

## **Dementia: continuation of health and ethnic inequalities in New Zealand**

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### **Abstract**

Dementia has been framed and seen as a condition associated with ageing and in particular with advanced age, especially amongst those over 80 years of age. For Māori and Pacific peoples in New Zealand dementia is not necessarily associated with age but is directly related to our respective histories within this country, patterns of migration and the socioeconomic determinants of health for both populations from different tribes and nations. Issues are discussed in relation to Māori and Pacific development and the importance of prevention and early detection of chronic health conditions.

Whānau Ora is proposed as a developing indigenous and Pacific model with one of its purposes being is to support individuals and families involved in the management of one or more of the chronic health conditions, that may lead onto dementia as part of the end of life process.

This paper proposes that the needs of Māori and Pacific, especially, in the Tamaki Makaurau area (Auckland region) must be included in the planning and decision making of policy and services related to dementia. The health and social inequalities of these populations during life and across generations also need to be considered in planning to prevent dementia from occurring early or in midlife.

Dementia is commonly associated with ageing, particularly in those over 80 years of age.<sup>1</sup> With Māori and Pacific peoples in New Zealand, other determinants of health such as socioeconomic status are significant factors in dementia which need to be factored into dementia policy and decision-making.<sup>2,3</sup>

Whānau Ora is proposed as a developing indigenous and Pacific model with one of its purposes is to support individuals and families involved in the management of one or more chronic health conditions, which often leads onto dementia as part of the end of life process.<sup>2,3</sup>

The health and social inequalities of these populations across the life course and across generations also need to be considered in planning to prevent dementia from occurring early or in midlife.<sup>4,5</sup>

New Zealand like many other countries is now recognising that our population is ageing and that there will be greater need for health and disability services.<sup>6</sup> The Māori population in 2013 was 598,605 and 107,391 people reported they had Māori descent forming a combined population of 668,724 and of this population 5.4% (36,111) were over 65 years of age.<sup>7</sup> For non-Māori there were 3,573,324 of which 570,921 were over 65 years of age, similar to the total size of those who identified as Māori.<sup>8</sup>

From 2011 to 2026, Statistics New Zealand predicts that Māori aged 65 year or more will grow by 7.1% almost twice the rate of non-Māori (3.3%) due to a greater number reaching and moving through midlife. Increase in the number of Māori over 65 years of age is predicated to increase by 121.8% compared to 60.3% for non-Māori aged 65 years within a decade.

In 2006, 1 in 5 Māori were aged between 50 to 64 years and 1 in 10 Māori was aged 65 years or more and was resident in the Auckland region. As the Māori population ages, the number of Māori aged over 65 years or more will continue to increase in the Auckland region, if this sub-population is supported and not actively encouraged to be displaced, such as encouragement to return to their tribal areas to free-up employment and housing for those who are recent immigrants to the area, such as those from Christchurch after the earthquake (2010–2011) and recent migrants from other countries seeking better life opportunities.<sup>9</sup> The 2013 Census has identified that Auckland is a place of residence for new migrants and those who have relocated from Christchurch.<sup>8</sup>

For Pacific nations as a group it is anticipated that this population will continue to increase from being 7.4% in 2013 and by 2026 1 in 10 of (9.6%) the New Zealand population will identify as belonging to a Pacific nation<sup>8</sup>. This population is similar to Māori, it is youthful with 4% of the Pacific population being over 65 years of age.

Two thirds of the total Pacific population in 2006 were resident in the Auckland region.<sup>10</sup> Both Māori and Pacific populations are creating changes and this will require those involved in planning and decision making to have greater understanding of the different profiles and diversity within and across ethnic populations who have their own sense of nationhood in New Zealand. There will also be a need to develop reciprocal and respectful relationships across and within ethnic populations as changes occur.

Populations with high health needs, such as those with high prevalence of chronic and co morbidities will require support and caregivers both formal and informal whom are able to provide palliative or end of life care. Poor health often shows visibly the inequalities and privileges that exist within a society and the support available to different groups.<sup>11</sup> Those marginalised may receive minimum support due to inability to afford or access services when needed.

Recently, the New Zealand Public Health and Disability Amendment Act (No2) was passed and was enacted in October 2013. This new legislation reaffirms that people will not generally be paid to provide health services or disability support services to their family member. But it confirms that the Crown and a District Health Board (DHB) may operate and is authorised to operate, policies in respect of family carers that allow payment in certain limited circumstances, or allow for payment at a lower rate than that for carers who are not family members.

These developments although limited at this stage give DHBs their own authority to develop their own policies to provide financial support to family members to provide care for severely disabled members in which care can be personalised to meet their needs. This form of care would support many Māori and Pacific whānau in the Auckland region caring for severely unwell kin.<sup>12</sup>

In all areas of the health, disability, corrections and accident compensation corporation sectors, the health and related workforces will need to become knowledgeable and skilled in working with older or frail people who are likely to have several chronic health issues which need to be diagnosed and managed with appropriate support.<sup>1,13</sup>

Recognition of the complexity of people with multiple health issues now requires health workers either to work in multidisciplinary teams or to develop the necessary skills to be aware if a person has a physical health problem, this has likely affected their mental health status or and vice versa. Poor health also affects others domains of their life, such as finance, relationships, work and recreational interests.<sup>14</sup> These changes all have flow on implications and affect the stability of a family, whānau, community and society generally.

## **Dementia**

Dementia is now increasingly an emerging public health issue on the radar of health decision makers.<sup>1</sup> Diagnosis and support to people with dementia is complex. It is generally assumed that it occurs from midlife, increasing with age and for those over 85 years of age they have been identified the greatest risk.<sup>15,16</sup>

Alzheimer's Disease International has estimated that there are 36 million people worldwide living with dementia and this figure will double in 2030. The increase predicted will be significantly in low to middle income countries and this would include low income populations in New Zealand.<sup>17</sup>

Early onset of dementia may occur suddenly or develop over time with a gradual loss of the brain to perform one or more functions and requires consideration of when to screen. Symptoms often include a decline in cognitive and intellectual abilities, loss of memory, confusion, problems with speech and increased reliance on others for support with daily living.

Te Pou, the National Centre of Mental Health Research, Information and Workforce Development recommend for a diagnosis of dementia to be given four criteria should be present. Firstly, disturbance of cognition, secondly, this has consequences, thirdly, it is progressive and fourthly, it occurs in the absence of delirium.<sup>1</sup>

Dementia occurs as a result of brain cell deterioration and as a result of the slow process of decline many with this condition may be unaware that their brain or cognitive function has changed over time.<sup>18</sup>

Increasingly, it is being recognised that the brain is the most important organ of the body. It affects how all parts of the body and systems functions including moods. This influences thinking, behaviour, feelings, emotions and decisions made in life.

Changes in the way the brain functions may be related to health conditions, medication, trauma, especially in early child and adolescent, such as head injuries and other significant life events, which are often considered as part of the process of ageing, such as loss of employment, loss of a partner, parent or child, the development of addictions and being diagnosed with one or more chronic health conditions.<sup>19</sup> With increasingly age, several of these events may occur in close proximity.

Interest in brain function and impact of brain trauma or injury at any stage of life is increasingly an interest of research by Māori for Māori, with consideration of cognition development, and intergenerational ancestral patterns of development and adaption and brain accident injuries.<sup>20</sup> Indeed, dementia research and health service development is a growing area of interest also for other indigenous populations, such as first nations in Canada and Aboriginal health and research workers in Australia.<sup>21</sup>

There is now recognition of the need to undertake development work in this area from an indigenous perspective. A need also to review and develop appropriate tools for cognition assessment for indigenous populations, as well as greater understanding of why dementia is increasingly becoming visible in these populations which have experienced intergenerational and historical trauma. There is also a need to address issues related to communication, that is verbal and nonverbal and ongoing cultural safety.<sup>22</sup>

It is envisaged that the use and development of new tools will be used by indigenous and allied health workers in different settings and who are competent to undertake such assessments and to offer help in improving functioning and quality of life of individuals with cognition issues as well as support those who are part of their social and kin support systems.

Communication has been identified as a challenge for those with dementia, such as those who have had a stroke and those who desire to communicate in a language of his or her choice, which affirms their ethnic and cultural identity. This development will likely occur in New Zealand as the number of Māori increase and who use te reo Māori as part of defining who they are and determining how they think and relate to the World.

This population may desire a cognitive assessment in either te reo Māori or bilingual. This development will likely occur for other populations as Pacific nations who choose to communicate in their own languages linked to their cultural identity. It will also challenge Alzheimer's New Zealand and other health and related organisations involved in chronic health care management and dementia support, to employ staff who are able to relate and communicate with Māori and other populations in the language of their choice.

Alzheimer's New Zealand has estimated that in 2011, 48,182 (1.1%) of the New Zealand population had dementia. Of that population 4% were Māori and for Pacific nations as a group 1.9%. The number of Māori and Pacific people with dementia and is predicted to increase and the prevalence rate of dementia is anticipated grow.

By 2026, it is predicted of those with diagnosed with dementia 5.7% will be Māori and 2.6% will be Pacific.<sup>23</sup> These prevalence rates are likely to under report the real situation, as currently, only 60% of all cases of dementia are diagnosed. Without regular and ongoing cognitive assessment of people with frailty and complex chronic health conditions, early onset of dementia may be missed or ignored.

This situation has been found for other indigenous populations which share similar historical trauma as Māori.<sup>21</sup> Accurate statistics of the incidence and prevalence of dementia is difficult to obtain in any country due to barriers to early detection, such as, reliability of cognitive assessment tools appropriate to the population concerned,

lack of community education and reluctance to give a diagnosis where limited support is available to those who have the condition.

Early diagnosis generally by a general practitioner or skilled primary health care practitioner is considered best practice and diagnosis early can help the individual, family and whānau concerned to understand what is happening, consider appropriate plans for the future and support which may be needed.<sup>17</sup>

## **Neurological research**

Research is now being undertaken internationally and nationally in New Zealand to explore how the brain operates and pathways which lead to a brain disease. Research, is increasingly finding how adaptive the brain is to changing new circumstances. Alzheimer's disease is now identified in New Zealand as the most common form of dementia for those over 80 years.

There is also recognition that there are other causes of dementia for those under 65 years which are related to cerebrovascular disease, such as Lewy Body disease, frontal lobe dementia and vascular dementia. Parkinson's disease, multiple sclerosis, Huntington's disease and Creutzfeldt-Jacob disease and significant mental health conditions as severe depression and schizophrenia.

Relationship of diabetes and dementia, high cholesterol, stroke and other cardiovascular conditions also affects how the brain functions.<sup>24</sup> Other health behaviours such as the use of alcohol, illegal and legal drug and excessive gambling also impacts upon the brain. Individuals' health and key relationships are often affected by these coping behaviours.<sup>25</sup>

Adverse impact of addictions on individuals, whānau and communities impacts on the quality of life of all involved especially vulnerable citizens as children and elders. Stress and adversity is increasingly being recognised and related to child abuse , domestic violence and elder abuse<sup>2,26-29</sup>

## **Recognition of dementia: implications for Tāmaki Makaurau**

Recognition and diagnosis of the different types of dementia, the cause and when they can occur in people's life is important. Diagnosis not only affects those with the condition but also those who are intimately connected and this has long term implications which then increases health, economic and social inequalities often for the whole whanau.<sup>30</sup>

Tamaki Makaurau (Auckland) is now home to the largest Polynesian population in the world. There is also a significant European population (56.5%) and a growing Asian population whom accounted for almost one in five (18.8%) also a small growing middle eastern population.

Changing demographic, ethnic, age and health status profiles of all five different ethnic populations' resident in the Auckland region now increasingly need to be recognised, even if populations are encouraged to relocate for lack of employment, poor health, breakdown of family relationships or to re-establish if desired cultural or ancestral links.<sup>31</sup> Considerable knowledge now exists in New Zealand in relation to ethnic disparities in health and their relationship to socioeconomic determinants of health.<sup>19,32-34</sup>

New Zealand is fortunate that it has an indigenous population which is maturing and is now negotiating increasingly for social, economic, cultural and political rights which are defined within Te Tiriti o Waitangi and now the United Nations Declaration of Indigenous Peoples' Rights.<sup>35,36</sup>

When Māori achieve their rights, they make changes in their families, whānau, and communities and this contributes to the development of hapu, iwi and other populations in New Zealand. Māori are also seen by other indigenous populations outside of New Zealand as a population constantly negotiating everyday their right to: good governance, self-determination or tino rangatiratanga and be treated equally the same as British subjects.

The Te Tiriti o Waitangi also provides the constitutional foundation for Māori as tangata whenua to be constantly in negotiation with the Crown and its agents to reclaim what they have lost and what they are entitled to expect as a treaty partner with the Crown. Changes that Māori achieve over time become available for other populations, such as the opportunity to speak one's own native language in this country and for children to attend a Kōhanga Reo or language nest.

Being bilingual and bicultural are now increasingly being recognised as protective factors in supporting health, wellbeing and this includes brain function and therefore Māori is actively promoted as one of New Zealand's official languages.<sup>6,37</sup> Changes Māori make also allow the possibility for other ethnic populations to negotiate similar developments using their culture to support their wellbeing and unique place within a region and country.

## **Health planning and decision-making**

Māori have the right to be treated the same as British subjects in the planning, delivery, implementation and assessment of outcomes from any health, accident or disability service and to achieve at least the same health outcomes as that population. Many health services have in their charter of operation recognition of the Te Tiriti o Waitangi yet they do not achieve the same outcomes for Māori compared to non-Māori.<sup>34,38</sup>

When Māori present to health services at a primary health care level, they often do not get the same level of investigation or referral onto a specialist secondary, tertiary or outpatient services as Europeans which can delay diagnosis and treatment.<sup>34</sup> Māori also experience twice the rate of health adverse events compared to the general population and a delay in diagnosis and treatment creates adverse events.<sup>39</sup>

Responsibility is now placed on general and primary health care practitioners to be knowledgeable in the detection of dementia and ability to communicate and discuss this diagnosis with the person concerned, their family, whānau and significant others<sup>18</sup>.

Primary health care workers also need to be able to develop relationships with other health, social, legal and other professionals to support their clients with changes that will occur over time.<sup>40,41</sup> Waiting for significant memory loss may be too late to intervene to help individuals with the onset of dementia or to assist family members understand and respond to events which are occurring and are often ongoing until death.



## Life expectancy

Throughout the health, disability, accident mental and justice systems Māori experience adversely the effects of socioeconomic determinants of health. This pattern is also now emerging for Pacific peoples.<sup>4</sup> Normalisation and acceptance of health inequalities for Māori and other ethnic groups in New Zealand must stop as the ongoing costs are far too high.

On average, Māori die 8 to 10 years earlier than non-Māori in terms of gender comparison Māori men die on average at least 20 years earlier than non-Māori women.<sup>34</sup> For Pacific peoples life expectancy is 6 to 7 years less than the total New Zealand population.<sup>10</sup> This is a total loss of human potential, development and contribution to New Zealand and globally.

At a conference held in Auckland in 2011 regarding excellence in dementia care I proposed that this condition was not necessarily related to chronological age but socioeconomic determinants of health which underpins poor biological health linked to chronic health conditions. This theme was verified with a recent webinar held on dementia with health specialists in this area working with indigenous communities in Australia.<sup>42</sup>

It was proposed that it is not enough to describe or research this issue, courageous decisions and practical actions needed to be taken now to where possible change the course of socioeconomic determinants of health for both Māori and Pacific populations to prevent the onset of multiple chronic health conditions and therefore, delay as long as possible the onset of dementia which is often associated with frailty or geriatric conditions.

The impact of diabetes is epidemic in New Zealand and amongst Māori and Pacific populations, has implications for the Auckland region, and it is only now being considered seriously the full impact across current and future generations, the financial costs involved and more importantly, loss of human potential.<sup>43,44</sup>

Prevalence of diabetes from a study in Auckland involving an equal size sample of Māori and Pacific randomly selected from the community found that Māori had 2.8 times greater risk and Pacific 4.1 times risk of diabetes than Europeans. For every one European diagnosed with diabetes, just under one person was undiagnosed and for every three Māori diagnosed with diabetes, one person was undiagnosed and for Pacific, for every five persons assessed with this condition, just over one person is undiagnosed.<sup>44</sup>

Poor health of specific populations and the neighbourhoods they live and or socialise in also affects their health.<sup>27,33,45</sup> The relationship of diabetes, frailty and dementia as part of the life course of this condition is now being explored.

The New Zealand Medical Association (NZMA) in 2011 took a leadership role and released a health equity position statement recognising the importance of addressing socioeconomic determinants of health throughout the life course. It was identified then two pathways which poor health occurs from the beginning to the end of life.<sup>19</sup>

Research now shows good health occurs when parents are healthy, they plan their children, each child is nurtured in the womb and when each person arrives in a family their parents are loving and supportive of each other and the newborn.

Healthy families develop where members feel valued and have a positive sense of identity and self-esteem. Further, members through life have access to quality education, housing and meaningful jobs which enable individuals and groups to participate, and be involved in different aspects of society.

The second pathway, material deprivation has been identified by the NZMA as the major cause of poor health along with the social structure of any family, whānau, ethnic population or community in society generally. Social position a person, family or ethnic group occupies determines and influences their access to material resources and this influences health status.

Māori are often used as a population to scapegoat and are encouraged by current power holders not to feel aggrieved that through political power, legislation and greed by non-Māori that they have lost significantly their ownership of resources as guaranteed through the Te Tiriti o Waitangi.

Since the 1980s, many whānau, hapu and iwi have been in the process of negotiating for the return or compensation for the loss of their resources as part of an ongoing process to rebuild an economic base which then provides the means for material and social wellbeing.<sup>46</sup>

Social costs of the loss of tribal resources have not yet been negotiated or compensated for; however, the visible effects are now becoming apparent, such as, the number of Māori who are under the supervision and custodial care of Corrections, the number who have mental health issues and now those with chronic health conditions which are life determining, have an ongoing process and are often badly managed.

Somewhere along the path, for many individuals dementia or neurological brain change occurs, often associated with poor health and is a loss of human potential.<sup>34,47,48</sup>

The cost of negotiating for a proportional return of Māori and tribal material wealth to create an intergenerational base has been considerable. Along the way, it has been forgotten that the most important resource any nation can have is healthy people. Good health of people is a value that any Government, political party, hapu, iwi or society should aim to achieve and hold dearly as it has a “value”, it is an asset and if maintained it builds dividends for the next generation.<sup>33</sup> This knowledge was known by ancestors who cited often the whakatauki.

“He aha te mea nui o te ao?  
He tangata! He tangata! He tangata!  
What is the most important thing in the world?  
It is people, it is people, and it is people

Past treatment of Māori and other marginalised ethnic populations have left now a “brown legacy”. Māori and Pacific populations as described are both young and are ageing. Both populations now biologically age earlier due to poor health. Those who are members of these populations face on a daily basis, social and economic stress which then becomes the accumulative effects of poverty. These populations by way of family or whānau are also faced with the care and development of young children and adolescents, the need to support themselves and where possible, to provide help to those who are dependent upon them, often unwell, living close or far away.



As a consequence of the ongoing process of colonisation and globalisation, these populations are also exposed to many unhealthy products, such as tobacco and alcohol with minimum protections in place which result in addictions, which then lead onto chronic health conditions and then this affects all domains of their lives, whānau and social and economic networks.<sup>28,49–51</sup>

Dementia for Māori and Pacific populations is one of the outcomes of their experience of poverty and social marginalisation in New Zealand's increasingly class structured society and in Auckland; it is particularly defined by way of domicile of residence and home ownership.

## **Recognition of the brown legacy**

There is now growing recognition of the current and future effects of a “brown legacy”.<sup>31,52,53</sup> World-class brain research occurs in Auckland (at Centre for Brain Research – Rangahau Te Roro me te Hinengaro, University of Auckland) and provides new information on how different brain conditions develop and intergenerational patterns.

Research is important, interventions may be developed but often they mask or cover for a situation rather than change the socioeconomic determinants of health, such as immunisation to address a particular health issue. Every effort must now be directed to improve material and social deprivation for Māori and Pacific peoples' populations so individuals, family and whānau have choices which most non-Māori accept as normal and their entitlement.

## **Brown legacy pot of gold**

It is important to celebrate the development and growth of Māori and Pacific populations and the human potential these populations offer. With appropriate education and support both populations will be able to assist those in need, that is the rapidly ageing European population, contributing to the ongoing development of this country and providing essential funding required for those who are eligible and have the health status to reach government funded superannuation. This will not be automatic reality of achievement for many Māori and Pacific individuals and these will effects future generations of these populations.

## **Planning of services**

To ensure that there is no colour blindness in Tāmaki Makaurau and nationally, dementia needs to be seen and reframed as not being defined as related to chronological age but instead viewed as being related to poor biological health, which is often linked to the trajectory of one or more chronic health conditions.<sup>54</sup>

Dementia is now increasingly being recognised as end of life, especially for non-Māori, predominantly, Europeans, for it is this population which has had the longest life expectancy in this country, and through the life course have enjoyed the benefits of both material and social wealth since their intergenerational settlement in New Zealand.

Caring for people nearing the end of their life create challenges in any family, whānau or social network, especially if they are involved in caring for one of more members

of a family or whānau whom have ongoing cognitive changes which then affects their personality, ability to handle stress, employment and have developed new patterns of behaviour which may be addictive to cope with brain changes occurring such as, excessive spending, alcohol consumption or gambling. Western countries vary in their response as to who is responsible for the prevention, detection, treatment and long term management of people with dementia.

In any discussions regionally and nationally regarding dementia or end of life care Māori and Pacific must be involved, so that there is a clear focus and an understanding of the importance of prevention of communicable and non-communicable diseases, the early detection and treatment of health issues across the life course and where possible the delay of the onset of one or more chronic health conditions so as to delay the development of dementia.

## **Whānau Ora**

Whānau Ora was introduced as a key policy of the Māori Party which has been supported by the National Party Government.<sup>2</sup> A number of government agencies and organisations are now involved working together with Whānau Ora collectives. These collectives now employ specialist people, often called navigators, whom are tasked to work with whānau and to help whānau members develop and co-ordinate their own life development plans. These plans often include care of whānau members who are frail, unwell or may have a serious disability.

To support the ongoing development of this policy moving from a focus on individual care to engagement of a whānau three new commissioning agencies are now in the process of being tendered to create new structures to channel funds from government and non-government agencies to support whānau development.

In the Tamaki Makaurau region the following Whānau ora collective providers are: Ngati Whatua o Orakei Whānau Ora Collective, Kotāhitanga, Te Ope Koiora, Alliance Health Plus Whānau ora Collective, Pacific Safety Prevention Project, and the National Urban Māori Authority. These collective providers have spent considerable time in the establishment of an infrastructure to provide services which are focussed on whānau defining the outcomes they want achieved.

Professionals' roles are changing as they become guides in supporting the development of whānau to address and manage their health and related issues and navigate and develop their own futures. (The author is a Ministerial Appointee to the Tāmaki Makaurau Whānau Ora Leadership Group.) Changes occurring within many whānau are also redressing intergenerational issues, such as, the loss of culture and language and responding to chronic health conditions, such as diabetes and cardiovascular conditions so that the next generation have better health and life circumstances.

The development of Whānau Ora as a model of care is indigenous and a Pacific home grown. As it develops now and in the future, it may provide a new model to support those whānau caring for a person(s) who have dementia including for non-Māori. The developments that are occurring for Māori and Pacific whānau are consistent with new developments occurring in such countries as in England which it has been

proposed the importance of personalised care and building a house of care around those who have chronic health conditions at home and in the community<sup>55</sup>.

This concept of course was espoused by Māori in the 1980s in relation to the Te Whare Tapu Wha model of health in which it was developed to meet the needs of individuals within a group context which nurtured their physical, mental, emotional and family wellbeing.<sup>56</sup> A connection also made to the importance of connection with whenua (land), te reo (language) and tikanga (customs) of the people involved.

## Conclusion

Prevention of chronic health conditions should be a priority in all whānau. If health issues occur they should be detected early and managed well, so the ongoing process of chronic ill health disease(s) and frailty can be delayed as long as possible. Māori and Pacific populations often experience chronic health conditions early in life leading to premature death, with dementia being part of that process.

Dementia is often not diagnosed for Māori or Pacific but is normalised and perhaps seen as related to poor health and linked to the history of being tangata whenua New Zealand or populations who have experienced migration and marginalisation. Dementia services for Māori and Pacific populations must be planned and funded, especially in Tamaki Makaurau due to the population profiles of this region and knowledge known associated with socioeconomic determinants of health and health inequalities.

He kitenga kanohi, he hokinga whakaaro  
To see a face is to stir a memory

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