


RESEARCH ARTICLE

Knowledge of dementia: A cross-sectional survey of Aboriginal and Torres Strait Islander community members and health-care workers providing care to Aboriginal and Torres Strait Islander people

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Abstract

Objectives: To examine (1) the knowledge of dementia among Aboriginal and Torres Strait Islander community members and health-care workers providing care to Aboriginal and Torres Strait Islander people; (2) the factors associated with higher levels of knowledge about dementia.

Methods: An online cross-sectional survey was conducted. Aboriginal and Torres Strait Islander community members were recruited through social media advertisements and an online market research platform. Health-care workers (general practitioners, nurses, Aboriginal health workers and allied health professionals) were recruited via emailed invitations from a peak body and a community service organisation. Participants answered an online survey containing 34 true/false items examining knowledge of dementia. Separate linear regressions were used to examine the factors associated with higher levels of knowledge about dementia among community members and health-care workers.

Results: Two hundred and twenty individuals (74 community members and 146 health-care workers) participated. The overall mean knowledge of dementia score for all participants was 26.80 (SD = 4.43). Health-care workers had higher knowledge ($M = 27.23$, $SD = 4.66$) than community members ($M = 25.96$, $SD = 3.82$, $p = .04$). Community members with higher levels of education answered 6% (95% CI 1%–11%) more items correctly than participants with lower levels of education. General practitioners and nurses had significantly higher knowledge of dementia; however, health-care workers who provided care to a family member or friend living with dementia had significantly lower knowledge of dementia.

Conclusion: Novel approaches are needed to increase knowledge of dementia amongst both Aboriginal and Torres Strait Islander community members and health-care workers who provide care to ensure culturally sensitive and effective support.

KEYWORDS

attitudes, Australian Aboriginal and Torres Strait Islander peoples, dementia, health knowledge, practice

1 | INTRODUCTION

Dementia is a major public health concern globally.¹ In Australia, it is estimated that more than four hundred thousand people are living with dementia, making dementia the second leading cause of death.² The prevalence of dementia has been estimated to be three to five times higher for Aboriginal and Torres Strait Islander people compared to non-Aboriginal peoples.^{3–6} Onset of dementia among Aboriginal and Torres Strait Islander people often occurs at a younger age⁵ and is associated with socio-economic disparities. The historical and ongoing impacts of colonisation have created systemic injustice and health inequities, and unique cultural factors that necessitate targeted and culturally sensitive approaches to diagnosis, care and support.

In the absence of any cure, early diagnosis of dementia is imperative as it is associated with better treatment and patient outcomes.^{7–9} However, it is estimated that up to 50% of cases of dementia are not diagnosed,⁷ and delays in dementia diagnosis and poor access to health care have been documented.¹⁰ In the community, seeking a timely diagnosis can be hindered by a poor understanding of dementia and its management, the denial of symptoms or lack of symptom recognition,¹¹ a belief that little can be done,¹⁰ lack of awareness of available services and how to access services,¹² and worry about loss of independence.¹³ General practitioners report that a lack of training and confidence are key barriers to the delivery of best practice dementia care.¹⁴ Among registered nurses and allied health professionals, knowledge of dementia and more positive attitudes towards people living with dementia have been found to be associated with the provision of higher quality care and improved quality of life for patients.¹⁵ High levels of knowledge about dementia for both community members and health professionals is therefore critically important to ensure timely and accurate diagnosis and the appropriate provision of care.

Research internationally^{16–19} and in Australia^{20–22} has found generally low rates of knowledge and awareness about dementia. In Australia and elsewhere, low levels of dementia knowledge have been found among the general public,²² family members of people with dementia²⁰ and health-care providers,^{21,23} with knowledge gaps related to early symptoms, risk factors for developing dementia and the terminal and progressive nature of the disease. Among

Practice Impact

Addressing knowledge gaps is critical for achieving timely and accurate dementia diagnosis and appropriate treatment and care. Targeted community-level interventions are needed to support better awareness of dementia in Aboriginal and Torres Strait Islander communities. Health-care providers should engage in ongoing professional development to enhance their knowledge of dementia care.

Aboriginal and Torres Strait Islander people, dementia remains largely unrecognised and is often viewed as a normal part of ageing.^{4,12,23} The need to address low rates of knowledge about dementia in order to support individuals to live well with dementia is recognised as a key action area by national^{24,25} and international^{26,27} dementia strategies and plans.

The number of Aboriginal and Torres Strait Islander people aged over 45 years in Australia is projected to increase threefold by mid-century,²⁸ and as such the burden associated with dementia among older Aboriginal and Torres Strait Islander people and their carers is expected to substantially increase.^{23,29} Despite this, limited research has examined knowledge of dementia amongst Aboriginal and Torres Strait Islander community members, or health-care workers who provide care in Aboriginal and Torres Strait Islander health-care organisations. Previous research has documented low rates of dementia knowledge among Aboriginal and Torres Strait Islander community members using structured surveys,^{12,30} and qualitative research has identified health-care provider perceptions of limited community awareness and understanding of the signs and symptoms of dementia.²³ However, these studies had small sample sizes, recruited participants from geographically limited areas, and none assessed knowledge of health-care providers. A contemporary understanding of current levels of dementia knowledge and gaps among Aboriginal and Torres Strait Islander people is crucial for developing culturally appropriate, evidence-based educational programs and activities that seek to improve knowledge for both individuals and health-care professionals.

This study aimed to examine among Aboriginal and Torres Strait Islander community members and health-care workers providing care to Aboriginal and Torres Strait Islander people (i) their knowledge of dementia, and (ii) the factors associated with higher knowledge of dementia.

2 | METHODS

2.1 | Design

A cross-sectional online survey conducted in Australia.

2.2 | Eligibility and recruitment

2.2.1 | Community sample

Aboriginal and Torres Strait Islander people aged over 18 years who did not have a diagnosis of dementia were eligible to participate. Community participants were recruited using two strategies. First, the survey was promoted through social media advertisement campaigns on Facebook, which included a link to the survey. Second, a quota sampling method was used to recruit participants via an online market research platform. The market research platform emailed survey invitations to eligible individuals on their database.

2.2.2 | Health-care worker sample

Health-care workers including general practitioners (GPs), nurses, Aboriginal health workers and allied health professionals aged over 15 years were eligible to participate. Invitations to participate in the survey were emailed by a peak body for Aboriginal and Torres Strait Islander health workers in Australia, and via a community service organisation providing care to primarily Aboriginal and Torres Strait Islander people in regional and urban communities in the Northern Territory.

2.3 | Data collection

For both community members and health-care workers, all study advertisements and invitations included a detailed participation information statement and a link to the online survey. Completion of the survey was taken as consent to participate. All participants who completed the survey were reimbursed with a \$25 electronic gift voucher. Data were collected between September 2021 and September 2022 inclusive.

2.4 | Measures

A systematic review of knowledge of dementia outcome measures found that of five available measures reviewed, all had limitations including weaknesses in psychometric properties, complex language, being outdated and having limited scope.³¹ While the Dementia Knowledge Assessment Scale has been validated for assessment of dementia knowledge in international studies involving diverse cohorts,³² it has not been validated for Aboriginal and Torres Strait Islander populations, and its content does not capture broader understanding and awareness of dementia-related issues. Therefore, a new measure to assess dementia-related knowledge in Aboriginal and Torres Strait Islander communities and among health-care providers was developed. Survey items were developed based on the *Lancet Commission's* evidence about dementia prevention, intervention and care,³³ a comprehensive literature review, and input from a panel of health behaviour scientists—including a geriatrician and the study team. The draft tool was then pilot tested by eight stakeholders from Aboriginal Community Controlled Health Services (ACCHSs) providing community aged care services. Stakeholders had extensive experience providing care to older Aboriginal people, including those with dementia. The revised tool then underwent further review by representatives from ACCHSs. The final survey comprised 34 true/false items, across the following five domains: general characteristics of dementia, risk factors, early symptoms of dementia, care and support for people with dementia, and community support for people with dementia and the people who care for them. Respondents were asked to answer whether each statement was True or False. A copy of the tool is provided in File S1. Participants self-reported their age, gender, postcode, Aboriginal and/or Torres Strait Islander identity and level of education. Community members were also asked whether they held a concession card and private health insurance, while health workers were asked to indicate their current occupation (GP, nurse, Aboriginal health worker or other) and their length of time in their current role. All participants were also asked to indicate whether in the last 5 years, they knew someone living with dementia or if they provided care to a person living with dementia. For health-care providers, it was specified that respondents should not include patients they may care for as part of their employment when answering this question.

2.5 | Data analysis

All statistical analyses were programmed using SAS v9.4.³⁴ Demographic characteristics were summarised for

community members, health-care workers and the total sample overall. The number and proportion of participants who answered each survey item in line with current evidence was determined, and an overall dementia knowledge score was calculated for each participant. The presence of a statistically significant difference between the mean knowledge of dementia score of the community and health-care worker samples was assessed via a *t*-test. The presence of a statistically significant difference between the median knowledge of dementia score of the community and health-care worker samples was assessed via a Kruskal–Wallis test. Statistical significance was assessed at the 5% level.

Linear regression models were used to estimate the difference in the mean knowledge of dementia scores due to factors associated with higher knowledge of dementia for the community and health-care worker sample separately. Models were produced for each factor individually (unadjusted model) and with all factors included within the regression model (adjusted model). Health-care workers who answered ‘other’ for their role were excluded from both the unadjusted and adjusted linear regression models, and participants who were GPs and nurses combined into a single category. An administrative error, only impacting the survey conducted via Facebook, resulted in 19 health-care workers having missing values for both ‘Role’ and ‘Time in role’. The number of missing observations represented 14% of the total health-care worker sample eligible for use in the regression models. Multiple imputation using fully conditional specification (FCS) was performed using 20 imputed data sets. Fully conditional specification was selected as the majority of variables in the regression model were categorical. The data set used for the multiple imputation comprised of all health-care workers surveyed, including those not eligible for inclusion in the regression models, as the missing observations could take on all levels available for ‘Role’ present in the administered survey. All variables from the adjusted model, as well as the outcome variable of proportion of correct answers, were included in the imputation model with this resulting in missing observations for ‘Highest level of education’, ‘Gender’ and ‘Aboriginal and/or Torres Strait Islander’, respectively, also being imputed. Due to variation in the number of health-care workers imputed as having a ‘Role’ category of ‘other’, the number of observations used in each regression model ranged from 133 to 139 with a mode of 138. No auxiliary variables were used. The final model was assessed for Variance Inflation Factor ($VIF < 10$), tolerance ($> .1$), multicollinearity and normality of residuals using histogram plots of the residuals, Q-Q plots and plots of residual versus predicted values (File S2). The final models were found to satisfy the key assumptions of linear regression. Sensitivity analyses

were performed to compare the impact to the interpretation of both the unadjusted and adjusted models when performed using the complete case data set or the multiply imputed data set.

2.6 | Ethics

This project was approved by the University of Newcastle Human Research Ethics Committee, (HREC Reference no. H-2021-0062), the Aboriginal Health & Medical Research Council of NSW (HREC Reference no. 1742/20), the Human Research Ethics Committee of NT Health and Menzies School of Health Research (2022-4321) and the Central Australian Human Research Ethics Committee (CA-22-4316). The study was overseen by an Aboriginal Advisory Group who ensured the research was culturally sensitive, ethically sound and aligned with the needs and perspectives of Aboriginal and Torres Strait Islander communities. The Aboriginal Advisory Group met regularly throughout the project and provided advice, guidance and direction about the design of the survey and study, implementation of research methods and interpretation of results. The Aboriginal Advisory Group was chaired by co-author Robert Davis and also included co-author Jennifer Rumbel.

3 | RESULTS

3.1 | Sample

A total of 220 participants ($n = 146$ health workers and $n = 74$ community members) completed data collection and were included for analysis. Participant demographic characteristics are provided in Table 1.

3.2 | Dementia knowledge

The scores achieved by item within each of the five domains, both as number and proportion correct, for community members, health-care workers and the total sample are shown in Table 2. Community members and health-care workers differed on at least one item with each domain (nine items in total across the domains). The difference in total domains mean scores and the proportion correct for community members, health-care workers and the total sample is shown in Table 3. Only the mean score for one domain varied between community members and health-care workers. Health-care workers achieved a higher mean score and proportion correct for the risk factors domain ($p = .02$ and $p = .02$, respectively). The overall mean knowledge of dementia score for all participants

TABLE 1 Demographic characteristics of the sample ($n = 220$).

	Community sample n (%)	Health-care worker sample n (%)	Total sample n (%)
	$n = 74$	$n = 146$	$n = 220$
Age category			
18–29	20 (27)	28 (19)	48 (22)
30–39	21 (28)	31 (21)	52 (24)
40–49	12 (16)	26 (18)	38 (17)
50–59	9 (12)	33 (23)	42 (19)
60+	12 (16)	28 (19)	40 (18)
Missing	0	0	0
Gender			
Male	33 (46)	34 (24)	67 (31)
Female	38 (54)	110 (76)	148 (69)
Missing	3	2	5
State			
ACT	–	2 (1)	2 (1)
NSW	18 (26)	25 (17)	43 (20)
QLD	24 (35)	16 (11)	40 (19)
NT	2 (3)	68 (48)	70 (33)
VIC	15 (22)	9 (6)	24 (11)
SA	5 (7)	4 (3)	9 (4)
WA	2 (3%)	14 (10)	16 (8)
TAS	3 (4%)	5 (4)	8 (4)
Missing	5	3	8
Aboriginal or Torres Strait Islander			
Yes	74 (100)	64 (44)	138 (63)
No	0	80 (56)	80 (37)
Missing	0	2	2
Highest level of education			
Primary school	2 (3)	0	2 (1)
High school	40 (54)	31 (22)	71 (33)
Trade or vocational	25 (34)	45 (31)	70 (32)
University	7 (10)	68 (47)	75 (34)
Missing	0	2	2
Concession card			
Yes	58 (78)	–	58 (78)
No	16 (22)	–	16 (22)
Missing	0	146	0
Role			
GP	–	3 (2)	3 (2)
Nurse	–	38 (30)	38 (30)
Aboriginal health worker/practitioner	–	36 (28)	36 (28)

(Continues)

TABLE 1 (Continued)

	Community sample n (%)	Health-care worker sample n (%)	Total sample n (%)
	$n = 74$	$n = 146$	$n = 220$
Personal care/support worker			
–	–	43 (34)	43 (34)
Other			
–	–	7 (6)	7 (6)
Missing			
–	–	19	19
Time in role			
<1 year	–	16 (13)	16 (13)
1–2 years	–	27 (22)	27 (22)
3–4 years	–	16 (13)	16 (13)
5+ years	–	62 (51)	62 (51)
Missing	–	25	25
Provide care to family member or friend with dementia			
Yes—spouse/partner	0	3 (2)	3 (1)
Yes—parent	6 (8)	8 (6)	14 (6)
Yes—sibling	0	4 (3)	4 (2)
Yes—other family member	2 (3)	1 (1)	3 (1)
Yes—friend	2 (3)	11 (8)	13 (6)
No	64 (86)	119 (82)	183 (83)
Missing	0	0	0

was 26.80 (SD = 4.43) out of a possible maximum score of 34. Health-care workers had significantly higher overall knowledge of dementia ($M = 27.23$, $SD = 4.66$) than community members ($M = 25.96$, $SD = 3.82$, $p = .04$).

3.3 | Factors associated with higher knowledge of dementia

The only factor demonstrating a statistically significant impact on the level of knowledge of dementia for community members was the highest level of education achieved (Table 4). Participants with a TAFE, Diploma, University or other level of education on average answered 6% (95% CI 1%–11%) more items correctly than participants who achieved a level of education of High school or below in the adjusted model. For health-care workers, providing care to a family member or friend with dementia and health-care worker role were both found to be significantly associated with knowledge of dementia in adjusted models (Table 5). Health-care workers in a GP or nurse role on average demonstrated statistically significant higher knowledge of dementia than Aboriginal Health Workers and those in personal care assistant or support

TABLE 2 Participant knowledge of dementia by domain items ($n = 220$).

	Community sample $n = 74$	Health-care worker sample $n = 146$		Total $n = 220$
	Correct ^a n (%)	Correct ^a n (%)	p	Correct ^a n (%)
Part A: About dementia				
Dementia is a normal part of getting older	47 (64)	117 (80)	.01	164 (75)
Dementia is a disease of the brain	72 (97)	140 (96)	.60	212 (96)
There are many different sorts of dementia, Alzheimer's disease is one type	68 (92)	136 (93)	.73	204 (93)
The symptoms of dementia stay the same and don't get worse over time	66 (89)	132 (90)	.78	198 (90)
Dementia can be cured by drugs	62 (84)	130 (89)	.27	192 (87)
Dementia shortens a person's life	53 (72)	110 (75)	.55	163 (74)
Young people get dementia more often than old people	65 (88)	130 (89)	.79	195 (89)
It is better to get diagnosed with dementia early	71 (96)	143 (98)	.39	214 (97)
Part B: A person's chance of getting dementia may be higher if they				
Don't exercise	32 (43)	87 (60)	.02	119 (54)
Lose their eyesight	63 (85)	119 (82)	.57	182 (83)
Smoke tobacco	36 (49)	96 (66)	.01	132 (60)
Drink too much alcohol	50 (68)	119 (82)	.02	169 (77)
Have a blood relative with dementia	54 (73)	109 (75)	.72	163 (74)
Spend lots of time with someone with dementia	68 (92)	139 (97)	.14	207 (95)
Have had a head injury	51 (69)	109 (75)	.32	160 (73)
Part C: Early signs of dementia can include				
Trouble finding the right words when talking	62 (84)	129 (91)	.12	191 (88)
Forgetting things from childhood or long ago	18 (24)	65 (46)	<.01	83 (38)
Suddenly not being able to speak	30 (41)	64 (45)	.52	94 (44)
Losing interest in activities they used to like	54 (73)	124 (87)	.01	178 (82)
Sudden weight loss	43 (58)	63 (44)	.06	106 (49)
Becoming lost in familiar places	69 (93)	134 (94)	.74	203 (94)
Having lots of ups and downs	62 (84)	129 (91)	.12	191 (88)
Back pain	58 (78)	127 (89)	.03	185 (86)
Part D: Care and support for people with dementia				
If someone is showing signs of dementia, they do not need to tell a doctor. They should be able to work it out for themselves	64 (86)	135 (95)	.03	199 (92)
Family and friends are an important support for people with dementia	68 (92)	136 (96)	.24	204 (94)
When someone is first diagnosed with dementia, it is usually too late for them to write a will	60 (81)	114 (80)	.89	174 (81)
Someone with dementia can choose who should make decisions for them if they can't make decisions for themselves anymore	65 (88)	120 (85)	.51	185 (86)
People with dementia should be put in a nursing home as soon as possible	61 (82)	121 (85)	.59	182 (84)
Family and friends should help the person with dementia to be as independent as possible	65 (88)	130 (92)	.38	195 (90)
Part E: Community Support for people with dementia				
There are services who can provide information and support to people with dementia	69 (95)	140 (99)	.03	209 (98)

TABLE 2 (Continued)

	Community sample <i>n</i> = 74	Health-care worker sample <i>n</i> = 146	<i>p</i>	Total <i>n</i> = 220
	Correct ^a <i>n</i> (%)	Correct ^a <i>n</i> (%)		Correct ^a <i>n</i> (%)
It is impossible to communicate with a person who has dementia	47 (64)	102 (72)	.23	149 (70)
We can do a lot now to improve the lives of people with dementia	70 (96)	135 (96)	.96	205 (96)
A person with dementia can be assessed to continue driving	34 (47)	76 (54)	.31	110 (51)
People with dementia and those who care for them can feel isolated and stigmatised	64 (88)	116 (82)	.31	180 (84)

Note: Bolded values are statistically significant at $p < 0.05$.

^aDeemed correct in line with current evidence.

TABLE 3 Mean (standard deviation) knowledge of dementia scores by domain and overall.

Domain	Questions correct	Summary statistic	Community	Health-care worker	<i>p</i>	Total sample
About dementia (/8)	<i>n</i>	Mean (SD)	6.81 (1.14)	7.11 (1.11)	.06	7.01 (1.13)
		Median (min, max)	7.00 (4.00, 8.00)	7.50 (2.00, 8.00)	.03	7.00 (2.00, 8.00)
	%	Mean (SD)	85 (14)	89 (14)	.07	88 (14)
		Median (min, max)	.88 (.50, 1.00)	.94 (.25, 1.00)	.03	.88 (.25, 1.00)
Risk factors (/7)	<i>n</i>	Mean (SD)	4.78 (1.49)	5.33 (1.61)	.02	5.15 (1.59)
		Median (min, max)	5.00 (2.00, 7.00)	6.00 (.00, 7.00)	.06	5.00 (.00, 7.00)
	%	Mean (SD)	68 (21)	76 (23)	.02	74 (23)
		Median (min, max)	.71 (.29, 1.00)	.86 (.00, 1.00)	.06	.71 (.00, 1.00)
Early symptoms (/8)	<i>n</i>	Mean (SD)	5.35 (1.28)	5.72 (1.56)	.08	5.60 (1.48)
		Median (min, max)	5.00 (1.00, 8.00)	6.00 (.00, 8.00)	.01	6.00 (.00, 8.00)
	%	Mean (SD)	67 (16)	72 (19)	.08	70 (18)
		Median (min, max)	.63 (.13, 1.00)	.75 (.00, 1.00)	.01	.75 (.00, 1.00)
Care and support (/6)	<i>n</i>	Mean (SD)	5.18 (1.15)	5.18 (1.35)	.99	5.18 (1.29)
		Median (min, max)	6.00 (2.00, 6.00)	6.00 (.00, 6.00)	.55	6.00 (.00, 6.00)
	%	Mean (SD)	86 (19)	86 (23)	.98	86 (21)
		Median (min, max)	1.00 (.33, 1.00)	1.00 (.00, 1.00)	.55	1.00 (.00, 1.00)
Community support (/5)	<i>n</i>	Mean (SD)	3.84 (.99)	3.90 (1.13)	.70	3.88 (1.08)
		Median (min, max)	4.00 (.00, 5.00)	4.00 (.00, 5.00)	.49	4.00 (.00, 5.00)
	%	Mean (SD)	77 (20)	78 (23)	.70	78 (22)
		Median (min, max)	.80 (.00, 1.00)	.80 (.00, 1.00)	.49	.80 (.00, 1.00)
Total (/34)	<i>n</i>	Mean (SD)	25.96 (3.82)	27.23 (4.66)	.04	26.80 (4.43)
		Median (min, max)	27.00 (15.00, 31.00)	28.00 (7.00, 34.00)	.01	28.00 (7.00, 34.00)
	%	Mean (SD)	76 (11)	80 (14)	.04	79 (13)
		Median (min, max)	.79 (.44, .91)	.82 (.21, 1.00)	.01	.82 (.21, 1.00)

Note: Knowledge of dementia scores are presented both as number correct and proportion correct. *p*-Values presented relate to *t*-tests associated with the comparison of the mean.

Bolded values are statistically significant at $p < 0.05$.

worker roles. Health-care workers who provided care to a family member or friend were found to have statistically significant lower knowledge of dementia. The final model was assessed for VIF, tolerance and multicollinearity

and was found to be acceptable. In sensitivity analyses, the significant association between dementia knowledge and providing care to a family member or friend with dementia found using the multiply imputed data set was no

TABLE 4 Factors associated with higher knowledge of dementia among community members ($n = 74$).

	Reference level		Unadjusted model		Adjusted model	
			Estimate (95% CI)	<i>p</i>	Estimate (95% CI)	<i>p</i>
Gender	Female	Male	.04 (−.02, .09)	.17	.04 (−.02, .09)	.18
Age	≤39	≥40	.02 (−.03, .07)	.51	.002 (−.05, .06)	.93
Highest level of education	High school or below	Technical cert, diploma, university, other	.05 (.01, .10)	.03	.06 (.006, .11)	.03
Provide care for family member or friend with dementia	No	Yes	.03 (−.05, .10)	.50	.01 (−.06, .09)	.72

Note: Bolded values are statistically significant at $p < 0.05$.

TABLE 5 Factors associated with higher knowledge of dementia among health-care workers (mode of $n = 138$, range of $n = 133–139$).

	Reference level		Unadjusted model		Adjusted model	
			Estimate (95% CI)	<i>p</i>	Estimate (95% CI)	<i>p</i>
Gender	Female	Male	−.07 (−.12, −.02)	.01	−.04 (−.09, .01)	.13
Age	≤39	≥40	.01 (−.04, .05)	.73	−.003 (−.05, .04)	.87
Highest level of education	Technical cert, Diploma, High school or below	University	.02 (−.03, .06)	.40	.02 (−.03, .07)	.40
Role	Aboriginal health worker	Personal care/support worker	.002 (−.05, .06)	.94	−.06 (−.15, .03)	.183
	Aboriginal health worker	GP or Nurse	.06 (.001, .12)	<.05	.015 (−.071, .101)	.74
	Personal care/support worker	GP or Nurse	.06 (.001, .11)	.04	.07 (.03, .12)	.003
Aboriginal and/or Torres Strait Islander	No	Yes	−.06 (−.10, −.02)	<.01	−.05 (−.13, .02)	.16
Provide care for family or friend with dementia	No	Yes	−.09 (−.15, −.03)	<.01	−.07 (−.14, −.01)	.03

Note: Bolded values are statistically significant at $p < 0.05$.

longer statistically significant in the complete case analysis (−.079 [−.159, .001], $p = .05$). All other significant findings remained the same.

4 | DISCUSSION

Culturally appropriate and evidence-based educational programs to improve dementia knowledge among Aboriginal and Torres Strait Islander people require a thorough understanding of existing knowledge levels and identification of key knowledge gaps, both among community members who may encounter signs of cognitive impairment and dementia, as well as health-care providers who undertake dementia diagnosis and management. This study used a novel measure to examine knowledge of dementia in line with the *Lancet Commission's* evidence about dementia prevention, intervention and care.³³

Moderate levels of knowledge of dementia were found, with health-care providers answering an average of 80%

of questions correctly and Aboriginal and Torres Strait Islander community members answering an average of 76% of questions correctly. These scores for both groups suggest a good baseline understanding about dementia, particularly related to the nature and progression of dementia, the importance of early diagnosis, and the significance of professional assistance, family support and independence in living with dementia. This is the first study to specifically compare Aboriginal and Torres Strait Islander community member knowledge to that of health-care workers providing care to Aboriginal and Torres Strait Islander people. In line with international research conducted in other population groups,³⁵ knowledge of dementia was significantly higher among health-care providers compared to community members, which is reflective of their training, education and contact with patients and families as part of their clinical roles. However, trends in correct response proportions by domain were consistent between groups with the exception that health-care workers exhibited significantly higher knowledge in the

domain of risk factors for dementia. This finding suggests common areas for knowledge improvement among both community members and health-care providers.

Although not directly comparable given the different measurement tools used, rates of knowledge amongst Aboriginal and Torres Strait Islander community members in this study were higher than that found in previous research.^{12,30} However, the specific knowledge gaps identified related to risk factors for dementia and early symptoms of dementia are similar to those identified in earlier research.^{12,30} These findings reinforce the continued need to raise community awareness about dementia in Aboriginal and Torres Strait Islander communities to enhance knowledge, improve health outcomes and support self-determination and autonomy in health care. Aboriginal and Torres Strait Islander people and communities have unique perceptions of well-being, ageing, dementia and memory loss.³⁶ While a number of dementia-related educational resources are available to the general public in Australia, there is a lack of culturally appropriate materials specifically developed by and for Aboriginal and Torres Strait Islander people.²³ Education strategies need to be co-designed with communities so that knowledge gaps can be addressed in culturally appropriate ways that incorporate Indigenous understandings of dementia. As educational attainment was a significant factor influencing community members' knowledge of dementia, strategies that are tailored to different levels of education are likely to be needed. The diversity in languages, cultures, knowledge systems and beliefs across Aboriginal and Torres Strait Islander people in Australia also means that approaches to increasing knowledge also need to be locally tailored.³⁷

Of note, one-fifth of health-care providers believed that dementia is a normal part of getting older and one quarter did not believe dementia was a terminal condition that would shorten a person's life. This finding indicates that knowledge is higher comparative to global data from the largest international survey of attitudes to dementia, which found that 62% of health-care providers believe that dementia is a normal part of ageing.³⁸ However, it underscores the significance of also addressing misconceptions surrounding dementia amongst health-care providers. Knowledge of dementia was found to differ significantly by health-care professional role, which aligns with other Australian research.²¹ In a study conducted with a random sample of 234 health professionals across eight Australian states, health-care providers with a university qualification or formal dementia training demonstrated higher knowledge of dementia than respondents without such educational backgrounds, showing a moderate association with prior education.²¹ These findings highlight the need for targeted training strategies to ensure uniform knowledge across diverse health-care roles.

Counterintuitively, and at odds with other studies,³⁵ lower knowledge scores were found for health-care providers who provided care to a family member or friend with dementia (not as part of their professional role); however, this finding was not statistically significant in sensitivity analysis. Previous research conducted in the general population has found that exposure to the lived experience of dementia through family, work and specific dementia education is significantly associated with higher knowledge of dementia. However, lived experience through caring for a family member with dementia had less impact on knowledge than work or education.³⁹ This could suggest that knowledge about dementia gained through personal experience of the disease may increase knowledge in some, but not all, domains of knowledge. It may also be the case that a participant's lived experience was not in line with evidence about dementia prevention, intervention and care.³³ For example, if the person they cared for was not a smoker, but smoking is suggested to be a risk factor for dementia. In our sample, health-care providers who reported providing care to a family member or friend with dementia were more likely to be male, younger than 39, and Aboriginal or Torres Strait Islander (results not reported). This underscores the complexity of factors influencing knowledge acquisition and highlights the need to consider how personal experiences influence health-care providers' knowledge of dementia and dementia care.

4.1 | Limitations

Study findings should be interpreted with reference to the following limitations. First, the sample of both community members and health-care providers was not representative given the convenience sampling methods used and the non-randomised observational study design. This may have resulted in the recruitment of participants with different levels of dementia knowledge compared to the whole population. This is particularly the case for the recruitment of health-care providers, who needed to be currently working to participate. This may have systematically excluded some health-care workers who may have stopped working to care for someone with dementia from participating in the study. The survey was conducted exclusively online, which may have excluded individuals with limited access to technology or lower computer literacy levels. Second, we used a novel measure to assess knowledge that was specifically designed for this study and had not undergone psychometric testing. However, a comprehensive process for item generation was implemented tied to the *Lancet Commission's* evidence about dementia prevention, intervention and care,³³ and content

validity was established through expert review and pilot testing. Future research should focus on validating the assessment tool and establishing what constitutes a meaningful change in scores within a clinical context. Finally, the sample of community members was relatively small, which limits the generalisability of study findings.

5 | CONCLUSIONS

Addressing identified knowledge gaps is imperative for prevention of dementia, achieving timely and accurate dementia diagnosis, as well as providing appropriate treatment and care within Aboriginal and Torres Strait Islander communities. Further research and policy responses are needed to raise knowledge and awareness of dementia both amongst the general Aboriginal and Torres Strait Islander community, and health-care providers who provide care to Aboriginal and Torres Strait Islander people.

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CONFLICT OF INTEREST STATEMENT

No conflicts of interest declared.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

This project was approved by the University of Newcastle Human Research Ethics Committee, (HREC Reference no. H-2021-0062), the Aboriginal Health & Medical Research Council of NSW (HREC Reference no. 1742/20), the Human Research Ethics Committee of NT Health and Menzies School of Health Research (2022-4321) and the Central Australian Human Research Ethics Committee (CA-22-4316). The study was overseen by an Aboriginal Advisory Group.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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