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Dementia prevalence estimation among the main ethnic groups in New Zealand: a population-based descriptive study of routinely collected health data

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ABSTRACT

Objective Estimates of dementia prevalence in New Zealand (NZ) have previously been extrapolated from limited Australasian studies, which may be neither accurate nor reflect NZ's unique population and diverse ethnic groups. This study used routinely collected health data to estimate the 1-year period prevalence for diagnosed dementia for each of the 4 years between July 2016 and June 2020 in the age 60+ and age 80+ populations and for the four main ethnic groups.

Design A population-based descriptive study.

Setting Seven national health data sets within the NZ Integrated Data Infrastructure (IDI) were linked. Diagnosed dementia prevalence for each year was calculated using the IDI age 60+ and age 80+ populations as the denominator and also age–sex standardised to allow comparison across ethnic groups.

Participants Diagnosed dementia individuals in the health datasets were identified by diagnostic or medication codes used in each of the data sets with deduplication of those who appeared in more than one data set.

Results The crude diagnosed dementia prevalence was 3.8%–4.0% in the age 60+ population and 13.7%–14.4% in the age 80+ population across the four study years. Dementia prevalence age–sex standardised to the IDI population in the last study period of 2019–2020 was 5.4% for Māori, 6.3% for Pacific Islander, 3.7% for European and 3.4% for Asian in the age 60+ population, and 17.5% for Māori, 22.2% for Pacific Islander, 13.6% for European and 13.5% for Asian in the age 80+ population.

Conclusions This study provides the best estimate to date for dementia prevalence in NZ but is limited to those people who were identified as having dementia based on data from the seven included data sets. The findings suggest that diagnosed dementia prevalence is higher in Māori and Pacific Islanders. A nationwide NZ community-based dementia prevalence study is much needed to confirm the findings of this study.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Routinely collected administrative health data are standardised and provide good national coverage but have limitations.
⇒ Dementia is under-recognised and underdiagnosed, so not all cases will be captured by administrative health data sets.
⇒ New Zealand does not routinely collect primary care dementia data, so this study likely underestimates the prevalence of dementia.
⇒ A community-based dementia prevalence study is needed to determine the true prevalence of dementia.
⇒ Community-based dementia prevalence studies are expensive. This study provides New Zealand-specific dementia estimates.

INTRODUCTION

Dementia is a common late-life neurodegenerative condition. In 2015, there were an estimated 46.8 million people living with dementia globally and this number was expected to double every 20 years.[1] The Dementia Economic Impact Report estimated there were 70 000 people living with dementia in New Zealand in 2020.[2] This estimate was extrapolated from findings of one small New Zealand and three Australian studies, three of which were published over 25 years ago[3–6] and none of them considered New Zealand's diverse ethnic population, which includes 70.2% European, 16.5% Māori, 15.1% Asian (mainly Chinese and Indian) and 8.1% Pacific Islanders.[7] A recent New Zealand study reported that the risk factor prevalence and weighted population attributable fraction for dementia are higher in Māori (51.4%) and Pacific Islanders (50.8%) but lower in Asian peoples (40.8%), compared with New Zealand as a whole (47.6%); therefore, dementia prevalence is also likely to vary across ethnic groups.[2]

Addressing the public health and cost impact of dementia requires an accurate estimation of its prevalence, but there has never been a community-based dementia prevalence study in New Zealand that represents all of the major ethnic groups. Prevalence

studies are costly to carry out, so linked electronic health records are increasingly being used to inform the epidemiology of various health conditions, including dementia. Integrated Data Infrastructure (IDI) is a state-of-the-art New Zealand research database holding microdata about people and households.[8] Data from a number of sources including government agencies, Statistics New Zealand surveys and non-government organisations are linked together to form the IDI. All data in the IDI are deidentified and information that could potentially be used to identify people, such as National Health Index (NHI) identifiers, are encrypted.

A previous New Zealand study linked health data sets (Mortality, National Minimal Data set—Publicly and Privately Funded Hospital Discharges and Pharmaceutical Collection) in the IDI and estimated the prevalence of dementia in the age 60+ population from 2012 to 2015.[9] The estimated dementia prevalence of 2% was much lower than the 6.9% estimated by the World Alzheimer Report 2015.[1] However, direct comparison of these dementia prevalence estimates cannot be made due to different methodology used in these studies. The IDI has since been expanded to include additional health data sets such as interRAI, which may increase the potential for identification of dementia cases. interRAI is a standardised geriatric assessment mandated by the New Zealand Ministry of Health since 2012 for all people assessed for publicly funded home support services and aged residential care. Approximately, 10% and 40% of all New Zealanders aged 65 years and 85 years or older, respectively, have had an interRAI assessment.[10] Therefore, we would expect its inclusion in a suite of linked data sets to identify more dementia cases and provide a better estimate of dementia prevalence in New Zealand.

This descriptive study aimed to use linked data from seven health databases within the IDI in order to: (1) estimate the crude 1-year period prevalence of dementia in the age 60+ and age 80+ populations for each of the 4 years between 1 July 2016 and 30 June 2020 and (2) calculate age–sex standardised rates to allow more accurate comparison of dementia prevalence across the four main New Zealand ethnic groups (Māori, Pacific Islander, Asian and European).

MATERIALS AND METHODS

This was a population-based descriptive study. We sought permission from Statistics New Zealand to access IDI and to conduct this project between November 2020 and February 2022 (Reference: MAA2020-12).

Identification of dementia cases and study period

Table 1 provides details of each data set and summarises the methods used to identify dementia cases in the seven health data sets (interRAI, Mortality, National Needs Assessment and Service Coordination Information System (SOCRATES), Pharmaceutical Collection, Privately Funded Hospital Discharges, Programme for the Integration of Mental Health Data (PRIMHD) and Publicly Funded Hospital Discharges).

The diagnostic codes for dementia in each database were defined as follows:

1. ICD-9 and ICD-10-AM codes for dementia (online supplemental appendix) in Mortality, PRIMHD, Privately Funded Hospital Discharges and Publicly Funded Hospital Discharges. We included ICD-9 codes because they were still being used in some of the health data sets such as Privately Funded Hospital Discharges and Publicly Funded Hospital Discharges.
2. Diagnosis of 'Alzheimer's disease' or 'Dementia other than Alzheimer's disease' in interRAI. An interRAI assessment routinely records these two diagnoses. These diagnoses are determined by interRAI assessors who undergo competency assessment to confirm they can accurately record assessment information. interRAI assessors use multiple sources of information to determine diagnoses, for example, referral documentation, person interview, observation and discussion with family, carers or health professionals.
3. Funded antidementia medications (donepezil tablets and rivastigmine patch) are used as proxies for a diagnosis of dementia in the Pharmaceutical Collection (see online supplemental appendix for medication codes) as these medications are not prescribed for any condition other than dementia in New Zealand. Donepezil is fully subsidised in New Zealand, while rivastigmine patch is available on a special authority application for funding, meaning certain criteria need to be met for subsidy to be obtained. Only data on subsidised medicines are contained in the Pharmaceutical collection, so we were unable to collect prescribing data regarding galantamine and memantine.
4. Diagnostic codes for dementia or dementia subtypes (online supplemental appendix) in SOCRATES.

Data linkage

Statistics New Zealand routinely cleans the IDI population data to avoid an individual having two Unique Person Identifiers. We also used the Structured Query Language (SQL) function 'COUNT DISTINCT Unique Person Identifier [snz_uid]' to ensure there were no duplicated individuals. After we identified all dementia cases in the IDI in our study period, we used the SQL 'JOIN' function, including 'LEFT JOIN', 'RIGHT JOIN' and 'INNER JOIN', to link the seven health datasets and sociodemographic details. The sociodemographic details include sex, date of birth, deceased date and ethnicity (in the prioritised order of Māori, Pacific Islander, Asian, Middle East Latin American and African (MELAA), Other and European).

Calculation of dementia prevalence

Using the deceased date, we were able to determine the number of dementia cases in the IDI (alive and deceased) in the four study years: 1 July 2016 to 30 June 2017, 1 July 2017 to 30 June 2018, 1 July 2018 to 30 June 2019 and 1

Table 1 Health datasets, their availability periods and dementia case identification in the New Zealand Integrated Data Infrastructure (IDI)

Health datasets	Description	Data availability period	Identification of dementia cases
1. interRAI	Mandated standardised comprehensive geriatric assessment for all publicly funded home support services and aged residential care.	July 2014–June 2021	► Diagnosis of Alzheimer's disease or Dementia other than Alzheimer's disease
2. Mortality	Data classifying the underlying cause of death for all deaths registered in New Zealand, including all registered foetal deaths (stillbirths), using the WHO Rules and Guidelines for Mortality Coding.	July 1907–December 2018	► ICD-9 and ICD-10-AM codes*
3. National Needs Assessment and Service Coordination Information System (SOCRATES)	Used by Ministry-funded Needs Assessment and Service Coordination agencies to record information about clients who are eligible for Disability Support Services.	September 1939–September 2020	► Diagnostic codes*
4. Pharmaceutical Collection	Contains information about subsidised dispensed medications processed by the General Transaction Processing System, including demographic information about healthcare users to whom these prescriptions were dispensed.	January 2005–June 2020	► Donepezil tablets ► Rivastigmine patch
5. Privately Funded Hospital Discharges	Subset of fields from the National Minimum Dataset. Includes discharge and event data about privately funded hospital events and demographic data reported for the population cohort.	March 1914–December 2018	► ICD-9 and ICD-10-AM codes*
6. Programme for the Integration of Mental Health Data (PRIMHD)†	Contains data about the referral, what services (activities) were provided, and demographic information. Excludes outcomes, diagnosis and legal status data.	November 1974–June 2020	► ICD-9 and ICD-10-AM codes*
7. Publicly Funded Hospital Discharges	Subset of fields from the National Minimum Dataset. Includes discharge and event data about publicly funded hospital events (including admissions occurring at private hospitals but are publicly funded) and demographic data reported for the population cohort.	May 1914–December 2020	► ICD-9 and ICD-10-AM codes*

*Refer to online supplemental appendix.
†PRIMHD contains information of PRIMHD data and Mental Health Information National Collection (MHINC) data, which was the mental health data collection prior to PRIMHD.

July 2019 to 30 June 2020. We used the same definition of 'total population at risk' as was used in the previous IDI dementia prevalence study[9] where all people who were alive or had died during each year of the study period were included. Each individual could only be counted once in each of the four study years.

$$\text{Total IDI population at risk} = \text{Total number of active and alive IDI individuals} + \text{Total number of deaths in IDI}$$

Statistics New Zealand defines an active IDI case by the presence of at least one activity in one of the following data sets within 12 months: (1) Inland Revenue; (2) Education; (3) Health; (4) Accident Compensation Corporation claims and (5) Aged under 5 and with a New Zealand birth registration or visa.

Dementia prevalence was calculated using the following formula:

$$\text{Prevalence} = \frac{\text{Number of active and alive dementia cases} + \text{Number of inactive but alive dementia cases} + \text{Number of inactive and deceased dementia cases}}{\text{Total IDI population at risk}}$$

We calculated crude 1-year period dementia prevalence in each of the four study years under the following categories: age 60+, age 80+ and per 5-year age bands from age 60+. Age 60+ was used in this study to allow direct comparison with the age 60+ figures reported by the World Alzheimer Report 2015 and the Walesby *et al*'s study.[1 9] We also estimated crude 1-year period dementia prevalence for the four main ethnic groups (Māori, Pacific Islander, Asian and European). Due to the relatively low number of older adults of MELAA and Other Ethnicities living in New Zealand, they were excluded from our interethnic analysis. We estimated dementia prevalence age–sex standardised to the New Zealand IDI population in each of the four study years because of the differences in age and sex profile between different ethnic groups. These were calculated using the following

formula to account for changing population numbers each year[11]:

$$\text{Directly standardized rate} = \frac{\Sigma\ (\text{stratum specific rates} \times \text{standard weights})}{\Sigma\ (\text{standard weights})}$$

$$\text{Directly standardised rate} = \frac{r_1\ N_1 + r_2\ N_2 + r_3\ N_3 + \ldots + r_n\ N_n}{N_1 + N_2 + N_3 + \ldots + N_n},$$

where, for $k=1, 2, \ldots, n$,

r_k = rate in k^{th} stratum of the study population

That is, For each ethnicity, calculate the rate for each gender by the formula:

$$r_k = \frac{\text{Dementia Count for } k^{th} \text{ Age Group}}{\text{Total Population for } k^{th} \text{ Age}}$$

N_k = number of persons in k^{th} stratum of the standard population

$$N_k = \frac{\left(\text{N(Year 1)}_k + \text{N(Year 2)}_k + \text{N(Year 3)}_k + \text{N(Year 4)}_k\right)}{4}$$

$\left(ie,\ N_k\ is\right.$ the average of k^{th} age subgroup of the total population of the three specific study periods

$N =$ total number of persons in the standard population $\left(\sum N_k\right)$

(ie, N is the sum of all the average age subgroup of the total population of the three specific study periods);

$\sum$ means summation over the k strata.

RESULTS

Identification of dementia cases

Table 2 shows the number of dementia cases identified in each of the seven health data sets. interRAI, Publicly Funded Hospital Discharges, PRIMHD and Pharmaceutical Collection data sets contributed the greatest number of dementia cases. Table 2 also shows the Venn diagrams to illustrate the intersects of these four health data sets.

IDI populations

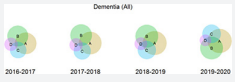
Table 3 shows the IDI populations from this study and Statistics New Zealand's national population estimates which give the best measure between census dates of the population size.[12] We found that the IDI 60+ and 80+ populations are higher than the Statistics New Zealand population estimates; whereas the IDI total (all ages) populations are lower than the Statistics New Zealand population estimates. The Statistics New Zealand population estimates are based on estimated natural increase (births minus deaths) and estimated net migration (migrant arrivals minus migrant departures). The IDI populations are not estimates; they represent the true number of people who have at least one activity in one of five data sets (including health) within 12 months. It is possible that older adults have more contacts with health services and, therefore, are more likely to be captured by the IDI. There is also some concern about the quality of the 2018 census.[13] There were no missing IDI data for age and sex; ethnicity data were missing in 0.2% and 0.6% of the age 60+ and age 80+ populations, respectively.

Calculation of dementia prevalence

Table 4 shows the crude 1-year period dementia prevalence for each study year by age and ethnicity in 5-year

Table 2 Number of dementia cases identified in the seven health data sets

Data set	1 July 2016 to 30 June 2017 N=**41 763,** n (%)	1 July 2017 to 30 June 2018 N=**43 416,** n (%)	1 July 2018 to 30 June 2019 N=**44 019,** n (%)	1 July 2019 to 30 June 2020 N=**44 136,** n (%)
1.interRAI	26 415 (63.2)	28 104 (64.7)	28 773 (65.4)	29 127 (66.0)
2.Mortality	3426 (8.2)	5157 (11.9)	2424 (5.5) *	NA
3.SOCRATES	330 (0.8)	342 (0.8)	348 (0.8)	351 (0.8)
4.Pharmaceutical Collection	13 185 (31.6)	14 007 (32.3)	14 598 (33.2)	15 012 (34.0)
5.Privately Funded Hospital Discharges	843 (2.0)	690 (1.6)	471 (1.1)	219 (0.5)
6.PRIMHD	6636 (15.9)	6093 (14.0)	4959 (11.3)	4074 (9.2)
7.Publicly Funded Hospital Discharges	24 747 (59.3)	25 683 (59.2)	25 914 (58.9)	25 317 (57.4)



The counts shown are the total numbers of alive and decreased individuals identified with dementia in each of the study periods. They are not individuals with a new diagnosis of dementia identified in each of the study periods.
Venn diagrams illustrating the intersects of the four health datasets with the greatest number of dementia cases: A (orange)=interRAI; B (green)=Publicly Funded Hospital Discharges; C (blue)=Pharmaceutical Collection; D (purple)=Programme for the Integration of Mental Health Data.

*Mortality data only available until December 2018.
NA, Mortality data not available; PRIMHD, Programme for the Integration of Mental Health Data; SOCRATES, National Needs Assessment and Service Coordination Information System.

Table 3 Integrated Data Infrastructure (IDI) total populations, age 60+ populations and age 80+ populations, compared with Statistics New Zealand population estimates from 30 June 2016 to 30 June 2020

	1 July 2016 to 30 June 2017	1 July 2017 to 30 June 2018	1 July 2018 to 30 June 2019	1 July 2019 to 30 June 2020
IDI total (all ages) population	4 770 897	4 843 773	4 909 617	4 984 836
Statistics New Zealand population estimate*	4 813 600	4 900 600	4 979 200	5 090 200
Difference†	42 703 (0.9%)	56 827 (1.2%)	69 583 (1.4%)	105 364 (2.1%)
IDI age 60+ population	1 001 367	1 031 247	1 061 691	1 095 192
Statistics age 60+ population estimate*	977 600	1 005 900	1 039 600	1 082 500
Difference†	–23767 (–2.4%)	–25347 (–2.5%)	–22091(–2.1%)	–12692 (–1.2%)
IDI age 80+ population	188 580	193 113	197 775	204 720
Statistics age 80+ population estimate*	168 800	172 300	177 400	185 200
Difference†	–19780 (–11.7%)	–20813 (–12.1%)	–20375 (–11.5%)	–19520 (–10.5%)

*Source: https://infoshare.stats.govt.nz/ Population estimates for the last month of the study period.

$$\text{†Difference} = \frac{\text{Statistics New Zealand Population Estimate} - \text{IDI Population}}{\text{Statistics New Zealand Population Estimate}}$$

age bands from age 60. Māori and Pacific Islanders have higher crude prevalence than Europeans in each of the 5-year age bands from age 60 to 95+ across the 4 years; while Asian people have lower crude prevalence than Europeans in each of the 5-year age bands from age 60 to 89 across the 4 years.

Table 5 shows that the crude 1-year period prevalence was 3.8%–4.0% in the age 60+ population and 13.7%–14.4% in the age 80+ population across the four study periods. Table 5 also shows the crude and age–sex standardised 1-year period prevalence in the four main ethnic groups for the age 60+ and age 80+ populations. After age–sex standardisation to the total IDI study population to account for the interethnic differences in age and sex profiles, dementia prevalence in Māori is 34%–46% higher in the age 60+population and 16%–29% higher in the age 80+ population compared with Europeans; while dementia prevalence in Pacific Islanders is 58%–70% higher in the age 60+ population and 49%–63% in the 80+ population compared with Europeans.

DISCUSSION

This is the first study to date that estimates the prevalence of dementia in New Zealand using linked administrative data from seven health datasets. Our study found an estimated crude 1-year period dementia prevalence of 3.8%–4.0% in the age 60+ population and 13.7%–14.4% in the age 80+ population, respectively. The age 60+ figures are nearly double that of the estimated prevalence of 2.0% in a previous IDI study that used four of the seven health data sets included in our study.[9] We only ascertained cases of identified *and* coded dementia but a substantial number of people with dementia living in the community will remain unidentified and/or uncoded for dementia.[14] A previous meta-analysis found the pooled rate of undetected dementia in the community, including residential care settings, of high-income countries was 61.7% (95% CI 55.0% to 68.0%).[15] In addition, a diagnosis of dementia may not get entered into clinical records by clinicians and, therefore, is undercoded in the relevant health datasets. Therefore, the true dementia prevalence in New Zealand is likely to be higher than that found in this study.

An important secondary finding of our study is the marked difference in dementia prevalence across New Zealand's four main ethnic groups. Our age–sex standardised dementia prevalence in 2019–2020 was 5.4% for Māori, 6.3% for Pacific Islander, 3.7% for European and 3.4% for Asian in the age 60+ population, and 17.5% for Māori, 22.2% for Pacific Islander, 13.6% for European and 13.5% for Asian in the age 80+ population. This suggests dementia prevalence in Māori is over 34% higher in the age 60+ population and over 16% higher in the age 80+ population compared with Europeans; and for Pacific Islanders, it is over 58% higher in the age 60+ population and over 49% in the 80+ population compared with Europeans.

Ethnic differences in dementia prevalence have been observed in previous international studies. For example, a systematic review of 114 US studies found age 65+ dementia prevalence ranged from 6.3% in Japanese Americans, 12.9% in Caribbean Hispanic Americans, 12.2% in Guamanian Chamorro and 7.2%–20.9% in African Americans.[16] Another meta-analysis of US studies also found African Americans had a higher dementia prevalence than Caucasians,[17] which is consistent with a UK systematic review where older African-Caribbean people had a higher prevalence of dementia than the White British population.[18] We found Māori, the indigenous people of New Zealand, have a higher dementia prevalence than the New Zealand European population, and this finding is consistent with a previous systematic review, which found indigenous populations from Canada, Australia,

Table 4 Crude dementia 1-year period prevalence per 5-year age bands from age 60 in the four main ethnic groups

Dementia cases by age range and ethnicity, n (% of IDI population)		1 July 2016 to 30 June 2017	1 July 2017 to 30 June 2018	1 July 2018 to 30 June 2019	1 July 2019 to 30 June 2020
60–64	All ethnicities	1077 (0.4)	1116 (0.4)	1140 (0.4)	1134 (0.4)
	Māori	195 (0.7)	195 (0.6)	207 (0.6)	204 (0.6)
	Pacific Islander	66 (0.6)	63 (0.6)	66 (0.6)	69 (0.6)
	European	708 (0.4)	729 (0.4)	738 (0.4)	726 (0.4)
	Asian	75 (0.3)	81 (0.3)	87 (0.3)	93 (0.3)
65–69	All ethnicities	1977 (0.8)	2010 (0.9)	1995 (0.8)	2004 (0.8)
	Māori	294 (1.4)	330 (1.5)	339 (1.4)	360 (1.4)
	Pacific Islander	93 (1.1)	90 (1.0)	117 (1.3)	126 (1.3)
	European	1455 (0.8)	1446 (0.8)	1383 (0.8)	1359 (0.8)
	Asian	93 (0.5)	102 (0.5)	102 (0.5)	117 (0.5)
70–74	All ethnicities	3513 (1.9)	3825 (2.0)	3993 (2.0)	4062 (1.9)
	Māori	435 (3.3)	483 (3.3)	519 (3.3)	561 (3.4)
	Pacific Islander	180 (3.3)	210 (3.7)	210 (3.4)	213 (3.2)
	European	2679 (1.8)	2880 (1.8)	3006 (1.8)	2985 (1.8)
	Asian	162 (1.5)	180 (1.5)	180 (1.4)	195 (1.3)
75–79	All ethnicities	6102 (4.4)	6360 (4.5)	6465 (4.4)	6489 (4.3)
	Māori	609 (6.7)	654 (7.0)	726 (7.5)	708 (7.2)
	Pacific Islander	273 (7.4)	291 (7.7)	285 (7.2)	306 (7.5)
	European	4863 (4.2)	5037 (4.3)	5055 (4.2)	5088 (4.1)
	Asian	273 (3.6)	291 (3.7)	300 (3.7)	282 (3.3)
80–84	All ethnicities	8193 (9.0)	8484 (9.0)	8715 (8.9)	8922 (8.7)
	Māori	594 (12.0)	684 (13.1)	720 (13.2)	771 (13.0)
	Pacific Islander	273 (13.1)	300 (13.8)	330 (14.3)	357 (14.5)
	European	6846 (8.8)	7005 (8.8)	7134 (8.7)	7206 (8.3)
	Asian	357 (7.8)	378 (7.4)	420 (7.6)	465 (7.9)
85–89	All ethnicities	9648 (15.9)	9786 (16.0)	9741 (15.8)	9501 (15.3)
	Māori	393 (17.6)	456 (18.5)	492 (19.2)	480 (18.3)
	Pacific Islander	240 (23.7)	261 (24.9)	255 (22.9)	252 (21.5)
	European	8601 (15.9)	8610 (16.0)	8475 (15.7)	8223 (15.2)
	Asian	306 (15.4)	321 (14.2)	354 (14.3)	387 (13.7)
90–94	All ethnicities	6402 (22.8)	6807 (23.6)	6885 (23.4)	6732 (22.4)
	Māori	171 (25.6)	186 (25.5)	222 (26.5)	231 (26.2)
	Pacific Islander	108 (31.3)	123 (32.5)	144 (35.8)	156 (35.6)
	European	5922 (22.9)	6237 (23.6)	6243 (23.3)	6024 (22.2)
	Asian	132 (20.9)	174 (24.2)	204 (24.7)	231 (25.0)
95+	All ethnicities	2532 (30.0)	2718 (30.4)	2763 (30.1)	2952 (30.5)
	Māori	42 (31.1)	60 (35.1)	63 (36.2)	63 (33.9)
	Pacific Islander	33 (50.0)	39 (59.1)	48 (55.2)	54 (66.7)
	European	2355 (29.9)	2505 (30.3)	2502 (29.5)	2682 (30.0)
	Asian	45 (27.3)	57 (28.4)	69 (31.5)	81 (32.9)

IDI, Integrated Data Infrastructure.

Table 5 Crude and age–sex standardised dementia 1-year period prevalence in the four main ethnic groups: age 60+ and 80+ populations

	Age 60+				Age 80+			
	1 July 2016 to 30 June 2017	1 July 2017 to 30 June 2018	1 July 2018 to 30 June 2019	1 July 2019 to 30 June 2020	1 July 2016 to 30 June 2017	1 July 2017 to 30 June 2018	1 July 2018 to 30 June 2019	1 July 2019 to 30 June 2020
Dementia cases by ethnicity, n (% of IDI population)								
All ethnicities	39444 (3.9)	41088 (4.0)	41682 (3.9)	41793 (3.8)	26772 (14.2)	27795 (14.4)	28104 (14.2)	28107 (13.7)
Māori	2733 (3.4)	3048 (3.6)	3288 (3.6)	3378 (3.5)	1200 (15.0)	1386 (16.2)	1497 (16.6)	1545 (16.1)
Pacific Islander	1266 (4.0)	1377 (4.2)	1455 (4.2)	1533 (4.2)	654 (18.7)	723 (19.7)	777 (19.9)	819 (19.7)
European	33429 (4.2)	34449 (4.2)	34536 (4.2)	34293 (4.0)	23724 (14.3)	24357 (14.4)	24354 (14.2)	24135 (13.7)
Asian	1443 (2.2)	1584 (2.2)	1716 (2.2)	1851 (2.2)	840 (11.4)	930 (11.2)	1047 (11.6)	1164 (11.8)
Dementia cases by sex, n (% of IDI population)								
Female	23697 (4.5)	24450 (4.5)	24717 (4.4)	24591 (4.3)	17268 (15.6)	17757 (15.7)	17826 (15.5)	17676 (14.9)
Male	15747 (3.3)	16656 (3.4)	16980 (3.4)	17205 (3.3)	9507 (12.3)	10038 (12.5)	10278 (12.5)	10431 (12.1)
Age-sex standardised dementia prevalence by ethnicity (%)								
Māori	5.1	5.4	5.5	5.4	16.4	17.5	18.0	17.5
Pacific Islander	6.0	6.3	6.2	6.3	21.0	22.3	22.0	22.2
European	3.8	3.9	3.8	3.7	14.1	14.2	14.0	13.6
Asian	3.4	3.5	3.5	3.4	13.1	13.1	13.4	13.5

IDI, Integrated Data Infrastructure.

USA, Guam and Brazil had higher dementia prevalence than non-indigenous populations.[19] International literature suggests higher rates of dementia in indigenous populations are associated with lower education level and poorer health conditions.[20]

Our finding that Māori and Pacific Islanders have higher rates of dementia than Europeans and Asians aligns very well with a recently published study, which found Māori and Pacific Islanders have higher burden of dementia risk factors (such as lower education, hypertension, obesity and smoking) compared with European and Asian populations living in New Zealand.[21] The estimated population attributable fraction (ie, the potential reduction in dementia prevalence if a particular risk factor was eliminated) was highest in Māori (51.4%) and Pacific Islanders (50.8%), compared with Europeans (47.6%) and Asians (40.8%). The lower dementia risk and prevalence in Asian ethnic groups warrants further investigation and possible separation into Indian and Chinese subpopulations as they are likely to have different risk factor profiles.[22]

Implications for future research

Our case identification methods mean we are likely to be detecting only those dementia cases that were assessed in secondary/tertiary inpatient settings (and were also coded in clinical records), received an interRAI assessment and/or received an antidementia medication. In New Zealand, dementia is not coded in secondary/tertiary outpatient settings, only in inpatient settings. Individuals early on in their dementia/cognitive impairment care pathway and known only to primary care will not be identified from our case identification methods, due to a lack of access to primary care data in New Zealand. Likewise, many people living with dementia may not be identified by our case identification methods if they have never been diagnosed and are cared for by family at home, so have not had an interRAI assessment to access publicly funded home support services or aged residential care. In order to make an accurate estimation of *all* people with dementia living in the community, there needs to be a New Zealand community-based dementia prevalence study. This will be critical to (1) ascertain the true prevalence of dementia, (2) compare the characteristics of individuals with dementia accessing health services with those who are not and (3) test the diagnostic accuracy of using New Zealand administrative data to estimate dementia prevalence and incidence in the future.

Implications for policy

Our results (and international studies of ethnic differences in dementia prevalence) challenge the traditional methods of estimating national dementia prevalence for policy, and reinforces the notion that a 'one size fits all' approach is not appropriate.[23]

Dementia prevalence data are used in the estimation of economic impacts, including the costs of formal and informal care for people living with dementia, and to inform service planning. Māori, Pacific Islander and Asian families are generally inclusive, have a strong obligation to care for their elders at home and are reluctant to admit their loved ones to aged residential care.[24–28] Māori and Pacific Islanders present with dementia at a younger age than New Zealand Europeans[29] and may live at home cared for by their families for many years.[30 31] Given our findings of higher rates of dementia in Māori and Pacific Islanders, dedicated and culturally appropriate resources allocated to meet the formal and informal care needs of Māori and Pacific Islanders and families living with dementia are essential.

Strengths and limitations

This is the first study to report New Zealand dementia prevalence figures that approximate to what we would expect based on the previous estimations[1 2] and the population attributable fraction estimations in a recent New Zealand study.[21] This study is not a replacement for a fully powered community-based dementia prevalence study but a good proxy measure that we might be able to use if it is shown to be valid by future research.

There are several limitations relating to the use of routinely collected health data that need to be acknowledged. First, we have already mentioned the issues of underdiagnosis, undercoding of dementia and the lack of capture of dementia cases in primary care, which are likely to have contributed to an underestimate of dementia prevalence. However, the estimated dementia prevalence across the four study years is relatively stable, suggesting these seven health data sets are reliable for dementia case identification once a dementia diagnosis is recorded on them. In addition, the limitations of the data in this study applied equally across all ethnic groups; therefore, the differential prevalence between ethnic groups is likely to be a true difference, even if the total number of dementia cases was underestimated. Since a fully powered community-based dementia prevalence study is very resource intensive, there is a role for using routinely collected health data to monitor the prevalence and incidence of dementia over time. However, the methods would have to be validated against real-world epidemiological data to prove its accuracy. Second, we did not report dementia subtypes in this study because subtyping of dementia is likely to be inaccurate as most people have mixed pathologies[32] and we are more concerned with the overall prevalence of all-cause dementia. Third, stigma around dementia is often an issue for non-European populations in New Zealand, which could lead to inequitable access of services and, therefore, proportionally greater underdiagnosis of dementia in some ethnic groups.[25 28 33] There is also evidence that Māori, Pacific Islanders and Asians have lower rates of accessing dementia community care and aged residential care.[2] Therefore, they are less likely to be registered in the administrative health data sets included in this study. However, both Māori and Pacific Islanders have higher rates of diabetes and hypertension than European[21]; dementia diagnosis might

be more likely to be considered alongside their vascular risk factors in these ethnic groups. It has also been shown that the optimal cut-off of a cognitive screening tool was lower for Māori than non-Māori,[34] which potentially could result in cultural bias in assessment and misdiagnosis of dementia. Fourth, since Māori and Pacific Islanders present with dementia at a younger age than New Zealand Europeans,[29] a more in-depth examination of the interethnic differences in dementia prevalence in the under 60 population is likely needed.

CONCLUSION

This study provides valuable insights into dementia prevalence in New Zealand. It provides the strongest evidence so far that dementia prevalence is higher in Māori and Pacific Islanders, which is likely to be a result of the higher prevalence of dementia risk factors in these populations. As the study relied on administrative data, a carefully designed nationwide New Zealand dementia prevalence study is needed to validate the findings of this study (and, thus, provide evidence that using routinely collected health data is an effective method for future surveillance of dementia prevalence) but to also provide further evidence regarding the extent and impact of dementia on families and society.

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Appendix: ICD-9/ICD-10-AM/SOCRATES diagnostic codes and medication codes used to identify dementia cases

ICD-9 Code*	Description
2900	Senile dementia uncomplicated
2901	Presenile dementia
29010	Presenile dementia uncomplicated
29011	Presenile dementia with delirium
29012	Presenile dementia with delusional features
29013	Presenile dementia with depressive features
2902	Senile dementia with delusional or depressive features
29020	Senile dementia with delusional features
29021	Senile dementia with depressive features
2903	Senile dementia with delirium
2904	Arteriosclerotic dementia
29040	Arteriosclerotic dementia uncomplicated
29041	Arteriosclerotic dementia with delirium
29042	Arteriosclerotic dementia with delusional features
29043	Arteriosclerotic dementia depressive features
2912	Other alcoholic dementia
29282	Drug-induced dementia
2941	Dementia in conditions classified elsewhere
29410	Dementia in conditions classified elsewhere without behavioural disturbance
29411	Dementia in conditions classified elsewhere with behavioural disturbance
3310	Alzheimer's disease
2948	Other specified organic brain syndromes (chronic)
3311	Pick's disease
ICD-10-AM Code*	**Description**
F00	Dementia in Alzheimer's disease
F000	Dementia in Alzheimer's disease with early onset (G30.0+)
F001	Dementia in Alzheimer's disease with late onset (G30.1+)
F002	Dementia in Alzheimer's disease atypical or mixed type (G30.8+)
F009	Dementia in Alzheimer's disease unspecified (G30.9+)
F01	Vascular dementia
F010	Vascular dementia of acute onset
F011	Multi-infarct dementia of acute onset
F012	Subcortical vascular dementia
F013	Mixed cortical and subcortical vascular dementia
F018	Other vascular dementia
F019	Vascular dementia unspecified
F02	Dementia in other diseases classified elsewhere
F020	Dementia in Pick's diseases (G31.0+)
F021	Dementia in Creutzfeld-Jakob disease (A81.0+)

F022	Dementia in Huntington's diseases (G10+)
F023	Dementia in Parkinson's diseases (G20+)
F024	Dementia in human immunodeficiency virus [HIV] disease (B22.0+)
F028	Dementia in other specified diseases classified elsewhere
F03	Unspecified dementia
F051	Delirium superimposed on dementia
G30	Alzheimer's disease
G300	Alzheimer's disease with early onset
G301	Alzheimer's disease with late onset
G308	Other Alzheimer's disease
G309	Alzheimer's disease unspecified
G31	Other degenerative diseases of nervous system not elsewhere classified
G310	Circumscribed brain atrophy
G311	Senile degeneration of brain not elsewhere classified
G318	Other specified degenerative diseases of nervous system
G319	Degenerative diseases of nervous system unspecified
SOCRATES diagnostic codes	**Referral Diagnosis/health Condition**
140	Dementia
1401	Alzheimer's (including early onset)
1403	Korsakov's syndrome / alcohol-related dementia
1404	Pick's
1405	Vascular dementia
1499	Other dementia (specify)

* ICD-9 and ICD-10-AM codes: Mortality, Privately funded hospital discharges, Programme for the Integration of Mental Health Data (PRIMHD) and publicly funded hospital discharges

DIM_FORM_PACK_SUBSIDY_KEY	TG_NAME2	CHEMICAL_ID	CHEMICAL_NAME	FORMULATION_ID	BRAND_NAME	BASE_UNITS	PHARMACODE
77756	Treatments for Dementia	3923	Donepezil hydrochloride	392325	NULL	tab	NULL
77757	Treatments for Dementia	3923	Donepezil hydrochloride	392326	NULL	tab	NULL
77775	Treatments for Dementia	3923	Donepezil hydrochloride	392326	Donepezil-Rex	tab	2349140
77776	Treatments for Dementia	3923	Donepezil hydrochloride	392325	Donepezil-Rex	tab	2349159
81399	Treatments for Dementia	3923	Donepezil hydrochloride	392326	Donepezil-Rex	tab	2349140
814XX	Treatments for Dementia	3923	Donepezil hydrochloride	392325	Donepezil-Rex	tab	2349159

83473	Treatments for Dementia	3923	Donepezil hydrochloride	392326	Donepezil-Rex	tab	2349140
83474	Treatments for Dementia	3923	Donepezil hydrochloride	392325	Donepezil-Rex	tab	2349159
57263	Stimulants/ADHD Treatments for Dementia	3750	Rivastigmine	375026	NULL	cap	NULL
57264	Stimulants/ADHD Treatments for Dementia	3750	Rivastigmine	375025	NULL	cap	NULL
81297	Treatments for Dementia	4037	Rivastigmine	403725	NULL	patch	NULL
81298	Treatments for Dementia	4037	Rivastigmine	403726	NULL	patch	NULL
81325	Treatments for Dementia	4037	Rivastigmine	403726	Exelon	patch	2273608
81326	Treatments for Dementia	4037	Rivastigmine	403725	Exelon	patch	2273616
85739	Treatments for Dementia	4037	Rivastigmine	403725	Generic Partners	patch	2581493
85740	Treatments for Dementia	4037	Rivastigmine	403726	Generic Partners	patch	2581507
85927	Treatments for Dementia	4037	Rivastigmine	403726	Exelon	patch	2273608
85928	Treatments for Dementia	4037	Rivastigmine	403725	Exelon	patch	2273616