



# The needs of Pacific families affected by age-related cognitive impairment in New Zealand: interviews with providers from health-care organisations

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## ABSTRACT

**INTRODUCTION:** Pacific populations in New Zealand are aging, but little is known in the health-care environment about their experiences with cognitive impairment.

**AIM:** The aim was to explore the needs of Pacific peoples affected by age-related cognitive decline from the perspectives of health-care providers.

**METHODS:** Six health-care service providers from organisations focused on Pacific patients were interviewed to determine services available to aged Pacific peoples, access, and whether they met Pacific people's needs.

**RESULTS:** Three areas of concern were identified by all participants: access to services; getting a diagnosis; and communication and language. Many experienced a lack of information and poor access to services. Diagnosis of cognitive impairment was frequently made difficult by inconsistent access to general practitioners in lower socio-economic areas. Communication was hindered by poor access to information in Pacific languages.

**DISCUSSION:** Common themes noted by all participating health-care providers indicated the needs of aged Pacific people experiencing cognitive decline were often not being met.

**KEYWORDS:** Dementia; cognitive impairment; Pacific peoples; access to services; equity; Health Services Research.

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## Introduction

The name 'Pacific peoples' is a term of convenience, used to encompass people from the vast geographical area of the Pacific Ocean, and gathering together nations with great diversity in resources, political systems and cultural practices. Pacific peoples have a long history of migration in pursuit of new opportunities meaning that, alongside people who reside in Pacific nations, there is also a

vibrant and growing diaspora of Pacific communities around the world.<sup>1–3</sup>

In New Zealand, Pacific peoples now comprise 8.1% of the total population<sup>4</sup> and this is projected to be 10.7% of the New Zealand population by 2043.<sup>5</sup> Although this is currently a relatively youthful population, with 43.6% aged <20 years (compared with only 26% of the total population<sup>6</sup>), the Pacific

## WHAT GAP THIS FILLS

**What is already known:** Pacific communities experience unmet health needs, with barriers to accessing and using mainstream health care, including cost of health services, transport and language.

**What this study adds:** This research adds information from a range of health-care providers about the experiences and challenges faced by aged Pacific peoples with cognitive impairment and dementia in the New Zealand health system. It does this by discussing results relating to accessibility of services; getting a diagnosis; and communication and language.

population aged >65 years is projected to increase from 0.4% of the total population in 2018 to 1.13% by 2043.<sup>7</sup> In addition, the context for healthy aging among Pacific peoples in New Zealand is complicated by exposure to inequities in socioeconomic circumstances<sup>8</sup> and subsequent high rates of health issues including obesity, hypertension, stroke, diabetes, and respiratory conditions.<sup>9–15</sup> Additionally, there is unmet health need among Pacific communities, with barriers to accessing and using mainstream health care that include cost of health services, transport and language.<sup>10,16,17</sup>

These factors add up to the reality that for many, elder years are likely to be truncated, with Pacific peoples in New Zealand having a life expectancy 5 years shorter than non-Pacific peoples.<sup>1,13,14,18</sup> Urgency in addressing these disparities is also underpinned by the cultural importance of Pacific elders in the wellbeing of their wider Pacific families and communities. Pacific peoples often consider old age as the most important life stage, with elders holding vital leadership roles in families and communities. In the context of diaspora, where almost two-thirds of Pacific peoples are now born in New Zealand, this role assumes additional importance as holders of key cultural knowledge about traditional values and practices that guide the wellbeing of extended families and communities.<sup>19</sup> In Pacific models of health, such as the Fonofale model, culture is positioned as the 'roof' of the house, providing shelter for other concepts such as physical, mental and spiritual wellbeing.<sup>20</sup> For this reason, the connection with cultural language, values and traditions provided by elder members of the community is a source of strength for all age groups.

The importance of these leadership roles, in particular, also invites a focus on the effect of cognitive impairment in Pacific communities, as little is currently known about Pacific people's experiences of, or views about, cognitive impairment. As the population of older people increases, the number of Pacific people with dementia is predicted to increase. In 2016, 2.3% of New Zealanders with dementia were Pacific peoples, and by 2038, this projected to be 3.3%.<sup>21,22</sup>

There is reason to suspect that the incidence rate of dementia may become higher in Pacific peoples than the general population<sup>21</sup> due to the high prevalence of risk factors such as socioeconomic deprivation, low educational level, and high rates of diabetes, hypertension, obesity, stroke, smoking, alcohol intake, and head injury.<sup>23</sup> One study showed that Pacific peoples were diagnosed with dementia at a younger age and they presented at a more advanced stage of dementia than the general population.<sup>23</sup> Conversely, Pacific people have strong interconnectedness, reporting high levels of overall life satisfaction, social contact, and less loneliness, all of which can be protective against dementia.<sup>8</sup> To reduce the risk of further exacerbating current health inequities, it is important that Pacific conceptions of aging, cognitive decline and health service needs are incorporated in the resources available in New Zealand.

We therefore aimed, in this study, to explore the needs of Pacific peoples and families affected by age-related cognitive impairment by identifying information and services currently used by Pacific people and families, and defining unmet needs.

## Methods

### Participants

We invited a range of health-care providers and organisations delivering age-related services to Pacific Peoples throughout New Zealand to participate in the study ( $n = 9$ ). Services were identified by conducting an internet search of Pacific health-care providers using the keywords 'Pacific', 'Pasifika', and 'Pacific peoples' in conjunction with health service terms. Searches of District Health Board websites and links to contracted organisations were included. In addition, we invited

organisations that were not Pacific-specific, but either worked in areas with a high Pacific population or were responsive to Pacific health needs. Six providers agreed to be interviewed.

### Data collection

Participating organisations were asked to identify the most appropriate representative in that organisation for interview. The interviews were undertaken face-to-face in English by the primary researcher at the organisations' premises, audio-recorded and transcribed verbatim. The interviews took approximately 1 hour to complete. The interviewer used an interview guide to facilitate a semi-structured conversation. This method allowed the interviewer to explore themes or issues raised by individual respondents.

The interview guide was developed by the research group and was divided into the following four groups of questions.

*Services:* Participants were asked to describe the services provided by their organisation, relate the experiences of their Pacific clients and their families in accessing that service, and explain how they meet the specific needs of Pacific peoples. They were asked to identify any gaps they perceived in the services they provided.

*Changes:* This series of questions examined who, how and when people observed changes in the cognition of older Pacific people, and how they sought help. It focused on cognitive decline and dementia.

*Poor health prevention and promotion of good health:* This series of questions examined health promotion and awareness of Pacific peoples of the risk factors for cognitive decline.

*Future research:* Participants were asked what they saw as health research priorities for aged Pacific peoples.

### Analysis

We conducted a thematic qualitative analysis of the interview transcripts using NVivo 11 software (QSR International Pty Ltd, Version 11). In the creation

of the themes, analysis was influenced by the research questions (listed above) as well as dimensions from the Fonofale model of health (culture, family, time, environment, context, physical, spiritual, mental and other), which were used as a guiding framework<sup>20</sup> to facilitate the inclusion of a holistic lens on the meaning of health and wellbeing for Pacific peoples in New Zealand. The analysis was undertaken by the primary researcher–interviewer, who was of Fijian descent. This ensured a Pacific lens when considering the thematic analysis.

### Ethical considerations

The study was given approval by the University of Otago Human Ethics Committee (D19/008).

### Results

Six providers consented to take part, with five providing one employee to be interviewed and one organisation having two employees at the interview. Interviewees represented a diverse group of health service contexts and included a medical centre, an in-home service provider, a dementia support non-government organisation, a community trust, a Primary Health Organisation with a focus on rural support, and a Ministry of Health contracted in-home service provider with a focus on disability information, service coordination, and cultural support. The employees interviewed were three Chief Executive Officers (CEOs), a general manager of operations, two health-care navigators and a disability co-ordinator. The geographical spread was organisations based in Auckland, Christchurch and Dunedin.

Three key themes were identified in responses: accessibility, diagnosis of dementia, and communication and language, which will be discussed in turn.

### Accessibility

A common theme shared by participants was concern over the lack of available information about dementia and dementia services, and therefore how to access those services for people with dementia and their families. They felt that their clients did not understand the New Zealand health system or who they should go to first for help when worried about a

loved one. This was particularly an issue for immigrant Pacific peoples whose experiences with health care in their nation of origin was very different from health care in New Zealand. In many Pacific nations, people went directly to a hospital rather than a general practitioner (GP) when unwell.

Access to information describing the New Zealand health system and its services was difficult for Pacific people to source. Paper resources were often available only in the English language, whereas Pacific language-specific brochures that were a direct translation from English often did not consider a Pacific world view and were therefore less useful than they might have been.

Some information about health services was available online in the form of websites and social media. Many participants commented that not all Pacific people had internet services at home or access to a computer, reflecting the constrained socioeconomic circumstances of many of the organisations' clients. Many older Pacific people did not own a computer and relied on their children accessing information from the internet. If this access was via a cellular phone, it was frequently from social media sources rather than official websites. Moreover, participants said that for older Pacific people trying to access information themselves, face-to-face interaction was the most useful, particularly if it was in their own language.

Another issue raised by participants in respect to accessibility to health services was equity. Health-care services delivery for patients living in areas of low socio-economic status was inferior to health service delivery in higher socio-economic areas. The example often cited was that GP services available in an affluent suburb were markedly different from the experiences of patients in South Auckland, which has a mainly Pacific population. The ability to access services was also influenced by social inequities.

'If you go to a GP most of it's biomedical really. But actually 50% of the issues of them turning up are actually social determinants. It's poverty, it's housing, it's all these other issues.' [Respondent C]

The socioeconomic disparity was amplified in Auckland, which had three District Health Boards (DHBs) with differing population demographics,

resources and services available. As stated by one provider:

'People are afraid to move across the street because it moves them into a different DHB. That post-code lottery...' [Respondent B]

### Diagnosis of dementia

Socio-economic constraints were a contributing factor to the difficulties families experienced in getting a diagnosis of dementia. In low socio-economic areas in Auckland, patients were often faced with a 2–4 h wait at a medical centre to be seen for 10 min. They seldom saw the same GP and presented with multiple and complex health issues. As one participant commented:

'The darkness of dementia is about subtlety. It's about witnessing change over time. If you never see the same health practitioner over years, and you only see them for 10 minutes, it's really hard for that diagnostic journey to be made.' [Respondent B]

Older Pacific people relied on their extended family for transportation to medical appointments. Due to the length of time taken to be seen at practices, relatives often had to take a day off work, which added further financial and time costs to seeking help.

Another theme shared by participants was the late diagnosis of dementia among Pacific peoples. They observed that Pacific families often did not reach out to medical services until their elder's dementia had progressed to a point that was difficult to manage at home. This was attributed to the barriers to getting access to medical services and a lack of awareness of the signs and symptoms of dementia. Changes in cognition of the elderly were often attributed to advancing age and therefore not a 'condition' to be treated.

### Communication and language

Communication and language differences were cited as a barrier to accessing services. Older Pacific people with cognitive problems did not always speak English at the level needed to access good quality care. For many, English was a second language and carers who spoke their language were not always available. The language barrier was not always a matter of direct translation, but also the

ability to communicate with clinicians due to a lack of understanding of the health system, of medical terminology, and different world views about health; for example, the role of spirituality. The barriers were linguistic and cultural. Again, when engaging about health care, face-to-face interactions were the most effective for aged Pacific people.

The participants noted the need for a Pacific workforce in all areas of the health system, including physiotherapy, dental, and aged care facilities. A Pacific workforce would more likely be culturally sensitive to the needs of Pacific people and some would be able to assist with language. Participants also noted the lack of clinicians who identified as Pacific, and the difficulty in recruiting them.

## Discussion

Pacific peoples in New Zealand have identified clear aspirations for thriving communities who are resilient, healthy and with strong ties to identity, language and culture.<sup>24</sup> It is in the latter that older Pacific people play a key role as leaders in language and culture for their extended family and beyond.<sup>19</sup> The goal of this study was to explore the needs of Pacific peoples and families affected by age-related cognitive impairment, and to identify unmet needs from the perspectives of providers of health services to Pacific peoples. Although this article discusses only three main areas of concern, the interviews with six health-care providers and support organisations identified many areas where the health system fails to meet the needs of older Pacific people.

The participants' observations resonate with previous research, with older Pacific people and their families experiencing difficulty in accessing health care due to a lack of information in their language and culturally appropriate, health service inequities and broader socio-economic effects.<sup>16,25</sup> Similar findings have been reported about Pacific communities in the United States and Australia, but to our knowledge, the particular issues around older adults with cognitive decline have not been explored in other studies.<sup>2,3,26–28</sup> In our study, the barriers identified contributed to difficulty in attaining diagnosis of dementia and the related access to support services. They also contributed to older Pacific people presenting and being diagnosed at an advanced stage.<sup>23</sup>

When offering potential solutions to these barriers to access, participants spoke of the need for language and culturally appropriate information that was available across many platforms, and the advantages of collaboration between providers and Pacific communities. Participants argued that health services for Pacific people were best delivered by a Pacific workforce, but the entire health services workforce would benefit from cultural competence training. Organisations working in the area of service delivery described difficulty in recruiting a Pacific workforce across all health professions, and also in the context of translation and advocacy, of knowing who and where Pacific health workers were. Increasing the Pacific health-care workforce is vital to meeting the needs of Pacific peoples. This will only be achieved by programme commitments made at a government and policy level. Health professional admissions programmes that mirror society begin to address this, but need a long-term commitment to support Pacific students and trainees. Many of the issues faced by Pacific peoples in accessing health care were caused by inequities in the health system and socio-economic disparities. This compounded the other access issues experienced by aged Pacific people with dementia. These are issues that need to be addressed at a policy level, and in consultation with Pacific communities.

There is no existing literature on the needs of Pacific families affected by age-related cognitive impairment in New Zealand. The findings of this study identify unmet needs from the perspective of a small number of organisations that can inform future research. The small sample size included the view of one individual from each organisation and therefore did not allow comparisons of like organisations and the effects of geographic location and their patients' socio-economic status. The results are specific to the experiences of the participant organisations and may not be transferable to organisations of similar nature. Further, the study interviewed health-care service providers, not patients, so the findings do not represent the voices of older Pacific adults with cognitive impairment and their families. Interviewing patients is an important future research focus.

## Conclusion

The current study engaged with providers of health care across a variety of service providers and



contexts. There were common themes across interviewees that provide some evidence that health-care needs of older Pacific peoples with dementia were often not being met. Given the growing elder population among Pacific communities and their importance to the wellbeing of Pacific communities as a whole, there is a need for further research to explore best practice policy and practice that places elders and their families at the centre.

### Competing interests

None of the authors declare any competing interests.

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### Data availability

The data used to generate the results in this paper are unavailable.

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