

Mate wareware: Understanding ‘dementia’ from a Māori perspective

Margaret Dudley, Oliver Menzies, Hinemoa Elder, Lisa Nathan,
Nick Garrett, Denise Wilson

ABSTRACT

AIM: To investigate Māori (Indigenous people of Aotearoa New Zealand) understandings of dementia, its causes, and ways to manage a whānau (extended family) member with dementia.

METHOD: We undertook kaupapa Māori research (Māori informed research) with 223 kaumātua (Māori elders) who participated in 17 focus groups across seven study regions throughout Aotearoa New Zealand and eight whānau from the Waikato region. We audio recorded all interviews, transcribed them and then coded and categorised the data into themes.

RESULTS: *Mate wareware* (becoming forgetful and unwell) (‘dementia’) affects the wairua (spiritual dimension) of Māori. The findings elucidate Māori understandings of the causes of *mate wareware*, and the role of aroha (love, compassion) and manaakitanga (hospitality, kindness, generosity, support, caring) involved in caregiving for whānau living with *mate wareware*. Participants perceived cultural activities acted as protective factors that optimised a person’s functioning within their whānau and community.

CONCLUSION: Whānau are crucial for the care of a kaumātua with *mate wareware*, along with promoting healthy wairua for all. Whānau urgently need information to assist with their knowledge building and empowerment to meet the needs of a member affected by *mate wareware*. This requires collaborative healthcare practice and practitioners accessing the necessary mātauranga Māori (Māori knowledge) to provide culturally appropriate and comprehensive care for whānau.

Similar to other countries, Aotearoa New Zealand is experiencing a growing number of people living longer. Numbers of kaumātua living beyond 65 years and 80 years of age have almost doubled in the last decade. In 2011, there were 1,928 Māori estimated to have dementia, and this number is projected to reach approximately 4,500 by 2026.¹ A recent study found Māori were significantly younger when the diagnosis of dementia was made. Māori are 8.5 and 3.3 years younger than Pākehā (English person of European descent) and Pasifika, respectively.² Current epidemiological estimates assume that Māori and Pākehā have the same rates of dementia.³ However, the actual incidence of this disease for Māori could be higher due to older Māori being: less likely to access primary care services; less likely to utilise mental health services;

and more likely to be cared for within the whānau rather than reside in long-term care facilities where they are more visible.⁴ In addition, Māori have a high prevalence of health conditions, such as diabetes, cardiovascular disease, stroke, and a history of traumatic brain injuries, which are risk factors for the onset of dementia. Further, Māori experience differential access to determinants of health, access to health services, and quality of healthcare compared to others living in Aotearoa New Zealand, which also increases their risk.⁵⁻⁸

The literature regarding Māori and dementia is lacking. As a result, dominant Western biomedical views influence the current understandings of dementia. For example, dementia affects the whole whānau, not just an individual, yet there are no explanations or descriptions of the

impact on whānau in the current literature. Furthermore, current protocols and tools used in the diagnosis of dementia have not included Māori in their development and validation, and are therefore culturally biased, inappropriate and lack accuracy for this population.⁹ A growing understanding of the importance of including Māori worldviews in healthcare together with the increasing impact of dementia for Māori signals the need for a dementia care pathway informed by mātauranga Māori. The current study 'Kaumātutanga o Te Roro (The Ageing Brain)' aimed to develop (1) a Māori understanding of dementia, and (2) a Māori-responsive assessment tool for the diagnosis of dementia ready for a full validation study. This paper reports Māori understandings of dementia, its causes, and ways the whānau manage a whānau member with dementia. An inclusive approach was adopted when referring to kaumātua. A broad definition of kaumātua as older people (men and women) within whānau, hapū (subtribe), iwi (tribe) and Māori communities was applied. This paper reports our findings related to the first aspect of the study, Māori understandings of dementia.

Method

A qualitative design using kaupapa Māori research methodology was used. Two hundred and twenty-three kaumātua from across Aotearoa, and eight whānau from the Waikato rohe were recruited using whanaungatanga (relationship building) as a form of purposive sampling. Kaumātua participated in 17 focus groups across seven study locations throughout Aotearoa (Kaitiaki, Auckland, Hamilton, New Plymouth, Whakatane, Wellington and Christchurch). Kaumātua were given the option to participate in a focus group in te reo Māori or English. The whānau interviews were conducted in English. All interviews were semi-structured and the same prompt questions were used across all focus groups with a different set of questions for the interviews, which were audio-recorded. Following the transcription and translation (for te reo Māori focus groups) of recordings, transcripts were checked for accuracy. Transcripts were coded and categorised into five key categories using Mahi ā-Roopū (a Māori collective qualitative analysis approach),^{10,11}

with the guidance of kaumātua. These five categories reflect the commonality of understandings, causes and management approaches of some with *mate wareware* that emerged across the dataset in both (focuuks groups and whānau interviews).

Results

Overwhelmingly, participants found the words 'dementia' and 'Alzheimer's' evoked feelings of despair and confusion. A clear preference for utilising kupu Māori (Māori words) to describe changes in behaviours such as absentmindedness and forgetfulness was evident. Participants used terms including wareware (forgetful), pōrangi (mad), rorirori (crazy), wairangi (unbalanced), māharatanga (remember), maumahara (reminisce), rangirua (confused) and whakapakeketanga (adulthood). Following whakawhiti kōrero (discussion) with the rōpū kaitiaki (kaumātua advisory group), *mate wareware* (pronounced phonetically *ma-te wah-ree-wah-ree*) lent itself for universal use among Māori across Aotearoa New Zealand. *Mate* refers to being sick, ill, ailing, unwell and diseased; while *wareware* means to forget or be forgotten. While participants used a variety of terms for a whānau member's forgetfulness and problems with thinking, for the most part their understandings of *mate wareware* were surprisingly similar.

Te Oranga Wairua (spiritual wellbeing) is the central and unifying category that emerged from the data. Living and functioning in Te Ao Māori is critical for *te oranga wairua* of whānau. *Mate wareware* does not just affect an individual, it impacts whānau, hapū and communities Māori live within. One important aspect of *te oranga wairua* was for kaumātua to continue to undertake their cultural roles, such as kaikaranga (caller) or whaikōrero (formal speech), despite any perceived changes in memory or behaviour. Whānau who embraced changes in behaviour, accommodated and adapted to the changing needs of kaumātua because they understood the importance of culture, environments, community and social contact for the ongoing functioning of whānau. The following is an example of *te oranga wairua* in action:

“I believe [be]cause of our way of life, our acceptance, our extendedness they were just drawn into the whānau, you know, and just cared for and just looked after [others]...”

“We got her to the doctors and [she] had a few assessments and scans. That’s when they came up with the vascular dementia. So we sort of got into a bit of a study and research and had a look at what that meant and things like that. We’ve sort of a built a little solid whānau around aunty.”

Whānau treasured and valued continuance of kaumātua roles, and therefore accepted changes and ensured the maintenance of familiar environments for optimal kaumātua engagement in daily life and cultural activities. For some whānau, changes compromised their cohesion when challenged by geographical distance and different views and understandings about *mate wareware*. This lack of cohesion appeared to negatively affect the *oranga wairua* of the whānau.

“...the impact that it had on my cousins, at the time, [be]cause even they started fighting against each other, saying ‘This is the best thing’ and ‘No she’s not [got dementia].’ ‘Yes, she has. Well you don’t live near. You only come home every so often. You didn’t see her, when it [mate wareware] really started...”

Five sub-categories explain *mate wareware* from a whānau Māori perspective, which are necessary for their *te oranga wairua* (Figure 1): *Ngā Pūtaka* (causes); *Ngā Rongoā* (protective factors); *Aroha and Manaakitanga* (acceptance of illness and behaviour change); *Kaitiakitanga* (caregiving); and *Ngā Ratonga* (dementia services). Table 1 provides examples whānau conveyed for each sub-category.

Ngā Pūtaka (causes)

Whānau held different understandings of *mate wareware*. Many whānau understood *mate wareware* to be a debilitating disease that had serious adverse effects on both the individual and the whānau. These beliefs were evident in the tone and manner in which they described the behaviours.

“...she’d go wandering and you couldn’t lock her in the house, she’d always find a way out. Jump out the window. Put her clothes on, put her coat on outside, and that was sad to see, such a forceful woman like that and suddenly she’s reduced to nothing. Yeah that’s

the hard bit to watch. Nearly burnt the house down. Put her food on, forgot about it.”

According to whānau, the *Ngā Pūtaka* (causes) of *mate wareware* related to the loss or change in socially oriented activities in a person’s life. *Ngā Pūtaka* was also seen as occurring within the broader context of the ongoing intergenerational effects of colonisation, such as loss of *rongoā* (Māori medicine), introduction of *Pākehā* medicines, loss of *tohunga* (traditional Māori healer), changes in cultural practices and lack of access to traditional foods for many Māori whānau.

“She had dementia because of loneliness. My father died and she had all her grandchildren, but it wasn’t enough.”

Often whānau interpreted the causes of *mate wareware* within historical, cultural and social contexts rather than as a physical illness or disease.

“I do think that the Pākehā environment has impacted on Māori memory and also the pills they give us to take. We are part of the Pākehā world. It’s a world that we can’t escape from and we’re victims of it. We have to live in it.”

Some whānau did not perceive *mate wareware* as an illness or disease, but rather as part of a spiritual journey and as a normal consequence of growing old and preparing to join their *tūpuna* (ancestors).

“I remember my aunts and uncles saying they were talking to the old people. They are with them. They are over on the other side. They are between two worlds. So, don’t worry about them, they are okay.”

Ngā Rongoā (protective factors)

Ngā Rongoā describes the protective factors that slow down or prevent *mate wareware*. *Kaumātua* reported that engagement in cultural activities were crucial protective factors. Listening to *te reo Māori* (the Māori language) and being engaged in a range of cultural activities promoted wellbeing and maintained a person’s ability to be socially active (Table 1).

“This is the hinengaro [psychological dimension]. We can sit here, close our eyes, comprehend everything that is being said, because we are listening not just with our ears, but with our minds, with our souls and whole physical being.”

Some whānau reported those with *mate wareware* demonstrated increased use of te reo Māori, which was their first language but suppressed in early childhood.

“They miss the reo because that is their first language.”

The value of te reo Māori was consistently highlighted as a vital healing and comforting factor for those who suffer from *mate wareware*.

“te reo Māori is a gift, it is a medicine. It is health for our thoughts.”

and

“My husband, he used to go in there and the minute he spoke in te reo, my father was there and for the whole hour they used to talk. You’d think that my father had nothing wrong with him, he remembered everything! But the minute you spoke English, that was it. He just didn’t want to know.”

Being able to utilise te reo Māori enabled those with *mate wareware* to engage more fully in cultural activities and events—in these ways engagement in cultural practices are seen as rongoā that slowed or prevented the progression of *mate wareware*.

Aroha and Manaakitanga (compassion and caring)

Many whānau appear driven by an inherent collective obligation to care for others with their sense of compassion and caring that enables their acceptance and tolerance of changes brought about by illness and disease. They do this by absorbing the changes that occur, and work around and with the person to ensure they are fully included in daily activities and life.

“I find Māori accept that either koro (grandfather), or nanny, or sister, or aunty or whoever have this unwellness, and the family just absorb it and deal [with it] and work around it..”

Thus, because some whānau did not always view changes resulting from *mate wareware* as something pathological, they accepted and accommodated these new behaviours as part of normal ageing.

“It pains me when I see so many elders told by tauwiwi (non-Māori) that there is something wrong with them.”

Instead, *mate wareware* involved whānau doing things differently in order to maintain a person’s independence and involvement in activities for as long as possible.

Kaitiakitanga (caregiving)

Kaitiakitanga occurs within a Māori collective cultural context and is a critical role in te oranga wairua of the whānau, especially in respect of children and older members.¹² The obligations to care for others, and the notion that Māori ways of doing things is best practice.

“Initially, koro (grandfather) was quite depressed and down. I said to him, ‘Just do what you want to do, be who you want to be.’ So every day he would say karakia (prayer) and work on the vegetable garden. It’s the sense of whānau, purpose (and) being productive...he knows where he belongs.”

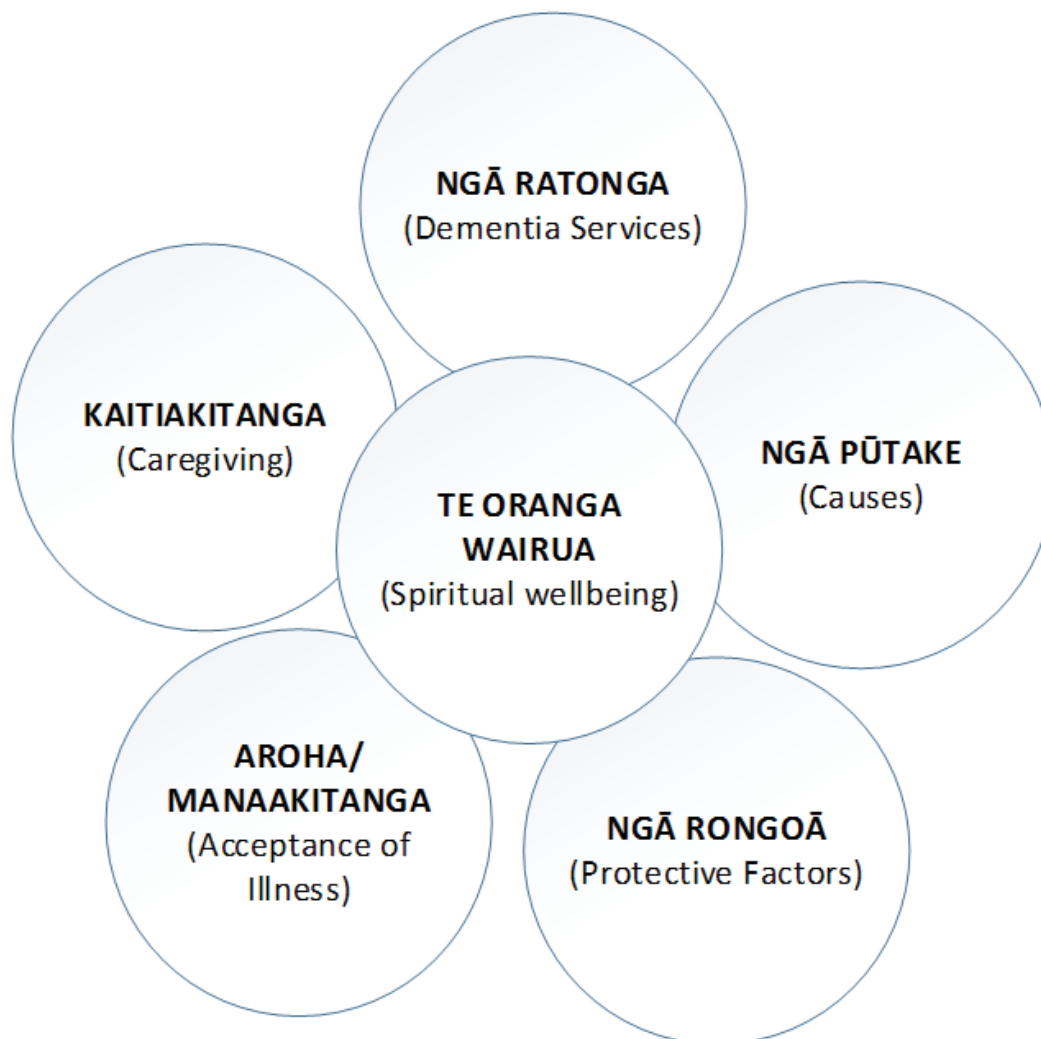
Ngā Ratonga (dementia services)

Ngā Ratonga are important to reduce the burden and stress on those whānau caring for their kaumātua with *mate wareware*. Clearly, whānau needed good support and advocacy to help them understand *mate wareware* and the growing needs of their kaumātua, and accessing necessary services. Often whānau needed practical help and resources, such as paid caregiving, home help, physical alterations to homes, equipment for activities of daily living (eg, hand supports for showers, toilets and beds), caregiver respite, social activities and access to resources such as continence products. While most whānau firmly believed in keeping their kaumātua at home and out of residential care facilities, there came a time when they needed to access greater support and care. Obvious in participants’ kōrero was their need for more information about available services and how to access them. However, whānau expressed concerns about the cultural competence of service providers and the monocultural nature of many residential care services when they did access services.

Table 1: Sub-categories: examples of whānau activities.

Sub-category	Examples
Ngā Pūtake (causes)	<ul style="list-style-type: none"> • Enduring effects of colonisation • Social isolation and loneliness • Loss of significant whānau member • Retirement • Lack of social and physical activity
Ngā Rongoā (protective factors)	<ul style="list-style-type: none"> • Te reo Māori • Waiata (song) • Whakapapa (genealogy) • Whaikōrero (formal speaking on marae) • Kapa Haka (song and dance) • Roopū Kaumātua (kaumātua groups) • Marae • Cariving, raranga (weaving), etc
Aroha and Manaakitanga (compassion and caring)	<ul style="list-style-type: none"> • Treating kaumātua with respect and aroha • Whānau working together • Pooling resources • Adapt the environment, when needed • Willing to alter own lives and daily routines in response to changes and to care for a person with <i>mate wareware</i>
Kaitiakitanga (caregiving)	<ul style="list-style-type: none"> • Collective cultural obligations • Māori ways of doing things is best practice • Whānau is optimal caregiving environment so avoid ‘mainstream’ residential care • Encountering challenging behaviours: such as hitting, swearing, wandering, arguing, aggressive, driving unsafely, frustration, abusive, paranoia • Encountering guilt when unable to fully care for a person with <i>mate wareware</i>
Ngā Ratonga (dementia services)	<ul style="list-style-type: none"> • Cultural competency of clinicians and dementia service providers • Lack of Māori services for <i>mate wareware</i> • Referral and access to specialist services that work in partnership with whānau • Advocacy to assist whānau • Sufficient to address kaumātua and whānau needs • Residential care facilities not including whānau in the care

Figure 1: Achieving Te Oranga Wairua in the presence of *mate wareware*.



Discussion

Māori understandings of *mate wareware*, commonly referred to as dementia, differs from the predominate Western conceptions. We noted respectful tolerance and acceptance of a whānau member displaying forgetfulness and problems with thinking. Whānau were generally inclusive of their whānau member's changes in their daily functioning and new emerging behaviours. They often talked about honouring their identity as older Māori and ensuring they were able to continue to participate in various activities like pōwhiri (traditional welcoming), waiata (singing), kapa haka (Māori performing group), and raranga (weaving). Te Oranga Wairua, the spirituality of older Māori with *mate wareware* is also a key difference in the understanding of *mate wareware*.

Whānau are crucial for the care of a kaumātua with *mate wareware*, along with promoting healthy wairua for all. The collective obligations of whānau are important for their wairua, and the care of those affected by *mate wareware*. Mana-enhancing (upholding whānau status) relationships with whānau are vital, and need to be informed by cultural concepts such as aroha, manaakitanga, whakapapa (genealogy) and whanaungatanga (relationships/connections). This highlights the need to not just work with an individual 'patient' but with whānau, and recognise the value and positive ways whānau make to the optimal wellbeing of someone with *mate wareware*.

These findings highlight the importance of whānau and their contribution to the health and wellbeing of all involved. Indeed, for some whānau experiencing isolation,

this resulted in loneliness with a profound impact on te oranga wairua. We found the wairua of whānau with *mate wareware*, as a collective and individuals, must be considered for their experiences and positive functioning.^{13,14,15} Elder has reported that insults to the brain have both physical and wairua elements, such as wairua ‘injuries’ impact on individuals’ and the collective whānau as a whole.^{14,15} These cultural ‘injuries’ necessitate culturally informed assessment and interventions.⁹

Whānau varied in their abilities to function as caregivers, from those who function cohesively to those whānau compromised by factors such as geographical distance and competing commitments. Despite the commitment by many whānau to care for a person with *mate wareware*, kaitiakitanga (caregiving) can be challenging. Poor knowledge and understanding about *mate wareware*, a lack of resources and necessary support services all contributed to difficulties in providing day-to-day care. Although on the one hand, it appeared that rural whānau were more likely to pool resources, on the other hand these whānau were more likely to encounter a lack of services available to them in the community. A lack of resources to support whānau in their kaitiakitanga role, forced them to make difficult choices about going into mainstream long-term care facilities.

We advise some caution in applying the findings to iwi and hapū outside the Waikato rohe where whānau data was collected. However, whānau-related information was collected in the course of the kaumātua interviews undertaken across Aotearoa. This research nevertheless reinforces the significance of mātauranga Māori informing the provision of comprehensive care for whānau with someone with *mate wareware*. This signals the need for the collaboration of medical and health professionals with whānau in recognising the vital role cultural knowledge has in working with and planning care for whānau. It also indicates the need for health professionals to access mātauranga Māori, and accessing local cultural advisors to assist in developing collaborative healthcare practice that integrates Māori cultural concepts and practices. The Meihana Model¹⁶ is one approach

that positions whānau centrally during assessment and intervention planning activities, and provides clinicians with a structured process for bringing together cultural and clinical concepts. This multi-dimensional model of practice promotes a collaborative approach to practice.

We found an urgent need for information sharing and knowledge building for whānau that empower them to manage *mate wareware* within their unique contexts. This involves building their health literacy, in culturally relevant and meaningful ways so they can utilise the information to their benefit. We also found whānau were challenged when accessing services for a range of reasons, indicating whānau access to resources is a crucial consideration.

Conclusion

This research is the first to describe Māori understandings of the ageing brain and ‘dementia’ in particular. *Mate wareware* has emerged as the preferred term for what might be termed ‘dementia’ and the manifestations of the ageing brain, although for Māori these changes are likely to occur at younger ages than for Pākehā. This cultural concept clearly positions the importance of using te reo Māori (the Māori language), and is underpinned by mātauranga Māori. These findings strongly support use of the term *mate wareware* in place of dementia along with other preferred kupu (words) in te reo Māori, and approaches informed by mātauranga Māori. This should occur in all contact with whānau who may be experiencing changes in memory, behaviour, thinking and emotions.

Te Oranga Wairua has been identified as central to Māori thinking (Figure 1). Five key themes were identified from kaumātua around Aotearoa New Zealand: *Ngā Pūtaka* (causes); *Ngā Rongoā* (protective factors); *Aroha and Manaakitanga* (acceptance of illness and behaviour change); *Kaitiakitanga* (caregiving); and *Ngā Ratonga* (dementia services). Te Oranga Wairua can be considered a deeply spiritual and uniquely Māori experience of connectivity. This links to previously published work emphasising the indication for cultural intervention when there is disruption to wairua.^{9,14,15}

Effective care for someone with *mate wareware* must therefore include cultural practices to strengthen wairua of the whole whānau. In addition, whānau require information, support and collaborative relationships with healthcare providers to ensure delivery of culturally appropriate and comprehensive assessment and

care. Healthcare providers need a more in-depth understanding of the ways in which Māori comprehend *mate wareware* and how whānau manage a member. This research contributes new knowledge to help bridge the gaps that exist for whānau and healthcare providers.

Competing interests:

Dr Garrett and Dr Menzies report grants from NZ Health Research Council during the conduct of the study.

Acknowledgements:

He mihi ki ngā kaumātua. We sincerely thank the kaumātua and kuia and their whānau who participated in our study. We are humbled by their generosity, their honesty and their willingness to participate to improve our understanding of *mate wareware*. E mihi ana mātou ki ngā kaiuru hōki, āra, mō ngā whakaaro nui i roto i ā rātau kōrero katoa. We appreciate the support and guidance of our kaumātua Piripi Daniels and Dr Waiora Port throughout the research.

We appreciate the support of Ngaire Kerse, Sarah Cullum and Gary Cheung at the kaumātua hui and their willingness to provide information to communities that we visited.

This study was funded by the Health Research Council (16/089).

Author information:

Margaret Dudley, The University of Auckland, Auckland; Oliver Menzies, Auckland District Health Board, Auckland; Hinemoa Elder, The University of Auckland, Auckland; Lisa Nathan, The University of Waikato, Hamilton; Nick Garrett, Auckland University of Technology, Auckland; Denise Wilson, Auckland University of Technology, Auckland.

Corresponding author:

Dr Margaret Dudley, School of Psychology, The University of Auckland, Symonds Street, Auckland 1010.

m.dudley@auckland.ac.nz

URL:

<http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2019/vol-132-no-1503-4-october-2019/8009>

REFERENCES:

1. Deloitte Access Economics. 2017. Updated dementia economic impact report 2016, New Zealand. Alzheimers New Zealand.
2. Cullum S, Mullin K, Zeng I, et al. Do community-dwelling Māori and Pacific peoples present with dementia at a younger age and at a later stage compared with NZ Europeans? *International Journal of Geriatric Psychiatry*. 2018; 33(8):1098–104.
3. Alzheimer's New Zealand. Dementia Economic Impact Report 2016, New Zealand 2017. Available from: <http://www.alzheimers.org.nz/getmedia/79f7fd09-93fe-43b0-a837-771027bb23c0/Economic-Impacts-of-Dementia-2017>
4. Baxter J, Kani Kingi T, Tapsell R, et al. Prevalence of mental disorders among Māori in Te Rau Hinengaro: The New Zealand mental health survey. *Australian & New Zealand Journal of Psychiatry*. 2006; 40(10):914–23.
5. Harris R, Cormack D, Tobias M, et al. The pervasive effects of racism: Experiences of racial discrimination in New Zealand over time and associations with multiple health domains. *Social Science & Medicine*. 2012; 74(3):408–15.

6. Harris R, Cormack D, Tobias M, et al. Self-Reported experience of racial discrimination and health care use in New Zealand: Results from the 2006/07 New Zealand Health Survey. *American Journal of Public Health*. 2012; 102(5):1012–9.
7. Cormack D, Stanley J, Harris R. Multiple forms of discrimination and relationships with health and wellbeing: findings from national cross-sectional surveys in Aotearoa/ New Zealand. *International Journal for Equity in Health*. 2018; 17:26.
8. Ministry of Health. *Tatau Kahukura Māori health chart book 2015*. 3rd ed. Wellington, New Zealand: Ministry of Health; 2015.
9. Dudley M, Wilson D, Barker-Collo S. Cultural invisibility: Māori people with traumatic brain injury and their experiences of neuropsychological assessments. *New Zealand Journal of Psychology*. 2014; 43(3):14–21.
10. Boulton A, Kingi TK. Reflections on the use of a Maori conceptual framework to evaluate complex health policy: The case of New Zealand's healthy eating, healthy action strategy evaluation. *Evaluation Journal of Australasia*. 2011; 11(1):5–10.
11. Gifford H, Wilson D, Boulton A. Māori perspectives: A deeper understanding of nursing and smoking. *Nursing Praxis in New Zealand*. 2014; 30(3):35–44.
12. Durie M. Measuring Māori wellbeing. *New Zealand Treasury Guest Lecture Series*, 12006. Available from: <http://treasury.govt.nz/news-and-events/our-events/measures-m%C4%81ori-wellbeing>
13. Moewaka Barnes H, Gunn TR, Barnes AM, et al. Feeling and spirit: Developing an indigenous wairua approach to research. *Qualitative Research*. 2017; 17(3):313–25.
14. Elder H. Indigenous theory building for Māori children and adolescents with traumatic brain injury and their extended family. *Brain Impairment*. 2013; 14(3):406–14.
15. Elder H. Te waka oranga: An indigenous intervention for working with Māori children and adolescents with traumatic brain injury. *Brain Impairment*. 2013; 14(3):415–24.
16. Pitama S, Robertson P, Cram F, et al. Meihana model: A clinical assessment framework. *New Zealand Journal of Psychology*. 2007; 36(3):118–25.