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Living with Dementia in Aotearoa (LiDiA): a feasibility study protocol for a dementia prevalence study in Aotearoa / New Zealand.

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Abstract

Introduction: Aotearoa New Zealand (NZ) is officially recognized as a bicultural country comprised of Māori and non-Māori. Recent estimations have projected a threefold increase in dementia prevalence in NZ by 2050, with the greatest increase in non-NZ Europeans. The NZ government will need to develop policies and plan services to meet the demands of the rapid rise in dementia cases. However, to date there is no national data on dementia prevalence and overseas data are used to estimate the NZ dementia statistics. The overall aim of the Living with Dementia in Aotearoa (LiDiA) study is to prepare the groundwork for a large full-scale NZ dementia prevalence study.

Methods and analysis: The study has two phases. In phase one, we will adapt and translate the 10/66 dementia assessment protocol to be administered in Māori, Samoan, Tongan and Fijian-Indian elders. The diagnostic accuracy of the adapted 10/66 protocol will be tested in older people from these ethnic backgrounds who were assessed for dementia at a local memory service. In phase two, we will address the feasibility issues of conducting a population-based prevalence study, by applying the adapted 10/66 protocol in South Auckland and will include NZ European, Māori, Samoan, Tongan, Chinese, and Fijian-Indian participants. The feasibility issues to be explored are: (i) How do we sample to ensure we get accurate community representation? (ii) How do we prepare a workforce to conduct the fieldwork and develop quality control? (iii) How do we raise awareness of the study in the community to maximize recruitment? (iv) How do we conduct door-knocking to maximize recruitment? (v) How do we retain those we have recruited to remain in the study? (vi) What is the acceptability of study recruitment and the 10/66 assessment process in different ethnic groups?

Ethics and dissemination

The validity and feasibility studies were approved by the New Zealand Northern A Health and Disability Ethics Committee, Number: 17NTA234 and 18NTA176 respectively. The findings will be disseminated through peer-reviewed academic journals, national and international conferences and public events. Data will be available upon reasonable request to the corresponding author.

Strengths and limitations of this study

- The results of the validity and feasibility studies will prepare the groundwork for the first population-based dementia prevalence study in New Zealand.
- The validity study will result in an internationally recognised dementia diagnostic tool to be used in research with Māori, Fijian-Indian, Samoan and Tongan elders living in New Zealand.
- Due to time and funding constraints not all ethnic minorities in New Zealand will be included in this phase of the study.

Introduction

Dementia is a global health priority and its prevalence is increasing in many parts of the world due to their ageing populations (1). Governments across the world are developing policies and planning services to meet the health care and social needs of people with dementia. Aotearoa New Zealand (NZ) needs to do the same but to date there is no prevalence data at a national level to inform the extent and impact of dementia on our population. Although it has been projected that over 60,000 people are currently living with dementia in NZ (at a cost of $1700 million per annum) and it will increase to 170,000 people by 2050 (2), these statistics are extrapolated from other countries data.

Globally, the prevalence of dementia in people aged 60 years and over is reported to be between 5.6% to 7.6% (3). However, the prevalence of dementia and risk factor profiles may be different among different ethnic groups within the same population. For example, the prevalence of dementia in Aboriginal Australians is three times higher than their non-indigenous counterparts (4); and head injury has been identified as a risk factor that is significantly associated with dementia in Aboriginal Australians (5).

Aotearoa NZ is officially recognised as a bicultural country which includes Māori and non-Māori people. Non-Māori are comprised of NZ Europeans, Asian, Pacific People, Middle Eastern, Latin American and Africans. The Treaty of Waitangi is NZ's constitutional document that places the obligation on the NZ government to be responsive to the health needs of Māori, including those living with dementia, and to ensure equitable health outcomes with non-Māori (6). According to the 2018 NZ census, approximately 70% of the people in the total population self-identified as NZ-Europeans, 17% as Māori, 15% as Asians, 8% as Pacific people and 2% as Middle Eastern/Latin American/African (7). The prevalence of dementia is likely to be different among the major ethnic groups in NZ. For example, the largest ethnic minorities

(Māori, Asian and Pacific populations) are increasing at a faster rate than NZ European (2); and we will expect a higher increase in dementia prevalence in these populations. There is also some evidence to suggest Māori and Pacific people are diagnosed with dementia at a younger age than NZ Europeans (8), possibly due to their higher rates of cardiovascular risk factors (9, 10). A previous study found that Asian people living in NZ are more likely to have their dementia undiagnosed and their true prevalence of dementia might be higher than what is reported in official reports (11).

Accurate estimates of dementia prevalence and associated risk factors in NZ are critical to measure the full impact of dementia, raise public awareness, reduce stigma, and inform policy development regarding the implementation of evidence-based prevention, treatment and support services for people with dementia and their families (12). Culturally appropriate and responsive services for dementia can only be developed if the true extent of the burden of dementia is known. There has never been a population-based dementia prevalence study in NZ, so we propose to test the methods required to conduct a fully representative multi-ethnic national prevalence study of dementia. The aim of this paper is to describe the study protocol of a validity study and a feasibility study that will prepare the groundwork for a future fully powered dementia prevalence study in NZ (Figure 1).

In urban areas of NZ, there are many diverse communities in which many different languages are spoken. In the 2013 NZ Census 64% of Chinese, 37% of Indian, 44% of Tongan, and 35% of Samoan elders aged 65+ years did not speak English (13). There is an inherent educational and cultural bias in many cognitive tests that were developed for European cultures. Thus, commonly used English dementia instruments are not appropriate to apply in those communities and there is a need to use fully adapted and validated instruments that can produce accurate and comparable ethnic-specific rates for a NZ dementia prevalence study. Due to the multi-cultural setting in NZ, we elected to use the 10/66 dementia assessment protocol, which

was developed to be culturally and linguistically fair and can be administered by trained lay interviewers (14). The 10/66 protocol has been demonstrated to have a sensitivity of up to 94% and a specificity of up to 97% in diagnosing dementia (14). It has been previously translated and validated in many languages, including Spanish, Portuguese, Mandarin and Cantonese (14). However, it has never been used in Māori or Pacific populations.

The objectives of the validity study are to (i) translate and adapt the 10/66 protocol for use in research with Māori, Samoan, Tongan, and Fijian-Indian (people of Indian ethnicity born in Fiji Islands) populations; and (ii) test the diagnostic accuracy of these adapted versions in the respective ethnic groups.

The objective of the feasibility study is to test the logistics and feasibility of using the culturally adapted versions of the 10/66 protocol as a research tool with NZ European, Māori, Chinese, Samoan, Tongan, and Fijian-Indian people living in the community. The results of the feasibility study will inform a future fully powered dementia prevalence study in NZ.

The largest minority ethnic groups (Samoan, Tongan, Fijian-Indian, and Chinese) will be included in the study based on availability of bilingual bicultural researchers and interviewers from the same ethnic groups.

Methods and analysis

Phase one - validity study

Stage 1: Translation and adaptation of the 10/66 dementia assessment protocol.

The 10/66 dementia assessment protocol takes approximately ninety minutes to administer; the main sections of which are described in Table 1.

We will adopt a translation procedure based on the World Health Organization translation guidelines (30). The procedure entails a four-stage process:

1) Forward translation: the English version of the 10/66 will be translated into Te Reo Māori (the Māori language), Samoan, Tongan and Fijian Hindi by professional translators, assisted by a clinician;
2) Expert advisory panels for the selected ethnicities will review the first draft of the translation and offer advice and possible solutions for acceptability, conceptual validity and tolerability of the translated instruments;
3) A bilingual dementia specialist will quality check and back translate the adapted/translated version;
4) Pre-testing in individuals with and without dementia and their families to assess how well the questionnaire will be received, and their feedback used to refine the final version.

We acknowledge the importance of building a research team that represents the ethnic backgrounds of the population groups we are seeking to engage for the study. Māori, Samoan, Tongan and Fijian Hindi researchers will assist in the recruitment of expert translators and members for each expert advisory panel and facilitate the meetings.

Stage 2: Diagnostic accuracy

We will recruit Māori, Samoan, Tongan and Fijian-Indian participants from the Counties Manukau District Health Board (CMDHB) memory service based at Middlemore Hospital in South Auckland, NZ. People who attend the memory service are referred either from primary care or secondary care services. The clinical criteria to access this service is that a person and/or their family living in the community have a primary concern of subjective and/or objective cognitive decline, irrespective of age.

To assess diagnostic test accuracy, we will compare the results of the 10/66 dementia assessment protocol with the clinical diagnoses. The clinical diagnoses will be made by a

multidisciplinary team of dementia specialists at the memory service, guided by standard clinical criteria, including NINCDS-ADRDA criteria for Alzheimer's disease dementia, (31), NINCDS-AIREN criteria for vascular dementia (32), criteria for Lewy Body dementia (33), and Lund criteria for frontotemporal dementias (34). Dementia severity is guided by the Criteria for Dementia Severity or CDR (35); a CDR of 0.5 indicates mild cognitive impairment, 1 is mild severity, 2 and 3 are moderate and severe severity (35).

Cases and controls

Eligible participants in the validity study will be 65 years or older and self-identify as Māori, Samoan, Tongan or Fijian-Indian. Participants must have had a full dementia assessment at the CMDHB memory service. The assessment or review must have taken place in the previous six months to avoid the potential progression of normal controls converting to dementia. By using convenience sampling, we will attempt to recruit a total of 30 participants with a dementia diagnosis in each of the four ethnic groups, and 30 age and sex-matched controls (who had a full specialist assessment and were found not to have dementia). Participants will be excluded if they suffer from any physical or sensory impairment that compromises their ability to participate in the interview.

Informants

All participants will have a family member or main caregiver (informant) who will complete the "informant" section of the 10/66 protocol (Table 1). An informant is defined as a person who knows the main participant well.

Blinding

The selection, recruitment, and clinical confirmation of case/control status will be carried out independent of the 10/66 interviewing process. Interviewers will be blind to the case or control

group to which the participant belongs, although blinding may be difficult to maintain in cases of more severe dementia.

Interview training and assessment process

Lay interviewers will be recruited via electronic resources (university website, email, blogs) or through contacts from people/students/health professionals known to the study's investigators. Interviewers must be bicultural and bilingual, identify with at least one of Māori, Fijian-Indian, Tongan or Samoan ethnicity, and be able to speak English and the ethnic group language fluently. We will select between two and six interviewers per ethnic group. The interviewers will be trained by a team of researchers familiar with the 10/66 assessment protocol. The Lead Co-investigator for each ethnic group will ensure that specific cultural guidelines are included in the training process. The training will consist of four sessions of approximately three hours each. In the first session, the "participant" questionnaires and cognitive tests will be reviewed. In the second session, the "informant" and "head of household" questionnaires, consent forms and participant information sheets will be reviewed. During the third session, interviewers will receive training on specific protocols to handle unexpected situations. For example, if mental health problems are detected during the interview (e.g. suicidal ideation), the PI will be immediately contacted by the interviewers and after assessing the situation and with their prior consent, the participant´s / informant´s GP or the appropriate mental health service will be contacted to inform them about the issue. In the fourth session answers will be provided to clarify any questions that the interviewers may have had during the training process, in particular cultural and language issues.

Interviews

After obtaining written consent, interviewers will conduct the assessment in a manner that is culturally appropriate and follows the respective cultural protocols. For example, in Māori

whānau (*families*), at the beginning of any hui (*social gathering*) and following the karakia (*prayer*), a round of mihimihi (*introductions and speeches*) usually occurs. During this time people may share information about where they come from and significant aspects of their whakapapa (*genealogy*). The interview is usually finished with another karakia. Similarly for Pacific families, the importance of taking time to build trust and rapport requires the incorporation of Samoan and Tongan customs - "fa'aSamoa"/ "anga fakaTonga" and an inherent understanding of Pacific values such as "Tausi le va"/ "Tauhi le va" (nurturing relationships) and "fa'aaloalo"/ "faka'apa'apa" (respect), which has specific connotations for interactions and engagement with the elderly. On completion of the assessment session a koha (*gift*) of a $100 NZD voucher will be offered to the person and their family as a gesture of appreciation for their participation.

For participants who are unable to give fully informed consent, we will follow the process recommended by the NZ's Code of Health and Disability Services Consumers' Rights (36). We will approach the family to discuss whether they believe their family member would want to participate. If the caregiver agrees we will seek written confirmation that they have been consulted, and are comfortable with the researcher making the decision as to whether their relative should participate in the study, and that they believe this would be consistent with their relative's wishes. If at any time the participant indicates they do not wish to participate, the interview will be terminated.

Analysis Phase 1

The predictive analytic software version 25 (SPSS, Chicago, IL) will be used for data analysis. Descriptive frequency distributions and mean values will be used to describe the demographic summary of each ethnic group. Dementia diagnosis will be made using the 10/66 dementia diagnostic algorithm, which has been described elsewhere (37), but in brief, the algorithm

uses the scores obtained from: 1) the Community Screening Instrument, 2) The verbal fluency test, 3) the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) word list memory test, and 4) the scores/diagnoses obtained from the Geriatric Mental State (GMS) interview. The algorithm is processed in two sequential stages: in stage one the total scores for each component are calculated and in the second stage the final diagnoses are arranged by a hierarchically structured imposed algorithm (37). In order to obtain the positive predictive value, negative predictive value, specificity and sensitivity, the resulting dichotomous variable derived from the algorithm will be assessed against the gold standard clinical diagnoses of "dementia case" or "no dementia case". To compare the subcomponents of the 10/66 protocol between cases and controls, descriptive analyses of categorical variables will be assessed using chi-square tests and normally distributed continuous variables with Student's t-test or one-way ANOVA. Non-parametric variables will be assessed with Mann-Whitney U test or Kruskall-Wallis.

Phase two – Feasibility study

Phase two is designed to answer the feasibility questions that arise when we attempt to use the culturally adapted 10/66 dementia assessment tools in community-dwelling participants living in selected geographic areas. South Auckland was selected for this purpose due to its ethnic diversity. The feasibility study will include the following ethnic groups: NZ European, Māori, Fijian-Indian, Chinese, Tongan and Samoan.

The six main feasibility questions to be answered are:

1) How do we sample to ensure we get adequate community representation from the included ethnic groups?
2) How do we prepare a workforce to conduct the fieldwork and develop quality control?
3) How do we raise the awareness of the study in the community to maximize recruitment?

4) How do we conduct door-knocking to maximize recruitment?
5) How do we retain those we have recruited to remain in the study?
6) What is the acceptability of study recruitment and the 10/66 assessment process in different ethnic groups?

The design of the feasibility study will replicate the design of the full dementia prevalence study. Potential participants will be identified and recruited using door-knocking in the selected areas that will allow over sampling of non-European ethnic groups. We will include aged 65 or over living in private residences in the selected areas, and their caregivers/co-residents. The exclusion criteria are participants unable to identify a friend or family member to complete the informant schedule, and people living in care homes and retirement villages (since their sociodemographic and general health status may differ from those in the community). The same procedures regarding the interview and interviewer training process will be used for the feasibility study. All stored data will be de-identified and coded with a unique participant identifier.

Feasibility issues

1) Sampling to ensure adequate community representation from the included ethnic groups

This phase is a cross-sectional survey of selected ethnicities identified by a standard procedure for a population-based sample. It includes a meshblock sampling frame and door-to-door knocking to recruit a representative sample in the selected areas (38). Meshblocks are defined as the smallest geographic unit for which Statistics NZ has demographic information (approximately 100 people). Using NZ Census demographic information and the expected rates of dementia by age, we will calculate the probability of finding dementia cases in the community in adults aged 65 years or older in the CMDHB region of South Auckland. We will then test our sampling methods by selecting meshblocks with the highest proportions of people

aged 65+ for each ethnicity. We aim to recruit 25 participants and informants from each of the groups, enabling us to test the study procedures and materials in all six ethnic communities.

2) Preparing a workforce to conduct the fieldwork and developing quality control

The interviewers will be fully trained as described in phase one of the study. Quality control processes will be conducted before and throughout the study interviews. Interviewers will practice interviews with volunteers aged 65 or older, without significant medical or psychiatric comorbidity. The volunteer interviews will be carried out during the training process and constructive feedback regarding their approach and the conduct of the interview will be provided.

After the training sessions the first two study interviews will be carried out under the supervision of one of the trainers and specific feedback regarding the interview process will be provided at the end of the interview. This will assure that the 10/66 assessment protocol is correctly administered across all the different ethnic groups and will clarify any questions that may arise during the interview process.

3) Raising awareness of the study in the community – participants and public involvement

Three to four months before starting the sample recruitment we will engage with the selected communities to co-design a study launch strategy in the communities we hope to reach, using traditional media, social media and ethnic-specific community activities co-facilitated with community leaders. We will also send information about the study by post to all potential households in the chosen locations. Once the community engagement activities are completed, we will start the recruitment of potential participants.

4) Maximizing recruitment by door-knocking

The feasibility study will use a door to door recruitment approach. Door knocking will be conducted at least once a week for 12 months in the selected areas or until a response has been recorded for each household. The door-knocking team will be composed of bilingual and bicultural interviewers (at least one per ethnic group). The initial questionnaire will be conducted on the doorstep and will last approximately ten minutes. If inclusion criteria are met, the study will be briefly described to the potential participant and, if agreed, we will ask them for contact details to send further information about the study. The door knockers will return to households up to four times to maximise response rates before registering a house as "not answered". Regardless of whether or not they agree to participate in the study, all participants who answer our initial questions will receive a koha/gift (a key ring) as a gesture of appreciation for their time.

Information about the study will be sent by mail to the potential participants who have agreed to be contacted. They will be given the contact phone details of the Lead Co-investigator for their ethnic group if they wish to discuss the study further. Approximately one week after sending these documents, a phone call will be made, with the aim of answering any questions that the potential participant might have and to make an appointment to carry out the interview. The call will be made by a bilingual bicultural researcher which will reduce any potentially coercive power differential, facilitating cultural safety. Interviews will be carried out either at the participant´s home, University of Auckland facilities or other suitable location of their choice.

5) Retaining those we have recruited to the study

Once the participant/informant agrees to participate in the study, he/she will be contacted to schedule an appointment. Appointments will be arranged by the ethnic-specific Lead Co-investigator or by someone trained and designated by them (for example, one of the bilingual

interviewers). We will contact the participants either by phone call or face-to-face, depending on which is most culturally appropriate. The contact will be made in the participant's native language or in English, depending on the participants' preferences. The interviewer will fully explain the study to all potential participants (including the head of household and family member participants) and will discuss any concerns. If they agree to participate, we will seek informed consent from the participant, the informant, and the household informant. Regular staff meetings will be held with interviewers to obtain feedback that will inform the adaptation of study protocols. We will also test our fieldwork protocol that includes verification of ineligible/refusal cases, contact with families to ask and measure that correct protocol was followed, quality control of data, and observation of interviews.

6) Acceptability of study recruitment and assessment in different ethnic groups

We will ask the participants and their families for feedback about the interview and the specific cultural approach. We will assess the consent procedures (for example, total time used to fill the consent form, answer questions about the consent form, difficulties around signing/reading the consent form); questionnaire administration (total time to finish the interview, appropriateness of the questions, participants' general opinions about the questionnaire); koha (gift) management (best way to offer koha to participants and participants' opinions about the koha). Finally, we will ask interviewers to feedback problems that they encounter and will use this information to refine our recruitment, training procedures, and fieldwork monitoring in the full study, and to help decide whether to outsource to a survey firm in the full study.

Quantitative data collection and reporting:

Recruitment will be assessed by the number of people screened in the selected meshblocks. We will register the total number of door-knocked houses, number of door-knocked houses answered and declined, numbers of people over the age of 65 that agree to be contacted, the

houses that agreed to be contacted but subsequently declined (and, if possible, the reasons for declining) as well as final interview response rate. For those who agree to be contacted, we will measure the retention rate, decline rate, proportion of baseline participants that agree to be interviewed and the completeness of collected data.

Overall, we will measure the proportion of potential participants (and informants) who were approached, consented and completed the research protocol and adapted 10/66 interview schedule as a quantitative measure of acceptability.

These measures will enable us to test the effectiveness of the sampling procedure and we will compare our results to NZ Census data to assess whether we reached a representative sample of the South Auckland population. The numbers of people with dementia identified in each ethnic group will inform the sample size and the weighted stratification method which is usually used to estimate prevalence in underrepresented groups in the population in the fully powered dementia prevalence study.

The data collection and analysis timeline are described in Table 2.

Patient and public Involvement

Discussion

There has never been a population-based dementia prevalence study in NZ. Thus, we do not have a clear idea of the true extent and impact of dementia both overall and, in particular, in Māori and Pacific people who may be at greater risk yet remain undiagnosed. A dementia prevalence study that represents all major ethnic groups in NZ is needed to (1) measure the true extent of dementia in NZ; (2) examine the risk factor profiles in each ethnic group; (3) measure the care arrangements and caregiver burden in families living with dementia, and (4) determine the economic impact of dementia on families and on society. The major impact of this study is the creation of new knowledge about the community prevalence of dementia in NZ, both

overall and for all major ethnic groups, which is essential to inform culturally appropriate strategies to reduce the impact of dementia. The findings from the full study will provide robust evidence about the numbers of people affected, the possible risk factors, caregiver burden and the financial impact on families. These NZ-specific data can be used by the NZ Ministry of Health to develop culturally informed policies to raise public awareness about dementia and dementia prevention, and to plan services that support families living with dementia in all NZ communities. The study will also demonstrate the benefits of recruiting a qualified, skilled research team that is representative of the families participating in the study. Taken together, this study will determine the essential elements required for conducting dementia research in a multicultural context in New Zealand.

Ethics and dissemination

The validity study was approved by the Northern A Health and Disability Ethics Committee, Number: 17NTA234; and the feasibility study was approved by the Northern A Health and Disability Ethics Committee, Number: 18NTA176. The findings will be disseminated through peer-reviewed academic journals, national and international conferences and public events.

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Authors contributions:

AMR, SC and GC drafted the manuscript and all co-authors critically revised the manuscript. SC, RK, GC, MD and NK contributed to the study design. SC, CRR, NK, SY, GC contributed to the study analysis design. All co-authors contributed to the study development.

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Competing interest

No competing interests declared

Patient consent for publication

Not required

Ethics approval

Both the validity (ref: 17NTA234) and feasibility (ref: 18NTA176) studies were approved by the New Zealand Northern A Health and Disability Ethics Committee – New Zealand Government / Ministry of Health.

Table 1. Sections of the 10/66 dementia assessment protocol

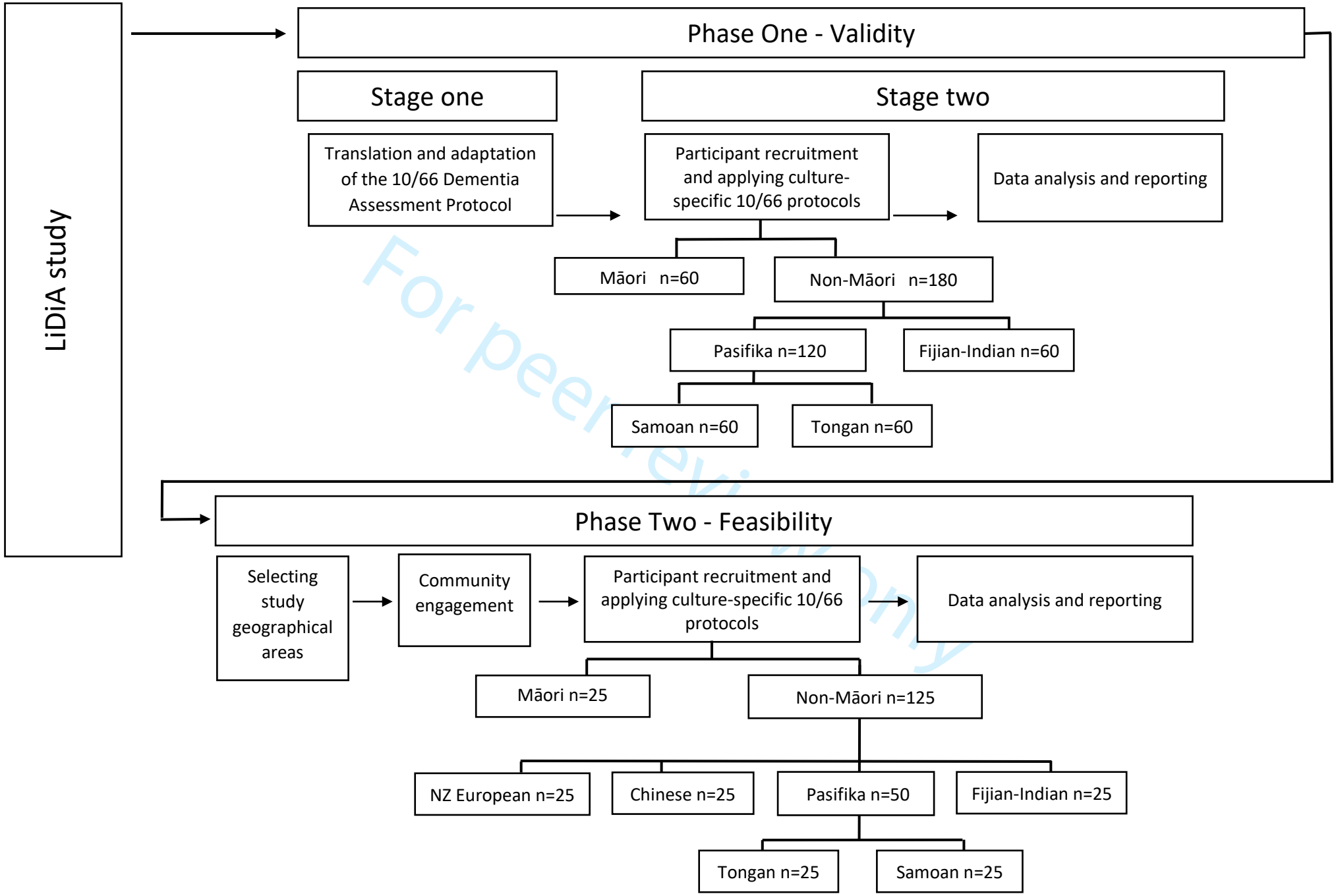
Questionnaire	Section	Instruments used
Participant	Clinical mental state interview	GMS B3 (15) generates hierarchically organized ICD10 (16) and DSM-IV (17) diagnoses including dementia
	Cognitive test battery	CSI-D participant version (18)
		CERAD word list memory test (immediate and delayed recall) (19)
		CERAD verbal fluency test (animal naming) (19)
		Palm-fist-hand test from the Luria battery of frontal lobe tasks (20)
	Sociodemographic status	Sociodemographic and risk factors questionnaire (participant version) (21)
Informant	Informant interview	Brief informant history from the CSI-D (18)
		Client Service Receipt Inventory or CSRI (22)
		Self-reported questionnaire (23,24)
		The Zarit Burden Interview or ZBI (25-27)
		History and Aetiology Schedule (28)
		Neuropsychiatric Inventory Questionnaire or NPI-Q (29)
	Sociodemographic status	Sociodemographic and risk factors questionnaire (proxy version)* (21)
Household	Head of household questionnaire	Questions about house and family income (21)

Abbreviations - ICD: International Classification of Diseases, DSM: Diagnostic and Statistical Manual of Mental Disorders, GMS: Geriatric Mental State; CERAD: Consortium to Establish a Registry for Alzheimer's Disease; CSI-D: Community Screening Interview for Dementia.
*Proxy version will be used if the main participant is unable to complete the participant version of Sociodemographic and risk factors questionnaire.

Table 2. Projected data collection and data analysis timeline by months

Study phases	Tasks	Months
Validity study	Adaptation of 10/66 dementia protocols for specific cultures	1 to 3
	Participant recruitment and interview using culture-specific 10/66 protocols	4 to 7
	Data analysis and report writing	8 to 12
Feasibility study	Door-knocking	8 to 12
	Participant recruitment and interview using culture-specific 10/66 protocols	13 to 20
	Data analysis and report writing	20 to 24

Figure 1. Living with Dementia in Aotearoa (LiDiA) feasibility study design.



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Living with Dementia in Aotearoa (LiDiA): A cross-sectional feasibility study protocol for a multi-ethnic dementia prevalence study in Aotearoa/New Zealand.

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Abstract

Introduction: Aotearoa New Zealand (NZ) is officially recognized as a bicultural country comprised of Māori and non-Māori. Recent estimations have projected a threefold increase in dementia prevalence in NZ by 2050, with the greatest increase in non-NZ Europeans. The NZ government will need to develop policies and plan services to meet the demands of the rapid rise in dementia cases. However, to date there is no national data on dementia prevalence and overseas data are used to estimate the NZ dementia statistics. The overall aim of the Living with Dementia in Aotearoa (LiDiA) study is to prepare the groundwork for a large full-scale NZ dementia prevalence study.

Methods and analysis: The study has two phases. In phase one, we will adapt and translate the 10/66 dementia assessment protocol to be administered in Māori, Samoan, Tongan and Fijian-Indian elders. The diagnostic accuracy of the adapted 10/66 protocol will be tested in older people from these ethnic backgrounds who were assessed for dementia at a local memory service. In phase two, we will address the feasibility issues of conducting a population-based prevalence study, by applying the adapted 10/66 protocol in South Auckland and will include NZ European, Māori, Samoan, Tongan, Chinese, and Fijian-Indian participants. The feasibility issues to be explored are: (i) How do we sample to ensure we get accurate community representation? (ii) How do we prepare a workforce to conduct the fieldwork and develop quality control? (iii) How do we raise awareness of the study in the community to maximize recruitment? (iv) How do we conduct door-knocking to maximize recruitment? (v) How do we retain those we have recruited to remain in the study? (vi) What is the acceptability of study recruitment and the 10/66 assessment process in different ethnic groups?

Ethics and dissemination

The validity and feasibility studies were approved by the New Zealand Northern A Health and Disability Ethics Committee, Number: 17NTA234 and 18NTA176 respectively. The findings will be disseminated through peer-reviewed academic journals, national and international conferences and public events. Data will be available upon reasonable request to the corresponding author.

Strengths and limitations of this study

- This is the first study, conducted by bilingual and bicultural researchers, to test a methodology aimed to determine the feasibility of conducting a multi-ethnic dementia prevalence study in Aotearoa/New Zealand.
- The study will use strict guidelines to adapt, translate and validate the 10/66 dementia assessment instrument in four of the largest ethnic groups living in Aotearoa/New Zealand.
- The study will use meshblock census data and over sampling to ensure inclusive representation of the non-European ethnic groups included in the study.
- Due to time and funding constraints, we will include only the major New Zealand ethnic groups in this feasibility study.
- We will use door-knocking to ascertain our sample; other sampling methods such as using the electoral roll may be more effective but are unlikely to be accurate in the geographic area we have chosen.

Introduction

Dementia is a global health priority and its prevalence is increasing in many parts of the world due to their ageing populations (1). Governments across the world are developing policies and planning services to meet the health care and social needs of people with dementia. Aotearoa New Zealand (NZ) needs to do the same but to date there is no prevalence data at a national level to inform the extent and impact of dementia on our population. Although it has been projected that over 60,000 people are currently living with dementia in NZ (at a cost of $1700 million per annum) and it will increase to 170,000 people by 2050 (2), these statistics are extrapolated from other countries data.

Globally, the prevalence of dementia in people aged 60 years and over is reported to be between 5.6% to 7.6% (3). However, the prevalence of dementia and risk factor profiles may be different among different ethnic groups within the same population. For example, the prevalence of dementia in Aboriginal Australians is three times higher than their non-indigenous counterparts (4); and head injury has been identified as a risk factor that is significantly associated with dementia in Aboriginal Australians (5). Other studies have included multi-ethnic samples (6). For example, a study conducted in Singapore used the 10/66 assessment protocol (7) to calculate the prevalence of dementia among their population (6). It included a sample of 2,565 subjects aged 60 years and over who speak Chinese, Malay, Tamil, or other dialects (Hokkien, Cantonese, and Teochew). The instrument was first translated and adapted into those languages that had not been translated before and subsequently applied. The results showed an overall dementia rate of 10% using the 10/66 diagnostic algorithm (6). Interestingly they also found that the Indian population had a lower probability of having dementia compared to the Chinese-speaking population (6). These results demonstrate how the prevalence and aetiologies may vary in different populations. Therefore, careful assessment of each population is essential to establish both the prevalence of dementia and community-specific risk factors related to it.

Aotearoa NZ is officially recognised as a bicultural country which includes Māori and non-Māori people. Non-Māori are comprised of NZ Europeans, Asian, Pacific People, Middle Eastern, Latin American and Africans. The Treaty of Waitangi is NZ's constitutional document that places the obligation on the NZ government to be responsive to the health needs of Māori, including those living with dementia, and to ensure equitable health outcomes with non-Māori (8). According to the 2018 NZ census, approximately 70% of the people in the total population self-identified as NZ-Europeans, 17% as Māori, 15% as Asians, 8% as Pacific people, 2% as Middle Eastern/Latin American/African and 1% as others (9). However, the 2018 NZ census also included those who identify with more than one ethnicity; thus, the proportion sum is higher than 100 percent. Also, in urban areas of NZ, there are many diverse communities in which a large proportion of the people are not able to speak English as reported in the Counties Manakau Population Census (10) (Table 1). This might be explained by recent New Zealand immigration policies in which many older people from these ethnic groups emigrated to NZ following their adult children in the last 20 years, therefore many have had no need to learn English prior to immigration. Also, they often live in close-knit communities, speaking their mother tongue in everyday life and hence usually there is no need to learn English after their arrival in NZ.

Table 1. Language indicator for the 2013 Counties Manakau population Census in people aged 65 years and over.

Ethnic group	% of people who are not able to speak English	% people who are able to speak their own language
Chinese	64	90[a]
Indian	37	56[b] – 85[c]
Samoan	35	97
Tongan	44	92

[a] Corresponds to the total of people able to speak a Sinitic language
[b] Corresponds to people who are able to speak Hindi.
[c] Corresponds to people who are able to speak Indian languages other than Hindi.
Totals do not add to hundred percent as people might be included in one or more category, and not all categories included in the report were described in this table.

The prevalence of dementia is likely to be different among the major ethnic groups in NZ. For example, the largest ethnic minorities (Māori, Asian and Pacific populations) are increasing at a faster rate than NZ European (2); and we will expect a higher increase in dementia prevalence in these populations. There is also some evidence to suggest Māori and Pacific people are diagnosed with dementia at a younger age than NZ Europeans (11), possibly due to their higher rates of cardiovascular risk factors (12,13). A previous study found that Asian people living in NZ are more likely to have their dementia undiagnosed and their true prevalence of dementia might be higher than what is reported in official reports (14).

Accurate estimates of dementia prevalence and associated risk factors in NZ are critical to measure the full impact of dementia, raise public awareness, reduce stigma, and inform policy development regarding the implementation of evidence-based prevention, treatment and support services for people with dementia and their families (15). Culturally appropriate and responsive services for dementia can only be developed if the true extent of the burden of dementia is known. There has never been a population-based dementia prevalence study in NZ, so we propose to test the methods required to conduct a fully representative multi-ethnic national prevalence study of dementia. The aim of this paper is to describe the study protocol of a validity study and a feasibility study that will prepare the groundwork for a future fully powered dementia prevalence study in NZ (Figure 1).

There is an inherent educational and cultural bias in many cognitive tests that were developed for European cultures. Thus, commonly used English dementia instruments are not appropriate to apply in those communities and there is a need to use fully adapted and validated instruments that can produce accurate and comparable ethnic-specific rates for a NZ dementia prevalence study. Due to the multi-cultural setting in NZ, we elected to use the 10/66 dementia assessment protocol, which was developed to be culturally and linguistically fair and can be administered by trained lay interviewers (16). The 10/66 protocol has been demonstrated to have a

sensitivity of up to 94% and a specificity of up to 97% in diagnosing dementia (17). It has been previously translated and validated in many languages, including Spanish, Portuguese, Mandarin and Cantonese (17). However, it has never been used in Māori or Pacific populations.

The objectives of the validity study are to (i) translate and adapt the 10/66 protocol for use in research with Māori, Samoan, Tongan, and Fijian-Indian (people of Indian ethnicity born in Fiji Islands) populations; and (ii) test the diagnostic accuracy of these adapted versions in the respective ethnic groups.

The objective of the feasibility study is to test the logistics and feasibility of using the culturally adapted versions of the 10/66 protocol as a research tool with NZ European, Māori, Chinese, Samoan, Tongan, and Fijian-Indian people living in the community. The results of the feasibility study will inform a future fully powered dementia prevalence study in NZ.

The largest minority ethnic groups (Samoan, Tongan, Fijian-Indian, and Chinese) will be included in the study based on availability of bilingual bicultural researchers and interviewers from the same ethnic groups.

Methods and analysis

Phase one - validity study

Stage 1: Translation and adaptation of the 10/66 dementia assessment protocol.

The 10/66 dementia assessment protocol takes approximately ninety minutes to administer; the main sections of which are described in Table 2.

Table 2. Sections of the 10/66 dementia assessment protocol

Questionnaire	Section	Instruments used
Participant	Clinical mental state interview	GMS B3 (18) generates hierarchically organized ICD10 (19) and DSM-IV (20) diagnoses including dementia
	Cognitive test battery	CSI-D participant version (21)
		CERAD word list memory test (immediate and delayed recall) (22)
		CERAD verbal fluency test (animal naming) (22)
		Palm-fist-hand test from the Luria battery of frontal lobe tasks (23)
	Sociodemographic status	Sociodemographic and risk factors questionnaire (participant version) (7)
Informant	Informant interview	Brief informant history from the CSI-D (21)
		Client Service Receipt Inventory or CSRI (24)
		Self-reported questionnaire (25, 26)
		The Zarit Burden Interview or ZBI (27-29)
		History and Aetiology Schedule (30)
		Neuropsychiatric Inventory Questionnaire or NPI-Q (31)
	Sociodemographic status	Sociodemographic and risk factors questionnaire (proxy version)* (7)
Household	Head of household questionnaire	Questions about house and family income (7)

Abbreviations - ICD: International Classification of Diseases, DSM: Diagnostic and Statistical Manual of Mental Disorders, GMS: Geriatric Mental State; CERAD: Consortium to Establish a Registry for Alzheimer's Disease; CSI-D: Community Screening Interview for Dementia.
*Proxy version will be used if the main participant is unable to complete the participant version of Sociodemographic and risk factors questionnaire.

We will adopt a translation procedure based on the World Health Organization translation guidelines (32). The procedure entails a four-stage process:

1) Forward translation: the English version of the 10/66 will be translated into Te Reo Māori (the Māori language), Samoan, Tongan and Fijian Hindi by professional translators, assisted by a clinician;
2) Expert advisory panels for the selected ethnicities will review the first draft of the translation and offer advice and possible solutions for acceptability, conceptual validity and tolerability of the translated instruments;
3) A bilingual dementia specialist will quality check and back translate the adapted/translated version;
4) Pre-testing in individuals with and without dementia and their families to assess how well the questionnaire will be received, and their feedback used to refine the final version.

We acknowledge the importance of building a research team that represents the ethnic backgrounds of the population groups we are seeking to engage for the study. Māori, Samoan, Tongan and Fijian Hindi researchers will assist in the recruitment of expert translators and members for each expert advisory panel and facilitate the meetings.

Stage 2: Diagnostic accuracy

We will recruit Māori, Samoan, Tongan and Fijian-Indian participants from the Counties Manukau District Health Board (CMDHB) memory service based at Middlemore Hospital in South Auckland, NZ. People who attend the memory service are referred either from primary care or secondary care services. The clinical criteria to access this service is that a person and/or their family living in the community have a primary concern of subjective and/or objective cognitive decline, irrespective of age.

To assess diagnostic test accuracy, we will compare the results of the 10/66 dementia assessment protocol with the clinical diagnoses. The clinical diagnoses will be made by a multidisciplinary team of dementia specialists at the memory service, guided by standard clinical criteria, including NIA-AA criteria for Alzheimer's disease dementia (33), NINCDS-AIREN criteria for vascular dementia (34), criteria for Lewy Body dementia (35), and the clinical criteria for frontotemporal dementias (36). Dementia severity is guided by the Criteria for Dementia Severity or CDR (37); a CDR of 0.5 indicates mild cognitive impairment, 1 is mild severity, 2 and 3 are moderate and severe severity (37).

Cases and controls

Eligible participants in the validity study will be 65 years or older and self-identify as Māori, Samoan, Tongan or Fijian-Indian. Participants must have had a full dementia assessment at the CMDHB memory service. The assessment or review must have taken place in the previous six months to avoid the potential progression of normal controls converting to dementia. By using convenience sampling, we will attempt to recruit a total of 30 participants with a dementia diagnosis in each of the four ethnic groups, and 30 age and sex-matched controls (who had a full specialist assessment and were found not to have dementia). Participants will be excluded if they suffer from any physical or sensory impairment that compromises their ability to participate in the interview.

Informants

All participants will have a family member or main caregiver (informant) who will complete the "informant" section of the 10/66 protocol (Table 2). An informant is defined as a person who knows the main participant well.

Blinding

The selection, recruitment, and clinical confirmation of case/control status will be carried out independent of the 10/66 interviewing process. Interviewers will be blind to the case or control group to which the participant belongs, although blinding may be difficult to maintain in cases of more severe dementia.

Interview training and assessment process

Lay interviewers will be recruited via electronic resources (university website, email, blogs) or through contacts from people/students/health professionals known to the study's investigators. Interviewers must be bicultural and bilingual, identify with at least one of Māori, Fijian-Indian, Tongan or Samoan ethnicity, and be able to speak English and the ethnic group language fluently. We will select between two and six interviewers per ethnic group. The interviewers will be trained by a team of researchers familiar with the 10/66 assessment protocol. The Lead Co-investigator for each ethnic group will ensure that specific cultural guidelines are included in the training process. The training will consist of four sessions of approximately three hours each. In the first session, the "participant" questionnaires and cognitive tests will be reviewed. In the second session, the "informant" and "head of household" questionnaires, consent forms and participant information sheets will be reviewed. During the third session, interviewers will receive training on specific protocols to handle unexpected situations. For example, if mental health problems are detected during the interview (e.g. suicidal ideation), the PI will be immediately contacted by the interviewers and after assessing the situation and with their prior consent, the participant´s / informant´s GP or the appropriate mental health service will be contacted to inform them about the issue. In the fourth session answers will be provided to clarify any questions that the interviewers may have had during the training process, in particular cultural and language issues.

Interviews

After obtaining written consent, interviewers will conduct the assessment in a manner that is culturally appropriate and follows the respective cultural protocols. For example, in Māori whānau (*families*), at the beginning of any hui (*social gathering*) and following the karakia (*prayer*), a round of mihimihi (*introductions and speeches*) usually occurs. During this time people may share information about where they come from and significant aspects of their whakapapa (*genealogy*). The interview is usually finished with another karakia. Similarly for Pacific families, the importance of taking time to build trust and rapport requires the incorporation of Samoan and Tongan customs - "fa'aSamoa"/ "anga fakaTonga" and an inherent understanding of Pacific values such as "Tausi le va"/ "Tauhi le va" (nurturing relationships) and "fa'aaloalo"/ "faka'apa'apa" (respect), which has specific connotations for interactions and engagement with the elderly. On completion of the assessment session a koha (*gift*) of a $100 NZD voucher will be offered to the person and their family as a gesture of appreciation for their participation. The GMS (18) will assess if the participant was not interviewed in their mother language or if the participant was using an unclear dialect or accent. We presume that some of the participants will be to some extent bilingual, however, this will depend on the characteristics of their life history and other socio-cultural factors. Since the interviewers will be bilingual, the participants will be able to decide in which language they prefer the interview to take place.

For participants who are unable to give fully informed consent, we will follow the process recommended by the NZ's Code of Health and Disability Services Consumers' Rights (38). We will approach the family to discuss whether they believe their family member would want to participate. If the caregiver agrees we will seek written confirmation that they have been consulted, and are comfortable with the researcher making the decision as to whether their relative should participate in the study, and that they believe this would be consistent with their

relative's wishes. If at any time the participant indicates they do not wish to participate, the interview will be terminated.

Analysis Phase 1

The predictive analytic software version 25 (SPSS, Chicago, IL) will be used for data analysis. Descriptive frequency distributions and mean values will be used to describe the demographic summary of each ethnic group. Dementia diagnosis will be made using the 10/66 dementia diagnostic algorithm, which has been described elsewhere (17), but in brief, the algorithm uses the scores obtained from: 1) the Community Screening Instrument (21), 2) The verbal fluency test (22), 3) the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) word list memory test (22), and 4) the scores/diagnoses obtained from the Geriatric Mental State (GMS) interview (18). The algorithm is processed in two sequential stages: in stage one the total scores for each component are calculated and in the second stage the final diagnoses are arranged by a hierarchically structured imposed algorithm (7, 17). In order to obtain the positive predictive value, negative predictive value, specificity and sensitivity, the resulting dichotomous variable derived from the algorithm will be assessed against the gold standard clinical diagnoses of "dementia case" or "no dementia case". To compare the subcomponents of the 10/66 protocol between cases and controls, descriptive analyses of categorical variables will be assessed using chi-square tests and normally distributed continuous variables with Student's t-test or one-way ANOVA. Non-parametric variables will be assessed with Mann-Whitney U test or Kruskall-Wallis.

Phase two – Feasibility study

Phase two is designed to answer the feasibility questions that arise when we attempt to use the culturally adapted 10/66 dementia assessment tools in community-dwelling participants living in selected geographic areas. South Auckland was selected for this purpose due to its ethnic

diversity. The feasibility study will include the following ethnic groups: NZ European, Māori, Fijian-Indian, Chinese, Tongan and Samoan.

The six main feasibility questions to be answered are:

1) How do we sample to ensure we get adequate community representation from the included ethnic groups?
2) How do we prepare a workforce to conduct the fieldwork and develop quality control?
3) How do we raise the awareness of the study in the community to maximize recruitment?
4) How do we conduct door-knocking to maximize recruitment?
5) How do we retain those we have recruited to remain in the study?
6) What is the acceptability of study recruitment and the 10/66 assessment process in different ethnic groups?

The design of the feasibility study will replicate the design of the full dementia prevalence study. Potential participants will be identified and recruited using door-knocking in the selected areas that will allow over sampling of non-European ethnic groups. We will include aged 65 or over living in private residences in the selected areas, and their caregivers/co-residents. The exclusion criteria are participants unable to identify a friend or family member to complete the informant schedule, and people living in long-term care facilities and retirement villages (since their overall dementia prevalence, sociodemographic and general health status may differ from those in the community, and thus it might introduce results bias in our relatively small community sample). The same procedures regarding the interview and interviewer training process will be used for the feasibility study. All stored data will be de-identified and coded with a unique participant identifier.

Feasibility issues

1) Sampling to ensure adequate community representation from the included ethnic groups

This phase is a cross-sectional survey of selected ethnicities identified by a standard procedure for a population-based sample. It includes a meshblock sampling frame and door-to-door knocking to recruit a representative sample in the selected areas (39). Meshblocks are defined as the smallest geographic unit for which Statistics NZ has demographic information (approximately 100 people). Using NZ Census demographic information and the expected rates of dementia by age, we will calculate the probability of finding dementia cases in the community in adults aged 65 years or older in the CMDHB region of South Auckland. We will then test our sampling methods by selecting meshblocks with the highest proportions of people aged 65+ for each ethnicity. We aim to recruit 25 participants and informants from each of the groups, enabling us to test the study procedures and materials in all six ethnic communities.

2) Preparing a workforce to conduct the fieldwork and developing quality control

The interviewers will be fully trained as described in phase one of the study. Quality control processes will be conducted before and throughout the study interviews. Interviewers will practice interviews with volunteers aged 65 or older, without significant medical or psychiatric comorbidity. The volunteer interviews will be carried out during the training process and constructive feedback regarding their approach and the conduct of the interview will be provided.

After the training sessions the first two study interviews will be carried out under the supervision of one of the trainers and specific feedback regarding the interview process will be provided at the end of the interview. This will assure that the 10/66 assessment protocol is correctly administered across all the different ethnic groups and will clarify any questions that may arise during the interview process.

3) Raising awareness of the study in the community – participants and public involvement

Three to four months before starting the sample recruitment we will engage with the selected communities to co-design a study launch strategy in the communities we hope to reach, using traditional media, social media and ethnic-specific community activities co-facilitated with community leaders. We will also send information about the study by post to all potential households in the chosen locations. Subsequently, we will ask study participants to feedback if/how they knew about the study beforehand, informing our launch strategy for the full study. Once the community engagement activities are completed, we will start the recruitment of potential participants.

4) Maximizing recruitment by door-knocking

The feasibility study will use a door to door recruitment approach. Door knocking will be conducted at least once a week for 12 months in the selected areas or until a response has been recorded for each household. The door-knocking team will be composed of bilingual and bicultural interviewers (at least one per ethnic group). The initial questionnaire will be conducted on the doorstep and will last approximately ten minutes. If inclusion criteria are met, the study will be briefly described to the potential participant and, if agreed, we will ask them for contact details to send further information about the study. The door knockers will return to households up to four times to maximise response rates before registering a house as "not answered". Regardless of whether or not they agree to participate in the study, all participants who answer our initial questions will receive a koha/gift (a key ring) as a gesture of appreciation for their time.

Information about the study will be sent by mail to the potential participants who have agreed to be contacted. They will be given the contact phone details of the Lead Co-investigator for their ethnic group if they wish to discuss the study further. Approximately one week after sending these documents, a phone call will be made, with the aim of answering any questions

that the potential participant might have and to make an appointment to carry out the interview. The call will be made by a bilingual bicultural researcher which will reduce any potentially coercive power differential, facilitating cultural safety. Interviews will be carried out either at the participant´s home, University of Auckland facilities or other suitable location of their choice.

5) Retaining those we have recruited to the study

Once the participant/informant agrees to participate in the study, he/she will be contacted to schedule an appointment. Appointments will be arranged by the ethnic-specific Lead Co-investigator or by someone trained and designated by them (for example, one of the bilingual interviewers). We will contact the participants either by phone call or face-to-face, depending on which is most culturally appropriate. The contact will be made in the participant's native language or in English, depending on the participants' preferences. The interviewer will fully explain the study to all potential participants (including the head of household and family member participants) and will discuss any concerns. If they agree to participate, we will seek informed consent from the participant, the informant, and the household informant. Regular staff meetings will be held with interviewers to obtain feedback that will inform the adaptation of study protocols. We will also test our fieldwork protocol that includes verification of ineligible/refusal cases, contact with families to ask and measure that correct protocol was followed, quality control of data, and observation of interviews.

6) Acceptability of study recruitment and assessment in different ethnic groups

We will ask the participants and their families for feedback about the interview and the specific cultural approach. We will assess the consent procedures (for example, total time used to fill the consent form, answer questions about the consent form, difficulties around signing/reading the consent form); questionnaire administration (total time to finish the interview,

appropriateness of the questions, participants' general opinions about the questionnaire); koha (gift) management (best way to offer koha to participants and participants' opinions about the koha). Finally, we will ask interviewers to feedback problems that they encounter and will use this information to refine our recruitment, training procedures, and fieldwork monitoring in the full study, and to help decide whether to outsource to a survey firm in the full study.

Quantitative data collection and reporting:

Recruitment will be assessed by the number of people screened in the selected meshblocks. We will register the total number of door-knocked houses, number of door-knocked houses answered and declined, numbers of people over the age of 65 that agree to be contacted, the houses that agreed to be contacted but subsequently declined (and, if possible, the reasons for declining) as well as final interview response rate. For those who agree to be contacted, we will measure the retention rate, decline rate, proportion of baseline participants that agree to be interviewed and the completeness of collected data.

Overall, we will measure the proportion of potential participants (and informants) who were approached, consented and completed the research protocol and adapted 10/66 interview schedule as a quantitative measure of acceptability.

These measures will enable us to test the effectiveness of the sampling procedure and we will compare our results to NZ Census data to assess whether we reached a representative sample of the South Auckland population. The numbers of people with dementia identified in each ethnic group will inform the sample size and the weighted stratification method which is usually used to estimate prevalence in underrepresented groups in the population in the fully powered dementia prevalence study.

The data collection and analysis timeline are described in Table 3.

Table 3. Projected data collection and data analysis timeline by months

Study phases	Tasks	Months
Validity study	Adaptation of 10/66 dementia protocols for specific cultures	1 to 3
	Participant recruitment and interview using culture-specific 10/66 protocols	4 to 7
	Data analysis and report writing	8 to 12
Feasibility study	Door-knocking	8 to 12
	Participant recruitment and interview using culture-specific 10/66 protocols	13 to 20
	Data analysis and report writing	20 to 24

Patient and public involvement

Before starting the study, we will engage with the selected communities to conduct educational sessions and also conduct qualitative research to identify the main concerns about dementia in each ethnic group. Other sessions have already been conducted through local non-governmental organisations serving older people in different ethnic groups living in New Zealand, plus cross-cultural interest groups with Asian health professionals regarding the best ways to conduct dementia research in their communities (40). We will also invite members from the different communities to a study launch.

Discussion

There has never been a population-based dementia prevalence study in NZ. Thus, we do not have a clear idea of the true extent and impact of dementia both overall and, in particular, in Māori and Pacific people who may be at greater risk yet remain undiagnosed. A dementia prevalence study that represents all major ethnic groups in NZ is needed to (1) measure the true extent of dementia in NZ; (2) examine the risk factor profiles in each ethnic group; (3) measure the care arrangements and caregiver burden in families living with dementia, and (4) determine the economic impact of dementia on families and on society. The major impact of this study is the creation of new knowledge about the community prevalence of dementia in NZ, both

overall and for all major ethnic groups, which is essential to inform culturally appropriate strategies to reduce the impact of dementia.

There are some limitations that need to be acknowledged: (i) the sampling methodology was based on convenience sampling. Although sample sizes between 24 and 50 have been recommended for pilot studies (41-43) and convenience sampling may provide accurate correlations and rich qualitative information, it will not offer generalisable results to the overall NZ population. However, this study will lay the foundations for a future national prevalence study representing all the ethnic groups included in our research. (ii) Not all ethnic minorities in New Zealand will be included in this phase of the study; other ethnic groups will need to be included in future studies, for example, people from other Pacific Islands, Middle Easterners, Latin American, and Africans. (iii) Another limitation is that we will only include people aged 65 years or over. Future studies, including people with younger onset dementia, particularly from the ethnic groups that have shown to be at a higher risk of developing dementia at a younger age (such as Maori and Pacific People), will be needed to clarify this issue (iv) The feasibility phase will only include people recruited from the community. Consequently, people living in long-term care facilities and retirement villages will be excluded from our study. However, we intend to conduct a future study using the Long-Term Care Facility version of the International Residential Assessment Instrument (interRAI) (44). interRAI routinely collects information on dementia diagnosis and is mandated by the Ministry of Health to be completed with every long-term care facility residents every 6 months. We also have planned to conduct a dementia prevalence study in long-term care facilities using the 10/66 instruments (reference standard) and compare the results against interRAI data to assess their utility for ongoing dementia surveillance. (v) Finally, our study will be carried out in a multi-ethnic urban area. Nevertheless, in less ethnically diverse regions, it may be more challenging to recruit bilingual interviewers for ethnic minorities other than Maori. It would mean looking for

alternatives to recruit interviewers for these populations—for example, mobilizing bilingual interviewers from one location to another, which will increase the study costs but present more accurate results. Additionally, in rural areas is likely that different engaging strategies will have to be sought. For example, disseminating the study in a rural population might require other engaging methods (such as face-to-face) compared to the methods used in urban areas. Also, due to cultural factors, the participation and declining rates might be different from less to more ethnically diverse areas and from rural to urban areas. A specific engaging method will have tested for these areas.

The findings from the full prevalence study will provide robust evidence about the numbers of people affected, the possible risk factors, caregiver burden and the financial impact on families. These NZ-specific data can be used by the NZ Ministry of Health to develop culturally informed policies to raise public awareness about dementia and dementia prevention, and to plan services that support families living with dementia in all NZ communities. The study will also demonstrate the benefits of recruiting a qualified, skilled research team that is representative of the families participating in the study. Taken together, this study will determine the essential elements required for conducting dementia research in a multicultural context in New Zealand.

Ethics and dissemination

The validity study was approved by the Northern A Health and Disability Ethics Committee, Number: 17NTA234; and the feasibility study was approved by the Northern A Health and Disability Ethics Committee, Number: 18NTA176. The findings will be disseminated through peer-reviewed academic journals, national and international conferences and public events.

Authors contributions:

AMR, SC and GC drafted the manuscript and all co-authors critically revised the manuscript. SC, RK, GC, MD and NK contributed to the study design. SC, CRR, NK, SY, GC contributed

to the study analysis design. AMR, SC, GC, MD, RK, FF, MR, ST, JFF, CRR, SK, EM, NK, and SC contributed to the study development.

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Competing interest

No competing interests declared

Patient consent for publication

Not required

Ethics approval

Both the validity (ref: 17NTA234) and feasibility (ref: 18NTA176) studies were approved by the New Zealand Northern A Health and Disability Ethics Committee – New Zealand Government / Ministry of Health.

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Figure 1. Living with Dementia in Aotearoa (LiDiA) feasibility study design.