Diagnostic accuracy of 10/66 dementia protocol in Māori kaumātua (elders) living in Aotearoa New Zealand

Adrian Martinez-Ruiz, Sarah Cullum, Gary Cheung, Susan Yates, Rita Krishnamurthi, Claudia Rivera Rodriguez, Ngaire Kerse, Makarena Dudley

ABSTRACT

AIMS: Dementia is an important health concern for Māori and therefore it is essential to explore the extent and impact of dementia in this community. The 10/66 dementia protocol, a widely used research tool for measuring the prevalence of dementia, was developed to minimise cultural and educational bias in comparisons of dementia prevalence across different countries and/or cultures. The aims of this study are to (i) adapt the 10/66 dementia protocol for use in research within the Māori community and (ii) test the diagnostic accuracy of the adapted (ie, Māori-friendly) 10/66 dementia protocol against the reference standard of a clinical diagnosis of dementia (or no dementia).

METHOD: The sample included Māori aged 65 and over who had been assessed at a local memory service. Ten dementia cases and 10 controls were included. The sample was further enriched by the inclusion of 6 controls from a concurrent dementia-prevalence feasibility study in the local community. The Māori-friendly 10/66 dementia protocol was measured against the reference standard. Sensitivity, specificity, positive and negative predictive values and Youden's Index were calculated.

RESULTS: The Māori-friendly 10/66 dementia protocol had a sensitivity of 90.0% (95% CI 62.8–99.4), specificity of 93.8% (95% CI 75.3–99.6), positive predictive value of 90.0% (95% CI 62.8–99.4), negative predictive value of 93.8% (95% CI 75.3–99.6) and Youden's Index of 0.83.

CONCLUSIONS: Our study results provide preliminary evidence that the Māori-friendly 10/66 dementia protocol has adequate discriminatory abilities for the diagnosis of dementia. Our study also demonstrates that the Māori-friendly 10/66 dementia protocol has the potential to be used in a dementia-population-based study for Māori in Aotearoa New Zealand.

Dementia is a neurodegenerative disorder that affects a person's ability to live independently. Its main clinical manifestations are significant cognitive impairment, functional impairment and the presence of neuropsychiatric symptoms.[1] The prevalence of dementia has been progressively increasing in recent decades, and the World Health Organization (WHO) has recognised dementia as a public health priority.[2] The projections for dementia prevalence indicate that it will increase worldwide, from 46.8 million in 2015 to 131.5 million in 2050.[3]

Aotearoa New Zealand is a bicultural country comprised of Māori, who are the tangata whenua (Indigenous people of the land) and represent 16.5% of the total population, and non-Māori (70.2% NZ Europeans, 15.1% Asians, 8.1% Pacific People, 1.5% Middle Eastern/Latin American/African and 1.2% of other ethnicities; this data include people who self-identify with more than one ethnicity; thus, the sum is higher than 100%.) The New Zealand Government has a constitutional obligation to respond to Māori health needs and ensure equitable health outcomes with non-Māori.[5] This obligation

was established in the Te Tiriti o Waitangi (the Treaty of Waitangi), which was signed in 1840 between the British Crown and rangatira (Māori chiefs) and guarantees Māori equity with non-Māori in health outcomes, including the needs of Māori living with dementia and their whānau (relatives).[6]

The prevalence of dementia in Aotearoa New Zealand is expected to increase from an estimated 60,000 in 2015 to 170,000 in 2050.[7] It has been reported that the total share of dementia cases in Māori will increase from 5.1% in 2016 to 8.0% in 2038, compared to a decrease from 87.5% to 77% in NZ Europeans in the same period.[7] Another study using routinely collected health data in Aotearoa New Zealand found that the aged-standardised prevalence of dementia was higher among Māori compared to other ethnic groups.[8] Furthermore, a secondary care-based study suggested that Māori presented with dementia 8.5 years earlier than NZ Europeans.[9] This might be expected, as dementia risk factors such as obesity,[10] hypertension[11,12] and type 2 diabetes mellitus[13] are more prevalent among Māori compared to NZ European. Likewise, the New Zealand Framework for Dementia Care reported that Māori have a higher rate of risk factors for dementia "when conditions such as depression, head trauma, and substance abuse disorders are considered."[14] A recent study about Māori understanding of dementia and how whānau provide care found that there is an urgent need for information "to assist with their knowledge building and empowerment to meet the needs of a member affected by mate wareware (dementia)."[15] This would involve a collaborative approach to provide culturally appropriate Māori services.[15] In addition, the effects of ongoing colonisation such as difficulties accessing healthcare services, education, and discrimination are some of the life-course social determinants that could place Māori at increased risk of developing dementia.[6]

Aotearoa New Zealand has never had a population-based dementia prevalence study. Instead, projections using data from overseas have been used to estimate its occurrence.[7] To carry out a population-based dementia prevalence study in Aotearoa New Zealand, a research tool that can accurately measure dementia in Māori is needed. Researchers should ideally be able to apply the same tool to non-Māori, in order to make appropriate comparisons on the prevalence of dementia among Māori and non-Māori.[6] The need for a non-biased dementia diagnostic instrument that can be applied across population-based studies in different countries was first recognised by the 10/66 Dementia Research Group in 2003.[16] This led to the development of the 10/66 dementia protocol, a fair culture and education instrument that has been validated in multiple languages (including Spanish, Arabic, Urdu, Fijian-Indian, Tamil, Malayalam and Chinese) and across different countries.[16–20] The 10/66 dementia protocol has demonstrated excellent sensitivity (up to 94%) and specificity (up to 94%).[16] However, in Aotearoa New Zealand, previous research has shown that Māori may have a negative response to cognitive tests that have been developed within a western culture.[21–23] Therefore, we adapted the 10/66 dementia protocol to include Māori words for a more Māori-friendly experience.

If the 10/66 dementia protocol is successfully adapted for use in Māori, it could be used to better estimate the prevalence of dementia in Māori in a population-based dementia prevalence study and in comparisons with the prevalence of dementia in non-Māori. Using the 10/66 dementia protocol to accurately estimate the prevalence of dementia in Māori communities would provide information regarding the full impact of dementia as well as the burden of dementia on whānau, which would help to inform policy- and decision-makers developing culturally appropriate dementia-prevention and dementia-care services.

Aim

The aims of this study are to (i) adapt the 10/66 dementia protocol for use in research within the Māori community and (ii) test the diagnostic accuracy of the adapted (ie, Māori-friendly) 10/66 dementia protocol against the reference standard of a clinical diagnosis of dementia (or no dementia).

Methods

Index test: 10/66 dementia protocol

The methods used for this study have been thoroughly described elsewhere.[24] Briefly, the 10/66 dementia protocol algorithm applies coefficients originated from (1) the Community Screening Instrument for Dementia (CSI-D),[25] (2) the Geriatric Mental State Examination (GMS)[26] and (3) the delayed recall memory test scores from the Consortium to Establish a Registry of Alzheimer's (CERAD) instrument.[27] The 10/66 dementia protocol takes about ninety minutes to administer and has three main sections, which are completed by the participant, the carer/informant and the head of household.[28]

Adaptation and translation of the 10/66 dementia protocol

The adaptation process engaged an advisory group of four kaumātua who were experts in te reo Māori (the Māori language) and had knowledge of the differences in dialect across iwi. Each individual kaumatua read the original 10/66 dementia protocol and suggested where modification was required so it was more acceptable for all Māori. This was followed by a group discussion until a consensus of changes was reached. For the translation of the 10/66 dementia protocol into te reo Māori, we applied a WHO-approved procedure previously used for the adaptation of the Composite International Diagnostic Interview from English into Malay[29] (described in Figure 1).

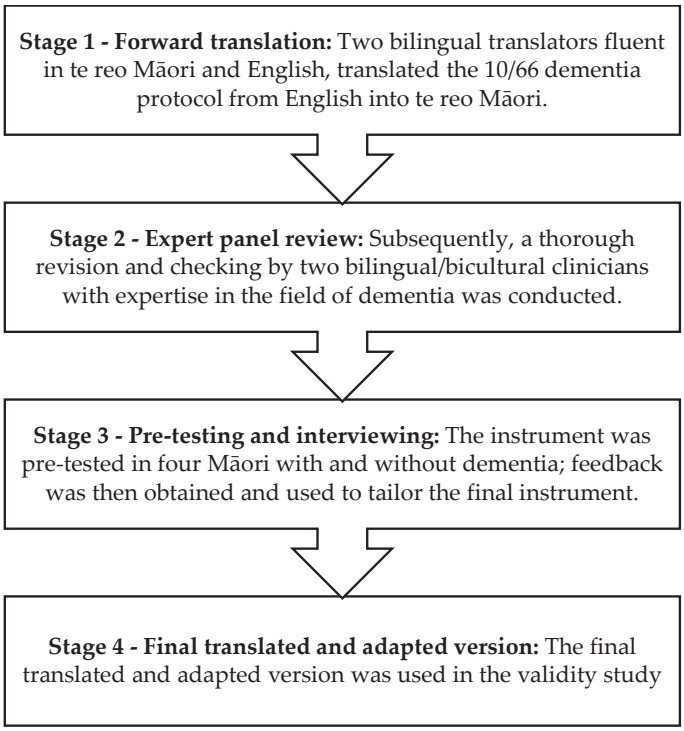
Validity study

Settings and participants

To examine the Māori-friendly 10/66 dementia protocol's diagnostic accuracy, we compared the binary Māori-friendly 10/66 dementia protocol outcomes ("10/66 dementia" or "no 10/66 dementia") against the clinical diagnosis received in the local memory service (reference standard: "clinical dementia diagnosis" or "no clinical dementia diagnosis"). Clinical diagnosis has been used as a reference standard in multiple 10/66 validity studies.[16–19]

The participants for this study were recruited from a publicly funded memory

Figure 1: Translation stages of the 10/66 dementia protocol te reo Māori version.



service, and additional controls were recruited from a concurrent dementia prevalence feasibility study. For our sample size calculation,[30] we used a prevalence of dementia of 60%, based on our previously published data from the memory service.[9] We found a minimum sample size of 52 participants (including 31 participants with a diagnosis of dementia) was required to achieve a minimum power of 80% to detect a change in the percentage value of sensitivity of a screening test from 0.70 to 0.90, based on a target significance level of 0.05.

Memory-service-based participants

We recruited participants from the Counties Manukau District Health Board memory service, located in South Auckland, Aotearoa New Zealand. The main criteria for someone to access the memory service are subjective or objective memory complaints made by the patient themself, members of their family or by a health professional. Both primary and secondary healthcare services refer the individuals to the memory service—who are usually assessed in their own homes.

Standard clinical criteria for dementia were applied by the memory service at their weekly multidisciplinary team meeting in order to make a clinical diagnosis (reference standard). These criteria included: DSM-IV and DSM-5 dementia criteria,[1,31] NINCDS-ADRDA criteria for Alzheimer's disease dementia,[32] NINCDS-AIREN criteria for vascular dementia,[33] criteria for Lewy body dementia[34] and criteria for frontotemporal dementia.[35] The participants were classified into either "clinical dementia diagnosis" or "no clinical dementia diagnosis." The steps followed by the research team to recruit the memory-service-based participants have been thoroughly described elsewhere.[24]

Eligibility criteria for participants

All memory-service-based cases ("clinical dementia diagnosis") and controls ("no clinical dementia diagnosis") self-identified themselves as Māori and were aged 65 years or older. Cases and controls without an informant, and those who were unable to complete the interview because of significant sensory or physical impairment, were excluded from the study.

Eligibility criteria for memory-service-based dementia cases

The memory-service-based cases were recruited if they had been assessed by the memory service within six months of starting the study. All had been diagnosed with dementia by the memory service team. The study followed the New Zealand Code of Health and Disability Services Consumers' Rights[36] (Right 7) in regards to participants who were unable to give informed consent. The interview was terminated if at any stage the participant requested or indicated they did not want to continue.

Eligibility criteria for memory-service-based controls

Controls were included if they had been assessed by the memory service as not having dementia within six months of starting the study. We decided to not exclude controls with mild cognitive impairment (MCI), as excluding them would have increased the risk of "spectrum bias" causing spuriously accurate results.[37]

Community-based participants

The community-based controls were recruited from a sample through a concurrent study aimed at assessing the feasibility of conducting a dementia prevalence study within two areas of the community (served by Counties Manukau District Health Board).[24] They did not have a full specialist assessment; instead, they were included in the study if they scored ≥27 in the Rowland Universal Dementia Assessment Scale (RUDAS)[38] and 1–3 in the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE).[39] The high cut-off scores for RUDAS and low scores for IQCODE were chosen as they effectively excluded any potential cases of dementia.

Validity study informants

All memory-service-based and community-based participants had an informant. An informant is defined as a person who knows the participant well—usually the primary caregiver, a family member or someone who was responsible for the participant's care. All informants signed a separate consent to participate in the study.

Blinding

For the memory-service-based participants, the Māori-friendly 10/66 dementia protocol was performed independently of the memory service clinical assessment. Therefore, the Māori-friendly 10/66 dementia protocol interviewers were blinded to the outcomes of the participants' clinical assessment. During a 10/66 interview, one interviewer assessed the informant while another interviewer assessed the participant. For the community-based controls, the interviewers swapped the informant and participant after the Māori-friendly 10/66 dementia protocol in order to administer the reference-standard cognitive screen (IQCODE and RUDAS).

Interviewers

All face-to-face and telephone contacts between the research team and potential participants were conducted either in English or te reo Māori, depending on the participant's preference. Interviews were conducted by research assistants with some health background who self-identified as Māori and were bilingual (in te reo Māori and English). All interviewers participated in four training sessions, each one lasting four hours. All sections of the Māori-friendly 10/66 dementia protocol, as well as the IQCODE and RUDAS, were included in the training sessions. These sessions also included the necessary training for obtaining informed written consent and the procedures to manage unanticipated situations. The first three interviews were supervised by the study's principal investigator and a dementia specialist. They gave detailed feedback after the conclusion of the interview, thereby ensuring that the Māori-friendly 10/66 dementia protocol was administered correctly. Furthermore, this enabled the research assistant to clarify any questions presented during the interview.

Interviewing process

The interview was conducted as soon as informed written consent was obtained from the informant and the participant. The interview adhered to tikanga (Māori cultural protocols) for whānau (families) at hui (meeting/gathering), beginning with karakia (prayer) and then mihi (introductions and speeches), whanaungatanga (developing rapport) and kaupapa (explaining the purpose of the interview and how it would proceed). The interview would finish with karakia, and a koha (gift) of NZ$100 was given to the participants and their whānau as a token of appreciation for their time.

Ethical approval

The validity and feasibility studies were approved by the New Zealand Northern A Health and Disability Ethics Committee (numbers 17NTA234 and 18NTA176 respectively).

Data analysis

Dementia 10/66 diagnosis

The 10/66 dementia diagnostic algorithm was applied to obtain the participants' dementia diagnoses. The algorithm establishes the outcome as either "10/66 dementia" or "no 10/66 dementia" according to the final score from the logistic regression equation developed in the 10/66 international pilot study.[16] The equation predicts the diagnostic probability of DSM-IV clinical dementia syndrome.[1]

Statistical analysis

Descriptive frequency distributions and mean values were used to describe demographic data. By comparing the 10/66 dementia protocol primary outcomes ("10/66 dementia" or "no 10/66 dementia") against the "clinical dementia diagnosis" or "no clinical dementia diagnosis," we calculated the sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV), positive likelihood ratio (PLR), negative likelihood ratio (NLR) and Youden's index. The 95% confidence intervals were calculated using the Clopper-Pearson statistical method.[40] Statistical Package for the Social Sciences (SPSS) version 25 (Chicago, IL) was used for data analysis.

Results

Translation and adaptation

The following changes were made to the 10/66 sub-components:

(i) The CERAD word learning list:[27] one word from the 10-word learning list ("queen" was changed to "sailor").

(ii) The CSI-D participant questionnaire:[25] one item for naming things ("watch" was changed to "table"), three items for the naming of body parts ("knuckles" was

changed to “fingers,” “elbow” to “ear” and “shoulder” to “cheeks”) and one item for describing things (“what is a bridge?” was changed to “what is a gate?”); all five items were changed to words that were considered by the kaumātua expert advisory group to be of more common usage in te reo Māori. One item for attention and language (the phrase “no ifs, ands or buts” was changed to “neither this nor that”) was modified as it was considered difficult to translate grammatically into te reo Māori. The general knowledge question “What is the name of the mayor/village head?” was changed to “What is the name of the rangatira (chief) of this rohe (area)?” This question was changed since the terms “mayor” and “village heads” are not of common use in te reo Māori. “Mayor” relates to a city in Aotearoa New Zealand and was therefore considered confusing, and “village” is uncommon. “Rangatira of this rohe” is a phrase used commonly by Māori and with the same inference as “mayor/village head.” The long-term memory item was also changed from “What is the name of the civil rights leader who was assassinated in Memphis in 1968?” to “What is the name of the kuia (elderly Māori woman) from Northland who led the Māori land march to parliament in 1975?” This is because few Māori would know the answer to the original question, whereas the answer to the adapted question is common general knowledge amongst Māori.

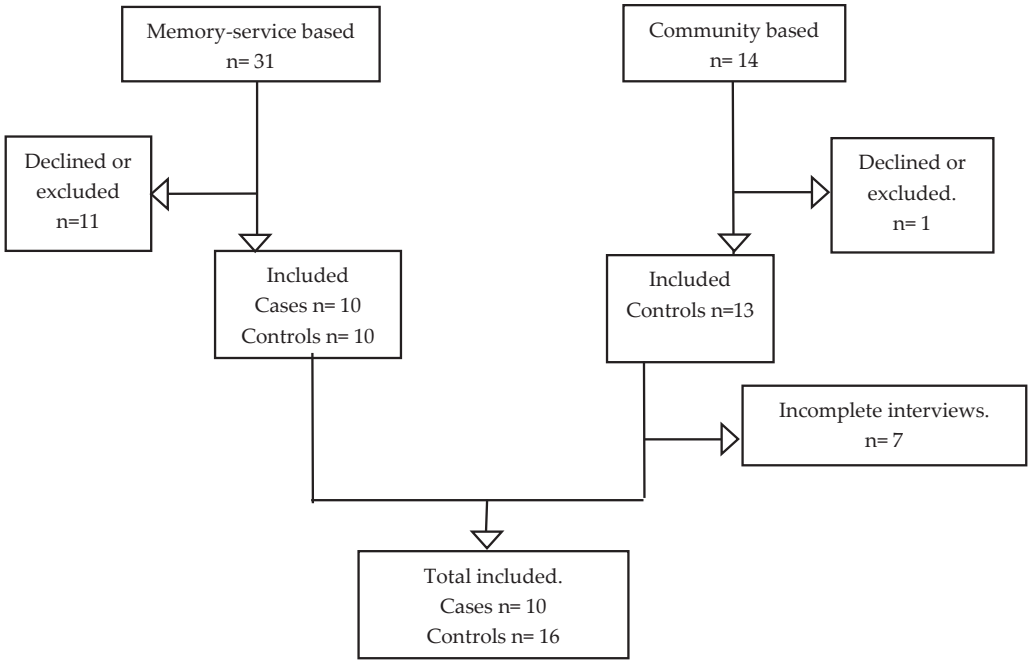
No changes were made to the CSI-D[25] informant questionnaire or the GMS.[26]

Sample characteristics

We recruited 26 participants: 10 dementia cases and 16 controls. All participants and informants completed the Māori-friendly 10/66 dementia protocol (Figure 2). The interviews were conducted in each participant’s preferred language; only one interview was conducted in te reo Māori, with the rest conducted in English.

The mean (SD) age of the participants was 75.3 (5.1) years. Fifty percent (n=13) were female. Seven participants (26.9%) were “married/cohabitating.” The mean (SD) age of the informants was 56.6 (16.9) years. Eighty-five percent (n=22) were female, and 34.6% (n=9) reported being the participant’s spouse. Other sociodemographic characteristics of participants and informants are described in Table 1.

Figure 2: Recruitment flowchart.



NZMJ 21 January 2022, Vol 135 No 1548
ISSN 1175-8716
www.nzma.org.nz/journal

Table 1. Sociodemographic characteristics of participants and informants by reference standard.

Variable	No dementia diagnosis n=16 (%)	Dementia diagnosis n=10 (%)
Age (years) Mean (SD, 95% CI)		
Participants	75.1 (3.5, 73.4–77.2)	75.3 (7.1, 70.1–80.4)
Informants	54.0 (21.9, 44.0–65.0)	58.4 (16.9, 45.4–71.4)
Gender (female)		
Participants	7 (43.8)	4 (40.0)
Informants	14 (87.5)	8 (80.0)
Marital Status (participants)		
Married/cohabitating	6 (37.5)	1 (10.0)
Never married	1 (6.3)	1 (10.0)
Widowed	5 (31.2)	2 (20.0)
Divorced/separated	4 (25.0)	6 (60.0)
Informant relationship with participant		
Spouse/partner	8 (50.0)	1 (10.0)
Child	4 (25.0)	5 (50.0)
Son or daughter in law	0	1 (10.0)
Friend	1 (6.3)	0
Other	3 (18.7)	3 (30.0)
Education level (participants)		
Primary completed	6 (37.5)	4 (40.0)
Secondary or above	10 (62.5)	6 (60.0)

SD: Standard Deviation, CI: Confidence Interval.

Diagnostic test accuracy

10/66 dementia diagnosis

Out of 10 participants in the "clinical dementia diagnosis" group, nine participants were correctly classified by the Māori-friendly 10/66 dementia protocol (true positives) and one participant was mis-classified as not having dementia (false negative). Out of 16 participants in the "no clinical dementia diagnosis" group, 15 participants were correctly classified by the Māori-friendly 10/66 dementia protocol (true negatives) and one participant was mis-classified as having dementia (false positive). Thus, the sensitivity and specificity of the Māori-friendly 10/66 dementia protocol were 90.0% (95% CI 62.8–99.4) and 93.8% (95% CI 75.3–99.6) respectively. The PPV was 90.0% (95% CI 62.8–99.4), NPV was 93.8% (95% CI 75.3–99.6), PLR was 9.3 (CI 1.4–60.4), NLR was 0.06 (CI 0.01–0.46) and Youden's index was 0.83.

Discussion

Our study showed that the Māori-friendly 10/66 dementia protocol has adequate clinometric properties, with a sensitivity of 90.0% and specificity of 93.8%. This demonstrates its discriminatory abilities for future population-based dementia studies that involve Māori. To the best of our knowledge, this is the first validity study of the 10/66 dementia protocol focusing on Māori in Aotearoa New Zealand or elsewhere.

The clinometric properties of the Māori-friendly 10/66 dementia protocol mirrored the results of other 10/66 dementia protocols reported in the literature (Table 2). The demographics of the Māori sample were weighted towards those with a low education and therefore our results are comparable to the original10/66 Dementia Research Group validity study, which found a sensitivity of 94% and a specificity of 94% in people with low education.[16]

There are some limitations that need to be acknowledged. The main limitation is that our study sample was small compared to previous 10/66 dementia protocol studies, and therefore there will be greater uncertainty about the results. Studies with a small sample size may increase the occurrence of Type II error. We designed our study according to the requirements for minimum sample size (n=52),[30] but we were only able to include full data for 16 controls and 10 dementia cases. This was because we experienced difficulties recruiting Māori from the memory service and the community. Only 12% (n=43) of the Counties Manukau District Health Board memory service attendees who received a new dementia diagnosis in a three-year period were Māori.[9] We also had a higher-than-expected rate of incomplete assessments in the community due to unavailability of informants (57% of the control group). Only one participant was interviewed in te reo Māori, as the remainder chose to be interviewed in English. However, it should be pointed out that we are testing the diagnostic accuracy of the adapted Māori-friendly 10/66 dementia protocol (as co-developed by an expert group of kaumātua). This Māori-friendly 10/66 dementia protocol has an English and a te reo Māori version. We took advice on this matter from Professor Martin Prince, Director of the 10/66 Dementia Research Group, as we knew that we were unlikely to find a sufficient number of participants who would chose to be interviewed in te reo Māori—as many Māori of this generation were banned from speaking te reo in their childhoods. Professor Prince's original 10/66 dementia protocol has already been adapted and validated in numerous cultures and languages (Table 2), and the aim of this study was therefore to test that our Māori-friendly 10/66 dementia protocol worked in the target population. We are confident that the Māori-friendly 10/66 dementia protocol is suitable for use in research within the Māori community. However, the diagnostic accuracy of this Māori-friendly 10/66 dementia protocol could be further confirmed in a validity study nested within a future prevalence study in order to confirm our findings. This approach has been used before in other studies using the 10/66 dementia protocol.[19]

To date, the extent and impact of dementia in the Māori population has never been assessed. The information obtained from a population-based study can be used to compare health outcomes and inequities related to dementia between Māori and

non-Māori in Aotearoa New Zealand.[6] Further analysis can also be used by government agencies to develop culturally appropriate dementia services for Māori living with dementia and their whānau, in addition to informing the development of strategies to reduce the impact of dementia and specific policies to raise public awareness about dementia and its prevention in the Māori community.

Conclusion

A Māori dementia prevalence study will provide the foundation to achieve equitable outcomes for Māori living with dementia. Our study has demonstrated that the Māori-friendly 10/66 dementia protocol has the potential to be used in a dementia population-based study for Māori in Aotearoa New Zealand.

Table 2: Comparison of sensitivity and specificity of the 10/66 dementia protocol in samples from different populations

Author, year	Place, language	Adaptation to local culture and language	10/66 dementia protocol		Sample size
			Sensitivity	Specificity	
Present Study	New Zealand, te reo Māori and English	Yes	90.0%	93.8%	26
Prince, 2003[16]	Multiple	Yes	94.0%	94.0%[b]	2,885
Prince, 2008[41]	Cuba, Spanish	Yes	93.2%	96.8%	1,887
Nozari, 2009[a42]	Iran, Farsi	Yes	98.3%	98.3%	120
Subramaniam, 2015[19]	Multiple	Yes	95.6%	81.8%	2,421
Phung, 2015[17]	Lebanon, Arabic	Yes	92.0%	95.1%	244
Khan, 2020[18]	Pakistan, Urdu	Yes	70.3%	91.7%	257

Clinical diagnosis was reference standard for all included studies.

[a] Published as a letter to the editor. [b] In people with low education.

Competing interests:
Nil.
Acknowledgements:
We acknowledge the support of the memory service staff at Middlemore Hospital CMDHB, the memory service and community participants and their families, without whom this study would not have been possible.
Author information:
Adrian Martinez-Ruiz: PhD student, Department of Psychological Medicine, The University of Auckland, Auckland, New Zealand.
Sarah Cullum: Associate Professor, Department of Psychological Medicine, The University of Auckland, Auckland, New Zealand.
Gary Cheung: Senior Lecturer, Department of Psychological Medicine, The University of Auckland, Auckland, New Zealand.
Susan Yates: Clinical Psychologist/Neuropsychologist/Research Fellow, Department of Psychological Medicine, The University of Auckland, Auckland, New Zealand.
Rita Krishnamurthi: Associate Professor, The National Institute for Stroke and Applied Neurosciences, Auckland University of Technology, Auckland.
Claudia Rivera Rodriguez: Lecturer, Department of Statistics, The University of Auckland, Auckland, New Zealand.
Ngaire Kerse: Joyce Cook Chair in Ageing Well, School of Population Health, The University of Auckland, Auckland, New Zealand.
Makarena Dudley: Te Rarawa, Te Aupōuri, Ngāti Kahu, Senior Lecturer, School of Psychology, The University of Auckland, Auckland, New Zealand.
Corresponding author:
Makarena Dudley PhD, Te Rarawa, Te Aupōuri, Ngāti Kahu, Senior Lecturer, School of Psychology, The University of Auckland, Auckland, New Zealand; m.dudley@auckland.ac.nz
URL:
www.nzma.org.nz/journal-articles/diagnostic-accuracy-of-10-66-dementia-protocol-in-maori-kaumatua-elders-living-in-aotearoa-new-zealand

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