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Mai ngā reo pou tangata

(From the voices of guardians)

**Māori whānau carers perspectives of caring for kaumātua with dementia
& service providers perspectives of working with Māori
and cultural service provision**

A thesis

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of the requirements for the degree

of

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Abstract

Globally the prevalence rate of dementia is estimated to be 50 million. In 2016, Aotearoa New Zealand prevalence projections reported 62,287 people were affected by dementia. Māori represented 5.1 per cent, which is expected to rise to 8 per cent by 2038. Māori people prefer to care for ill kaumātua (older people) at home and are experiencing greater stress and increased caregiver burden due to the cultural expectations of caring for kaumātua at home. The two aims of this study were first, to explore the perspectives of Māori whānau carers caring for kaumātua with dementia, and the second aim was to explore the perspectives of staff who work for dementia service providers, addressing areas such as staff's experiences with Māori whānau carers and cultural competency in service delivery.

Semi-structured interviews were conducted with eight whānau (11 whānau carers) within the Waikato region of New Zealand and seven service provider staff participants. Whānau carers were interviewed first. They were asked to share information about their kaumātua. The topics explored the diagnosis process; the behavioural changes of the kaumātua living with dementia and the whānau caring experience. Thematic analysis was conducted on the resulting transcripts to identify themes and to identify potential service providers to approach for interviews. Five service provider organisations were selected, of which four service providers were able to commit to an interview. One service provider could not commit to an interview due to thesis time constraints. Seven staff participants across the four service providers were recruited and invited to share their perspectives of working with Māori whānau. Again, thematic analysis was conducted on the verbatim transcripts to identify salient themes.

Two major findings amidst the perspectives of whānau carers was identified. First, the systemic lack of support across three dimensions, and second the negative impact of caregiver burden. The first deficiency was the lack of support from whānau members, second, the lack of support from community services and third, the lack of support from the government. Whānau experienced poor health as a result of caregiver burden. Staff participants findings were firstly staff believed they were culturally inclusive and responsive, second they reported going beyond their roles and the system to support Māori and third staff identified barriers which exist for Māori in terms of accessing services.

Whānau carers are struggling to find support from other whānau members. Some whānau members are critical of caring methods, while others place additional burden on the carers. Whānau are often described as an interconnected unit, however findings show that Māori whānau carers are feeling isolated and alone, and as a result are experiencing poor health.

Whānau carers perceive a services in their community as not being culturally inclusive or appropriate. Staff participants said that they incorporate respect and compassion into their service delivery. Staff recognise that the numbers of Māori represented at services are low, compared to non-Māori clients. Services need to be integrate cultural training on a regular basis to ensure Māori are comfortable with being Māori in service settings.

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Abbreviations

<i>Term</i>	<i>Abbreviation</i>
Alzheimer's Australia	AA
Alzheimer's Disease International	ADI
Dementia New Zealand	DNZ
District Health Board	DHB
Kaumātuatanga o te Roro	KoTR
Staff participant	SP
Whānau carer participant	WP
World Health Organisation	WHO

Glossary

<i>Te Reo Māori term</i>	<i>English translation</i>
Aotearoa	New Zealand
hapu	sub-tribe
hōhā	annoyed, upset
iwi	tribe
kai	food
kaitiaki	guardian, steward
kanohi te kanohi	Face to face, one to one
karakia	prayer, blessing
kaumātua	male or female elders
kaumātuatanga	old age, ageing
kaupapa	topic, matter for discussion, purpose
koha	gift, offering, donation
kōrero	talk/speech/conversation
koroheke	elderly male
kuia	elderly female
manaakitanga	hospitality, kindness
Māori	Indigenous people of Aotearoa
mātauranga	knowledge
o	of
Pākehā	non-Māori
rongoā	Traditional Māori remedies
roro	brain
taha hinengaro	psychological, mind
taha tinana	physical
taha wairua	spiritual
taha whānau	family
te	the
Te Ao Māori	The Māori world
Te Reo Māori	The Māori language
tikanga	custom, right way
whakawhānaungatanga	the process of establishing relationships,
mihi whakatau	official welcome, speech of greeting
whānau	family

Chapter 1: Literature Review

Part 1: Dementia

Dementia is an umbrella term for several diseases affecting memory, cognition and behaviour that significantly interferes with a person's ability to maintain activities of independent living (World Health Organisation (WHO), 2019).

Globally, prevalence rates for dementia are estimated at 50 million people, with nearly 10 million new cases each year. It is estimated that 5 to 8 per cent of the general population who are aged 60 years and over will live with dementia. The projected prevalence rate is estimated to be 82 million by 2030 (World Health Organisation, 2017a). In 2016 New Zealand prevalence projections reported 62,287 people were affected by dementia (Alzheimer's New Zealand (ANZ), 2017). The majority were 'European and Other' (87.5%), followed by Asian (5.1%), Māori (5.1%) and Pacific Island peoples (2.3%). In 2038, the 'European and Other' is expected to decrease to 77%, while the other ethnicities are projected to rise, Asian (11.7%), Māori (8%) and Pacific Island (3.3%) (ANZ, 2017).

The onset of dementia occurs mostly among older adults, but onset can occur among a younger population (WHO, 2017a; Perkins, 2013). Dementia is often attributed to the normal ageing process, however the symptoms of dementia usually go well beyond normal ageing. Ageing is a known and strong risk factor of dementia, but risk factors may also include physical inactivity, obesity, unhealthy diets, tobacco use, harmful alcohol use, diabetes, and hypertension (WHO, 2017a; Alzheimer's New Zealand (ANZ), 2017; Lo Giudice et al., 2016).

Dementia is categorised as a syndrome rather than a disease. Its unique grouping of symptoms varies from person to person and results in the progressive

deterioration of cortical functions (Alzheimer's Disease International (ADI) & Alzheimer's Australia (AA), 2014). Dementia is a degenerative illness and the prognosis is terminal (Dementia New Zealand (DNZ), 2017), however the rate of progression (which will be discussed in more detail later) for each individual living with dementia is idiosyncratic and varies by subtype. Over 70 subtypes related to gradual memory loss fall under the term dementia (Perkins, 2013).

There are four main subtypes of dementia. These include Alzheimer's disease; Vascular Dementia, Frontotemporal Dementia and Lewy Bodies disease. Globally, Alzheimer's disease is the most common of the dementing disorders and accounts for about 60 to 70 per cent of dementia cases (World Health Organisation, 2017b). In the Asia Pacific Region, Alzheimer's disease represents the largest proportion of dementia cases (64%), followed by Vascular dementia (25%) and Frontotemporal dementia (7%). Lewy Bodies disease represents the smallest proportion (4%) (ADI & AA, 2014). Other subtypes of dementia which are not as common include Younger Onset dementia, Korsakoff Syndrome, Traumatic Brain Injury and Parkinson's disease.

Consequently, there is a long list of dementia symptoms. These symptoms include but are not limited to memory loss, becoming lost in familiar places, forgetting familiar names or faces, difficulties in communicating, repeating stories, wandering, confusion, disorientation, mood changes, aggressive or violent behaviour, and so on (WHO, 2017a; ANZ, 2017). The most common symptom of dementia is memory loss. Although memory loss is commonly attributed to normal ageing, memory loss in this instance is gradual and includes deficits across many forms of memory such as personal memories, memory of places, faces and things, procedural memory, concepts, rules, general knowledge, immediate

memory and new learning (Perkins, 2013). Other symptoms of dementia include difficulties in executive planning and the loss of control of bodily functions, e.g. urinal and faecal incontinence. The complexity of these symptoms are influenced by a constellation of cognitive, biological, environmental, socioeconomic, and social factors. Understanding the severity of these symptoms provides an insight into the stage of the disease's progression (Perkins, 2013).

There are three stages of progression, early, moderate and severe. It is in the early stages of dementia where symptoms feature subtly (Rahman, 2015). Early diagnosis should be investigated sooner rather than later because of the high rate of undetected dementia internationally (Martinez-Ruiz et al., 2018). For some older people it is difficult to accept a diagnosis of early onset dementia, therefore denying the existence of symptoms. Others choose to face it head on. According to Perkins (2013) once a person knows they have dementia, they will either take each day as it comes and maintain hope, or they will want to create a sense of control by being fully informed and prepared. Acquiring an early diagnosis of dementia creates many benefits for both the carer and care recipient. Examples include the identification of potentially reversible causes, the person living with dementia can be actively involved in the decision making of their care or treatments can be used early to slow down the illnesses rate of progression (Martinez-Ruiz et al., 2018).

The moderate stage is determined by the impact it has on living independently. Perkins (2013) states that the moderate stage of dementia occurs when the person cannot manage on their own and requires assistance. As the dependence on carers increases, the person living with dementia requires more assistance and consequently, the carer needs more support.

Historically it was more common for older persons with severe dementia to be diagnosed in the later stages, causing sudden distress for spouses and families. People with severe dementia are less likely to be able to communicate their wishes, and have been considered '*objects*' that have dementia rather than '*people*' living with dementia (Rahman, 2015). The severe stage is determined when symptoms become more and more difficult to manage. Perkins (2013) explains that this stage occurs when a person becomes dependent on their carer for daily support. This is the point where the person is very disabled. Speech may be disorganised and unintelligible, they are noticeably frail, and may experience both urinary and faecal incontinence and are frequently non-responsive. The impact of these symptoms inevitably creates emotional issues, such as depression, guilt and shame (Perkins, 2013) for both the care recipient and the carer. If a family member suspects that their loved one is exhibiting some of these symptoms, the first step is to seek professional medical advice.

Part 2: The healthcare system

Managing dementia has traditionally used a biomedical model of care, therefore relying on the use of pharmaceutical medications to relieve symptoms (Rahman, 2015). The New Zealand Framework of Dementia Care report (Ministry of Health, 2013) agrees, stating that people living with dementia have only ever been offered a medical model of care. Only recently have models of care moved toward a person-centred approach, incorporating both health and social aspects of care (MoH, 2013). *Te Whare Tapa Wha* (Durie, 1998) is used as a foundational Māori model of health throughout New Zealand's health sector. It provides a practical and theoretical holistic approach to culturally appropriate care for Māori. According to Durie (1998) Māori reap the benefits of optimum health and

wellbeing by maintaining balance and stability across each of the four dimensions of Te Whare Tapa Wha. These dimensions are taha wairua (spiritual), taha hinengaro (mental), taha tinana (physical) and taha whānau (family). Non-Māori professionals can use this model as a tool to understand Māori perceptions of health (Martin & Paki, 2012). Martin & Paki (2012) proposed a bi-cultural model of care as a means of working toward inclusion of Māori in dementia care services. The model was presented as a pyramid and was divided into four levels. The top or first level is client based and whānau-centred, the second level represents dementia related community services, the third level represents iwi health providers, and the fourth or foundational level of the pyramid represents the extended whānau system or the Māori community (e.g. whānau, hapu, iwi).

Worldwide governments and healthcare organisations are recognising the importance of integrating healthcare with cultural competency strategies (Ministry of Health, 2014, Health & Disability Commissioner, 2019). It is well documented that health disparities exist among vulnerable minority groups, such as indigenous and migrant populations. Echeverri & Chen (2016) predict that for the first time in U.S. history, the year 2043 will see a majority-minority nation. In other words, there will be no majority ethnicity, but a population of mixed ethnicity, race and culture. Cultural strategies need to be planned and integrated into healthcare services now to accommodate for the increasing diverse population.

The Whānau Ora: Report of the Taskforce on Whānau-Centred Initiatives (Durie et al., 2010) intention was to “foster collaborative relationships between health providers, and between government and community agencies”. The goal was to integrate these support systems to enhance the overall wellbeing of Māori, and ultimately to inform and influence policy (Durie et al., 2010). Whānau-

centred services are the prime focus of Durie et al. (2010) report. It is encouraging services to design their provision with the whole whānau in mind. “The purpose of whānau-centred services is to create whānau-centred methodologies influenced by values, protocols and knowledge contained within Te Ao Māori.” (Durie et al., 2010, p. 2). Furthermore, the Code of Health and Disability Services Consumer Rights pamphlet (Health and Disability Commissioner, 2019) states that the rights of consumers and the obligations and duties of service providers is to ensure “every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social and ethnic groups, including the needs, values and beliefs of Māori.”

Major health service reforms were initiated in 1991, in which two Māori-led initiatives were designed to improve access to services for Māori. These initiatives included the creation of Māori healthcare provider services and the development of cultural safety education (Ellison-Loschmann & Pearce, 2006). The integration of western and Māori services can be viewed as a response to the principles of partnership, participation and protection found in Article 3 of Te Tiriti o Waitangi (the Treaty of Waitangi). Advances in cultural competencies and responsiveness are preferred by certain Māori, because it demonstrates a willingness to acknowledge past grievances and validates the importance of this founding document.

Part 3: Practising cultural competence

Healthcare professionals are required to adopt “transnational and transcultural approaches to transform healthcare systems” (Echeverri & Chen, 2016, p. 1).

There is a lot to consider when working with indigenous and migrant populations.

Do they speak English, and if so how much? Are there barriers to engagement, such as knowledge gaps in cultural values, religious belief, sexual orientation, racial or ethnic values? Are healthcare professionals aware of their own biases which may prevent them from caring in a culturally competent manner? Levy, Like & Shabsin (2009) report that healthcare professionals stereotypes and biases are highly likely to interfere with patient comprehension, i.e. patients do not clearly understand what is wrong with them. Professional reflection is required when attempting to engage competently with patients or clients of cultures different to their own. This highlights the importance of developing culturally competent healthcare professionals. Providing a robust and effective intervention strategy prepares healthcare professionals to provide quality and meaningful service provision for Māori.

Healthcare services need to be accountable for providing regular cultural training to staff members, so they in can deliver a culturally competent service. Management must recognise the importance of not only delivering a person-centred approach (Purnell, 2014), but they must consider a whānau-centred approach (Ellison-Loschmann & Pearce, 2006) and a culturally inclusive approach (Martin & Paki, 2012). Geri-Ann Galanti (2015) (a lecturer at the University of Pennsylvania) provided nursing students with an assignment to develop cultural sensitivity. Student nurses interviewed ethnic patients about how the hospital could improve cultural engagement and provide culturally appropriate care. They were also challenged to implement those changes by involving existing staff members. After listening to the patients needs, students felt motivated to improve their service. Galanti commented that her students learnt more from experiential learning than what she could have taught in a classroom

(2015). Galanti was successfully able to turn self-practise and experiential learning into a self-evaluative and reflective learning process which ultimately yielded positive outcomes for their clients. This method of learning could be used to design cultural competency training for existing and budding healthcare professionals.

Determining best practises for educating staff in cultural competency was admittedly elusive according to Echeverri & Chen (2016). A literature review yielded little information on best practises in teaching cultural competency. There was some debate surrounding cultural competence measurements and interventions. Echeverri & Chen (2016) report that measurements of effectiveness are lacking, and that only a few systematic reviews substantiate their impact. Subsequently, the measurement tools which have been used to date have failed to meet reliability and validity thresholds. Even though this finding is disappointing, caution must be taken in the interpretation of these measurements and concessions must be made to account for the variability in cultures. Essentially, best practises are reached only after attempts to refine the process has been achieved, so further recommendations need to be considered here.

Anderson et al. (2003) recommends that healthcare organisations should provide a mix of culturally diverse staff that reflects the community served; provide translators who speak the client's language; provide culture and language training; provide instructional educational materials consistent with the client's cultural norms and language; and foster culturally specific healthcare settings. According to The New Zealand Framework for Dementia Care (MoHa, 2013) care strategies and treatments should be designed to address the mental health needs for older people. These needs include training health care practitioners in

engaging and providing care for older people; prevention and management of age-related diseases; designing policies on long term and palliative care and age and culturally friendly services and settings.

Part 4: Informal carers

Historically care was provided in state funded institutions but costs needed to be reduced to save public finances, and as a result the government made changes to shift state caring to informal carers in family homes (Power, 2010). Fortunately for families, government remained partially involved in supporting carers and care recipients by creating government care packages (Power, 2010). Care packages were designed to assist older people with maintaining healthy and independent lives.

More recently care packages provide access to community based support services which are purposed to meet the specific health needs of older people. If the older person is suddenly injured or impaired, then family members may be obligated to become carers and make decisions on their behalf (Henry, Hubbard, Struckmeyer & Spencer, 2018; Revinson et al., 2016). Family members may not be able to care for an older person based on a host of reasons, such as family or work commitments. If this is the case then family members may decide to place the older person in an aged care facility. Alternatively, caring for dependent older people in a family home might be the decision of choice (Revinson et al., 2016).

Older people living with dementia have a strong preference to remain in their homes (Townsend, 2011; You et al., 2014), but as their dependence increases, care recipients require informal carers to fulfil that desire. As the carer/care recipient dyad is formed, each person will undoubtedly possess different personalities, express differences of opinion and potentially engage in

contentious interaction. At the same time care recipients are aware that they rely on their carer for assistance and some will make a conscious effort to be less burdensome. Henry et al. (2018) stated that carers who are responsible for dependent care recipients assume new responsibilities beyond self and family. Carers tend to be responsible for navigating through various healthcare systems, such as doctor appointments, hospital visits, coordinating community support services, home care support as well as providing meals, carrying out personal care and household chores for the care recipient. Informal carers are typically family members who volunteer and the role is unpaid. Being a carer of an older person living with dementia increases the risk of caregiver burden and poor health outcomes for carers. As the aging population increases, so too will this social issue, thereby increasing the economic costs for government.

A Canadian study revealed that the cost of unpaid caregiving had been estimated at \$25 billion (Bremault-Phillips et al., 2016). In 2016 New Zealand's economic costs of unpaid caregiving was estimated at \$1.7 billion. According to Alzheimer's New Zealand, that is a 75 per cent increase since 2011. As the care recipient's health begins to decline, the demands of caring increase and the carer will most likely experience 'caregiver burden'.

Caregiver burden is the stress that carers perceive when experiencing the challenges and behaviours of a care recipient. A study comparing demographically similar caregivers and non-caregivers revealed that perceived burden and chronic stress associated with caregiving is related to negative health outcomes such as depression, social isolation, poor health habits, increased cortisol levels, and obesity (Vitaliano, Zhang & Scanlan, 2003, cited in Dassel & Car, 2016). Caswell et al. (2003) study found that caregivers experience a

significant negative impact on cognitive functioning in comparison with non-caregivers. Caregivers experience slower mental processing, inattention and concentration difficulties. Unfortunately these difficulties remain long after the caring has ceased.

Generally protective factors for carers caring for older people living with dementia are social support, emotional support and physical support (Inagaki & Orehek, 2017). Two essential aspects of our social world that contributes to health is social support and social integration. Social support involves psychological and physical support provided by people who intend to help individuals cope with stress. Social integration, involves emotions, intimacy and a sense of belonging to different social groups, such as being part of a family or a community. Experts suggest that being integrated into such a social environment provides a protective benefit against maladaptive behaviours and damaging health consequences (Inagaki & Orehek, 2017). Emotional support is sometimes provided by the people in one's life. When a situation is difficult to bear, these are the people that can be relied upon to be there for you. Such support is important when people have immediate needs that must be addressed.

People can also provide what is known as informational support. This can be guidance, advice, information, and mentoring. Such support can be important when making decisions or big changes in one's life. By having this form of support, people may feel less anxious and stressed out.

Part 5: Māori whānau in New Zealand

Māori are the indigenous people of Aotearoa New Zealand, and represent about 15 per cent of the New Zealand population (Statistics New Zealand, 2018).

According to Te Kupenga, Statistics New Zealand's first survey on Māori

wellbeing, almost all Māori (95%) stated their whānau included parents, partner, children, brothers and sisters. Seventy per cent of Māori reported that it was at least somewhat important for them to be involved in things to do with Māori culture, and 10 per cent said it was not important. In relation to tikanga, 89 per cent of Māori adults said they knew their iwi and Te Reo Māori was spoken among 55 per cent of Māori adults. Lastly, 66 per cent of Māori adults felt spirituality was important to wellbeing (Statistics New Zealand, 2014). As mentioned 5.1 per cent of people with dementia are Māori and is projected to increase to 8 per cent over the next 20 years. In response to the rapid increase of the ageing population and the growing presentation of dementia symptoms among Māori, attention needs to be given to Māori focussed supports and services.

Martin & Paki (2012) reported that protective factors for kaumātua with dementia include a culturally safe meeting place (i.e. the marae), a strong sense of cultural identity, a Te Ao Māori worldview, whakawhānaungatanga, manaakitanga and whakapapa. These protective factors could potentially be applied to some Māori whānau carers too, especially those who prefer a cultural and holistic approach.

The current health status of Māori in Aotearoa can be attributed to the historical, social and political circumstances of the past. During the industrial era, whānau gradually separated into smaller family units, disrupting the natural collaborative network of whānau support (Martin & Paki, 2012). Traditionally Māori were a collective, through groups, whānau, hapu, and iwi. As the industrial era progressed, more and more Māori migrated to urban cities in search of work, thus fragmenting the whānau dynamic. It can be difficult to find family members

to share the care of kaumātua, so the default attitude is to turn to family members who are close in proximity to the kuia or koroheke (Mead, 2016).

Part 6: Exploring the perspectives of whānau carers & service providers

Service providers in Aotearoa are based on a biomedical model and commonly offer pharmaceutical medication to relieve symptoms and behaviours. The services are designed using a western model approach, catering for the majority of service users who are predominantly Pākehā (New Zealand European). It was not until recently that services began to move toward a person-centred, and whānau-centred approach to service delivery. The foundational Māori health model Te Whare Tapa Wha continues to influence service provision for Māori. Working collaboratively with Māori and other services demonstrates a commitment to a whānau-centred approach to care. Healthcare services acknowledge the importance of integrating cultural competency and cultural education training into services, especially if the intention was to fulfil the principles outlined in the Te Tiriti o Waitangi.

Māori are the indigenous people of Aotearoa New Zealand. The majority of Māori whānau consist of a partner, parent, children, brothers and sisters. According to Te Kupenga, (the Māori wellbeing survey) most Māori believe that Māori culture, Te Reo Māori and spirituality are important. Māori carers prefer to care for kaumātua at home and avoid placing kaumātua in aged care facilities. For optimum wellbeing kaumātua want to remain at home, and desire to be in culturally safe spaces, maintain a secure cultural identity, and enjoy the benefits of a Te Ao Māori worldview, by practising principles such as whakanwhānaungatanga, manaakitanga and whakapapa. Māori carers have a demanding role, which requires organisation and planning. Māori carers actively

seek support from other whānau members, from services and from the government to support their kaumātua. Unfortunately caregiver burden features significantly in the lives of Māori carers due to lack of education and the increasing demands of kaumātua living with dementia.

Māori whānau carers perspectives were explored to identify what it is like to care for kaumātua living with dementia. Staff of dementia service provider organisations were also interviewed to explore their perspectives of Māori whānau and to identify whether current services are responsive to the cultural needs of Māori carers and their whānau. Part One of this chapter will focus on the interviews with whānau carers. Whānau carers perceived either a lack of support from family members, from support services in their community and the government. The experience for many Māori whānau carers was this feeling of isolation and loneliness when caring for their kaumātua living with dementia. Part Two will address the perspective of staff participants. Staff believe that the services in which they work do provide a culturally inclusive and responsive service, and they will go beyond their system to provide good outcomes for Māori whānau. Staff also address some of the barriers which prevent Māori whānau from accessing their services.

Chapter 2: Method

This study stems from a Health Research Council of New Zealand grant awarded to the University of Auckland's project Kaumātuatanga o te Roro (KoTR) – A Māori approach to the diagnosis and management of dementia. The KoTR project aims to establish a culturally responsive dementia diagnostic assessment tool specifically for Māori. My role was to interview whānau carer's in the Waikato region for the KoTR project, transcribe the interviews and present preliminary findings to the KoTR select committee. I sought permission from the University of Auckland to use the whānau interview transcripts for this smaller study (Master's thesis). This master's thesis explored the issues surrounding whānau carers and their ability to care for kaumātua with dementia. Dementia related service provider organisations were also interviewed. The focus of this study was to explore the perspectives of whānau carers and the perspectives of staff working within dementia related service provider organisations, and to identifying patterns of interest.

Ethics approval for the whānau carer interviews was obtained by the University of Auckland from the Health and Disability Ethics Committee on 5 October 2016, ref: 16/STH/154. Consequently, the researcher sought and received an ethics exemption (because the study had received ethics approval from another committee) from the University of Waikato on 8 July 2017 to interview the whānau carers. To interview service providers, ethics approval was sought from the University of Waikato Human Research Ethics Committee. Ethics approval was granted on 25 October 2017, ref: HREC (Health)#2017-39.

Part 1: Whānau carer interviews

Participants

Eleven whānau carer participants across eight whānau were interviewed, however only ten participants gave consent (see Table 1 & Table 2). All whānau carer participants who were recruited were over the age of 30. Nine participants were female, two participants were male. One male participant declined to consent, but wished to contribute to the interview. His data was not transcribed for inclusion in this research. The mean age of the ten participants was 52.5 years. The ages ranged between 32-71 years. Whānau participants included a wife, daughter(s), granddaughter-in-law and a nephew. At the time of the interview, participants lived in the following locations: Hamilton, Morrinsville, Pukekawa, Te Awamutu, Tokoroa and Tuakau. Of the ten participants, six were married, three were single and one was in a relationship. Seven participants lived with more than one person, including their kaumātua. One lived alone with their kaumātua, and two lived with their spouse separate from the kaumātua, who lived semi-independently in their own home. Although the majority of participants (8) indicated that they did not speak Māori, choosing options “not at all” or “not very well”, one of the eight did indicate Māori fluency between “not very well” and “fairly well.” Two participants spoke Māori “fairly well” revealing that they learnt Te Reo during adulthood. All ten of the participants spoke English. Five participants stated that high school was the highest level of education they had obtained, four participants stated tertiary qualifications and one participant did not answer. Six participants indicated that their annual personal income was between \$10,000-\$20,000; four participant’s annual income was respectively \$20,000-\$30,000; \$50,000-\$60,000; \$60,000-\$70,000, and \$80,000 and above. Two

participants were employed full-time, while eight participants were unemployed because they were full-time carers.

Whānau carer participants cared for eight kaumātua, each of Māori descent. Seven kaumātua were female and one kaumātua was male. The mean age of kaumātua was 78.4 years. The ages ranged between 65 to 94 years. Of the eight kaumātua, six kaumātua spouses/partners were deceased, and two kaumātua were still living with their spouse/partner. Kaumātua had between four and eleven children. All the kaumātua spoke English; but of the eight kaumātua, four spoke fluent Te Reo Māori (their first language), two kaumātua spoke a little Te Reo Māori and two spoke no Māori at all. The main occupations of kaumātua were housewife, chef, bricklayer, mental health caregiver, cleaner and home carer. The iwi of the kaumātua included Ngāpuhi, Tūwharetoa, Ngāti Paretekawa, Ngāti Whawhake, Tainui, Ngāti Ruanui, Ngāti Toa, Maniapoto, Ngāti Paoa and Ngāti Pīkiao. Demographic information for the whānau carer and kaumātua can be found in Tables 1 & 2.

Table 1. *Whānau carer participants & Kaumātua demographics*

<i>Whānau demographics</i>						<i>Kaumātua demographics</i>							
<i>Whānau</i>	<i>Participant</i>	<i>Age</i>	<i>Sex</i>	<i>Ethnicity</i>	<i>Relationship to Kaumātua</i>	<i>Age</i>	<i>Sex</i>	<i>Spouse living?</i>	<i>Home owner</i>	<i>Languages</i>	<i>Employment history</i>	<i>Diagnosis</i>	<i>No. of children</i>
1	1	59	Female	Māori and Pakeha	Daughter	83	Female	No	No	Te Reo Māori, English	Housewife	Dementia – Moderate	10
1	2	32	Female	Māori and Pakeha, Māori and other	Granddaughter-in-law	-	-		-	-	-	-	-
2	3	54	Female	Māori	Daughter	84	Female	No	Yes	Te Reo Māori, English	Domestic Supervisor / Nurse	Dementia	7
3	4	71	Female	Māori	Wife	71	Male	Yes	No	English	Bricklayer	Parkinson's / Alzheimer's	-
3	5	39	Female	Māori and Pakeha	Daughter	-	-		-	-	-	-	-
4	6	52	Female	Māori	Daughter	81	Female	No	Yes	English	Housewife	Alzheimer's	10
5	7	62	Male	Māori	Nephew	76	Female	No	No	Te Reo Māori, English	Chef	Dementia, Alzheimer's	4**
6	8	64	Female	Māori	Daughter	94	Female	No	Yes	Te Reo, English	Home carer	Dementia, Alzheimer's	8
7	9	42	Female	Māori	Daughter	65	Female	Yes	Yes		Mental Health caregiver	Dementia – early onset	11
8	10	50	Female	Māori	Daughter	73	Female	No	Yes	English	Cleaner	Dementia, Alzheimer's – early onset	4**
8	11*	-	Male	-	-	-	-		-	-	-	-	-

*Declined consent

** At least

Table 2. *Whānau carer demographics continued*

<i>Whānau</i>	<i>Participant</i>	<i>Iwi</i>	<i>Relationship status</i>	<i>Who do you live with?</i>	<i>Do you kōrero Māori?</i>	<i>Is Reo Māori your first language</i>	<i>Are you in paid employment?</i>	<i>What is your income?</i>	<i>Highest level of education?</i>
1	1	Ngāpuhi, Tuwharetoa	Married	Husband & Mother	Not Very Well	No	No	\$10,000-\$20,000	High School
1	2	Ngāti Porou	Married	Husband and four boys	Not very Well	No	No	\$80,000 and above	Diploma
2	3	Ngāti Awa, Ngāti Maniapoto	Married	Husband, Mother & two mokopuna	Fairly Well	No	Yes - Full time carer	\$10,000-\$20,000	6th Form
3	4	Kahungunu, Tūwharetoa, Tainui	Married	Husband, daughter, mokopuna	Not very Well	No	No	\$10,000-\$20,000	High School
3	5	Tainui, Ngāti Kahungunu, Ngāti Tūwharetoa	Single	Mother, Father, son	Fairly Well	No	No	\$20,000-\$30,000	Cert 4 - Tertiary School
4	6	Ngāti Hine (Ngāpuhi), Tainui, Tūwharetoa, Maniapoto, Ngāti Ruanui, Ngāti Toa, Morehu	In a relationship	Mother, whāngai brother, niece, nephew and mokopuna	Fairly well, Not very well	No	No	\$10,000-\$20,000	Bachelor Social Sciences degree
5	7	Raukawa, Maniapoto, Ngāti Mahuta	Single	Aunty	Not at all	No	No - Full time carer	\$10,000-\$20,000	6th Form
6	8	Tainui	Married	Husband	Not at all	No	Yes	\$60,000-\$70,000	Three years college
7	9	Ngāpuhi, Ngāti Pīkiao	Single	Son, niece, grandson	Not very Well	No	No	\$10,000-\$20,000	n/a
8	10	Tainui	Married	Husband, sons	Not very Well	No	Yes - Accountant	\$50,000-\$60,000	NZ Diploma in Business
8	11*	-	-	-	-	-	-	-	-

*Declined consent

Measures

Using the Kaumātuatanga o te Roro Interview Schedule (see Appendix 1), semi-structured interviews were conducted with each whānau carer participant. Three whānau were interviewed with two whānau carers present. The remaining five whānau carers were individual interviews. A semi-structured qualitative interview schedule was used, however in keeping with the kaupapa Māori interview approach of the larger project KoTR, the interview was conducted in a natural conversation style (Dahlberg & McCaig, 2010). This style allowed respondents to say as little or as much as they wanted, for the sake of individual relevance (Breakwell, Hammond, Fife-Schaw, & Smith, 2006). The questions were not always strictly adhered to because the conversation would often generate other questions that were not included in the interview schedule. Generally all the interview questions were asked because each topic in the interview schedule addressed relevant information for this study. The first topic obtained kaumātua demographics; the stage of dementia and the process of assessment and diagnosis; Next, participants were asked to talk about the changes in the person living with dementia and the whānau experience; helped to identify the level of stress among whānau carers; Whānau understandings of dementia offered insight into the whānau carer's dementia education level; services for Māori with dementia and their care partners helped to identify issues around access and potential barriers; and their cultural view of caring for person with dementia afforded perspectives pertaining to the importance of culture in caring. A separate demographics form (see Appendix 4) was also given to whānau carer participants to complete.

Procedure

The principal investigator of Kaumātuaatanga o te Roro and I called various dementia related support services within the Waikato region to recruit potential participants. Managers of the respective support services identified eligible candidates and distributed KoTR research information sheets to whānau members who were currently caring for Māori kaumātua living with dementia. In order to meet the research criteria, whānau participants must have a kaumātua who was living at the time of the interview. The kaumātua needed to be of Māori descent or identify as Māori, and the whānau participant must live within the Waikato region of Aotearoa. Whānau participants did not need to be of Māori descent, but it was preferred. A combination of people living in urban and rural residences were recruited.

Whānau participants who accepted to be interviewed advised the manager of the relevant support service, who then passed on contact details to the research team. The researcher made direct contact with each whānau participant either by phone, text message or email to initiate communication. Phone calls were then made to each participant, and the kaupapa of the research was explained.

The first interview was conducted by both the researcher and the principal investigator of KoTR, Dr Margaret Dudley, and I conducted the remaining seven interviews alone. All whānau interviews were home based, and kai was shared either during or at the end of the interview. Interviews often began with karakia followed by whakawhānaungatanga. The purpose of the study was explained to the whānau carer(s) using the Participant Information Sheet (see Appendix 2), and then the participants were asked to complete the required paperwork (i.e. Consent form (see Appendix 3), Demographics form (see Appendix 4) and Contact details

form (see Appendix 5). Once the consent forms were signed, two digital dictaphones were used to audio record the interviews. Written notes were taken occasionally by the researcher throughout the interviews. Interviews took between one to two hours. At the completion of the interviews, the participant received a koha consisting of a University of Auckland tote bag, a University of Auckland pen, a KoTR t-shirt and scarf and MTA vouchers valued at NZ\$50.

The interviews were conducted in the English language, however karakia and whakawhānaungatanga were sometimes offered in Te Reo Māori. Ten participants gave written consent however one participant opted not to sign a consent form. He chose to remain in the interview and contribute kōrero so both responses were audio recorded, but his comments were omitted from the anonymized transcript.

A one page summary of the research results were sent to all the participants who requested summaries. Participants will be sent an email from the researcher with an online link to the finalised and published Master's thesis. Whānau interviews were conducted and transcribed prior to the start of the service provider interviews.

Part 2: Staff of service providers

Participants

Seven staff participants were recruited across four service provider organisations. Six participants were female, one participant was male. The ethnicities represented were one New Zealand European; one European.; two Filipino, two Māori and one Cook Islander (see Table 3). No other personal demographics were taken, other than the positions they held in the organisation. The titles of their positions and the names of the organisations have been omitted to protect the

anonymity of the staff participants. General occupations were reported in Table 3 to assist in understanding the type of expertise each staff participant possessed.

Table 3. *Service provider demographics*

<i>Service Provider Participant</i>	<i>Sex</i>	<i>Ethnicity</i>	<i>Occupation</i>
1	Female	NZ European	Registered Nurse
2	Male	Filipino	Registered Nurse
3	Female	Filipino	Manager
4	Female	European	Coordinator
5	Female	Māori	Coordinator
6	Female	Māori	Coordinator
7	Female	Cook Island	Coordinator

Measures

Similar to the whānau carer interviews, semi-structured interviews were conducted with each staff participant. One service provider had three staff participants present, another had two staff participants present and the remaining two were individual staff participant interviews. A qualitative semi-structured interview schedule was used. Again, in keeping with the kaupapa Māori interview style, the interview was conducted in a natural conversation style (Dahlberg & McCaig, 2010) to allow participants to say as little or as much as they wanted (Breakwell, Hammond, Fife-Schaw, & Smith, 2006). The questions were not always strictly adhered to because the conversation would often generate other questions that were not included in the interview schedule. The following topics were explored to ascertain staff participants experiences when working with Māori whānau who care for kaumātua affected by dementia; their awareness of supports or services available to Māori whānau carers and kaumātua; their

perceived strengths and weaknesses of their service; exploring dementia education issues that Māori whānau carers may experience and explore issues around accessibility, flexibility, inclusivity and responsiveness of their respective service. A topic covering the use of rongoā, traditional Māori treatments or remedies and medical treatments was also explored.

Procedure

After analysing the whānau carer transcripts, the researcher identified five service provider organisations where whānau carers had received support. The researcher contacted the managers of the five service provider organisations in the Waikato region to seek permission to interview a staff member. Of the five service provider organisations, four agreed to participate. The fifth organisation was unable to commit to an interview within the required timeframe. Managers of the respective support service identified eligible candidates and distributed KoTR research information sheets to staff who were working with Māori kaumātua and whānau carers. The purpose was to recruit staff members who work directly with Māori whānau who care for kaumātua living with dementia. In collaboration with the managers of each organisation, the researcher contacted a potential staff participant from the four service provider organisations. Emails were sent to potential staff participants to invite them to participate in the research. Attached to the email was the Participant Information Sheet (Appendix 6), the Consent Form (Appendix 7) and the Service Provider Interview Schedule (Appendix 8). A confirmation email was sent to the staff participants detailing the agreed date, time and location of the interview.

Interviews were conducted at the service provider's offices during work hours, in a private meeting room or office where only the researcher and the

participants were present. Thirty minutes were allocated for each service provider interview, however interviews were extended if the researcher deemed necessary and if the participant(s) were willing. Before the interview began, the researcher briefly explained the Participant Information Sheet to ensure the participant understood their role during the interview process. The ethical principles of privacy and anonymity was also explained to each staff participant. The interviews were conducted in the English language, however karakia and whakawhānaungatanga were sometimes offered in Te Reo Māori. Prior to the interview staff participants were asked if they had read the Participant Information Sheet, to which the participants responded affirmatively. Next participants were asked to complete the required paperwork (i.e. Consent form (Appendix 6)). Once the participant completed the research paperwork the researcher then asked the participant if they had any further questions before proceeding to the interview. After the consent form was signed, two digital dictaphones were used to record the interview and written notes were taken occasionally. At the completion of the interviews, each staff participant received a koha of supermarket vouchers valued at NZ\$20 each.

Part 3: Data Analysis

Thematic analysis

Thematic analysis was used to explore the perspectives of whānau carers and service provider staff and to identify relevant themes and patterns across participant's raw data (Braun & Clarke, 2006). Part of the analysis process included an exploration of the research findings to see if these findings supported the current literature.

Transcription and coding

Whānau carer and staff transcripts were coded separately to identify the salient themes within each of the groups. Analysis of the data was achieved by listening to audio recordings, transcribing those recordings verbatim, then reading and coding salient themes and subthemes which were relevant to the research. Māori have a unique cultural style of communication, for example their language, voicing, intonation, and body language is subtle, and may be important to the interpretative process (Braun and Clarke, 2006) As a Māori researcher, it is important to consider different types of communication, such as body language, non-verbal and verbal communication when carrying out this interpretation.

The initial codes identified among the whānau carer transcripts consisted of separating the most common statements across each of the whānau carers. The majority of whānau carers reported on the challenges of caring, the lack of education about dementia, the lack of support from whānau, the stigma of aged care facilities, the issues of attending services, cultural concerns, attitudes toward western ideals and the relationship quality between the carer and the kaumātua. After rereading and redefining the data, an overarching theme of support was identified. The subthemes for the whānau carer data was defined as the lack of support from whānau, the lack of support from the government and the lack of support from service providers. There was also an extra code added to address the issue of self-care for whānau carers because they were often feeling isolated and alone.

Staff participants transcripts were also initially coded to include the most important and common features. The initial codes were defined as Going beyond their roles to help Māori, little Māori representation at services, Not all Māori

want Māori services, cultural training and resources are available, strengths and weaknesses of services, manipulating the system, whānau are not comfortable in a pakeha system. Again, after rereading the data numerous times, three themes were most common, 1) Cultural inclusive and responsive services, 2) Going beyond and 3) Barriers to accessing services for Māori.

Part 4: Conducting research

All Māori researchers are intimately connected to Māori society, whether it be through whakapapa links or through active participation in their Māori community, however the degree to which they understand Te Ao Māori or the degree to which they identify as Māori varies due to the historical impact of colonisation and assimilation. As a result researchers knowledge level may directly or indirectly influence the reliability and validity of a kaupapa Māori approach. Although this sounds problematic, the use of cultural advisors (experts in tikanga Māori and Te Ao Māori) and the combination of Māori and Western research approaches are predicted to produce a positive synergy.

Each Māori researcher has an implicit duty to use their knowledge from both the western world and Te Ao Māori to protect and advance the welfare of their people and the wider Māori community. As a Māori researcher with basic reo Māori fluency and basic knowledge of tikanga Māori and Te Ao Māori principles, it seemed appropriate to combine a kaupapa Māori approach and a western approach to this research. A cultural advisor was sought to clarify processes and guide research practise. The research process was predominantly guided by the ethical principles of whakawhānaungatanga: building relationships by being authentic; manaakitanga: sharing, hosting and being generous; aroha: giving love and respect; mahaki: demonstrating humility in the sharing of

knowledge and building trust; mana: showing respect, and dignity; titiro whakarongo kōrero: look, listen and then speak; kia tūpato: be cautious and keep safe, both culturally and politically and be reflective of my influence and interaction with Māori; He kanohi kitea: be genuine and familiar to participants in order to naturally build a connection and trust (Pipi et al., 2004).

Chapter 3: Results

Māori whānau carers (whānau participants) perceptions were explored to identify what it is like to care for kaumātua living with dementia. Staff of dementia service provider organisations were also interviewed to explore their perspectives of Māori whānau and to identify whether current services are responsive to the cultural needs of Māori carers and their whānau. Part One of this chapter will focus on the interviews with whānau carers. Whānau carers perceived either a lack of support from family members, from support services in their community and the government. The experience for many Māori whānau carers was this feeling of isolation and loneliness when caring for their kaumātua living with dementia. Part Two will address the perspective of staff participants. Staff beliefs about culturally inclusive and responsive service, and their views on the health care system and Māori whānau. Staff also address some of the barriers which prevent Māori whānau from accessing these services. The aim of this study was to explore the perspectives of whānau carers and the perspectives of staff working within dementia related service provider organisations, and to identifying patterns of interest.

Part 1: Whānau carers perspectives of caring for kaumātua

Thematic analysis outline

Table 4. *Whānau perspectives of caring for kaumātua living with dementia*

<i>Theme</i>	<i>Subthemes</i>
Lack of support	From whānau
	From service provider organisations
	From government
Carer wellbeing	

Two main themes were identified amidst whānau carer perspectives of lack of support and caring for self (see Table 4). The first theme, ‘Lack of support’ contained three subthemes which identified the lack of support from whānau, the lack of support from service provider organisations and the lack of support from government.

Lack of support from the whānau

Before delving into the reasons why whānau carers feel unsupported by their family members, it is important to understand how they came to be carers. Deciding who would be responsible for caring for kaumātua was often a collaborative whānau effort. It was based on factors such as availability, the ability to adjust one’s lifestyle, the illness progression of the kaumātua, proximity to the kaumātua and essentially a volunteer who was willing to take on the caring role. Once a collective decision was made, it was usually one individual, a primary whānau carer who took on the day-to-day responsibilities of caring for kaumātua.

My siblings wanted one of us to come and stay (at the kaumātua home in urban city] so I opted, cause I had just finished my job and I was moving out of my house anyway, so I thought well I’ll come in.... and my kids are gone ... nobody else could do it. Plus the moko that was here with her started a relationship and moved on, and I couldn’t very well leave her by herself (WP6).

Being a carer is a huge responsibility for one person and requires a great deal of patience, organisation, affection for the kaumātua, and resilience. One important research finding was that the contemporary ‘whānau’, (which is a term

that is often referred to as a collective or family group) was not always a supportive network in this modern context. The notion of collective whānau caring for kaumātua was acknowledged in some cases, but for most carers caring was not necessarily proportionately shared across whānau members. The majority of whānau carer participants felt like they carried the burden alone, and received very little support from other whānau members. Most whānau carers were living with or near immediate or extended whānau members who were capable of supporting the kaumātua and the whānau carer to some degree, but not all of their whānau were keen to help. One whānau carer shared that her daughter-in-law would support her regularly, but did not want to rely on her because she had small children to take care of. This whānau carer wished her siblings lived closer so she could share the responsibilities of caring for their kaumātua with them, so they could understand the difficulties associated with caring for someone living with dementia.

I wish we were closer (proximity) in some aspects, so that she could be shared around a little bit more, you know, even if it was for a couple of hours a day, with each of them. So they could have at least a couple of hours with her to look after, and then they can see. It would be great in a perfect world for that to happen (WP1).

Some whānau members expect that the carer look after the bulk of the responsibility when caring for their kaumātua. This attitude was reiterated by another participant who found it difficult to receive support from her immediate whānau, so she returned home to New Zealand to seek support. As she remembered the lack of contact and support from her adult children she said that ‘some people are just different’ (WP4), meaning sometimes people choose not

want to help. Another participant reasoned that it is probably because they (her adult children) do not know what it is like to be a carer for someone who is living with dementia. One whānau carer was surprised by the lack of support from whānau who lived nearby and another whānau carer had to rely on a sibling, who lives half way across the world to provide support.

I think a lot of them [carers siblings], I'm trying to be nice about it, but I think they just expect Mum to do the bulk of it (WP2).

It gets frustrating, you know, when you've got another sibling here that could do a little bit more than she is doing (WP8).

My older sister lives in America and she's actually coming over. I mean out of all my [siblings], I've got 10 of them, my sister that lives in America is coming over to give me a holiday (WP1).

Whānau carers shared their views on why there were deficits in sharing the responsibility of care among their respective family members. In fact there were a number of reasons given, such as work commitments, own family commitments, indifference and resentment.

They're quite full on with their own families, with their children and their daily living ... I had the time then to do, to help her out and to take her to her appointments. And she felt comfortable with being with me. (WP9)

The thing is, Sam's got half a dozen kids and the youngest one is just starting school. Kylie has got all her kids and they are troublesome kids, they wag school and do all that sorta carry on, and Julie, the other daughter, yeah, she doesn't want to have much to do with her mother

because there's a bit of animosity there that happened years ago and she hasn't really forgiven her mother (WP7).

Whānau carers were also expected to take care of additional family members, such as grandchildren, nieces or nephews. There seemed to be an expectation that because whānau carers are at home caring for kaumātua, they should be able to care for others too. Some whānau carers were not opposed to looking after others, even though the extra responsibility was clearly impacting on their wellbeing. While other carers were frustrated by the unnecessary demands placed upon them by whānau who tended to lack consideration for others. Another issue carers faced was criticism from whānau members about their quality and method of care. Kaumātua living with dementia are vulnerable, and whānau carers can be vulnerable too. The rigid expectations of whānau can cause distress for carers, which adds additional pressure to an already demanding role.

Why is Mum like that?" or "What do you feed her?" and I'm going, "No ways, mate, you's aren't interrogating me. You's are here to do a job [find paperwork] and do it. Mind your own business. If there's a drama, yeah okay, you can say all that, but there's none (WP6).

People use to comment 'Oh she looks so skinny,' but I says, 'She's always been tiny for goodness sake,' so I got hōhā and so I started changing the diet a bit. So I put in, we gotta have fish'n'chips every now and again, you know and a nice big burger ... man she can eat. She'd demolish the whole plate. And then, ... I gave her a dessert of ice cream, cause that's what her dessert has to be, ice cream and fruit. Demolished the whole lot. Couldn't believe it. Here's a little lady and she's getting bigger and I says

‘See now they can’t bloody say that you’re skinny. Not anymore.’ She’s got a big butt now (WP7).

Furthermore, a whānau carer explained that her husband was frustrated by the amount of work that his wife was required to do, and suggested that it was time to put the kaumātua in a home (aged care facility). The carer felt torn between the wishes of her kaumātua (to remain in the family home) and the urging of her husband. It seems that whānau carers must also evaluate and negotiate the wants and needs of both the family and the kaumātua to ensure everyone is appeased.

He [whānau carer’s husband] just thinks that this is too hard, and there’s too much responsibility on one person. But I have to listen to that voice, cause he, you know, lives here too and it’s balancing that. He’s been very patient to a certain degree and I don’t know how long that will last, and that puts extra pressure, so you know, if her toileting gets worse, if she starts exhibiting any other strange behaviours, then he’s going to be wanting her to leave my house. Our house (WP1).

Whānau members collaborate when making decisions for their kaumātua, but often that is where the collaboration ends. There appears to be a tendency for whānau members to avoid sharing the burden of care once a person has been delegated to care for their kaumātua. Whānau members seem to expect that the designated carer will take care of all the duties relating to their kaumātua. There are whānau members who are supportive, and then there are whānau members who are not. While there are valid reasons why some whānau members cannot share the responsibility of caring, there seem to be more whānau members who

could help, but choose not to. Essentially, the common factor among whānau carers is that they feel isolated and alone in their caring role. Furthermore, some whānau members scrutinise the caring efforts of whānau carers suggesting they meet their expectations, while others are ignorant of the daily demands of caring, expecting whānau carers to take on more responsibilities, for example looking after the children of other whānau members. Whānau carers have an enormous job, and yet they are charged with placating whānau members and kaumātua to maintain harmony in the home. If immediate or extended whānau members cannot be relied upon to help whānau carers, then carers have no other choice but to seek external supports to help them provide quality care for their kaumātua, and to reduce the negative effects of carer burden and burnout.

Lack of support from services in the community

For the purpose of this research, a lack of support from service provision organisations will be defined as a systemic blind spot for Māori focussed, inclusive, and responsive services. Before identifying the deficits in current services from a whānau perspective, a model example of Māori focussed services can be found in the Māori whānau wraparound service. During the whānau interviews, most of the participants were engaged with a Māori health service, and praised this service. Unfortunately, this service was not interviewed by the researcher because of timeframe constraints required for this research. Whānau are seeking Māori services that will appropriately meet their cultural and social needs. They want culturally appropriate, inclusive and responsive services. They want a workforce who understands them and can deliver services using principles such as manaakitanga and whakawhānaungatanga.

Is there any dementia based Māori organisations, like there are at the Pākehā ones? ... I know with a Māori organisation involvement with the family would be quite paramount in the structure ... but it's just weird for me to come home (to New Zealand) and meet that same Pākehā whakaaro (approach to care) ... whereas Māori, the whole whānau are included in the sharing of information and decision making that kind of stuff, so that was a little weird to meet that coming home and not have that Māori understanding and compassion for the family, even though they do in their own ways, they do, but it's very, the white dominated way of doing things. I would like to know if there's anything, if you's know of anything or if there is anything in place that is available to Māori? (WP5).

Participants were asked if they were aware of any other services that delivered culturally appropriate services. The response was 'No'.

Probably not Alzheimer's Waikato or Parkinson's. Probably not the hospital, not the doctor, not the aged one, ... like the OT, the ones in those areas (Waikato Hospital services) ... They're all Pākehā's (WP4).

Whānau participants commented that they preferred not to engage with services because they still see it as a Pākehā system, made by Pākehā for Pākehā and they would prefer to engage with health professionals and services that are appropriate for Māori.

I've got a whānau, you know and I have to cater for her (kaumātua) and everybody that's in here. And that's what I was trying to tell Sarah, who supports me ... because it (the programme) made me like I was doing

wrong, that whole programme. ... I need some help to figure out what to do with her at times ... because I was peed off that it (the programme) was making me feel down, rather than help me. There should be a Māori programme that fits us. Because I don't fit that (WP6).

They were lovely, lovely people (at the support group). They really, really were, but at the time I needed some real people. Someone that I could say, 'F*ck, how's your f*cken day going?' (WP3).

I expressed that anybody that came to see Mum, or within that support thing had to be a Māori. ... It was just to make her feel comfortable with it, so yeah (WP10).

To address the systemic cultural blind spot, current service models need to be adapted to include a Māori focus. Services are likely to increase Māori representation if they designed an inclusive environment for Māori and their whānau. Most of the whānau carers who participated in this research have attended educational programmes and support groups, however they were quick to express their discomfort when attending these services, especially when they noticed they were the only Māori in the room. Māori carers noticed that they were alone, and felt uncomfortable as a result. No one wants to be an outsider, and no one wants to feel alienated, which is essentially a theme that was echoed throughout the whānau carer interviews.

Just me, yeah. That's how odd it felt ... Yeah, yeah I thought it would help me. But it just made me feel so bad, like I was guilty ... this model doesn't fit because I'm not alone, and yet I am (WP6).

Well, okay my first experience was to go to one of their meetings and was all Pākehā's. I was the only Māori there (WP4).

If current services remain unchanged, whānau carers will likely continue to disengage with services. Two whānau participants said that they used American websites to learn about dementia, and to receive support as a carer. Although these online sites are not Māori focussed, these sites provide an opportunity to avoid the services in the community, and yet receive the help they need in the safety of their own home. The sites were described as the MERCK website and a Facebook group. Each participant found the online education and support group useful and continued to refer to the sites for help when needed. Another interesting find was that the online support group comments were homogeneous with the language the whānau participant was accustomed. A whānau carer explained that she could not freely express herself at the 'nice' support groups held in her community because her language (profanity) would not have been appropriate in that setting.

I went on Facebook and online there was a dementia group, and they were in America, and I'm still part of that group. I opened the first page and the first thing that I read was this woman saying "Get me the f*ck out of here," and I thought "That's me!" ... and I read it, and it really, it helped. ... it's just wonderful, honestly the people are getting in there and I could relate to everything that was being said in there (WP3).

Furthermore, if whānau continue to avoid the services in their community and do not have access to online education, whānau will continue to be unprepared and ill equipped for their caring role. The majority of whānau

participants did not know the exact meaning of the term dementia. There seemed to be some confusion between Alzheimer's disease and dementia and more often than not the participants asked the interviewer what the difference was. Some participants thought dementia and Alzheimer's disease were different diseases, but couldn't confidently explain why. To support the whānau, an explanation was offered to the whānau carers by the researcher.

So Alzheimer is the umbrella that dementia comes from or is dementia the umbrella in which Alzheimer comes from (WP3).

Dementia comes from the word demon. She is possessed by demons, because that's how people would observe her, as being possessed by demons (WP7).

Māori whānau carers are seeking Māori dementia related services but they cannot find any. Most carers are only aware of one service, a whānau focussed, wraparound service. But this service covers a range of health areas, not just dementia. All of the dementia services known by whānau participants are structured using a Pākehā model, which does not suit Māori carers and their whānau. Whānau are avoiding services in their community and either seeking online supports to acquire the education they need, or not accessing services at all. Whānau carers are feeling more isolated and alone. By adapting the current services and focussing on a Māori model of service provision, this strategy most likely will increase the number of Māori representation. Support from service provision is vital, however these services cannot address all of the challenges whānau face. Financial burden represents another stressor for full-time whānau

carers, and access to financial support through government schemes can be challenging.

Lack of support from the government

Full-time caring was financially burdensome for nine of ten whānau carers who were interviewed. One whānau carer was opposed to receiving government welfare, believing that they could work and support themselves. Although the intention to support themselves was admirable, the reality of caring coupled with the financial struggle took its toll and the decision was made to apply for government support.

My husband didn't really want us going on the benefit. He didn't want to be a part of that system, so it took two years of us slowly just struggling, struggling, struggling, struggling, before I said to him, 'No, we're gonna go on the bloody benefit. I can't look after Mum, and we can't cope.'
(WP3).

Most of these whānau lived hand to mouth, barely having the income to meet their basic necessities. Financial stressors add to the complex nature of caring 24 hours a day, seven days a week. The caring role becomes more and more difficult as the dementia condition worsens, so access to financial support provides relief, however participants said the amount of financial aid is not enough. Managing tight budgets while caring for kaumātua living with dementia becomes another added stressor.

That's one change that I'd like to see. More assistance maybe from the government in terms of the financial side of things, with especially those who are home caring ... it becomes very costly looking after them, but I

mean, they [support services] tend to tell you to just put them in a home (WP2).

Caring for kaumātua at home can sometimes be risky, especially when little support is given to help homes feel safe and secure. Safety is a primary concern among whānau carers. Older who are in the advanced stages of dementia are vulnerable to the deviant behaviours of others and rely on the protection of their carers. One participant explained that his Aunt, who was in an advanced stage of dementia, had wandered into a house where she had previously lived and startled the current residents. She too was confused and distressed. The Aunt had also entered a vehicle with neighbouring gang members and was taken for a drive. Government funding or schemes could help whānau improve the safety of the home, thus providing peace of mind for the carer.

“Hey! Where you going?! You can’t just get into just anybody’s car” and these young fullas says “You can’t talk to my whānau like that.” and I says “You fullas aren’t our whānau!” you know? And so I’m having an altercation and the next thing I know, I go over to the car to get her outta there and they threaten me and then they drive off with her (WP7).

We ordered a tracking device, because she’s been out that gate about four times and just walked off and it’s good that the community here know her and know that she’s sick ‘cause they’ll come and get me (WP6).

Another whānau carer commented on the need for railing to be installed in their home, so their kaumātua could move up and down the stairs safely. When the carer enquired about installing railing in her home, the service told her that

their budget had been cut, and they no longer provided that service. Bearing in mind that most Māori prefer to care for their kaumātua in the home, safety is a real concern, especially if carers are caring alone. If the kaumātua is injured, whānau members may make the carer accountable. It could also be construed as neglect. This is a very vulnerable situation for a carer, and adds to the already mounting pressure of an already demanding role. It could be argued that the home is not secure or safe enough to care for kaumātua in these later stages of dementia, and they should be placed in a secure aged care facility with staff resources and safety implementations, however whānau still feel that home is the best place for their kaumātua, and kaumātua agree.

Yeah, cause just from experience we've seen other friends and family, they decline extremely quickly once they've been put in [an aged care facility]. I think the longer they are with us, the better aye. At home (WP2).

Government funding or government schemes are sought to relieve the financial burden whānau carers face, as a result of being a full-time carer. Whānau carers do not want to use government welfare, but feel that they have no other choice. The financial support received was considered to be meagre, and so whānau carers have to manage their small budgets carefully, sometimes having to make personal sacrifices, such as delaying or forgoing medical treatment for themselves. Home caring is costly and the financial aid does not adequately cover the expenses of caring. The safety and protection of kaumātua is also a concern for whānau carers. More attention is needed to address the funding requirements for whānau carers, for kaumātua and for the homes in which they live. Whānau

carers are making unnecessary sacrifices, which negatively impacts on their ability to care for themselves and their kaumātua.

Carer wellbeing

Whānau carers are feeling isolated and alone. When supports for both the whānau carer and the kaumātua are inadequate, whānau carers must expend more energy and more effort to meet the challenges of their role. It is not uncommon for whānau carers to work too hard at the expense of their own health.

I've been stressing out. I've never had shingles before. And I went up to the doctor and I says, 'What the hell's this?' and he said 'Oh you've got shingles,' and he gave me these pills and I went to go and get 'em and 'They're antidepressants doc,' and he says 'Yeah. It's your job.' Well, I didn't know you see, you're trying to be happy, happy, happy around her and you know, inside you're screaming, 'You've got to be kidding me.' This is me talking to myself and that's what's flipping me out, getting shingles and all sorts of things, but also ... try to be calm and collected around Aunty, because she's challenging (WP7).

Whānau carers are feeling unsupported across a number of domains, which is causing whānau carers to feel isolated and alone. The lack of support from whānau members, the lack of support from the services in their community because of the systemic blind spot for cultural inclusiveness and responsiveness, and the lack of financial support from the government is causing negative and unnecessary outcomes for whānau carers. More often than not, whānau carers are tolerating these challenges, and as a result they are a greater risk of burnout and developing negative physical and psychological health outcomes.

Part 2: Service providers perspectives of services

Seven staff from four service providers in the Waikato region were interviewed to ascertain their perspectives about their personal experiences working with Māori and their perspectives of service delivery for Māori. The salient themes that were identified were 1) Cultural inclusive and responsive service delivery, 2) Going beyond, and 3) Barriers to accessing services.

Cultural inclusive and responsive service delivery

A common theme among staff participants was the need to engage with Māori people in a respectful and culturally sensitive way. All of the staff participants felt that their service was culturally inclusive and responsive. Each staff participant had received some form of cultural training to help them engage with Māori clients. Cultural training was obtained during employment orientation, during tertiary education learning or from cultural advisors brought into the service. The frequency of the training varied. When asked if they utilised Māori services, staff acknowledged that they were aware of access to these secondary Māori services, but many had not engaged with, or referred to these services for some time. One staff participant said it had been almost a year since the employees had engaged in cultural training. Other participants said that training occurs on an ad hoc basis, while other participants said cultural training was ongoing, however the rate of frequency remained vague. The Māori services were described by staff participants as utilising the services of a Māori chaplain, Te Reo Māori interpreter or a cultural advisor. When asked about the strengths of the service, one staff participant had this to say,

Our compassion for older Māori that come into our service, there's an acknowledgement that we don't get as many that come into our service

that identify as Māori. The numbers of Māori that come into our service is quite less. There is a strength of caring. We find out if people identify as Māori - do we want to call the chaplain service or is there anyone else we need to get involved and there is always a respect there. I think it's a very respectful service (SP1).

Staff believe that they are providing a culturally inclusive and responsive service to Māori whānau, however they do appreciate that there are some improvements that need to be made within each of their services because of the low rate of Māori representation. To overcome the disparity, staff go beyond the service, and sometimes their respective roles to assist Māori whānau carers and their kaumātua.

Going beyond

Two staff participants explained that as Māori, working outside of normal working hours to support a whānau in need is ‘just the right thing to do’ (SP6). It is what makes a Māori workforce unique and whānau respond positively to this type of care and support provided by staff. For example, one participant visited a whānau at their home after working hours to discuss how to care for a kaumātua, while maintaining his mana. The kaumātua was well known, and the whānau did not want his reputation, his mana, his dignity to be damaged by dementia. This staff participant acknowledged that going beyond the role, providing one-to-one (kanohi te kanohi) personal attention is an important factor for Māori engagement. This sentiment was reinforced by a non-Māori staff participant who said delivering education in the home, one-to-one with the whole whānau was an effective and positive experience for Māori. Even when support is beyond the capacity of the staff participants, the staff participants will search for other providers that may be able to provide the necessary support for whānau. Two other staff participants said they have made special allowances for whānau, especially when whānau want to visit their loved ones who were in a secured residential facility. Whānau often arrive as a big group to the service and one staff participant said they understood the importance of being together as a whānau, so offered the whānau a larger room so everyone could visit. For non-Māori staff participants, the common theme was they too, try to go beyond the parameters of their service. They acknowledge that services are primarily designed using a western approach, and admit that they need to manipulate the system to find the best outcomes for Māori.

One to one is the most effective form of delivering education to whānau (SP4).

We have special, because our rooms are only good for like one people, so if it's like a palliative, we try to put the person in a bigger room so we can accommodate the whole family (SP2).

I think it's always difficult for people who identify as Māori to be in a Pākehā world and a Pākehā system ... its driven by a Pākehā world, so you [staff] have to manipulate the system to get the best outcome ... you learn to play with the system to get the best out of it (SP1).

Staff are consistently going beyond their roles or actively seeking other services that can support Māori whānau and their kaumātua living with dementia. Staff participants recognise that the current services are not sufficiently designed for Māori, and so staff are finding ways to work around the system to provide good outcomes for Māori. Despite their best efforts, Māori are still not accessing services, and staff recognise the barriers that may be contributing to this.

Barriers to accessing services

Māori staff participants have a distinct advantage of understanding the cultural and social norms of Māori whānau. The staff participants shared that they use a Te Ao Māori worldview when engaging with Māori, and listen to their complaints about current services, for example how they feel uncomfortable, or feel alone. One non-Māori staff participant shared that some staff are just not aware of the cultural norms of Māori, for example removing their shoes before entering a home. While another participant said that institutionalised racism remains a concern. In order to improve Māori engagement and build good relations, staff

said they can utilise the expertise of their designated Māori cultural advisors, or work colleagues on a regular basis to upskill staff members on cultural competencies in their practise. However, staff have to be willing to attend, willing to learn and be willing to practise in a culturally sensitive way. By understanding Māori cultural norms and being sensitive to the uniqueness of the culture, this may help reduce barriers between non-Māori staff, service provision and Māori whānau. With the growing influx of foreign staff members in healthcare, services and aged care residential facilities, Māori cultural training is more important now than ever before.

We see it, not all the time, you see it, time and time again, is that you have non-Māori and this is no stick to our non-Māori providers out there and the professionals working in those areas, but clearly a lack of understanding from a Māori worldview is very evident, it's very evident, very evident (SP6).

For a lot of [non-Māori staff] who have not had that experience coming in working with Māori families, it can be culturally different for them. They're not use to tikanga practices and that kind of thing. Even little things like taking off your shoes when you go into someone's house. They are just not aware often of those protocols. ... it can be viewed almost as a sign of disrespect you know (SP4).

We're slow (staff attitudes), you know, institutionalised racism is everywhere, and it's how we navigate that carefully (SP7).

Staff participants admitted the lack of Māori representation across each of the services. The belief is that Māori do not want to participate in Pākehā services. One staff participant explained that their service needs to be focused more on Māori, because the activities they provide may not suit them.

... I think perhaps having a more Māori focus within our ... [service] that we deliver here ... I think could break down some barriers to people attending. ... We have delivered education at marae's. Wherever we're invited to go, we will go ... for like community groups and that kind of thing. Our education is free of charge. (SP4)

What we're finding out is Māori families don't accept much of that kind of support [Pākehā services] unless it's also from a whānau (SP3).

A lot of them will say No, because they've heard of it or it's a Pākehā organisation (SP5).

Māori staff have a unique understanding of where the barriers exist for Māori whānau. They can identify the lack of cultural awareness and institutional racism among some existing staff members. Some staff members are willing to practise in a culturally sensitive way, where others are either not willing or uncomfortable with cultural engagement. Staff acknowledged that their services are targeted towards Pakeha, and may not suit Māori. They also said that Māori avoid their services because of this fact.

Chapter 4: Discussion

Māori whānau carers (whānau participants) were interviewed to understand what it is like to care for kaumātua living with dementia. Staff of dementia service provider organisations were also interviewed to explore their perspectives of working with Māori whānau. The aim of this research was to explore the perspectives of whānau carers who care for kaumātua living with dementia, to explore the perspectives of staff who work for dementia related service provision organisations and to identify whether current services are responsive to the cultural needs of Māori carers and their whānau. Whānau carers shared one overarching theme, which was the lack of support they perceived across three domains, namely from their whānau members, from services in their community and from the government. Subsequently, caregiver burden was commonly expressed, and poor health outcomes often resulted. Some staff participants identified the cultural deficits in service delivery, and commented on the importance of utilising a cultural worldview. All service provider staff thought their services were culturally inclusive and responsive but admitted the need for further improvement. They also acknowledged some of the barriers Māori encounter when trying to access support.

Investigating perceptions of support

Whānau

Whānau carers are struggling to find the support they need to care for their kaumātua living with dementia. Being a delegated carer may be a collaborative whānau decision, but for some this is where the collaborative support network ends. Deficiencies in whānau support is one important finding in this research.

The lack of support is three-fold, whānau carers are either 1) not finding adequate support among their whānau members to assist them with caring for their kaumātua, 2) they are not comfortable with accessing support services within their communities, or 3) the government schemes or funding are inadequate for their caring needs (MoH, 2013). This study found that whānau are experiencing at least one (if not more) of these deficiencies in support. Consequently, these deficits cause whānau carers to feel helpless, frustrated, isolated and alone, which is contrary to what whānau actually means.

Whānau are often described as a connected network of Māori relatives who work and collaborate together. Sadly, in this context the definition of whānau is flawed. Despite being surrounded by whānau in the family home, some whānau carers feel a lack of whānau support across a number of domains, such as emotional, physical or informational support (Inagaki & Orehek, 2017). Caregiver burden creates tremendous stress for a carer and as stressors mount, the carers resilience tends to wane (Henry et al., 2018; Kim, Chang, Rose & Kim, 2012), negatively affecting the carer's health. There may be valid reasons for why whānau members cannot support whānau carers, such as work and family commitments, but findings show that some whānau members lack consideration for the carer's plight.

Whānau members can cause emotional stress by criticizing the carers efforts. Findings show that whānau will work harder to meet the expectations of other whānau members to avoid judgement and disapproval. This yet again, adds more stress to the carers workload. Social networks and social support is integral to a carers health (Inagaki & Orehek, 2017). Carer's require psychological and physical support however this is not occurring for some whānau carers. They are

unable to share the load of caring, and are feeling disconnected from whānau and social activities.

Poor social support is strongly linked to depression and loneliness and has been shown to increase the risk of depression, suicide, alcohol use, cardiovascular disease and cognitive function (Vitaliano, Zhang & Scanlan, 2003, cited in Dassel & Carr, 2016; Caswell et al., 2003). These social connections are key components for a carers wellbeing during the most critical times of need. One study claims that even after the older person with dementia has passed away, the stress that was inflicted on the carer continues to endure (Dassel & Carr, 2016). Protective factors are needed to support the perceived lack of support from whānau. Whānau carers are encouraged to learn about dementia and how to cope with the symptoms and behaviours of kaumātua. Education can empower and help carers become more resilient when they become distressed. They need to develop a care plan, know where to seek assistance when needed, monitor their own wellbeing, connect with supportive friends or utilise services in the community to assist with the burden of caring (Henry et al., 2018).

Service provision & cultural service delivery

This study revealed that whānau carers perceive a systemic blind spot for Māori focussed, inclusive, and responsive services. This may be due to the western design of health care systems, and the popular biomedical approach to care throughout New Zealand. The findings reveal that whānau are actively seeking appropriate Māori services and do not regard the current services in their communities as culturally inclusive or responsive. Whānau carers are frustrated by the current services because they are not providing a model that suits Māori, and are consciously disengaging with services. As whānau carers distance

themselves from services, carers are at risk of missing out on useful dementia related education and support, thus being exposed to vulnerabilities such as insufficient coping strategies. Whānau carers have noticed that the people who attend the support groups are predominantly Pākehā and believe they are nice people, but whānau carers are noticing that they are the only Māori in attendance which makes them feel like they do not belong. Whānau feel uncomfortable, and are seeking environments where they can express themselves in a way in which they are accustomed, without offending others (e.g. using profanity). If services are attended by Māori, it is usually out of necessity rather than choice.

A common finding among staff participants was this need to be respectful and to engage with Māori in a culturally sensitive way, but the pro-cultural attitudes of staff and the western model of services are incongruous with a Māori appropriate approach to service delivery. This bilateral view of being culturally sensitive may inadvertently tolerate disparities in service provision, thus allowing barriers to remain. Whānau carers continue to seek and ask for appropriate Māori focused support, and even though staff are empathetic, the service supports are not addressing their core values and needs. The majority of whānau carers want services which include a Te Ao Māori worldview approach, fostering whakawhānaungatanga, manaakitanga, whānau, and some prefer a Māori workforce (Durie et al., 2010; Anderson et al., 2003). A working model of Māori focussed services can be found in the Māori whānau wraparound service based in the Waikato region of New Zealand. During the whānau interviews, most of the participants were engaged with this service, and praised the service. Unfortunately, the service was not interviewed by the researcher because of timeframe constraints required for this research. Other models worth mentioning

include Te Whare Tapa Wha (Durie, 1998) and Martin & Paki's (2012) bicultural model for dementia care.

Although the structure of the services may not be meeting the needs of Māori, staff participants attitudes toward Māori reflect respect and inclusion. Many go beyond their roles and the system to provide appropriate services for Māori. The service provider participants who identified as Māori and Pacific Island explained that within their role they often operate 'outside the box' which loosely translated means, they go above and beyond what is expected of them in their respective roles. Service providers are having to work outside of the system, or having to identify ways to manipulate the system in order to make services work for Māori whānau, as in making them more culturally inclusive and responsive, so they feel less isolated and more supported. One staff participant explained that as a Māori, working outside of normal working hours to support a whānau in need is just the 'right thing to do'. It is what makes a Māori workforce unique and whānau respond positively to this type of care and support provided by service providers, especially Māori service providers. Even when support is beyond the capacity of the staff participants, the staff participants will search for other providers that may be able to support the whānau. Service providers will make special allowances for whānau, especially when whānau want to visit their loved ones who are in a secured residential facility. Whānau often arrive as a big group and one staff participant acknowledged the importance of being together as a whānau by offering a larger room for the whānau so everyone could visit.

Staff have access to cultural advisors but the majority of the staff participants rarely employed their services. A participant shared that in her years of experience, there were not many Māori represented at her sessions, especially

in rural areas. A participant also shared that non-Māori staff are just not aware of the cultural norms, for example removing your shoes before entering a home. It is important for all staff to remain culturally safe (Echeverri & Chen, 2016). In order to improve Māori engagement and relations, service organisations may find it beneficial to utilise the expertise of their designated Māori cultural advisors on a regular and compulsory basis to upskill staff members on cultural competencies in the workplace. By understanding Māori cultural norms and being sensitive to the uniqueness of the culture, this may help reduce barriers between non-Māori staff and Māori whānau (Martin & Paki, 2012). With the growing influx of foreign staff members in healthcare systems, services and aged residential facilities, Māori cultural training is more important now, than ever before.

Cultural training was a feature in each of the services of this study. Nursing degrees in New Zealand have a compulsory cultural competency component, and any nurses who are from overseas are required to complete this training. The frequency of cultural training among service provider organisations was either held on an ad hoc basis or ongoing (but the rate of frequency for the later was vague). Galanti (2015) experiential and applied training could possibly be advantageous for new staff members.

Government support

Full time caring was financially burdensome for most families who were interviewed (MoH, 2013). One whānau was opposed to receiving government welfare, believing that they could work and support themselves. Although the intention to support themselves was admirable, the reality of caring coupled with the financial struggle took its toll and the decision was made to apply for government support. Most of these families lived hand to mouth, barely having

the income to meet their basic necessities (see Table 2). Financial stressors add to the complex nature of caring full time for kaumātua living with dementia. Sadly as dementia symptoms worsens, behaviours of kaumātua intensify impacting on the carer in more extreme and significant ways.

Whānau carers identified that caring is costly, and found it difficult to find the financial support they needed from government schemes or welfare benefits. Although some whānau carers received government benefits, the amount of money received is inadequate and places further burden on the carer. The safety and protection of kaumātua is also a concern for whānau carers. More attention is needed to address the funding requirements for whānau carers, for kaumātua and for the homes in which they live. Homes require modifications to care, but they also require funds to ensure homes and their environments are safe and secure. Most whānau with low incomes live in sub-standard housing, in low socio-economic and often dangerous communities. Government funding policies need consider these issues in care packages for carers and kaumātua. Whānau carers are making unnecessary sacrifices, which consequently impacts negatively on their ability to care for themselves and their kaumātua. Whānau carers want to keep their kaumātua at home, but the reality forces them to rely on the government and rely on their last resort option, aged care facilities. Government policies need to change to ensure that whānau are able to care in a safe, but also supportive manner.

Currently there are little subsidies or benefits available for whānau carers in New Zealand. A number of publications address the redesign or reconfiguration of dementia care facilities, residential care facilities or rest homes, and dementia hospital care, but little attention is given to the families who prefer to home care.

The Ministry of Health's work programme includes a focus on the development of home and community support services for older people while working to improve health outcomes for older people. An important aspect of this is development of a continuum of care approach for older peoples' support services, and a greater emphasis on development of home and community-based services.

Carer wellbeing

As discussed, whānau carers are dealing with a number of challenges. Whānau are having to navigate through healthcare systems, doctors, specialists, hospitals, whānau members, finance concerns, behavioural issues of the kaumātua, managing attitudes of the whānau and so on. Whānau carers often feel stressed, isolated and alone in the caring role for their kaumātua. The majority of our whānau carers are aged between 40-60 years old, and there is a great deal of research that recognises that being a carer increases the risk of adverse physiological, psychological and social outcomes (Braun et al., 2009 cited in Dassel & Carr, 2016) as well as mortality compared with non-caregiving spouses (Schulz & Beach, 1999 cited in Dassel & Carr, 2016). Spouses are more likely to experience increased frailty over time when compared to non-dementia carers, and unfortunately the negative health consequences acquired during the caring phase persists after their loved one has died (Dassel & Carr, 2016).

Whānau carers often live with other family members, for example a husband, wife, children and so on. This research found that carers must take on other duties beyond self and family (Henry et al, 2018). They also manage the impact a kaumātua's behaviour has on all members of the household. One participant expressed her husband's concern regarding the burden that was being placed upon her as the primary carer. The participant seemed torn between the

wishes of her husband and the duty she felt to care for her ill mother. Her husband expressed his wish for the kaumātua to be admitted to an aged care facility, while the kaumātua was strongly opposed to the idea. This situation put the whānau carer in a difficult position. Who should she listen to? Her husband or her mother? Clearly there is no correct answer, but this is a prime example of the additional challenges carers encounter.

Although whānau find it challenging caring for kaumātua living with dementia, coping strategies have been acquired either through education programmes, advice from support workers, or whānau who were carers (Inagaki & Orehek, 2017). Being active is good for physical and mental health, so ensuring kaumātua are active is a positive wellbeing strategy. Sometimes whānau learned how to deal with repetitive conversations the hard way, before realising that it was easier to just agree with their kaumātua. One participant removed her mother from medication (after consulting with a medical professional) and discovered that her mother was lucid and coherent at times.

Whānau carers are feeling isolated and alone. Loneliness and negative affect significantly predicted higher caregiver burden (Vitaliano, Zhang & Scanlan, 2003, cited in Dassel & Car, 2016, Perkins, 2013). Caregivers may feel more responsible for care recipient's emotional well-being, which leads them to think that they should allocate more time for their care recipients. Care recipients loneliness, especially, may place more interaction related pressure on caregivers. Caregiver's guilt may also explain the association between caregivers perceptions and care burden. Caregiving guilt has been reported as a cause of caregiver burden. Once caregivers recognise that their care recipients experience negative emotions, they may feel guilty from failure in satisfying or protecting care

recipient feelings. Caregivers self-evaluation on how efficiently they perform their role can create caregivers guilt. (Lee, Martin & Poon, 2017).

Limitations

This study has a number of limitations, firstly the majority of the whānau participants were sourced using one service provider and so selection bias is a notable factor. Also the majority of our whānau and staff participants were female. Each of our kaumātua were at different stages of dementia, and so the demands of caring would have varied. I also relied upon the self-reports of diagnosis, since I was unable to find or get official documentation about the kaumātua's diagnoses. Alzheimer's disease was reported to be the most common. At times whānau carers guessed the specific diagnosis, but they were able to report that the diagnosis was definitely dementia. I acknowledge that the sample of whānau and service provision staff were of a modest size and that the sample was acquired by accidental sampling, so we cannot scientifically make generalisations about the total population because it would not be representative enough. I was unable to secure one major service provider to investigate their perspective of working with Māori due to timeframe constraints. I was also interested in interviewing General Practitioners, however due to timeframe constraints I was unable. Inasmuch as this research explores the impact it has on Māori whānau carers, it is important to acknowledge that although the ethnicity of concern for the purpose of this research is Māori, the information contained in this thesis cannot be generalised to the whole Māori population because of the qualitative and narrative nature of the data.

Further research

Further research could investigate the systemic blind spot among service provision and staff in addressing cultural engagement areas which are lacking for Māori clients. Furthermore the attitude toward care by Māori could be investigated to ascertain if there is a significant difference between the attitudes of contemporary Māori who are disengaged or disinterested in the principles of whakawhānaungatanga and manaakitanga and whānau carers who understand the cultural obligation of whakawhānaungatanga.

Conclusion

Whānau carers are struggling to find support from other whānau members. Some whānau members are critical of caring methods, while others place additional burden on the carers. Whānau are often described as an interconnected network, however findings show that Māori whānau carers are feeling isolated and alone, and as a result are experiencing poor health. Government funding and care packages are inadequate for whānau carers who want to care for kaumātua living with dementia in the home. Whānau are increasingly distressed by the various psychological, social and environmental issues they are faced with. Whānau continue to avoid aged care facilities due to the stigma attached, however government funding is used to support these facilities, but not individual carers providing care at home.

Whānau carers perceive services in their community as not being culturally inclusive or appropriate. Staff participants said that they incorporate respect and compassion into their service delivery, but it is not engaging Māori clients. Staff recognise that the numbers of Māori represented at services are low, compared to non-Māori clients. Services need to be integrate cultural training on a regular basis to ensure Māori are comfortable with being Māori in service settings.

Waiho i te toipoto, Kaua i te toiroa

Let us keep close together, not wide apart

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Appendices

Appendix 1. Interview Schedule (Whānau)



Kaumātutanga o Te Roro

Whānau Interview Schedule

INTRODUCTION

- Karakia
- Whakawhanaungatanga.
- Read through PIS with whānau. Explain that the interview will be audio recorded.

Explain how the information will be used, how anonymity will be protected, limitations, recording (notes and audio)

- Obtain written consent.
- Assist whānau to fill out Demographic Form and Contact Form
- Ask if there are any questions before starting the interview. Explain that whānau can ask questions at any time during the interview

QUESTIONS

DETAILS OF PERSON LIVING WITH DEMENTIA

I would like to ask you a few questions about the person you care for?

- a. What is their name?
- b. What is their age?

- c. Where does (name) currently live?
- d. With whom does (name) live?
- e. What is (name) relationship to you?
- f. Where is (name) from?
- g. Do you know what iwi or hapu (he/she) belongs to?
- h. What is (name) first language?
- i. Does (Name) speak any other languages? If yes, what are they?
- j. What is/was (name) main occupation (past or present)?

DIAGNOSIS OF PERSON LIVING WITH DEMENTIA

Now I would like to ask some questions about (name) diagnosis ...

- a. What is (Name) diagnosis? (past, present diagnosis, are there more than one?)
- b. Who diagnosed (Name)?
- c. Do you remember when they were diagnosed?

CHANGES OBSERVED IN PERSON LIVING WITH DEMENTIA

- a. When did you notice any behavioural changes starting?
- b. Tell me about the “types” of changes you noticed? (past & present)
- c. These are some behavioural changes that other persons with dementia have presented with? Do any of these behavioural changes sound familiar to you? (*Getting lost in your own home, forgetting what a credit card is used for, repeating story to same person many times in a day, forgetting what you ate 15 mins ago, not understanding what a calendar is used for, etc.*)
- d. Are there any activities that are important (e.g. karanga, whaikōrero) that (Name) is still able to do?

KICA ADLs

1. *Can s/he still do her own work? (paid and unpaid eg. cooking/cleaning)*
2. *Can s/he still eg. Go fishing, play cards, raranga (activities they enjoy)*

3. *Can s/he look after his/her own money?*
4. *Can s/he feed himself?*
5. *Can s/he put on his/her clothes?*
6. *Can s/he shower himself/ herself?*
7. *Does s/he have trouble finding the toilet?*
8. *Does s/he mimi in bed in the night?*
9. *Does s/he mimi in trousers/dress in the daytime?*
10. *Does s/he tutae/have a bowel motion in his trousers/dress?*

KICA Behaviours

1. *Is s/he happy most of the time?*
2. *Is s/he sad most of the time?*
 - 2.1 *If yes, is this different from before?*
3. *Is s/he sleeping well at night?*
 - 3.1 *If no, is this different from before?*
4. *Is s/he sleeping all the time? Sleep day and night?*
 - 4.1 *If yes, is this different from before?*
5. *Is s/he eating properly?*
 - 5.1 *If no, is this different from before?*
6. *Is s/he growling a lot?*
 - 6.1 *If yes, is this different from before?*
7. *Does s/he laugh for no reason?*
 - 7.1 *If yes, is this different from before?*
8. *Does s/he blame people for no reason?*

8.1 *If yes, is this different from before?*

9. *Does s/he see things that are not really there?*

9.1 *If yes, is this different from before?*

10. *Does s/he hear things that are not really there?*

10.1 *If yes, is this different from before?*

11. *Is s/he frightened of people for no reason?*

11.1 *If yes, is this different from before?*

12. *Does s/he hit people for no reason?*

12.1 *If yes, is this different from before?*

13. *Is there anyone in their family who forgets things all the time? (alive today)*

Write relationship: _____

14. *Was anyone else in their family like that before they passed away?*

WHĀNAU EXPERIENCES OF DEMENTIA

Now I'd like to hear about your experiences and/or key issues you face caring for (Name)

- a. *How many hours on average are you a care partner for (Name) at your home?*
- b. *Describe what caring you provide.*
- c. *How does your caring routine impact your daily living?*
- d. *Do you talk with others about your role as a care partner? How do you do this?*
- e. *Is caring for kaumātua the sole responsibility of the few who undertake the role?*
- f. *What is your reason for taking on the role of care partner?*

WHĀNAU UNDERSTANDINGS OF DEMENTIA

- a. Why do you think people get problems with thinking and remembering?
- b. What kupu (words) does your whānau use when talking about (Name) memory and thinking ?
- c. What information do you remember being given from your doctor about dementia?

SERVICES FOR MĀORI WITH DEMENTIA AND THEIR CARE PARTNERS

- a. What services are you aware of for supporting you as a care partner?
- b. How often do you access these services?
- c. Do you feel these services are useful?
- d. Do you feel that these services support Māori sufficiently?
- e. Can you suggest how services can be improved to assist whānau living with dementia

CULTURAL VIEW OF CARING FOR PERSON WITH DEMENTIA

- a. Do you think there are cultural expectations about caring for our kaumātua and if so, what are they?
- b. Why is the concept of aged residential care a culturally sensitive topic?

BRINGING INTERVIEW TO A CLOSE

- a. Do you have any ideas of other ways to effectively care for (Name)?
- b. Are there any other matters that you would like to discuss?
- c. Any further comments?
- d. Thank whānau for participation
- e. Briefly explain what's next
 - Data analysis
 - Opportunity to comment on interview summary
 - Dissemination??

Karakia whakamutunga

Appendix 2. Participant information sheet (Whānau)

29 September 2016



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The University of Auckland
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PARTICIPANT INFORMATION SHEET

Whānau Interview

Study Title: Kaumātuatanga o Te Roro: A Māori approach to the assessment and management of dementia.

Ethics Committee Reference: 16/STH/154

Locality: Kaitaia, Tāmaki Makaurau, Waikato, Taranaki, Whanganui-a-tara, Ōtepoti

Lead Investigator: Dr Margaret Dudley

Contact Number: 0212711155

Tēnā koe

My name is Dr Margaret Dudley (Te Rarawa, Te Aupōuri, Ngāti Kahu),
University of Auckland

The other people on this study are:

Dr Oliver Menzies (Ngāti Kahungunu), Auckland District Health Board

Professor Denise Wilson (Ngāti Tāhinga), Auckland University of Technology

Ms Moe Milne (Ngāti Hine), Independent Cultural Consultant

Dr Hinemoa Elder (Ngāti Kuri, Te Aupōuri, Te Rarawa), Te Whare Wānanga o
Āwanuiārangi

Dr Nick Garrett (Ngāti Maniopoto), Auckland University of Technology

I would like to invite you to take part in a study about dementia in Māori. Taking part in this study is your choice. You do not need to give a reason if you do not want take part. If you take part in the study and change your mind, you can withdraw from the study at any time.

This information sheet tells:

- why we are doing the study,
- what taking part would involve,
- what the benefits and risks might be, and
- what will happen at the end of the study.

We will talk about this information with you and answer any questions you may have.

If you agree to take part in this study, you will be asked to sign a Consent Form. It is on the last page of this document. You will be given a copy of both this information sheet and the Consent Form to keep.

This document is 7 pages long, including the Consent Form. Please read this information sheet. It is important that you understand all the pages.

WHAT IS THE PURPOSE OF THE STUDY?

Kaumātua are living longer than ever before. Some kaumātua will have diseases as they get older, like dementia. The questions health professionals use to detect dementia in Māori have been developed by Pākehā. Some questions are not always right for Māori. This study hopes to gather information from Māori about dementia and the ageing brain. We will use this information to develop better questions for Māori to help detect dementia.

We would like to talk to you about what you know about dementia. We also want to talk about any experiences you have had with this condition.

This study has been approved by The Health and Disabilities Ethics Committee, Reference Number: 16/STH/154

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You have been chosen to participate in this study because you have contacted the researchers and identified as having a whanau member who suffers from dementia. You have indicated that you would like to be a part of the study.

A researcher will visit you at your home or at a place of your choosing. You will be asked to share your knowledge and your experience of the condition of dementia. The interview will take place over one session and will take no longer than 1.5 hours.

You may speak in Te Reo Māori or English or both.

WHAT ARE THE POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

We see the risks in taking part in this study are small. Talking about your experiences with dementia might be upsetting. You can stop taking part in the interview at any time and not give a reason for doing so. A health professional and a therapist will be available by phone if you need to talk to someone. As health professionals we see this study has more benefits than risks.

WHO PAYS FOR THE STUDY?

The study has been funded by The Health Research Council of New Zealand. The host institution is the University of Auckland.

Taking part in this study will not cost you any money. We will give you a \$50 MTA Petrol Voucher to value your input into the study.

WHAT ARE MY RIGHTS?

Taking part in this study is voluntary. You are free to not take part in the study and you don't have to give a reason for doing so. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

The information from this study will be kept confidential for your privacy. Only members of the research team will have access to the information.

Nothing that could identify you will be used in any reports about this study. We will give you a code. Any place name or other names that could lead to you being identified will be removed.

You have the right to access information that has been collected about you as part of the study.

WHAT HAPPENS AFTER THE STUDY OR IF I CHANGE MY MIND?

The study data will be stored in a locked cabinet in the Principal Investigator's office throughout the duration of the study. At the end of the study the Principal Investigator will make sure the data is stored in a secure place in the School of Psychology at the University of Auckland. It will be kept for 10 years and then destroyed.

The study data may be used in future studies.

A summary of the study findings will be presented back at a public hui within 2 years of completion of the study.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Dr Margaret Dudley
Principal Investigator
0212711155

m.dudley@auckland.ac.nz

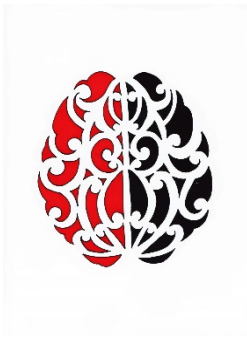
If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Appendix 3. Consent form (Whānau)



Building 721, Level 3
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School of Psychology
The University of Auckland
Tamaki Innovation Campus
Private Bag 92019
Auckland 1142
New Zealand

CONSENT FORM

An interpreter is available on request.

Please tick to indicate you consent to the following

I have read, or have had read to me in my first language,
and I understand the Participant Information Sheet. Yes No

I have been given sufficient time to consider whether or not
to participate in this study. Yes No

I have had the opportunity to use a legal representative,
whanau/ family support or a friend to help me ask
questions and understand the study. Yes No

I am satisfied with the answers I have been given
regarding the study and I have a copy of this consent form
and information sheet. Yes No

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.

Yes No

I consent to the research staff collecting and processing my information, including information about my health.

Yes No

If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.

Yes No

I consent to my GP or current provider being informed about my participation in the study and of any significant abnormal results obtained during the study.

Yes No

I agree to an approved auditor appointed by the New Zealand Health and Disability Ethic Committees, or any relevant regulatory authority or their approved representative reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.

Yes No

I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.

Yes No

I understand the compensation provisions in case of injury during the study.

Yes No

I know who to contact if I have any questions about the study in general. Yes No

I understand my responsibilities as a study participant. Yes No

I wish to receive a summary of the results from the study. Yes No

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature:

Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature:

Date:

Appendix 4. Demographic form (Whānau)



Kaumātutanga o Te Roro

A Māori approach to the assessment and management of dementia.

Participant Demographics

Location:

Identifier:

What is your ethnicity?	<i>Please tick</i> Māori <input type="checkbox"/> Māori and Pākehā <input type="checkbox"/> Māori and other <input type="checkbox"/>
Do you kōrero te reo Māori?	<i>Please tick one box</i> VERY WELL <input type="checkbox"/> WELL <input type="checkbox"/> FAIRLY WELL <input type="checkbox"/>

	NOT VERY WELL <input type="checkbox"/> NOT AT ALL <input type="checkbox"/>
Do you consider Te Reo Māori your first language?	<i>Please tick one box</i> Yes <input type="checkbox"/> No <input type="checkbox"/>
How old are you?	
What is/are your iwi?	
What is your gender?	<i>Please Tick</i> MALE <input type="checkbox"/> FEMALE <input type="checkbox"/>
What is the highest level of education/schooling that you obtained? <i>E.g. Primary school, form 4</i>	
What is your personal income?	<i>Please tick one box</i> \$10,000-\$20,000 <input type="checkbox"/> \$20,000-\$30,000 <input type="checkbox"/> \$30,000-\$40,000 <input type="checkbox"/> \$40,000-\$50,000 <input type="checkbox"/> \$50,000-\$60,000 <input type="checkbox"/>

	<p>\$60,000-\$70,000 <input type="checkbox"/></p> <p>\$70,000-\$80,000 <input type="checkbox"/></p> <p>\$80,000 AND ABOVE <input type="checkbox"/></p>
<p>Relationship status</p>	<p><i>Please tick one box</i></p> <p>MARRIED <input type="checkbox"/></p> <p>SINGLE <input type="checkbox"/></p> <p>WIDOWED <input type="checkbox"/></p> <p>DIVORCED <input type="checkbox"/></p>
<p>Who do you live with?</p>	
<p>Are you in paid employed?</p>	<p><i>Please tick one box</i></p> <p>Yes <input type="checkbox"/></p> <p>No <input type="checkbox"/></p> <p>If you answered “Yes” what is your job?</p> <hr/>

Appendix 5. Contact details form (Whānau)



Kaumātutanga o Te Roro

A Māori approach to the assessment and
management of dementia.

Contact Details

Location:

Identifier:

Name: _____

Address: _____

Phone: _____

Landline: _____

Email: _____

Appendix 6. Participant information sheet (Service provider)



PARTICIPANT INFORMATION SHEET

Service Provider Interview

Study Title: Perceptions of Dementia Service Provision for Māori: Perspectives of Māori whānau carers & the perspectives of service providers in the Waikato region.

Researcher: Lisa Nathan

Contact Number: 021 108 3837

Tēnā koe

My name is Lisa Kiriwai Nathan (Ngāti Maniapoto, Tūwharetoa, Te Atiawa). I am a School of Psychology Masters student at the University of Waikato.

My supervisors are:

- Dr Nicola Starkey, University of Waikato
- Dr Margaret Dudley (Te Rarawa, Te Aupōuri, Ngāti Kahu), University of Auckland

I would like to invite you to take part in a study about service provision for Māori whānau carers who care for kaumātua affected by dementia.

What is the purpose of this study?

Māori whānau carers of kaumātua affected by dementia were interviewed throughout the Waikato region. They were invited to share their perspectives of service provision and support for themselves as carers and their kaumātua. These carers predominantly care for their kaumātua in a home based environment. The researcher is interested in gaining the perspectives of service providers who engage directly with Māori whānau carers.

This study hopes to gather information from service providers about working with and supporting Māori who care for kaumātua affected by dementia. It hopes to identify the locations for dementia specific services, trainings and meetings. The accessibility, responsiveness and flexibility of services for Māori. It will also address the dementia education gap Māori currently face. Perceived strengths and weaknesses of service provision overall may also be explored. The researcher is also interested in identifying what services are available to Māori whānau. The researcher intends to use this information to assist Māori whānau and improve service provision.

This study has been approved by The University of Waikato's School of Psychology Human Research Ethics Committee.

What will my participation in the study involve?

Firstly, the researcher would like to contact the manager of your organisation by phone. It is the researcher's intention is to seek approval from the manager (or authorised person) of each organisation and explain the purpose of the research. With the manager's help, the researcher will invite them to recruit an appropriate participant within their organisation. Upon agreement in writing from the organisation (via email or letter), the researcher will send the manager this Participant Information sheet to read, together with the Interview Schedule questions. After liaising with the manager, the researcher will contact the recommended person for an interview.

Together, the researcher and the participant will coordinate a time and date for the interview. Prior to the interview, the participant will receive information about the study to read, i.e. a Participant Information Sheet, an Interview Schedule (questions which outline the topics that will be explored during the interview), and a Consent Form. The participant may seek professional, or whānau assistance to help them understand the information.

At the time of the interview, the researcher will ask the participant if they have read the information provided. The researcher will briefly explain the study, and ask the participant to complete and sign a consent form. Upon receipt of their written consent, the researcher will turn on the dictaphone and invite the participant to share their experiences working with Māori whānau carers and kaumātua. The researcher may also invite the participant to respond to some questions, challenges, issues whānau have raised around service provision for whānau carers and kaumātua with dementia.

The interview should take about 30 minutes.

The research findings will be used for the purpose of the researcher's Masters Thesis. Individual participant identities will be kept confidential. Only the researcher and supervisors will have access to confidential information. The service provider's organisation name will also be kept confidential.

What are the possible benefits and risks of this study?

Taking part in this study has a number of possible benefits. Māori research is sparse and service providers may yield great benefit from the findings of this study. The risks in taking part in this study are seen to be small. Talking about your experiences may be upsetting. You can stop taking part at any time and not have to give a reason for doing so. This study intends to keep participant's identities anonymous, however due to the nature of your position in the organisation, you may be identified by someone familiar to you and this study. You may also be identified if you choose to disclose your involvement. The researcher will do their utmost to ensure your identity is kept anonymous in any reports issued as a result of this study.

Who pays for the study?

There are two parts to this study. Part One of the study involved whānau interviews. It was funded by The Health Research Council of New Zealand. This masters study is linked to a larger national study – Kaumātuatanga o te Roro. The host institution is the University of Auckland. Whānau interviews were conducted in the Waikato by the researcher as part of this national research project.

Part Two involves service provider interviews. This part is being funded by the University of Waikato and the researcher.

Taking part in this study will not cost you any money. The researcher will offer a koha (\$20 supermarket voucher) to the participant or participant's organisation, whichever is acceptable to the manager of the participant's organisation.

What are my rights?

Taking part in this study is voluntary. You are free to choose whether or not to participate. If you choose to participate now, but change your mind later, you can withdraw from the study at any time during the interview, or up to three weeks after the interview. Beyond three weeks, you will no longer be able to withdraw. This is because it will be difficult to remove your information once it has been anonymized into the report.

As mentioned, your identity will be kept confidential to protect your anonymity and privacy. Only members of the research team will have access to confidential information. In order to ensure your anonymity, the researcher will give you a pseudonym and/or code in the reporting. It is the researcher's intention to ensure that nothing that could identify you will be used in any reports issued as a result of this study.

You have the right to access information that has been collected about you as part of this study.

What happens after the study or if I change my mind?

The study data will be stored in a locked cabinet at the researcher's residence throughout the duration of the study. At the end of the study, the researcher will make sure the data is stored in a secure place. It will be kept for up to 5 years and

then destroyed. The study data may be used in future studies. Each participant will be notified when the results of the study have been published.

Who do I contact for more information or if I have concerns?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Lisa Nathan
Researcher
Masters Student - University of Waikato
Mobile: 021 108 3837
Email: lisa.k.nathan@gmail.com

You may also contact the researcher's supervisor:

Dr Nicola Starkey – email: nstarkey@waikato.ac.nz

This research project has been approved by the Human Research Ethics Committee (Health) of the University of Waikato under HREC(Health)#2017-39. Any questions about the ethical conduct of this research may be addressed to the Secretary of the Committee, email: humanethics@waikato.ac.nz, postal address: University of Waikato, Te Whare Wananga o Waikato, Private Bag 3105, Hamilton 3240.

Appendix 7. Consent form (Service provider)

UNIVERSITY OF WAIKATO
FACULTY OF ARTS & SOCIAL SCIENCES

PARTICIPANT CONSENT FORM

I have received a copy of the Information Sheet describing the research project. Any questions that I have, relating to the research, have been answered to my satisfaction. I understand that I can ask further questions about the research at any time during my participation, and that I can withdraw my participation at any time (*up to three weeks*) after the interview.

During the interview, I understand that I do not have to answer questions unless I am happy to talk about the topic. I can stop the interview at any time, and I can ask to have the recording device turned off at any time.

When I sign this consent form, I will retain ownership of my interview, but I give consent for the researcher to use the interview for the purposes of the research outlined in the Information Sheet.

[I understand that my identity will remain confidential in the presentation of the research findings]

Please complete the following checklist. Tick [✓] the appropriate box for each point.	YES	NO
I have read the participant information sheet (or it has been read to me) and I understand it.		
I have been given sufficient time to consider whether or not to participate in this study.		
I have had the opportunity to use a legal representative, work colleague, whanau / family support or a friend to help me understand the study.		
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.		

I understand that taking part in this study is voluntary and that I may withdraw up to three weeks after the interview, without penalty.		
I understand that written notes will be taken of the information I provide in this interview, and that the interview will be audio recorded.		
I understand that my participation in this study is confidential and that the research team will do their utmost to ensure that no material, which could identify me personally, will be used in any reports in this study. There is a possibility that I could be identified by people familiar to me because of my role, and involvement with working with Māori whose whanau is affected by dementia.		
I know who to contact if I have any questions about the study.		
I understand my responsibilities as a study participant.		
I wish to receive a summary of the results from the study.		

Participant :

Researcher :

Signature :

Signature :

Date :

Date :

Contact Details :

Contact Details :

_____	_____
_____	_____
_____	_____
_____	_____

Appendix 8. Interview Schedule (Service Provider)



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

INTERVIEW SCHEDULE – Service Provider

Introduction

- Karakia (ask interviewer if they wish to start with a karakia)
- Whakawhanaungatanga: Introduce self and then give the interviewee the opportunity to reply and introduce herself/himself
- Briefly introduce the study, purpose and reason for the interview using the Participant Information sheet.
- Invite the interviewee to complete the relevant forms (i.e. Consent form and contact details form)
- Explain the right to refuse or skip questions, leave interview at any time, withdraw up to three weeks following the interview by contacting the researcher.
- Ask if there are any questions before starting the interview.

Topics for discussion

1. Service providers experiences with working with Māori whanau who care for kaumātua affected by dementia.
2. Service providers knowledge of supports or services available to Māori whanau carers.
3. Perceived strengths and weaknesses of current services for Māori whanau carers.
4. Explore dementia education issues Māori whanau carers face.
5. Explore accessibility, flexibility and responsiveness of services.
6. Explore and/or discuss the use of Rongoā/traditional treatments and medical treatments.

Closing

- Thank interviewee for participation.

Explain what's next

- Reminder that participant can withdraw up to 3 weeks after the interview.
- Data analysis is next.
- Dissemination of masters thesis report – participant will be notified