Do Māori and Pacific Peoples Living with Dementia in New Zealand Receive Equitable Long-Term Care Compared with New Zealand Europeans?



RESEARCH

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ABSTRACT

Context: Compared to Europeans, Maori and Pacific peoples living with dementia in the Counties Manukau District Health Board region are three times less likely to use Aged Residential Care (ARC).

Objectives: The aim of this study was to investigate whether reduced ARC utilisation by Maori and Pacific peoples living with dementia is equitably compensated by an increase in Home Based Support Service (HBSS).

Methods: Routinely collected sociodemographic and clinical data for people diagnosed with dementia at an NZ memory service (2013–2019) were linked with administrative ARC and HBSS invoicing data. Two-part models were used to estimate adjusted costs of HBSS utilisation or ARC placement.

Findings: six hundred fifty-seven people of European, Maori and Pacific ethnicity were included in the analysis. Compared to Europeans, both unadjusted and adjusted ARC costs per person-year were significantly lower for both Maori (–NZD\$3580, 95%CI: –\$6890, –\$140) and Pacific peoples (–NZD\$3110, 95%CI: –\$5590, –\$540) but HBSS cost per person-year was only higher for Pacific peoples (+NZD\$640, 95%CI: \$100, \$1180) and not Maori (+NZD\$180, 95%CI: –\$470, \$840). There was no significant difference in the combined HBSS and ARC cost per person-year for Maori (–NZD3460, 95%CI –7200, 280) or Pacific peoples (–NZD2490 95%CI –5090, 110).

Conclusions: Lower ARC utilisation amongst Maori and Pacific peoples living with dementia does not translate to an equitable increase in HBSS spend. The difference is likely to be compensated by care provided by unpaid family carers. Addressing the wider determinants of long-term care use in these populations and providing alternative culturally appropriate services must be prioritised to address this inequity in allocation of public sector resources.

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INTRODUCTION

As the Aotearoa New Zealand population ages and the proportion of the population aged 65 years and older increases, the prevalence of dementia is projected to more than double from an estimated 69,700 in 2020 to almost 170,000 by 2050 (Ma'u et al., 2021b). New Zealand's Maori and Pacific populations are ageing at a faster rate than the national average (Statistics New Zealand) and since age is the greatest risk factor for dementia, there will be a greater increase in the prevalence of dementia in these populations compared to people of European ethnicity (Ma'u et al., 2021b). This increase in dementia prevalence in may be further magnified by the differential prevalence of modifiable risk factors for dementia in Maori and Pacific populations (Ma'u et al., 2021a).

New Zealand is a bicultural country with a majority population of European descent (70.2%). Maori, the indigenous people of New Zealand, make up 16.5% of the population and Pacific peoples are a sizeable minority at 8.1%, two-thirds of whom were born in New Zealand. Non-European populations in New Zealand have higher levels of socioeconomic deprivation, carry a higher burden of many chronic diseases, and have poorer health outcomes compared to Europeans (Harris et al., 2006; Gurney et al., 2020). These inequities are perpetuated by the social determinants of health, individual and systemic racism (Harris et al., 2019), and structural variables such as the effects of migration (Lotoala et al., 2014) and colonisation (Reid et al., 2019).

The preference of most people with dementia is to be supported to remain living in their own homes (Smith, 2019). The New Zealand Health Ageing Strategy (Associate Minister of Health, 2016) emphasises bringing services closer to home for older adults and the Ministry of Health (MoH) funds home based support services (HBSS) to facilitate independent community living amongst older adults (Ministry of Health, 2022a). These services include assistance with personal care, such as dressing and showering, and home management, such as shopping and housework. As dementia progresses to more severe stages with declining cognition and functioning, the amount of care and supervision required increases. Routinely collected HBSS assessment data in NZ (interRAI New Zealand, 2017) reports over one third of people with dementia living at home require extensive assistance and are 4.5 times more likely than those without a diagnosis of dementia to require full time care from family or friends. The impact of caring for someone living with dementia is significant, with 44% of primary carers reporting distress or anger due to the demands of caring, and 55% reporting feeling overwhelmed by the person with dementia's support needs (interRAI New Zealand, 2017) People caring for individuals with

dementia are also over twice as likely (37% versus 18%) to report feeling unable to continue in caring activities, compared to those caring for someone without dementia (interRAI New Zealand, 2017). These findings are in line with international studies describing the significant mental and physical health impact on carers of people with dementia (Gilhooly et al., 2016).

Access to funded disability support services in New Zealand is overseen by Needs Assessment and Service Coordination (NASC) organisations. NASC organisations are contracted to facilitate an assessment of an individuals' needs, and coordinate access to appropriate services (Ministry of Health, 2022b). Assessments utilise interRAI, (interRAI New Zealand) a standardised and comprehensive clinical assessment designed to understand the clinical and social support needs of an individual, and are repeated as needs change. These assessments are then used to inform the development of a personalised care plan and include recommendations on whether HBSS and/or entry into an aged residential care (ARC) facility is required to adequately meet their needs.

The amount of funded HBSS in New Zealand is limited and does not usually cover overnight support, (Ministry of Health, 2022a) so additional care is often provided and/or funded by families or friends. Unpaid care is conservatively estimated at over 1 million hours per week for people living with dementia in New Zealand (Ma'u E, 2021b). When an individual's care needs exceed the support needed (both paid and unpaid) to be safely cared for at home, admission into an aged residential care (ARC) facility is often recommended. However, ARC admission may not be an acceptable option for many families, particularly for those from a non-European or non-English speaking background (Cheung et al., 2022; Krishnamurthi et al., 2022). Thus, even when individuals meet NASC criteria for ARC, they and/or their families may choose to remain living in the community.

In a longitudinal study of a cohort of 657 consecutive newly diagnosed dementia patients in New Zealand, Cullum et al. (2021) showed that those who were older, lived alone, and diagnosed with a more severe dementia on presentation were more likely to enter an ARC facility. However, Maori and Pacific Peoples were over three times less likely to be admitted to an ARC facility during the follow up period compared with NZ Europeans, and this difference remained after adjustment for sociodemographic and clinical differences. This suggests that reduced ARC uptake in Maori and Pacific populations may be due to socio-cultural differences in the acceptability of ARC as an option or the perceived appropriateness of current ARC facilities to meet the needs of people living with dementia. This was confirmed in recent qualitative research in Maori (Dudley et al., 2019) and Pacific (Fakahau, Faeamani & Maka, 2019) communities in New Zealand.

The differences in long-term care expenditure across ethnic groups were recently quantified by the New Zealand Dementia Economic Impact Report 2020 (Ma'u E, 2021b). The DEIR 2020 showed the annual spend on ARC, averaged across all people living with dementia in each ethnic group, was lower in Maori (NZD\$12,600 per person) and Pacific peoples (NZD\$12,450 per person) compared to Europeans (NZD\$17,820 per person) and the average annual spend on community care was NZD\$2,410 per person in Maori, NZD\$2,680 per person in Pacific peoples and NZD\$1,920 per person in Europeans. This suggests that the lower utilisation of ARC by Maori and Pacific peoples is not compensated for by an equitable increase in community care, with the combined annual spend of ARC and community care per person with dementia almost 25% less for Maori and Pacific peoples. This difference highlights an inequity in the allocation of resources for dementia services, with the differential burden and cost of care therefore borne by the individual, their families, and carers in the form of unpaid care. However, these estimates were based on summary national data where the accuracy of dementia diagnosis might be called into question, and which did not control for potential confounding by sociodemographic or clinical differences between ethnic groups such as age, living situation and severity of dementia.

The aim of this current study is to quantify the costs associated with ARC placement in a previously identified cohort of Maori, Pacific and European peoples with well characterised newly diagnosed dementia (Cullum et al., 2021), adjusting for potential confounding factors associated with use of long-term care. The second aim of this study is to investigate whether the differential costs associated with a lower proportion of Maori and Pacific peoples entering ARC is equitably compensated for by an equivalent increase in HBSS after controlling for group differences in sociodemographic and clinical factors.

METHODS ETHICS APPROVAL

The NZ Health and Disability Ethics Committee (HDEC) approved this project, reference 17/NTB/191.

SETTINGS AND PARTICIPANTS

Routinely collected data from all referrals to the Counties Manukau District Health Board (CMDHB) memory service who received a new diagnosis of dementia between 14 June 2013 and 14 December 2019 were included in the analysis. CMDHB is one of 20 District Health Boards in New Zealand, with a 65+ population of approximately 50,000 people. CMDHB serves a diverse ethnic population with the proportion of Maori population similar to that of the national population (16% versus 15%) and a significantly higher proportion of Pacific peoples (22% versus 7%) (Lees & Winnard, 2021).

The CMDHB memory service is a non-acute specialist service for the assessment and management of cognitive impairment. Referrals are received from both primary and secondary healthcare services for any individual, of any age, living in the community with a primary complaint of objective or subjective cognitive impairment. ARC residents are not assessed by this service.

DATA COLLECTION BASELINE DATA

Baseline demographic data were extracted for all new referrals including age, gender, ethnicity, and whether they lived alone. Clinical characteristics were also extracted, including dementia subtype, dementia severity, and chronic physical comorbidity using the Cumulative Illness Rating Scale-Geriatric (CIRS-G) Index (Miller et al., 1992). Diagnoses, subtypes, and severity of dementia were identified by consensus at the weekly memory service multidisciplinary team meetings, using clinical and neuroradiological findings. Diagnoses were made using the DSM-IV criteria (American Psychiatric Association, 1994) and severity of dementia informed by the Clinical Dementia Rating (CDR) (Morris, 1997).

For the purpose of this analysis, dementia severity was rated as 'mild' (CDR score is less than or equal to one) or 'moderate to severe' (CDR score is two or more). The CIRS-G is a rating scale of physical co-morbidity designed for use in older patients, allowing the calculation of a score based on the number and severity of co-morbid illness present in an individual. Comorbidity was scored from the automated medical history generated in the referral letter. Higher CIRS-G scores indicate a higher burden of illness. The CIRS-G index for each patient was determined through dividing the overall score by the number of categories of CIRS-G. CIRS-G indices were then dichotomised into scores <1.5, and \geq 1.5. The details of data collection have been described previously (Cullum et al., 2021).

OUTCOME DATA

Duration of follow up

Study participants were prospectively and consecutively recruited over a six year period and were followed up for varying durations of time. The events of interest in the time-to-event analysis were date of first receipt of HBSS and date of entry into ARC. Time to first receipt of HBSS or first permanent ARC utilisation were calculated as the number of days from time of referral to the memory service to the date of the first HBSS or ARC invoice respectively.

For those that did not utilise either HBSS or ARC, the censoring date was the last date of any registered contact with CMDHB, or the date of death if that occurred before the end of the follow-up period. The censoring date for the HBSS analysis also included the date of entry into ARC as HBSS is not required once an individual enters residential care. The number of HBSS hours and ARC days were divided by the total follow up time (in years) to give the average quantity of each per person-year.

Home Based Support Services (HBSS)

Following a MoH mandated NASC assessment (Ministry of Health, 2022a), people living with dementia may be eligible for HBSS to provide assistance with personal care (e.g. showering) and/or household management (e.g. housework). HBSS are fully funded for eligible individuals, with the CMDHB invoice data capturing all cost information on funded HBSS. This provided information on the number of HBSS hours received per week and the date HBSS commenced. Assistance with personal cares is fully subsidised but eligibility for assistance with household management is means tested, so invoicing data will not capture those who required household management but funded it through private means. As we are only concerned with the equitable distribution of public sector funding, we did not estimate the cost of privately funded care. The date of the first invoice was taken as the date of first receipt of HBSS.

Aged Residential Care (ARC)

The NASC assessment may also identify greater needs and recommend entry into ARC. There are four levels of ARC in New Zealand: rest home level of care; hospital level of care which provides care for those with greater physical care needs; dementia level of care which is utilised for people with dementia who need a secure facility and/or present with significant behavioural and psychological symptoms; psychogeriatric care which is reserved for people with complex mental, cognitive, or physical needs (Ministry of Health, 2022c). In this cohort, most individuals entering ARC required hospital level care (61.6%) followed by dementia level care (18.6%) and rest home level care (17%). Only 2.8% required psychogeriatric care. All residents at the level of hospital, dementia, and psychogeriatric care, but only 70% of those in rest home level care, are eligible for a subsidy from CMDHB. Therefore, the CMDHB invoicing data captures over 90% of all ARC admissions, only missing the 30% who did not receive any subsidy at rest home level of care (Cullum et al., 2021) (i.e. approximately 7% of all ARC admissions). The date of the first invoice was taken as the date of admission to ARC.

Costs

The unit costs for HBSS and ARC represent an average national cost in New Zealand Dollars*, as cost varies across regions and levels of care. In 2020 the average cost per day for ARC was NZD\$160 for rest home, NZD\$257 for hospital, NZD\$216 for dementia, and NZD\$287 for psychogeriatric level of care (NZACA, 2020). For this analysis, the national bed-weighted average cost of NZD\$207 per day across all four levels or care was used (Ma'u et al., 2021b). For HBSS, the average hourly rate of a carer in 2020 was NZD\$22.60 per hour (Ministry of Health, 2022d), marginally higher than the 2020 legislated minimum wage of NZD\$20 per hour (Ministry of Business, Innovation, and Employment, 2022). The total number of days of ARC and the total number of hours of HBSS for each person were obtained from the CMDHB invoicing data for each person in receipt of those services, that is each person's total cost was calculated by multiplying the ARC days by NZD\$207 and total hours of HBBS by NZD\$22.60, and these were summed to provide the total cost of each service across the whole cohort.

*USD\$1.0 = average of NZD\$1.4 in 2016–2021 (Reserve Bank of New Zealand, 2022).

DATA LINKAGE

Using the National Health Index (NHI) identifier, demographic and clinical data of the 657 individuals with a new diagnosis of dementia identified in the memory service cohort were linked to the ARC and HBSS invoicing data, as well as mortality data from MoH held by CMDHB, to create a combined dataset. After data linkage, the resulting dataset was de-identified for analysis.

DATA ANALYSIS

Statistical analysis was carried out using STATA 16.1 (StataCorp, 2019).

DESCRIPTIVE STATISTICS

Continuous data are summarised by means and standard deviations (SD) and proportions expressed as percentages. For continuous variables, t-tests and ANOVA were used as appropriate for comparisons of groups. For categorical variables, Chi-square tests of independence were used to compare groups.

TWO-PART MODEL ANALYSIS

Since a person living with dementia may utilise both HBSS and ARC on their care pathway, the costs associated with each outcome were calculated separately using twopart models. Two-part models are commonly used to model healthcare costs because a large proportion of individuals do not incur any costs in a given period of time (Belotti et al., 2015). As such, the first part of the model estimates the probability of HBSS utilisation or ARC admission while the second part estimates the costs for those who actually received HBSS and/or ARC service. This allows an inference of overall cost conditional on both the probability of service uptake and associated costs if the service is utilised.

The *twopm* command was used in STATA to run the two-part model. In part 1, logistic regression was used to model the probability of receiving HBSS or ARC. In part 2, the costs associated with HBSS or ARC were modelled using a generalised linear model (GLM) with loglink and gamma family distribution. The marginals command in STATA was used to obtain the marginal effects for each parameter.

RESULTS

Figure 1 illustrates the care pathways of the cohort and the proportion of patients receiving HBSS, ARC, or both. Almost half (47.3%) of all patients did not receive any formal care, with Maori (55.8%, p < 0.001) and Pacific peoples (58.7%, p < .001) more likely to receive no formal care compared to Europeans (36.1%). Compared to Europeans (44,5%), Pacific peoples (33.8%, p = 0.009) but not Maori (36.0%, p = 0.159) were less likely to receive HBSS. Compared to Europeans (19.4%), both Maori (8.2%, p = 0.013) and Pacific peoples (7.5%, p < 0.001) were less likely to enter ARC directly without receiving HBSS first. If HBSS was received, Europeans (42.2%) were more likely to enter ARC compared to Maori (25.8%, p = 0.013) or Pacific peoples (24.7%, p = 0.007). The overall proportion of patients entering ARC, with or without prior HBSS, was significantly lower for both Maori (17.4%, p < 0.001) and Pacific peoples (15.9%, p < 0.001) when compared to Europeans (38.2%).

Table 1 describes the baseline demographics, clinical characteristics, and HBSS/ARC utilisation of the 657 patients in the cohort, with a mean follow up duration of 829 days. There were 319 Europeans, 86 Maori and 252 Pacific peoples newly diagnosed with dementia during the study period. The mean age was 76.1 years, 56% were female, and 21% lived alone. Most of the cohort had mild dementia (62%) with the remaining 38% diagnosed with moderate-severe dementia, and 73% of the cohort had a CIRS-G index \geq 1.5 (indicating more severe comorbidities). Comparing across the ethnic groups, there were significant differences in age at diagnosis (European 80.1 years, Maori 72.7 years, Pacific peoples 75.5 years; p < 0.0001), proportion living alone (European 31%, Maori 26%, Pacific peoples 8%; p < 0.0001), CIRS-G index ≥1.5 (European 69%, Maori 74%, Pacific peoples 77% years; p = .014), and proportion of people with moderate-severe dementia at diagnosis (European 31%, Maori 33%, Pacific peoples 48%; p < 0.0001).

HBSS UTILISATION

HBSS were received by 255 (39%) people living with dementia at least once during follow up. Compared to Europeans (45%), HBSS utilisation was less in Pacific peoples (33%, p = 0.007) and in Maori (34%, p = 0.072). Across the whole cohort, the mean number of HBSS hours received was 65.6 hours per person-year (hrs/py). Compared to Europeans (53.7 hrs/py), Pacific peoples (82.0 hrs/py, p = 0.022) but not Maori (61.8 hrs/py, p = 0.583) received more HBSS hours per person year.

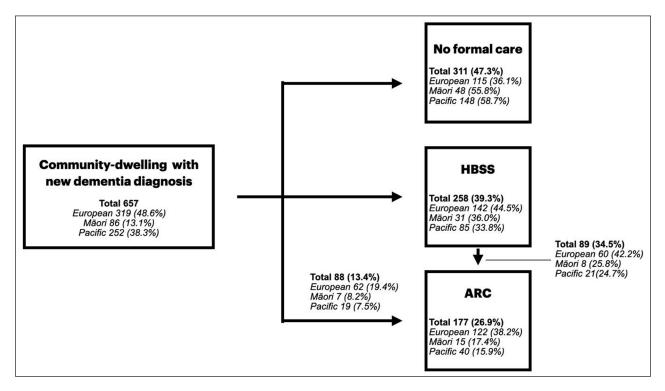


Figure 1 Flow diagram outlining the proportion of patients receiving HBSS and/or ARC following diagnosis of dementia.

		TOTAL N = 657	EUROPEAN N = 319	MĀORI N = 86	PACIFIC PEOPLES N = 252	SIG.
Age (years)	Mean (SD)	76.1 (8.0)	80.1 (7.3)	72.7 (7.9)	75.5 (7.6)	<0.0001
Gender (%)	Female	369 (56%)	171 (54%)	54 (63%)	144 (57%)	0.289
	Male	288 (44%)	148 (46%)	32 (37%)	108 (43%)	
Living alone (%)		141 (21%)	100 (31%)	22 (26%)	19 (8%)	<0.0001
CIRS-G index*	<1.5 (%)	177 (27%)	98 (31%)	22 (26%)	57 (23%)	0.014
	≥1.5 (%)	480 (73%)	221 (69%)	64 (74%)	195 (77%)	
Dementia Severity (%)	Mild	408 (62%)	219 (69%)	58 (67%)	131 (52%)	<0.0001
	Moderate-severe	249 (38%)	100 (31%)	28 (33%)	121 (48%)	
Home-Based Support Service	es (HBSS)					
HBSS received (%)		258 (39%)	142 (45%)	31 (34%)	85 (33%)	0.026
HBSS hours per person-year (unadjusted)	Mean (SD)	65.6 (150.3)	53.7 (102.1)	61.8 (175.6)	82.0 (186.7)	0.081
Aged Residential Care (ARC)						
ARC Placement (%)		177 (27%)	122 (38%)	15 (17%)	40 (16%)	<0.0001
ARC days per person-year (unadjusted)	Mean (SD)	29.5 (73.9)	37.5 (77.7)	20.2 (66.3)	22.5 (70.5)	0.025

Table 1 Baseline demographics, clinical characteristics, and HBSS or ARC utilisation, by ethnicity.

* CIRS-G index – Cumulative Illness Rating Scale-Geriatric index.

This indicates that, although fewer Pacific people utilise HBSS overall, those that do receive significantly more hours.

TWO-PART MODEL

Table 2 presents the two-part model analysis adjusting for age, gender, living situation, dementia severity, and CIRS-G index. Part 1 of the model compares the probability of ever receiving HBSS between the ethnic groups. Compared to Europeans, there was no significant difference in the adjusted odds of HBSS utilisation for Maori (OR 1.06, p = 0.839) or Pacific peoples (OR 0.89, p= 0.530). Part 2 of the model compares the mean HBSS hrs/py received in those that did utilise HBSS. Compared to Europeans, Pacific peoples received 2.32 times (p < 0.001) and Maori received 1.46 times (p = 0.081) the number of hours of HBSS per person-year. Combining parts 1 and 2 of the model shows that compared to Europeans (46.4 hrs/py), Pacific peoples (101.2 hrs/py, p = 0.001) but not Maori (69.7 hrs/py, p = 0.165) received significantly more HBSS after adjusting for demographic and clinical variables.

ARC utilisation

176 people (27%) entered ARC during the follow up period. Compared to Europeans (38.2%), a lower proportion of both Pacific peoples (15.9%, p < 0.0001) and Maori (17.4%, p < 0.001) entered ARC during the follow up period. Across the whole cohort, the mean unadjusted ARC admission duration was 29.5 days/py.

Compared to Europeans (37.5 days/py), the mean ARC admission duration per person-year was shorter for Pacific peoples (22.5 days/py; p = 0.018) and for Maori (20.2 days/py; p = 0.06).

The results of the two-part model analysis after adjustment for age, gender, living situation, dementia severity, and CIRS-G index are presented in Table 2. Part 1 of the model compares the probability of ever entering ARC between the ethnic groups. Compared to Europeans, both Māori (OR 0.38, p = 0.006) and Pacific peoples (OR 0.31, p < 0.001) were *less* likely to utilise ARC. Part 2 of the model compares the mean ARC duration for those that *did* utilise ARC, and shows that, compared to Europeans, Pacific peoples utilised 1.45 times (p = 0.031) more ARC days/py. However, when parts 1 and 2 of the model are combined together it shows that, overall, both Māori (18.8 days/py, p = 0.018) and Pacific peoples 22.8 days/py, p = 0.034) utilise less ARC days/py compared to Europeans (37.3 days/py).

COST ANALYSIS: HBSS AND ARC

Table 3 applies the unit costs of an ARC bed-day or HBSS hour of care to the findings in Table 2 and details the total costs per person-year associated with HBSS or ARC use, both unadjusted and adjusted following multivariate regression analysis using the two-part model. The combined cost of both HBSS and ARC is then presented at the end of the table.

Compared to Europeans (NZD\$1210; 95%CI \$960, \$1470), the mean additional HBSS cost per person-year

HBSS (REF EUR	OPEAN)			
	PROBABILITY OF HBSS UTILISATION (PART 1)	HBSS HOURS/PERSON-YEAR IF UTILISED (PART 2)	ADJUSTED HOURS/PERSON-YEAR OF HBS (PARTS 1 AND 2 COMBINED)	
	OR (95%CI)	EXP(B) (95%CI)	MEAN (95%CI)	
European	1	1	46.4 (36.1-56.7)	
Māori	1.07 (0.62, 1.84)	1.46 (0.96, 2.25)	69.7 (38.5, 100.8	
Pacific peoples	0.89 (0.60, 1.31)	2.32 (1.69, 3.20)**	101.2(71.1, 131.4)*	
ARC (REF EURC	OPEAN)			
	PROBABILITY OF ARC ADMISSION (PART 1)	ARC DAYS/PERSON-YEAR IF UTILISED (PART 2)	ADJUSTED DAYS/PERSON-YEAR IN ARC (PARTS 1 AND 2 COMBINED)	
	OR (95%CI)	EXP(B) (95%CI)	MEAN (95%CI)	
European	1	1	37.3 (28.6-46.1)	
Māori	0.38 (0.2, 0.74)*	1.01 (0.6, 1.6)	18.8 (6.5, 31.12)*	
Pacific peoples	0.31 (0.19, 0.49)**	1.45 (1.03, 2.04)*	22.8 (13.0, 32.6)*	

Table 2 Two-part model estimates, by ethnicity, for probability of HBSS and ARC uptake and amount of utilisation per person-year after adjusting for age, gender, living situation, dementia severity, and CIRS-G index.

* p < .05 ** p < .001.

Exp(b) is the ratio of the expected hours of HBSS or days of ARC received and is the percentage change in the estimated hours HBSS or days of ARC received by Māori or Pacific peoples relative to Europeans.

		EUROPEAN N = 319	MĀORI N = 86	PACIFIC PEOPLES N = 252
Home based support service	es (HBSS) cost per p	erson-year^		
Unadjusted	NZD (95% CI)	1210 (960, 1470)	1390 (550, 2250)	1850 (1330, 2380)
Unadjusted net difference	NZD (95% CI)		+180 (-470, +840)	+640 (100, 1180)*
Adjusted**	NZD (95% CI)	1050 (820-1280)	1580 (870, 2280)	2290 (1610, 2970)*
Adjusted net difference**	NZD (95% CI)		+530 (-220, +1270)	+1240 (510, 1970)*
Aged Residential Care (ARC)	cost per person-ye	ar#		
Unadjusted	NZD (95% CI)	7760 (6000, 9540)	4180 (1220, 7120)	4660 (2860, 6480)*
Unadjusted net difference	NZD (95% CI)		-3580 (-6890, -140)*	-3100 (-5590, -540)*
Adjusted **	NZD (95% CI)	7720 (5920, 9540)	3890 (1350, 6480)*	4720 (2690, 6750)*
Adjusted net difference**	NZD (95% CI)		-3830 (-7020, -660)*	-3000 (-5800, -230)*
Total cost per person-year⁺				
Unadjusted	NZD (95% CI)	9030 (7230, 10820)	5570 (2390, 8740)	6540 (4640, 8430)
Unadjusted net difference	NZD (95% CI)		-3460 (-7200, 280)	-2490 (-5090, 110)
Adjusted **	NZD (95% CI)	8750 (6880, 10620)	5570 (2960, 8190)	7050 (4930, 9180)
Adjusted net difference**	NZD (95% CI)		-3180 (-6430, 70)	-1700 (-4570, 1180)

Table 3 Unadjusted and adjusted (using two-part models) cost estimates by ethnicity, for HBSS hours and ARC days per person-year. * p < .05.

** Calculated using two-part models adjusting for age, gender, living situation, dementia severity, and Cumulative Illness Rating Scale-Geriatric (CIRS-G) index.

[^] Calculated as the product of the mean number of HBSS hours/PY received and the average hourly rate of a carer (NZD\$22.60).

[#] Calculated as the product of the mean number of ARC days/PY and the national bed weighted cost of an ARC bed-day (NZD\$207). ⁺ Calculated as the sum of the unadjusted and adjusted HBSS and ARC costs respectively.

was significantly higher for Pacific peoples (+NZD\$640; 95% CI \$100, \$1180) but not for Maori (+NZD\$180;

95%CI -\$470, \$840), and these differences remained after adjusting for demographic and clinical variables.

Compared to Europeans (NZD\$7760, 95% CI \$6000, \$9540), the mean ARC cost per person-year was lower for both Maori (–NZD\$3580 95% CI –\$6890, –\$140) and Pacific peoples (–NZD\$3100; 95% CI –\$5590, –\$540), and these differences remained after adjusting for demographic and clinical variables.

Compared to Europeans (NZD9030; 95%CI 7230, 10280), there was no significant difference in the total HBSS and ARC cost for Maori (-NZD3460, 95%CI -7200, 280) or Pacific peoples (-NZD2490 95%CI -5090, 110). There were no significant differences between the ethnic groups after adjustment for demographic and clinical variables.

DISCUSSION

To our knowledge, this is the first New Zealand study to quantify the costs associated with long-term care utilisation (ARC and HBSS) in a cohort of individuals with a new diagnosis of dementia. Cullum et al. (2021) have already demonstrated that Maori and Pacific peoples with dementia living in CMDHB are over three times less likely to enter ARC facilities, and that this reduced uptake remained even after controlling for sociodemographic factors and clinical factors such as dementia severity and physical comorbidities. Using the same cohort, and after adjusting for demographic and clinical factors, this study has shown that Maori and Pacific peoples with dementia are utilising an adjusted 18.5 and 14.5 fewer ARC days/ py respectively and this difference is not explained by demographic or clinical differences. This translates to a reduced public sector spend on ARC in Maori and Pacific peoples of NZD\$3830/py and \$3000/py respectively, compared to Europeans.

Despite the lower probability of utilising ARC and fewer ARC admission days/py, Maori and Pacific people were not more likely to utilise HBSS after adjusting for demographic and clinical factors, presumably due to the confounding effects of younger age at presentation and a lower likelihood of living alone. In the cases when HBSS was utilised, Pacific peoples received over twice the number of HBSS hrs/py (101.2 hrs/py) compared to Europeans (46.4 hrs/py), and Maori almost 50% more (69.7 hrs/py). When applied across the whole cohort this means Maori received an adjusted mean of 23.3 hours and Pacific people 54.8 hours more HBSS hrs/py compared to Europeans. This translates to an additional spend of NZD\$530/py for Maori and NZD\$1240/py for Pacific peoples (Europeans received an adjusted spend of NZD\$1050/py on HBSS).

The increased cost associated with higher HBSS hours received by Maori and Pacific peoples compared to Europeans does not compensate for the lower entry into, and therefore costs, associated with ARC. In this

study, the combined total of HBSS and ARC costs was lower for both Maori (-NZD\$3460, p = .055) and Pacific peoples (-NZD\$2490, p = .247) but these differences were not statistically significant. It is likely the relatively small sample size for Maori, as well as the low proportion of Maori and Pacific peoples entering ARC resulted in the study being underpowered to detect statistically significant differences. Overall, these findings suggest the reduced costs associated with lower ARC entry for Maori and Pacific peoples is not compensated for by an equivalent increase in the spend on HBSS and are similar to those reported for national data in DEIR 2020 (Ma'u et. al, 2021b). This leads us to conclude that there is inequitable distribution of public sector funding for dementia across ethnic groups in CMDHB, even after adjustment for potential confounding factors.

Our findings are comparable to international studies examining the cost of dementia in residential and/or community settings. Knapp et al. (2016) analysed medical records of community dwelling people with dementia on a register in south east London to determine predictors of ARC admission amongst different ethnic groups within a six month period. They showed that people of Caribbean/African and mixed/unknown ethnicity, but not East/South Asian, were less likely to enter ARC compared to White people after adjustment for sociodemographic and clinical factors.

Most people living with dementia in the community require additional unpaid care (Ma'u et al., 2021b) and these costs need to be accounted for. Henderson et al. (2019) analysed service use, costs of care, and unpaid care for people with mild-moderate dementia in the UK IDEAL cohort study over a three month period. They found that the cost of unpaid care accounted for three quarters of total costs. Living situation significantly influenced unpaid care costs, with those living alone 77% less likely to receive unpaid care compared to those living with others and therefore more likely to need paid care. A Finnish study (Pitkala et al., 2021) on unpaid dementia care costs (including the costs associated with lost productivity) demonstrated that individuals with dementia who lived alone incurred almost three times the public sector costs compared to those living with others. They also showed that if unpaid care costs were included, the costs of community care associated with those with at least a moderate dementia exceeded the average cost of residential care. In our cohort, Pacific peoples were significantly less likely to live alone compared to Europeans, and were likely to have more severe dementia, so will likely incur higher unpaid care costs given their reduced rates of ARC use.

In this study we have demonstrated that while Maori and Pacific peoples were three times less likely to enter ARC compared to Europeans, there was no compensatory increase in their utilisation of HBSS.

Indeed there is evidence from qualitative studies that Maori have a strong sense of filial duty to care for their loved ones at home (Dudley et al., 2019; Holdaway et al., 2021) and Pacific peoples have concerns about the cultural appropriateness and quality of care available in ARC facilities (Fakahau, Faeamani & Maka, 2019). Overall, the poor acceptability and subsequent reduced uptake of ARC results in a significantly higher proportion of Maori and Pacific peoples newly diagnosed with dementia requiring management in the community. Despite evidence from the previous three Dementia Economic Impact Reports (Deloitte Access Economics, 2012; Deloitte Access Economics, 2017; Ma'u et al., 2021b) of the significant cost savings associated with delaying entry into residential care, the current funding model for community care means the ceiling of funding for HBSS is significantly less than the costs of an ARC bed day.

Inequities within the New Zealand health system have been shown to play a role in reduced access and utilisation of health care services (Sheridan et al., 2011), and there is little evidence this inequity is being addressed (Goodyear-Smith et al., 2019). Our findings of the significantly lower costs associated with ARC utilisation for Maori and Pacifc peoples is in line with both these NZ findings as well as international studies on the experiences, and health care access, of minority ethnic groups with dementia. Mukadam et al. (2011) systematically reviewed the literature on presentation of minority ethnic groups to specialist dementia services and identified significant barriers to early diagnosis and intervention including beliefs around symptom aetiology, stigma, and a lack of understanding or awareness of available services. Another systematic review of barriers and facilitators in accessing dementia care by ethnic minority groups by Kenning et al. (2017) identified service level barriers including access to diagnosis and management as well as health professional assumptions about carer preferences. This review also identified an overarching influence of cultural habitus - the impact of cultural norms on beliefs and behaviour - manifesting as stigma around dementia and a mistrust of the health system that were further reinforced by perceptions of institutional racism.

Our finding that Maori and Pacific peoples are less likely to be admitted to ARC but not more likely to receive HBSS compared to Europeans has also been shown in the international literature, Cooper et al. (2010) systematically reviewed the literature comparing dementia service access between minority- and nonminority ethnic groups. They found evidence that minority ethnic groups in the US presented with more severe cognitive impairment and were less likely to be prescribed anti-dementia medication or be admitted to a long-term care facility. However, they did not differ in their use of community services. Maori and Pacific 230

peoples carry a higher burden of many chronic diseases and experience a disproportionate impact on their quality of life (Gurney et al., 2020). Despite this they are consistently shown to have reduced access to care and poorer health outcomes for many chronic conditions (Harris et al., 2019; Thompson et al., 2022). A systematic review of access to healthcare services in older minority ethnic groups with dementia (Co et al., 2021) identified more frequent hospitalisations in African American/Black ethnic groups in the U.S., positing differential health seeking preferences as well as reduced access to routine dementia care were contributing factors.

STRENGTHS AND LIMITATIONS

The population served by CMDHB is ethnically diverse with a similar population of Maori and a higher population of Pacific peoples compared to the national average. We have adequate representation of these ethnic groups attending the memory service to draw some meaningful conclusions from the findings. While Asians are the second largest ethnic group in the CMDHB catchment, they were not included in the analysis because, at the time of the study, the CMDHB memory service did not cover the catchment areas where most Asians reside and the sample size was therefore small. It is likely ARC utilisation in Asians is also lower than for Europeans as the DEIR 2020 (Ma'u E, 2021b) reports an even lower annual spend on ARC per person with dementia for Asians than for Maori and Pacific peoples. Furthermore, recent qualitative research in Chinese (Cheung et al., 2022) and Indian (Krishnamurthi et al., 2022) people with dementia and their families suggests similar cultural issues around attitudes towards ARC as for Maori and Pacific peoples. All assessments occurred in the memory service and followed a standardised assessment process. This means sociodemographic and clinical variables of interest were comprehensively captured and the multidisciplinary diagnostic process was robust. A limitation of using a specialist service cohort is selection bias in those who are referred so may not capture people with more healthcare access barriers, for example, those with lower health literacy or other social determinants of health. A limitation of this routinely collected data is that it did not include measures of ADL or iADL abilities which are an important measure of support requirements and therefore service utilisation. In this study we have used dementia severity as a proxy for ADL/iADL abilities but acknowledge the limitations associated with taking this approach.

Invoicing data is an accurate reflection of care provided. All levels of care, except rest home level, receive at least a partial subsidy from the state so most people entering care are captured. A limitation is that approximately 7% of all ARC placements will not have qualified for the residential care subsidy due to being from higher income/ households so were missed by the invoicing data (Ministry of Health, 2022c). However, these individuals are more likely to have been European (Rashbrooke et al., 2021) so their inclusion will have magnified the differences compared to Maori and Pacific peoples. There is also the possibility that some individuals did not initially qualify for the ARC subsidy but subsequently did when their assets reduced to sufficiently to meet the financial subsidy threshold or they were reassessed at a higher level of care that qualified for a partial subsidy. This means the date of first invoice will not have captured this initial period of time and subsequently undercount the number of days they were in ARC. As with those who never received a subsidy, these individuals were also more likely to be European (Rashbrooke et al., 2021), so the inclusion of these additional ARC days will also likely accentuate the differences with Maori and Pacific peoples. For HBSS, assistance with personal cares is fully subsidised but eligibility for assistance with household management is means tested, so invoicing data will not capture those who required household management but funded it privately. As with the ARC subsidy, this is more likely to have impacted Europeans and therefore reduce the observed differences in HBSS provision between the groups.

IMPLICATIONS FOR FUTURE RESEARCH/ POLICY

In line with the findings of the DEIR 2020 (Ma'u E, 2021b), this study demonstrates that reduced entry into ARC, and therefore spend, for Maori and Pacific peoples is not compensated for by an equivalent increase in HBSS uptake, and this is not due to sociodemographic and clinical differences. The broader socio-cultural and health system factors accounting for these differences in current dementia service utilisation is required to better understand and address the identified inequity for Maori and Pacific peoples. For example, concerns identified around the cultural appropriateness and acceptability of ARC may also apply to the acceptability and uptake of HBSS by Maori (Dudley et al., 2019) and Pacific peoples (Fakahau Faeaman & Maka, 2019).

This study has also demonstrated that, while there are limitations to analyses using routinely collected administrative data, this is a highly cost-effective method of exploring health inequities given the cost and resource intensive nature of epidemiological studies.

CONCLUSIONS & RECOMMENDATIONS

Our findings indicate that, despite more severe dementia on presentation and lower rates of entry into ARC, the proportion of Maori and Pacific people utilising HBSS is lower compared to Europeans. Furthermore, the cost savings associated with lower ARC utilisation by Maori and Pacific people do not translate to an equitable increase in HBSS allocation. The implications of these findings are significant. If these costs are not being met by the state, this means they are being differentially borne by Maori and Pacific peoples and their families. This burden of care is further magnified, occurring as it does within population groups where the median income is less than the national average and family finances are more likely to be stretched. Further research is needed to explore the underlying reasons for lower uptake and utilisation of both HBSS and ARC in Maori and Pacific people. This can then inform the development of appropriate and acceptable services to improve access to, and uptake of, these services.

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COMPETING INTERESTS

The authors have no competing interests to declare.

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