The case for a bicultural dementia prevalence study in Aotearoa New Zealand
Sarah Cullum, Makarena Dudley, Ngaire Kerse

As the world's population ages, the prevalence of dementia is projected to increase from the current 50 million to 130 million in 2050. The present cost of dementia is over one trillion US dollars and is expected to double in 10 years. In response, the World Health Organization (WHO) has declared dementia a global public health priority and has called on all 194 member states to produce a national dementia plan or strategy for 2017–2025.

In Aotearoa New Zealand, there are estimated to be currently over 60,000 people living with dementia and this number is projected to reach 170,000 by 2050. The annual national cost of dementia is estimated to be $1.7 billion NZD, and projected to increase to $2.7 billion NZD by 2030. The Ministry of Health has acknowledged the major economic challenge of dementia but, to date, there has been no planning to address the rapidly increasing future demands of dementia on our health and social care systems, nor the psychological and economic consequences on whānau and families living with dementia. This is partly due to the fact that the figures given above are only estimates, extrapolated from other countries' dementia prevalence data because there has never been a dementia prevalence study in Aotearoa New Zealand. The Government requires accurate New Zealand-specific data to inform its spending and policy decisions, which would only be available from a carefully conducted epidemiological survey.

Aotearoa New Zealand is officially recognised as a bicultural (Māori and non-Māori) nation. In recognition of the Treaty of Waitangi, attention to equity in health and social services is mandated, and this applies as much to dementia as it does to other health conditions. Globally, there is increasing recognition that dementia outcomes differ across different communities, thus research designed for different cultures is required rather than a 'one size fits all' approach. For that reason we present in this viewpoint the justification for a bicultural dementia prevalence study in Aotearoa New Zealand.

Evidence that dementia may be different for Māori

The sparse research evidence that is available suggests that Māori may present with dementia up to 10 years earlier than NZ Europeans. This might be expected as recent studies have found that a considerable proportion of dementia is attributable to modifiable risk factors such as diabetes, hypertension and obesity, risk factors that are more common and present earlier in Māori. The ongoing impact of colonisation and its sequelae contribute to an increased risk of dementia for Māori. Socioeconomic disadvantage, such as less access to education and healthcare, and discrimination are more prevalent in Māori communities. These socioeconomic risk factors are also linked to dementia and will increase the likelihood of negative outcomes for Māori. On the other hand, despite higher levels of comorbidity, Māori with dementia presenting at a memory service in South Auckland had a lower age-adjusted risk of mortality compared to NZ Europeans, which suggests the possibility of a different aetiology that might be responsive to different and potentially more effective treatment options. These questions can only be answered by a community-based dementia prevalence study.

The impact of dementia on Māori whānau (families) is also significant. Recent research and interRAI data suggest that care arrangements and caregiver input are disproportionately higher in Māori.
whānau. The current societal structure where economic success dominates, coupled with poor access to, and culturally inappropriate, public services for kaumātua (Māori elders) means that traditional care practices, where the person is cared for at home, add to whānau burden as family members forgo paid work. A national dementia prevalence study would document potential disparity for Māori and provide evidence for the impact of dementia on whānau, which will inform the future development of culturally responsive services.

**Measuring dementia in a bicultural prevalence study**

The largest epidemiological study of dementia in Māori was conducted as part of the *Life and Living in Advanced Age*, a Cohort Study in New Zealand (LiLACS NZ). LiLACS NZ engaged over 400 Māori aged 80–90 and 500 non-Māori aged 85 years in 2010 and has actively followed up study participants for five years. Careful validation of the dementia screening tool, in this case the 3MS showed that a different cut point was needed for Māori, as the screening tool developed for NZ European populations overestimated the likelihood of dementia in Māori. To allow equal comparison across groups, a national dementia prevalence study would therefore require diagnostic assessment tools that are both scientifically robust and not biased by culture. Such tools have been used in cross-country comparison of dementia prevalence worldwide. The most frequently used tool is the 10/66 dementia protocol, which is considered to be the global gold standard for comparative dementia epidemiology. It is a dementia diagnostic assessment tool that is relatively unbiased by language or culture, and therefore can be adapted for use in communities outside of the UK where it was developed. The 10/66 dementia protocol takes approximately 90 minutes to administer and includes an interview with the main participant and an informant (the main participant's co-resident or main caregiver) to assess care arrangements, caregiver burden and the economic cost to the family. These are sensitive issues in some cultures and consequently the tool requires adaptation, translation and revalidation for each cultural group. Studies to develop and validate the tool have taken place in Latin America, China, India, Nigeria and South Africa and more recently in higher income countries such as Singapore. It has achieved excellent results against a gold standard diagnosis: sensitivity (94%) and specificity (97% in high education controls and 94% in low education controls).

A bicultural prevalence study ensures inclusion of dementia-related outcomes that incorporate values that are important to Māori communities. Recent research contributes to this body of knowledge. The study ‘*Kaumātutanga ō Te Roro (The Ageing Brain)*’ conducted 17 focus groups with 223 kaumātua (Māori elders) throughout Aotearoa New Zealand and the findings demonstrated that Māori understanding of mate wareware (dementia) includes its effect on the wairua (spiritual dimension) of Māori. The roles of aroha (love, compassion), manākitanga (hospitality, kindness, generosity, support, caring) and cultural activities are important elements of care. The output of this research is being used to develop a Māori-responsive assessment tool for the clinical diagnosis of dementia that includes the assessment of wairua, aroha, manākitanga and cultural roles.

**A proposed bicultural dementia prevalence study in Aotearoa New Zealand: aims and methods**

The aim of a community-based study in Aotearoa New Zealand would be to measure the extent of dementia in the older population and its associated health and sociodemographic risk factors, plus its impact of dementia on individuals, their families and larger society. The methods for a bicultural national dementia prevalence study would require two parallel arms of data collection, one for Māori and one for non-Māori. Both arms would include the following elements in common to ensure comparability across groups: (i) a culturally unbiased diagnostic assessment tool that is relatively unbiased by language or culture, and therefore can be adapted for use in communities outside of the UK where it was developed. The 10/66 dementia protocol takes approximately 90 minutes to administer and includes an interview with the main participant and an informant (the main participant's co-resident or main caregiver) to assess care arrangements, caregiver burden and the economic cost to the family. These are sensitive issues in some cultures and consequently the tool requires adaptation, translation and revalidation for each cultural group. Studies to develop and validate the tool have taken place in Latin America, China, India, Nigeria and South Africa and more recently in higher income countries such as Singapore. It has achieved excellent results against a gold standard diagnosis: sensitivity (94%) and specificity (97% in high education controls and 94% in low education controls).

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knowledge. Kaupapa Māori methodology, a unique approach to research that reflects the philosophies, values and practices of Māori, would inform all aspects of engagement with Māori. There would be Māori leadership and collaborative and consultative input from Māori groups to ensure Māori aspirations and outcomes are central to the research.

A culturally unbiased diagnostic assessment: development and testing

A bicultural dementia prevalence study will require a culturally unbiased diagnostic assessment that can be used to accurately compare findings across both Māori and non-Māori arms of the study. The 10/66 dementia protocol has been demonstrated to be a suitable instrument but, as it was developed in the UK, would need to be adapted for use in Māori and translated into te reo Māori. This would involve an iterative review process with refinement by a Māori advisory panel (including a bilingual dementia specialist) to confirm cultural acceptability, conceptual validity and tolerability. The adapted tool would then be piloted in a sample of Māori families to ensure that it is acceptable, before testing its diagnostic accuracy. The diagnostic accuracy of the Māori-adapted version of the 10/66 dementia protocol would be blindly tested against a ‘gold standard’ dementia assessment in Māori with and without dementia, and their whānau. Once demonstrated to have validity it could be used in the proposed dementia prevalence study.

The subcomponents of the English version of the 10/66 dementia protocol have been used in multiple research studies in the UK but not in NZ Europeans. Accordingly, we intend to also evaluate the cultural appropriateness and acceptability of the original English version in a planned feasibility study that will include community-dwelling NZ Europeans. The feedback we receive from NZ Europeans and other major New Zealand ethnic groups will help inform a future dementia prevalence study.

Sampling procedures that ensure adequate representation of Māori

The sampling method for a representative population-based sample would be similar to the methods used in the New Zealand Mental Health Study Te Rau Hinengaro. This consisted of a mesh-block sampling frame (the smallest unit for which Statistics NZ has demographic information, comprising approximately 60–100 people) and door-to-door knocking for recruitment. Under ideal circumstances the prevalence study would be conducted in several different geographical areas based on socioeconomic deprivation indices to ensure adequate representation of Māori and non-Māori from all socioeconomic backgrounds, in addition to sampling in both urban and rural areas of North and South Island. This would ensure that sufficient Māori are included to allow equal sampling power for accurate estimations of prevalence. Census data for the selected areas could be used to calculate the probability of finding dementia cases in adults aged 65 years or older, and then oversampling for Māori to ensure adequate representation. As an example of sample size calculation, we used census data to discover that approximately 6,800 Māori and 31,000 NZ European people aged 65 and over were living in South Auckland at the time of the 2013 census. Based on a probable 10/66 dementia prevalence of 10%, we estimated that sample sizes of approximately 750 Māori and 850 NZ European people aged 65 or over would be required in South Auckland to generate prevalence estimates with an acceptable degree of certainty.

Dementia presents up to 10 years earlier in Māori compared to NZ Europeans therefore, it would be preferable to extend our cohort to include 55–65 year olds. However this would double the cost of the study because there as many Māori aged 55–64 years as there are >65 years old and the prevalence of dementia in the younger age group is lower. An alternative option would be to establish a separately funded younger cohort that would enable thorough investigation of dementia incidence and risk factors in these populations.

Community engagement and recruitment

Communities would need to be involved in design of the project to encourage ownership of the project by the community it aims to benefit. Dementia is still a misunderstood disorder so engagement with local
Communities to provide education would be essential. Activities such as dementia roadshows at community venues allow the audience to fully interact, ask questions and learn about dementia; this approach raises awareness and interest in the study itself. These could be held at sites that serve older people from both non-Māori and/or Māori communities such as local marae, churches and organisations providing services for older people. Community groups can co-design the best ways to connect with local families and whānau using different strategies such as traditional media, social media and community activities. In addition, we intend to work with relevant NGOs such as Alzheimers New Zealand, Dementia New Zealand, Age Concern, as well as newly formed National Māori Dementia Advisory Group, organisations that have agreed to support the study.

The recruitment of participants to a dementia prevalence study will involve door-knocking in pre-selected areas to establish ages and ethnicities of people over 65 years living in each household, and to determine whether the household would be willing to have a researcher return to conduct the 10/66 interview. Effective recruitment at this stage of the study will be crucial for the success of the intended prevalence study and the generalisability of its findings, therefore it is essential that cultural safety is observed. Māori door-knockers and interviewers will be required in accordance with kaupapa Māori methodology. A key concept of cultural safety is the recognition of the unequal distribution of power inherent in relationships.28 The use of ethnic-matched door-knockers is essential to safeguard the cultural safety of the public who may feel less empowered with a person who is not of the same ethnic background.

Māori-specific measures and methods

Māori philosophy is based on a holistic approach to health and wellbeing. Te Whare Tapa Whā is one such model that encompasses four cornerstones of health including wairua (spirituality), whānau (family), hinengaro (mind) and tinana (body), and provides an appropriate framework for understanding dementia from a Māori perspective.29 In research studies, Māori researchers must be involved at all stages, from research leadership, through study design and conduct. Processes of the study are governed by tikanga such as karakia (prayer) to start and finish meetings, whakawhanaungatanga (relationship building) when initially meeting potential participants, and manākitanga (carrying of participants). The project is overseen and guided by a Rōpu Kaitiaki (Māori guidance group) consisting of kaumātua (Māori elders) who will oversee the cultural safety of the research and play an integral role in facilitating community relationships.

Impact of the findings of a bicultural dementia prevalence study in Aotearoa New Zealand

This viewpoint argues the need for and describes the groundwork required to conduct a bicultural dementia prevalence study in Aotearoa New Zealand. The study findings would describe the current extent and impact of dementia for Māori and non-Māori families, highlighting any potential disparities across ethnic groups, with each group containing enough participants for ethnic specific analyses. Furthermore, the findings would inform the development of interventions that would hopefully make a positive difference to Māori and non-Māori families living with dementia.

Culturally appropriate service provision

Considerable work is needed to address disparities in health outcomes for Māori at all levels.30,31 Accurate information is needed to understand inequity, and develop Māori-specific responses.32,33 In recent years the focus of dementia research has shifted from cure to prevention and care, particularly support for carers.8 To support people with dementia in New Zealand, we need to support the families and whānau that look after them. One successful strategy in the UK, STrategies for RelaTives (START), uses psychological therapies to develop individually tailored and cost-effective coping strategies for carers of people with dementia. START reduces anxiety and depressive symptoms of carers for at least six years.34 To date, these approaches have not been considered, adapted or implemented in whānau living in Aotearoa New Zealand,
nor have therapeutic and care models been developed by Māori for Māori. A well-designed bicultural dementia prevalence study would provide data to start this process and address the government goals of reducing inequalities in health and social outcomes.

**Cost of dementia for Māori and non-Māori**

The inclusion of survey questions asking about the direct and indirect costs of care could provide valuable data regarding the current cost of providing support for people living with dementia in Aotearoa New Zealand. Findings may highlight potential inequities in care provision and cost, not only for health and social care services but also for families and whānau. The prevalence of dementia is predicted to triple in the next three decades. Simulation modelling will help to estimate the costs of providing culturally appropriate services to families and whānau living with dementia, and to develop a model projecting financial and organisational demands under different assumptions of dementia prevalence, care pathways and service models.

**Non-Māori living in Aotearoa**

In addition to Māori and NZ Europeans, numbers of older people are rising rapidly in other ethnic groups living in Aotearoa, in particular Pasifika, Chinese and Indian, with an associated increase in dementia prevalence in these populations. Consequently, there is a need for more epidemiological information about dementia in these groups too. Our intention is to adapt the instruments and methods described above to enable adequate representation of Pasifika, Chinese and Indian older people, as well as Māori and NZ Europeans in future dementia prevalence studies.

**Conclusion**

A bicultural dementia prevalence study in Aotearoa New Zealand would provide population-based data and projected costs of dementia for Māori and non-Māori. Health inequities for Māori will be described, and data will be available to begin Māori-informed and developed responses. The data will help inform the Ministry of Health in responding to identified needs with culturally appropriate dementia services, as well as improving public awareness and reducing stigma. If successful, the methods could be extended to other non-Māori communities. This will strengthen development of an up-to-date national dementia plan for Aotearoa New Zealand.

**Competing interests:**

Nil.

**Author information:**

Sarah Cullum, Senior Lecturer, Department of Psychological Medicine, The University of Auckland, Auckland; Makarena Dudley, Senior Lecturer, School of Psychology, The University of Auckland, Auckland; Ngaire Kerse, Joyce Cook Chair in Ageing Well, School of Population Health, The University of Auckland, Auckland.

**Corresponding author:**

Dr Sarah Cullum, Senior Lecturer (Honorary Consultant in Old Age Psychiatry), Department of Psychological Medicine, Faculty of Medical and Health Sciences, The University of Auckland, Auckland 1142.

sarah.cullum@auckland.ac.nz

**URL:**

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