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**Māori and Dementia: Māori health professionals’
perceptions of dementia, support offered and
suggested improvements**

*A thesis submitted in fulfilment of the requirements for the degree of
Master of Social Sciences in Psychology at
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THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

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Abstract

E iti noa ana, nā te aroha

(It is the giving that counts and not the size of the gift¹)

The purpose of this thesis was to investigate the perceptions of Māori health professionals about Māori elders and dementia. The study aimed to describe: Māori health care providers' understandings of dementia; traditional versus contemporary understandings; how cultural beliefs affect experience; how Māori cope with dementia; key issues relevant to Māori people with dementia; and how services can be improved to meet the needs of aged Māori. The usefulness and possible cultural adaptation of the biomedical model has been explored within the context of a Māori worldview and the perceptions of participants. Semi-structured and in-depth interviews were conducted with eight mental health professionals and one caregiver. The information gathered at interviews was recorded within verbatim transcripts, which were written and returned to the participants for feedback. A qualitative data analysis was carried out on the approved transcripts.

The main findings suggest that Māori health professionals recognise that many Māori perceive dementia both from a traditional cultural perspective, associated with spirituality as well as a holistic understanding of wellness. Key issues identified by participants were: that there is fear associated with mental health facilities; the exclusion of cultural values and understandings from service providers is detrimental to the wellbeing of Māori elders; Māori do not understand the symptoms typically associated with dementia as an illness; there is a need for information and education within an appropriate frame for whānau; disjointed and multiple service providers inhibits Māori from accessing facilities offered; and that there is a real need for further services. It was considered important that mental health services are culturally appropriate, show respect for Māori values;

¹ All whakataukī were sourced from Mead and Grove (2003), see reference list.

are coordinated and sensitive; encourage and continue the development of a Māori mental health workforce; and further develop kaupapa Māori services for Māori elders.

The main implication of this research is that further investigation into Māori and dementia is required. Recommendations are made with a view towards better addressing some of the mental health needs of Māori elders.

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Aroha mai, aroha atu

(Love received demands love returned)

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Glossary

Aotearoa	Māori name for the country of New Zealand
aroha	to love, sympathy
aroha ki te tangata	respect or regard for others, empathy
atua	god, uncanny, supernatural
awhi	embrace
hāpati	Sabbath day of the Ringatū faith
hapū	sub-tribe, pregnant
hara	transgression, breaking or violating or breaching tapu
haumate	be spiritless, lacklustre, unhealthy, weak, ailing (in body, mind or spirit), depressed
hauora	healthy, good spirits
he taha wairua	spiritual side
he whānau	a family
he aha Hāhi?	what is your religion?, what is your church?
hōhā	bored, boring
iwi	tribe
ka tau te hinengaro	a person's mind, heart, thought or conscience
kai	food, to eat
kai āwhina	assistant, aid, support worker, caregiver
kaimahi	worker, operator, support worker, caregiver
kanohi kitea	the seen face, present yourself to people face to face
karakia Ringatū	a prayer from the Māori Christian faith founded by Te Kooti in the 1860's, mainly in the Bay of Plenty and East Coast tribes
karakia	prayer, blessing
katoa	all, every
kaua e māhaki	don't flaunt your knowledge
kaua e takahia te mana o te tangata	do not trample over the mana of the people

kaumātua	old man, respected elder, singular is leading male, collectively as old people or elders
kaupapa	agenda, philosophy, theme, subject
kaupapa Māori	Māori ideology: a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society
kia tau te wairua	acknowledging ones spiritual beliefs, calmness of ones spirit, spirituality comes first for the people
kia tūpato	be cautious, careful, wary, suspicious
koha	donation, gift
kōrero	to tell, say, speak, read, talk, address
koro	old man, grandfather
koroua	old man, grandfather
kuia	old lady, grandmother, elderly women
ma te whanau i te whanau	by family for family
māhunga	head
māhunga wai	dipstick, idiot, a colloquialism used to refer to someone flaky, participant specific meaning: brain is nothing, full of water, everything just flows, used when people get forgetful
mākutu	inflict physical or psychological harm through spiritual powers, sorcery, magic, spell
mana	power, authority, prestige, rights
mana tāngata	power and status accrued through one's leadership talents, human rights, mana of people
mana wahine	power, status, rights of women
manaaki aroha ki te tangata	respect for elders
manaakitanga	hospitality, kindness
manaaki ki te tangata	share and host people, be generous
manaaki whānau	respect or care for family
Māori	indigenous people of New Zealand
marae	meeting ground, community facility

matakite	seer, second sight, prophecy
mātauranga	knowledge
mate Māori	death or illness caused by diseases that are non-European
mate wairua	spiritual infliction
māuiui	tired, weary
mauri	life principle, special character
mihi	greet, admire, acknowledgement
mihi me ngā koutou te wairua	acknowledging spiritual beliefs of all
mimi	urine, to urinate
mirimiri	massage
mokemoke	lonely
moko	tattoo, personal mark; in context of this research it was used as a shortened version of mokopuna and referred to grandchild/ren
mokopuna	grandchild/ren
ngākau māhaki	pleasant person, mild mannered, one with a good heart, humble
noa	free of tapu
pae	orators' bench
Pākehā	European, not Māori
papa kāinga	original home, home base, village
porangi	mad, in a hurry
puihui	flax skirt
pūtahi	entirety, join, meet, cross roads, centre
pūtea	bag, clothes basket, fund, finances
rangatahi	fishing net, modern youth
rangatiratanga	leadership, kingdom
rohe	boundary, district
rongoā	physical natural remedies
runanga	assembly, debate
taha hinengaro	mental health
taha tinana	physical health

taha wairua	spiritual health
taha whānau	family health
Tainui	crew of this canoe from Hawaiki are claimed as ancestors by tribes of the Waikato, King Country and Tauranga areas
tāne	husband, male
tangata (plural tāngata)	person, man, people, human
tangata whenua	local people, indigenous people of the land
tangi	to cry, weep, mourn, grief, sorrow
tāniko	boarder for cloaks made with finger weaving
tapu	sacred, prohibited, restricted, forbidden; the concept of tapu was often used as a form of social control to caution or warn of danger
taonga	treasure, property, goods
tauiwi	foreigner
tautoko	support, advocate
Te Pounamu	visual aid employed within assessment and treatment (model used at Te Whare Marie, specialist Māori mental health service in Porirua)
te reo	Māori language, official language of New Zealand
te whare tapa whā	four sides of the house, model used to explain holistic health
te whetū	model employed to explain holistic health
teko	faeces
tikanga	custom, rule, code, meaning, practice
tikanga kaupapa Māori	Māori culture and custom
tino rangatiratanga	self determination
tipuna	ancestor
titiro	to look
tohunga	expert, specialist, priest
Tokanui/ Carrington	mental institutions
Treaty of Waitangi	Treaty between the British and the Māori people, signed 1840

Tūhoe	tribal group of the Bay of Plenty, including the Kutarere-Ruātoki-Waimana-Waikaremoana area
tupuna	ancestor
tūturu	permanent, reliable, door post, leak, fixed, real, true
wahine	woman, wife
waiata	song, to sing
wairua	spirit, soul, faith
wairua kōrero	spiritual language
wareware	to forget, forgotten
whai kōrero	make a speech
whakamā	the concept of whakamā is complex and includes many Western emotions, such as: shame, shyness, self-doubt, inadequate, remorse, inferior, embarrassment, guilt for wrong doing, sensitive, degrading, conscious of being at a disadvantage
whakapapa	genealogical table, cultural identity
whakarongo	listen
whakataukī	proverb
whakawhanaungatanga	process of establishing relationships, relating well to others
whānau	family
whanaungatanga	relationship
whānau ora	Māori families being supported to achieve their maximum health and wellbeing

Chapter One

Introduction

**He nui maunga, e kore e taea te whakaneke; he ngaru maoana, mā te ihu o te
waka e wāhi**

**(A big mountain cannot be moved along, but a great ocean wave can be
pierced by the prow of a canoe)**

This chapter outlines the researcher, why the topic was chosen, and provides a brief description of the aims of the research project.

Contextualising the Researcher's Interest in this Study

I am a clinical psychology student, half way through my training, within the Clinical Psychology Programme at the University of Waikato. My personal interest in the elderly sector, Māori, and dementia has been inspired by a variety of life experiences originating from my grandmother's deteriorating state of mental health, combined with a desire to understand how values or beliefs impact experience. It is of importance to note that my ancestry is of Pākehā lineage however my family now includes numerous members of Māori descent.

Studying psychology at the Waikato University has led to papers which focus upon New Zealand history, Māori culture, Women and Gender studies, people and behaviour. Working as a caregiver in a specialised dementia unit initiated research opportunities and a prospective area of employment. The research theme resulted from a discussion regarding possible areas of research with Dr P.S.D.V. Prasadarao.

The combination of life experience and study has ignited a passion to investigate how Māori perceive deteriorating states of mental health in their elderly, and in particular dementia. I acknowledge that contemporary directions within research on Māori health are guided by kaupapa Māori methodologies and a preference for research to be carried out by Māori. However as Smith (1999) states “it does not mean that academics simply took notice of Māori and stopped all research, but that they sought other ways of thinking about their projects and proceeded with far more caution when entering the domain of Māori concerns” (p. 176).

Consultation and tautoko from extended family and supervisors was imperative to ensuring a genuine respect for Māori, and personal development as a researcher. Due to the limited workforce in this specific area and lack of Māori researchers, employing a Māori-centred approach with an emphasis upon appropriate guidance was envisaged to initiate sound methodologies and outcomes. It was my intention that this investigation would contribute valuable insight towards the provision of culturally responsive services for Māori elders. It was hoped that my research would be beneficial to Māori affected by dementia and their whānau, promoting a greater understanding by professionals, plus enhancing the level of appropriate information and services available.

There is evidence to suggest that cultural understandings of health and wellbeing impact upon the presentation of health related symptoms (Durie, 2001; McNeill, Paterson, Sundborn, DeSouza, Weblemoe, McKinney & Smith, 2010). Dominant Western understandings, based upon dementia being a neuropsychiatric condition, appear to neglect cultural conceptualisations within ethnic minorities (Martin, 2009; Perkins, 2006). Within the New Zealand context there is little research or evidence to support a Māori viewpoint on dementia. This thesis explored a Māori cultural understanding of dementia through undertaking a study on Māori health workers perceptions of deteriorating states of mental health within the ageing Māori population. An examination of literature pertaining to New Zealand health policies and population statistics, and Māori cultural approaches to health and wellbeing highlighted an absence of research on a specifically Māori cultural understanding of dementia. It also identified a range of underlying values, beliefs and practices that Māori associate with best health outcomes for tangata whenua. A review of international research and cross cultural perspectives on dementia, in

relation to indigenous peoples, provided the justification and direction for investigating a Māori cultural understanding of dementia from a Māori viewpoint.

This research project explored an assumption that Māori whānau experience the ageing process differently than non-Māori, and are therefore more likely to be cared for at home by whānau. In addition, this thesis explored whether Māori elderly are less likely to be pathologised by whānau which may in turn result in a reduced likelihood of receiving diagnosis and treatment under the biomedical model. Western understandings based on the biomedical model often result with institutionalisation in a specialised rest home facility. So a further assumption was that being a Māori elder or kaumātua may be a protective factor for wellbeing, in isolation from diagnosis and treatment within the Western biomedical model of dementia. Therefore, the research sought to increase understandings of dementia from a Māori cultural perspective, with the aim of improving services offered to Māori families affected by dementia in the future.

Purpose Statement

The purpose of the investigations of this Masters thesis was to present a grounded theory approach of how Maori health workers conceptualise deteriorating states of health within Maori elders, and in particular dementia.

Aims

The aims of this research were to investigate how Māori health care providers perceive mental health and dementia among older Māori. Current research and knowledge about the mental health of Māori elders has significant gaps. To date, research indicates that Māori are not accessing mental health services within the elderly bracket. Contributing to an increased understanding of cultural perspectives of dementia and the mental health needs of aged Māori may assist with the provision of culturally responsive services and development of the gerontology workforce in the future. The project undertook a qualitative study which investigated Māori health workers conceptualisations of mental health and dementia among older Māori. The research investigated the following topics:

- Māori health care providers understandings of dementia

- Traditional versus contemporary understandings of dementia
- How cultural beliefs affect experience
- How Māori cope with dementia
- Key issues relevant to Māori people with dementia
- How services can be improved to meet the needs of aged Māori

A thematic analysis was carried out to explore whether participants findings supported the current literature (as reviewed in Chapter Two) surrounding Māori and dementia. The usefulness of the biomedical model was explored within the context of a Māori worldview and the perceptions of participants. It was hoped that this research would provide an opportunity to contribute to a culturally responsive service to support, and improve upon the existing biomedical model.

Chapter Two

Literature Review

He tangata i kākahuria ki te rimu moana e kore e ora ki te noho tuawhenua

(Such a person, accustomed to dwelling on the seaside and having seafood, will have difficulty living inland in an entirely different environment)

Introduction

This chapter examined the literature on New Zealand health policies and population statistics pertaining to Māori and dementia. Concepts of Māori cultural approaches to health and wellbeing will be highlighted underlining an absence of research in this area. A range of values, beliefs and practices that underpin Māori concepts of best health outcomes for tangata whenua² will also be identified. How these concepts impact Māori attitudes towards the aging population was extrapolated from international literary discussion.

International demographic trends indicate an increasing aged population “worldwide (e.g. Statistics New Zealand, 2007)”. The prevalence of mental illness within the New Zealand society will increase according to the aging population. One area of elderly mental illness is dementia. Dementia is defined as a neuropsychiatric condition by the Western biomedical model which is the dominant ‘best practice’ approach at this time (Kurz & Lautenschlager, 2010). However, cultural worldviews impact the experience of, and meaning applied to health and illness. In a New Zealand context there is a dearth of information about Māori cultural views of mental health within the elderly which needs to be

² Please refer to glossary on page xiii

redressed to respond to the Government's strategy to develop culturally responsive services for Māori.

This thesis explored Māori health workers' conceptualisations of dementia with the aim of providing information to the mental health workforce about Māori perceptions of elderly mental health, with a specific focus on dementia. It was envisaged that this information will contribute to an increased knowledge base, and assist the development of a deeper understanding of cultural issues as they pertain to elderly Māori. One of the central aims was to increase understanding among the gerontology workforce by providing a culturally relevant contribution to the development of culturally responsive services in the future. A review of international research and cross cultural perspectives on dementia in relation to indigenous peoples provided the justification and direction for investigating a Māori cultural understanding of dementia from a Māori viewpoint.

Prevalence of Dementia within the Māori Population

Official New Zealand dementia statistics show that Europeans account for 92.7% of dementia-related illness in comparison to Māori statistics which indicate a prevalence of 3.6% (Alzheimers New Zealand, 2008). These figures directly contrast with statistics showing that Māori account for 15.2% of the New Zealand population (Statistics New Zealand, 2007). This information indicates that there are approximately 1483 Māori currently affected by a dementia-related illness (Alzheimers New Zealand, 2008). Internationally the prevalence of dementia is relatively equal across culture. However, it appears that Māori elders are not presenting in mental health settings at the same rates as other New Zealanders. Therefore statistics may underestimate prevalence rates within Māori (Alzheimers, 2008). In fact, New Zealand disability statistics indicate that 10% of the Māori population over the age of 65 have significant problems with memory (Statistics New Zealand, 2010b). Changing demographics and an ageing population are expected to increase the prevalence of dementia within the Māori population to 5.8% by 2026, equating to 4338 affected individuals, an increase of 192% (Alzheimers New Zealand, 2008).

Similar to other indigenous population's dementia may be under-diagnosed within the Māori elderly population. Iliffe and colleagues (2009) reported that:

Although wide variations exist internationally dementia in general is probably under-diagnosed and under treated with an estimated 50% of primary care patients over 65 not diagnosed by their primary care physicians. (And continues) Although therapeutic nihilism (the belief that 'nothing can be done') persists among primary care physicians, there is evidence that it is declining. Under-diagnosis may also be due to a reluctance of the patient and family to acknowledge the symptoms and perhaps different cultural beliefs about normal ageing (p. 897).

Cultural Perceptions of Dementia within Ethnic Minorities and Māori

As stated there is very little research on how Māori perceive deteriorating states of mental health within their elderly, or the Western concept of dementia. The Western term 'dementia' implies that all people experience the disorder in the same manner (Traphagan, 2009). However, cultural worldviews impact the way in which old age is experienced, perceived and understood (Sokolovsky, 2009). Dementia is also experienced from a personal perspective where the intersection of values, experience, social and personal histories impact understandings. Models of disease are culturally and socially constructed, where understanding subjective experience requires knowledge of cultural values employed within the interpretation of health or illness (Traphagan, 2009).

In comparison to Europeans ethnic minorities have an elevated risk of the predisposing factors of dementia (Mahoney, Cloutterbuck, Neary & Zhan, 2005). For example, African Americans and the first nation's people of America are more likely to have hypertension, obesity, alcohol abuse or smoking, diabetes and stroke, all of which are precursors to vascular dementia (Henderson & Henderson, 2002; Richards & Brayne, 1996). Māori have an increased prevalence rate of these same precursors to vascular dementia (Statistics New Zealand, 2010b). Therefore it would be expected that prevalence rates within these minorities would be higher than the European frequency.

Māori Disability and Services Accessed by Māori

Research by Kingi and Bray (2000) found that contemporary Māori conceptualise disability differently from the dominant European perspective. Māori view disability holistically, not separate from the environment, society, or spiritual beliefs. Individuals with a disability are treated with respect and acceptance, as all people are, within the Māori worldview. Disability may also be viewed as a gift from this perspective (Kingi & Bray, 2000).

Māori have a disability prevalence of 17%, where disability is inclusive of all physical and mental impairments. Examining these figures further indicates that 11,000 Māori who have a disability are over the age of 65. Although these prevalence figures of disability are higher than other New Zealanders, these individuals are less likely to be in full time care. In fact, statistics reveal that 99% of Māori who have a disability live in whānau households, and less than 1% reside in residential facilities. In addition, only 32% of Māori who have a disability receive assistance within their home. Consequently there are numerous unmet needs within this population (New Zealand Statistics, 2010b).

Within the context of this research, behaviour deemed as pathological or meeting the criteria of dementia may have alternate meanings within the Māori worldview. There is a lack of research outlining Māori cultural understandings of dementia. However, to illustrate the importance of culture within definitions of dementia, an overseas example may be instructive as what may be defined as normal or abnormal. For example, Chinese women establish authority over their children through family relationships, denoting respect and obedience. Parental decisions are not to be questioned and children do not have the authority to instruct or force their elders to behave in a certain manner (Elliot & Di Minno, 2006). Within investigations by Elliot and Di Minno (2006) this custom was apparent, as represented below:

Throughout the family interview being conducted by the medical anthropologist, Mrs C grew increasingly restless, telling her son that it was time to leave, and that she wanted to go shopping. She interrupted more and more frequently, and insistently, and her son pleaded submissively with her to stay just a little longer..... But in the end nothing could be

done. Mrs C announced once and for all that she had had enough and she was leaving. She subsequently headed for the exit with great determination, shoved the door open and zipped quickly down the front path of the building towards the sidewalk..... With an apologetic glance back at the clinicians, her son rushed out the door.... Once she decided in the midst of the diagnostic process that she had had enough and wanted to leave, she asserted her authority and did just that, ignoring respectful pleas from her son and later from her son-in-law to stay. It was clear on both occasions that these younger family members did not have the authority to force her to stay once she had decided to end the team's evaluation of her (p. 166-167).

This behaviour could easily be deemed pathological by those unaware of traditional Chinese values (Elliot & Di Minno, 2006). Therefore it is imperative that clinicians consider the question posed by Elliot and Di Minno (2006): "From whose perspective are patient and family behaviours irrational, uninhibited, inappropriate, dysfunctional or outrageous?" (p. 166). The above example emphasises the importance of understanding cultural values of ethnic minorities within mainstream services, and is analogous to experiences of Māori within New Zealand facilities.

In general, Māori are at twice the risk of mental and physical illness in comparison to their European counterparts (Ministry of Health, 2008). The Ministry of Health (2008) report stated:

The evidence shows that disparities continue to exist between Māori and others. Te Rau Hinengaro showed that the Māori population experiences a greater prevalence, severity and burden of mental illness, and a greater lifetime risk of developing a mental illness than others (defined as non-Māori) (p. 6).

For example: Māori are more likely to develop a mental illness in comparison to other New Zealanders; Māori experience co-morbid mental disorders more frequently; and Māori are a younger population which places them at higher risk of mental illness, where the high rates of suicide directly impact the Māori

population. In addition, research indicates that socio-economic disadvantage is directly related to health disparities (Ministry of Health, 2008; Oakley Browne, Wells & Scott, 2006). Consequently, Māori of all ages are over represented within mental health systems (Baxter, Kingi, Tapsell, Durie & McGee, 2006). Furthermore, Māori are found within mental health settings with atypical symptom profiles (Tapsell, 2007).

In contrast to the disparity within prevalence rates, there is a large number of Māori who do not receive assistance from specialised mental health services when required. Research by the Mental Health Commission (2004) indicated that in times of need Māori are most likely to seek assistance from informal sources, such as whānau and friends, defined within the frame of whanaungatanga. Heperi (1996) presented evidence that this preference is driven by Māori experiencing ethnocentric philosophies within mental health settings. Durie (2003) stated:

A secure identity is a necessary pre-requisite for good health and well-being, and cultural identity depends not only on access to culture and heritage but also on the opportunity for cultural expression and cultural endorsement within society's institutions. Māori are confronted by barriers on both scores. Too many are unable to have meaningful contact with their own language, customs, or inheritance. And too few institutions in modern New Zealand are geared towards the expression of Maori values, let alone language. Ethnic identity has assumed increasing importance in the broad mental health field, not only in relationship to positive health and development but also as a key determinant of successful counselling outcomes (p. 68-69).

Consequently, Māori underutilise mainstream medical services. However, the Māori values of manaakitanga and whanaungatanga may provide protective factors buffering the need for seeking assistance within mainstream service providers (Heperi, 1996). When assistance is sought research indicates that Māori are most likely to seek assistance within primary health care settings (Ministry of Health, 2008; Statistics New Zealand, 2010b). In addition, Māori are less likely to have primary care providers refer them onto secondary or specialist services (Ellison-Loschmann & Pearce, 2006).

As a consequence, Māori are more likely to enter facilities with more severe impairments and disabilities (Ministry of Health, 2008; Statistics New Zealand, 2010b). In relation to the current research, statistics indicate that older Māori (over the age of 65) are less likely to utilise mental health services and more likely to be cared for within whānau households (Baxter et al., 2006; Ministry of Health, 2008; Statistics New Zealand, 2010b). Research carried out by Bonita and colleagues (1989) indicated that 4.3% of the elderly Māori population in Auckland reside within long term care facilities, in comparison to 7.8% of the European population. Later research indicates that 95% of residents within New Zealand care facilities are European and only 2% are Māori (Kiata, Kerse & Dixon, 2005a). The majority of these Māori elder residents were isolated cases within rest homes where poor levels of Māori staff were available (Kiata et al., 2005a). In addition rates of psychiatric hospitalisation for Māori over the age of 60 are between 0.5-0.7 of the non-Māori population (Sachdev, 1989). Therefore older Māori have a lower rate of long term care in comparison to non-Māori (Bonita, Broad, Thomson, Baskett & Richmond, 1989).

Defining Features of Cultural Assessment

Cultural assessment is defined by the Mental Health Commission (2004) as

The process through which the relevance of culture to mental health is ascertained. Cultural relevance relates to the significance tangata whaiora place on their identity as Māori and how they perceive the role of their cultural heritage in assisting them to achieve wellness. The purpose of cultural assessment is to identify a person's cultural needs and any cultural supports or Māori healing practices needed to strengthen identity and enhance wellness (p. 3).

Cultural assessment is imperative to clinical formulation and treatment as outlined by the Mental Health Commission (2004):

Cultural assessment is integral to cultural safety and the development of effective treatment plans. It is widely accepted by practitioners working in mental health services that cultural identity plays a significant part in the wellness of individuals and their communities' whatever the culture.

Cultural assessment acknowledges the link between identity, wellness, treatment and recovery (p. 3).

For Māori, this process would identify the importance of Māori culture and worldviews to the individuals overall wellbeing. Therefore cultural needs, supports, and traditional methods of healing may be techniques employed to strengthen treatment plans (Mental Health Commission, 2004).

Assessment of Dementia within Māori Elders

Māori are assessed for dementia under the same biomedical model as all other New Zealanders. There are no diagnostic guidelines for cultural distinctions which outline normal or acceptable behaviours, thus no allowance is made for cultural variations³. Within New Zealand the diagnosis and treatment of dementia is conducted using the biomedical model outlined in the American Psychiatric Association Diagnostic and Statistical Manual of Psychiatric Disorders (DSM-IV-TR).

The biomedical model defines mental illness as a functional impairment, where labels may distinguish or categorise individuals as abnormal and subject them to stereotypes and stigmatisation (Nicholls, 2010; Nikora, Karapu, Hickey & Te Awekotuku, 2004). This scientific perspective discounts alternative explanations of illness and defines the experience as disheartening, requiring management and treatment with the use of medication (Nicholls, 2010). However, it must be noted that diagnosis clearly presents benefits for those concerned (Ilfie, Robinson, Brayne, Goodman, Rait, Manthorpe, & Ashley, 2009). Ilfif and colleagues (2009) emphasised the advantages of diagnosis as: “ending uncertainty, confirming suspicions, increasing understandings of problems, giving access to support, promoting positive coping strategies, facilitating planning and fulfilment of short term goals” (p. 899). Extending this Cornett and Hall (2008) stated:

Disclosure respects the patient’s autonomy and makes it possible for the patient to be a more active participant in their treatment to whatever degree their level of cognitive functioning allows. If the patient is early in the

³ P.S.D.V. Prasadaraao, personal communication, August 19, 2010

dementing process disclosure ensures that the patient can be an informed participant in treatment decisions. Timely knowledge of the diagnosis may help the patient make lifestyle changes and put their personal affairs in order prior to becoming incapable to do so on their own (p. 254).

Early diagnosis is supported by an international consensus as it leads to treatment and the provision of support (Ilfie et al., 2009). The benefits are recognised as differentiating and treating medical conditions responsible for symptoms, accessing information, obtaining treatment, and encouraging future planning (Mahoney et al., 2005).

Although clinicians aim for cultural competence and endeavour to evaluate the functional impairment of Māori elders with the inclusion of cultural understandings, a lack of forthcoming information entrusts clinician judgement. The specific lack of research into Māori cultural understandings of deteriorating states of mental health within the elderly has resulted in diagnosis of dementia being dependent upon clinical judgement, which may be culturally subjective⁴. There is a clear lack of evidence provided in the available literature defining cultural variations within the diagnosis of dementia. However, clinicians are bound by professional ethics inclusive of respect for the dignity of persons and people which clearly outlines respect for the indigenous people of New Zealand (The New Zealand Psychological Society, 2008).

Culture is an essential element within any psychological assessment and treatment, especially when clients are from a cultural background that differs from the diagnostician (Sadock & Sadock, 2003). Sadock and Sadock (2003) outlined the cultural formulation described within the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) and included the following:

- (i) The cultural identity of the patients, including ethnicity, involvement with original and host cultures, and language abilities
- (ii) The cultural explanations and idioms of distress used by patients and their community concerning their illness or situation

⁴ P.S.D.V. Prasadaraao, personal communication, August 19, 2010

- (iii) The cultural factors impacting patients' social situations, including work, religion, and kin networks
- (iv) The cultural and social status differences between the patient and clinician that may affect assessment and treatment, including problems with communication, negotiating a patient-clinician relationship, and distinguishing between normal and pathological behaviours
- (v) The formulation of an overall cultural assessment for diagnosis and care (p. 167).

Therefore clinicians assessing Māori for a diagnosis of dementia are clearly bound by ethical practice promoting the wellbeing and safety of their client. Also, by the cultural formulation outlined above where clinicians must provide a cultural assessment as part of the overall diagnosis and care plan for any patient.

New Zealand Demographics

In accordance with other OECD (Organisation of Economic Cooperation and Development) countries New Zealand's demographics are changing and the population is ageing (Statistics New Zealand, 2007). Within New Zealand, the 'elderly' are defined as being over the age of 65 years, as this coincides with the current retirement age (Ministry of Health, 1997). The aged population is expected to rise rapidly over the next four decades. The predictions forecast that the population of aged people is expected to double by 2051, mainly due to the influx of the baby boom cohorts (defined as those born between 1946 and 1965). Statistics New Zealand forecasts that the elderly will account for 25% of the New Zealand population by 2051. This will amount to a substantial increase from 12.5% defined in the 2006 census. Increased longevity means that this sub-group is also ageing where the number of individuals over the age of 85 is expected to quadruple from 2006, to a predicted total of 322,000 in the year 2051 (Statistics New Zealand, 2007).

In summary, demographics indicate that the New Zealand population is ageing at the same time as fertility rates are decreasing across all demographic groups. Therefore the prevalence of age related disability, such as dementia, is likely to

increase (Statistics New Zealand, 2002). Consequently research aimed at improving cultural responsiveness for Māori elders in mainstream mental health services needs to be carried out promptly.

Māori Demographics

Māori account for 15.2% of the New Zealand population, and on average are 15.4 years younger than their European counterparts. In 2006, the average age of Māori was 22.7 years in comparison to 38.1 for Europeans (Statistics New Zealand, 2007). Māori life expectancy as at December 2009 was 75.1 years for females and 70.4 years for males, in comparison to 82.4 and 78.4 respectively for non-Māori. The difference equates to a life expectancy 7.6 years shorter for Māori (Statistics New Zealand, 2010a). Current statistics indicate that Māori account for 4% of those aged 65 and over. This figure decreases with age, where Māori account for only 2% of the population over the age of 80 (Statistics New Zealand, 2004). However, an increasing life expectancy and decreasing fertility rates are expected to result in the Māori population following international trends of an ageing society. Consequently, the population of elderly Māori is projected to increase from a total of 17,640 in 2001 to 56,000 in 2021. Therefore Māori are expected to account for the largest increase in older people during this period (Statistics New Zealand, 2007). Hence, increased longevity will see the needs of Māori elders become more prominent in the near future (Cram, 2010; Durie, 1999; Statistics New Zealand, 2004).

Exploring Dementia

Dementia is a neurological disorder defined by declining capacity of intellectual functioning. The period of deterioration is dependent upon subjective experience and the type of disorder (Alzheimers New Zealand, 2005; Perkins, 2006).

Dementia is the result of physical changes in the structure of the brain, causing gradual deterioration of cognitive abilities, and results in altered states of language, memory, personality, thought patterns, behaviour, emotion and perception (Alzheimers New Zealand, 2005; Perkins, 2006; Sadock & Sadock, 2003). The debilitation impacts significantly upon ones social and occupational functioning (Sadock & Sadock, 2003). Dementia is most commonly found in

people over the age of 65, and is uncommon in younger people. It is important to note that dementia is an illness, and not part of the normal ageing process (Hooyman & Asuman Kiyak, 1999; Perkins, 2006).

Symptoms of dementia are defined by the American Psychiatric Association Diagnostic and Statistical Manual of Psychiatric Disorders (DSM-IV-TR) as memory impairment and one or more of the following: language disturbance, difficulty carrying out motor activities, failure to recognise or identify objects, and/or difficulty with planning and organising. The deficits need to cause significant impairment within social or occupational functioning and represent a decline in the individual's level of functioning. The course of dementia is characterised by a gradual onset and a progressive decline in cognitive functioning. The symptoms must not coincide with an episode of delirium, or be better accounted for by other medical conditions or mental disorders (Perkins, 2006; Sadock & Sadock, 2003).

The most prominent symptom of dementia is failing short term memory (Alzheimers New Zealand, 2005). It must be noted that symptoms are heterogeneous in nature, where individuals exhibit different symptoms at different points in time. Other characteristic symptoms are repetitive speech patterns, difficulty making decisions, disorientation, mood changes, modified behaviour or personality, losing things, failure to recognise objects or people, difficulty with finances, incessant walking, difficulty performing everyday tasks, confusion, distractibility, and impaired conversational skills (Alzheimers New Zealand, 2005). These symptoms are generally grouped into three categories: cognitive impairment (memory, speech, language, recognition, and confusion); psychiatric and behavioural features (depression, hallucinations, agitation, repetition, emotional, incessant walking or wandering); and dysfunction within activities of daily living (Alzheimers New Zealand, 2008).

The most common types of dementia are Alzheimer's, vascular dementia, and mixed Alzheimer's - vascular dementia. Other causes of dementia are Huntington's disease, Picks disease, frontotemporal dementia, Parkinson's disease, Lewy body dementia, normal pressure hydrocephalus, Creutzfeldt-Jakob,

Kuru and Korsakoff (see for example, Hooyman & Asuman Kiyak, 1999; Sadock & Sadock, 2003). Differential diagnosis is difficult and sometimes impossible as functional symptoms across these diseases may be quite similar (Hooyman & Asuman Kiyak, 1999).

The most common form of dementia is Alzheimer's disease (Alzheimers New Zealand, 2006). Alzheimer's is characterised by premature degeneration of brain systems, where the main features are loss of short term memory and gradual decline of cognitive ability. The exact cause of Alzheimer's is unknown. However research indicates that the most likely cause is a complex integration of age, genetic and environmental factors (Alzheimers New Zealand, 2005). Overall, the greatest risk factors are age and head injuries (Perkins, 2006; Sadock & Sadock, 2003).

The second most common type of dementia is vascular dementia. Distinguishing features of vascular dementia are neurological weakness in limbs or face, abnormal reflexes, or evidence of cerebrovascular disease in a scan. Vascular dementia is often predisposed by hypertension, cardiovascular disease, diabetes, smoking, or a family predisposition to these conditions. It is caused by an inadequate supply of blood to the brain, resulting with an insufficient supply of oxygen, and cell death. Vascular dementia results in a wide variation of symptoms, as affected areas of the brain are different in each case (Perkins, 2006; Sadock & Sadock, 2003). Vascular dementia is distinguished from Alzheimer's by its typical stepwise deterioration, caused by mini strokes. Behavioural changes are often found to be sudden and followed by a plateau of stability, then another sudden deterioration (Perkins, 2006; Sadock & Sadock, 2003). Māori and Pacific Island people have a higher prevalence of vascular dementia in comparison to other ethnicities in New Zealand. This phenomenon is correlated to the higher incidence of hypertension and other predisposing conditions within these populations (Perkins, 2006).

Diagnosis of Dementia

Diagnosis of dementia is not a straight forward process, nor is it based upon a homogenous set of symptoms (Alzheimers New Zealand, 2006). Initially a full

medical examination is carried out to eliminate the possibility of other conditions underlying the presenting symptoms (Alzheimers New Zealand, 2006). The symptoms of decline in memory and cognitive functioning may be affected or caused by delirium, depression, the side effects of medication or alcohol, head injury, or other medical problems (Perkins, 2006). Diagnosis of dementia normally includes tests of memory and functional skills, which may include the mini mental status examination, and other psychometric tests (Alzheimers New Zealand, 2006; Perkins, 2006). Diagnosis is dependent upon a detailed personal history, presentation of symptoms, current concerns, and level of social functioning. This information is sourced from the individual and their family or caregivers (Iliffe et al., 2009; Perkins, 2006). From a Western medical perspective, a diagnosis of dementia should be considered in anyone over the age of 40 who has exhibited signs of a personality change (Sadock & Sadock, 2003).

At this point in time the literature acknowledges that assessment and diagnosis employing a Western-based measure in isolation from indigenous and non-Western populations is problematic. The assessment of dementia requires a thorough representation of the person, their regional, cultural and social dynamics (Pollitt, 1997). Griffin-Pierce and colleagues (2008) stated that “an important step toward diagnosing Alzheimer’s Disease in underserved communities is the development of culturally appropriate instruments to determine cognitive status” (p. 293). The researcher was unable to locate any literature highlighting different medical presentations across culture during the investigations. Therefore, it was assumed that the biomedical model is employed to diagnose dementia across cultures at this point.

When someone begins to show signs of dementia concerned family members normally seek the guidance of their general practitioners. General practitioners screen clients with basic psychometric tests, such as the Mini Mental Status Examination. Provisional diagnosis may be made within the primary care setting; however, the majority of clients are referred on to specialist services. If appropriate, a referral is made to the mental health services for older persons, older person’s health clinics, or memory clinics. Diagnosis is based upon a comprehensive assessment including clinical judgement, neuropsychological

testing, neuroradiological investigations, functional assessment, biochemical investigations and other tests as deemed appropriate⁵ (Iliffe et al., 2009). Treatment provided is dependent upon the individual, their needs, stage of dementia, living situation, and support available (Perkins, 2006).

Stages of Dementia Impairment

Deterioration of cognitive abilities is heterogeneous and dependent upon the individual, their health, the type of dementia, pre-morbid intelligence, and age of onset. Later onset normally results in slower deterioration. Diagnosis is often delayed due to the subtlety of symptoms, and the fact that many people attribute the indications to old age. Following a diagnosis, the average length of survival is eight years, and mortality rates of those afflicted with dementia are double in comparison to those without dementia (Sadock & Sadock, 2003).

Dementia is diagnosed within one of three stages (Alzheimers New Zealand, 2008). Mild dementia is recognised within early stages of the disorder where the individual can still live independently, is normally orientated, and able to attend to personal daily care activities. Mild dementia is represented by symptoms of forgetfulness, and significant functional impairments within the activities of socialisation, employment and relationships. The symptoms of mild dementia are often attributed to the ageing process. Moderate dementia is diagnosed when the individual exhibits symptoms of severe memory loss, disorientation of time and place, lack of judgement or problem solving, inability to manage money, and assistance with personal cares is required. A diagnosis of severe dementia requires 24 hour supervision and care. Those with severe dementia suffer from acute memory loss, complete disorientation, an inability to complete self-care activities, and may be incontinent (Alzheimers New Zealand, 2008).

Prevalence of Dementia

Research estimates that Alzheimer's affects twelve million people worldwide (approximately 10% of the older population), and that the increasing statistics will

⁵ P.S.D.V. Prasadaraao, personal communication, August 19, 2010

see this figure double over the next fifteen years (Vierck & Hodges, 2003). There is some difficulty predicting prevalence as rates are dependent upon affected individuals or families seeking help. Families who do not seek assistance are unaccounted for within statistics (Elliot & Di Minno, 2006). Problems associated with cognitive decline are most likely in the older age brackets, where statistics indicate that 50% of those over the age of 85 are impacted by the symptoms of dementia. There is a significant difference between those with normal age related cognitive decline and those affected by dementia. Elevated prevalence rates are also evident within older people residing in care facilities (Vierck & Hodges, 2003).

Within New Zealand the estimated prevalence of dementia is 5-8% of the elderly population (over 65 years), equating to approximately 40,746 affected individuals. However, the ageing population is expected to increase this estimated prevalence to 74,841 by 2026, and predicts further escalation with the changing population demographics. Similar to international statistics, New Zealand prevalence is predicted to increase with age, where rates are currently estimated between 20-40% of the population over the age of 80 years (Alzheimers New Zealand, 2008).

Treatment of Dementia

There is no cure or effective treatment for dementia (Alzheimers New Zealand, 2008). As a result, treatment is centred upon the biomedical model, minimising risk factors, treating and managing behavioural and psychological symptoms, and improving the quality of life for the individual and their caregivers (Alzheimers New Zealand, 2008). Early diagnosis is important for treatment, the provision of care, acquiring educational material, and establishing long term strategies.

Treatment is generally centred upon psychosocial approaches, medication and improving the quality of care provided. Psychosocial interventions emphasise support and education for the individual and their family. Behavioural management strategies and the prevention of secondary symptoms, such as depression and anxiety, are important factors for maintaining a quality of life for all concerned. These interventions include accessing community organisations for support and information. Medication is utilised to treat cognitive decline, memory loss, and manage behaviours or secondary symptoms. The progression of vascular

dementia can be slowed with the use of blood thinning agents used to preserve blood vessels and reduce the risk of stroke (Alzheimers New Zealand, 2008; Perkins, 2006). However, antipsychotics used to treat challenging behaviour have significant side effects, such as increasing the number of falls, sedation and worsening cognitive decline (Martin, 2009).

An alternative viewpoint is presented by the New Zealand Council of Christian Social Services (NZCCSS) emphasising a whānau-centred approach, developed from person-centred care, focusing upon enabling, recovery, and maintenance of language and capacity. It encourages appreciation of life and continuing identity. For example, when communication patterns change, meaning making is based upon personal history and identity. This approach provides support for affected individuals and their family or carers, aiming to improve the quality of life for all concerned. It allows a continuum of care as required and includes culture and spirituality. Therefore it is multidimensional and holistic in nature (Martin, 2009).

Traditional Māori Concepts of Mental Health

Little is known about perceptions and responsiveness towards disability or mental health within traditional Māori society (Nikora et al., 2004). However, the history of New Zealand indicates that prior to colonisation Māori lived in a harsh and challenging environment (King, 2003). Social controls provided elderly Māori with status and care, but it is unclear how disabled or impaired people were treated. Nikora and colleagues (2004) suggested that the impaired or disabled were cared for within hapū when resources were abundant. However if sickness was attributed to a breach of tapu or mākutu then it is most likely that the individual was exiled from the community. In addition, expulsion from communities may have occurred during times of unrest or when resources were scarce (Nikora et al., 2004).

Before Europeans arrived in New Zealand, Māori were believed to have treated mental illness with awe or fear (Gluckman, 1976). Within traditional Māori societies mental illness or complaints such as insanity, were believed to be the influence of mystical or superstitious origins (Best, 1924; Goldie, 1998; Metge, 1976). In addition, mental illness was often correlated with geographical areas,

due to places being deemed sacred or tapu (Gluckman, 1976). This viewpoint conceptualised mental illness with an underlying cause of hara, infringement of tapu, mate Māori, mākutu, or mate wairua (Dansey, 1992; Lyndon, 1983; McNeill, 2005; Metge, 1976). Another understanding of insanity was that a hostile or evil spirit had entered the physical body of the affected person (Best, 1924; Goldie, 1998). Where speech became incoherent or presented as mutterings or ravings, the individual was believed to be forwarding messages from the gods or ghosts (Goldie, 1998).

The most common forms of mental illness among early English diagnosis of Māori were idiocy, senile mania, dementia, morbid impulse, and paralysis of the insane⁶ (Goldie, 1998). Goldie (1998) continued to state that senile dementia was the second most common form of mental illness, affecting a significant portion of ageing Māori⁷, as represented by a ‘torpid and inanimate state’. Individuals affected by the disorder were permitted to meander freely at their liberty. These individuals were respected as it was thought that those with dementia had the power to contact the other side (Goldie, 1998). In contrast, Gluckman (1976) reported that it was most likely that the individual afflicted with a mental illness would have been excluded from community life and left to die. This behaviour was founded on the belief that being unhealthy or unwell was an experience of tapu caused by the gods. Best (1924) reported that medicine could not assist those inflicted by tapu, and the individual posed a risk to others, so care or assistance was not provided.

Complementary Therapy

Traditional Māori worldviews would have guided individuals to tohunga for healing and treatment of mental disturbances (Perkins, 2006). Holistic perspectives of wellbeing remain within contemporary society and signify that healing extends beyond treatment from health professionals. In the first instance, healing requires the individual and their family have faith in the applied treatment

⁶ These medical terms were used in the 19th century and continued to be used in the mid 20th century.

⁷ Ageing Māori was not defined in years.

method. Within the Māori worldview karakia is an important aspect of healing and all aspects of life. Karakia would normally be employed across all aspects of treatment: assessment, meetings, ongoing care, towards the end of life, and following death. In addition, the balance of life and wellbeing requires the support of ones whānau across all stages of life (Perkins, 2006). Karakia has been found effective at calming and settling Māori elders affected by dementia (Martin, 2009).

Goldie (1998) and Metge (1976) reported that ailments caused by infringements of tapu were traditionally cured by tohunga. Tohunga performed ceremonial acts based upon shamanistic principles to drive out evil spirits (Best, 1924). Another practice to clear evil spirits was the cutting of hair from the person suffering from insanity. The hair was tied to a stalk of grass and floated down river while karakia was employed to remove the spirit from their community (Gluckman, 1976). Where illness is believed to be caused by mākutu or mate Māori, Māori consider Western medicine to be ineffective.

Hallucinations, occurring as symptoms of dementia, may be understood from an alternative and positive perspective where origins are spiritual and not problematic. Hallucinations may be conceptualised as a spiritual gift or contact with the other side. If the person becomes distressed when hallucinating, traditional forms of healing may be more effective than medication to calm the person or provide meaning out of the experience (Perkins, 2006).

There is a need to integrate traditional and complementary treatments within current practice. Kepa (2006) presented a model for the care of Māori elderly entitled 'He Whānau' which includes karakia, rongoā, the services of tohunga, mirimiri, hauora and holistic models of health, interconnected relationships with all living things, all combined with the importance of history, whānau and ancestors. Care for Māori elders within this model is based upon cultural values, and the provision of aroha and manaakitanga, in conjunction with the provisions of mainstream services (Kepa, 2006).

Kaumātua - Māori Elders

Western understandings of old age are based upon numerical age, the loss of independence, and general decline within physical and mental capacity. In contrast, Māori observe old age by physical characteristics such as grey hair, behaviour and having grown up grandchildren (Kepa, 2006; Metge, 1967). Therefore Māori recognise old age as a positive experience where the elderly are ascribed value and respect (Durie, 1999; Metge, 1967). Older women are referred to as kuia and older men as koroua or koro, both terms denote respect (Waldon, 2004).

Māori society depends on their elderly to provide cultural knowledge and guidance, and to ensure mātauranga Māori is reproduced (Durie, 1999; Waldon, 2004). Consequently the Māori worldview emphasises age as important, with significant roles more likely to be appointed to the elderly (Durie, 1999). Māori elders who are ascribed leadership roles are known as kaumātua, and are treasured members of the Māori society (Metge, 1976; Waldon, 2004). The status of kaumātua is not inferred from age alone, as value is placed upon wisdom, skill and knowledge (Durie, 1999; Waldon, 2004). Not all older Māori are denoted leadership roles or kaumātua status. However the term kaumātua, in its more traditional sense, refers to older members of the whānau in a collective or plural sense. In contemporary society kaumātua most commonly defines men who hold leadership roles (Barlow, 1994; Metge, 1976). Leadership roles relate to whakapapa, knowledge of tikanga and protocol, genealogical descent, and place of residence (Durie, 1999). Hohepa Kereopa, in Moon (2003), stated:

To be a kaumātua, you must first wade through life, because that's what the word means: to wade through something. And only when you wade through can you begin to understand life and the context of life..... You have to have the experience, plus you have to have the knowledge to do the things of a kaumātua. Otherwise you are not one (p. 118).

Kaumātua have active responsibilities and obligations within the whānau and community, where their wisdom is a hallmark. Associated with mana, kaumātua are recognised for their rangatiratanga status of iwi, and provide guidance to their communities and whānau (Durie, 1999; Waldon, 2004). The roles of kaumātua

may include dispute resolution, passing on traditions and culture, tribal protocols, ceremonial duties, spiritual leadership, nurturing children and young people, speaking on behalf of their whānau or iwi, attending tangi, and the delegation of responsibilities (Durie, Allan, Cunningham, Edwards, Forster, Gillies, Kingi, Ratima & Waldon, 1997; Durie, 1999). Kaumātua are relieved of more challenging roles with advanced age. These kaumātua become protected taonga retaining a supportive role (Durie, 1999).

In contrast to Western values Māori view old age as a period of increased opportunity where kaumātua and the elderly are treated with respect and status within a caring environment (Durie, 2001; Waldon, 2004). Traditionally younger members of whānau, iwi and hapū have taken care of the needs of kaumātua in exchange for the tribal responsibilities ascribed to age. The principle of manaakitanga within iwi has been central to the care of kaumātua and elderly members of the whānau. Therefore kaumātua or elderly Māori are less likely to live in facilities for aged care, and are more likely to reside in whānau households (Durie et al., 1997; Kepa, 2006).

Māori Models of Wellbeing

It is well established that culture and customs impact understandings of health and wellbeing (McNeill, Paterson, Sundborn, DeSouza, Weblemoe, McKinney & Smith, 2010). In comparison to the Western definitions of health being an absence of illness (Capstick, Norris, Sopoaga & Tobata, 2009), Māori appreciate health from a unique perspective of holistic interconnectedness (McNeill et al., 2010; Ministry of Health, 1997; Shaw, Tyacke, Sherrard, Hikuroa & Corbett, 2010). Spirituality is an essential element of wellness, and traditionally all states of ill health have a spiritual component (McNeil et al., 2010).

The most commonly employed framework used to explain the holistic approach of how Māori perceive health is Te Whare Tapa Whā (Durie, 2004; Kumar & Oakley Browne, 2008). The four components, or walls of the house, are described as taha wairua, taha hinengaro, taha tinana, and taha whānau. Within this model, wellbeing requires a balance between the four components or walls of the house. Each element provides strength and support for the others. If one wall of the

house fails or is weak then the house loses its strength and support (Durie, 1998). Optimal health or wellbeing is maintained when all components are balanced and interconnected providing strength and stability (Durie, 2001; Ministry of Health, 2002). Illness results from an imbalance or disruption in the connections, or where one element has weakened (Durie, 1998).

Extending Te Whare Tapa Whā, Mark (2010) has represented wellness within a model titled Te Whetu. In addition to the four components of Te Whare Tapa Whā, Mark (2010) added the factor of land, and presented the model as a star to symbolise the interconnectedness of all elements. Te Whetu is grounded within indigenous knowledge, where all forms of life are interrelated and there is no distinction between physical and mental concepts. The inclusion of land is imperative to Māori understandings of wellbeing as people are one with the environment (Mark, 2010).

In addition, Māori look to the past for their understanding of the present; history is a crucial factor of the holistic approach (Moon, 2003). Hohepa Kereopa, a respected Tūhoe tohunga, believed that many contemporary problems are caused by a disconnection from ancestry and core beliefs. He also believed that in time, all Māori will return to their culture as it is an integral part of their identity and wellbeing (Moon, 2003). Therefore cultural identity is an essential element within the Māori model of wellness. Identity is viewed under the holistic umbrella where individuals are whole when connected with Māori worldviews, values and tikanga (Durie, 2001).

The principle of pūtahi emphasises the importance of understanding a Māori worldview in the context of its entirety. Therefore to understand the mental health of ageing Māori, wellbeing must be acknowledged within a holistic approach, residing in the larger context of existence (Ritchie, 1992). This phenomenon was evident in McNeill's (2005) research into the mental wellness of Tūhoe kaumātua where wellness was inseparable from language, spirituality, natural environment and culture.

To summarise, in the context of the current research, it is imperative for the researcher, readers and mental health professionals to employ Māori models of wellbeing when attempting to understand dementia from a Māori cultural viewpoint.

Directions within Māori Demographics

The changing demographics within New Zealand will see the number of Māori elderly increase (Statistics New Zealand, 2007). Statistical evidence shows that the number of Māori elders has increased from 17,640 (3.4% of the total population) in 2001 to 23,127 (4.1%) in 2006. These numbers are expected to increase to 56,000 (7% of the total population) by 2021 (Statistics New Zealand, 2007). The ageing Māori population will lag behind the overall New Zealand rate due to differences in fertility, mortality and migration (Statistics New Zealand, 2006). The increasing numbers of older Māori may place strains on the ability of whānau to provide care and protection for their elderly (Durie, 1999). As the Māori population increases, older Māori may be unwilling, or unable, to fulfil the roles of kaumātua. In addition, urbanisation may lead to Māori being alienated from their culture and unfamiliar with the significant roles that elders hold (Durie, 1999; Statistics New Zealand, 2006).

The future will result in a greater diversity among Māori where kaumātua may not all hold traditional knowledge or fulfil leadership roles within iwi or whānau. Furthermore, traditional Māori values may be weakened or displaced by children coming from cross-cultural backgrounds, as not all will have made connections with marae or iwi. Therefore the elderly may have a reduced ability to depend upon Māori cultural norms of reciprocal care arrangements within whānau (Durie, 1999; Martin, 2009; Statistics New Zealand, 2006). This situation may also arise when urban families have commitments to employment or other organisations and are unable to provide adequate care. Whānau and iwi may be financially stretched as the population ages, and may be unable to provide a home or full time care for the aged. This in turn means that Māori may require the services of rest homes and residential care facilities more in the future (Durie, 1999; Maaka, 1993; Martin, 2009; Perkins, 2006).

Historical Review of Cultural Models of Understanding

Perkins (2006) argued that Europeans fear the loss of independence and dignity, where becoming a burden to one's family is an undesirable experience. These fears arise from the management of the infirmed across history. For example, in the Victorian era, older family members who became frail and dependent were forced to live in humiliating conditions. This humiliation was continued in more recent times where people were institutionalised within large mental hospitals when it became evident that intellectual functioning and behaviour had deteriorated beyond the socially accepted norms (Perkins, 2006).

Ancient societies often exhibited death-hastening behaviours towards those who were no longer able to contribute to society or care for themselves. For example, in ancient times within rural Japan older people were transported to remote areas of the mountains and left to die alone. Geronticide or senecide (euthanasia of the elderly) were functional methods of eliminating burdens to society (Glascock, 2009; Hooyman & Asuman Kiyak, 1999). In contrast, ancient Greek and Roman cultures valued the elderly and placed them in positions of authority. Wisdom and knowledge of the group's history, culture and customs entitled older individuals to social status and protection (Hooyman & Asuman Kiyak, 1999).

Cultural Models of Understanding Dementia

Dementia is conceptualised through a variety of explanatory models or lens, and understanding this variability is important to the provision of responsive care in the future (Hinton, Franz, Yeo, Levkoff, 2005; Richards & Brayne, 1996). Factors impacting understandings and experiences of dementia are a complex interaction of personal and cultural history, social interactions, and how others perceive those affected (O'Connor, Phinney, Smith, Small, Purves, Perry, Drance, Donnelly, Chaudhury & Beattie, 2007).

Models of Stigmatisation and Morality

The Asian worldview attaches significant levels of stigmatisation to mental illness and its underlying causal mechanisms (Liu, Hinton, Tran, Hinton & Barker, 2008). These beliefs are often founded upon morality and loss of status for the

affected family. According to Confucian ethics, part of which outlines moral behaviour, loss of face is the most unpleasant thing that can happen to a Chinese family. The stigmatisation surrounding dementia within Asian American families originates from the changes in cognitive abilities and behavioural symptoms. Consequently the affected individual is hidden at home in order to avoid the shame and guilt attached to mental illness (Elliot & Di Minno, 2006; Liu et al., 2008).

In Japan, the symptoms of dementia are viewed as a moral concept based upon the breakdown of personal characteristics (physical, mental and social), originating from a lack of activity. Engaging in activities that involve the mind and body are viewed as making an effort to avoid the onset of cognitive deterioration. Dementia may then be understood within a social and moral framework (Traphagan, 2009).

Models of Spirituality

Models of spirituality permit the loss of cognitive ability and the presence of hallucinations to be understood as a supernormal phenomenon, representative of being in contact with the afterlife (Henderson & Henderson, 2002). For example, the first nation's people of America and the Chinese interpret the symptoms of dementia through a spiritual or supernatural lens. Living entities are understood in connection with the physical, social and supernatural worlds (Elliot & Di Minno, 2006; Henderson & Henderson, 2002). Therefore delusions or hallucinations are understood as normal phenomena, if not gifts from the spirit world.

Extending this model is the belief that dementia arises from profound culture shock. A number of indigenous people from Asia and the Pacific Islands believe that dementia originates from the traumatisation of immigration (Richards & Brayne, 1996). Causal mechanisms are ascribed to depression, loss of culture and social support, and the ancestors calling the individual to their homeland (Capstick et al., 2009; Kane & Houston-Vega, 2004).

Model of Normal Ageing

The normal ageing model rationalises prominent symptoms, or typical behaviours, of dementia. Consequently, behaviours defined by the Western biomedical model

are simply understood as part of the normal ageing process (Elliot & Di Minno, 2006; Gray, Jimenez, Cucciare, Tong & Gallagher-Thompson, 2009; Hinton et al., 2005; Mahoney et al., 2005). For example, the first nation's people of America commonly associate the characteristic symptoms of agitation, incessant wandering and hallucinations to the normal ageing process (Kane & Huston-Vega, 2004). This phenomenon is also found within traditional Chinese culture in which longevity is regarded as a reward for abiding by moral values throughout life (Ikels, 2002).

Model of Family Obligations

Western culture values autonomy, privacy and independence (Hooyman & Asuman Kiyak, 1999; Perkins, 2006). Therefore intergenerational living is a rare occurrence in Western families. However intergenerational living, extended families, and reciprocal support arrangements are more common within ethnic minorities (Hooyman & Asuman Kiyak, 1999). These cultures believe that family members are responsible for the care of their elderly. These obligations often take precedence over the needs of individual family members (Kane & Houston-Vega, 2004). For example, Asian worldviews emphasise filial piety (family obligations). This value provides elderly family members with respect and a caring environment, even when their mental health deteriorates (Ikels, 2002).

Models of Contrast

Pollitt (1997) reported that the Aboriginal population of Australia views dementia as tiredness or childlike behaviour. Consequently the affected individual is assisted by the community and treated in a childlike manner. However, the later stages of dementia are viewed as a social death and the individual is no longer identified as a person (Pollitt, 1997).

The provision of care for the elderly, within the Pacific culture on the island of Nuie, is dependent upon social status (Barker, 2009). Older members of the community who remain in good health and hold social importance are respected and provided with appropriate levels of care. However, those who are frail or

impaired are unattended and neglected. Consequently, individuals presenting with dementia like symptoms often receive inadequate attention or care (Barker, 2009).

Impact of Different Cultural Health Models

As represented by the five models described in the immediately preceding section, dementia can be viewed from a variety of worldviews. Interpretations impact how individuals and families cope with the demands of cognitive and behavioural decline. For example, some Latino-Hispanic immigrants living in the United States understand dementia as a punishment for wrong doing, or an act of God, which may result in the family being obliged to suffer along with the affected individual (Kane & Houston-Vega, 2004).

The consequences of models based upon normalisation and stigmatisation is delayed help seeking behaviour and increased suffering (Elliot & Di Minno, 2006; Gray et al., 2009; Liu et al., 2008; Mahoney et al., 2005). Stigma, stereotypes and negative emphasis surrounding mental illness affects self worth, the lived experience, help seeking behaviour, how symptoms are interpreted, and how individuals and their families cope (Connor, Copeland, Grote, Koeske, Rosen, Reynolds & Brown, 2010).

For example, the Nuian culture values those who can contribute to sustaining their society. According to Barker (2009) those who become a burden or are unable to assist with daily chores are neglected and left to die. In addition, these individuals are offered to the young as a method of social control, where individuals affected by dementia are ridiculed and illustrate wrong doing (Barker, 2009).

Placing positive values, emphasis and interpretation on the experience of dementia appears to result in a more constructive encounter for both the family and the affected individual (O'Connor, Phinney, & Hulko, 2010). Ethnic minorities are less likely than Europeans to employ the biomedical model, and more likely to understand dementia from an alternative viewpoint (Gray et al., 2009; Hinton et al., 2005). Developing an understanding of the disorder based upon knowledge of both the biomedical and folk models seems to provide piece of mind and a less stressful experience (O'Connor et al., 2010).

This positive emphasis is evident within the spirituality model where the symptoms and experience of dementia are signified as valued incidents (Henderson & Henderson, 2002). The family obligation model demonstrates that the caregiver has a strong moral character. Furthermore, the normal ageing model reduces fear, stigma and caregiver burden (Ikels, 2002). These models may challenge the pathological approach of the Western biomedical model and eradicate stigmatisation.

Overall cultural differences around coping strategies and help seeking behaviours were more evident when symptomatic behaviours became more challenging or difficult. For example, African Americans were found to respect their elders and tolerate unusual behaviour. This population was found to seek help from church ministers (Mahoney et al., 2005). In comparison, Latino families attributed deteriorating behaviours to religious beliefs, such as the will of God or punishment for wrongdoing. This belief leads to help being sought from friends and family (Kane & Houston-Vega, 2004; Mahoney et al., 2005). In the later stages of dementia, where incapacitation and changes in personality are more evident, the stigma within Asian cultures intensifies. Unfortunately this may lead to neglect, abuse and exclusion of the afflicted elderly individual (Liu et al., 2008).

Impact of Contrasting Indigenous Versus Biomedical Models of Care

The holistic principles of wellness are both interdependent, and paramount to a responsive approach to the care of aged Māori (Ministry of Health, 1997). However, these principles contrast with the individualistic nature of the biomedical model of illness. The application of universals and the omission of spirituality from the Western approach may confound understanding and treatment of mental health for kaumātua and Māori elderly (Durie, 2001; Smith, 1999). Western understandings which focus on loss due to the disease process, allow family members to view the ageing individual as a non-person or shell of their former being. Within this frame of understanding the individual may lose their personal value and identity to family members. Consequently they are treated as though their mind has died and their spirit has departed their body (Martin, 2009; Perkins, 2006). In contrast, the holistic understanding of health

means that Māori are able to acknowledge those affected by dementia as valued people, maintaining a relationship based upon respect and love. Within the Māori worldview people are respected for characteristics outside of autonomy and cognitive functioning. This explanation may encourage acceptance, affectionate care, and improve the individual's quality of life based upon their human rights (Martin, 2009; Perkins, 2006). Furthermore, it is believed that Māori elders who are isolated from their marae and a cultural life suffer from greater degrees of memory loss. However, it is believed that the mana of Māori elders affected by dementia is retained through the collective memories of whānau and hapū (Martin, 2009). Consequently, in order for mental health services to be responsive to Māori clients, clinicians need to understand Māori worldviews, and that affected individuals and their whānau are searching for meaning within their current situation (Tapsell, 2007).

Barriers to Accessing Mental Health Services for the Elderly and Māori

Literature reviews and research indicates that Māori may experience barriers when accessing disability support services. Potential barriers are: low socio-economic status, high costs, institutional or attitudinal discrimination, lack of transport, a shortage of Māori staff within organisations, insufficient awareness of Māori perspectives or appropriate service provision, exclusion of whānau, and inadequate use of tikanga and te reo Māori⁸ (Baxter, 2002; Nikora et al., 2004). Kingi and Bray (2000) indicated that the needs of Māori are not being recognised due to differences in understandings or definitions of disability. Furthermore, the lack of both Māori staff and an ethnocentric approach within mental health organisations is disempowering for Māori clients and their whānau (Barnett & Barnes, 2010).

Research into experiences of health care for Māori highlighted a general dissatisfaction plus concerning levels of inappropriate interactions with health professionals (Ellison-Loschmann & Pearce, 2006; Jansen, Bacal & Crengle, 2008). In these studies, Māori reported being treated with disrespect. Clients often felt talked about, not to, and frustration arose with the unexplained use of

⁸ Te Reo Māori is an official language of New Zealand

medical jargon. In addition, the lack of cultural appreciation or understanding was found to result in culturally inappropriate practice, and offence. Consequently, the lack of kaupapa Māori services, conscious and unconscious biases of health workers, and negative past experiences were found to contribute to delays in help seeking behaviour and result with significant impairment (Ellison-Loschmann & Pearce, 2006; Jansen et al., 2008). Therefore, Māori perceived the inclusion of culture within mainstream services as add-ons, not a priority for care (Tapsell, 2007).

Tapsell (2007) noted that Māori experience care within mental health services differently than Europeans. For example, research into psychiatric seclusion within Waikato Mental Health Service indicated that Māori are more likely to be secluded, have longer periods of hospitalisation, and are more likely to be readmitted, than Europeans. This phenomenon was not substantiated with clear evidence, but was represented by Māori being viewed as more dangerous and suffering from more severe psychopathology (El Badri & Mellso, 2002). These differences were found to extend into the practices of treatment and medication, where reports have found greater levels of coercion and restrictions for Māori clients (Tapsell, 2007).

Additional barriers for all older people accessing assistance within mental health organisations commonly include: a lack of minority employees, institutional racism, a lack of appropriate norms for psychometric tests, lack of assistance with transportation, financial restrictions, being unaware of available services, shame or stigma, and culturally insensitive or unaware employees (Hooyman & Asuman Kiyak, 1999; Kane & Houston-Vega, 2004). Additional factors reducing the likelihood of assistance may include: lack of knowledge about support available, language barriers, education (both schooling and health), racism, understandings of deteriorating mental health, and culturally inappropriate services (Hinton et al., 2005; Hirini, Flett, Long, Millar & MacDonald, 1999; Kiata & Kerse, 2005).

In addition, research indicates that more than half of mental health problems within the elderly sector receive inadequate diagnosis and treatment. The lack of care arises when assistance is sought from general practitioners who often lack

specialist training in gerontology and/or mental health (Hooyman & Asuman Kiyak, 1999; Vierck & Hodges, 2003). Furthermore, mental health problems in older people are conspicuously different in manifestation and presentation than other age groups. For example, older people are inclined to focus upon physical rather than psychological symptoms, and indicators of mental illness may be denied or masked. Consequently psychological problems are often attributed to physical difficulties or normal age-related concerns (Hooyman & Asuman Kiyak, 1999; Vierck & Hodges, 2003).

Cultural context impacts one's perception of ageing, problematic behaviour, how to care for older people, and who should be responsible for ageing family members (Kiata & Kerse, 2005). Research by Kiata and Kerse (2005) indicated that intercultural care results in misunderstandings and inappropriate treatment, as people from different cultural backgrounds have diverse views on age, and care practices. In addition, Māori within residential facilities have reported feeling distressed at the exclusion of culture, and variations in care giving styles (Martin, 2009). Consequently, help seeking behaviours are determined by interpretations of health (Kumar & Oakley Browne, 2008). Pākehā are guided by dominant Western beliefs that imply a lack of independence indicates a need for residential care, as value is often attached to autonomy. However, extended family and patterns of reciprocal support are more common in ethnic minorities. Cultural values which prioritise the family are more likely to care for aged family members within the home environment (Kiata & Kerse, 2005).

Elders from ethnic minorities often face multiple layers of jeopardy as a consequence of institutionalised racism, the failure of practitioners to be culturally competent, socio-economic status, age, sex, and problematic mental health. Consequently, compounding inequalities result in disempowerment and dissociation from service providers (Forbat, 2003). Research investigating New Zealand psychiatrist's attitudes towards Māori clients found that 20% of practitioners clearly identify with racist beliefs. For example the high prevalence rates of mental disorders within Māori are commonly explained by New Zealand psychiatrists as a biological predisposition (Johnstone & Read, 2000). A failure to

understand the mental health needs of Māori within a socio-cultural frame may result in discrimination and inappropriate interactions (Sachdev, 1989).

In sum, it is imperative that diagnosis and treatment consider cultural norms (Elliot & Di Minno, 2006). Health professionals may define behaviour as pathological when it is actually culturally acceptable or respected. Misinterpreting behaviour from an ethnocentric position may result in culturally insensitive and inappropriate treatment (Elliot & Di Minno, 2006).

The Impact of Weakening Traditional Values

Weakening links with traditional values and assimilation into dominant cultural practices may negatively impact upon identity, social networks and mental health (Kumar & Oakley Browne, 2008). Māori residing within urban locations are more likely to be isolated from affiliations with their iwi and the support traditional connections provide (Families Commission, 2008). Consequently, the universal ageing population may place a strain on family obligations or responsibilities in the future, and impact the capacity of families to care for their elderly (Hooyman & Asuman Kiyak, 1999; Kiata & Kerse, 2005; Kane & Houston-Vega, 2004; Kumar & Oakley Browne, 2008). This phenomenon is evident within Japan where the rapid increase in the aging population has seen increases in negligence and abuse of older people (Hooyman & Asuman Kiyak, 1999).

The strain within more traditional ethnic minorities may be related to relationships, marital, financial or social pressures (Kane & Houston-Vega, 2004). Therefore, combined pressures upon whānau may lead to an increased vulnerability of elder abuse within New Zealand. Research indicated that abuse or neglect of Māori elders is hidden. Common issues underlying elder abuse include caregiver burden and inadequate resource provision. The risk of abuse or neglect was found to increase with the deteriorating behaviours associated with dementia. In contrast, endorsing cultural values and identification by those employed within health care facilities was found to be a protective factor against abuse or neglect (Families Commission, 2008).

Community Researchers' Critique of the Biomedical Model

Growing concern about unequal treatment towards New Zealand's indigenous population has led to some minor research projects being carried out within recent years. The findings suggested that the biomedical model of assessment and care may require some improvement to include cultural models of wellness, and engage Māori more appropriately within mainstream services.

Western understandings of illness are dominated by the biomedical model and physiological changes within the body (Broom, Nicholls & Deed, 2010). Subsequently, the biomedical model has been recognised as one of the most likely sources of discrimination within mental health settings in New Zealand (Moeke-Maxwell, Wells & Mellsop, 2008). The diagnostic practice labels and marginalises people (Nicholls, Mpofu & Shaw, 2010), where dominant paradigms defining the states of normal and abnormal behaviours may ignore culturally diverse understandings of health (Kingi & Bray, 2000). Diagnostic labelling and the stigma attached to mental illness was found to direct family attention away from underlying or environmental causes, to the biomedical model, chemical imbalances and a deficit approach (Moeke-Maxwell et al., 2008). Labels have been identified as a possible source of difference and segregation, often ignoring the individual, their identity and diversity (Ballard, 1994). In addition, the stigma attached to mental illness may result in shame where the individual is hidden from extended family and close friends (Barnett & Barnes, 2010). Shame may also lead to mental illness being hidden from immediate family, a reduction in help seeking behaviours and availability of support (Moeke-Maxwell et al., 2008).

Māori may perceive the Western term of 'dementia' as a cause of whakamā or shame, especially if it is viewed as suffering caused by hara or transgression of tapu. The distinction between acceptance and shame directly impacts the seeking of assistance and the level of support for the affected family member (Barnett & Barnes, 2010; Nikora et al., 2004).

Shame is underscored by fear where others may place judgement on the individual or their family, resulting in rejection (Barnett & Barnes, 2010; Moeke-Maxwell et al., 2008). Māori consumers commonly report that mental illness is a form of

whakamā where individuals are hidden, excluded and even shunned (Barnett & Barnes, 2010; Moeke-Maxwell et al., 2008). Some Māori believe this phenomenon has arisen from colonisation and urbanisation, where traditional values such as manaakitanga have been broken down. However, the most significant problems within mainstream mental health settings were identified within the recent research as: the exclusion of whānau, lack of information provided for the individual and their family, the dominance of the biomedical model, and discrimination (Barnett & Barnes, 2010).

Many Māori emphasise whānau and spirituality as essential elements of wellbeing, where the inclusion of family and spirituality are imperative to treatment and healing (Barnett & Barnes, 2010; McNeil, 2005). Māori are somewhat reluctant to discuss spiritual beliefs and cultural conceptualisations of mental illness with medical professionals as these understandings deviate from dominant norms. Misunderstandings between Māori conceptualisations and the biomedical model have led to Māori being inappropriately labelled ‘mentally disturbed’ (Lyndon, 1983; Metge, 1976). Therefore Māori may be disadvantaged by diagnosis within mental health settings which are culturally insensitive or ill-equipped (McNeill, 2005). Furthermore, some authors feel that the emphasis upon medication as the main form of treatment may exclude a holistic approach (Barnett & Barnes, 2010).

These recent criticisms of mainstream mental health and the biomedical model may be understood in a productive and positive frame in relation to international literature as follows. Research by Fontaine and colleagues (2007) emphasised that South Asian people, residing in the United Kingdom, conceptualised dementia from the following perspective:

There was a great sense of stigma and lack of knowledge about mental illness and mental healthcare services. There seemed to be quite a strong sense of exclusion from these services. It was striking that there was no mention of dementia, either directly or using lay terms, implying a lack of awareness of dementia as an entity. Thus not only was dementia not mentioned but also the cognitive and other symptoms were understood as

being caused by social, physical or emotional factors rather than organic brain disease (p. 611).

Although Fontaine and colleagues (2007) implied that the dominant Western biomedical model may disagree with the beliefs and values of non-Western populations they clearly stated that the biomedical model may have some benefits for South Asian persons:

This is not to suggest that traditional biomedical viewpoints have no role or relevance for this population, but rather that these must be balanced against cultural beliefs and perceptions in order to be acceptable. Health promotion, early identification and intervention may benefit both the individual and their family, and these models of understanding may help to offer a more constructive alternative to blaming the individual and open pathways to a better quality of life for the affected individual within their community. Thus, a dialogue which respects dominant South Asian lay beliefs about dementia, whilst also offering alternative ways of understanding, may prove fruitful in relation to finding ways of providing acceptable and appropriate services (p. 612).

Therefore, as represented with current international literature, reviewing models may result in productive and positive extensions to current practice.

Caring for Māori

It was recognised in the 1980's that the mental health needs of Māori were not being met, and change was required to provide quality, culturally appropriate care within psychiatric facilities. In order to meet these needs and effectively engage Māori during treatment within mental health services there was a requirement for the inclusion of Māori conceptualisations of wellbeing, worldviews, and values (Dyall, Bridgman, Bidois, Gurney, Hawira, Tangitu, & Huata, 1999; Mason, Ryan & Bennett, 1988).

Research by Nikora and colleagues (2004) found that Māori carers wanted to receive more appropriate levels of information and knowledge in order to provide more effective and efficient support for their whānau member. Participants

reported that information provided by health care experts would be of more value if it was written in a clear and less technical language. Furthermore, whānau desired more information about the availability of services, practical assistance within the home, increased numbers of Māori service providers and Māori staff within organisations (Barnett & Barnes, 2010; Hirini et al., 1999; Nikora et al., 2004). Caregivers also reported the need for assistance within their role to avoid stress, burnout, and abuse or neglect. According to relevant studies, it was suggested that these concerns could be partially addressed if medical professionals took the time to listen to whānau concerns and requests, rather than dismiss this valuable input (e.g., Barnett & Barnes, 2010; Nikora et al., 2004).

Research into recovery from mental illness identified that beneficial factors for Māori suffering from mental health include: whānau care, the inclusion of Māori models of wellness, traditional methods of healing, cultural understanding, and a Māori focus within mental health settings. This research also identified that Māori may reject diagnosis of psychopathology in favour of understandings developed from the Māori worldview, where their experience or behaviour is normalised. Rejecting the biomedical model was found to reduce stigmatisation, encourage more positive outlooks, and aid the recovery process (Lapsley, Nikora & Black, 2002). Therefore research indicated that conceptualising mental health within a Māori worldview was found to be a protective factor.

Investigations by Goldsbury (2004) found that Māori service users acknowledged beneficial factors within psychological services and effective interactions as: support based upon patience and understanding, reflective listening, the use of everyday language, taking the time to build rapport, offering a range of services and suggestions for improvement, empowerment for the client, and relationships based upon respect and support. Goldsbury (2004) stated that:

Most participants would have liked the psychologist to acknowledge and discuss the differences in their ethnicities when they initially met, and most also thought that it was relevant for the psychologist to explore what their culture meant to them when they began working together. Cultural assessments or assistance from a cultural worker provided significant help for some participants. Approximately half of the participants felt that their

cultural identity impacted on their problems of concern. These issues included feeling displaced, empty, like they did not belong and powerless. Several participants felt that spirituality and the impact and influence of their whānau were important areas for the psychologist to explore. Most psychologists explored the role of the whānau in participant's lives, but few asked about spirituality. When the psychologist showed respect for Māori tikanga, it helped some participants to build trust (p. 86-87).

In addition, having mainstream organisations recognise the importance of informal health care offered by Māori social networks, cultural understandings of illness, and institutional barriers was found to be helpful foundations encouraging Māori service users to obtain assistance from appropriate services (Hirini et al., 1999).

Māori mental health consumers reported that receiving a diagnosis does not address the need for support, or provide assistance with the management of difficult behaviours (Moeke-Maxwell et al., 2008). Factors which may provide positive levels of support towards understanding mental health include: familial and social support, provision of appropriate information, language employed by medical experts, cultural values of person affected, their whānau, and the clinician (Moeke-Maxwell et al., 2008). In addition, Māori reported a preference for stability within psychological services, and struggled with the constant questioning within multidisciplinary teams of professionals. Positive experience increased where the approach was founded upon consultation and collaboration with the affected individual, and their family (Manna, 2003; Moeke-Maxwell et al., 2008).

Cultural awareness and sensitivity are essential to successful health interventions (Cappsick et al., 2009), where cultural knowledge can de-pathologise behaviour deemed irrational or abnormal by Western diagnosis (Elliot & Di Minno, 2006). It is imperative to listen carefully to family concerns, and why they have sought help before diagnosing the elderly person (Elliot & Di Minno, 2006). Older generations often like to choose between cultural services, mainstream services or a combination of both (Hooyman & Asuman Kiyak, 1999; Kane & Houston-

Vega, 2004). Therefore responsive care of Māori elders must acknowledge and understand Māori values and needs (Kepa, 2006). Furthermore, these concepts lack meaning if services fail to provide active participation for Māori across the establishment, organisation and operation of services (Mental Health Foundation of New Zealand, 1997a and 1997b).

Kepa (2006) presented a theoretical model for the care of vulnerable Māori elders emphasising cultural values and social relationships, in conjunction with health related services. It is a holistic approach which views the care of Māori elders beyond problematic health issues. It is inclusive of traditional healing, Māori cultural values, Māori models of health, awhi, aroha, and culturally sensitive service providers (Kepa, 2006). Manna (2003) also described a theoretical model titled Te Pounamu which is defined as “a way of knowing that assists the clinician in having a meaningful understanding of all presenting issues, how they impact on one another, and how to bring about change” (p. 40). Te Pounamu is used as a visual aid within assessment and treatment at Te Whare Marie, a specialist Māori mental health service in Porirua⁹. This model employs partnership, collaboration and consultation for the individual and their whānau (Manna, 2003).

Government policy aims to reduce disparities currently seen within mental health statistics by prioritising the needs of Māori to assure more positive outcomes for Māori with significant mental health problems. Prioritising Māori needs is essential as the numbers of Māori clients seen by mental health providers is 1.2 times that of non-Māori, where there is clearly a disparity within hospitalisation rates. Policies are founded upon a collaborative approach where addressing the needs of Māori consumers and barriers to mental health services, cultural responsiveness, early intervention, greater provision of Māori health services, and emphasising whānau orientated services, are essential elements (Baxter, 2008; Ministry of Health, 2002, 2007 & 2008). The research has identified two key factors central to the improvement of the mental health of Māori as the continuing development of the Māori mental health workforce and increasing the number of

⁹ Porirua is a city in the Wellington region, 25 kilometres north of the city of Wellington.

specialist services. The objective of national initiatives is to increase the number of Māori working in mental health professions to total of 20%, in the aim of improving the responsiveness of services and the wellbeing of Māori consumers (Te Rau Matatini, 2006; Ministry of Health, 2008). The government also has policies to address the specific needs of the elderly population and kaumātua (Ministry of Health, 1997 & 1997a).

Waikato District Health Board has a strategy titled 'Mauriora ki ngā Kaumātua' which aims to support, enhance and promote wellbeing of Māori elderly in the Waikato area. As with most Government policies this strategy aims to have Māori participate actively in all planning and development involving the Māori health workforce, additional Māori health providers, and culturally responsive services (Waikato District Health Board, 2009).

New Zealand Council of Christian Social Services identified that Māori elders affected by dementia found enjoyment and satisfaction from social engagement, and facilities based upon Māori culture and tikanga. The most important factors for individuals affected by dementia and their whānau were found to be responsiveness, flexibility, de-stigmatisation, inclusion, low cost, respite or day care programmes, kindness and a cultural connection (Martin, 2009).

Overall, the research indicated that there is a shortage of services specifically for Māori elders, and that improving the care of Māori should be founded upon a holistic and cultural approach with emphasis on: improving the provision of appropriate information outlining the symptoms and associated behaviour involved in mental illness; hauora Māori; access to culturally responsive services; the inclusion of a collaborative approach based upon consultation; the inclusion of whānau; access to appropriate support systems; complementary therapy (traditional and mainstream); cultural education for all health professionals; free or low cost services; mobile services or transportation; increased numbers of Māori staffing; and services where health professionals value Māori opinion and cultural worldview. Elderly Māori consumers should be provided with the choice of services without barriers to care.

Concluding Statement

This chapter examined national and international literature associated with dementia, including theories, indigenous health approaches, national policy and population statistics. The evidence presented here suggests that there has been a lack of research defining Māori cultural understandings of deteriorating states of mental health within the elderly, and in particular dementia. Many Māori appreciate health and wellness from a holistic perspective, where identity is inseparable from collective understandings emphasising interconnectedness and the importance of whānau. Optimal health is a product of maintaining balance with the environment. Old age is a time of opportunity and significance for Māori elders, who are ascribed with value as taonga, and guardians of mātauranga Māori, tikanga, and cultural knowledge. Principles of manaakitanga and whanaungatanga provide Māori elders with care during old age and deteriorating states of health.

Investigating the international literature has provided an understanding of the diversity of knowledge and awareness of the concept of dementia. Contemporary definitions of dementia are dominated by explanations founded upon a Western biomedical model, emphasising physiological changes in the body, and significant deterioration of physical and mental functional capacity. However, as outlined within the international literature dementia can be defined outside of the Western biomedical model and interpreted from a cultural perspective. Defining behaviours as abnormal or pathological from a biomedical viewpoint that excludes cultural understandings and values may discriminate against ethnic minorities. However, the literature also indicated that a combination of lay explanations, or a person's socio-cultural context, and biomedical models construct more positive outcomes for the individual and their subjective experience. Exploring how the biomedical model can be improved by incorporating cultural values would be of significance to effective practice and personal wellbeing. This notion is summarised by O'Connor and colleagues (2007) who stated:

There is growing evidence to indicate that at least some of the negative consequences associated with dementia may be mitigated or delayed by an approach to care that respects and supports each individuals personhood,

and that facilitates its transformation and development throughout the disease (p. 122).

Changing demographics will produce an increasing population of elderly Māori, and heightened prevalence of deteriorating states of mental health in this population, such as dementia. Given the differing views of wellness reviewed in this chapter, there is a need to investigate dementia from a Māori cultural understanding. With an increasing ageing Māori population, demands upon whānau will escalate and mental health services need to be responsive to Māori elders in order to provide appropriate, beneficial and supportive services. Therefore investigating Māori health workers perceptions of dementia to gain a deeper understanding and awareness of Māori cultural understandings of deteriorating states of mental health within their elderly would appear both timely and appropriate.

Chapter Three

Methodology

Tuatahi a Pakatauia, e tata Waiotahe

(Something begun is half finished, whereas a task not started is a long way from being accomplished)

Introduction

The evidence presented within the previous chapter suggested that there has been a lack of research defining Māori cultural understandings of deteriorating states of mental health within the elderly, and in particular dementia. In addition to the understandings based on the Western biomedical model employed within mainstream services, the international literature indicated that there is a diverse range of cultural knowledge and personal awareness surrounding dementia. Commensurate with these changes, the changing demographics will produce an increasing population of elderly Māori in New Zealand, and heightened prevalence of deteriorating states of mental health. When these issues are viewed together, it promotes an opportunity to investigate dementia from a Māori cultural understanding reflecting a holistic and culturally relevant paradigm.

This project employed a Māori-centred methodology, utilising qualitative research techniques involving in-depth interviews. Grounded theory was employed to thematically analyse the data. Qualitative data was gathered from interviews with Māori health workers, in one-off face-to-face interviews. Māori health workers were interviewed as their life experiences provided insight and expertise on Māori culture, tikanga, values, practices, beliefs, and te reo, all of which contribute to cultural understanding. Māori health workers are a valuable source of cultural knowledge as they have a rich sense of awareness acquired through immersion in health organisations assisting Māori elders and their whānau affected by dementia

and mental health problems. It was anticipated that their expertise and knowledge would assist the researcher to consider the issues facing Māori individuals who have a diagnosis of dementia and their whānau.

This chapter provides a detailed account of how the research project was conducted. The chapter begins with a description of the Māori-centred methodology employed in this study, and an overview of qualitative research. Subsequently, there is a section regarding the justification for the methodology, as well as discussion of potential barriers and ethical considerations involved in cross-cultural research. The chapter concludes with a discussion of the recruitment process, interview schedule, transcript verification and data analysis.

Conducting Māori Research

Māori-Centred Approach

A Māori-centred research approach necessitates that the needs of Māori and their whānau are fundamental to the research investigations and outcomes. A central theme of research is the protection of the interests and needs of Māori where improving outcomes and/or available services are paramount (Wilson & Roberts, 2005). One of the central principles within the Treaty of Waitangi¹⁰ is that of partnership. When conducting research Pākehā have an obligation to include and investigate Māori under the Treaty of Waitangi. However, research must be carried out under the guidance of Māori consultation, and the researcher should acquire bicultural knowledge through sound education. Furthermore, the researcher should be comfortable in both cultural environments. Consequently research carried out by Pākehā with Māori must be both safe and appropriate, and founded on a firm objective of beneficial outcomes for Māori people (Powick, 2003). The researcher should establish a partnership with each participant, permitting concepts to be reciprocally constructed and revised. Ethically, the methodology must have a sincere focus upon tikanga, respect, patience, face-to-face interviews, being cautious and thoughtful, reciprocal interaction, appreciation, and the appropriate distribution of knowledge to empower Māori

¹⁰ Agreement between Māori and the British Crown, signed in 1840.

people. Self-reflection of the researcher and consultation are paramount to cultural sensitivity within any research investigation. Therefore Māori and their experience must be located at the centre of the research, its methodologies and outcomes within Māori-centred research (Cram, 2001; Powick, 2003).

Kaupapa Māori Research

In contrast to traditional methods of research which have misrepresented Māori knowledge, marginalised and disempowered Māori people (Bishop, 1999), Cram (2001) defined kaupapa Māori research as “an attempt to retrieve space for Māori voices and perspectives. It is also about providing a framework for explaining to tauwiwi what we have always been about” (p. 40). Traditional methodology allowed researchers to benefit from outcomes, where Māori were subjects secondary to professional advancement (Bishop, 1999). Subsequently, traditional research methodology was used to continue oppression, maintain power differentials and emphasise the negative difference of the ‘other’ (Teariki & Spoonley, 1992). The process invalidated Māori worldviews through misinterpretation and objectification (Bishop, 1999). Traditional methodologies were based upon the cultural deprivation theory where Māori were viewed through a deficit lens (Cram, 2001). Positivism resulted in Māori failing to benefit from research, or having claim to ownership of the knowledge and outcomes (Bishop, 1999).

Therefore, kaupapa Māori research methodology has arisen out of discontentment and dissatisfaction with the status quo as represented by traditional Western empirical models of research. Kaupapa Māori methodology has challenged dominant philosophies and established research paradigms that benefit Māori. Māori values and customs, such as a collective and holistic approach, are valued within this methodology. The general principles of the methodology are whakapapa, te reo, tikanga, rangatiratanga and whānau. However, the fundamental element was identified as tino rangatiratanga and reclaiming control over research programmes and outcomes. The aim was to protect and validate Māori knowledge, for the benefit of Māori (Bishop, 1999; Powick, 2003). Consequently, the foundations of kaupapa Māori methodology are partnership, collaboration, beneficial outcomes for Māori and accountability, along with

ownership and validity of cultural understandings (Teariki & Spoonley, 1992). Kaupapa Māori research has emphasised that Māori values, language, culture, and knowledge are legitimate and valid in their own right (Smith, 1992). The methodology has highlighted the importance of research for and with Māori by Māori.

Smith (1999) summarised the concepts for conducting kaupapa Māori research as follows:

- aroha ki te tangata (respect the people)
- kanohi kitea (the seen face, that is present yourself to people face-to-face)
- titiro, whakarongo kōrero (look, listen ... speak)
- manāki ki te tangata (share and host people, be generous)
- kia tūpato (be cautious)
- kaula e takahia te mana o te tangata (do not trample over the mana of people)
- kaula e māhaki (don't flaunt your knowledge) (p. 120).

Culturally Safe Research

Research on Māori health should be founded on the principles of the Treaty of Waitangi (Kearns & Dyck, 2005). Kearns and Dyck (2005) identified the key aspects of culturally safe research as:

1. respect for cultural knowledge, values and practices of others
2. an awareness of one's own way of seeing and doing
3. analysis of the effect of our actions on the knowledge that is produced (p. 79).

The formation of a partnership between researcher and participants encourages the development of an in-depth understanding of cultural interpretations. In order for a partnership to be forged the researcher must understand the imbalances of power. The history of Aotearoa/New Zealand has created power differentials and Māori remain oppressed within contemporary society. Consequently it is imperative for the researcher to acknowledge New Zealand history along with Māori history, beliefs and customs. Methods of overcoming barriers to culturally safe research may include interviewing participants where they are most

comfortable, employing methodologies that promote subjective experience and understandings, and aiming to benefit the people being researched (Kearns & Dyck, 2005).

The objective of Māori health research is to ensure that Māori have the right to define their health needs and identify the most appropriate services. Research based upon partnerships and collaboration between Māori communities and non-Māori researchers can assist in the process of increasing beneficial outcomes between health professionals and Māori. Therefore emphasising consultation permits the researcher to gain the trust of participants and ensures a meaningful interaction (Health Research Council, 2008).

In order to meet the objectives of culturally sensitive and safe research I acquired the support of the Māori and Psychology Research Unit and the tautoko of Tess Moeke-Maxwell, co-supervisor of the research project. In addition, my extended whānau fully supported this research project and provided ongoing encouragement and assistance throughout. Consultation was continued throughout the project to ensure appropriate and safe practices during the research investigation and interviews. The consultation process, with supervisors and participants, required the researcher to remain flexible and open, redefining the topic or procedures as necessary. Personal values, attitude and culture, along with the history of Aotearoa and power imbalances were constantly considered, monitored and reflected upon throughout the research project.

The investigation included the exploration of Māori culture and social practices in detail. Methodologies and interview questions were developed in conjunction with all forms of support available and in consultation with professionals in the field. Face-to-face interviews allowed personal explanation of the research aims, the researcher's interest in the topic, and how the research aimed to benefit Māori. The interviews drew out subjective experience, knowledge and understandings beyond the literature or the researcher's opinions. Subsequently, it was imperative not to impose Western definitions into the research interviews. Outcomes and findings were disseminated in a format and manner that would maximise benefits for Māori health and well-being. The aims were clearly outlined within the

research information sheet and preamble to the interview in order to emphasise the possibility of ‘change’ to current practice and improvement within the cultural responsiveness of mainstream services. A sound foundation was provided by Smith’s (1992, p. 23) “empowering outcomes model” to deliver information that would benefit Māori.

Distribution of Findings

Smith (1999) stated that “like networking sharing is a process which is responsive to the marginalised contexts in which indigenous communities exist” (p. 160). She continued “sharing is a responsibility of research..... For indigenous researchers sharing is about demystifying knowledge and information and speaking in plain terms to the community” (p. 161). Keeping the principles of responsiveness, legitimacy and validity in mind a copy of the thesis was made available to organisations involved in the research and local mental health providers. A short report of the findings was sent to participants in a simplified and easy to understand summary format. A personal goal was to discuss the findings with local mental health providers, such as Mental Health Services of Older People, once the thesis has been marked and finalised. Furthermore, it was my aim to have the results published in a reputable journal where professionals within the field can access the information.

Qualitative Research

This study set out to gather qualitative data from interviews with Māori health workers in one off face-to-face interviews. Qualitative research methodology is defined by Creswell (2007) as:

Qualitative research begins with assumptions, a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis that is inductive and establishes patterns or themes. The final written report or presentation includes the voices of participants, the reflexivity of the researcher, and a

complex description and interpretation of the problem, and it extends the literature or signals a call for action (p. 37).

Simply stated, qualitative investigations provide rich and descriptive accounts, and capture individual experience within the frame of subjective worldviews. Therefore qualitative studies lead to comprehensive understandings and insights into particular phenomenon (Patton, 2002).

Qualitative research draws on numerous theoretical viewpoints inclusive of phenomenology, cultural studies, psychology and women and gender studies. The methodological approach embraces the ontological notion that multiple and subjective realities exist concurrently. Qualitative investigations are founded on social constructivism where subjective representations provide individual meaning. In addition, the postmodern perspective encourages the author to deconstruct Western discourses and emphasise the significance of alternative and cultural perspectives. The process is referred to as interpretive inquiry as the researcher interprets the findings within a holistic perspective, where context is crucial (Creswell, 2007; Patton, 2002; Rice & Ezzy, 1999).

The emphasis of qualitative research is acquiring an understanding of subjective experience, interpretation, and meaning (Rice & Ezzy, 1999; Strauss & Corbin, 1998). Rice and Ezzy (1999) stated: “In order to understand people’s behaviour, we must attempt to understand the meanings and interpretations that people give to their behaviour” (p. 2). Therefore, qualitative research permits participants to construct their own definitions, and requires the researcher to understand the world as seen by the participant. The goal is to contribute quality information pertaining to more extensive understandings of social realities and highlight patterns of meaning (Rice & Ezzy, 1999; Tolich & Davidson, 1999).

Qualitative research has three components: data collection, finding meaning within the data, and systematic analysis (Straus & Corbin, 1998). The philosophy underlying the qualitative approach is inductive reasoning, as theory develops from the data collected. Interview questions are asked in a manner that permits the participant to detail their understanding of the phenomena in question. The

transcribed interviews provide the researcher with detailed information, interpreted to allow an explanatory and descriptive understanding of the informant's beliefs. The value of qualitative research is the ability to generate theory grounded in the data collected (Strauss & Corbin, 1998; Tolich & Davidson, 1999).

Limitations and Strengths

The limitations of qualitative research are a reduced capacity to generalise results, due to the small number of participants, the personal values or biases of the researcher and the fact that qualitative research is time consuming. However, Patton (2002) stated that “the validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational and analytical capabilities of the researcher than the sample size” (p. 245). The credibility of the researcher may impact quality of the interpretation, along with the validity and reliability of the findings. Best outcomes are provided when the researcher is open and honest about a personal interest in the research topic and how personal values may impact the data collection, analysis and interpretation. Finally qualitative research is uncertain and lacks definitive direction (Patton, 2002; Straus & Corbin, 1998).

Qualitative research has numerous strengths and advantages. It provides a scientific technique to investigate complex situations, establishing rich and grounded descriptions, and personal insights, all within individual context. Face validity and credibility are acquired through the provision of subjective understanding and experience. The emergent design provides flexibility, where change is encouraged to acquire the collection of quality information (Creswell, 2007; Patton, 2002; Rice & Ezzy, 1999). Supporting the credibility of qualitative research is the neutrality of the researcher where there are no predetermined hypotheses to support. The qualitative approach empowers the participant and permits each individual to define their own reality, in their own time. Furthermore, qualitative research permits interpretations to be integrated into larger systems of meaning (Creswell, 2007; Patton, 2002; Rice & Ezzy, 1999).

Cultural and Ethical Considerations

The Psychology and Research Ethics Committee of the School of Psychology, Waikato University, approved the research procedures for this thesis. Ethical guidelines were based upon the New Zealand Psychological Society Code of Ethics. Points of particular relevance were privacy and confidentiality of participants, minimising harm and discomfort, and establishing informed consent. These factors are discussed below.

All participants were provided with pseudonyms, and all distinguishable details were removed from the findings, to protect individual identities. Audio recordings, transcripts of interviews and completed questionnaires were stored in a locked cabinet at the researcher's home address until the completion of the research, at which time they were destroyed. The only people with access to this information were the supervisors and the researcher.

It was the researcher's intention to prevent harm (personal, psychological, social or cultural) to participants. As the researcher and participants were from different ethnic backgrounds it was imperative to consider personal biases and the impact of my approach on others. Participants were invited to bring a support person along to the interview. Participation was voluntary and each individual made the decision whether they met the criteria for participation. I interacted in a respectful and sensitive manner with all participants. I made sure each participant clearly understood their rights, including the option of withdrawal at any stage of the research process. The participants were provided with a copy of their transcript and encouraged to ensure accurate recording of their understandings. I also provided participants with my contact details to ensure they could contact me at any point in time with concerns, questions or suggestions. Following the interview, I provided an opportunity for participants to supply feedback on the interview process and any questions or concerns were addressed.

Acquiring informed consent included ensuring the participants fully understood all aspects of the research project. This included the nature and aims of the research, my interest in the topic, how data will be integrated, and the participant's ethical rights (confidentiality, anonymity, withdrawal, complaint

procedure, approval of transcripts, and access to the final reports). When the participants were comfortable to continue on with the interview, written consent was obtained.

The interviewer supplied a plate of food and a drink, where available within the organisations, for each participant. In addition, participants were thanked with hand-made cards and organisations with gift baskets. *Koha* is a form of *manākitanga*, where a reciprocal exchange occurs. In the context of this investigation, the researcher provided food, drink and a copy of the findings as *koha* for the participants' knowledge and input, as follows:

Koha

The provision of a forum to discuss Māori cultural understandings of dementia was considered *koha* for this research project, as there is very little opportunity to deliberate over this topic within society. Therefore participants were provided with a forum to discuss and extend knowledge about Māori conceptualisations of deteriorating states of mental health within Māori elders, and in particular dementia. This opportunity offered participants the chance to discuss concerns about services provided for Māori elders. It was endeavoured that participants' contributions would assist in the process of increasing a cultural understanding of dementia and the mental health needs of aged Māori. In addition, *koha* included a summary of the findings. It is endeavoured that the findings will be published within a reputable journal and a copy of the article will be sent to each participant.

Furthermore, I have not used the findings for personal benefit beyond receiving my Masters degree. It was of utmost importance to me that Māori benefit from the research, and thus information was only used in conjunction with permission from participants.

Justification of Methodology

Effective research requires a match between the procedures of the investigation and the phenomenon in question (Smith, 1999). Qualitative research methodologies are particularly relevant to the exploration of health issues as the

aims are to describe and understand subjective experience. Exploring individual worldviews allows the researcher to understand belief patterns which guide actions and behaviour (Rice & Ezzy, 1999).

Qualitative research methodology has numerous features making it particularly relevant for this project. The investigation required the exploration of participants' personal experiences and ascribed meanings. Little is known about the Western concept of dementia from a Māori cultural perspective. Qualitative research methodology provided a neutral forum for Māori participants to construct their own definitions from a cultural framework. Therefore qualitative research provided the opportunity to obtain rich and in-depth narratives of participants' understandings of dementia. Consequently, qualitative research permitted the validation of a unique cultural perspective of dementia.

Furthermore, the principles of a Māori-centred research approach align closer with qualitative methodologies. Qualitative research is participant focused, interactive and sensitive to subjective opinions. Consequently, qualitative research addresses concerns that Māori have surrounding research methodology. This research project aimed to move beyond deficit models, universal understandings and ethnocentric interpretation. This project provided Māori health workers with a forum to initiate change towards the improved quality of services in the future.

Recruitment Process

The recruitment process targeted Māori health professionals (gerontologists, nurses, and social workers), academics, key Māori health experts and kaimahi or caregivers within community organisations who assist Māori families affected by dementia.

Participants were recruited by approaching organisations that assist those with dementia, requesting that management distribute the information sheet to staff. Māori health workers, who have insight into how cultural understandings impact experience, and how support services could cater for whānau more effectively, were invited to participate. An important prerequisite was knowledge about how

Māori and their whānau perceive dementia. Participants were asked to share their views on how whānau could be provided with improved support in the future.

The people recruited to participate within this research self-identified as being Māori and knowledgeable about Māori culture. Participants contacted the researcher (via telephone, post or email) to volunteer for participation. The study aimed to recruit between 5-10 participants. A suitable time and location to complete the interview was arranged collaboratively with each participant. The researcher then sent a letter of invitation, information sheet and a consent form to the participant, confirming the appointment and providing a list of their participant rights. When the researcher made contact with each participant they were advised that the inclusion of a support person was welcomed within the interview process.

Locating community organisations and Māori health workers was found to be difficult. There are a limited number of organisations that specialise in assisting Māori elders with mental health problems, and even fewer employees of Māori descent within mainstream services. For example, the Alzheimers Association does not currently employ any Māori field workers in the Bay of Plenty, Waikato or South Auckland regions. The Mental Health Services of Older People who serve the geographical area of the Waikato District Health Board currently employ two Māori health workers. Consequently, the geographical area included in this research project was expanded, following ethics approval, to include the Bay of Plenty and South Auckland regions to locate suitable participants.

Snowballing

The researcher found snowball sampling an effective technique to recruit participants. Snowballing involves the researcher requesting referrals or the identification of well informed individuals from participants. Thus the participants act as informants, identifying other individuals rich with information appropriate for the research project. This sampling technique is particularly useful where the researcher has difficulty identifying or locating suitable participants (Patton, 2002). Participants within this investigation were obtained using a snowball

technique. This method was found to be particularly effective within the Māori health work force.

Data Collection: In-depth Interviews

This research project employed in-depth, face-to-face interview techniques. The face-to-face interview provided a suitable and comfortable environment to establish rapport and build trust between the researcher and participant. The researcher was considerate of the participants needs and adjusted any element that would increase their comfort. Furthermore, face-to-face interviews provided the opportunity for participants to question the research, its aims or the researcher's personal interest in the topic.

Open-ended questioning allowed the researcher to inquire about subjective understandings of the phenomenon being investigated, beyond structured questionnaires. This methodology provided a framework for participants to reflect and respond accurately in an exhaustive manner, from a personal viewpoint. The participant's responses guided the researcher to the most significant information and permitted reciprocal clarification. Therefore qualitative research, employing open ended questions, was able to obtain the feelings, perceptions and knowledge of participants (Patton, 2002).

The advantage of employing in-depth interviews is that it provides the flexibility to explore the complexity of participant's worldview, areas of interest, interpretations, expert knowledge, and experience (Hopf, 2004; Maykut & Morehouse, 1994; Rice & Ezzy, 1999). The methodology is based upon the flexibility of an emergent design, providing responsiveness to pursue avenues of interest as they transpire (Patton, 2002). Consequently the schedule can be modified, have the order of questions altered, or have additional questions included as appropriate for the interview and the participant to enhance the information gathered. This flexibility means that the time and attention given to specific details can be tailored to the interviewee, their expertise and experience. Thus areas not originally considered by the researcher can be addressed and included (Banister, Burman, Parker, Taylor & Tindall, 1994). Banister and

colleagues (1994) stated “the approach can empower disadvantaged groups by validating and publicising their views” (p. 51).

This investigation employed in-depth interviews using a semi-structured interview schedule to gather comprehensive information about Māori health professionals’ perceptions of dementia within older Māori. The approach permitted the participants and the researcher to engage in conversations about cultural perspectives of mental health and dementia in a culturally appropriate manner which provided descriptive and insightful information as the participant was able to describe the concept in their own words.

In summary, the rationale for adopting the in-depth interview technique was to embrace the participant’s personal perspective. This methodology ensured that each participant’s perspective was given adequate consideration and value. The outcome had a focus on exploration of the concept of dementia from a Māori cultural perspective, not preconceived theories.

Interview Schedule

A semi-structured interview schedule was developed in conjunction with the literature review, and discussions with supervisors. The interview schedule (see Appendix Two) consisted of six categories. Each category had between two and four key questions, and contained several prompts, initiating a more in-depth understanding of the participant’s perspective. The categories are described below.

The first category provided information about the participant’s role within the organisation and their experience with those affected by dementia. It allowed rapport and trust to be established in non-threatening manner. The second section explored the participant’s understanding of dementia and whether the biomedical model is useful for Māori elders. The third category investigated dementia within traditional Māori society, and whether traditional values impact the care of elderly within contemporary society. The fourth category explored how understandings impact experience and help seeking behaviours. Section five investigated how Māori cope with dementia and the services they find most supportive. The sixth

category explored the issues central to Māori and how services could be improved. Following the interview schedule participants were given the opportunity to share any further information they believed would be of value to the study.

The questions were not written as an exhaustive list of areas to be covered in the interview, rather they were a guide. Further areas developed from individual conversation, experience and perspective.

Following the interview each participant was requested to complete a short questionnaire (see Appendix Two). The questionnaire covered demographics and employed closed ended questions. Responses involved ticking the most appropriate box, simply yes or no. This information was collected to support the information gathered within the in-depth interviews.

Interview Procedure

The interviews were held at the participant's place of employment, a local cafe or residential address of the participant, at a time of their convenience. The researcher ensured the participant was comfortable and provided a plate of food, and drink if available.

The interview began with the researcher explaining her personal interest in the investigation. Continuing on, the researcher assured the participant that the results would represent their subjective viewpoint on Māori elders and dementia. The researcher then discussed the participant's rights, and the consent form. The emphasis was voluntary participation, informed consent, and the right to withdraw. The conversation also assured the participant of confidentiality and anonymity throughout the research process. As the interviews were digitally recorded the consent form also confirmed the participant was happy for this to occur. All participants agreed to have their conversations digitally recorded.

When the participant was willing to continue the consent form (see Appendix Two) was signed by both parties. The participant retained their copy of the consent form, where their rights were clearly stated. The information sheet and

consent forms provided the participant with contact numbers for both the researcher and the ethics committee. The researcher explained the interview process and the questionnaire (see Appendix Two), handed out at the conclusion of the interview. If time permitted the questionnaire was completed within the interview, otherwise the participant was provided with a stamped, addressed envelope for its return. Six participants completed the questionnaire during the interview, and three chose to return it through the post. Before the formal interview began participants were offered a further chance to ask questions or clarify any concerns.

Upon completion of the formalities I invited each participant to offer karakia. If the invitation was declined I considered a silent karakia to request guidance and protection during the interview. When the participant offered a karakia I appreciated the sentiment and spiritual experience. Following the completion of karakia the interview process began.

Interview conversations were digitally recorded and the researcher took notes during the course of the conversation. This permitted the researcher to return to points of interest or questions unanswered. The estimated length of the interviews was one hour. The actual length was dependent upon the flow of conversation and the information shared. Interviews ranged from 45 minutes through to three hours 30 minutes. Participants were provided with the option of taking a break and encouraged to express their needs during the interview.

A pilot study was undertaken within the first two interviews to test the suitability of the interview schedule and the researcher's approach. Supervisor Tess Moeke-Maxwell, attended these interviews to assist and support the researcher. The pilot study permitted questions or strategies to be adjusted, as appropriate, to acquire the best understanding possible. The schedule was slightly modified after the pilot study, and discussions with Tess. This mainly involved re-arranging the order of questions, adding prompts for the researcher, and deletion of unsuccessful questions. These adaptations provided clarity for both the researcher and participants within later interviews.

Initially interview questions began by following the interview schedule. However, as participants shared their experiences and perspectives, questioning was adjusted to inquire about participants' areas of knowledge. This approach meant questions could emerge and interviews were tailored to the individual and their experiences.

At the conclusion of the interview each participant was thanked, and asked if they had any concerns about the interview process. Feedback was extremely positive, and no concerns were shared. For those who offered karakia at the onset of the interview, I invited them to close with karakia. I reminded the participant that the interview would be transcribed and returned to them for feedback. The researcher noted any participant reactions to the interview process, or any changes to be made in future interviews. The researcher also made personal reflections on the interview process. The interviews were followed up with a telephone call (approximately 24 hours later) to ensure personal wellbeing of participants, and to discuss any issues arising from the interview. There were no further changes made to the interview schedule or process.

Verification of Transcripts

Interviews were transcribed in verbatim by the researcher using Microsoft Word software. Anonymity was provided to participants and all identifying characteristics were removed.

Participants were sent a copy of the transcribed interview to check that the researcher had accurately recorded the information provided. The participants were encouraged to make alterations, omissions or provide additional information to reflect their knowledge and intentions. A letter was attached to the transcript outlining the procedure and thanking them again for their contributions (see Appendix Three). The researcher contacted each participant directly by telephone to check that they were happy with their transcript. In addition, the researcher requested that the transcripts were returned in the prepaid envelope supplied, within two weeks. However if the transcript was not returned, additional telephone contact was made to ensure accuracy and approval of the written material. There were two transcripts returned via mail. When feedback was

received or changes requested the transcript was corrected as per the request. Following telephone contact no changes were made to the transcripts.

Participants were offered a copy of their transcript, and those who accepted were provided with a spiral bound copy at the conclusion of the investigation.

Data Analysis

Qualitative research findings are commonly long, detailed and heterogeneous in their content. Subsequently, data analysis is difficult as open ended questions encourage subjective responses (Patton, 2002). Transcripts varied in length according to the duration of the interview. Due to the volume of information generated from the interviews management of the data required grouping into categories.

This investigation employed grounded theory to analyse the interview transcripts. Grounded theory is employed when there is a deficit of prior understandings or theories outlining a particular phenomenon. Grounded theory allows the researcher to start out with an area of interest, in isolation from preconceived theories. Within this approach, theory emerges inductively from the research findings (Rice & Ezzy, 1999; Strauss & Corbin, 1998). During the research process concepts, categories and themes are identified and elaborated upon. Research outcomes provide meaningful findings and direction for future action. The advantage of the grounded theoretical approach is that it permits theory to be generated from the findings, where the theory is grounded within the data (Creswell, 2007; Rice & Ezzy, 1999; Strauss & Corbin, 1998).

Therefore the inductive approach permitted the researcher to establish themes from the bottom up. The emphasis was upon exploring the participant's perceptions of the phenomena under investigation (Creswell, 2007). Within this approach, categories and theories emerge from patterns contained by the data. Exploring the relationships and interconnectedness among categories beyond predetermined hypotheses permits the discovery of unique understandings (Patton, 2002). Grounded theory allows the phenomena to be explained and described from the participants' unique perspective (Straus & Corbin, 1998).

The inductive approach required that each interview be written up and understood in isolation. After this had been completed cross case analysis began where the researcher searched for patterns or themes. The analysis of the data was then carried out in three stages. Firstly, open coding was employed to identify the main categories and subcategories of information. Next, axial coding directed the researcher to recognise the main category of the research project. Other categories were also identified within axial coding, often highlighting factors which underlie or influence the core phenomenon, contextual information, and consequences or actions which follow the application of the understanding. The concluding stage was referred to as selective coding where the researcher develops hypotheses, describing the relationship between categories. A visual representation of the results clarified the explanation (Creswell, 2007; Patton, 2002).

As the researcher read through each transcript coding began by identifying keywords within statements, which were noted in the margin. These keywords were used to identify themes across the transcripts, and categories were established. Six clear themes emerged from the transcripts. The categories were then explored in order to identify how they connected, and the principle relationships. This process allowed the researcher to describe an understanding of the topic and present it in a logical manner. Analysing the data was a time-consuming process which required patient and consistent referral to the transcripts. Referring to the transcripts ensured that the content was represented accurately and no significant issues had been omitted. An important element was reducing the volume of information to a manageable amount, which required the elimination of irrelevant information. This process resulted in a clear structure for describing and understanding the results.

Reliability and Validity

Consistency (i.e., reliability) was maintained by the continual revision, refinement and clarification of categories and emerging themes. Development of initial categories required the analysis of transcript data to be carried out several times, allowing the modification of categories. This process was continued into higher order coding. Accuracy of themes and theories emerging from the data was emphasised within this practice.

The richness of the data along with the skill and vigour of the researcher are substantial factors enhancing validity of qualitative analysis. Validity, commonly referred to as meaningfulness within qualitative research, can also be strengthened by employing triangulation and negative case analysis (Patton, 2002). However these processes were not employed in this project. Instead, participants were sent a copy of their transcript and provided with the opportunity to give feedback. Encouraging participants to edit, correct, or provide additional information within their transcript enhanced accountability and validity of the interview data, reducing the possibility of researcher bias, and empowered the participant. In addition, organisations involved in the research received a copy of the thesis and participants received a summary of the findings.

Participants

This project interviewed a total of nine participants, including eight Māori health workers or experts, and one caregiver. All nine participants had a thorough understanding of dementia, its symptoms and the basic progression. Participants self-identified as being of Māori descent. Participants were interviewed in Hamilton, Tauranga and Whakatane. Organisations who willingly participated were Mental Health Services of Older People, Rauawaawa Kaumātua Charitable Trust, and Te Runganga o Kirikiriroa, all of which were located in Hamilton.

Recruitment Issues and Process Issues

The investigation was guided throughout by the principles of culturally sensitive and safe research. It was imperative that the researcher was explicit about personal values and experiences and their impact upon this research project. The researcher was of Pākehā descent and the participants were Māori, therefore it was important to acknowledge cultural frames of reference that may have influenced the research.

The researcher found identifying and locating organisations and recruiting participants somewhat difficult. Although once participants were located, communication was found to occur naturally. However, there was an awareness that some information may have been withheld as the researcher was trained

through a Western based organisation. As mentioned under the section on kaupapa Māori research, resentment surrounding research founded upon positivism may impact projects such as this.

The findings may not be representative of all Māori, due to the small number of participants. However, it must be noted that validity or meaningfulness is established when the participants provide rich and in-depth information. In addition, the participants were located in the Waikato and Bay of Plenty regions, which may not represent other geographical areas or iwi.

Summary

This chapter has outlined the methodological process employed within this research project. The aim of the research was to explore a Māori cultural understanding of dementia, and initiate improvement within the quality of service for Māori elders within mainstream services.

A Māori-centred qualitative approach was employed to accurately reflect Māori cultural knowledge, and protect the interests of participants, the researcher, and the needs of Māori elders. A Māori-centred approach has arisen from a combination of kaupapa Māori research methodologies and culturally safe practices, where the researcher and the participants are from different cultural backgrounds. This methodology ensured that Māori are able to define their health needs and what services are most appropriate. Cultural guidance and support was acquired from the Māori and Psychology Research Unit, and co-supervisor, Tess Moeke-Maxwell.

A qualitative research methodology was chosen as it is participant focused, interactive and sensitive to subjective opinion, effectively aligning with a Māori-centred approach. Qualitative research empowers subjective reality and allows participants to construct their own meaning and understandings of a given concept, within a personal framework. Face-to-face interviews encouraged a partnership between the participant and the researcher. These techniques allowed the researcher to discuss the research aims and her personal interest in a Māori understanding of dementia in person. In addition, the participants were able to

discuss their experience and knowledge, where understandings could be explored in-depth with the researcher. Therefore, a Māori-centred qualitative approach was chosen to obtain rich and in-depth information about a Māori cultural understanding of dementia, in order to validate a unique cultural perspective.

Participants were recruited from within organisations assisting Māori elders and their whānau affected by deteriorating states of mental health and dementia, in conjunction with snowball sampling. Participants were Māori health workers, experts and caregivers with insight into cultural understandings of dementia and the impact of beliefs upon experience. Data was collected through one-off face-to-face in-depth interviews. Analysis employed an inductive approach and grounded theory. This approach allowed theory to emerge from the findings, theoretically beyond preconceived notions or researcher bias. The findings are presented in the following chapters and a discussion of the findings in relation to other literature is presented in the discussion chapter (Chapter Six).

Chapter Four

Findings Part One

Participants' Perspectives on how Māori Frame and Cope with Dementia

He taonga tonu te wareware

**(The Māori, like all other people, is not gifted with a perfect memory and
forgetfulness is accepted as a fact of life)**

The findings have been divided into two chapters. These chapters will be followed by a discussion chapter, where a critical analysis of the findings is presented. Chapter Four outlines the participant's personal perceptions of how Māori conceptualise dementia, Māori values employed within these understandings, how whānau manage when an elder has dementia and the impact of values upon experience. The chapter has four sections developed in conjunction with the research plan and reflections of key findings from the participant responses, as follows:

- (i) Māori concepts of dementia
- (ii) How whānau perceive dementia and the impact of these understandings
- (iii) How Māori cope with dementia
- (iv) Questionnaire results

The perceptions and knowledge of the participants in this research project are represented through the use of unedited verbatim quotes. This technique was employed to encourage the reader to engage with the participants thoughts

(Patton, 2002). A thematic analysis highlights dominant themes emergent from the data and forms the basis of critical analysis of the findings within Chapter Six (Braun & Clarke, 2006).

Māori Concepts of Dementia

This section presents a summary of how the participants perceived dementia from both a traditional Māori worldview and contemporary perspective. It also explores diagnosis, the inclusion of culture in the diagnostic process and whether Māori find diagnosis useful.

Traditional Understanding of Dementia

The possibility of a traditional Māori understanding of dementia was explored by asking, “Do you think there is a traditional view Māori hold about dementia or elderly mental health?” This question was used to draw out ideas about how Māori may have understood dementia in traditional society. A variety of themes arose from this question; however a dominant theme referred to dementia being perceived from a spiritual foundation of knowledge, as illustrated by the following participants’ responses:

Roimata

Mental illness wasn't really mental illness back then, if you heard voices or saw things you were very blessed by the Gods.... you had matakite...

Marama

Whānau who had a mental illness were never ostracised, in fact they were looked upon as atua, because there are things they say, that they know comes from their old people, so they are regarded as people with gifts...

Riana

Well I guess a lot of them used it as mākutu... to them, it is because someone has pointed the bone at you basically... they didn't really understand... to a lot of our older people it was mākutu... something someone had done to you... and that is why they called in their tohunga or their matakite...

Spiritual foundations of knowledge may result in people fearing those with gifts or those affected by a curse, employing superstition to make sense of a confusing situation, as suggested by Marama:

But for Māori he taha wairua... that there were people who were fearful that these people with gifts could read people... and they sense that these people are dangerous in their spirit and their soul... and those are the people who would fear them the most... and would start rumours...

A minor theme of contextualising dementia within the normal process of ageing also emerged, as illustrated by Pania:

Personally I think that it would have been seen as getting old and forgetful, you know old people get it... yes part of that ageing process...

Contemporary Understandings

Participants were asked “How is dementia viewed in a contemporary Māori worldview?” The aim of this question was to elicit information about how Māori understand dementia in today’s society. Two main themes emerged from the responses; the first was that Māori do not understand the behaviours associated with dementia as an illness. The following responses represented this theme:

Riana

They know nothing of it... it is a new thing... all they think of is mad... porangi...

Roimata

They have no understanding about it...

As a consequence of this lack of understanding a fear of the illness or the person may develop. This fear appears to be centred on uncertainty about the illness and the possibility of it being contagious. The apprehension may result from traditional spiritual understandings and superstitious fears. The theme was evident within the following responses:

Roimata

Because they have no understanding about it ...they shroud it in mystique, it becomes a tapu...

Riana

A lot of people think you are going to catch it... a lot of Māori say 'oh dear, will I get that, would I get like him, is it contagious?'

Tui

People don't come and see her because they know she has got the Alzheimer's...

The most prevalent theme, suggesting comparisons to some traditional understandings, was that Māori are a spiritual people and understand the deterioration of behaviours as a connection with their ancestors or possibly a curse. The following responses emphasised a spiritual understanding:

Rangi

The whānau would think he was talking to the old people... or thinks he has a mākutū or has been cursed or something...

Marama

Our house has got lots of whānau treasures in it... my Aunty could feel that about the house and was always talking to the walls... that is part of wairua kōrero...

Riana

For us as Māori with dementia... spiritually they are actually having a conversation... hallucination is the Pākehā word for it... but for some Māori it is actually physically seeing their tipuna...

Further, Riana considered that personal perceptions of dementia may be dependent upon cultural influences within one's life and upbringing.

The ones that society have been brought up as townies will always think like townies and they will go with the dementia type Alzheimer's.... where those who have bought up in the country... and been bought up tūturu Māori-fied will always refer to it as wareware...

The centrality of spiritual values and understandings was also supported within participants' responses identifying that older Māori affected by dementia commonly retain associations with karakia and religion.

Marama

She would do karakia... karakia Ringatū and me and my daughter would have karakia with her... my Aunty was very good at that... she could lead a whole hāpati all by herself... it took about 45 minutes to do... but she could remember word for word, line for line...

Riana

The one thing I have found with our people, the one thing they remember is their... he aha Hāhi Aunty? (What church are you?)... They might not remember anything else but they remember their church...

A second theme emerged which highlighted the lack of a traditional cultural perception related to dementia. This was illustrated by responses acknowledging that loved ones commonly revert back to another period of their life. As a consequence whānau may struggle with these behaviours.

Marama

Conversation wise with her... she could talk about my father, she could talk about my grandmother, Dad's mother, and she could talk about my grandfather which is Dad's father.... amazing stories... my Aunty could recollect her childhood but when it came to things of today... she couldn't tell me...

Tui

I think Mum is at the stage now when she has got photos up on the walls of us and our grandchildren but she can't relate to them now... so I am looking at getting photos of her Mum and Dad and her brothers and sisters... those are the ones she can relate to....

Wiremu

I worked with many who were still Second World War sailors on the bridge of their ship...

The Impact of Western Understandings upon Māori Worldviews

Following on from this, participants were asked “Are contemporary understandings of dementia influenced by Western understandings of dementia?”

The key theme that emerged from the participants' responses was that Western understandings impact strongly upon Māori worldviews about health.

Pania

Oh absolutely... I think it is something that is imposed... this is what we have found out about the disease.... and so when you have got it, you have got it basically... a one size fits all approach...

Roimata

I do think that dementia is very much associated with the medical model of being... because we know that a lot of the descriptors are almost coined to create a mystique around particular illnesses... but the terminology is designed to keep the power in terms of knowledge in one sector and keep the others kind of like guessing really...

When participants were asked if Māori health experts find the characteristics of dementia as defined by the DSM-IV-TR helpful or useful, responses indicated that the diagnostic criteria fails to acknowledge a holistic perspective of wellness. This was illustrated within Wiremu's response:

Well I guess it describes behaviours and symptoms that is all... though when talking about Māori views towards health then I guess it would take a more holistic approach toward the totality of that person, who they are, the context of their family, and life long lived, whakapapa and all those things...

Appropriate Terminology for Māori

The key theme emerging from the question "Do you think that dementia is an appropriate term for Māori?" was that a phrase defined by Māori would be more inclusive of a holistic approach to wellness. Te Reo Māori was explained as a softer and more descriptive language where one word is inclusive of many concepts. Defining dementia with the use of te reo was perceived by the participants as a positive foundation towards the provision of a connection with Māori people. Framing dementia within a cultural lens was believed to be the key to encouraging understanding and engagement with service providers.

Marama

It is worse when tauwiwi language is used to identify what my whānau are... We would call them māhunga wai, because their brain is just nothing full of water everything just flows.... so that is one of the terminologies we use

when our people forget something.... whatever Māori want to call it I think that is their prerogative...

Roimata

The language itself is a much softer language it isn't quite as stark... much more flowery or much more descriptive of what is happening... so it would help...

Hinimona

I think if it can actually connect with the group that it is affecting then it makes a lot more understandable to them, they will engage in it a lot better...

Wiremu

Māori terminology would be much more inclusive of a Māori worldview of caring, so therefore would be appropriate...

Riana

The Pākehā terminology is Alzheimer's dementia... there is no other word for it, that is the word for Pākehā terminology... the Māori ours is wareware... wareware means memory loss, Alzheimer's dementia... it is all of those things put together... because in Māori one word means a lot...

The Value of Diagnosis: Helpful or Unhelpful?

This section explores whether culture is included within the diagnostic process and whether Māori find diagnosis helpful. The first question presented to participants was “Do you believe that culture is considered when doctors provide a diagnosis to a Māori elder?” Participants’ responses revealed a strong and relatively consistent theme that culture is excluded from the diagnostic procedure. As a result participants believed their elders may be disrespected, as an integral part of their being was ignored. This theme was illustrated by the following responses:

Aroha

They don't know your background or your identity or why you think the way you do...

Roimata

No, no, never... it is just a straight medical diagnosis...

Wiremu

No, not in general, because it is just basically describing, or observing, and interpreting a set of symptoms to a predetermined criteria which is not based on Māori constructs of wellbeing... so therefore you can only call it through the gaze you are looking at it from... it is just not holistic...

Hinimona suggested that the exclusion of culture has resulted from historical practices within health care systems and a lack of cultural education for staff within health services:

No... I think that is two things... one is that our health system has never catered for that before.... and the other thing is... do they have the skills or any knowledge?

Responses from Rangi and Marama illustrated a possible solution to the exclusion of culture from the diagnostic process, as follows:

Rangi

A lot of them don't because there are a lot of different ethnic doctors... unless someone of our culture comes in, like a facilitator...

Marama

I would say she is talking about cultural stuff... you should have a cultural advisor in here... but the wairua of my Aunty wasn't looked after by those people...

The second theme that emerged was that dementia is a consistent set of behaviours across cultures, where Māori are no different than any other culture.

This theme was illustrated within these responses:

Tui

I think they were sensitive... because they had an understanding of the dementia, I don't think it is different across cultures... I think dementia is whatever nationality you are, the sickness is always the same...

Riana

You know the geriatrician is there to give a formal diagnosis... in that field of work I guess they know what they are looking for... there is a pattern...

all Alzheimer's patients, Māori included, have all got the same story to tell...

The second question asked about diagnosis was “Do you think diagnosis is helpful to Māori?” Exploring the value of diagnosis to Māori resulted in two conflicting themes. The first theme was that diagnosis is not of value to Māori as it diminishes mana and does not result with constructive or effective assistance.

Pania

Not at all... my personal opinion is no, it is not...

Wiremu

It does diminish mana to some set of symptoms, that a person becomes a set of symptoms and depersonalises. I do believe that in a Māori worldview is that mana isn't diminished by that illness or set of symptoms...

The second and contrasting theme emerging was that diagnosis provides understanding, relief and the opportunity to make plans for the care of the affected elder. The following two responses illustrated the importance of receiving a diagnosis:

Riana

I think it is because then they know what they are dealing with... it is the not knowing that causes a lot of frustration and confusion to our people... now how can we deal with it?

Tui

Yeah I think so... it was just someone acknowledging what I already knew... so yes I found it quite good...

Whereas Marama emphasised how the value of diagnosis may vary across the generations. She inferred that younger generations have a greater understanding and acceptance of mental illness, as follows:

Today if you said that about someone... not my age group... someone younger... they would say 'so that is why she is doing those funny things'... it would probably be a relief... but for my cousins or myself... they think

our whānau is mad, there is a stigma around our whānau... they would have thought we can't have our background tarnished by that...

How Whānau Perceive Dementia and the Impact of these Understandings

This section explores Māori worldviews and values that possibly influence the provision of care for Māori elders within contemporary whānau. The most prominent values discussed were those of manaakitanga and whanaungatanga. These values reflected upon traditional beliefs influencing contemporary society and the care of elders. Another topic investigated within this section was the possibility of whānau shame or whakamā resulting from an elder being affected by dementia. The overall aim of this section was to explore the consequence and impact of understandings and values upon whānau coping strategies and the seeking of assistance.

Māori Worldviews

Within the Māori worldview, there is a holistic perspective regarding wellbeing and a positive focus upon maximising the quality of life. This perspective was emphasised within the following participants' responses:

Riana

I mean we want to go from haumate to hauora... you want to go from being unwell, to being well... from unhealthy to healthy basically... hauora is health...

Wiremu

When talking about Māori worldviews towards health then I guess it would take a more holistic approach towards the totality of that person, who they are, the context of their family, and a life long lived... whakapapa and all those things...

Searching for Understanding and Making Sense of Behaviours

The absence of knowledge surrounding dementia or failing to understand that dementia is an illness outlined by a set of behaviours, results in whānau searching for understandings outside of the biomedical model. Participants reported that whānau often seek understanding within the environment, the affected individual's personality, or the grief process associated with the loss of loved ones. Several themes emerged from this meaning-making process. The first theme surfacing from participants' responses was that symptoms may be masked, hidden or denied as outlined in the following responses:

Rangi

They have their own reasons for their Mum or Dad being like that... mind you we (indicating Māori) are always covering up... and find some Māori always mask it, and say nah nah they are not normally like that, he can do this and do that...

Hinimona

The problem is that sometimes it is just a slow progression that creeps in, that families kind of slowly adjust... oh that is all right they are just not well at the moment, or... there is always some kind of reason that they cover it up with and not really wanting to address it...

Riana

There is a lot that have hidden... what their family has got... I think it is more the denial of not knowing, or not wanting to accept what it is...

The second theme that emerged from family searching for meaning and understanding was where whānau interpret their loved ones behaviours as a deliberate means of aggravating their caregiver. This point was illustrated within the response from Roimata:

So they actually think this person is being a pain in the neck, being stupid, being awkward, all those sort of things.... a deliberate behaviour by the person to annoy them.... they just don't have that understanding of what is happening to their person... a lot of people think that... I think that actually a potential outcome of that is a lot of elder abuse in homes... because they have no understanding about it... they shroud it in mystique... and it

becomes a tapu... oh Nanny is with our tupuna and she is saying we have to go and do this...

A third theme identified was that whānau may seek understanding within the person's personality or causal factors within the environment. The understanding related to family viewing the deterioration of behaviours as an extension of personality factors, such as being eccentric or hoarding. Environmental causes were also believed to be underlying factors in the development of unusual behaviours. An illustration of these themes was represented within the following responses:

Tui

We just thought that is was part of her personality... I talked to my brother and he said 'oh she has always been like that'...

Marama

I think some can be quite eccentric... I think some of that is that people think that they are a bit nutty... if we have an understanding that this person has always been like that... this is part of his whakapapa... then why give it a name... that is not what it is...

Riana

She had always been a hoarder, she had always had the stuff in her bedroom... it was just like Fort Knox...

Aroha

We think Uncle got contaminated from the water because he was drinking the water from the creek where the old wood mill was running... also cooking out of the old aluminium frying pans and pots, he used those and his cooking utensils, we actually pointed it back to that too...

The fourth theme identified within this section surrounding searching for meaning was a referral to the heartache and the isolation resulting from the grief process.

Riana

Here is a woman who had been very astute, but when Uncle died she never remarried... and she had two sons killed in Australia... and then she just ploughed herself into work, not even so much into her mokopuna... it is like your loved one is gone... a lot of it is grief...

Aroha

When Uncle left Aunty, I just saw her go into withdrawal... they get lonely on their own, they become creatures of habit...

Rangi

I think the other part is if the partner is gone maybe that person is fretting and is lost without that other partner, because they were with them all the time... mokemoke...

Extending this search for understanding behaviours within personality and family trends was normalisation. This belief appeared to result with improved coping strategies as illustrated by Marama:

I think if it is part of that whānau, and as you become older, that thing becomes more pronounced... so I don't think that is dementia... I think that is just part of that whakapapa... it is a good thing that you are able to cope with your whānau like that...

Normal Ageing Process or Problematic Behaviour?

To explore the possibility that behaviours associated with dementia may be interpreted as part of the normal ageing process participants were asked “Are the symptoms of dementia such as memory loss understood as part of the normal ageing process or viewed as problematic behaviour in Māori society?” A dominant theme emerged from this question that the symptoms are viewed as part of the developments involved with old age. The following responses were employed to illustrate this theme:

Marama

I think a lot of it is due to age... age and some of those things are the things that happen with people... you start growing hair, or lose hair, or become tubby, or become wrinkled... and all the things that come with age... but your mind goes too... and that is an acceptance...

Tui

We just looked at silly old age behaviours and accepted it like that. We never questioned that something was wrong... that is probably why we never picked it up early... we just thought oh this is her, her personality....

Wiremu

All that I have ever heard from whānau is that it has been seen in a developmental context, a condition of the elderly.

As a consequence of understanding the behaviours associated with dementia as part of the normal ageing process there was a consistent and strong belief that dementia commonly goes undetected in Māori, as illustrated below:

Marama

Yes I do because we take it for granted...

Roimata

I think it goes undetected in a significant number of Māori elders because they don't know what is happening...

Being Māori: Values Impacting the Care of Māori Elders

This section explored how Māori employ a worldview or value system to make choices around the care of an elder affected by dementia. Participants were asked “Do you think Māori have alternative or different ways of dealing with elderly affected by dementia? What are the differences?” Two main themes emerged from the question. The first was that Māori perceive a sense of obligation or duty to care for their elders. This obligation is founded upon the values of manaakitanga and whanaungatanga, as represented in the following responses:

Aroha

My Uncle was 78-79... he was diagnosed with Alzheimer's and the family being Māori they wanted him at home... because our culture is to look after our own people.... they didn't want to go for help they were too proud.... this is our Dad we can look after him...

Roimata

As far as possible we would not let our Mum go into a specialised unit... I believe that we have a duty of care to our Mum... just to share the duty of care to us... and that is what we call it... that is the whanaungatanga thing... she is probably too precious to any of us to put in a home...

Wiremu

Manaaki whānau... I guess young people caring with koroua and kuia in that context is I guess very much ingrained in those values of manaaki

aroha ki te tangata... respect for your elders... I believe ma te whānau i te whānau or by family for family is still strong or is still the prevailing attitude...

Marama

I think it is a good word manaakitanga because it does work and people do need it and some of our people do practice it... with our whānau I suppose it is more ngākau māhaki rather than manaakitanga... ngākau māhaki is one with a good heart that is open to what is happening... manaaki is more about caring... to care for someone you have to have a good heart, spirit and soul, especially to look after people with dementia...

The second theme was a belief that this traditional expectation is not always realistic in a changing society, where whānau need to work and are often geographically separated. This theme came with the acknowledgement that loved ones become someone who is no longer a reflection of the person they used to be.

Tui

It is an expectation of our culture, to look after our elders.... to me its not a good expectation to put on other people... it should be a personal decision not a cultural expectation... but there is still that there, that expectation which is not fair... if there wasn't that expectation that I look after my Mum, culturally... she probably would have gone into a home earlier... you do it out of love or duty... because her behaviour is not who she is...

Hinimona

Across Māori-dom it will differ... for example the kaumātua that we serve here, a lot of their family member's are actually over in Australia... so their whānau are the Māori health providers... that social support system becomes like a whānau to them... so it is definitely a different Māori world to what it used to be... it was the families responsibility... but now the world has changed and you don't have Mums at home, you have Mums in the workplace... there are a lot of kids in institutions now... how are they going to know whanaungatanga... they have grown up different...

Riana

The times have changed, work ethics have changed... not everyone can stay home and be a paid carer...

There was also an acknowledgement that Māori prefer to utilise traditional methods of healing such as karakia and rongoā, as outlined within Riana's response:

I think that we try, and they try to do the karakia and the rongoā stuff... I think that the karakia is always first paramount you know...

In addition to manaakitanga and whanaungatanga participants referred to a deep seated respect for elders within the Māori worldview. This respect may lead to situations where younger people acknowledge elders instability but are unable to question motives of persons older than themselves. Participants' responses illustrated the theme as follows:

Wiremu

Mana wahine, mana tāne, is important in terms of maintaining in and caring for the dignity of the tangata... of the person... being respectful of their mana, especially in consideration of advanced age, and Māori views towards advanced age... kaumātua kuia are the vessels or mauri of our culture... so there is that deep seated respect... that they are not past their used by date...

Marama

When they stand to do their whai kōrero, now that is a worry too because the kōrero is just so jiberous... a couple of times I have heard that happening and seen that happening on our pae... to the point you say to the koroua don't let him speak, I don't think he knows what he is saying... and of course you get looked at as if to say, well what do you know...

These cultural values may be dependent upon influences within childhood, upbringing, and experience with cultural practices, as Riana highlighted in the following response:

Māori that are very Pākehā-fied that haven't been bought up tikanga kaupapa Māori are very happy to go into a rest home... but Māori that are tūturu... the real McCoy... that have been bought up with tikanga kaupapa Māori... that is why they put up their horns to go into a rest home care... because that is not how it is done... you look after me till I die, that is their thing...

Whakamā and Shame Associated with Dementia

To explore the possibility that whānau may experience shame or whakamā when an elder is affected by dementia participants were asked “Do you think dementia would be considered a source of shame or whakamā for whānau?” Responses were divided into two conflicting themes. The first theme was that having an elder affected by dementia does not result in feelings of shame or whakamā as the following comments illustrated:

Hinimona

Personally I don't think so... in my experiences Māori are quite open to their kaumātua having that type of disease...

Wiremu

No... I have never observed that with whānau...

The second theme contrasted with the first where participants believed that dementia or mental illness within whānau can result in a feeling of whakamā. It must be acknowledged that dementia is not an isolated disorder and shame is a common response to mental illnesses within mainstream worldviews. There is a stigmatisation surrounding mental illness within society. To emphasise this theme the following comments are illustrated:

Pania

Absolutely... I think it can be...

Tui

Sometimes I bring it on myself... I think it depends on the caregiver... but there is a stigma...

Riana

Yeah they do... I think it shouldn't be, but a lot of people do get whakamā... they are embarrassed of the fact that their loved one has lost the plot...

How Beliefs Impact the Seeking of Assistance

To explore the impact of Māori worldviews and understandings upon the seeking of assistance participants were asked “Do you think that beliefs around dementia affect the seeking of assistance or support?” One participant emphasised the importance of the mental health act and historical understandings whilst someone

else felt that the shame of mental illness may inhibit the seeking of assistance, as follows:

Pania

I think it is probably historical... I think it is where it sits under our mental health act that whānau are more reluctant to seek help... because you are actually basically committing your Koro or Nanny...

Marama

I think it does hinder some whānau... and maybe it is about the shame of knowing that my person like my mother or father is going mad...

Others acknowledged that the consequence of attributing the early symptoms of dementia to old age or deliberately difficult behaviours was delayed help seeking behaviour. Expanding upon this theme was the recognition that delayed help seeking results in the advancement of symptoms and increases the demand for an elevated level of care.

Roimata

Its two fold... there is the beliefs around dementia and not understanding it... for those who think that their elderly parent or grandparent is just being a pain in the arse, they aren't going to go and seek help... and then the lack of forthcoming information, prevents them from going and seeking help...

Riana

Yes... by the time they get a diagnosis they go straight to stage three... stage three is psycho geriatric... they normally by pass the rest home side of things... because of their behavioural issues...

In conjunction with spiritual understandings, Riana acknowledged that alternative forms of assistance may be sought prior to seeking medical support, or in combination with care services. This form of assistance is commonly sought when whānau have more traditional and spiritual beliefs, as illustrated:

... so you know for us Māori, we will have our Māori doctors, and our own rongoā... the Pākehā will go to the geriatrician, and prescribe you risperidone (antipsychotic)... whereas Māori will go 'oh nah we have got a

rongoā out in the bush’... we will pray and have our karakia... the minute you do karakia, it is like a calming ... see our people are very spiritual...

Inclusion of Affected Individual

Participants were asked “Do you think the family member affected by dementia is included in wider family events?” in the aim of exploring the extent that those affected by dementia are included within whānau events. Responses indicated a dominant theme of inclusion, even when difficult or challenging behaviours are being exhibited.

Aroha

Yea... definitely, Uncle would come to tangi, go out to dinners... celebrating his wedding anniversary, or a child’s, mokopuna’s birthday... you know he is there... we still involve him in it...

Roimata

In general I think they are... certainly... I mean they see that there is a family responsibility and her as the elder should be there... whether her mind is there or not, it doesn’t really matter... it was delightful to hear her sit there one day and someone is in full flight... one of the men of the marae, in full flight doing a... and she said ‘oh shut up you are just saying bullshit’ ... it was so funny...

Expanding upon inclusivity was the recognition that affected elders presented a learning opportunity for others, especially the younger generations. This theme was illustrated in Tui’s response:

At the beginning Mum was actually good because she was the elder, the kaumātua of our family and she was good to have when we have things to get together... because the little ones... and we explain to them that you can’t see Nan’s sickness but she is sick... I think a good learning for them...

Subsequent to inclusivity, Tui also acknowledged that marae are not always appropriate or safe environments for those impacted by the more serious behavioural concerns of dementia. This point is illustrated below:

Yeah they do... but it is hard... marae aren’t good places for her now... (Indicating others often don’t realise the level of support required)...

The second and contrasting theme was that dementia may lead to isolation from extended whānau. The theme of isolation may be linked to the misunderstanding, fear and stigma referred to in previous responses. The following responses illustrated this notion:

Tui

When they do come it is like she is just over there and we are yakking over here... and she is not being involved in the conversation... they probably don't know what to say or do... I suppose because you can't see that she has got it...

Riana

A lot of whānau won't take their mokopuna... 'oh I am not taking my moko's round she has lost the plot... oh Nan, I don't want them to see Mum and Dad like that'... That is another social factor... is that your people stop visiting you... because they think well what can we talk about, really, are they going to remember, they think they can't hold a conversation with you anymore... so they don't visit and they don't come... leads to isolation...

How Māori Cope with Dementia

This section presents a summary of how the participant responses reflected upon the coping strategies of whānau when an elder is affected by dementia, the role of hapū and iwi in the provision of services, the provision of cultural needs within care facilities and what services are available within the community.

Whānau Coping Mechanisms

Exploring the coping strategies and support offered in the community for whānau impacted by dementia resulted in a strong theme emerging from the responses. The theme emphasised a lack of appropriate support in the community for whānau caring for an elder at home. The investigation commenced with the following question “How do whānau cope when an elder has dementia?” The dominant

theme was supported by other arguments centring upon whānau struggling to adapt to changes in their loved ones personality, largely due to the lack of knowledge about dementia and its symptoms. This assertion is illustrated in the following comments:

Aroha

Well they don't, they don't cope.... because they are seeing another side of their loved one, no they don't cope... they want their loved one back... it takes a while because they need to understand what dementia is...

Pania

Whānau don't have the resources to cope... not that they don't want to but that they don't have the resources to cope and sometimes the skills... whānau coping mechanisms and resources are limited...

Participants also acknowledged that coping strategies are dependent upon dynamics within families, how intact whānau units are or the availability of support within the community.

Wiremu

I guess there is a practical side to it... in terms of what resources there are in the whānau and who is able to care for... I think some of it goes back to how intact whānau units are in contemporary nuclear New Zealand...

Hinimona

A few of them have coped by putting their kaumātua in rest homes... and a lot of it is because some of them are at stages where they have to get 24 7 care... and they aren't in those positions to give it... but I do know of some whānau who still look after their Mum, and they time share...

Marama emphasised a possible difference in coping strategies across the generations. She presented a view where younger generations have different upbringings and values in comparison to older generations. This point was emphasised in the following response:

I don't think the rangatahi of today... unless they are bought up in a world like we were bought up... aroha ki te tāngata... I don't think they would be able to cope... but I think people like myself... my age group could probably cope with it...

As an extension of the dominant theme where whānau do not have the resources to manage, a minor theme surfaced about whānau reaching a ‘breaking point’. This breaking point was defined as a realisation that behaviours have developed into actions that are too difficult for whānau to manage at home without support. Subsequent to whānau accepting that their loved ones behaviours are beyond that expected of an elder, and that a real problem exists, assistance was sought. This point is illustrated below:

Aroha

You know Dad was peeing everywhere and anywhere... and they just thought it was a real shock to them... he didn't even recognise his own sons... when the crunch came they didn't cope... and they realised, shit we need help...

Riana

Because when she was at home she wouldn't shower, she wouldn't change, wouldn't let anyone in her room, she would be in the same clothes, her hair was long...

(And later continued) She was going teko or going to the toilet in her room... she walked out and a bloody cattle truck nearly hit her... that was the last straw...

From a health professional's perspective, there was an acknowledgement that it is important to view the complete context and think carefully about what is best for your loved one affected by dementia, your whānau and yourself, as reflected in Riana's response:

It is hard you have got to work... and because the behaviour patterns change... I always say to whānau 'look at what is best' or 'look at the need, what does your Mum or Dad need, can you fulfil that high need'... just remind them that the safety aspect is the biggest...

Organisations Available to Support Whānau

The exploration of service provision and appropriate support available for Māori elders and their whānau began by asking participants: “What support services do you know of that might be appropriate for Māori with dementia? What support is offered to Māori families? Which organisations?” A variety of themes emerged

from this question; however the dominant theme was that there is a lack of appropriate support for Māori elders affected by dementia, as illustrated in the following comments:

Aroha

No... is there?

Pania

With dementia... none... there are some really good Māori providers here... but nobody in the Waikato are specialising in dementia care... they don't understand... and culturally they are not equipped...

Wiremu also emphasised that suspicion around mental health organisations has led to traditional values predominating contemporary belief patterns. This distrust has resulted in a resistance to interact, as illustrated here:

I believe ma te whānau i te whānau or by family for family is still strong or is still the prevailing attitude... I think we probably still consider mistrust towards institutions... I am not necessarily talking about residential institutions... the health and disability sector in general... a lot of mistrust by hard experience...

However, other participants believed there are appropriate services available in the community. These responses indicated that the provision of services was dependent upon individual whānau getting out there and looking for what they require, beyond whānau dynamics. This theme is illustrated in the following responses:

Rangi

I think so... they just have to get out there and look for it because it is there...

Tui

All my support has come from government departments... all the support I have for my Mum, there is none of it comes from my whānau... I just started with Alzheimer's... the family is probably not coming near to help with Mum because they think 'oh she is getting Mum's benefit money... that is her job'... She does go to the kaumātua programme... they are great...

Riana acknowledged the development of responsive services as vital. Whilst, Wiremu presented the notion that the establishment of appropriate programmes is a relatively new approach to care for Māori elders. The following two responses illustrated these ideas:

Riana

Day care programmes... now they were a big must... now the kaumātua programmes...

Wiremu

But I guess organisations such as that are really quite contemporary... contemporary organisations in the context of... and urban environments... so whether that replaces for instance or runs conjunctive to the marae... but they are also still very new institutions... even within the Māori framework... runanga Māori health providers they are all developments in an endeavour to be... to provide health care services or social support services to Māori that could make... or could make a difference... rebuilding those organisations of whānau and hapū... it is about to care for and support their own...

The Inclusion of Cultural Needs within Services

This section aimed to investigate whether cultural needs are met within organisations offering support for whānau. The intention was to understand if Māori felt service provision is appropriate, and understanding of cultural values. Participants were asked the following question: “Within your professional role are Māori elders with dementia cared for adequately? Or is there room for improvement?” The dominant theme emerging from responses was that organisations are not equipped to place importance upon, or practice cultural responsiveness for Māori elders. This premise was illustrated in Pania’s comment, whilst Marama and Wiremu extended it further to emphasise possible abuse.

Pania

You know our kaumātua weren’t accessing the services because they aren’t appropriate... that hasn’t changed today... Māori are still disadvantaged in regards to accessing appropriate health care... you know culturally appropriate health services...

Marama

Part of cultural competence practice... within all those allied professions... yes I think we can (referring to improvement)... because it is not just about the elderly, it is about support that you provide for the elderly who has got dementia and it is about how you support the whānau... and so it is about how do you support them... and if there is nothing out there oh good grief... then you get those issues around abuse of the elderly...

Wiremu

I mean I know there is a lot more support options and services available than there was 10, 20 years ago... so in the terms of being able to care for people within their homes, Māori have always done that... but I guess there are now more services that are able to go and support them to do that... I wouldn't trust my Mum to go to any rest home... mainstream rest homes services aren't geared to respond to Māori in my view... as a consequence they can run the risk of being very abusive towards whānau Māori without even necessarily knowing that...

The Role of Whānau, Iwi and Hapū

When enquiry probed into the role of whānau, iwi and hapū in caring for elderly affected by dementia, a strong theme emerged that iwi have the capacity to assist with the establishment and maintenance towards the provision of appropriate support for whānau. Participants were asked “What role does the whānau, hapū and iwi play in coping with a family member’s dementia?” This premise was illustrated in the following comments:

Pania

I think everyone can play a role our marae, our hapū, can play a stronger role... and I definitely believe the iwi here could play an even bigger role... providing some better resourcing to support the whānau and providers... they have got the capacity to do it...

Hinimona

The kaumātua have already indicated that they want a kaupapa Māori rest home... I think that would be great... and they would love to see new kaumātua programmes in rest homes... and make it about wellbeing, and I think they feel that Tainui's investment in rest homes would be a really

good thing... but for me there has to be a real difference between investment in terms of returns, and investments in terms of influencing cultural behaviours within the organisation...

Wiremu

Rebuilding those organisations of whānau and hapū... it is about to care for and support their own... so how we might see that today is through whānau or through family or through hapū run health initiatives or iwi health services may also see that... under a Māori organisation, kaupapa Māori organisations, that work under Māori value systems... Māori values and practices...

Changing Trends of Māori Utilising Rest Home Care

Consequent to a lack of support in the community and whānau being unable to care for their elders in their own homes, there appears to be an increasing trend of Māori elders being placed in the care of rest homes. This trend was found to correlate with changing demands within society and urbanisation. In this context, changing demands can be defined as modified gender roles, where mothers no longer stay at home, and that every adult requires employment to support their family needs (Giddens, 2001).

Riana

When I was first doing this, ten years ago, rest homes were an unspoken word... but now you find it is the younger ones looking after the ones who have got the dementia... it is hard, you have got to work...

Pania

What I have seen more recently, certainly in the last four or five years, that there is more of a trend occurring where kaumātua have been put in care... and I think this is sad...

Wiremu

You know we are increasingly so, or are, an urbanised people, and the more one is disassociated from traditional roots, values and practices, they are less likely to do the... (indicating care for the elderly)...

Interestingly, this increasing trend was extended towards a lowered expectation of participants' children, as evident within the following quotes:

Roimata

Interestingly, if I was to get dementia, I have told my children I want them to put me into a home... whether they will or not is another matter... but I have actually said that to my children... I am sure if my mother thought she would have dementia she would have told us the same thing... not that we would have taken a bit of interest... my relationship with my children is quite different to my mother's relationship with us... I have worked all of my children's lives... my Mum was home with us, all of our growing up you know... she was home with my children because I was working... things have changed over the years in terms of our parenting skills, and our working...

Tui

I have always told my kids that if anything happened just put me in care... because I wouldn't want my family to... not want to be a burden... I wouldn't want someone to stop their life to look after me and miss out on opportunities...

Rest Home Care and Guilt

The increasing trend of placing Māori elders in rest home care has resulted in an internal conflict between traditional values and survival in a changing environment. To explore the possibility of whether guilt is attached to placing a loved one in care, the question “Is there guilt attached to placing a loved one in care?” was asked. A strong theme emerged from the responses denoting a sense of guilt for whānau when making the decision to place an elder in rest home care, as represented in the following quotes:

Pania

Yeah absolutely... I would... you know me personally... oh it would be terrible for me, my kids and the kaumātua concerned...

Riana

He was the first of our whānau that ever went into a rest home... it was traumatic actually... they really couldn't come to terms with it... that is not what Māori... Māori don't do that...

Tui

I could still look after her here on our own... I am probably not being as good to her as what... probably getting too depressed about being here... so the care she is getting is not as good as she should be getting... so then I think I should stay here and look after her... but if I do that I am not going to be a good person and she doesn't need that...

Summary of the Findings Presented in Chapter Four

Several persuasive themes have emerged from this chapter centring upon Māori worldviews, understandings of dementia, the impact of values upon help seeking behaviours and the value of diagnosis. The participants present strong arguments for contemporary beliefs being founded in traditional belief patterns and spiritual understandings. Traditional values that dominate current belief patterns converge on manaakitanga, whanaungatanga, the value of traditional healing and inclusivity.

One theme that arose from the data was that contemporary understandings of dementia were often shrouded in uncertainty and a lack of awareness about dementia or the symptoms defining the illness. The absence of specific medical knowledge produced an apprehension or fear about unusual behaviours, possible sources and transmission. There was a consistent premise emerging from the participants' responses that the symptoms outlined by the diagnostic criteria of dementia are often attributed to age related behaviours.

However, another theme that arose was the acknowledgement that dementia is likely to have a consistent set of symptoms across culture. Medical diagnosis was viewed both positively, where it provided relief and understanding, and negatively, where it was believed to diminish the Māori elder's mana. In addition, there was a suggestion that the biomedical model could be more effective with the inclusion of a holistic approach. The holistic perspective was defined as viewing the complete context, including medical and cultural experiences and

understandings. Extending this premise was the usefulness of cultural advisors, and emphasis on cultural competence within medical practice.

The belief patterns of whānau caring for a Māori elder surrounding dementia may result in delayed help seeking behaviours. Furthermore, the lack of knowledge about the medical condition of dementia results in whānau struggling to cope with changes in behaviour. The lack of appropriate support within the community and suspicion surrounding mental health organisations often leaves whānau struggling to cope and somewhat isolated. However, participants also indicated that there are increasing trends of support options within the community, and that Māori elders are being placed in care facilities due to changing demands within society.

Findings

Outcome of Questionnaires

In conjunction with the findings outlined in the immediately preceding sections, the findings of the questionnaires (Appendix Two) are presented below in Table One. The analysis is based on a small number of participants ($n = 9$). Themes identified within the individual interviews are supported by the conclusions from questionnaire totals. For example, manaakitanga is a strong value in contemporary society, and the symptoms of dementia are commonly attributed to normal age related behaviours. Consequently, there was an acknowledgement that Māori elders are predominantly cared for within whānau homes, family members would experience guilt if an elder was placed in a rest home, cultural barriers are emphasised as problems within mental health settings, and Western values are believed to impact the care of older Māori.

Table 1: Participant Responses within Questionnaires

Question	Response		
	Yes	No	Unsure
Are kaumātua recognised by health professionals as having dementia?	7	1	1
Do you believe Māori suffer from dementia?	6	2	1
Is dementia an appropriate term for Māori?	3	5	1
Do you believe Māori acknowledged kaumātua mental illness within traditional society?	5	3	1
If yes.... would the elder have been included?	6	1	2
Does the principle of manaakitanga apply to the care of elderly in contemporary society?	8	1	
Do you believe whānau view the symptoms of dementia as part of the normal ageing process?	6	1	2
Do whānau accommodate behaviour of older family member's more than non-Māori?	4	3	2
Do whānau seek assistance outside of the whānau?	4	3	2
Would dementia be considered embarrassing or shameful?	2	6	1
Are elders with dementia predominantly cared for within a family home?	8		1
Would the affected individual be included with whānau events?	6	2	1
Do Western values influence the care of older Māori?	7	1	1
Do whānau receive adequate and appropriate information?	3	6	
Is there adequate support in the community for Māori families affected by dementia?	3	6	
Would the whānau feel guilty if an elder was placed in a full time care facility?	8		1
Do you believe cultural barriers are a part of the problem with mental health services?	8	1	

Chapter Five

Findings Part Two

Barriers for Service Users and Suggested Improvements

E tūtaki ana ngā kapua o te rangi, kei runga te Mangōroa e kōpae pū ana

(No matter how gloomy the outlook, there is always something favourable to be found in the background)

Chapter Five outlines barriers identified by participants obstructing the effective provision of appropriate support, and explores services that may be of more value for Māori. In addition, key issues for Māori elders, and suggestions for implementing improved and appropriate services for Māori elders in the future are discussed. The chapter has been divided into two sections to clarify the findings, as follows:

- (i) Key issues relevant to Māori people with dementia
- (ii) Suggested improvements for services

Key Issues Relevant to Māori People with Dementia

This section presents a summary of the participants' views about potential barriers impacting the provision of services and key issues for Māori elders and whānau affected by dementia.

Barriers to Seeking Service

Exploration of potential barriers to gaining access to support services was initiated with the question “What are the barriers, if any, to Māori receiving diagnosis, treatment, and ongoing support?” The first and dominant theme that arose indicated that Māori elders have a very real fear, or reluctance to utilise, mental health services. Participants perceived that this fear may have developed from the decades of institutionalisation. The following responses emphasised this premise:

Riana

The impact on Māori is huge, they have come out of that Tokanui and Carrington era¹¹, so that is all these ones have grown up knowing.... ‘oh he porangi, put them in there’.... so getting them now to understand that ‘no you are not porangi, no you are not going to go into the nut house’, is a big thing...

Pania

Because it sits under the mental health act that whānau are more reluctant to seek help... being labelled... I am really concerned that our kaumātua are labelled under the mental health act and that they are placed in wards like Henry Bennett¹²... it is so unfair... I think taking along the line of the palliative care model and having them at home...

Wiremu extended this distrust from mental health services to the general ‘health and disability sector’, as illustrated:

I think we probably still consider mistrust towards institutions... what I mean by institutions whether they be general practitioners or health professionals in general... I am not necessarily talking about residential institutions... the health and disability sector in general... a lot of mistrust by hard experience...

¹¹ Tokanui and Carrington were long-stay psychiatric hospitals, closed in the late 1990’s as a result of deinstitutionalisation.

¹² Henry Rongomau Bennett Centre provides inpatient care for people suffering from an acute mental illness. There are three major services of care, including: adult, elderly and forensic services.

Reflecting on this fear of mental health services, participants believed that there needs to be a greater acceptance of mental illness to overcome these barriers of the mind.

Aroha

I think Māori need to accept mental illness around dementia... once they understand it I think they will cross that barrier... that it is ok to ask for help...

Roimata

Māori have been conditioned to believe that Māori are second class citizens... so if you go to a Māori provider you get a second class service... and then further more they are going to charge you... that is a barrier of the mind...

Hinimona

Māori aren't well known for stepping forward and having a crack at, or finding out, or asking too much... if they don't think it looks very appealing then they don't tend to, not even go there... if you want Māori to engage earlier then you have got to try to reduce those access barriers, like the big language, like the scary terms, and make it a bit more grassroots, so that it is understandable...

A second theme evolving from discussions surrounding barriers inhibiting whānau from accessing services was failing to understand what dementia actually is. This was represented in Hinimona's response:

I think one of the first barriers would just be lack of clarity around what it is that... your whānau member has... and so that... if you don't have that you don't even engage in the process... it is just information...

The third barrier emerging was the language difficulties between those affected by dementia and staff within services. This theme transpired in relation to the number of immigrants employed within rest homes and support services. Riana illustrated the language barrier, as follows:

But the language barrier is a huge breakdown... Māori can understand English... but if a person doesn't communicate, they could be the best carer in the world... but if they don't speak the language... English you

have a breakdown straight away... and our Māori people have got no patience...

The fourth barrier identified was the confusion arising from a lack of forthcoming information and networking between organisations. Participants reported that for Māori accessing services for elders is confounded by professionals failing to ‘advocate’ for other services. This was illustrated in a response from Riana:

Professionals don't advocate or tell you necessarily what is out there...

Further probing into the lack of networking between organisations presented the opinion that organisations compete for funding, therefore don't want to share clients, as Riana commented:

A lack of networking between organisations... they won't work together... they all jump in to get their pūtea, their money... you have got all of these Māori providers you know... they are doing the same thing but none of them will come together because it is that rohe and that iwi...

The fifth barrier identified was that Māori have a preference for face-to-face explanations, in comparison to the provision of information pamphlets. The responses from participants indicated that brochures are an inappropriate form of distributing information, as illustrated in the following comments:

Pania

I think you can go in and give a pamphlet till the cows come home... and all it ends up doing is lighting the fire...

Riana

Yeah... but to be honest Māori don't read it... they don't want to read the pamphlets and notes.... they want to hear it, face-to-face... if you went out and explained it all and told them all about it.... that is the best way...

Key Issues for Māori Elders and their Whānau

The dialogue around key issues overlapped significantly with barriers to receiving services. Participants were asked “What do you think are the key issues for Māori elders and their whānau affected by dementia? How could this be improved?” The second part of the question was addressed in section three which summarises

suggested improvements. The first theme, endured from the previous section, was that participants suggested appropriate language and explanation were key factors to the engagement of Māori elders. The theme was illustrated in the following responses:

Hinimona

I think whānau member's it would just be over their head, it is about the use of language in a way that people can understand... because if you don't understand you can't support people properly...

Riana

You have to talk in the Māori kaupapa first and then explain to them what it is. 'He wareware.... well that is Pākehā terminology for dementia'... explain it as a breakdown of a bodily part... your body needs to keep that part of the brain going, or feeding that part of the brain... it wears off just like a battery dies down... well it is a bodily function... your head is your māhunga, your brain is part of your body... your eyes deteriorate with age, your hearing goes with age... your brain has to have some wear and tear too...

The second dominate theme was the provision of 'appropriate and culturally responsive support', all within a respectful framework. This theme has several elements, one of which was the number of people involved in each individual's case. This premise was illustrated in the following responses:

Wiremu

Appropriate support... so care that is culturally responsive and meaningful... support that enables whānau to be able to be carers for whānau... general support and information that is relevant and understandable to Māori... Māori aren't slow... so we often talk about saying things in a way that is understood by Māori, is not necessarily that Māori don't understand English... so its not just about in terms of the information that is given, it is about a whole orientation or way or looking at the world... in terms of culture and understanding and a Māori worldview...

Pania

I think that what is lacking is the resourcing to enable whānau to care at home... you know the decreased... if you are a son or daughter you are not entitled to carers benefits... so I think the government has taken away the ability for whānau to look after their koro or kuia as a result of our current health systems... not because whānau don't want to do it...

Riana

Having too many people involved... it is so important with our people with wareware dementia... not having too many people involved... it is frustrating for families...

(And continued)... just knowing they are getting the right treatment... the right care... they have got the right resources... knowing they have got the support... that is a biggy for our people...

Extending upon this theme was the premise that Māori require relationships, rapport, and personal interaction prior to acquiring knowledge and understanding. These relationships are founded upon Māori cultural beliefs such as whanaungatanga and whakapapa. The establishment of relationships is essential to engaging and interacting with Māori in the provision of services. This theme was illustrated below:

Wiremu

I believe that process is... properly more so or is important... well sometimes process in terms of mihi... that those and attention to wairua will often... so you can give all the knowledge in the world but its not necessarily going to make the whānau any more comfortable and responsive to what they need to be doing... you can spell it out nice and easy 1 2 3 4 5... it goes out the door... so you are talking about relationships there... whakawhanaungatanga... all those things in terms of setting whānau at peace with what's going on here... I believe the knowledge is secondary... kia tau te wairua... mihi... me ngā koutou te wairua ... ka tau te hinengaro...

Roimata

There is no development of a relationship or anything... so how do you expect people to actually feel comfortable enough to say 'oh my Mum or

Dad is displaying these unusual behaviours'... the person you are sitting in front of doesn't know your Mum and Dad... they don't know your family... so you know there is many barriers to your being able to get past first base... in order then to have someone assigned to you who can help you... it just doesn't happen...

Hinimona

I think for Māori whānau to have confidence in mental health services, its about the mental health provider being known, and the kaimahi being known... when they are not known, that whole label or stigma of mental health, its kind of like 'oh no you's are way too serious, this is just dementia... she is just losing her memory, I don't want her mixed up with them'... it is a label attached to organisations...

The third consistent theme emerging was a grave concern about respect for cultural protocols and values within the provision of services. This premise relates directly to the second theme of appropriate support and the above mentioned respect for tikanga and customs. Of particular concern was respecting tapu and the importance of karakia. The following responses illustrated this theme:

Hinimona

Will their heads be probed, because you know heads are really tapu for Māori... the other thing that was a real problem when I was working in the rest home was about people putting food on the commodes... oh gosh small things like that... for me it seems obvious...

Riana

Flannels... you know one is for the face, you don't use the same one down on your bottom... followed by... the one thing is our Māori people miss and do a lot when they get māuiui is karakia...

Wiremu

My experience of the traditional medical models is that they are not necessarily sensitive to mana, to tapu, to noa... I guess one because of the era they come from... and two their status and roles of kaumātua and the roles of whānau in terms of being holders of knowledge... so the issues of tapu, noa, mana tangata, mana wahine, and appropriate respect and observance of that is really important... some things you might consider

basic common sense in terms of leaving mimi bottles on the kai tables and those sorts of things... that can be very... bring about depression for elderly if they are exposed to that in an inappropriate way... when they are powerless to be able to care for themselves in that way...

The fourth theme emerging from discussions about key issues for Māori accessing appropriate services for elders was that isolation from whānau and cultural values within rest homes is detrimental to the wellbeing of kaumātua. The theme is illustrated in a direct manner from Pania, whereas Riana discussed the premise from a resistance perspective of whānau, as follows:

Pania

One thing that I do know is that when we put our kaumātua in rest homes that specifically look after the dementia side of things... we isolate them straight away... and that is a cultural barrier before you even start... so I think the isolation when they have been diagnosed with dementia is pretty sad for our kaumātua particularly... but my heart just bleeds for our kaumātua in that situation you know...

Riana

Some whānau don't even bother to go and see them... they don't bother going back again... 'oh they don't know me'... 'I don't go and see her... no point in me going to see her, she doesn't know who I am... can't have a bloody conversation with her'... you know that is the typical thing on Māori, what is the point... or they don't want to remember them like that... and a lot of Māori are frightened by it...

A minor theme identified by Marama emphasised that a lack of knowledge about the history of Māori elders may result in whānau being unable to relate to the kōrero or behaviour.

I suppose it would be a lack of support and lack of knowledge of the old fellas.... I think having access to kaumātua that grew up with those people.... you know if you didn't grow up with their grandparents or didn't grow up with the old fellas then you won't know much about them at all... but having a relationship with other kaumātua of the area that grew up with whānau, if they are around... to know more about the lives they have

lived... what the context they are talking about, when they are having those conversations... recognising that historical stuff...

An additional minor theme emerged which emphasised the responsibility of the Government's national policy in the care of Māori elders.

Roimata

It is absolutely endemic that as the government successive funders have insisted more and more and more on accountability of providers to met the funding regime and criteria... the standard of care is actually slipping over... because what you actually do is demoralise your workforce and you shift the focus from care or the quality of care to the quality of reports you produce...

Pania

The other thing that really concerns me is how kaumātua dementia fits under the mental health act... you know being a risk... I really struggle that they are sitting under the mental health act... when it really sits under wellness and being unwell... more than mentally...

Suggested Improvements

The third section of this chapter is a summary of suggestions for implementing an improved quality of service for Māori and whānau affected by dementia.

Participants were asked “What services do you believe would be of more value or additional value to Māori affected by dementia?” Wiremu summarised an acknowledgement of positive changes to date, and followed this with recognition of the challenges that mainstream services face in order to become culturally responsive, as follows:

I think there is lots that can be done and lots that has been done over the last period... say introduction of codes of practice, national health and disability standards, cultural safety, health care plans and so forth... they are all new... however more employment of Māori staff, more recognition of culture specific care, and be regardful of other cultures as being implicit in the values and practices of an organisation... my observation

and views is that for mainstream organisation with all the good will in the world, is hugely challenging... in terms that it does require a huge mind shift and orientation to how a service care is provided... so I don't believe they can do it to the adequate standard so... that is where by Māori for Māori orientated services have a very important role to play...

Themes emerging from this section were closely linked with the dominant premises from the discussions about barriers and key issues for Māori affected by dementia. The first theme transpiring here was that services need to respect and nurture the mana and wairua of Māori elders. Māori elders are ascribed with prestige and value, and service provides need to acknowledge this status. The following responses illustrated this theme:

Marama

Its just about being supportive in the language that you use to support your whānau, so you are not actually being derogatory to them... and not hurting the mana of that whānau either...

Wiremu

It is important in terms of maintaining in and caring for the dignity of the tangata, of the person... being respectful of their mana, especially in consideration of advanced age, and Māori... views towards advanced age... kaumātua kuia and being the vessels or mauri of our culture... so there is that deep seated respect... that they are not passed their used by date... so support services and care that attends to wairua is important as any information...

The second theme evolving from discussions about improvements within service provision was the delivery of appropriate resources to empower whānau and support Māori values. The provision of resources emphasised additional support for whānau, enabling them to keep their loved one at home in a safe environment, beyond the pressures of financial restraints. The following response from Pania summarised this theme:

Being able to keep our kaumātua at home is first and foremost... in an environment that is safe for them... one way of providing appropriate service is going back to papa kāinga... so that is going back to having our

people live together... but also being able to have the clinical expertise to support their health and wellness needs... the other concept is around having kai āwhina, culturally appropriate staff, and staff giving respite care... you know giving the whānau a break, taking care of the kaumātua in a culturally appropriate setting... I think that is the key... then I think that education and awareness for our whānau... so running some practical training around caring for our kaumātua... I think that hands on training and support for the whānau... appropriate resourcing... whānau have still got to eat, they have still got to live, they have still got to care for their kids, so I think they should be paid...

Expanding upon this theme resulted in the promotion of several premises. The first sub-category within the theme of providing appropriate resources was the consistent contention of developing a Māori workforce within the mental health sector. Hinimona illustrated the importance of Māori working with Māori, as follows:

Start with a work force who can support whānau with dementia... if you can get a Māori health work force developed and in process ... I think that will definitely benefit Māori-dom non stop... but also I think that there is just something about when you are a Māori, I think there is something about having another Māori to connect to when you are sick... when you are feeling unwell, or feeling a bit vulnerable... it is just easier...

The second sub-category was that of education and practical support in a way that respects the caregiver and their skills. The participants believed that education would encourage whānau members to understand their elder's behaviour and make the appropriate adjustments. The following responses illustrated this point:

Roimata

A lot of the cares for someone with dementia need to be taught, and they need to be taught in an environment that doesn't make people feel whakamā... supporting them in a way that is strength based and uplifting...

Tui

I had to educate myself because I had no idea and it was good to say 'oh when she is being repetitive... it is a sickness... she is not just doing that to brass me off...'... yeah but understanding it, I think is powerful...

Hinimona

Dementia is.... look you are going to have to have 24 7 care or supervision... they are not going to be allowed to stay home and cook tea because they might cook the house... you know just things like that, just practical things that families can understand... 'oh gosh we can't get Mum to look after the kids all the time now'... just practical things that make it easier for families...

Riana

In the old days you didn't have showers... all they had was bath tubs and coppers... body washing... and the hose... they revert back to the old days of what they grew up with... you have to understand and cater for that persons needs... the shower was a threat... so get an adjustable shower head and take it off the wall, turn it on... then it is like a tap... then they will know what to do...

The third sub-category was providing caregivers more support and showing concern for their welfare, as well as the individual affected by dementia. Caregivers have an essential role in keeping an elder at home and if their personal wellbeing is not maintained, care will not be provided.

Riana

They only allocate 28 days a year carers support.... that is no good for someone working full time looking after someone like this.... it is terrible... I mean carers, Pākehā Māori katoa, are the biggest... I mean take them out of the equation and you are buggered... Sleep deprivation is a big thing too, with our people... and then Māori people get hōhā... they get hōhā and are quick to fire off the wick... they are tired... this is what happens the well one will go before the sick one... because you are mentally stressed...

Tui

The Māori culture is to focus on Mum (indicating a respect for the elderly)... more so than the person looking after her... I feel isolated... nobody rings up to see how I am...

The fourth sub-category was the provision of information about services that caregivers are entitled to, as early as possible. The early distribution of services available to whānau was identified as an essential element to caregivers' wellbeing. The following two responses illustrated this point:

Tui

I have only just got onto the health board that provide 30 days care... I only found that out last year... Mum was already in the system for seven years and I only found out a year ago... I was a bit brassed off because it took me so much tears to find that support...

Wiremu

How the families are supported and empowered to maximise wellbeing... for the person and for themselves collectively...

The third central theme was effective communication and listening skills of those professionals working in the dementia field. This theme emphasised fine-tuning the delivery of services and methods of approach. Participants' responses indicated that the following points are imperative for engagement within services: respect for both the affected individual and their whānau; not having information dismissed without gaining a thorough understanding of the person and their situation; feeling listened to not spoken at; and being included in the whole process.

Hinimona

It is about communication... it is not about all of these symptoms...

Riana

I think just being listened to... people telling them what to do instead of asking them... being asked and guided... the carers don't get listened too... 'I get really pissed off, they come in here to talk to Mum, Mum doesn't understand a word they are saying, straight over the top, ask me, they

don't even ask me for my view, and yet Mum has got Alzheimer's'... being listened to that is a major barrier...

Roimata

Right from the outset they don't do the whānau ora thing... they don't talk to the family as a whole that is involved in this... what needs to happen to help this family to meet their needs... well this person is still well enough to be involved in the arrangement of care... what do we need to do to help the family through the stages... who is going to be the contact person... what is their responsibility... that should be happening at the get go...

A fourth strong theme emerged where the majority of participants indicated that whānau need an advocate to work with the family and co-ordinate services, with the aim of reducing stress and ensuring a smooth flow between services. This premise related to the previous theme of rapport, being known to the whānau and not having to deal with multiple professionals. The importance and value of providing an advocate was illustrated in the following responses:

Hinimona

You have got to have somebody with a whānau member who is open to listening... because quite often they will hear things that they don't want to... and that will end the listening phase...

Roimata

Being assigned a navigator... being assigned someone to work with the whole family to look at what needs to happen, and for that navigator to make things happen for that family... because I think families get worn down by the bureaucracy... they have enough to do... so having a navigator assigned to look at their total needs... it might be the needs are about the person with dementia, or it might be the needs are about the family who is looking after or taking care of them...

Riana

Show them in the direction of where to go and who to access... and knowing that they are not having to deal with another person, and another person, and another person... they don't have to repeat their story over and over again... the Māori that have accessed the Alzheimer's, our

mental health services of older people... I have had to open the door for them... we have a Māori social worker there, but our people won't go...

The fifth theme emerging from responses was that the inclusion of complementary forms of support, such as karakia and rongoā, should be acknowledged and included within treatment and support services. These practices were specified as essential elements for the wellbeing of Māori elders and nurturing mana.

Roimata

They don't even talk about things like rongoā...

Riana

For us as Māori we believe in karakia... we will have our own Māori doctors and our own rongoā... the Māori rongoā is the same as the Pākehā one, only it is in its neat natural form... When I did karakia with her... it calmed her down... see very spiritual for our Māori people... even if they are dementia Alzheimer's or whatever... the minute you do karakia it is like a calming... Because for us as Māori, is that we look at life from the spiritual side of things...

Aroha

Prayer, that is a big one... so long as they have their karakia...

Rangi

I said just show him that karakia can work... and give him the belief that yes it is working you know, and he might not be like he is...

The final theme within this section was the appeal for the establishment of additional culturally-based care facilities, such as reliable kaumātua programmes. The emphasis upon culturally appropriate programmes was the importance of maintaining skills and being involved in an environment that provided and nurtured cultural practices. The theme was believed to be a central factor for Māori elders and caregivers, as illustrated below:

Tui

Yeah Mum goes there with them and she likes to dance... she loves to dance... they are aware of her forgetfulness and that is good... they do all the craft things... because Mum used to weave... do tāniko, make puipui

and all that... But because it is a Māori thing (indicating the kaumātua programme) if there is a funeral they are gone... they can change it when they want to... there is no accountability for them really... then I can't really plan...

Pania

Kaumātua still have skills and abilities... and what happens when they are being diagnosed, they tend to go downhill because everyone thinks oh well they have dementia, so they don't know what is going on... I know for one of our kaumātua that is in a rest home at the moment, and we bring him out on a Friday... you sit him at the piano and he plays that piano like he had never ever left it... and what happens when they go into the homes is that they lose those abilities... that is what keeps them alive... you know they are engaging and they are interacting and they are hearing things that are familiar to them... the waiata and the actions and all of that...

During the interview process the suggestion of a kaupapa Māori rest home was raised on numerous occasions. The participants were then questioned whether they believed a kaupapa Māori rest home facility would be appropriate for Māori elders affected by dementia. The central theme was an enthusiastic response, and majority support, as illustrated:

Rangi

If it is run properly and if they are educated and if they have the depth like a lot of these people have (indicating consultants at the hospital)... I think a facility like that would be awesome... you know something to really look forward to.... because your traditions and customs would always be upheld... I reckon it would be so awesome if we could see Māori consultants...

Hinimona

It is interesting because the trust has already indicated that they want to have a kaumātua rest home... the kaumātua have already indicated that they want a kaupapa Māori rest home... I think that would be great... make it a bit about well-being...

Roimata

I do think that if you have the right nous it would just be a perfect solution... because there is a way of interacting and a way of doing and a way of being...

Riana

Well it is working here... and that is only respite... but yes definitely...

However there were some reservations about the ability of such an organisation to provide a professional operation, and a care-based facility under the proviso of wellbeing, beyond the realms of financial gain. This point is emphasised within the following responses:

Rangi

If Māori run it they got to be on to it, I mean on to it... they have got to have the brains like the consultants... they have got to have done their training...

Hinimona

But for me there has to be a real difference between investment in terms of returns, and investments in terms of influencing cultural behaviours within the organisation... the level of good will they have, and the commitment to the cause... the kaupapa, and you have just got to be connected... you just can't be there for a thing job because it shows...

Roimata

Just to assume that by Māori for Māori will heal it or solve it is pretty naive... so you have got to be really mindful of the quality of the staff and the training of the staff... and their knowledge and understanding of what it is to provide a kaupapa Māori service... the decider is that you have got to have someone who knows what they are doing...

Riana

It is not that easy to put a brown face to something... But it is up to the whānau, hapū and iwi I believe... it shouldn't be something that is driven by Pākehā...

Common Themes Emerging Across the Chapter

In conjunction with Chapter Four, and supported by the numerical component, a number of influential themes have emerged across Chapter Five. The participants presented strong arguments for the provision of appropriate support services enabling Māori to care for their elders within the home environment, in accordance with traditional values. The medical diagnosis of dementia does not infer a holistic perspective of health, and as a result reinforces long-established apprehensions about mental health services. In addition, participants reported that services could improve the provision of support with measures such as: staff being patient and building rapport with clients, utilising the values of whanaungatanga and whakapapa, providing whānau with an advocate, providing practical information in a respectful manner, and effective networking between organisations.

The section which explored key issues for Māori affected by dementia emphasised the role of education, both of mental health professionals and Māori communities. Education of mental health professionals placed importance upon cultural protocols, appropriate language and explanation, and the appropriate distribution of knowledge about dementia. Education required for Māori communities centred upon understanding dementia and the associated symptoms, and the promotion of a greater acceptance towards mental illness. The advantages of promoting education were presented as the reduction of the stigma associated with mental illness and institutionalisation.

The central theme within the section exploring possible improvements was the acknowledgement that the current biomedical model could be fine-tuned, or positively extended, to permit more effective interaction with Māori elders. The main premise was that the inclusion of a holistic approach, affirming the central importance of Māori culture and identity in a holistic approach, would enhance the care of Māori elders. An integral part of the suggested improvements was the inclusion of rongoā and karakia, along with the continuing development of a Māori mental health workforce. It was also recognised that younger generations and shifting values may impact the care of Māori elders in the future.

Chapter Six

Discussion

Ahakoā iti, he pounamu

(The thought or intention gives value to even a small gift)

This chapter discusses the most important findings from the research, how the findings relate to the literature reviewed in Chapter Two, and what the implications of the findings are for Māori affected by dementia, and mental health organisations providing services to Māori elders with dementia. This will be followed by an assessment of the limitations of this research project, suggestions for future research and recommendations for service providers.

The aims of this research project were to describe:

- Māori health care providers understandings of dementia
- Traditional versus contemporary understandings of dementia
- How cultural beliefs affect experience
- How Māori cope with dementia
- Key issues relevant to Māori people with dementia
- How services can be improved to meet the needs of aged Māori

The aims were explored within individual interviews with Māori health care workers and supported with information gathered from questionnaires. All nine participants were found to have a thorough understanding of dementia, its symptoms and the progressive nature of deterioration. At this point it is important to note that the findings cannot be generalised to all Māori and are representative of nine Māori health workers. This chapter has been divided into five sections in accordance with the presentation of the findings in Chapters Four and Five.

Māori Concepts of Dementia

The first aim of this research project was to explore Māori health workers perceptions of dementia. The responses produced a dominant theme founded on spirituality. This was accompanied by behaviours being understood within the frame of normal ageing. A further finding was that explanation is often sought within the environment or the affected individual's personality. The final comments relate to the impact of the Western biomedical model upon Māori worldviews.

Spiritual Influences

The findings illustrated that Māori commonly conceptualise dementia from a spiritual foundation, where superstition and connections with ancestors prevail. This worldview appears to arise from traditional understandings and has retained strength in contemporary society. These understandings refer to mental illness as a possible curse or a blessing from the gods. The reviewed literature indicated that culture and custom directly impact personal interpretation of illness (McNeill et al., 2010). Māori often appreciate wellness from a holistic perspective, where spirituality and interconnectedness are fundamental components (McNeill et al., 2010). Spiritual models sanction illness to be understood as a supernormal phenomenon. This perspective provides value to unusual behaviours, as the individual is believed to be in contact with the afterlife. Models based upon spirituality often lead to individuals affected by mental illness being treasured or viewed as gifted (Henderson & Henderson, 2002; Kingi & Bray, 2000). This perspective directly contrasts with the Western biomedical viewpoint defining unusual behaviours such as those exhibited within dementia as a psychological disturbance (Hinton, et al., 2005).

A spiritual appreciation of the symptoms associated with dementia was also emphasised within the findings framing the importance of karakia and rongoā. The holistic worldview of Māori places importance upon karakia and traditional healing, where these practices are emphasised within the restoration of wellbeing (Perkins, 2006). Martin (2009) reported that karakia has a calming influence upon Māori elders affected by dementia, and this was supported within participant

responses. The findings supported the literature accentuating the important role of karakia and rongoā within treatment sought for elders impacted by the behaviours associated with a diagnosis of dementia.

However, spiritual models may create mystique around unusual behaviours, resulting in fear of the individual, along with apprehension about the source of the illness or the possibility of the behaviours being contagious. This finding appears to contradict the literature reviewed. The apprehension may result from fears surrounding curses and the unknown, or the stigma attached to understandings based upon the biomedical model. Research indicated that employing models based upon stigmatisation reduces help seeking behaviours and quality of life for both the affected individual and their caregivers (Connor et al., 2010).

The lack of awareness about dementia and its associated symptoms may be addressed through community based education programmes with an emphasis upon positive relationships, effective interaction and cultural understanding (Mahoney et al., 2005; Pollitt, 1997). Within this process it would be valuable to improve the existing biomedical model through the inclusion of holistic and cultural belief patterns. Hinton and colleagues (2005) stated:

By placing dementia in socio-cultural context, clinicians will be better positioned to conduct a cultural formulation of cases, because culture is not a thing; it is a process by which ordinary activities acquire emotional and moral meaning. Attention to these meanings, conveyed in family narratives, provides opportunities for improved and more culturally appropriate clinical care (p. 1409).

The objectives of planning for the predicted ageing within international populations is emphasised by Kurz and Lautenschlager (2010): “to improve knowledge about dementia, provide better education and training for professionals, ensure that people with dementia are properly diagnosed, and develop a range of services for people with dementia and their carers” (p. 40).

Normal Ageing

The findings emphasised that dementia is largely an unknown illness within the Māori worldview. Consequently, the behaviours associated with a diagnosis of dementia are more likely to be understood as part of the normal ageing process. Literature specified that understanding behaviours typically correlated with a diagnosis of dementia as part of the ageing process is a common phenomenon within ethnic minorities (Gray et al., 2009). The findings implied that a lack of knowledge about symptoms related to dementia creates fear, especially about the possibility of the illness being contagious. This directly contrasts with the model of normal ageing where research reports a reduction in fear, stigma and caregiver burden when referring to behaviours associated with dementia as simply part of old age (Ikels, 2002).

A possible method of addressing the normalisation of understanding dementia through a normal ageing lens is education and terminology. Education was addressed in the immediately preceding section. Another method of reducing stigma and encouraging interaction with ethnic minorities is to utilise culturally appropriate terminology. Kurz and Lautenschlager (2010) highlighted this:

An interesting example of relabeling is provided by a national project in Japan. The word for dementia “chihoushou” which carries the deprecatory meaning of “stupidity” or “simple-mindedness,” was replaced by the more technical term “ninchishou” which stands for disease of knowledge and understanding” This apparently simple change of words and characters has led to more positive ways of responding to the changes of brain aging (p. 40).

This phenomenon was reflected in participant findings which suggested that the use of a te reo Māori term would be inclusive of Māori worldviews, connect with the group and encourage engagement with service providers.

Environment and Personality

The findings indicated that when the symptoms characteristics of dementia are understood outside the frame of illness, whānau search for meaning within the environment, the individual’s personality, or the grief process. The literature

suggested that Māori comprehend wellness from a holistic and interconnected approach, inclusive of the environment and spiritual beliefs (Kingi & Bray, 2000; McNeill et al., 2010). As a consequence, whānau search for meaning within their current situation and worldview (Tapsell, 2007).

Participants' comments indicated that Māori may try to mask or hide their elder's symptoms, especially when the illness progresses slowly. The literature implied that family members are hidden when models of stigmatisation and morality are employed (Liu et al., 2005). However the findings indicated that, in general, Māori elders are included and valued members of the whānau. The literature also stated that stigmatisation may result from diagnosis of a mental disorder (Moeke-Maxwell et al., 2008). The masking of symptoms within this research most likely arose from stigmatisation resulting from the shame of having a mental illness, in comparison to devaluing whānau elders.

The findings suggested that the search for meaning may lead to negative interpretations of an elder's behaviour. For example, the affected individual is construed as deliberately behaving in a manner to annoy or frustrate their caregiver. Consequently, the participants emphasised the risks associated with interpreting challenging behaviour in this manner, as potential abuse and/or neglect. Within the literature, stigmatisation and the subsequent masking of behaviour were identified as possible sources of neglect and abuse of the affected individual (Liu et al., 2008). The risk of elder abuse was found by the Family Commission (2008) to increase in conjunction with the deteriorating behaviours associated with dementia. Interpretations based upon negative models impact the family or caregivers ability to cope with distressing and unusual behaviours (Connor et al., 2010).

Within the findings an additional interpretation was implied, where the deterioration of behaviour was understood as an intensification of personality traits, or behaviours associated with specific whakapapa, such as eccentricity. This was extended to include the association between deterioration in behaviour and significant personal loss, such as grief and the resulting withdrawal or depression. These factors were not represented within the literature discussed in

Chapter Two. However, the notion corresponded with Tapsell's (2007) research which indicated that Māori search for meaning within a cultural and family context.

The Influence of the Biomedical Model

Participants believed that Western understandings of dementia, based on the biomedical model, impact negatively upon Māori worldviews of wellness, and subsequently invalidate alternative viewpoints. Specifically, the biomedical model was found to exclude the holistic approach employed by many Māori to understand people within their totality, values and Māori constructs of wellbeing. The findings supported the literature which emphasised that the individualistic approach of the Western biomedical model negatively impacts the care of Māori elders (Durie, 2001). Furthermore, Martin (2009) reported that the exclusion of holistic and interconnected approaches negatively impacts the wellbeing of Māori elders. The biomedical model has been identified as one of the most likely sources of discrimination within mental health services. Defining normal and abnormal behaviour may exclude cultural understandings and result in stigmatisation and marginalisation (Moeke-Maxwell et al., 2008).

In conjunction with the biomedical model, framing dementia from a cultural perspective was believed to promote engagement with mental health and support services. The literature presented an argument that culturally responsive services require medical professionals to embrace and understand Māori culture and worldviews (Tapsell, 2007). The findings made reference to the value of te reo Māori terminology to define dementia and the employment of cultural facilitators within the diagnostic process, as viable methods of improving interactions between Māori and health professionals.

The findings also indicated that diagnosis under the biomedical model may diminish the mana of Māori elders, by reducing the individual to a set of symptoms. This appeared to contrast with the status and value placed on Māori elders. The literature indicated that the Māori worldview upholds the mana of elders despite deterioration in health or behaviour. In addition, memory is retained collectively by whānau and hapū, thus the elder retains value and prestige

(Tapsell, 2007). In comparison, diagnosis of a mental illness frequently leads to segregation and stigmatisation. Shame surrounding mental illness negatively impacts inclusion, help seeking, and quality of life (Moeke-Maxwell et al., 2008). Therefore it is important to acknowledge what a cultural perspective might contribute to the biomedical model.

Along with the suggested improvements mentioned above, the findings also emphasised the positive changes that have been made within policy and approaches of mental health professions over recent years. This notion was also supported by comments that the biomedical model can be fine-tuned to include holistic and cultural understandings to engage Māori within services more effectively in the future. Furthermore, diagnosis was found to provide relief, understanding and an opportunity to plan for the future for some whānau. The literature supported these findings where diagnosis is internationally encouraged for best outcomes for all concerned. Diagnosis leads to the access of information, the provision of support, ending uncertainty, treatment, and future planning (Iliffe et al., 2009; Mahoney, 2005).

How Whānau Perceive Dementia and the Impact of these Understandings

Following on from Māori health workers' perceptions of dementia, the second aim of this thesis was to understand the impact of perceiving illness from a cultural viewpoint.

Undetected

The findings clearly indicated that dementia frequently goes undetected within Māori elders affected by behaviours characteristic of dementia. The perception was that dementia is undetected due to misconceptions and misunderstandings of the behaviours associated with a diagnosis of dementia. This finding supported the literature that the prevalence rates of dementia in Māori are unrepresentative of

the population (Alzheimers, 2008), similar to other ethnic minorities (Fontaine et al., 2007; Griffith-Pierce et al., 2008).

This premise also supports the notion that there is a need for culturally sensitive education regarding dementia and the associated symptoms.

Māori Values

The findings indicated that Māori have a sense of obligation to care for their elderly under the principles of manaakitanga and whanaungatanga. This sense of duty arises as a reciprocal arrangement where parents care for their young and in return will receive care in their older years. Manaakitanga was presented within participants' responses as an ingrained value that remains important within today's society. These values were emphasised in conjunction with the deep seated respect that Māori elders are given. Māori elders are assigned with authority and are treasured as vessels of knowledge. These findings supported the literature which indicated that within the Māori worldview old age is ascribed with value and respect (Durie, 1999). This respect arises from the assurance that mātauranga Māori is reproduced, as elders are ascribed leadership roles and obligations. Traditionally the responsibilities of old age are connected with the principle of manaakitanga, where elders are provided with care in exchange for tribal responsibilities (Durie et al., 1997).

As a result of values such as manaakitanga, whanaungatanga and treasuring older members of whānau and iwi, the findings indicated that elders affected by dementia are included within wider whānau events. The literature supported the notion that Māori elders are less likely to live in rest home facilities, as care is predominantly provided by whānau (Kepa, 2006), and that elders are respected within a caring environment (Durie, 2001). The literature failed to specifically identify the inclusion of those who are affected by deteriorating states of mental health or behaviour. However, the holistic approach was identified as a basis for maintaining value towards elders based upon acceptance, affectionate care, respect, and love (Martin, 2009).

The findings also acknowledged that traditional expectations may not be realistic in a changing society where whānau are geographically spread out, and financial demands mean that less people are able to stay home and care for their elderly. Consequently, it was suggested that organisations and social supports may become a form of whānau for some elders. The literature implied that weakening links with traditional values negatively impact support and social networks. Urbanisation has been linked with isolation from iwi affiliations and cultural values. In addition, increased financial pressures of modern society combined with the ageing population may lead to an increased vulnerability of elder abuse, as whānau are unable to meet cultural values emphasising reciprocal care arrangements (Durie, 1999; Families Commission, 2008; Kumar & Oakley Browne, 2008).

Furthermore, the findings identified that cultural values are dependent upon influences within personal upbringing and experiences with cultural practices. The literature implied that society may become more diverse in the future where traditional values may be displaced by children growing up in culturally diverse homes and society. This may lead to weakened connections with marae and iwi (Durie, 1999; Martin, 2009). However the literature did not acknowledge the direct implications of a changing society or the increase in kaupapa Māori organisations and reminiscence.

Whakamā and Shame

The findings revealed contradicting information concerning whakamā and whether it evolved from a whānau being affected by dementia. However, it must be acknowledged that shame is a common response to mental illness, and dementia falls within this general umbrella. Shame may be dependent upon the following factors: the individual, the whānau, the iwi, interpretations of behaviours, and the resources available. According to the literature Māori may perceive dementia as a source of whakamā, especially if it coincides with a belief that behaviour is founded upon a transgression of tapu (Barnett & Barnes, 2010). Mental illness is commonly associated with whakamā or shame for Māori. Shame generally emphasises a fear that other people will judge and possibly reject the individual or their whānau (Barnett & Barnes, 2010; Moeke-Maxwell et al.,

2008). In contrast, traditional values such as manaakitanga, whanaungatanga and a holistic approach to wellness may be protective factors where elders are cared for and supported within a wider community framework (Heperi, 1996; Martin, 2009).

Seeking of Assistance

The findings suggested that belief patterns directly impact the seeking of assistance. For example, if a whānau felt shame about their loved one suffering from a mental illness they may be more resistant to requesting assistance. As a result behaviours are often more advanced for the Māori elder when assistance is sought. The literature indicated that Māori are most likely to seek assistance from whānau and hapū, within the frame of whanaungatanga, in contrast to medical settings (Heperi, 1996; Mental Health Commission, 2004). In addition, spiritual beliefs may guide the individual or whānau to more traditional forms of healing such as karakia or rongoā. The combination of mainstream services and cultural values, including aroha and manaakitanga, were emphasised in the literature to be of significance to the wellness of Māori elders (Kepa, 2006; Martin, 2009). However, theoretical models outlined in the literature review (Chapter Two) illustrated by Kepa (2006) and Manna (2003) are not supported by practical experience within research or literature to date, in relation to the care of Māori elders.

The findings illustrated that misunderstanding, fear and stigma may be factors which negatively impact the seeking of assistance, and the subsequent exclusion from wider whānau events. Exclusion and isolation were identified within the literature as potential risk factors for abuse or neglect. The Families Commission (2008) identified common issues underlying abuse or neglect of elders as caregiver burden and inadequate support, both of which would occur if an elder was excluded from whānau events and assistance was not sought.

How Māori Cope with Dementia

Appropriate Support

The findings clearly indicated a lack of appropriate support for Māori elders and their whānau affected by dementia. The first point within these discussions was that whānau struggle to cope with behaviours of their elder on a daily basis. Participants' responses suggested that a lack of knowledge about dementia or its symptoms resulted in caregivers struggling to meet the needs of an elder with a deteriorating state of mental health. The lack of knowledge directly impacts help seeking behaviour and initiating support services. The literature indicated that barriers for older people accessing appropriate support services is negatively impacted by shame, lack of knowledge about the availability of support services, level of health education, and cultural understandings of deteriorating states of health (Hirini et al., 1999; Kiata & Kerse, 2005). Help-seeking behaviours are directly impacted by interpretations of health (Kumar & Oakley Browne, 2008).

The findings also indicated that when caregivers sought assistance, there is a lack of appropriate support for Māori elders and their whānau. Dyall and colleagues (1999) reported that the mental health needs of Māori were not being met. Schoen and Doty (2004) reported that Māori adults were nearly twice as likely to struggle to attain necessary health care within their locality, as non-Māori. The article also reported that Māori are more likely to go without health care due to financial restrictions. The literature suggested that engaging Māori within mental services required the inclusion of Māori worldviews, values and holistic understandings of wellness (Dyall et al., 1999; Waldon, 2004). Within this research project it appeared that these requirements are yet to be met, however recent national and local policies have been adopted to address the issues.

In addition, the findings emphasised that kaupapa Māori health providers in the Waikato and Bay of Plenty do not specialise or cater for those affected by dementia, although the organisations clearly meet the health needs of Māori in other areas. As a consequence of the reported lack of appropriate resources, it would be reasonable to suspect that whānau struggle to sustain or manage the care required for an elder who has dementia.

Mistrust of Services

The findings indicated that a mistrust or fear persists in contemporary society despite some advances in the provision of cultural competence within mental health services. Consequently, it was suggested that traditional values dominate contemporary belief patterns and a resistance to interact with mainstream health organisations remains. The fear acknowledged in the findings was also associated with misunderstanding the term dementia and the associated behaviours. The literature implied that ethnic minorities face multiple inequalities and jeopardy within mental health services. Heperi (1996) found that Māori are more likely to seek assistance from whānau and friends due to ethnocentric philosophies within mental health settings. The consequence of compounding obstacles for ethnic minorities is disempowerment and dissociation from service providers (Forbat, 2003; Heperi, 1996). However, some of the participants suggested that whānau should challenge their fears and seek assistance, as there are organisations providing valuable services within the community. Local organisations (i.e., near or within the Waikato region of New Zealand) suggested by one participant were Te Whare Aroha, the Crisis Assessment Team, Māori counsellors, and Graceland's Health Care.

Changing World

The findings acknowledged that whānau dynamics and the impact of a changing society influence the capacity of families to manage the daily care required for an elder affected by dementia. The findings also indicated that younger generations or rangatahi may have different values than older generations as a result of urbanisation and parents needing to work for financial survival. Therefore younger generations may not place importance upon the traditional values of manaakitanga and whanaungatanga as the population ages. Colonisation and urbanisation have been acknowledged in the literature as factors impacting contemporary understandings of mental health and traditional values, such as manaakitanga (Barnet & Barnes, 2010).

Rest Homes

The findings demonstrated that families reach a breaking point when behaviours become difficult and unmanageable within the home environment. The participants reported that a combination of insufficient resources and unmanageable behaviours has resulted with an increasing trend of placing Māori elders in rest homes, within the last 5-10 years. This trend was expected to increase as a result of decreased expectation upon younger generations, as indicated within the participants' requests of their children. For example, participants recognise the changing demands of society and request to be placed in a rest home if they are impacted by a mental illness, such as dementia. The literature specified that Māori elders do not present in mental health facilities at the same rates as other New Zealanders, and that 99% of Māori with a disability reside in whānau homes (Alzheimers, 2008; New Zealand Statistics, 2010b). Subsequent to mistrust and delayed help seeking behaviour Māori are more likely to present in mental health facilities with more severe impairments (Statistics New Zealand, 2010b). The literature implied an increasing prevalence rate of Māori elders with dementia and that weakening traditional values may strain the ability of whānau to provide care in the future. However the increasing trend of Māori elders being placed in rest home care is evident within the findings.

There was a clear demonstration of guilt when an elder was placed in rest home care within the findings. The guilt was related to an internal conflict for whānau members making the decision to place an elder in full time care, resulting from a failure to fulfil duties of traditional values due to the changing environment and increased pressures within society. Although the literature did not specifically identify guilt, the concept of whakamā is broad and covers guilt in this context. The feelings of guilt result from a position or concept of inadequacy, and guilt for wrong doing. Health professionals need to be aware of this concept as whānau may withdraw or become depressed as a result of placing an elder in care.

The Role of Iwi and Hapū

The findings illustrated that hapū and iwi could play a significant role in the provision of services for Māori elders. The suggested role of iwi was one of caring and supporting their own people, such as the provision of iwi health

services, under a kaupapa Māori organisation. Martin (2009) identified that Māori elders affected by dementia engaged with services based upon Māori culture and tikanga.

Key Issues Relevant to Māori People with Dementia

Fear of Health and Mental Health Organisations

The findings illustrated a fear or reluctance to utilise mental health services. Within older Māori this fear relates to years of institutionalisation, and the knowledge that dementia is situated under the mental health umbrella. In fact, it was suggested that this fear may be associated with the health and disability sector in general, as represented by the reluctance of Māori to seek help from the medical profession. Many Māori have an inclination to delay help-seeking behaviour and often present to medical professionals when symptoms have significantly manifested. The literature acknowledged that Māori understand disability from a holistic perspective connected with the environment, society and spirituality (Kingi & Bray, 2000).

Statistics New Zealand (2010b) reported that a large number of Māori do not receive assistance from specialised mental health services. In conjunction with a cultural worldview and a preference to seek assistance from whānau, it is possible that historical experience has led to negative expectations, mistrust, demoralisation, and apprehension towards medical and mental organisations. Consequently, the underutilisation of mainstream services results in needs being unmet within this age group. When the models of normal ageing and family obligations are combined the elderly person affected by dementia should be cared for within a nurturing and accepting environment, where the needs of the affected individual would be prioritised over those of the caregivers. However, fear of medical institutions is not factored into the literature or the models reviewed. This fear may have a negative impact upon help seeking behaviour and quality of life for the affected individual and their whānau.

Exclusion of Culture

One of the obstacles identified within the findings was the inadequate application of Māori cultural values within mainstream mental health services. Some participants indicated that mainstream organisations are not equipped to practice culturally responsive services appropriate for Māori elders. For example, rest homes were identified as alienating Māori elders from cultural values, which may lead to depression. The protocols and values identified by participants were straightforward practices and knowledge, such as: heads are tapu, food is not to be placed on the commode, a flannel is not used for heads and bottoms, karakia is an important element of many elders' beliefs, and Māori elders have status within the Māori worldview. The absence of appropriate cultural understandings and tikanga within mainstream services may lead to these facilities being inadvertently offensive or inappropriate towards Māori elders. The exclusion and isolation from whānau, cultural protocols and values may also be detrimental to elder's wellbeing. Kiata & Kerse (2005) identified that the consequence of intercultural care is inappropriate treatment. Extending this finding, Martin (2009) reported that Māori elders express significant concerns and distress when their culture is excluded from care giving practices.

However, the findings also indicated that positive change has occurred within recent years. For example, the implementation of codes of practice, national health and disability standards, cultural safety, and health care plans. These initiatives are all positive amendments to current practice. Continuing the education of mental health professionals utilising current literature may initiate further change, where Māori elders are engaged in mainstream services and are cared for within a respectful environment based upon cultural awareness and knowledge.

Knowledge and Education

The lack of knowledge about dementia, its symptoms and the progressive deterioration means that Māori elders and their whānau often delay the seeking of medical assistance until behaviours become difficult to manage and are significantly advanced. Normalising and accepting behaviours leads to the affected family trying to cope with difficult and deteriorating behaviours in the

home environment without the support of mental health professionals. The literature emphasised that understanding an illness from this perspective leads to delayed help seeking behaviour and increased suffering (Elliot & Di Minno, 2006). It must also be acknowledged that placing positive value on the individual and the interpretation employed, leads to a more constructive encounter for all concerned as the affected individual is respected and loved. The most positive outcome appears to result from a combination of the biomedical model and folk models where assistance is sought but cultural values are maintained (O'Connor et al., 2010). The findings indicated that minor modifications to current practice based upon the biomedical model would result in a greater degree of successful and valuable service provision. The suggested changes were simple and included: placing value on communication, listening carefully, involving the whole family, and providing information in an appropriate manner. Therefore, education of mental health professionals may be imperative to future services being culturally appropriate, and emphasising the wellbeing of Māori elders from a holistic perspective.

The Presentation of Information

One of the biggest barriers identified within the findings was the language difficulties between Māori elders and staff employed with support services. The literature highlighted the lack of te reo Māori within mainstream mental health services as a barrier for Māori elders (Nikora et al., 2004). Language barriers include medical jargon, education about dementia, labelling affected individuals, and cultural understandings of wellness. The divide between Māori and medical professionals will continue to be a considerable barrier if health professionals fail to implement practical cultural skills. However, as noted by one participant Māori are not uneducated, unintelligent or slow. It is about the provision of appropriate and responsive support that is meaningful to the audience.

The findings also indicated that professional practices within diagnosis, treatment and caring for Māori elders require careful explanation. These explanations require an understanding of tapu, noa, and practices that may cause offence. These practices not only cause offence or breach tapu but may initiate depression for the vulnerable elder. The biomedical model is employed within the diagnosis of

Māori elders; unfortunately this may result in labelling and stigmatisation, as alternative worldviews may be discounted. Further to previous discussion, the renaming of dementia employing a term defined by Māori may be an effective method of reducing the stigma and encouraging the seeking of medical assistance. In addition, the inclusion of whānau, personal history, Māori values and identity may provide a supportive, positive and effective outcome for all concerned.

The provision of information in the form of brochures or pamphlets was identified as problematic and inappropriate. It was suggested that Māori prefer to receive information within a personal discussion, face-to-face. The findings indicated that it is about appropriate and respectful use of language, employing Māori worldviews. Utilising the values of whanaungatanga and whakapapa to establish relationships was suggested as an effective means of interacting and engaging whānau. Respecting the value of elders and the importance of a holistic approach was believed to be more important than the provision of knowledge and information.

Disjointed Services and Multiple Providers

The findings accentuated the disconnection between support services as a significant barrier for whānau. Firstly, when organisations do not promote other services it leaves vulnerable individuals unaware of services available. In addition, having numerous organisations involved within support plans creates difficulties in administration and co-ordination, and results with whānau having to explain their situation over and over again. Having too many people involved was identified as a clear barrier for Māori. The literature emphasised factors reducing the likelihood of assistance being sought and included a lack of knowledge about services offered and the constant questioning of multidisciplinary teams or multiple services. In contrast, consultation and collaboration was found to provide a more positive experience, emphasising continuum of care with a Māori worldview (Martin, 2009; Moeke-Maxwell et al., 2008).

Overall, the lack of culturally sensitive and appropriate resources was emphasised as one of the most prominent barriers obstructing whānau from caring for their elder affected by dementia within the home.

Suggested Improvements

The suggested improvements are directly aligned with the barriers mentioned in the preceding section and the research outlined in the literature review. Although change takes time, some of the suggested improvements have been acknowledged for over thirty years within the literature. The Government has policies in place for the ageing population, and Māori elders, however change at the grass roots level appears to be a very slow process.

Respect for Māori Values

The findings emphasised that demonstrating respect for Māori values and the mana of Māori elders was imperative to the effective and appropriate provision of service. The literature identified that Māori elders have prestige and status, where elders are vessels of knowledge (Waldon, 2004). Māori elders are ascribed leadership roles within whānau, hapū and iwi. Future generations are dependent upon their elders to pass on mātauranga Māori, te reo Māori, and tikanga. Subsequent to the reciprocal values, such as manaakitanga and whanaungatanga, Māori elders are expected to be cared for within whānau environments (Durie, 1999).

The findings also indicated that a respect and inclusion of traditional Māori healing, such as rongoā and karakia, would benefit the overall wellbeing of Māori elders. For example, karakia can be used as a method of calming the agitated Māori elder, in contrast to medication. The literature indicated that physical and mental ailments in traditional society were cured by tohunga (Metge, 1976). In addition, hallucinations which may be a symptom of dementia within the biomedical model, may be understood as a spiritual connection with tipuna or the afterlife (Perkins, 2006). Hirini and colleagues (1999) identified the need for mainstream services to acknowledge the importance of informal health care offered by Māori social networks. Consequently, if services within contemporary society embraced Māori values, a holistic perspective of wellness, and complementary forms of treatment, such as employing tohunga, rongoā and karakia, Māori would be more likely to engage.

Provision of Services

The provision of support that would enable whānau to look after their elder at home, within a safe environment, was identified as the most prominent and desired improvement to services. The findings indicated that caregivers also require support and concern from health professionals. The personal wellbeing of the caregiver is essential to the overall wellbeing of the affected individual. It is often a difficult and stressful role that requires support and understanding. Barnett and Barnes (2010), along with Nikora and colleagues (2004), reported that caregivers require more assistance to avoid burnout, and possible abuse of those being cared for. In addition, whānau desired improved communication surrounding availability of services, and practical assistance within the home. The suggested improvements were: that there is a need to increase the cultural competence of non-Māori staff, that medical professionals need to take the time to listen to whānau concerns, and there is a need to increase the number of Māori service providers.

Education

Education about dementia, and practical skills for caregivers, were suggested as important factors in the provision of effective care from whānau. The participants believed that showing respect for the caregiver and their foundation of skills was imperative to the long term care of the Māori elder. Therefore education should empower the caregiver. Practical skills need to be taught, as it is not easy to care for someone with dementia. When considering the behaviours associated with dementia it must be acknowledged that providing care takes patience, and requires an understanding that those affected by dementia often revert back to behaviours of previous time frames. For example, understanding that the elder may have used a long drop toilet, or washed outside earlier on in life, is important. Subsequently, caregivers need to understand why their elder is unable to use the shower or toilet when they previously could. These elements are part of understanding the illness of dementia, and the provision of education within services for whānau. The provision of appropriate information has been identified as a prerequisite of effective service provision in the literature (e.g. Barnet & Barnes, 2010; Nikora et al., 2004).

Appreciating the symptoms of dementia from a Māori cultural perspective and/or normal ageing model rejects diagnosis (Lapsley et al., 2002). Moeke-Maxwell and colleagues (2008) reported that mental health consumers described diagnosis as an unhelpful process towards the implementation of support and assistance. It is possible that the inclusion of cultural values and protocols within the biomedical model and the process of diagnosis, combined with effective networking between service providers, may improve access to support services for mental health consumers.

Māori Workforce Development

The continuing development of a Māori mental health workforce was a priority within the suggested improvements. The findings indicated that having a Māori person care for you, as a Māori, was a valuable method of improving wellbeing and maintaining rapport. Developing the Māori mental health workforce across all professions has been identified as an imperative requirement within Government policy addressing the quality of services provided and overall wellbeing of Māori consumers (Te Rau Matatini, 2006).

Communication

The findings identified effective communication and listening skills of health professionals as essential ingredients to engage Māori within services. These concepts relate directly to building rapport and relationships prior to offering knowledge or advice, and are founded upon the principles of whanaungatanga and whakapapa. These skills include talking to both the affected individual and the whānau caring for the person. Thus, talking to the caregiver requires the inclusion of the whānau, not just one member. These factors were consistent with the components emphasised in research by Goldsbury (2004).

An appropriate method of improving communication and the integration of services was the suggestion of providing whānau with an advocate. The advocate would coordinate services and reduce the need of whānau to repeat their story. Managing bureaucracies and paperwork may reduce the stress of caregivers and assist the affected individual to receive the most appropriate care. This approach

could embrace a holistic perspective based on a Māori worldview. The proposed system could also address the needs of the caregiver and make the advocate responsible for the provision of a total care “package”. Moeke-Maxwell and colleagues (2008) identified that Māori prefer stability within psychological services, and find it difficult to answer the same questions repetitively. In addition, services were found to be viewed more positively when approaches are founded on consultation and collaboration with the affected individual and their whānau.

Kaupapa Māori Facility

The findings illustrated that a culturally-based care facility and rest home may well be an appropriate provision of resources for elderly Māori. Kaupapa Māori facilities foster the Māori culture and assist with the maintenance of previously learnt skills. Keeping active and relating to activities that are familiar nurtures wellbeing for the Māori elder. Kaumātua day care programmes under a kaupapa Māori framework were identified as a successful environment and support service. The suggestion of a kaupapa Māori rest home was supported by participants. In addition, the participants believed that this initiative was to be driven by iwi and hapū, rather than Pākehā organisations. The support for the rest home option was based upon the provision of an environment for Māori elders that respects and nurtures traditions and customs. Participants reported that a holistic approach would meet the needs and wellbeing of both the Māori elder and their whānau. Martin (2009) distinguished that Māori elders impacted by dementia find pleasure and happiness from social engagements within facilities based upon kaupapa Māori service. However, within the Waikato and Bay of Plenty region there appears to be a shortage of specialist services offered to Māori elders and their whānau affected by dementia. There is an obvious need for permanent and fulltime day care and live in facilities for Māori elders in these regions.

Limitations of the Study

There were a number of limitations to this research project. Firstly, Māori are a diverse people, both within and between iwi. As a consequence of the small and localised sample size, the results cannot be generalised to the wider population of Māori. Although the sample size was small, many of the factors raised in the current findings supported previous literature which suggested that many Māori value their culture, spirituality, and a holistic perspective of wellness. The collaboration with previous findings suggested that the current research outcomes may be indicative of experiences held by other Māori mental health consumers, and their whānau. However, as emphasised in the literature review, research is required to answer specific questions relating to Māori elders in light of the ageing population. Without further research, service providers may struggle to identify the needs of Māori elders or offer responsive services, resulting in offensive and inappropriate outcomes.

The second limitation was the possibility of cultural barriers between the researcher and the participants. Due to the sensitivity and importance of Māori knowledge, some participants may have withheld information as the researcher is of Pākehā descent, and the awareness that some Māori may have a general mistrust of Western researchers (Smith, 1999). The researcher's descent may also have impacted the recruiting of participants within the initial recruitment process. At this point it is important to acknowledge that Māori prefer face-to-face contact in comparison to the distribution of information sheets. However, this was also found difficult as arranging meetings with mental health professionals within kaupapa Māori organisations was complicated by extremely busy work schedules. Utilising personal connections and snowballing techniques were found to be the most effective method of recruiting participants. Furthermore, the researcher took all precautions and implemented all resources available in the aim of eliminating possible barriers within research interviews.

Suggestions for Future Research

The findings of this current research project, investigating the possibility of a Māori cultural understanding of dementia, could be enhanced by future research endeavouring to strengthen or expand the existing results. Suggestions are made as follows:

- Explore changing values towards elders across the generations of Māori
- Expand the participant pool to include mental health workers, caregivers, Māori elders, and those working closely with Māori elders
- Research focusing on effective methods of engaging Māori elders within mainstream mental health services
- An investigation of the efficiency of traditional forms of healing for Māori elders affected by deteriorations within mental health
- Modifying the current research to include a wider geographical region to explore if the understandings and concerns found in this research project are consistent with other regions
- A thorough evaluation of services offered to Māori elders affected by dementia, as the findings indicated that there is an insufficient range of services within the Waikato and Bay of Plenty for Māori affected by dementia
- An evaluation of Alzheimers New Zealand, and how this organisation could become more actively involved with Māori elders and their whānau affected by dementia
- An investigation into the differences or similarities between traditional and contemporary knowledge bases about the mental health of Māori elders
- A more thorough investigation into contemporary values held by Māori elders.

Implications of the Research

It is evident from this research project that there is a clear need to investigate the deterioration of mental health within Māori elders, especially in light of the

ageing population. Hopefully this thesis will operate as a motivation and inspiration for future research. Additional large-scale investigations will allow the trustworthiness of these findings to be tested.

A further implication of this project is that the biomedical model, in its current format, is not applicable to best outcomes for all people. The embracement of alternative and equally valid models of health may positively impact outcomes and the provision of service for Māori elders. This may be achieved with minor modifications to current practice based upon the biomedical model in mental health settings through the provision and effective implementation of education and knowledge about Māori cultural values and protocols.

Recommendations

There is evidence to suggest that an improvement in the current delivery of services for Māori elders affected by dementia is required. It is recommended that mental health agencies catering for older people consider the following factors as essential elements in the provision of services aimed at meeting the mental health needs of older Māori:

- Māori cultural frames of health and wellness
- Cultural responsiveness
- Sensitivity to cultural values and practices
- The provision of information in a format that best meets the needs of clients
- Respite care
- Appropriate day care programmes
- Support for caregivers and whānau
- Include whānau within all stages of assessment and treatment
- Provide advocates to liaise with whānau and government departments
- Education about conditions of the elderly and practical skills

Within these recommendations is the suggestion that mainstream mental health services address inappropriate interactions between mental health professionals and Māori elders, with the aim of establishing culturally responsive services. Implementing change requires the inclusion of alternative methods of healing, such as rongoā and karakia.

One of the most important suggestions made by participants was the requirement for caregivers and whānau to be provided with support that would enable Māori elders to remain within their whānau homes. In addition, Māori require culturally appropriate live in facilities which may be provided by iwi or national government. The government policy designed to implement an increase in the number of Māori staff within mental health services should be embraced by all services and education providers.

In addition, key mental health workers within New Zealand should meet and share information relevant to the services provided to Māori elders in the aim of improving the engagement of Māori elders and their whānau within such services.

A further suggestion indicated within the findings was to remove dementia from mental health services and place it under the umbrella of general health. Participants suggested this may have the advantage of removing stigma from mental health and embracing the importance and prestige held by Māori elders. This may also enable Māori elders to be cared within a palliative care model within future provisions of service.

Conclusion

This research project set out to gather information pertaining to Māori health workers' perceptions of dementia in the Waikato and Bay of Plenty region. This investigation has provided the groundwork from which future research can develop. Implementing the recommendations may result in an improved quality of service provided for Māori elders and their whānau.

The fundamental findings from this research project suggested that Māori appreciate dementia from a holistic perspective, where spiritual understandings are imperative, and that the mental health needs of older Māori are not being adequately addressed within mainstream services at this time. In conjunction with the literature, the findings indicated that Māori require a holistic approach based upon Māori worldviews in order to achieve a maximum degree of wellness. Responsive care must therefore acknowledge and appreciate Māori values and associated cultural needs. Models such as those designed by Kepa (2006) and Manna (2003) are valuable sources of knowledge and information for service providers.

The reviewed literature recommended that cultural values be employed within mainstream services. Therefore these findings strengthened the knowledge that the inclusion of appropriate cultural values and protocols within practice based upon the biomedical model would be a valuable method of engaging Māori elders and maintaining their wellbeing in a caring environment.

Concluding Whakataukī

He manako te koura i kore ai. Kaua e hoki i te waewae tutuki, a pa ano hei te upoko pakaru!

(Never turn back because of stumbling feet, but only because of a broken head. Despite obstacles that may present themselves forge ahead with an undertaking and don't give up)

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Appendices

Appendix One

Information Letter

Marie Townsend
c/- School of Psychology
The University of Waikato
Private Bag 3105
Hamilton

Date.....

Tēnā koe.....

Re: Māori and Dementia: Perceptions of how Māori health care providers understand dementia

I am writing to inform you about a research project I am involved with regarding Māori elderly and dementia through the School of Psychology, University of Waikato. I am hoping that you and your organisation will be interested in supporting me to undertake interviews with some of your staff to help me to gain a better understanding of elderly mental health.

I am a mature graduate student and am currently studying Clinical Psychology. I am undertaking research for my Masters (Social Sciences) and my aim is to investigate Māori health care provider's conceptualisations of deteriorating states of mental health among older Māori and in particular, dementia. I am interested to *learn* more about Māori aspects of elderly health care, especially dementia. As you are aware, little attention has been paid to this very important aspect of health care for Māori. The research will investigate the following areas:

- Māori health care providers understandings of dementia
- Traditional versus contemporary understandings of dementia
- How cultural beliefs affect experience

- How Māori cope with dementia
- Key issues relevant to Māori people with dementia
- How services can be improved to meet the needs of aged Māori

It is of utmost importance that my research is beneficial to Māori and their whānau, affected by dementia, promoting a greater understanding by professionals, enhancing the level of appropriate information and services available. Research indicates that Māori are not accessing mental health services within the elderly bracket. Understanding the mental health needs of aged Māori will assist with the gerontology workforce development. Through contributing to an increased understanding of a Māori cultural perspective of dementia and deteriorating states of mental health it is hoped that services may increase their responsiveness to Māori elderly in the future.

I am approaching community organisations that provide services for older Māori with mental health problems, to recruit participants. The recruitment process is targeting Māori health workers, kaimahi (support workers or caregivers), academics and key Māori health experts within community organisations who assist Māori families affected by dementia. Māori health workers have been chosen as their life experience (both personal and within employment) provides insight and expertise in Māori culture, values and beliefs, tikanga, te reo and knowledge. This information will allow the exploration of a unique understanding of dementia from a Māori cultural viewpoint. Therefore Māori health workers are a valuable source of cultural understanding and awareness, as they have personal experiences and employment within organisations who assist Māori elders, and their whānau, affected by dementia. The participants and their knowledge will be treasured and treated with respect as taonga. Participation is completely voluntary and individuals are able to withdraw from the research at any stage. The final report will provide anonymity to all participants.

I am writing to request permission for staff members in your organisation to participate in this research project. Furthermore I am requesting permission to interview staff during office hours within your organisations premises. However if this is inconvenient I could interview participants during their lunch time or

immediately after work, at an alternative location. I envisage the interview will take approximately one hour, however this is dependent upon the knowledge and information shared. The interview could be carried over two shorter sessions if this would be more appropriate for your organisation.

In order to maximise the benefits to Māori I will be distributing the research findings as follows: all participants will receive a short summary of the findings; a copy of the thesis will be provided to organisations involved in the research and local mental health providers. I also plan to discuss the findings with local mental health providers, such as Mental Health Services of Older People. Furthermore it is my aim to have the results published in a journal where professionals within the field can access the information to improve quality of future services.

I would appreciate it if you were able to forward the attached information sheets to Māori health professionals and support workers within your organisation that may be able to assist with this research. I would appreciate any input from yourself or others who have knowledge and awareness within this area. These experiences may draw from current or past work experiences or from your personal experiences from within your own whanau.

My supervisors are Dr Tess Moeke-Maxwell (Ngāi Tai ki Umupuia and Ngāti Pukeko), from the Māori and Psychology Research Unit, and Associate Professor Doug Boer, from the School of Psychology, both located at Waikato University.

If you require any further information or would like to discuss my research investigations, the value of this research to Māori, and the recruitment of participants from within your organisation I would happily arrange a meeting with you. My contact details are: telephone 856 7376 or 0273 349 490 or mdt7@waikato.ac.nz

Thank you for your consideration of my research topic.

Kind Regards

Marie Townsend

Information Sheet

Māori and Dementia: Perceptions of how Māori health care providers understand dementia

My name is Marie Townsend and I am a mature student at Waikato University. I am studying Clinical Psychology and this research is part of my Master of Social Sciences Degree.

The research aims to investigate how Māori health care providers conceptualise deteriorating states of mental health and in particular dementia among older Māori. The research will investigate the following areas:

- Māori health care providers understandings of dementia
- Traditional versus contemporary understandings of dementia
- How cultural beliefs affect experience
- How Māori cope with dementia
- Key issues relevant to Māori people with dementia
- How services can be improved to meet the needs of aged Māori

Current research indicates that older Māori may be reluctant to access mental health services. Contributing to an increased understanding of cultural perspectives of dementia and the mental health needs of aged Māori may assist with the provision of culturally responsive and appropriate services. It is anticipated that this research will contribute to building the competencies of the gerontology workforce by increasing awareness and understanding.

It is my intention that this investigation will benefit an ageing Māori society, and hopefully assist the process of initiating change within organisations towards cultural inclusivity, based upon appropriate, personal, and respectful levels of service. It is of utmost importance that my research is beneficial to Māori and their whānau, affected by dementia, promoting a greater understanding by professionals, enhancing the level of appropriate information and services available.

Participation in the research will involve an interview in your place of employment or at the university. The interview will take approximately one hour, or as long as is required to gain a comprehensive interpretation of the participants understanding of mental health issues within older Māori. If more convenient to the participant the interview may take place over two shorter sessions. The interview will request information such as your opinion or views and experiences with dementia. These experiences may draw from current or past work experiences or from your personal experiences from within your own whanau. The interview conversation will be digitally recorded to allow accurate recording. Participants will receive a copy of their interview transcript to allow alterations, omissions or the addition of information. Following the interview the researcher will request that the participant completes a short questionnaire. Participation is completely voluntary, and you are able to withdraw at any stage. The final report will provide anonymity for all participants.

If you are interested in participating in this research project, or require further information, please give me a call, or send me an email. Alternatively you can complete the attached form and return it to me in the self addressed envelope.

The university supervisors for this research project are Dr Tess Moeke-Maxwell (Ngāi Tai ki Umupuia and Ngāti Pukeko), from the Māori and Psychology Research Unit, and Dr Doug Boer, from the Psychology Department, at the University of Waikato. The research has approval from the School of Psychology Research and Ethics Committee, of the University of Waikato. The Ethics Committee may be contacted as follows: Robert Isler, email r.isler@waikato.ac.nz or telephone (07) 838 4488 ext 8401.

For further information please feel free to contact me:

Telephone: (07) 856 7376 or (027) 334 9490 Email: mdt7@waikato.ac.nz

Kind Regards

Marie Townsend

Māori and Dementia: Participant Consent Form

Kia ora Marie

My name is _____ and I have received an information sheet about this research project.

- I agree to participate in this research project.
- I understand that participation is voluntary and that I may withdraw at any stage of the research.
- I understand that the interview will be digitally recorded.
- The project will provide anonymity to all participants in the final report.
- A copy of the interview transcript will be provided to participants to allow alterations, omissions, or the addition of information.
- If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee, (Robert Isler, email r.isler@waikato.ac.nz or telephone (07) 838 4488 ext 8401).

I can be contacted by:

- Mail, my address is below
- Telephone, my number is below
- Email, details listed below

My postal address is

My phone number is

My email address is

Thank you for volunteering to participate in this research project, I appreciate your time and thoughts.

Appendix Two

Interview Schedule

Thank you for taking the time to meet with me. The knowledge you share will be invaluable and I am humbled that you are willing to entrust me with it.

Ask participant if they would like to offer a karakia before we begin

Firstly I will discuss your rights as a participant, and then we can sign the consent form. Your rights are as follows:

- You are entitled to refuse to answer any question you are uncomfortable discussing
- You may end the interview at any point in time
- You can withdraw the information provided up until two weeks after you receive the transcript of the interview
- You can ask for the transcript to be changed, reworded, or sections removed, if it doesn't reflect the meaning of our conversation, or you can have thoughts added if you reflected after the interview and thought of other valuable information
- All participants will be provided with anonymity, with the use of pseudonyms, and identifying characteristics will be removed from the findings

The outcome of the research is dependent upon accurately recording the knowledge you share with me. With your agreement I will digitally record our discussion. The recording will be stored safely in a locked cabinet at my home address. No one else will have access to it. Furthermore, I may take notes as we talk.

Sign the consent form – both the participant and researcher.

As you are a professional working with older Māori (OR have personal experience with dementia within your whānau) affected by dementia I am interested in understanding what you believe are the key issues for Māori families

and how dementia affects their lives. My research aims to investigate the following:

- Māori health workers understandings of dementia (OR personal experience)
- Traditional versus contemporary understandings of dementia
- How Māori cope with dementia
- Key issues relevant to Māori people with dementia
- How cultural beliefs affect experience

I have a number of questions about the impact that dementia has upon Māori elders and their whānau. Please feel free to add any information you believe is relevant to the research. Following the interview I would appreciate it if you could complete a short questionnaire. If you are unable to complete it straight away I will provide you with a self-addressed envelope so you can return it at your earliest convenience.

Part One

Job description

1. Can you tell me a little about your job? (may not be appropriate)
2. What is your relationship with older Māori who have dementia?
3. What is the most common age of people you see with dementia? (what age was your family member affected?)

Part Two

Dementia

1. DSM-IV criteria and diagnosis (Have DSM criteria printed out in case they are unfamiliar with it)
2. What do you understand by the term dementia (OR Alzheimers)?
3. Is this different from the DSM criteria? How?
4. Do Māori health experts find the defining dementia characteristics/terms/behaviours useful? (may not be appropriate)
5. Do you believe that 'culture' is considered when doctors provide a diagnosis? *

Part three

Contemporary understandings versus traditional understandings

1. How is dementia viewed in the contemporary Māori worldview?
2. Are contemporary Māori understandings of dementia influenced by Western understandings of dementia?

Part four

How beliefs affect experience

1. Are the symptoms of dementia (loss of memory, wandering, agitation, loss of ability, inability to attend to personal care) understood as part of the normal ageing process or viewed as problematic behaviour in Māori society?
2. Do beliefs surrounding dementia affect the seeking of assistance?
 - 2a. How?
3. Do you think Māori have different ways of dealing with elderly affected by dementia?

3a. How?

Part five

How Māori cope with dementia

1. How do whānau cope when an elder has dementia?
2. What is the role of whānau/hapū/iwi in coping/dealing with a member's dementia?
3. What support is offered to Māori families? Which organisations?
4. Within your professional role are older Māori with dementia cared for adequately? Or is there room for improvement (lack of appropriate information or support)? *

(If personal experience: does your whānau receive adequate care from community and hospital services)

Part six

Key issues relevant to Māori people with dementia

1. What are the barriers, if any, to Māori receiving diagnosis, treatment, and ongoing support?
2. What services do you believe would be of more value or additional value to Māori?
3. What do you think are the key issues for Māori elders and their whānau affected by dementia?

Conclusion

1. Is there anything you would like to do with clients but are unable to?
2. Is there anything else you would like to add to the conversation?
3. Do you know anyone else who may be interested in participating in my research – either as a health worker in an organisation assisting those with dementia or they may have personal experience?

Offer karakia

Thank the participant sincerely for sharing such privileged information!

Note: Questions marked with an asterisk will only be discussed if time permits.

Questionnaire

- Do you have a recognised qualification? YES NO
- Are kaumātua with deteriorating states of mental health identified by professionals (such as GP's) as having dementia? YES NO
- Do you believe Māori suffer from dementia? YES NO
- Is dementia an appropriate term for Māori elders? YES NO
- Do you believe Māori acknowledged kaumātua mental illness within traditional Māori society? YES NO
- If yes would the individual have been included or excluded from society?
- Does the principle of manākitanga apply to the care of elderly in contemporary society? YES NO
- Do you believe whānau view the symptoms of dementia as part of the normal ageing process? YES NO
- Do whānau accommodate behaviour of older family member's more than non-Māori families? YES NO
- Do whānau seek assistance outside of the whānau? YES NO
- Would it be considered embarrassing or shameful to have an older family member with mental health problems, such as dementia? YES
NO
- Are elders with dementia predominantly cared for within a family home? YES NO

- Would the affected individual be included or excluded from whānau events?
- Do Western values influence the care of older Māori with dementia?
YES NO
- Do whānau receive adequate and appropriate information?
YES NO
- Is there adequate support in the community for Māori families affected by dementia?
YES NO
- Would the whānau feel guilty if an elder was placed in a full time care facility?
YES NO
- Do you believe cultural barriers are a part of the problem with mental health services?
YES NO

Thank you for sharing this privileged information with me.

Consent Form

University of Waikato

School of Psychology

CONSENT FORM

PARTICIPANT'S COPY

Research Project: Māori and Dementia: Perceptions of how Māori people understand dementia

Name of Researcher: Marie Townsend

Contact number: (07) 856 7376 or (027) 334 9490

Name of Supervisor: Dr Tess Moeke-Maxwell and Dr Doug Boer

- I have received an information sheet about this research project or the researcher has explained the study to me.
- I have had the chance to ask any questions and discuss my participation with other people.
- Any questions have been answered to my satisfaction.
- I agree to participate in this research project.
- I understand that participation is voluntary and that I may withdraw at any time.
- I understand the interview will be digitally recorded.
- The final report will provide anonymity to all participants.
- Participants will receive a copy of their transcript and be provided with the opportunity to make alterations, omissions, or add information.

If I have any concerns about this project, I may contact the convenor of the Research and Ethics Committee (Dr Robert Isler, phone: 838 4466 ext. 8401 e-mail r.isler@waikato.ac.nz)

Participant's Name: _____ Signature: _____

Researcher's Name: _____ Signature: _____

Date: _____

University of Waikato

School of Psychology

CONSENT FORM

RESEARCHER’S COPY

Research Project: Māori and Dementia: Perceptions of how Māori people understand dementia

Name of Researcher: Marie Townsend
Contact Number (07) 856 7376 or (027) 334 9490

Name of Supervisor: Dr Tess Moeke-Maxwell and Dr Doug Boer

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Participant’s Name: _____ Signature: _____
Researcher’s Name: _____ Signature: _____
Date: _____

Appendix Three

Transcript Letter

Marie Townsend
c/- School of Psychology
The University of Waikato
Private Bag 3105
Hamilton

Date.....

Tēnā koe.....

Re: Māori and Dementia: Perceptions of how Māori health care providers understand dementia

Thank you for taking the time to meet with me, and I appreciate your willingness to assist me with my research. Your knowledge is extremely valuable and I am privileged that you shared this information with me.

Attached please find a copy of your interview transcript. The purpose of sending this summary is so that you can verify that I have accurately captured what you said. Please read through it and advise me of any changes you would like made. I am able to edit the data, remove sections, or add extra thoughts to this transcript. For example if you had further thoughts around Māori understandings of dementia I would willingly add this information to your transcript. Please return the transcript within two weeks of this letter in the enclosed prepaid envelope. If I do not receive your transcript I will make contact with you by telephone or email to ensure accuracy of the transcript details.

If you wish to discuss any matters further with me please do not hesitate to contact me as follows: telephone (07) 856 7376, 0273 349 490, email mdt7@waikato.ac.nz

I will send out a summary of my findings when I have compiled the results so you can see what I have found from my discussions with Māori health experts, kaimahi and whānau affected by dementia. Furthermore a copy of my thesis will be forwarded to the organisation you are employed within.

Finally thank you so much for taking the time to talk with me and help me with my research. Without participants, such as you, the research would not have been possible.

Kind Regards

Marie Townsend