitive Assessment tool (KICA) was developed and validated initially in the Kimberley region, where many Aboriginal people had limited or no education, and English was the third or fourth language spoken. This tool is still commonly used in remote and regional areas of Australia.[14] Urban and Torres Strait Islander versions of KICA have been adapted,[15,16] and a shorter KICA-Screen is also available.[15,16] The KICA has been shown to be effective in a telehealth setting.[17] The psychometric properties are similar to those of common screening tools.[18] For those First Nations people who have experienced a more Western-style education and have good literacy skills, the Standardised Mini-Mental State Examination (SMMSE) is frequently used.[19] Neither the KICA nor SMMSE is sensitive to executive function, and therefore, the clock-drawing test can be added, as appropriate,[20] for example as part of the General Practitioner assessment of Cognition (GPCOG).

People may have cultural beliefs about changes in thinking or memory and/or changes in behaviour or personality. They may attribute these changes to the normal effects of ageing or another influence rather than something that may be addressed by healthcare and health services.[21,22] The wording and way of asking questions will vary depending on the cultural context and relationship between clinicians/healthcare workers and patients. ATSIHWPs play an essential role in the detection and management of chronic diseases,[23] including cognitive impairment and dementia. However, for younger ATSIHWPs, questioning older people about cognitive impairment may be seen as disrespectful, and therefore education about ways to approach this issue needs to be supported within the multidisciplinary team.[24] Having older ATSIHWPs of the same gender as the patient providing care can also be useful. Family involvement is paramount in the diagnostic process, although guilt about

Box 1. Fictional case study of Aunty Joy and her son Fred

Aunty Joy is a 74-year-old Noongar woman who lives in a regional city of Australia with her son Fred. Aunty Joy has obesity and was recently admitted to hospital with a fractured hip, complicated by delirium. Aunty is a member of the Stolen Generations. Fred is worried about his mum because she is forgetting things and her mood has changed a lot lately. Aunty doesn't acknowledge that she has memory problems. She is normally cheerful and likes yarning with community members, but has become more withdrawn and grumpy, and gets upset with Fred when he tries to help her. Her diabetes is poorly controlled, and Aunty is eating lots of biscuits. Aunty Joy used to enjoy attending the Elders' group, but now makes excuses and refuses to go.

Aunty Joy agreed to yarn with an older Aboriginal health worker who she was familiar with and agreed to undertake the urban KICA, with a result of 25/39. She described performing well on her tests saying, 'See, there is nothing wrong with my memory.' A more detailed informant history was obtained from Fred by healthcare staff while Aunty Joy was having a health check. An appointment was made for Aunty to see her general practitioner (GP), who undertook a holistic health check that included reviewing Aunty Joy's mood and obtaining details of her recent admission to exclude a potential cerebrovascular event.

Aunty Joy was referred to the visiting geriatrician via telehealth and a diagnosis of mild–moderate mixed dementia (Alzheimer's disease and vascular cognitive impairment) was made. The Aboriginal Health Worker sat in with Aunty Joy and her son Fred during the consultation. The diagnosis of dementia was disclosed during this session. A trial of dementia medication such as donepezil was recommended, and a care plan was developed with Aunty Joy and Fred over the next few visits (see Table 3).

Further meetings were organised with Fred to provide education about dementia and ways to support other members of his family who were 'a bit scared' of Aunty's grumpiness because they had never seen her like this before. Fred describes distress at the change in his mother's demeanour, and is worried that he cannot care for her properly, exacerbated by the fact that other family members are not supporting him. He is committed to caring for his mother because she had bad expereinces in institutions and does not want her to go to residential care. Fred agrees to make a time to see his GP for a health check-up including addressing his social and emotional wellbeing.

Table 1. Modifiable protective and risk factors for dementia

Protective factors for dementia: Strengthening, building cognitive reserve
Early life
• Healthy pregnancy
• Secure home environment
• Good diet
• Good hearing and language acquisition
• Strong development and engagement in education and learning
Middle and later life
• Social and cultural connection
• Healthy lifestyle
• Good diet and healthy weight
• Smoking cessation
• Regular physical activity
• Safe alcohol consumption
• Education and employment
• Cognitive stimulation
Risk factors for dementia: Damaging, reducing or limiting cognitive reserve
Childhood and adolescence
• Childhood trauma and early life adversity[A]
• Middle ear disease and hearing impairment
• Low level of education
• Smoking
Middle life
• Hearing impairment[A]
• Hypertension[A]
• Other cardiovascular risk factors including atrial fibrillation, dyslipidaemia
• Smoking
• Diabetes
• Obesity
• Psychosocial stressors
• Excessive alcohol intake
• Traumatic brain injury
• Air pollution
• Low physical activity[A]
• Chronic kidney disease[A]
Later life
• Stroke[A]
• History of head trauma[A]
• Epilepsy
• Delirium
• History of depression/chronic grief
• Social isolation/loneliness
• Physical inactivity
• Anticholinergic medications[A]
• Polypharmacy[A]
• Vision problems[A]

[A]These factors have been derived from cohort studies in the Kimberley, Far North Queensland and urban and regional New South Wales.[3–5]

disclosing concerns, poor health literacy about dementia and multiple competing carer roles need to be considered. Making time to speak with family separately is important, and health service staff can assist with obtaining information, supporting carers and educating them about cognitive impairment and dementia.

A diagnosis of dementia is usually conducted over several consultations to accumulate levels of evidence to fulfil the diagnostic criteria of dementia or mild cognitive impairment (Table 2). Review by a specialist, such as a geriatrician, is recommended, acknowledging this might be problematic in remote areas. Telehealth offers an alternative, and studies have shown the effectiveness of cognitive assessments by this modality,[17] or a diagnosis can be made with telephone support by a geriatrician or other specialist if required.

Communicating the diagnosis and initial planning

Communicating the diagnosis of dementia needs preparation and time in the presence of an appropriate Aboriginal support person (eg ATSIHWP), family and carers. There are a number of general misconceptions about dementia (eg it is just old age or the person is going mad) and there may be culturally based beliefs (eg the changes may be payback for previous wrongdoing). In addition, mistrust of services may be a factor, and some may fear being taken off Country and/or placed in institutions.[21,22] Older people value, and fear the loss of, their independence. Information about the diagnosis needs to be delivered sensitively, accurately and simply, often over a number of consultations. Discussion should include co-designing a care plan to optimise wellbeing, which can be enhanced by appropriate community supports. Key elements of ongoing management are documented in Table 3, which presents an example of a possible care plan for Aunty Joy.

Improving community awareness about dementia[25,27] is important, as are ways to keep Elders living with dementia involved in ceremony and cultural activities (eg ways to continue attending Elders groups, securing culturally appropriate

in-home support and educating the family about ways to communicate and engage with the older person). Encouraging people with dementia to consider possible future preferences and wishes is important, including formal arrangements such as appointing powers of attorney and making funeral plans, and these need to be revisited regularly.[27] The Good Spirit, Good Life tool is a co-designed and culturally validated quality of life tool that can be used to optimise wellbeing (Table 4),[28,29] and the Dying to Talk Aboriginal and Torres Strait Islander resources can be helpful to support end-of-life discussions.[30]

Primary care of a person with cognitive impairment or dementia is best managed by a multidisciplinary team, which may include traditional healers. Home assessments are valuable to determine the needs of the older person, who may live in intergenerational households and with limited socioeconomic supports. People living with dementia may be vulnerable to elder abuse, and this may be initially detected by the primary care team. Links to appropriate community services can be best facilitated through primary care.[31]

Conclusion

Cognitive impairment and dementia occur in one in five First Nations people over the age of 50 years. Best practice approaches are required and are available for general use. This paper describes practical tips on how to use these principles in the detection and management of cognitive impairment in an older First Nations person attending primary care, in the context of that person's family, carers and community.

Key points

- Cognitive impairment and dementia are common in Aboriginal and Torres Strait Islander people.
- A case finding approach to cognitive impairment and dementia is recommended from the age of 50 years.
- Annual health checks and care plans can support case finding, risk management and dementia care.
- Culturally safe and trauma-informed approaches to risk management and dementia care are strongly recommended.

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Competing interests: None.

Funding: NHMRC, Dementia Training Australia.

Provenance and peer review: Commissioned, externally peer reviewed.

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Acknowledgement

This paper is based on the Best Practice Guide that was developed as part of the Let's CHAT Dementia project, funded by NHMRC and Dementia Training Australia. The authors acknowledge the health professionals and the older Aboriginal and Torres Strait Islander people with cognitive impairment or dementia, their carers and families who participated in this project.

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Table 2. Factors to consider in the diagnostic process of cognitive impairment

Evidence of cognitive decline	KICA-Cog , KICA-Screen, SMMSE, GPCOG, clock-drawing test
Evidence of functional decline	Informant; health practitioners/community (particularly when visiting the home), OT home assessment; evidence of difficulty with medication, forgetting appointments
Noticed by family and/or others and change from previous level	KICA-Carer Informant questions on GPCOG
Exclusion of other factors that may be contributing	Depression (KICA-Dep or aPHQ-9) Contribution of medications, particularly anticholinergics Chronic pain Alcohol Infection
Dementia screen	Bloods, renal, FBE, vitamin B_{12}, folate, TFTs CT scan (to exclude reversible factors; eg stroke, bleed, normal pressure hydrocephalus)

aPHQ-9, adapted nine-item patient health questionnaire; CT, computed tomography; FBE, full blood examination; GPCOG, General Practitioner assessment of Cognition; KICA, Kimberley Indigenous Cognitive Assessment; KICA-Cog, KICA component on cognition; KICA-Dep, KICA component on depression; KICA-Screen, short form of the KICA; OT, occupational therapy; SMMSE, Standardised Mini-Mental State Examination; TFT, thyroid function test.

Table 3. Elements to include in a care plan to optimise brain health

Care needs in general to consider	Actions taken for Aunty Joy	Potential staff involved and referrals
Cognitive assessment	Repeat KICA-Screen in six months	Geriatrician review +/– telehealth six months GP, ATSIHWP, nurse
Monitor mood and anxiety, BPSD	Check PHQ in three months Check in with Fred regarding emergence of BPSD	Mental health team GP Dementia Australia or Dementia Support Australia
Risk assessment: falls, incontinence, pain, weight, nutrition Elder abuse	Check regularly for evidence of falls, incontinence, pain, weight and nutrition	OT, physiotherapy, podiatry Dietician Dental review Home visit Continence service
Track function: ADL, driving, managing finances	Consider capacity regarding financial matters; discuss appointment of powers of attorney with Aunty and Fred	GP, nurse, ATSIHWP Home visit Review by geriatrician for capacity may be required
Medication review	Aunty Joy is taking a tricyclic antidepressant (many years); consider weaning and changing to mirtazapine Review polypharmacy Review donepezil side effects	GP Pharmacist Consider referral to old age psychiatrist
Healthy lifestyle advice: physical activity, healthy diet, healthy weight, smoking cessation, safe alcohol	Encourage Elders gentle gym Diet review with regard to diabetes and healthy weight	ATSIHWP, dietician Exercise physiologist
Dental care	Yearly dental review, especially in the setting of weight loss	GP, nurse, ATSIHWP
Vision and hearing check	Encourage audiology review and encourage remediation of hearing impairment Encourage the use of glasses	GP, nurse, ATSIHWP referral
Planning	Discuss with Aunty and Fred who will be involved in decision making Formalise powers of attorney and an advance care plan Discuss Aunty's preferences and wishes and consider advance care planning	Consider case conference Consider family meeting Give information (eg *Taking control* book)
Clinical and support services	Review services involved Encourage referral to My Aged Care	Consider case conference Consider family meeting Refer to My Aged Care
Carer health and wellbeing	Organise regular checks with Fred, including MBS annual health check, and screen for mental health issues	Consider SEWB service, Carers Australia, Dementia Australia
General health review	Complete annual MBS Item 715 Develop GPMP annually and review regularly (three monthly)	ATSIHWP, nurse, GP Appointment reminder

ADL, activities of daily living; ATSIHWP, National Association of Aboriginal and Torres Strait Islander Health Workers and Practitioners; BPSD, behavioural and psychological symptoms of dementia; GP, general practitioner; GPMP, general practitioner management plan; KICA-Screen, short form of the Kimberley Indigenous Cognitive Assessment; MBS, Medicare Benefits Schedule; OT, occupational therapy; PHQ, patient health questionnaire; SEWB, social and emotional wellbeing.

Table 4. Good Spirit, Good Life elements to improve the wellbeing of older First Nations people

Do you get to have a yarn and spend time with family and friends?	For example, support attendance at Elders' group, educate family about the importance of inclusion
Do you spend enough time connecting to Country?	Facilitate yarning sessions to share stories about Country, assist with medical management to support trips to Country
Do you feel connected to the Aboriginal Community?	Promote community events (eg NAIDOC), link with appropriate community groups
Do you feel connected to cultural ways (eg attending Aboriginal events)?	Staff to complete cultural competency Assist with access to traditional healers, bush medicine
Do you do things to take care of your health?	Support attendance at appointments, support management of chronic health, run health group sessions
Do you feel respected and valued as an Elder/older person?	Engage active listening, responsiveness and sensitivity Address the person appropriately (eg Aunty or Uncle if they are comfortable with this)
Do you feel you can share your knowledge and stories with the younger mob?	Encourage to share knowledge and culture within the community
Do you feel the services you use are respectful and support your needs?	Adopt a family-centred care approach to service provision Encourage culturally appropriate community supports
Do you feel you have a safe space to live?	GP support letter for safer housing, refer to financial services
Do you feel safe and supported in your spiritual beliefs (eg yarning about culture or going to church)?	Encourage family about the importance of supporting traditional or spiritual practices
Do you feel you have things in place as you grow older?	Discussion regarding advance care planning, documenting funeral wishes and whether want to be buried on Country
Do you feel you have enough money to get by?	Link with appropriate community services If concerns regarding Elder abuse, refer to appropriate services

GP, general practitioner; NAIDOC, National Aborigines and Islanders Day Observance Committee.

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