Struggling to be Involved: A grounded theory of Māori whānau engagement with healthcare
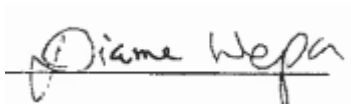
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Faculty of Health and Environmental Sciences
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ATTESTATION OF AUTHORSHIP

I herby declare that this submission is my own work and that, to the best of my knowledge, it contains no material previously published or written by any other person (except where explicitly defined), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed: Dianne Wepa

Dated: 1st August 2016

ABSTRACT / PITOPITO KŌRERO

Aspirational whānau enable future generations to succeed in an Indigenous world and a Western world. Relationships that are positive within the whānau become mutually beneficial when access is being sought for a range of services. The world that Māori whānau exist in today is vastly different from that of past generations. What has endured over this time is the whānau unit and the processes that contribute to its longevity.

The aims of this study were to explain the processes that Māori and their whānau used to have their spiritual and cultural needs met when engaging with health care services, and generate a substantive theory of what happens for Māori and their whānau when they engage with health care services. The research question was, "What is happening with Māori and their whānau when they engage with health care services?"

Twenty Māori whānau were interviewed about their engagement with healthcare services in Hawke's Bay. Constructivist grounded theory developed by Kathy Charmaz (2006, 2014a), was utilised as the methodology for this study and Kaupapa Māori processes ensured that both whānau and the researcher were kept culturally safe. **Struggling to be Involved** emerged as a core process and substantive theory that explained how Māori whānau experienced healthcare services. *Being Māori* and *surviving the experience* provided positive mediating factors as whānau management strategies and a natural resource to assist with obtaining a healthcare service.

The discrimination faced by Māori whānau while they were seeking to improve their health was a constant struggle. Despite the many negative experiences, collective ownership or we-dentity contributed to their resolution to receive the best healthcare, as they deserved no less. Current healthcare interventions in New Zealand are not working for Māori whānau. **Struggling to be Involved** contributes new knowledge about Māori whānau engagement with healthcare services by providing an original contribution to reduce continuing inequities between Māori and other New Zealanders.

ABSTRACT / PITOPITO KŌRERO

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Tenei te karanga

o te kawa whakaruruhau

Nau mai, haere mai

Mauriora mai ra te aroha e

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CHAPTER ONE: INTRODUCTION / KO TE PŪ

Health services should have the capacity to respond positively to whānau and whānau should be able to negotiate freely with health providers to achieve the best results (Bay of Plenty District Health Board, 2015, p.2).

In New Zealand, health inequities persist across the population. Inequities between Māori and non-Māori remain the most consistent and compelling (Robson & Harris, 2007). Health inequities are defined as "differences which are unnecessary and avoidable, but in addition are considered unfair and unjust" (Whitehead, 1992, p. 431). Reducing health inequities among Māori has been emphasised in legislation such as the New Zealand Public Health and Disability Act 2000, strategic health policy documents including the New Zealand Health Strategy (Ministry of Health, 2000, 2016), and He Korowai Oranga: Māori Health Strategy (Ministry of Health, 2002, 2014a).

This thesis aimed to explain the processes that Māori whānau experience when engaging with health services. This is considered important as there appears to be a strong link between discriminatory practices toward Māori and the quality of healthcare they receive (Bolitho & Huntington, 2000: Cram, 2014; Harris et al., 2012, Rumball-Smith, Sarfarti, Hider & Blakely, 2013; Wilson, 2004; Wilson & Barton, 2012). Furthermore, the ability to access quality health services is essential because Māori have the poorest health status of any ethnic group in Aotearoa/New Zealand. They are also:

- younger than other groups
- likely to be living with a long-term health condition, and
- likely to die sooner than non-Māori (Carter, Blakely, & Soeberge, 2010).

The Bay of Plenty District Health Board's statement that opens this chapter, acknowledges the ways in which whānau function as a whole when engaging with healthcare services. District health boards, Māori providers and other health service providers have declared similar intentions, with varying emphasis on engagement strategies with Māori whānau (Asthma Foundation, 2015; Auckland District Health Board, 2014; Bay of Plenty District Health Board, 2015; Capital and Coast District Health Board, 2013; Hawke's Bay District Health Board, 2014; Health Safety and Quality Commission, 2015; Southern District Health Board, 2014; Waikato District Health Board, 2015; Waitemata District Health Board, 2014). The overall goal, therefore, is to achieve maximum wellness for whānau. Regardless of what the future holds for Māori whānau, they are entitled to optimal health and wellbeing as a human right afforded to all people. The major barriers to overcome, however, are

persistent inequities in health status, outcomes and access to health services (Wilson & Hickey, 2015).

This chapter will present the research's aim and purpose as well as the research question. First, I will provide background information to this study including my personal perspective. Historical influences on Māori whānau in relation to colonisation and post-World War II era, are considered and the effects of historical trauma on Indigenous peoples is examined. The evolving nature of Māori whānau will be deliberated and includes a discussion about contemporary health status. The move towards re-interpreting ethnicity where health inequities have impacted on cultural and spiritual needs will then be examined. A discussion about Te Tiriti o Waitangi/Treaty of Waitangi follows in relation to the Crown's responsiveness to Māori whānau within the Whānau Ora initiative. Definitions of key concepts and terms referred to in the study are then provided, namely, Māori epistemology, a Māori world view, Kaupapa Māori theory, Māoritanga, whānau, whakawhanaungatanga, whakapapa, Māori identity, tangata whenua, we-dentity and healthcare workers, providers and services.

Background

As a Māori researcher of Ngāti Kahungunu descent working in the health system, I have been concerned about health inequities for Māori. My experience of whānau dying in their 50s is commonplace within my world view. It wasn't until I studied the effects of colonisation on Māori ways of being, that I started to question why all my relatives endured such a short life expectancy. From my perspective, whānau were compliant and visited their general practitioners (GPs) for their respective health conditions. However, what was not known from such interactions was the level of comprehension by GPs of whānau concerns. The process of engagement appeared to fulfil a medical imperative, focused on refilling prescriptions and 15-minute appointments. I wanted to understand the healthcare engagement process from a whānau perspective, as I believed the whānau imperative was missing.

I suspected that my whānau experiences were not isolated. Therefore, I examined views from people in other countries. I considered the term 'Indigenous', which I believe not only describes my whānau, but also locates them within Aotearoa/New Zealand. The word Indigenous is derived from the Latin root *indu* or *endo,* which is related to the Greek word *endina*, which means 'entrails'. Indigenous literally means being so completely identified with a place that the people reflect its entrails, its insides, its soul (Walters, Beltran, Huh, & Evans-Campbell, 2011, p. 166). Furthermore,

any disruption in Indigenous land, place, or culture clearly has a potentially harmful effect on Indigenous health and wellness, which may then persist for generations to come (United Nations, 2002, 2008). One reason offered for this effect is where Indigenous peoples express a relationship to the natural world that can only be called 'ensoulment'. This connection is represented at the deepest level of psychological involvement with the land and provides a map of the soul (Walters, et al., 2011, p. 165).

The concepts of health and survival are similar to Māori in terms of being collective, intergenerational and holistic in nature (Adams, 2007; Cunningham, 2008; Durie, 2001; Goold & Liddle, 2005). Furthermore, Indigenous peoples also share similar world views on health, which include four fundamental dimensions: spiritual, intellectual, physical and emotional (United Nations, 2002, 2008). Today, many Indigenous peoples have become part of mainstream society with similar views and values, although many have also remained tied to traditional ways of life, and to their socio-cultural past (Harawira, 2007; Mitchell, 2008; Nash & Sacre, 2006). The close association between people and their environments – land, waterways, the air, beaches, harbours, the sea, native flora and fauna – also continues to be part of the knowledge base of Indigenous people's view of health (Walters, Beltran, et al., 2011).

Historical influences on Māori whānau

Colonisation

The population collapse of Indigenous peoples and removal from their lands following colonisation is well documented in New Zealand, the Pacific Islands, Australia, Hawaii and Canada (Goold & Liddle, 2005; Harris, 2002; Kunitz, 1994; Waldram, Herring & Young, 2006). Colonisation predictably removed people's economic and political base, which in turn resulted in poverty and susceptibility to diseases (Durie, 1998). The link, therefore, between inequalities in socio-economic status and health for Indigenous colonised populations, compared to others, is consistent globally (Browne et al., 2012; Kirmayer, 2015; Lowe, Liang, Riggs, Henson & Elder, 2012).

In New Zealand, inequities in health are the most consistent between Māori and Pākehā (people of European descent) (Robson & Harris, 2007). With the loss of land due to colonisation, came a dramatic change in lifestyle for Māori whānau. Healthcare services involved traditional approaches to healing and were provided within the whānau where tikanga (cultural protocols) provided answers for any illnesses that would arise. However, from the late 18th century, the healthy lifestyles enjoyed by whānau soon changed with settler contact. Constant physical activity, a protein-rich and

plant-based diet was replaced with processed food and living in overcrowded villages with little sanitation (Durie, 1998).

Despite the many historical influences on Māori whānau, this discussion highlights how as a foundational unit for Māori society, the capacity to endure and evolve has ensured its survival into the 21st century. In pre-European times, the whānau was central to everyday life. More than an extended family unit, whānau was based on kinship ties and a shared ancestor. Whānau provided an environment where certain responsibilities and obligations were maintained (Durie, 1994; Metge, 1995). Whānau were typically independent work groups that gathered food and cultivated crops for their own consumption. Hapū were large groups of closely related whānau that chose to settle in a particular area for access to food resources and for defence purposes (Petrie, 2006). Due to New Zealand's isolation from other nations, and strict adherence to culturally-based public health protocols, Māori were a healthy population with little prevalence of disease. The clear separation of people, places and activities as either tapu (requiring protection) or noa (considered safe to use) guaranteed their survival over several hundred years (Durie, 1998).

The roles of men and women in the whānau involved the Māori world view of whanaungatanga where all living things were interrelated and there was a principle of balance (Mikaere, 1994). Both men and women formed essential parts of the collective whole where whakapapa (genealogy) played a key role supporting interdependence, which ensured the survival of the whānau. Every person within the whānau contributed towards the collective, and it was the collective's responsibility to see that their respective roles were valued and protected (Wilson, 2004).

Instances of abuse against women and children were regarded as whānau and hapū concerns and action would inevitably be taken against perpetrators (Pere, 2006). Child-rearing was a collective responsibility and communal living required constant interaction with other members in a concerted effort to keep the group functioning for the good of the collective. This form of social organisation ensured a degree of flexibility for women allowing them to perform a wide range of roles including leadership roles (Mahuika, 1975).

Historical forces contributed to changes for Māori whānau that were linked to Pākehā contact in the late 1700s (Moeke-Pickering, 1996). Introduced diseases such as typhoid, tuberculosis and measles were unknown to Māori and had devastating effects resulting in a reduction in the population from an estimated 100,000 to 40,000 from 1774 to 1896 (King, 1983). New Zealand's isolation had

benefited several generations, but also contributed to a lack of immunity from diseases for Māori. By the early 1900s, Māori fatalities had increased due to the 1918 influenza epidemic. Mortality and fertility levels were high, and the estimated life expectancy at birth was 30 years (Pool, 1991). Through Crown purchases, confiscation, title individualisation, and private purchase, more than eighteen million acres of land had been surveyed and was in individual ownership by the early 1900s (Te Puni Kokiri, 2007). Through the removal of land as a base, Māori whānau lost their autonomy and much of their capacity to develop their economic potential. The effect was the destabilisation of Māori social organisation. Some Māori whānau were dispersed or departed from their homelands (Walker, 2004). Moving from the hill-top pā where a healthy lifestyle ensued to low-lying swampland and the loss of access to traditional food, created fertile conditions for infectious diseases and the erosion of traditional public health practices (Durie, 1998).

Missionaries and early settlers also brought with them culturally specific understandings of the role and status of women. The Native Land Act 1909 declared Māori customary marriages to be valid for some purposes only and required Māori to undergo legal marriage ceremonies. These provisions, coupled with the parliamentary debates of the time, signalled a renewed determination on the part of the state both to redefine and intrude into the whānau (Mikaere, 1994). Māori collectivism was philosophically at odds with the settler ethic of individualism. Whānau were eventually forced to break into nuclear families and move to towns and cities in search of work. Forcing Māori women away from their whānau towards the Pākehā model of the nuclear family, left them vulnerable in a host of ways. They became dependent on their husbands as breadwinners, while they became increasingly isolated as caregivers at home. Some women were expected to work both outside and inside the home, as economic hardship required them to contribute financially, while Christian values about what constituted a good wife and mother compelled them to maintain that role as well. Husbands increasingly became the head of the family and wives felt obliged to remain with them no matter what (Pihama, 1998). Working for a wage, especially for men, further destabilised traditional gender roles within the whānau structure (Pihama, 1998). Negative behaviours such as whānau violence increased (Kruger et al., 2004) and the loss of Māori language and health practices culminated in a world that valued independence as opposed to interdependence within the whānau (Durie, 1998).

Post-World War II
The prognosis for Māori whānau and their population was not favourable until after World War II. The combination of antibiotics, increased immunity and sanitation in rural areas, reduced Māori

mortality and increased life expectancy (Pool, 1991). Māori population growth levels peaked at 4% between 1956 and 1966, when Māori numbered 250,000 or 7.5% of the population. This was a significant increase from the all-time low of 40,000 in the late 19th century when there was the expectation that Māori whānau would die out (McIntosh & Mulholland, 2011).

A rapid decline in Māori fertility began in the late 1960s with the introduction of the contraceptive pill and urbanisation (McIntosh & Mullholland, 2011). In 1965, nearly two-thirds of Māori lived in rural areas but by 2006, 84.4 percent of Māori lived in urban areas. Urban migration for Māori often meant better opportunities for good housing, full-time employment, and education. Māori were significantly under-represented in higher levels of education, and therefore, became predominantly represented in low-skilled and low-paid occupations, such as factory work, forestry, and meat processing. By 1986, Māori fertility had dropped from 5.1 births per woman to just 2.1 (Pool, 2005). Contributing factors for this change included socio-economic status, marital status and the young median age of childbearing for Māori women of 22 years old (Pool, 2005). At the 1986 Census, 12.4% (404,778) of the total population identified as Māori with 71% under 30 years if age (Pōmare & de Boer, 1988). In 2013, the Census noted that Māori birth rates had settled at 2.49% and in terms of overall growth trajectories, the Māori population is predicted to grow at a constant annual rate of 1.3% through to 2026 (Statistics New Zealand, 2014).

The third annual Families and Whānau Status Report developed a new set of indicators to measure whānau wellbeing (Families Commission, 2015). The report reviewed the New Zealand Census, the General Social Survey and Te Kupenga – the Māori social survey. A matrix of whānau capability dimensions and five wellbeing principles were developed to highlight the complexities of whānau in the 21st century. Overall, the report found that whānau enjoyed good levels of wellbeing with single-parent whānau facing more challenges within their lives.

Historical trauma – enduring effects on health and wellbeing

Historical trauma has become increasingly important in considerations of wellness among historically oppressed communities (Evans-Campbell, 2008). Preliminary work on historical trauma by Maria Yellow Horse Brave Heart (1999) and her colleagues at the Takini Network, has made significant contributions to this developing body of knowledge. Historical trauma is considered to be:

> a collective complex trauma inflicted on a group of people who share a specific group identity or affiliation – ethnicity, nationality, and religious affiliation. It is the legacy of numerous traumatic events a community experiences over generations and encompasses the psychological and social responses to such events (Evans-Campbell, 2008, p. 320).

The concept is both a description of trauma responses among oppressed peoples and a causal explanation. Indigenous health has been increasingly linked to historical trauma stemming from historically traumatic events. The history of traumatic assaults is well documented and includes centuries of targeted attacks on Indigenous people and land including massacres, pandemics, forced relocation, and the prohibition of spiritual and cultural practices. Historical assaults also include place-based, environmental assaults such as radioactive dumping on tribal lands, flooding of homelands, outlawing of traditional hunting practices, and the introduction of diseases (Whitbeck et al., 2004).

The appropriation of Indigenous land by force or coercion, has been a central theme in colonial interactions with Indigenous people. Land has been at the heart of colonial attempts at conquest, and historical trauma events have been the primary vehicle for land dispossession and displacement of Indigenous people. Moreover, American Indians and Alaska Natives live with the constant reminders of historical trauma (for example, living in areas where massacre sites are visited by tourists and proudly mislabeled as battle sites) (Walters et al., 2011). Although historical trauma and intergenerational trauma is still in relatively early stages of empirical examination, preliminary research indicates that the impact on health of these events persists for some individuals or families over generations (Walters, Beltran, et al., 2011).

Much of the initial work in this area has explored trauma among Holocaust survivors. However, the concept has also been usefully applied to other groups such as Japanese Americans, Armenians and American Indian and Alaskan (AIAN) peoples (Evans-Campbell, 2008). The concept of historical trauma has been embraced by many people with AIAN communities searching for ways to make sense of, and respond to, their traumatic histories (Whitbeck et al., 2004). The concept suggests that it is capturing an important part of their individual and communal experience that other models, such as the social determinants of health, have missed (Walters, Beltran, et al., 2011).

Embodiment of trauma

A number of authors also argue that historical processes and contexts become embodied (Stone, 2008; Walters, Beltran et al., 2011; Walters, Mohammed et al., 2011). The notion of embodiment considers how people literally incorporate biologically – from conception to death – social experiences and express this embodiment in population patterns of health, disease, and well-being (Walters, Mohammed, et al., 2011, p.180). There is growing evidence that at the cellular level, powerful stressful environmental conditions can leave an imprint or mark on the epigenome (cellular genetic material) that can be carried into future generations with devastating consequences; for example, poor prenatal maternal nutrition can lead to descendents developing obesity and cardiovascular disease in adulthood (Godfrey et al., 2011; Kuzawa & Sweet, 2009; Stone, 2002, 2008). Further development to establish the link between the body and social inequities first gained attention in the 1840s when social scientists found that the impact of working conditions, poor access to food, and inadequate health care in childhood led to premature mortality. However, it was not until the Great Depression that American researchers began to move away from faulty gene research to explore how social, economic, and political forces are expressed in bodies (Walters, Mohammed, et al., 2011).

The high rates of chronic disease in Indigenous communities can be viewed as bodies telling the stories of the catastrophic upheavals imposed upon them by the colonial process. What happens to the land happens to bodies, what happens to bodies happens to spirits, and it happens individually, collectively, and globally.

Post-traumatic stress disorder

Post-traumatic stress disorder has been considered a similar process that Indigenous peoples encounter as part of historical trauma. According to Stone (2002), post-traumatic stress disorder is an anxiety disorder that exists on a continuum with depression. The anxiety presents as a high level of arousal most of the time. If a person does not have a coping mechanism to help reduce or regulate that anxiety, they are susceptible to becoming depressed. For Indigenous peoples, ceremonial community-based spiritual activities help to reduce anxiety. When tribal spirituality was disrupted, the Indigenous person's anxiety rose with no mechanism to control it. Indigenous people then began experiencing a shift in the anxiety-depressed continuum. They developed depressed moods stemming from uncontrollable anxiety that was no longer ameliorated by the use of tribal spiritual practices as coping mechanisms.

During the first generation of colonisation, tribal people experienced anxiety and depression disorders manifested in families and in the caregiver's behaviour towards the children. Furthermore, these tribal families were in continual stress from other external factors predicated on colonisation. Combined with trauma, post-traumatic stress has had a more serious effect on the descendents of survivors. The stress would be confounded if both parents experienced the event and the trauma would become differentially experienced by women compared to men. The trauma literally became embodied, manifesting as poor mental health and physical health in later generations (Walters, Beltran, et al., 2011, Walters, Mohammed, et al., 2011). Descendents of survivors, however, are not more likely than others to have poor mental health for example. Rather, they may have a higher vulnerability to stressful events, and when faced with a lifetime stressor, descendents may be more likely than others to develop post-traumatic stress disorder symptomology (Walters, Mohammed, et al., 2011).

At the individual level, the impact includes impairment in family communication, anxiety, depression and substance abuse. At the community level, collective responses include the disruption of traditional customs, languages and practices (Walters, Mohammed, et al., 2011). Studying the embodiment of historical trauma and corresponding health consequences, allowed researchers to determine the forces driving intergenerational patterns of health and disease among AIAN peoples. Moreover, such knowledge will likely yield important directions for developing culturally relevant policies and practices to reduce AIAN health inequities and ultimately grow AIAN health and wellness for future generations (Walters, Mohammed, et al., 2011).

Drawing upon survival stories rather than focusing on victimisation, is a recent movement to develop a warrior mind state. Rather than causing further trauma, authors argued that an exploration of how people survived historical trauma may provide a protective factor against chronic health conditions and the embodiment of stressful events (Walters, Beltran, et al., 2011).

Strength-based strategies
Walters, Simoni, and Evans-Campbell (2002) concluded that Indigenous health and wellness cannot be decontextualised from historical place-based processes, particularly historical traumatic event exposure and its association with physical and mental health outcomes. A focus on strengths-based familial and tribal survival strategies is recommended, which can be integrated into multi-level treatment approaches, particularly for communities and individuals who experience high rates of lifetime traumatic events (Whitbeck et al., 2004). An example of such an approach is the Indigenist,

stress-coping model which acknowledges the devastating impact of historical trauma and ongoing oppression of AIAN. The model emphasises cultural strengths, such as the family and community, spirituality and traditional healing practices, and group identity attitudes (Walters et al., 2002).

Historical trauma is now being discussed within Aotearoa/New Zealand (Wirihana & Smith, 2014). The similarities encountered by Māori have occurred over a relatively short period of colonisation (176 years versus 400 years for AIAN peoples). Nevertheless, the effects are the same in terms of health disparities which are linked to land loss and general lack of access to health and land environments. The relevance to this study involves the consideration of inter-generational trauma that has affected Māori whānau in terms of marginalisation, racism and the embodiment of lifetime events.

Evolving nature of Māori whānau

Whānau remains the primary support system for Māori, providing care and nurturance, not only in physical terms but culturally and emotionally (Collins & Wilson, 2008). Nevertheless, just as Māori whānau were never static in pre-European times, their ability to evolve to meet the changing conditions of the country has continued. Whānau have become as much about a common mission or kaupapa as a common heritage (Lawson-Te Aho, 2010). Māori whānau have endured in the 21st century and changed to become much larger than its classical counterpart, often comprising more than one household. Whānau health and wellbeing now includes friends and family, work colleagues, or sporting associations, which act as if they were a kin group of whānau in pursuit of some common purpose such as health or education. The term whānau ā kaupapa is applied in these instances where the whānau is seen as multi-dimensional and includes changing realities to meet contemporary demands. According to Walker (2006) and Durie (2011), the interconnections noted from within modern-day interpretations of whānau have served as a protective factor whereby the intrinsic value of supporting each other has survived into the 21st century. The protective factors highlighted have endured since before European contact. They include the ability of whānau to draw on the strengths of the collective by using whakawhanaungatanga (the process of making relationships) to take control of their healthcare journeys and participate fully in society.

Contemporary health status

Although Māori are not dying from the diseases of the 18th and 19th centuries, inequities in healthcare are evident in relation to morbidity, mortality and the use of primary health services

(Wilson & Hickey, 2015). During the 1980s and early 1990s, Māori mortality was seriously undercounted due to the different definitions of ethnicity on death registration, birth registration and census forms (Ajwani, Blakely, Robson, Tobias & Bonne, 2003; Blakely, Tobias, Atkinson, Yeh, & Huang, 2007).

Māori life expectancy rapidly increased up until the late 1970s, after which it was static, while non-Māori life expectancy continued to increase. Since the late 1990s, Māori life expectancy has been increasing at about the same rate as non-Māori, or even slightly faster (Blakely et al, 2007). The gap between Māori and non-Māori life expectancy at birth narrowed to 7.1 years by 2012–14. (Statistics New Zealand 2015). Ischaemic heart disease remains the leading cause of death for Māori males and the second leading cause of death for Māori females. Lung cancer is the leading cause of death for Māori females and the second leading cause of death for Māori males. Suicide was the third leading cause of death for Māori males, with diabetes featured in the top five causes of death for Māori (Ministry of Health, 2015). Māori also experience a disproportionate amount of the country's injury burden with an estimated loss of health due to twice that (12% of Disability Adjusted Life Years [DALYs]) of non-Māori (6% of DALYs) (Ministry of Health, 2013a). Māori aged 15–64 years have considerably higher rates of hospitalisation for unintentional injury than non-Māori (18 per 1,000 compared to 11 per 1,000) (Ministry of Health, 2015a).

Factors that contribute high morbidity and mortality rates for Māori can be attributed to differences in access to determinants of health, healthcare and the quality of care. Access is described as both access to and access through healthcare, the latter concept taking into account the quality of the service being provided (Ellison-Loschmann & Pearce, 2006). For example, socioeconomic position is regarded as a major determinant of health (Howden-Chapman & Tobias, 2000; Wilkinson & Marmot, 2006). Factors such as income, employment status, housing and education can have both direct and indirect impacts on health. These impacts can be cumulative over lifetimes (Robson, Cormack & Cram, 2007). NZDep2013 is a small-area-based index providing a measure of neighbourhood deprivation, by assessing the comparative socioeconomic positions of small areas and assigning them decile numbers from 1 (least deprived) to 10 (most deprived). The index is based on nine socioeconomic variables from the 2013 Census. It describes the general socioeconomic deprivation of an area. An area's decile score does not necessarily mean all individuals living in that area experience an equivalent level of deprivation.

Nonetheless, higher proportions of Māori live in areas with higher NZDep2013 scores; that is, in more deprived areas. In 2013, 23.5 percent of Māori lived in decile 10 areas (compared with 6.8

percent of non-Māori), while only 3.8 percent lived in decile 1 areas (compared with 11.6 percent of non-Māori) (Atkinson, Salmond & Crampton, 2014). There is a strong evidence to suggest that there is an association with deprivation and high rates of violence (Statistics New Zealand, 2015b; Wilkinson & Pickett, 2010). In New Zealand, Māori are more likely to be living in the most deprived areas in over-crowded houses (Ministry of Health, 2015a). These factors contribute toward whānau violence amongst Māori, with Māori women in particular identified as a high risk group.

Improving access to care is critical to reducing health disparities, and increasing evidence suggests that Māori and non-Māori differ in terms of access to primary and secondary health care services (Bolito & Huntington, 2006; Cram, 2014; Cram, Smith & Johnstone, 2003; Ellison-Loschmann & Pearce, 2006; Jin, Sklar, Min Sen Oh & Cheuen Li, 2008; Wilson & Barton, 2012). The quality of healthcare for Māori tends to be poorer due to their shorter stay in hospital than non-Māori despite encountering more adverse events for admission (14% versus 11%) (Davis, Lay-Yee, Dyall, Briant, Sporle, Brunt, et al., (2006).

The cost to access healthcare is emerging as a key barrier and is linked to higher deprivation where Māori are continually over-represented compared to their population (Jantrana & Crampton, 2009; Walker, Signal, Russell, Smiler, & Tuhiwai-Ruru, 2008). The experience of racial discrimination is also associated with poor health outcomes and has an impact on a wide range of risk factors (Harris, Cormack, & Stanley, (2013). For Māori adults, the prevalence of self-reported experiences of racial discrimination and unfair treatment on the basis of ethnicity, were almost twice as likely than non-Māori adults to have experienced any type of racial discrimination (Ministry of Health, 2015). The combination of differences in access to determinants of health and healthcare result in less than optimum quality of care and higher rates than non-Māori for chronic diseases, including cancer, diabetes, cardiovascular disease, asthma and disablility (Ministry of Health, 2015).

Considered a litmus test for determining the current health status for Māori whānau, the rate of infant mortality and adverse birth outcomes has not improved. Māori children are more likely to be overweight than non-Māori children and more than twice as likely to be obese (Cram, Gulliver, Ota & Wilson, 2015). In 2013, life expectancy at birth was 73.0 years for Māori males and 77.1 years for Māori females; it was 80.3 years for non-Māori males and 83.9 years for non-Māori females (Ministry of Health, 2015). Cram et al., (2015) conducted a study of New Zealand children which recommended a re-interpretation of the over-representation of the Māori cohort. Rather than considering risk and bias as competing explanations, the authors recommended an acknowledgment

of the impact of colonisation and the existence of systemic bias generating increased risk as the key drivers.

Similar contemporary studies have noted that research on barriers and facilitators to primary healthcare for Māori remain limited. The most recent data has been provided by the Ministry of Health's *Tatau Kahukura Māori Health Chart Book (2015)*. The data noted that Māori adults were more than one-and-a-half times as likely than non-Māori adults to have experienced an unmet need for a GP due to cost and lack of transport was more than twice as likely to be a barrier to accessing GP services for Māori adults as it was for non-Māori adults. In particular, there remains an embedded racist agenda within the predominantly New Zealand/European primary healthcare services (Reid, Cormack & Crowe, 2015). For example, despite an increased focus on reducing health inequities by the New Zealand government, a person belonging to the dominant European ethnic group, was reported in a sub-sample of a broader Hauora Manawa study, to be a protective factor (Pitama, Wells, Faatoese, Tikao-Mason et al., 2011). In contrast, Māori were perceived to be associated with the risk of exposure to differential and discriminatory healthcare.

The re-interpretation of data recommended by Cram et al. (2015) and Reid et al. (2015), support previous studies such as Callister, Didham, Potter and Blakely's (2007) examination of the development of new tools for analysing links between ethnicity and health outcomes. In the 21st century, data that determines health status for Māori is now being challenged and reframed to account for factors such as the effects of differential access to healthcare services. New Zealand provides a microcosm in which to consider ethnicity, indigeneity, migration and intermarriage, and their effects on society, culture, identity and health outcomes (Callister et al., 2007). While ethnic group disparity studies have been useful in the past for policy makers, people actually live in more diverse realities.

Cram et al. (2015) argue, therefore, that empirical data needs to keep pace with such diversity and requires more sophisticated ways of conceptualising and analysing ethnicity data in relation to health disparities and colonisation in New Zealand. Furthermore, whānau participation needs to be considered a key component of the re-interpretation of data when considering the contemporary health status for Māori. As a feature of Māori culture and society, whānau appears within most Māori models of health (Bennet, 2009; Durie, 1994, 2004, 2007, Edwads, 2005; Eketone, 2008; Pere, 1994) and its significance cannot be underestimated in relation to enhancing health outcomes.

Te Tiriti o Waitangi/Treaty of Waitangi

Te Tiriti/The Treaty of Waitangi is regarded as the foundation document that guarantees good health for Māori whānau (New Zealand Board of Health, 1987). The key dimensions of kawanatanga (governorship), tino rangatiratanga (self-determination) and oritetanga (equity) contained within Te Tiriti/the Treaty, provide certain rights and privileges to protect the health and wellbeing of Māori whānau.

The protection of Māori health has been on the political agenda since before the signing of Te Tiriti/the Treaty. For example, in 1832, the Queen of England's British Resident, James Busby was concerned that the Māori population would disappear entirely (Durie, 1989). Together with the Church Missionary Society, Busby convinced the Colonial Office to intervene, as Māori were vulnerable to disease and death due to ad hoc British settlement. Te Tiriti/the Treaty was the proposed solution along with Lord Normanby's instructions to protect the economic, social and health and wellbeing of the native population (Walker, 2004).

Signed on 6th February 1840, Te Tiriti o Waitangi or the Treaty of Waitangi was confirmed. Over 500 Māori chiefs signed the Māori version and just over 50 Waikato chiefs signed the English version. Much controversy has existed over the translation of both versions, suffice to say, the English version surfaced to become the Treaty. The Treaty disappeared from the political landscape in 1877 as a result of the Wi Parata vs the Bishop of Wellington court case. Judge Prendegast ruled that the courts lacked the ability to consider claims based on aboriginal or native title. He declared the Treaty of Waitangi, a 'simple nullity' because it was signed by a civilised nation and a group of savages. In his view, the Treaty had no judicial or constitutional status because Māori were not a nation capable of signing a treaty (Durie, 1998).

Te Tiriti/the Treaty re-emerged after the Labour Minister, Matiu Rata introduced the Treaty of Waitangi Act (1975), and the later Treaty of Waitangi Act (1985). Both Acts allowed for a Tribunal to be established and for hearings to be conducted to hear grievances against the Crown since 1840. Māori pressure groups in the 1980s argued for health to be acknowledged as a taonga under Article 2 of the Māori and English versions of the Treaty, thereby requiring protection. This stance was eventually accepted by the government's Waitangi Tribunal in 1986. Further lobbying from the Standing Committee on Māori Health, argued that the Treaty of Waitangi as a whole, needed to be regarded as a foundation for good health (New Zealand Board of Health, 1987). Māori have come to view the Treaty as the ideal framework for Māori health development. While some have interpreted

the Treaty as affording Māori additional rights or privileges, it is clear that above all else, it is concerned with equity and the promise that Māori can enjoy – at the very least – the same health and wellbeing as non-Māori (Kingi, 2006). Accordingly, government initiatives for Māori were developed on this basis and culminated with the publication of He Korowai Oranga: Māori Health Strategy in 2002 and the refreshed version in 2014 (Ministry of Health, 2014a).

With a focus on reducing inequity, He Korowai Oranga requires the Crown and Treaty partners to work together in good faith. There is also a condition where all agencies and organisations involved in health need to work collaboratively, to create a system with defined processes and mechanisms that achieve improved outcomes for whānau. Latterly, another government initiative called Whānau Ora, has extended He Korowai Oranga, to effectively target areas relevant to Māori concepts of health (Ministry of Social Development, 2010). Whānau Ora focuses on whānau wellbeing and aims for an inter-agency approach to providing health and social services. The goal is to empower whānau as a whole rather than focusing separately on individual family members in isolation.

There has been a degree of ambivalence and confusion about Whānau Ora, whereby it has been labelled either ''big in flowery rhetoric but small on specifics'' (Breaking Views, 2010), or ''family and people-centred care at its best'' (Matheson & Neuwelt, 2012). A study conducted by Boulton and Gifford (2014) acknowledged this perception and interviewed Māori whānau about their views of Whānau Ora. Their findings support Durie's (1995) view that Māori are diverse and cannot be offered a one-size-fits-all approach when engaging with services. The whānau in Boulton and Gifford's study believed that Whānau Ora was a multi-dimensional concept and access to government services was most important to them. To ensure its relevance in the future, He Korowai Oranga was updated in 2014 with the inclusion of the following goals: Pae Ora (Healthy Futures), Mauri Ora (Healthy Individuals) and Wai Ora in addition to Whānau Ora (Healthy Environments) (Ministry of Health, 2014a).

Within initiatives such as Whānau Ora, Te Tiriti/the Treaty is regarded as a source of health equity when honoured, and a source of disparity when breached. Nevertheless, Te Tiriti/the Treaty has been accepted by the government as the founding document of New Zealand, and in so much that Māori health will be considered within a context that is meaningful both in terms of New Zealand's historical development and the contemporary aspirations of Māori whānau (Durie, 1994). The Treaty of Waitangi is now framed as a policy action within Whānau Ora for the purpose of engaging Māori

in the health sector (Ministry of Health, 2014b). How effective health services have been from the perspective of Māori whānau is a key focus area within this study.

Research question and aim

Given the persistent health inequities Māori endure, research is needed to gain insights into what is happening for Māori and their whānau, and how they can keep culturally and spiritually safe when they engage with health services. It is essential to examine and explain the social processes Māori use as there appears to be a disconnection between the reality of health care providers, patients and patients' whānau (Egan et al., 2014). This led me to ask: *what is happening with Māori whānau when they engage with health services?*

This study aims to generate a theoretical explanation of the processes Māori whānau use in health care services to have their cultural and spiritual needs addressed. I used Charmaz's (2006, 2014a) constructivist grounded theory to consider how and why Māori whānau construct meanings and actions when engaging with health services. This approach has meant more than looking at how Māori whānau view their situations, it also acknowledged the interpretive work that the whānau did to keep culturally and spiritually safe. Kaupapa Māori informed the research process, particularly with regard to consultation, data collection, and dissemination of the findings. As a Māori researcher and of Ngāti Kahungunu descent, I was connected to the whānau through whakapapa, therefore, my commitment and connections with the whānau sustained my drive to ensure all aspects of the research process were culturally safe.

Definitions of key concepts

The following concepts are used in this thesis. Each concept is operationally defined for the purpose of this thesis and is considered important to the study. This facilitated the framing of the whānau and researcher's shared understanding of Māori terminology that was used during the interviews.

Māori epistemology

Māori epistemology focuses on knowledge and belief systems based in the Māori world. Māori epistemology relates to the views that Māori hold about their reality and its meaning (Durie, 2003; Edwards, 2005; Walker, 2004). Traditional and contemporary Māori culture, tikanga (customs) and practices are key components of Māori epistemology.

A Māori world view

A Māori world view involves the material and spiritual worlds connecting (Marsden, 2003). Features of a Māori world view include: Māori language, culture, knowledge and values. Marsden uses the term Māoritanga to describe a Māori world view, which is "the corporate view that Māori hold about ultimate reality and meaning" (p. 3). In terms of the effects of colonisation on a Māori world view, a constructivist perspective emphasises the knowledge that has been changed and re-constructed by Māori over time. Despite colonisation, Kaupapa Māori knowledge and processes have persisted (Ka'ai, 2004). Ka'ai notes that one of the most significant features of a Māori world view is the overriding sense of commitment Māori have to the collective interests of the Indigenous community with which they are associated.

Kaupapa Māori theory

Kaupapa Māori theory was developed by Graham Hinengaro Smith (1997) as a tool for guiding research and practice. Kaupapa Māori has been described as a form of critical theory that focuses on emancipation when undertaking research by Māori, with Māori, and for the benefit of Māori (Bishop, 1996). Kaupapa Māori affirms the right to be Māori (Pihama, Cram & Walker, 2002) and has been described as the conceptualisation of Māori knowledge (Hollis-English, 2012; Nepe, 1991). Kaupapa Māori theory is not only applicable to research, it is directly relevant for practical interventions when working with Māori whānau as the ultimate outcome must benefit them and their communities (Moyle, 2014).

Māoritanga

The relevance of this concept within the study helped frame the historical influences on whānau as whānau. There were many instances throughout the study where the term Māoritanga was referred to in a positive sense to maintain whānau integrity against the pressures of Pākēhātanga (European-based culture and norms). From 1961-1978, the New Zealand government focused on integrating Māoritanga within an overall Pākehā framework. With the publication of the Hunn Report in 1961, Māori were conferred equal rights with practices such as 'pepper potting' (Hunn, 1961). This initiative involved placing Māori into state-owned houses among Pākehā, where they would become more Pākehā in their outlook and daily cultural practices. The intention was to have Māori dispersed among Pākehā so that they would become more Pākehā in their behaviour and relinquish their tribal tendencies (Durie, 1998). The policy of integration merely served to disguise the assimilative intent of the government where Māori differences were tolerated as long as they fell within the rules of

the government and Māori acquiesced their tribal traditions of congregating together in large groups.

Whānau

A key concept and process Māori use to connect with a Māori world view is whānau or family. A whānau comprises the most intimate circle of social relationships (Winiata, 1956). The basic social group within Māori society was, and still remains, the whānau where members not only live together, but they also work together as a group (Ka'ai, et. al, 2004) . A whanaunga is a relation or whānau member. In this study, the term whānau is used to refer to whānau and is used inter-changeably with the terms 'whānau' and 'Māori whānau'. Engagement with healthcare services is considered from the collective viewpoint of the whānau, despite treatment being primarily focused on an individual within the whānau. The participants in this study provided data within the collective voice of whānau. At times the participants' whānau was referenced and at other times it was the participant. Both terms are used interchangeably.

Whakawhanaungatanga

Whakawhanaungatanga is the process of establishing relationships. Maintaining one's identity within the whānau, hapū (sub-tribe), and iwi (tribe), and establishing one's relationship to people and places, are all reliant on knowledge of whakapapa (genealogical descent) (Te Rito, 2007). In recent times, various authors have discussed whakawhanaungatanga as a key engagement strategy when working with Māori. Northern elder, Pa Tate (1993) noted that whakawhanaungatanga is the birthplace of the collective. More specifically, whakawhānau refers to 'family' and to 'giving birth', ngā refers to 'the', and tanga refers to the 'collective'. In this study, whānau act as a collective body to ensure their survival and to maintain healthy relationships with each other.

Whakapapa

According to Te Rito (2007), whakapapa provides not just a familial connection, but also connects Māori to the land, stories and histories. The term refers to the genealogical descent of all living things from the gods. Whakapapa is a term used frequently in this study to denote kinship connections within the whānau.

Māori identity

As a construct, Māori identity does not belong solely to an individual but is a product of relationships with other people and social groups. The symbolic representations that Māori identity exhibits, take on significant meanings. As a consequence Māori identity is socially derived and people may be

assumed to be something they are not. Māori identity, therefore, is imbued with certain assumptions and attributes to being a member of that group, when in reality a person may have little knowledge of these conventions (Paringātai, 2014). According to Durie (1995) Māori have diverse realities and they may not necessarily follow the cultural protocols that a healthcare provider may assume they require, simply based on their ethnicity. Durie (1995) does recommend, however, a cultural safety approach whereby the overall level of cultural input should be guided by the expectations of the patient and not the preferences of the service.

In this study, 'being Māori' is considered as an active construction around one's identity. In keeping with Durie's (1995) recommendation, rather than having others ascribe meaning to the individual, being Māori involves a person actively constructing themselves in relation to others. Their constructions include whakapapa links as well as participation as whānau in cultural events, language and customs to name a few.

We-dentity

We-dentity refers to the collective identity many Māori subscribe. Shane Edward's (2009) PhD captured the dynamic *I am because we are* which is referred to as we-dentity. Consistent with Davey and Dwyer's (1984) assertion that the Māori world view, as in Edward's (2009) study, is de-centred, we-dentity is based on viewing the universe as dynamic, complex and continuous with no one centre. Within this paradigm, human beings are not the centre of consciousness and knowledge. Durie (2003) extended this viewpoint and argued that Māori constantly attempt to find meaning in bigger pictures and higher-order relationships. For example, Durie discussed how Māori tend to avoid a micro-focus in their oratory and metaphors, preferring to position themselves within a broader perspective. The term 'centrifugal thinking' was coined by Durie in 2007 when he stated that as Māori "we start at the micro and move to the macro level in a centrifugal fashion. Within centrifugal thinking understanding is achieved through relationships with other things rather than the detail" (p.6). As with Wilson's (2004) study, the discourse generated by the whānau in this study focused briefly on themselves and moved swiftly away from 'I' as an individual to 'we-dentity' with a focus on their relationships and associated responsibilities with, and obligations to, others.

Health workers, providers and services

Healthcare providers and services are in a position of authority when it comes to knowledge about, and navigation of, the healthcare system (Egan et al., 2014). In this study, a range of people working in health came into contact with the whānau. They included doctors, nurses, administrators and

service providers such as Māori providers, specialists and non-government organisations (NGOs). Their work and practices were grounded in the dominant culture and a biomedical world view that focused predominantly on individuals, disease or illness and curing. Consequently, the lack of engagement issues noted by whānau, led them to refer to healthcare providers as a homogenous group. They generally did not distinguish between a health professional, an administrator or an entire department or organisation, for example. For clarity, the terms health worker or healthcare provider is used throughout the thesis to indicate this cluster of people or services, unless the whānau specifically refer to a particular person or service by a profession or title.

Thesis outline

Chapter one has explained how the aims and scope of the study have been developed and provides a justification for the study and an overview of what will be presented.

Chapter two discusses the strategies used to locate the literature. The chapter begins with a discussion on other Indigenous peoples that have encountered similar healthcare challenges to Māori whānau as a result of colonisation. The developing body of knowledge generated from research affecting Māori access to, and utilisation of, healthcare services is examined, where the effects of racism and inequities are most noticeable. Culturally based solutions are presented as frameworks and models to guide health professionals' practice to reduce Māori health disparities. To conclude, the gaps in the literature are identified and the justification for the study is presented together with its anticipated contribution to a body of research.

Chapter three presents the methodological positioning of the research and data collection processes. Justification for using the research at the interface framework which includes Kaupapa Māori and Kathy Charmaz's constructivist grounded theory is provided. An overview of grounded theory is then offered including an explanation of the four stages of analysis and reasons why grounded theory is differentiated from other types of qualitative research. The goals of grounded theory are provided and the focus on formulating hypotheses based on conceptual ideas is promoted. Criticism surrounding grounded theory is referred to and leads onto the methodological split between the two creators, namely Barney Glaser and Anselm Strauss. The use of the constructivist variant that Kathy Charmaz developed as a student of Strauss and Glaser, is then justified. Key concepts that inform Charmaz are explained, namely constructivism, interpretivism, symbolic interactionism and pragmatism.

Chapter four explains the data collection methods and ethical considerations employed by the study. Participant selection and theoretical sampling techniques are explained. Kaupapa Māori protocols are examined to demonstrate how all parties were kept culturally safe. Additional data collection processes and items, such as notes and memos, are then elaborated to provide an audit trail of actions undertaken during the study. Charmaz's use of initial and focused coding processes are explained as methods to organise and integrate data. The constant comparative method used during data analysis and the flexibility it offered, is discussed. The use of semantic relationships between categories is demonstrated to show how the data became more analytic as part of theory development. The process of member checking is clarified and strategies to support researcher reflexivity are deliberated. The process of ethical approval is noted, together with how the storage and destruction of data has been managed. The criteria for evaluating the emerging grounded theory concludes this chapter.

Chapter five presents the findings of the study under the title, **Struggling to be Involved: A grounded theory of Māori whānau and health service engagement**. The theory comprises of two categories: *being Māori* and *surviving the experience*. The categories are presented and an explanation of the properties within each category is discussed. Excerpts from whānau illustrate when the properties occurred within each category.

Chapter six provides a discussion of the findings and their location in existing literature. A review of the aims of the study are examined together with the implications for Māori whānau, health professionals and service development. Limitations and recommendations for further research are also proposed. The thesis concludes with a critique of the rigour of the study according to Charmaz's criteria of credibility, originality, resonance and usefulness.

Conclusion

In conclusion, my personal reasons for engaging in this research have been provided as part of the background to this study. Historical influences on Māori whānau in relation to colonisation and post - World War II era, have been considered and the effects of a growing body of knowledge on historical trauma within Indigenous peoples. The evolving nature of Māori whānau lead to a discussion about contemporary health status and the move towards re-interpreting ethnicity where health inequities have impacted on cultural and spiritual needs. An examination of Te Tiriti o Waitangi/Treaty of Waitangi followed, in relation to the Crown's responsiveness to Māori whānau within the Whānau Ora initiative. Definitions of key concepts and terms referred to in the study have

been provided, namely: Māori epistemology, a Māori world view, Kaupapa Māori theory, Māoritanga, whānau, whakawhanaungatanga, whakapapa, Māori identity, we-dentity and healthcare providers and services.

The next chapter reviews the literature to justify the need for this research. Although a variety of literature on Māori health disparities exists, very little research focuses on the processes that Māori whānau utilise when engaging with healthcare services. Explaining what occurs for Māori whānau is a key aim of this research.

CHAPTER TWO: LITERATURE REVIEW / KO TE WEU

Introduction

The challenges faced by Māori whānau when engaging with healthcare services raise questions about what is currently known about how they manage that process. This chapter begins with a discussion on the strategies used to locate the literature to clarify their inclusion in this chapter. A broad discussion follows about where other Indigenous peoples have encountered similar healthcare challenges to Māori whānau as a result of colonisation. The developing body of knowledge generated from research affecting Māori access and utilisation of healthcare services is examined, particularly where the effects of racism and inequities are most noticeable. Culturally-based solutions are also critiqued as frameworks and models to guide health professionals' practice and reduce Māori health disparities. To conclude this chapter, gaps in the literature are identified and justification for the study is presented together with its anticipated contribution to the body of research.

Locating the literature

National and international literature were drawn from several database searches together with government and non-government documents, texts, theses and journal articles from 2000-2015. Databases researched included Google Scholar, CINAHL, CINAHL Plus, SCOPUS, MEDLINE, Pro-Quest Central, Academic Search Premiere, Web of Science and AUT Scholarly Commons. Combinations of search terms for Māori whānau healthcare experiences included: *Māori, health, whānau, healthcare, patient experiences, hospitalisation, grounded theory and Kathy Charmaz's constructivist grounded theory.*

The inclusion criteria included those articles that focused on whānau and healthcare experiences within the previous five to ten years. As my interest was in the collective experience of Māori, the exclusion criteria, therefore, included health research that focused on individual Māori as whānau. However, what I soon found was that very little research existed that canvassed Māori whānau experiences of healthcare, as the majority of articles related to Māori as individuals. The literature in this area was then included to assist with identifying gaps in the literature on Māori whānau. When health was used as a keyword, the search criteria included a focus on health treatment within primary and secondary healthcare settings.

When the term Charmaz's constructivist grounded theory was searched two studies were identified. The first study mentioned the use of Charmaz's constructivist grounded theory within Awatere's (2011) examination of non-Māori osteopaths' treatment of rural Māori. The analysis of data, however, utilised thematic analysis. The findings were relevant to my study as the osteopaths viewed engagement and effective relationship building as vital to their clinical practice with rural Māori. Further research with this occupational group is needed as they comprise a small percentage of healthcare providers in New Zealand, and are beginning to have their practice become more visible with the support of Māori researchers such as Awatere. Second, Stuart's (2009) master's thesis drew on Charmaz's constructivist grounded theory to explain how Māori women negotiated drinking alcohol during pregnancy. The focus, however, was on individual women and not on Māori whānau. Nevertheless, the findings were relevant to my study as 'trading off' was a core social process the whānau used to make decisions about drinking in pregnancy. Stuart argued that trading off is a theory that Māori use to manage their health promoting or health risk-taking behaviours surrounding alcohol consumption. Other processes identified by Stuart, involved the whānau taking control of their role as women which were at times at odds with cultural expectations of gender roles.

This dearth in literature prompted me to include different sources to explore my substantive area. According to Charmaz (2014a), it is important to acknowledge the multiple realities represented by various standpoints for scientific enquiry and to recognise that there are different ways to view and report on topics. Extant contributions from an international perspective and fields of social science were included such as nursing, social work, psychology, and Indigenous research. Information generated from these fields provided a backdrop and contributed towards sensitising concepts on Māori whānau experiences of healthcare.

What the literature revealed

A range of the following keywords were then included to determine a connection with other Indigenous cultures' experience of healthcare services. The terms used were: *Indigenous, Māori health knowledge, inequities, inequalities, racism, patient safety, cultural safety,* and *cultural competence*. This search resulted in over a hundred articles, so I commenced the review by examining literature from international authors and funnelled the remaining literature by including categories such as Indigenous/Aboriginal health and inequities in health, minority groups, Pacific health, New Zealand and Māori health. I excluded categories that were not specific to health, which resulted in a systematic process for managing the vast amount and range of literature related to

Māori whānau experiences of healthcare. The following discussion identifies and examines the literature according to the key terms described at the beginning of this chapter.

Indigenous health, racism and inequities

Despite advances in modern technology, health disparities for Indigenous peoples living within white settler societies still remain (De Souza, 2015). Socio-economic factors have been considered to either help or hinder access to healthcare (Davis et al., 2006). However, for Indigenous peoples, more pervasive factors come into play when receiving health care, such as institutional, interpersonal and internalised racism (McDermott, 2014). Institutional racism occurs when there is differential access to goods, services and opportunities based on race (Reid & Robson, 2007). The Health Equity Assessment Tool (HEAT) was developed by the Ministry of Health to help health workers understand the influence of institutional racism upon their practice (Signal, Martin, Cram & Robson, 2008). The HEAT tool encourages the evaluation of equity within policies, programmes or services as part of routine on-going quality improvement within health services. The Whānau Ora Health Impact Assessment (HIA) tool was developed at the same time by the Ministry of Health to complement the HEAT tool (Ministry of Health, 2007). The Whānau Ora HIA assesses the positive and negative impact of policies on Māori and aims to identify ways in which these could be enhanced or adapted.

Inter-personal racism includes differential assumptions about the abilities, motives and intentions of people according to their race and subsequent discrimination towards them on a personal level (Jones, 2000). This type of racism has been associated with Māori receiving less than optimal healthcare as it occurs at the inter-personal level between healthcare worker and patient (Harris et al., 2006, 2012, 2013). Internalised racism involves the acceptance of negative messages about self-worth based on race (Reid and Robson, 2007). Pitama, Huria and Lacey (2014) suggest clues to these negative messages are present in the clinical setting where Māori patients may say, "I'm not into that Māori stuff" (p. 113).

A constructivist grounded theory project in Canada noted that while health disparities experienced by Indigenous peoples reflected the influence of multiple factors, increasing evidence has highlighted health practitioners' contribution to disparities in healthcare outcomes (Thurston et al., 2014). For example, Thurston et al. noted that healthcare providers framed Indigenous patients as 'toughing it out' with their chronic health conditions and lacked 'buy-in' with healthcare providers. Such statements revealed the racist attitudes held by healthcare providers that have led to Indigenous patients 'working around' the system, often resulting in long delays in treatment.

Thurston et al. developed a framework to support culturally safe relationships and environments for healthcare providers to simultaneously engage and retain relationships with patients.

Within New Zealand, Kearns, Moewaka Barnes and McCreanor (2009) challenged researchers to name and claim racism as a public health issue. The authors extended Krueger et al., (2004) research where race was added as a contributing factor within the social determinants of health framework. The authors argued that if policy planners and researchers are silent on the issue of racism, then their silence supports its continuation. Strategies were provided to achieve equitable outcomes for Māori. For example, naming a particular policy, procedure or process as racist would tend to make it less nebulous and more tangible to confront. Actions could then be taken to resolve the issues such as anti-racism education.

Māori experience of health services

There is a limited, albeit growing body of research on Māori experiences with healthcare services. Most of the literature has focused on barriers to accessing healthcare for Māori. Quantitative literature has highlighted socio-economic factors, higher deprivation and lower heath status for Māori as barriers to healthcare (Maclennan, Wyeth, Davie, Wilson & Derret, 2014; Marriott & Dalice, 2014; Reid & Robson, 2007). Furthermore, once Māori received healthcare within a hospital setting for example, unplanned readmission rates were higher than for non-Māori (McElnay, 2016; Rumball-Smith et al., 2013).

One explanation for unplanned re-admission rates has been considered by Jansen and Smith (2006). The authors examined the communication style of primary healthcare providers towards Māori patients. They found that Māori accessed emergency services at the same rate as non-Māori because of protocols that were in place to ensure patient turnover. In the primary care setting, however, the communication style by providers varied according to the ethnicity of the patient. Māori reported less satisfaction with the service where there was less 'concordance' in the relationship with the provider. In other words, less time was spent communicating effectively with Māori patients which led to decreased adherence to treatment and a lack of follow up. A study of GPs' perception of Māori patients supported Jansen and Smith's study where Māori were blamed for their poor health status (McCreanor & Nairn, 2002a, 2002b). As with other Indigenous peoples, the effects of colonisation (discussed in Chapter 1), and the lack of culturally acceptable services available for Māori, have also contributed to poorer health outcomes and a reluctance to utilise health services (Kerr, Penney, Moewaka Barnes, & McCreanor, 2009; Ring & Brown, 2003; Tayal, 2003).

Access and patient journey

Previous negative experiences when accessing healthcare have been shown to impact on a person's decision to access healthcare services again in the future. When individuals feel they have been poorly treated they are reluctant to access that service at a later date (Cram, et al., 2003; Jin, et al., 2008; Wilson & Barton, 2012). Bolitho and Huntington's (2006) study provided an insight into the experiences of four Māori families when accessing health services for their children. These findings highlighted that despite changes in the New Zealand health system aimed at improving accessibility and affordability for Māori families, mistrust existed.

Similar experiences have been examined and explain how to overcome barriers for Māori accessing health services. For example, Cram (2014) studied healthcare providers' views on Māori cancer, diabetes and cardiovascular health. Cram found that Māori access to healthcare was not only about entry into healthcare, but also their journey through healthcare. Overcoming financial and logistical barriers to access such as cost and transport were important. Facilitating Māori access through intermediaries such as community health workers, navigators and health practitioners who had the time to build relationships of trust with Māori patients and their whānau was recommended.

What appears to be emerging from the literature at this point, (Indigenous health, racism, inequities and Māori experience of health services from 2002-2014) is a re-occurrence of racism from healthcare providers towards individual Māori. With the exception of Bolitho and Huntington's (2006) study which focused on families, the literature has not yet captured whānau actions and processes when engaging with healthcare services. My study aimed to fill this gap so that whānau voices can be heard and acted upon.

Hospital settings

The following studies by the Asthma Foundation (2009), Davis et al. (2006), McKinney (2006), Wilson and Barton (2012) have all focused on Māori within hospital settings. The Asthma Foundation commissioned a literature review on respiratory health for Māori. The review found that asthma was the most common cause of hospital admission for Māori, and that Māori females were hospitalised at twice the rate of non-Māori females. Māori males were hospitalised at a 73% higher rate than non-Māori males and across all age groups. Māori rates were consistently higher than for non-Māori. The review concluded that low access to optimal treatment and prevention services in the community was a contributing factor to high rates of hospitalisation for Māori.

Davis et al. (2006) undertook a nationally representative cross-sectional survey of admissions to general public hospitals with more than 100 beds providing acute care. Māori accounted for 15% of admissions and were on average younger, more likely to be from deprived areas, had a different case mix, and resided in hospital for a shorter stay compared with non-Māori. Overall, after age standardisation, 14% of admissions for Māori were significantly associated with an adverse event, compared with 11% for non-Māori. For preventable, in-hospital events, this disparity persisted after controlling for age, other socio-demographic factors, and case mix. The findings suggested that the hospital care received by Māori was poorer than for non-Māori.

McKinney's (2006) qualitative study about Māori admissions to Auckland Hospital found an overall negative experience by the whānau. McKinney concluded that despite cultural safety education programmes becoming standard throughout the schools of nursing, there was little effect in terms of outcomes for Māori patient experiences within the hospital setting. McKinney recommended a review of graduates' practice, as her study revealed a disconnect between the undergraduate programme and the implementation of cultural safety in practice. Wilson and Barton (2012) utilised a Māori-centred approach and combined quantitative and qualitative data to explore Māori experiences of hospitalisation in surgical or medical settings. These authors also examined how these experiences influenced their length of stay. Consistent with Davis et al. (2006), they also found that Māori had a shorter than average length of stay than non-Māori. Combined with the lack of culturally responsive care and a belief by the whānau that hospitals were not conducive to healing, early discharge became the norm. The results from this study reinforced the finding of McKinney's study that healthcare providers needed to attend to the caring component of service delivery to the same level as curing.

Māori children and youth

The New Zealand Child and Youth Epidemiology (NZCYE) research group has provided child and youth health reports to district health boards since 2005. In 2013, NZCYE published a report focusing on the health needs of Māori children and young people with chronic conditions and disabilities (Ministry of Health, 2013b). The report titled *Te Oho Ake (To Wake Up),* noted that hospital admission rates for medical conditions and injuries were higher for Māori than non-Māori. Exposure to household overcrowding and cigarette smoking in-utero and during childhood, remained much higher for Māori than non-Māori. Access to mental health services for schizophrenia and other psychotic disorders was at a much higher rate than non-Māori. The report recommended an inter-sectorial focus to reduce the inequalities in health experienced by many Māori children and young

people, such as improving the quality of housing stock including insulation and heating. In 2014, the report was updated and titled *Te Oho Ngā Ake (The Awakening)* and concluded that the growing rate of ethnic inequalities for Māori children and youth could be reduced with specific interventions such as immunisation at 24 months of age (Craig et al., 2014).

The Expert Advisory Group on Solutions to Child Poverty (EAG) report *Reducing Child Poverty in Māori Whānau* (2012), supported the inter-sectorial approach recommended by Te Oho Ake (Office of the Children's Commission, 2012). EAG found that Māori children were over-represented in child poverty statistics and also recommended Māori-centric data to capture Māori concepts of poverty and wealth. For example, terms such as pōhara (the condition of being poor), tōnui (prosperous in relation to the collective good), and kōkiri (coming together for a collective purpose) were used to inform the development of Māori-centred measures. The authors argued that such an approach would inform Māori-centred adaptive solutions to child poverty.

Labelling

Labelling theory suggests that particular social groups are more likely to be labelled than the general population (Scheff, 1999). The following authors found that being labelled as either disabled or a victim of stroke was counter-productive to dealing with relevant health issues. Māori whānau experience of caring for members disabled from the effects of stroke by Corbett (2003), and the examination of cultural needs for Māori with disability (Hickey, 2008), noted similar findings. For Hickey, the whānau were more amenable to the term 'whānau hauā' instead of being considered disabled, which inferred experiences of marginalisation and discrimination. Having whānau at the beginning of the term 'whānau hauā', identifies Māori as whānau members first, while the term hauā refers to the environment. Joined together, whānau hauā encompasses the whānau journeying together to deal with the environmental change to them as a collective. Similarly, Corbett found the labelling surrounding the term stroke was reductionist and did not encompass other aspects of the person's health, strengths and wellbeing.

The collective nature of whānau is highlighted by Hickey (2008) and Corbett (2003) as a protective factor when one of the members encountered a less than desirable health outcome. Both studies, therefore, focused on the whole whānau experience of a health condition which is similar to my study's aims and objectives. My study, however, has not set out to examine the whānau experience through the lens of a condition or disability. The learnings from Hickey and Corbett have, nonetheless, helped frame the research process when interviewing whānau in a group setting.

Whakawhanaungatanga / relationship building

A study by Slater et al. (2013) examined Māori patients and whānau cancer journeys for identified factors that facilitated or inhibited access to, and through, cancer care services. Primary care played a key role in supporting continuity of care. Given the long-term relationship with health providers, interpersonal rapport facilitated a more positive experience of the cancer care journey. Longstanding relationships with GPs and Māori health providers, assisted patients and whānau with the provision and understanding of information, alongside practical support.

A longitudinal study of whānau experiences of childhood asthma utilising a Kaupapa Māori approach revealed positive outcomes for the whānau (Jones, Ingham, Cram, Dean, & Davies, 2013). These authors noted that the prevalence of asthma for Māori children remains the highest in the world. Furthermore, ethnic differences in asthma symptom prevalence in New Zealand have widened, with asthma symptoms and hospitalisation rates consistently higher for Māori across all age groups, especially children and adolescents. The study occurred over one year and successfully achieved a 100% retention rate of all the whānau over this period. The high engagement rate of the whānau was a key finding from the study as well as the use of whakawhanaungatanga by providers with whānau.

Jones et al. (2013) argued that an Indigenous approach supported the whānau to have their voice heard due to the collaborative and collective nature of the methodology. Utilising Kaupapa Māori, including whakawhanaungatanga within the clinical context, is recommended so that culturally relevant interventions can reduce the disparities within childhood asthma for Māori, since the use of whakawhanaungatanga or relationship building is important when working with Māori patients. It will be interesting to see if these recommendations have been implemented by GPs, since this study occurred four years after these guidelines were published.

The interpersonal relationships highlighted by Slater et al. (2013) and Jones et al. (2013) and the Kaupapa Māori methodology are key areas that have also informed my study. Relationship building is important to my study, as I consider this process to be an integral part of engaging in a culturally-safe manner with the whānau.

Māori men

Williams et al. (2003) examined Māori men's perceptions and experiences of health-seeking for prostate health problems. The Wellington-based qualitative study interviewed 20 men. A number of

barriers were described for not seeking prostate healthcare, and the majority of these were related to the health system not dealing appropriately with cultural issues. Solutions offered by whānau were also largely culturally related, for example, whānau, te reo Māori (Māori language), rongoā (traditional Māori medicine) and more Māori health professionals. The results reaffirmed the need for attention to culturally safe healthcare and access to appropriate prostate health information. The findings have implications to countries with Indigenous populations who share similar health experiences to Māori.

The Hauora Tāne study utilising Kaupapa Māori, interviewed 66 Māori men from throughout New Zealand (Jones, Crengle, & McCreanor, 2006). The study involved the first phase of a larger study to determine what aspects of the interviewing process would maintain the mana (integrity) of the men as members of whānau. The authors acknowledged the negative statistics that portrayed Māori men presenting to tertiary healthcare services in an acute state of ill health. The study aimed to develop a framework that would capture the voice of the whānau using Kaupapa Māori strategies such as whanaungatanga (building relationships), manaakitanga (showing concern) and tapu (showing respect). The second phase of the study was not available during this literature review. The recommendations from the study, however, are relevant to my study in terms of embracing tikanga Māori philosophy and protocols when engaging Māori in the research process.

Whānau violence

Health agencies' responsiveness to Māori mothers experiencing violence from children was investigated by Ryan and Wilson (2010). The impact of the violence on the whānau was analysed using a Kaupapa Māori approach. The findings highlighted a lack of assistance and responsiveness by support and health agencies. The important role of nurses in facilitating whānau ora (family wellbeing) for the women was recommended. This research contributed an Indigenous perspective to the growing literature on child to mother violence, and provided direction for future research.

Māori women

Wilson (2008) explored Māori women's interactions with health services utilising grounded theory and a Māori-centred approach. Wilson asked 38 Māori women about what was important for their health and wellbeing and their interactions with mainstream health services. A Glaserian grounded theory explained the weaving of the women's health and wellbeing. The theory partially explained the importance of determining Māori women's cultural world views and practices when assessing and planning interventions. Cultural safety and cultural competence were explored as vehicles to

improve culturally appropriate and acceptable healthcare for Indigenous women. My study also uses Kaupapa Māori and grounded theory and examines the processes used by Māori whānau as opposed to individual women that have received a healthcare service.

Māori sole mothers' primary care experiences were explored by Lee and North (2013). The study utilised a general qualitative design informed by Kaupapa Māori to interview seven Māori sole mothers. The major barrier to access reported was cost as well as transport difficulties and location or scheduling of services. Child-related issues also posed a barrier, including prioritising children's needs and childcare over personal health needs. This study, although informed by Kaupapa Māori, did not identify any cultural issues as barriers to access for the whānau. Nevertheless, the exploration of an under-researched topic has started to build a body of knowledge within this important area.

A study of maternity care involving 44 pregnant or recently pregnant young Māori women aged under 20 years, found that despite their youth and possible implications of finding out they were pregnant, most whānau were proactive in taking steps to confirm their pregnancy with primary care services, such as the GP or a school or community-based youth-specific health service (Makowharemahihi et al., 2014). However, their positive health-seeking behaviour was often met with inadequate information and support for young pregnant women navigating the next steps in their maternity care journey. The study used the experiences of the whānau to identify where, and at what point, the system and services were not working well for these women. Recommendations included emphasising an integrated seamless model of care with maternity care beginning at the first interaction with healthcare services. For example, GPs could take responsibility for screening in the first trimester and navigation to a lead maternity carer.

The commonly held perception that Māori are not engaging with healthcare services is dispelled in the studies by Wilson (2008), Lee and North (2013) and Makowharemahihi et al. (2014). Once access is gained, the information is not supporting the healthcare journey for whānau which highlights once more, the lack of cultural responsiveness of healthcare services towards Māori.

Disparities

As previously noted, disparities in health status between different groups within a population are found worldwide. These include disparities by age, gender, socio-economic position, ethnicity, impairment and geographical region. However, compared to other Indigenous populations, Māori

are reported to have the poorest health outcomes than any other population groupings (Bramley, Hebert, Tuzzio, & Chassin, 2005). Bramley et al. (2005) examined the health statistics from the Indigenous populations in the United States (American Indians/Alaska Natives) and New Zealand (Māori). In both countries, poorer health outcomes were reported among their respective Indigenous populations. However, in almost every health status indicator assessed, disparities were more pronounced for Māori people than for American Indians/Alaska Natives, despite significant gains in the health measures investigated over recent decades.

The Ministry of Health's *Tracking Disparity* report analysed trends from 2001-2014 (Blakely, Tobias, Atkinson, Yeh, & Huang, 2007). A key finding from the report is that inequality in health has decreased slightly, however, Māori are still over-represented in the following statistics: mortality, cardiovascular disease, stroke, cancer, lung disease, unintentional injury and suicide. The report recommended a number of strategies to reduce the disparities for Māori which included promoting cultural safety policies, special measures to combat racial discrimination and culturally appropriate health promotion programmes.

Stroke is a health issue highlighted by the *Tracking Disparity* report and was investigated by Feigin, McNaugton, and Dyall (2007). Feigin et al. stated that stroke is becoming more of a disparity for Māori over time. The researchers found that approximately 800 Māori were admitted to hospital each year with stroke and 140 per year died from this condition. The researchers highlighted an urgent need to introduce effective measures and delivery systems to reverse this trend and improve Māori health outcomes. In 2012, Harwood, et al. began to address this concern with the development of the Hua Oranga outcome tool to facilitate self-directed rehabilitation after stroke for Māori. Orginally developed as an outcome measure for Māori experiencing mental illness, Hua Oranga (translated as fruits of health) was considered useful to assess other health conditions. It is based on a holistic Māori view of well-being, Te Whare Tapa Wha; taha wairua (spiritual), taha hinengaro (mental), taha tinana (physical), and taha whānau (family).

Gillies, Tomlin, Dovery, and Tilyard (2013) investigated over 80,000 New Zealand children's asthma medicines and treatment plans. The study found disparities where Māori children under the age of 15 years were not offered more intensive treatment options for their asthma compared to non-Māori. The healthcare provider was more likely, therefore, to prescribe oral steroids to control asthma rather than other more intensive treatment options. As a result Māori were more likely to be hospitalised for asthma (5.1%) compared to non-Māori (2.8%). The researchers recommended a

review of treatment options for Māori to include more comprehensive assessments of asthma which would likely prevent a more costly admission to hospital and stress on the whānau.

According to health statistics noted in this discussion on disparities, Māori carry a disproportionate burden of morbidity and mortality (Robson & Reid, 2007). Racism and other forms of exclusion, such as class and gender, are seen as important determinants that affect marginalised populations and manifest as health disparities (Wilkionson & Marmot, 2006). The *Tracking Disparity* report noted a slight decrease for Māori. The research by Feign et al. (2007) and Gillies et al. (2013), however, stressed an urgent need towards developing culturally responsive treatment options and health promotion strategies to improve health outcomes for Māori.

Health inequities

Health inequities are a universal phenomenon related to the history and organisation of societies in which people live (Dew & Matheson, 2008). Described as unnecessary, avoidable and unjust (Whitehead, 1992), inequities in health are attributed to the unequal distribution of, and unequal access to, the social and economic determinants of health. Access to housing, education, employment and income all have an obvious impact on the wellbeing of people, but health outcomes are also influenced by gender, geographical place, age, occupation, impairment and ethnicity.

The term 'inequities' is preferred in the literature as not all inequalities are unexpected or unfair. For example, men get prostate cancer but women cannot, and likewise women get cervical cancer and men cannot. These are inequalities (differences) but not inequities (unfair or unjust differences). Health equity is defined as "the absence of systematic disparities in health (or in the determinants of health) between different social groups who have different levels of underlying social advantage/disadvantage – that is, different positions in a social hierarchy" (Braveman & Gruskin, 2003, p. 254). The term inequalities is widely used to mean inequities, as are the terms disparities and gaps. Although each of the terms is used interchangeably within the literature (Cormack & Robson, 2010; Robson & Harris, 2007), inequities is located more within the literature on social justice and rights frameworks (Lundy, 2011; United Nations, 2006).

In New Zealand, the most persistent and compelling inequities in health exist between Māori and Pākehā, despite a recent increase in life expectancy (the gap in 2014 was 7.3 years) (Statistics New Zealand, 2014). Māori bear a disproportionate burden of risk, morbidity, mortality and disability in

all of the major diseases: diabetes, cardiovascular disease and cancer (Robson & Harris, 2007; Cram, 2014). The negative statistics for Māori in education, housing, employment and income as well as health, are well documented (Robson & Harris, 2007). Inequalities in socio-economic status are illustrated by the different deprivation profiles of Māori and Pākehā. More than half of the Māori population reside in the most deprived areas (deciles 8-10), while Pākehā are evenly distributed across all profiles with an upward trend towards the least deprived areas (deciles 1 and 2) (Reid, Robson, & Jones, 2000). Within Hawke's Bay where the whānau resided, Māori comprised 25% of the district's total population and were youthful with a median age in 2013 of 23.6 years. Life expectancy was 75.9 years for Māori females (7.7 years lower than for non-Māori females) and 71.7 years for Māori males (8.2 years lower than for non-Māori males) (Robson et al., 2015). Matched with negative health outcomes, this information confirms the link between social and economic positions and health.

Studies show that irrespective of education, occupation and income level, Māori still have poorer health than Pākehā. Findings in the *Decades of Disparity* report (Fawcett et al., 2006) confirmed that the socio-economic position only explained half of ethnic inequalities in mortality. Issues of Māori access to health services may account for the other half (Shaw & Deed, 2010). Institutional and personal racism has been identified as a barrier to Māori accessing healthcare services (Bécares, Cormack, & Harris, 2013; McLeod, Blakely, Kvizhinadze, & Harris, 2014). This barrier is borne out from studies noting differential treatment and a difference in the quality of care for Māori within health services (Harris et al., 2012; Harris et al., 2006; Huria, Cuddy, & Pitama, 2014).

Socio-economic inequalities between Māori and Pākehā do not fully account for the health inequalities between these two groups (Howden-Chapman & Tobias, 2000; Sporle, Pearce, & Davis, 2002). Indeed, socio-economic explanations do not take into account the factors that lead to the marginalisation of Māori and the unequal distribution of resources by ethnicity to begin with. It can be argued, therefore, that both interpersonal and institutional racism contributes to Māori and Pākehā health disparities in New Zealand. Racism refers to "a mix of prejudice, power, ideology, stereotypes, domination, disparities and/or unequal treatment" (Berman & Paradies, 2010, p. 228). Various forms of racism have been described with the two main types noted as institutional and interpersonal. Institutional racism occurs when organisational policies and practices discriminate based on race and tend to be relatively invisible compared to interpersonal racism, which is directed on a one-to-one level through verbal, physical and emotional interactions (Moewaka Barnes, Taiapa, Borell, & McCreanor, 2013). Jones (2000) and Reid, Robson and Jones (2000), noted that institutional

and personally mediated racism are not mutually exclusive of one another. Both processes tend to co-exist where individuals leverage off the institution's policies and procedures to support their internalised, personal actions towards someone of another race.

In a survey of over 10,000 New Zealanders, Māori reported high levels of racism when treated by a health professional (4.5% Māori vs. 1.5 Pākehā) (Harris, Cormack, & Stanley, 2013; Harris et al., 2012). Harris et al. showed that deprivation and racism have contributed to inequalities in health outcomes for Māori. Furthermore, 14% of hospital admissions for Māori were as a result of poor practice by health professionals, compared with 11% for Pākehā and Māori were at a high risk of something going wrong in their treatment in hospital. These findings suggested that if Māori were categorised as European only, then they would experience significantly lower levels of racial discrimination. Being identified as European only, was associated with health advantage and receiving optimal care. This finding is consistent with international data where racism is considered as a determinant of health (Harris, Cormack, & Stanley, 2013).

Culturally based models to reduce Māori health disparity
Hera (2013), Vernon and Papps (2015), and Wilson and Hickey (2015), and Pitama, Huria and Lacey (2014) have offered a discussion on frameworks and models to reduce Māori health disparities. They include: cultural safety, cultural competence, patient-centred care and cultural responsiveness. An examination of each concept follows.

Various frameworks and models have been referred to within the literature that seek to reduce Māori health disparity. Perhaps the most well-known model developed by Sir Professor Mason Durie (1994), depicts the walls of a four-sided house or whare called Te Whare Tapa wha. Each side or wall of the whare represents Māori health and wellbeing, namely, te taha whānau (family wellbeing), te taha tinana (physical wellbeing), te taha hinengaro (mental and emotional wellbeing), and te taha wairua (spiritual wellbeing). If a health worker does not consider each side of the house when treating Māori then a holistic health assessment and treatment regime will not occur. Another model developed by Māori nurses is called Te Kapunga Pūtohe (the restless hands) (Barton & Wilson, 2008). This Māori-centred nursing practice model uses the hands to illustrate how Māori knowledge, together with nursing knowledge, allow the voices of Māori to be heard and in turn, inform best practice and improve Māori health outcomes.

Within nursing education, cultural safety emerged in the 1980s and developed to challenge nurses' power and to support healing (Wright, 1995). The concept has been through many iterations to keep pace with the changing expectations of the people receiving care. The latest definition from the Nursing Council (2011), proposed that cultural safety would exist if a nurse interacted with patients in such a way that it satisfied the cultural needs and wellbeing of the patient or family:

> The effective nursing practice of a person or family from another culture, is determined by that person or family. Culture includes, but is not restricted to, age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability. The nurse delivering the service will have undertaken a process of reflection on his or her own cultural identity and will recognise the impact that his or her personal culture has on his or her professional practice. Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and wellbeing of an individual (Nursing Council of New Zealand, 2011, p.x).

Te Tiriti o Waitangi/The Treaty of Waitangi provides a framework, which initially aimed to shift power in the healthcare arena from nurses to those receiving care. According to Ramsden (1990), this transfer of power would enable the recipients of care to define culturally safe practices. In other words, the experience of patients determines whether or not a nurse is safe to attend to their cultural needs.

Cultural safety is now more complex and includes those beyond the nursing profession, in disciplines such as physiotherapy (Haswell, 2002; Main, McCallin, & Smith, 2006), psychology (Waitoki, 2012), osteopathy (Awater, 2011), occupational therapy (Watson, 2006), medicine (Durie, 2011; Pitama et al., 2014) and midwifery (Wepa & Te Huia, 2006, 2015; Williams, 2007). Cultural safety has also been explored within Australia (Baker, 2007), the United Kingdom (De & Richardson, 2008) and Canada (Browne et al., 2011). The perspective dominating cultural safety literature across these professions and countries, however, is that of the health professional rather than the experience of the service user (Baker, 2008; Richardson, 2004; Wilson, 2004). It is interesting to note that while cultural safety best practice guidelines and intervention support have been developed and implemented in New Zealand, there has been little improvement in service delivery for patients, especially for Māori (Cram, 2014).

In recent times, the literature has considered other related concepts such as Hera's (2013) patient-centred approach to healthcare which argued that competency requires safety and safety requires competency. Therefore, a patient-centred approach needs to be central to both cultural safety and cultural competency. Vernon and Papps (2015) were of the same view and noted that the discourses surrounding cultural safety and cultural competence are different and that the differences do not matter. These authors aligned their argument to the Nursing Council of New Zealand's competencies to practice and the Health Practitioners Competence Assurance Act (2003). They concluded that the issue is about the competence of all health practitioners to respect cultural differences and provide competent and safe care to health consumers.

Wilson and Hickey (2015) advocated for a culturally responsive approach that draws on knowledge, action and integration (KAI) to reduce Māori whānau health disparities. KAI involves health workers utilising knowledge about cultural safety and Māori values and beliefs to inform practice. The culturally responsive approach is aligned with international literature that places emphasis on the capacity of the healthcare providers to respond. In practice, this approach relies on healthcare providers utilising a set of tools – questions and skills for negotiation to elicit pertinent cultural knowledge – which they can incorporate into their interactions with patients from diverse cultural backgrounds. A similar approach has been developed by the Victorian government in Australia where a cultural responsiveness framework requires the healthcare provider to ask about the patient's history of present illness, their health beliefs and use of alternative treatments, expectations of care, linguistic challenges, and culturally based family dynamics to guide decision-making processes (Victorian Government, 2009). Hera (2013), Vernon and Papps (2015), Wilson and Hickey (2015) and the Victorian government supported the view that it is important for physicians to not only be aware of cultural factors, but to also demonstrate an ability to manage and negotiate them in order to improve health outcomes.

Within the medical setting, Pitama, Huria and Lacey (2014) developed the Indigenous Health Framework to implement cultural competency and cultural safety for Māori patients/whānau. The framework is based on a combination of other models, namely, the Hui Process (Lacey, Huria, Beckert, Gilles, & Pitama, 2012), the Meihana model (Pitama, et al., 2007) and the Calgary-Cambridge model (Kurtz, Silverman, Benson, 2003). The Hui Process involves relationship building or whakawhanaungatanga with Māori patients. The Meihana model extends history taking and involves addressing racism, colonisation, migration and marginalisation. Māori beliefs, values and experiences are explored and the practitioner is encouraged to enquire about tikanga (protocols), whānau (family), whenua (land) and ahua (personal indicators). The Calgary-Cambridge model

recommends including the patient perspective alongside the biomedical perspective of disease. The Indigenous Health Framework is taught to undergraduate medical students during their fourth to sixth year of study. The framework has been evaluated and has been rated favourably as a clinically relevant framework that supports medical graduates to work effectively with Māori patients and whānau (Pitama, Huria, & Manna, 2012).

Bécares et al. (2013), found that when Māori live in close proximity to each other, it acts as a protective factor against racial discrimination. Although the authors have not identified this as a culturally based model, the term 'ethnic density' supports the notion that a higher concentration of people from the same ethnic background increases self-reporting of good health and decreases reports of racial discrimination. Similar findings have been found with other Indigenous peoples where there is a spiritual connection to the land and they live in close proximity to each other.

An example of a culturally responsive initiative was a pilot conducted in 2011 by the Ministry of Health. The pilot aimed to reduce cancer treatment inequities for Māori living in rural areas. Auckland, Rotorua and the west coast of the South Island were sites used, as Māori were over-represented in these districts. The pilot noted that culturally based patient support programmes reduced barriers and inequalities, increased patient and whānau satisfaction with healthcare providers, and improved cancer outcomes in terms of a self-perceived increase in quality of life. Of special mention in the report, was the quality of relationships that were formed and that built on trust and openness and a way of delivering services that made service users feel as if they were more than just a 'cancer patient'. Service users demonstrated their satisfaction in a number of ways, some of which contributed to service sustainability (for example, volunteering to work with the cancer support team; engaging in service promotion with friends and whānau) (Ministry of Health, 2011a).

Conclusion

This chapter has discussed the strategies used to locate the literature, to clarify their inclusion in this chapter. The lack of literature on the collective experience of Māori whānau engaging with healthcare services and Charmaz's constructivist grounded theory have been highlighted. The effects of colonisation on other Indigenous peoples has been explored and compared with the healthcare challenges faced by Māori whānau. The developing body of knowledge generated from research affecting Māori in general as well as children, youth, women and men has been examined and the negative effects of racism, labelling and inequities have been deliberated. Culturally based solutions,

frameworks and models such as whakawhanaungatanga/relationship building, whare tapa wha, cultural safety, cultural competence, cultural responsiveness, Te Tiriti or Waitangi, Te Kapunga Pūtohe, KAI and the Indigenous Health Framework have been critiqued, as each considers different aspects of Māori ideology to guide health professionals' practice to reduce Māori health disparities.

Gaps in the literature have been identified and the justification for the study has been presented together with its anticipated contribution to the body of research. The pre-data literature review identified gaps so that a theory explaining what is happening for Māori whānau when engaging with health services could be developed. With the exception of single health conditions such as cancer, diabetes or cardiovascular health for example, the literature did not consider the processes that Māori whānau used to navigate through the health system. The following key areas, therefore, that have arisen from the literature, have informed the next phase of the research. They include:

- the paucity of information about Māori whānau experiences of healthcare providers
- a growing focus on improving access for Māori whānau to healthcare providers, and,
- a concerted effort to stop racism towards Māori whānau.

It is these three aspects that have informed the development of the methodology and methods framework. In the following chapter Charmaz's (2014a) constructivist grounded theory informed by Kaupapa Māori will be explained and justified as a suitable research approach for this topic.

CHAPTER THREE: METHODOLOGY / TE KUPENGA MATAURANGA

Introduction

This chapter begins with the reasons why I decided to use the research at the interface framework which includes Kaupapa Māori and Kathy Charmaz's (2006, 2014a) constructivist grounded theory. A discussion of each paradigm is provided along with the approach I took to implementing the relevant theories. An overview of grounded theory is then offered, which includes ongoing interaction with data collection and analysis. The genesis of grounded theory follows with an explanation of the four stages of analysis and reasons why grounded theory is differentiated from other types of qualitative research. The goals of grounded theory are provided and the focus on formulating hypotheses based on conceptual ideas is promoted. Criticism surrounding grounded theory is referred to and leads onto the methodological split between the two creators, namely Barney Glaser and Anselm Strauss. The use of the constructivist variant that Kathy Charmaz developed as a student of Strauss and Glaser is then justified. Key concepts that inform Charmaz are explained, namely: constructivism, interpretivism, symbolic interactionism and pragmatism.

Research at the interface

Durie (2004a) developed a research at the interface framework that provides a basis for integrating Western and Indigenous methodologies, without compromising the integrity of either. Durie asserted that research at the interface should be differentiated from Kaupapa Māori research, that is, research that is conducted entirely within the context of Māori knowledge and Māori methodological approaches. The framework also needed to be distinguished from scientific research that employed only those approaches consistent with positivist scientific principles. As an example of interfacing with Western and Indigenous methodologies, this study integrates Kaupapa Māori with constructivist grounded theory and aims to draw on explanations within both approaches to create new knowledge. The two sets of values and methods that arise from each, will ultimately produce gains for Indigenous peoples, most of whom live at the interface (Berryman, 2008).

Kaupapa Māori and constructivism

Kaupapa Māori is derived from the mātauranga (knowledge) of te Ao Māori (the Māori world). Eketone (2008) argued that Kaupapa Māori as a concept is mostly aligned to constructivism where

knowledge is validated through a social construction of the world. Eketone does not support L Smith's (1999) view where Kaupapa Māori is underpinned by critical social theory. Eketone maintained that many in the Māori community do not believe that their world view is a form of resistance to the Western hegemony of structures, power and knowledge. Eketone draws on Bishop's (1994) view that critical approaches to research have failed to address the issues that Māori face, and that the development of alternative approaches by Māori is a form of resistance to critical theory. Similarly L Smith (2012) noted that the localised component of Kaupapa Māori theory, is where the emancipatory goal of critical theory is practised. Furthermore, Smith challenged Western academics who have attempted to universalise critical theory independent of history, context and human agency. A constructivist description of Kaupapa Māori ideology for this study is, therefore, favoured:

> … (as) a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society that have emanated from a Māori metaphysical base. It informs Māori about the way in which they best develop physically, spiritually, emotionally, socially and intellectually as a people (Ka'ai, 2004, p. 203).

The following Māori constructive values are considered to inform Kaupapa Māori, namely: "tikanga, rangatiratanga, Māori cultural ethics, Māori language, values and culture" (Eketone, 2008, p.5). According to Eketone, Kaupapa Māori is about being Māori, using Māori processes, and viewing and judging the world via Māori values. Although, admittedly a Western-defined concept, constructivism connects with Kaupapa Māori, as it provides an explanation for why people do what they do so that Māori can construct their own theory, explanations and outcomes.

Similarly, in using constructivism, Hollis-English (2012) noted that she was able to treat the knowledge offered by the whānau as a taonga (treasure).The significance of the taonga was that it would be passed from herself as a Māori researcher to other Māori, for the future benefit of Māori social work development. Hollis-English reconciled using Kaupapa Māori theory with constructivism, arguing that constructivism can be over-focused on the micro as opposed to the macro approach. In this study, the integration of Kaupapa Māori theory has ensured the macro perspective is encompassed from a de-centred paradigm which considers all parts of the whole when working with whānau.

Kaupapa Māori research

Kaupapa Māori was used to inform the process of this research, particularly with regard to consultation, data collection, and dissemination of the findings. As a Māori researcher of Ngāti Kahungunu descent, I connected to the whānau who were also Māori through whakapapa (genealogical descent) or through community. Kaupapa Māori, therefore, was a natural fit with my world view and that of the whānau.

Māori world view

Derived from te ao Māori (a Māori world view), Kaupapa Māori (Māori ideology) and mātauranga Māori (Māori knowledge) are combined to comprise Kaupapa Māori theory. Known commonly as Kaupapa Māori, Graham Hinengaro Smith (1997) developed the theory as a tool for guiding research and practice. He considered it a form of critical theory that focuses on emancipation and promotes thinking about and undertaking research by Māori, with Māori, and for the benefit of Māori (Bishop, 1996). Kaupapa Māori affirms the right to be Māori (Pihama, Cram, & Walker, 2002) and has been described as the conceptualisation of Māori knowledge (Hollis-English, 2012). Kaupapa Māori theory is not only applicable to research, it is directly relevant for evaluative projects (Kerr, 2012) and practical interventions when working with Māori whānau (Eruera, 2010; Moyle, 2014).

Six principles comprise Kaupapa Māori theory: Tino Rangatiratanga (self-determination), Taonga Tuku Iho (cultural aspiration), Ako Māori (culturally preferred pedagogy), Kia piki ake I ngā raruraru o te kainga (socio-economic mediation), whānau (extended family structure) and kaupapa (collective philosophy) (Smith, 1992). These principles have been supplemented by Pihama (2001) with Te Tiriti o Waitangi (Treaty of Waitangi), and by Pōhatu (2004) with Āta (growing respectful relationships). According to Mead (1997), while Kaupapa Māori research focuses on empowerment of Māori, researchers understand the concept in different ways. Glover (1997, 2002) argued that as with mainstream culture, there is no one way of knowing, and therefore, no single form of Māori theory. L Smith (1995) claimed Kaupapa Māori research can recruit methodologies from the past or from anywhere as long as the process is under Māori ownership and control.

Related to Kaupapa Māori is the concept of Māori-centred research. Durie's (1996) three principles central to a Māori-centred approach include: whakapikitangata (empowerment), whakatuia (integration), and mana Māori (Māori control). Cunningham (1998) supported Durie's principles, however, he argued that a Māori-centred approach involves Māori at all levels of research but the control inevitably rests with mainstream institutions. In this study, Kaupapa Māori has provided the

mechanism for whānau to remain central as well as providing a pragmatic function to keep Māori values and practices prioritised and visible during the research process. For example, drawing on the whānau principle highlighted by G Smith (1992), I have recognised the entire whānau taking collective responsibility for their loved one's health issue. Equally important to this study is G Smith's (1990) principle of collective philosophy whereby any initiative by whānau reflects a shared or collective philosophical approach to a given situation.

Approach being taken

As part of implementing a Kaupapa Māori approach within this study, components were integrated throughout the phases to keep whānau and myself culturally safe. Combined with constructivist grounded theory, such an emergent approach located whānau in their own environments where they would feel most comfortable. Bevan-Brown (1998) maintained that Kaupapa Māori research involves commitments and relationships that extend beyond the research project. This view was uppermost in my mind, as I was connected to the whānau either through whakapapa or the community. Inherent in the conceptualisation and operation of Kaupapa Māori research, is the utilisation of appropriate traditional kawa (protocols) and tikanga (practices) by their members (Berryman, 2008). I engaged the process of whakawhanaungatanga (making connections) and pepeha (reciting my whakapapa) to commence all interviews so that the mana (integrity) of people would remain intact. The venue for interviews was negotiated with the whānau and the interviews commenced with karakia (prayer) followed by kai (food) as part of the pōwhiri (welcoming) process and ended with a poroporoāki (farewell) (Bridgeman & Dyall, 1998). Beyond the engagement phase I integrated Kaupapa Māori by ensuring their voices were heard and interpreted as part of developing the substantive theory. How I implemented each of these processes is outlined in the methods chapter.

Grounded theory

Grounded theory was developed in a period when other qualitative methods were often considered "impressionistic, anecdotal, unsystematic, and biased" (Charmaz, 2014a, p.6). Grounded theory provided a set of flexible analytic guidelines that enabled researchers to focus data collection and to build theories through data analysis (Glaser & Strauss, 1967). As a method and product of inquiry, researchers commonly used the term to refer to a specific mode of analysis. The ongoing interaction of data collection and analysis (which gives direction to further data collection), and the generation and construction of theory distinguishes grounded theory from other qualitative approaches (Charmaz, 1990; Holloway & Todres, 2005).

Grounded theory is a research method that operates almost in a reverse fashion from traditional research, where rather than developing a hypothesis, researchers inductively gather data first then systematically analyse the data to discover theory grounded in the data (Glaser, 1978; Glaser & Strauss, 1967; Strauss, 1987). From the data collected, the key points are marked with a series of codes, which are extracted from the text. The codes are grouped into similar concepts in order to make them more workable (Allan, 2003: Dey, 1999: Walker & Myrick, 2006). From these concepts, categories are formed, and are the basis for the creation of a theory (see Table 1) (Charmaz, 1983).

Stage	Purpose
1. Codes	Identifying anchors that allow the key points of the data to be gathered
2. Concepts	Collections of codes of similar content that allow the data to be grouped
3. Categories	Broad groups of similar concepts that are used to generate a theory
4. Theory	A collection of explanations that explain the subject of the research
5. Properties	Characteristics of a category

Table 1: Four Stages of Analysis within Grounded Theory

Origins and evolution of grounded theory

Grounded theory was developed by two sociologists, Barney Glaser and Anselm Strauss. Their collaboration in research on dying hospital patients, led them to write the book *Awareness of Dying* (Glaser & Strauss, 1965). This publication was also the first application of grounded theory. Upon visiting hospitals, Strauss discovered that dying was a highly problematic issue. Strauss appointed Glaser to assist in researching this area of concern and they both suspected early on, that the expectation of death by both the dying and their relatives provided insights to understanding the interactions between those people. Their choice of hospitals and stations allowed them to compare various kinds of expectations. On a premature infant station, mortality was high but the patients were not aware of their impending deaths, while on an oncology station, dying was slow and the differences in the awareness of dying were very pronounced. The typical situations were again different for emergency rooms and geriatrics or paediatric departments.

Glaser and Strauss developed a theory on the influence of awareness on the interaction among dying people, patients, their families and hospital staff. For example, if patients were not aware that they were dying, nursing was often limited to the absolute necessary in order to prevent open

awareness (Legewie & Schervier-Legewie, 2004). The social processes of dying in hospitals focused on the consequences of who did and who did not recognise that a patient was dying (Charmaz, 2014b).

Glaser and Strauss later published *The Discovery of Grounded Theory*, a text on the methodology they developed while working on *Awareness of Dying*. From their initial research they developed grounded theory based on two concepts: constant comparison of data which is collected and analysed simultaneously, and theoretical sampling, where decisions about which data should be collected next are determined by the theory that is being constructed (Glaser & Strauss, 1967). Classic grounded theory as it eventually became known, emphasised creating analyses of action and process or the basic social process that the researcher discovers in the field (Glaser & Strauss, 1967; Glaser, 1978). What is happening here? is the first question to ask when conducting grounded theory where researchers reflects on everything he or she see and hear no matter how significant or trivial (Glaser, 1978).

Symbolic interactionism

The emphasis on actions within the *Awareness of Dying* study was linked to George Herbert Mead's (1934) symbolic interactionism, where the behaviour of individuals and the roles they adopt are determined by how they interpret and give meaning to symbols. Symbolic interactionists argue that "a collective interactive process occurs when people derive meaning from their interactions with others and their environment" (McLennan, Ryan, & Spoonley, 2000, p. 43). Herbert Blumer's (1969) seminal work, *Symbolic interactionism: Perspective and method,* promoted symbolic interactionism as a unique and important perspective that regards human beings as active in their environment and not simply responding to the environment. Symbolic interactionism rests on three simple premises:

1. Human beings act toward things on the basis of the meanings that the things have for them.
2. The meaning of things arise out of the social interaction that one has with one's fellows.
3. Meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters (Blumer, 1969, p. 2).

Blumer argued that meaning arises in the process of interaction between people as opposed to perception, cognition, repression, transfer of feelings, and association of ideas. In doing so, the use of meanings by a person (or actor) in his action involves an interpretive process. Strauss followed the work of Blumer and his colleague Robert Park and adopted symbolic interactionism within his research (Park & Burgess, 192). As a student of Strauss, Charmaz (1990, 1995, 2006, 2014a) believed that a symbolic interactionist perspective supported a constructivist view, as it assumes an emergent reality fundamentally shaped by social interaction. For the purposes of this study, the importance of symbolic interactionism is its emphasis on meaning and the interpretative processes that inform the interactions within healthcare providers. The influence of symbols and shared meanings revealed what was most important for the whānau as Māori. As an oral-based culture, Māori traditionally have used imagery to convey specific meanings. Particular interactions identified within the study give rise to symbolic understandings that conveyed different levels of meaning and importance to whānau.

Pragmatism

Developed by American philosophers, John Dewey, William James, George Herbert Mead and Charles Pierce, pragmatism informs symbolic interactionism, and is a theoretical perspective that assumes society, reality, and self are constructed through interaction (Charmaz, 2014a). Pierce (1931-58) coined the term 'pragmatism' which later became developed as a good fit with grounded theory with its emphasis on process and change (Peirce, 1931). Pragmatism views "interaction as relayed through language and is open to people making multiple interpretations by people in relation to their environment" (Charmax, 2006, p. 7). According to Charon (1998), pragmatists believe that the use of facts and values informs how people determine what is real within their situation and how to intervene to create a desired outcome. Charmaz (2006) proposed that pragmatist foundations encourage researchers to construct an interpretive rendering of the worlds we study, rather than external reporting of events and statements. In this study, Māori and their whānau concerns, bring into focus areas that have been ignored in the past through constructions of reality about them instead of with them. It is envisaged that this approach may highlight changes and make a substantial contribution to practice, by considering the realities of the present that have emerged from the past and are yet to be resolved (Strauss, 1964).

Categories, codes and codings

Important concepts of grounded theory are the categories, codes and codings. For Glaser and Strauss (1967), Glaser (1978), and Strauss (1987), the basic elements every grounded theory approach should include are:

1. *Theoretical sensitivity* that is, generating through coding, theoretically strong concepts from the data to explain the phenomenon researched and not from preconceived hypotheses.
2. *Theoretical sampling*, that is, deciding whom to interview or what to observe next according to the state of theory generation. This implies starting data analysis with the first interview, and writing down memos and hypotheses early.
3. *Simultaneous* involvement in data collection and analysis which advances theory development.
4. *Comparing* relationships between phenomena and contexts to make the theory strong.

In the beginning of a study everything is coded (from field notes or transcripts) into either open codes or substantive codes to assist with conceptualisation of the problem and how it is being resolved (Denscombe, 2007). Wilson's (2004) study of the health and well-being of Māori women utilising a Māori-centred approach to grounded theory, integrated theoretical codes by weaving the basic fractured story of the whānau that helped explain their main concern. Wilson's use of theoretical sampling indicated that the substantive theory that emerged was a good fit and was relevant to the area of inquiry. Furthermore the interviews, in vivo codes and memoing were all important tools that did not force the theory beforehand, but allowed it to emerge during the process of constantly comparing the data and reflected the multiple interpretations of the whānau. Wilson has, therefore, made grounded theory accessible to Māori researchers in-so-far as Barton (2008), Baker (2007) and McKinney (2006) have included Wilson's substantive grounded theory in their respective research topics investigating Māori experiences of the healthcare system in New Zealand.

Criticism

As with most research methods, grounded theory does not exist without its critics. Various authors have differing ideas on the philosophical underpinnings of grounded theory. For example, Locke (2001) argued that grounded theory is a positivist/objectivist method, due to the language used by Glaser and Strauss (1967) such as 'emergence' and 'discovery,' which suggests only one 'true' reality. Charmaz (1990) rebuked this criticism by arguing that the reason for this assumption that grounded theory is an objective method was because Glaser and Strauss established an argument for a structured method of qualitative analysis that produced theory development.

Other critics have challenged grounded theory's focus on individuals and producing a structural analyses (Burawoy, 1991; 2000). In other words, grounded theory focused on narratives or situations of the whānau and did not address structural issues that affect people. Research by Garrett-Peters (2009) began to confront this concern when he investigated displaced workers suffering job losses. Garret-Peters theorised how structured inequality, such as social stratification, contributed toward feelings of vulnerability by workers during times of economic insecurity. There is increasing evidence that grounded theory can and does, consider larger units of analysis such as global organisations and large social structures (Clarke, 1998: Clarke & Montini, 1993: Michel, 2007; Rivera, 2008: Santos & Buzinde, 2007: Sheridan, 2008: Star, 1989, 1999).

According to Charmaz (2014a) some critics have based their arguments on earlier works within the publication of *Discovery* or have only critiqued one version of grounded theory. What most of the criticisms of grounded theory have tended to focus on is the misuse or misunderstanding of the method. According to Charmaz (1990; 2014a, 2014b), problems with grounded theory lie in glossing over the method's epistemological assumptions and minimising its relation to extant sociological theory. The connection between subjectivist and objectivist realities is unspecified and the use of prior knowledge is ambiguous. For example, Glaser and Strauss's proposed reading of literature after developing a set of categories, is now interpreted to mean 'delaying' the use of literature (Charmaz, 1990). The idea that a researcher should not engage in a literature review before conducting grounded theory research is naive and unrealistic in many cases. In order for a scholar to know that an area is worthy of new research, he or she will likely need to engage in a literature review beforehand (Charmaz, 1990, 2014a). If someone has never performed a literature review on the subject, it is possible that the grounded research will re-discover theories that already exist, and the results of the research may not be interesting to the scholarly community since the findings add little new knowledge to the field.

Similarly, avoiding a literature review prior to commencing a study will not necessarily eliminate any preconceived ideas. If the phenomenon under study is related to the researcher's own practice setting, then knowledge and experience of the phenomenon is inevitable (Morse et al., 2009). In this study, I engaged in pre-data collection which included literature so that I would become aware of the gaps that existed within my substantive area. After I collected data, I engaged further with the literature to develop my theory.

Methodological split

Since their original publication in 1967, Glaser and Strauss have disagreed on 'how to do' grounded theory, resulting in a divergence in the theory between Straussian and Glaserian approaches. This situation occurred after Strauss (1987) published *Qualitative Analysis for Social Scientists*. According to Kelle (2005), the controversy between Glaser and Strauss is due to the question of whether the researcher uses a well-defined coding paradigm and always looks systematically for causal conditions, phenomena/context, intervening conditions, action strategies and consequences in the data, or whether theoretical codes are employed as they emerge in the same way as substantive codes emerge. Glaser continued with his method of discovery whereas Strauss (1987) and one of his students, Juliet Corbin, developed grounded theory as a method of verification (Corbin & Strauss, 1990; Strauss & Corbin, 1990, 1998).

Thereafter, Strauss, together with Corbin, published *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* in 1990 (Strauss & Corbin, 1990). This was followed by a rebuke by Glaser (1992) who set out, chapter by chapter, to highlight the differences in what he argued was original grounded theory and why, according to Glaser, what Strauss and Corbin had written was not grounded theory in its 'intended form'. This divergence in the grounded theory methodology is a subject of much academic debate, which Glaser (1998) called a 'rhetorical wrestle'. Strauss never responded to Glaser's objections as he believed "the world would do with it (grounded theory) as it pleases, rather than necessarily please you" (Charmaz, 2000b, p. 168).

Grounded theory's suitability to this study

Grounded theory is well suited to this study as little is known about cultural safety and what happens for patients and their whānau. Grounded theory depends on methods that take the researcher into, and close to the real world, so that the results and findings are grounded in the empirical world. The inductive, comparative, emergent and open-ended approach of Glaser and Strauss (1967) provided enough flexibility for qualitative inquiry and guidelines to conduct this study. I decided to choose the constructivist variant of grounded theory because it included myself as the researcher co-constructing the research with the whānau. Taking the researcher's reality, perspective and interactions into account as part of the research process as opposed to a passive, neutral observer role was a condition that drew me to Charmaz's approach. I felt constructivist grounded theory sat comfortably with my values of acknowledging my subjectivity and involvement with the whānau who were connected to me in some way (through whakapapa or community involvement).

Constructivist grounded theory

Developed by Kathy Charmaz (2000), a constructivist grounded theory approach, imbued by symbolic interactionism and pragmatism, provided value in analysing an individual's interpretation of an experience. Constructivist grounded theory asks how and why whānau construct meanings and actions in specific situations. This approach means more than looking at how patients and whānau view their situations, as it not only theorises the interpretive work that whānau do, but also acknowledges the resulting theory as an interpretation (Charmaz, 2014a). Differences and distinctions between people may become visible during the study, and a constructivist approach highlights the conditions under which these arise and are maintained.

Charmaz's point of difference to Glaser and Strauss involved a variation in coding practices. Charmaz did not favour the Straussian concrete, rule-bound, prescriptive approach to coding and argued that it stifled and suppressed the researcher's creativity (Charmaz, 2008). As an alternative, Charmaz promoted flexible coding guidelines which were more interpretative, intuitive, and impressionistic than the classic or Straussian grounded theory (Charmaz, 2006). Glaser (2002) rejected Charmaz's coding procedure and argued that her constructions and interpretation of data inappropriately elevated the researcher to the status of co-creator and composer of the story (Glaser, 2002). Charmaz defended her position and asserted that the researcher was "part of the world we study and the data we collect" (Charmaz, 2006, p. 10). Henceforth, the interaction with whānau involved an interpretive process about how people create, enact, change meanings and actions as the analytic pathway. A summary of the differences are that classic grounded theory was designed to discover an emergent theory through systematic analysis of data (Glaser & Holton, 2004; Glaser & Strauss, 1967). Straussian grounded theory involved a rigorous coding structure which was focused on creating rather than discovering a theory (Strauss & Corbin, 1990). Constructivist grounded theory was more impressionistic in its coding and constructs and offered a conceptual interpretation rather than an exact portrayal of phenomena (Charmaz, 2006, 2008, 2014a).

Co-constructing data with the whānau and recognising the subjectivity that influences their lives is in keeping with my focus in the study, that is, Māori and their whānau within healthcare settings. The use of Charmaz's interpretive analysis of data assisted in examining social processes surrounding the healthcare experiences so the disconnect between the reality of health professionals, Māori and whānau could be better understood. A substantive grounded theory is developed to provide a theoretical interpretation of Māori and their whānau when engaging with healthcare services.

Constructivism

According to a constructivist perspective, meaning is derived out of engagement with the world around us and multiple meanings or truths can exist (Patton, 2002). Meaning is not discovered but constructed. Crotty (1998) argued that people construct meaning in different ways in relation to the same phenomenon. Constructivism enables the researcher to explore the views of the different whānau, and recognises that each may have experienced a different understanding of the same situation. Constructivism informed this study by capturing different perspectives and the multiple realties of patients and their whānau through the use of open-ended interviews and the examination of those realities. In keeping with the constructivist primary assumption that truth is a matter of consensus among patients and their whānau, questions in this study focused on the processes whānau used when they constructed a perspective during their engagement with healthcare services.

Intrepretivism

Interpretivism and constructivism are related philosophical stances informing research that is characteristic of particular philosophical world views. Proponents of interpretivisim share the goal of understanding the complex world of lived experience from the point of view of those who live it. Constructivism focuses on how, and sometimes why, whānau construct meanings and actions in specific situations. Similar to constructivists, interpretivists reject the notions of theory-neutral observations and the idea of universal laws, rather maintaining that multiple knowledge co-exists to be understood (Guba & Lincoln, 1994). Crotty (1998) highlighted the ability of interpretivism to interpret cultural understanding of people's social worlds. For this study, the cultural interpretation of the lives of whānau is a key focus which assisted with the discovery of processes, patterns and links associated with the multiple realities of those living with the phenomena under study, rather than an exact picture of it (Charmaz, 2014a, 1995, 2000). Interpretive theory, therefore, aims to:

- conceptualise the studied phenomenon to understand it in abstract terms
- articulate theoretical claims pertaining to scope, depth, power, and relevance
- acknowledge subjectivity in theorising and hence the role of negotiation, dialogue, and understanding
- offer an imaginative interpretation (Charmaz, 2014a, p. 231).

Interpretivism informed this study by seeking to generate an explanation of the healthcare experiences of Māori and their whānau. The multiple realities that form different perspectives of the whānau were collectively interpreted to show what was happening for them.

Conclusion

The methodological positioning of this research and data collection processes has been justified as the approach preferred for this study. The benefits for considering research at the interface vis-à-vis constructivist grounded theory informed by Kaupapa Māori theory, have been provided and include the flexibility of the methodology, the constant comparative nature of the analysis, and the culturally safe framework to maintain the integrity of the researcher and whānau. The chapter that follows explains the data collection methods and ethical considerations employed by the study. Following constructivist principles, I have co-constructed the data with the whānau. The Kaupapa Māori processes used during data collection are explained to demonstrate how I implemented the correct kawa (protocols) according to the tikanga (practices) of the whānau.

CHAPTER FOUR: METHODS / TE AKA

Introduction

This chapter explains the data collection methods and ethical considerations I have used in this study. To begin with, the methodological intentions discussed in section one are operationalised within this chapter. The selection of whānau utilising purposive sampling is explained, during the first phase of data collection. A profile of the whānau is outlined, including the criteria for their inclusion and exclusion. The next phase involving theoretical sampling is explained and justified, as a key step to differentiating grounded theory from other qualitative methods.

Data collection involving Kaupapa Māori protocols during the interviews, is conveyed to demonstrate how all parties were kept culturally safe. Additional data collection processes and items, such as notes and memos, are then elaborated to provide an audit trail of the actions undertaken during the study. The use of Charmaz's initial and focused coding processes is explained, as methods utilised to organise and integrate data within the middle phase of the research. The constant comparative method used during data analysis and the flexibility it offered is discussed. The use of semantic relationships between categories is explained, to demonstrate how the data became more conceptualised as part of theory development.

The process of member checking and strategies to support researcher reflexivity are deliberated. The process of ethical approval including informed consent, is presented to demonstrate how opportunities were provided for people to be involved on a voluntary basis – fully informed of expectations – and with the right to withdraw from the study. Processes to protect the whānau confidentiality are noted, together with the management of the storage and destruction of data. The criteria for evaluating the emerging grounded theory concludes this chapter.

Participant recruitment

Twenty Māori whānau aged between 18 and 70 years and their whānau were recruited into the study. Whānau fulfilled the following criteria:

- identified as Māori
- resided within the Hawke's Bay region
- had received healthcare from either a hospital-based or primary healthcare provider (such as a general practitioner) within the last 12 months; and
- they and their whānau were willing to be included in the interview process.

Whānau were excluded if they did not want to be interviewed with their whānau, or their whānau did not want to participate in the interview. The rationale for including whānau was their concern to ensure that their whānau member, the patient, was cared for and that their needs were met by the healthcare system. They were considered to be rich informants of the patient's experiences because the patient may not be able to recount their experiences because of their health status at the time. In Wilson and Barton's (2012) research, whānau also provided an added dimension to the healthcare experience as opposed to relying on one data source, such as an individual.

Whānau were recruited through pānui/posters disseminated through iwi liaison services and consultation with local marae and health services. Seventy-four people in total were interviewed from 20 whānau. Iwi or tribal affiliations were varied with all participants connecting to the local iwi in some way. Five whānau lived rurally and fifteen lived in urban areas. The median age was 40 years. The youngest was 18 years old and the oldest, 70 years. Half of the participants were men and half were women.

Semi-structured group interviews took place for one and a half hours, and included key informants in Māori health policy as well as whānau. Data in the form of interviews and memos were gathered simultaneously. This process was in keeping with grounded theory where data is collected from the beginning of the project, so that theoretical analysis can be developed.

Data collection

Grounded theory is generated with diverse kinds of data such as field notes, interviews, information in records and reports (Charmaz, 2006). In this study, the data collection processes involved group interviewing of whānau and memos.

Interviews

According to Charmaz (2006), the purpose of interviews is "to gain information in the participants' own words, situations elicit details" (p. 25). I therefore asked "tell me about, how, what, and when". A constructivist interview emphasises eliciting the whānau definitions of terms, situations and events, and uncovering assumptions and tacit meanings. This contrasts with an objectivist approach which is concerned with gathering information about the chronology of events and behaviours (Charmaz, 2014a). I found 'tell me about', elicited information related to the other questions as a matter of course.

- Tell me about your healthcare experience and what it was like for you and your whānau.

- How well were important beliefs and practices recognised and included in your healthcare experience?

- Tell me about your spiritual and cultural wellbeing during your healthcare experience.

- Tell me about the things you and your whānau did, so that you felt safe and in control.

- Tell me about any occasions when you did not feel safe or in control.

I noticed during the first interview that I did not speak often for fear of interrupting the flow of the whānau narratives. When I read the transcript from the first interview, what emerged was confronting. The transcripts revealed that I was engaging in an objectivist paradigm which necessitated an amendment to my interviewing technique that would reflect a constructivist and interpretive approach. To engage in interpretive inquiry and co-construct the data, I re-focused and started to implement reflective listening skills that would interrogate the whānau positions and assumptions (Hesse-Biber, 2007: Rubin & Rubin, 2005). In other words, I had to overcome my feelings of being disrespectful to the whānau by questioning their statements more than I had been.

Charmaz (2014a) argued that the researcher needs to be engaged in active listening by attending to the participant's language with research questions grounded in that emergent language. Charmaz (2002) provided practical advice on how to elaborate or specify certain areas with whānau, while still maintaining their mana. For example "could you describe … further?" was a question I used that helped examine statements such as "you know". The use of "you know" is a common verbal filler when a participant is struggling to articulate an experience and may want the interviewer's concurrence on the topic being discussed (Charmaz, 2002). As the whānau and I identified as Māori, the use of "you know" was a tacit form of communication where the whānau thought I could relate to their situation as Māori. Ezzy (2010) noted that emotional orientations of both the researcher and participant, inevitably influence the research process and should be engaged with. Recommendations by Charmaz and Ezzy helped reframe my thinking and assisted with the interviews from this point on. The data generated became a co-construction, or a 'third voice' of collaboration between the whānau and myself (Atkinson, Coffey, & Delamont, 2003).

Kaupapa Māori

Kaupapa Māori practices informed the process of undertaking the research, particularly with regard to consultation, data collection, and dissemination of the findings. As a Māori researcher of Ngāti Kahungunu descent, I was mindful that I was working with Māori whānau and needed to use a culturally safe process during the interviews (Kearns & Dyck, 2005). After seeking advice from my

kaumātua (elder) on the appropriate protocols, I engaged in whakawhanaungatanga (making connections) and pepeha (reciting my whakapapa/genealogy) to begin interviews. A critical aspect of whakawhanaungatanga is to allow for time and space to establish relationships (Edwards, McCreanor, & McManus, 2005). Establishing a genuine connection either through whakapapa or community associations meant that the whānau and I were committed to upholding the mana (integrity) of each other. The relationship, therefore, would endure beyond the study as I was part of the community through personal and professional involvement in education and health over thirty plus years. People knew me and my whānau and I knew them, so the time invested during this initial phase helped build a high level of trust with the whānau, so that they felt safe in sharing their experiences.

The concept of manaakitanga (nurturing and looking after people respectfully) was enacted throughout the different encounter processes with the whānau. For example, the venue for conducting the interviews was negotiated with the whānau so that they felt comfortable during the interviews. As mentioned in chapter three, interviews began with a karakia (prayer) followed by kai (food), as part of the pōwhiri (welcoming) process, and ended with a poroporoāki (farewell) (Bridgman & Dyall, 1998). There were opportunities to discuss the interview questions, rather than the whānau simply being handed a list of questions. This co-construction of the interviews in collaboration with the whānau, was in keeping with the concept of manaakitanga and Kaupapa Māori theory (Pipi et al., 2004).

Data analysis overview

Two key premises are evident during grounded theory data analysis. The first is that everything that appears to explain or describe meaning is a concept; and second, analysis should relate to the research question and aims (Birks & Mills, 2011). In this study, the constructivist approach to grounded theory developed by Charmaz (2014a), provided the framework where data generation and analysis occurred simultaneously. The process began with memo writing, which was undertaken constantly and was necessary for conceptualisation of the emerging concepts and categories. In terms of the data generated from interviews, initial or open coding was the first step in grounded theory analysis (Charmaz, 2014a).

Charmaz used gerunds (verbs used as nouns that always finish with 'ing') when coding as a way to identify processes in the data, as well as focusing on the whānau experiences as a source of conceptual analysis (Birks & Mills, 2011). Glaser (1978), coined the term 'in vivo' codes, whereby the

naming of the code is suggested by a participant. The term 'in vivo' is Latin for 'within the living' and this type of code captures multiple whānau spoken words and meanings. 'In vitro' codes are constructed by the researcher and reflect the data (Charmaz, 2014a). A combination of both in vivo and in vitro codes was used throughout the analysis stages. The use of gerunds helped to identify processes during the data analysis (Glaser, 1978). Analysis of transcripts involved:

1. breaking up the data into component parts or properties
2. defining the actions on which they rest
3. looking for tacit assumptions
4. explicating implicit actions and meanings
5. comparing data with data
6. identifying gaps in the data (Charmaz, 2014a, p231)

Focused coding was the next process in data analysis and the constant comparison of data, categories and sub-categories, while I continued to question the relationship between the concepts that began to emerge. Exploration of relational statements contained in memos was an important aid during data analysis. Refining categories assisted in identifying any gaps in the data. Theoretical sampling helped address the series of questions identified and progress the stages of analysis, until theoretical saturation was achieved. Saturation of the emergent categories, and theoretical sampling, signalled their completeness (Charmaz, 2014a). A discussion of how the saturation process occurred now follows.

Constant comparative analysis

Developed by Glaser and Strauss (1967), constant comparative methods make assessments at each level of the research, where data is continually compared with the goal of finding similarities and differences. This type of analysis uses an inductive process, where analytical ideas emerge moving from comparing data with data, to codes with categories, to categories with other categories, and to categories with concepts (Bryant & Charmaz, 2007; Charmaz, 2006; Glaser & Strauss, 1967). The comparisons included interviews and statements. Charmaz (2014a) recommended constant comparative analysis be undertaken in a sequential manner, so that the analysis can commence during the early stage of the research. Careful coding assisted the analysis before I started to imbue the data with my own 'pet' assumptions and attitudes (Glaser & Strauss, 1967). I engaged in the constant comparative analysis process recommended by Charmaz (see table 2).

I reviewed all relevant substantive codes then interviewed whānau, read literature on all in search of more information about this problem, **struggling to be involved**. I analysed the new data and then compared new substantive codes with existing codes. What were the similarities? What were the differences?

I gained more and more knowledge about the problem from several data sources, as I performed constant comparative analysis. I became more aware of how the whānau managed and adapted. Whānau discussed certain strategies. These behaviours constituted an emerging basic social psychological process. My temporary label to this process was **surviving the experience**. Further interrelated processes implemented by Māori whānau when **engaging with healthcare services** emerged. **Struggling to be involved** led to **surviving the experience** which was identified as a management strategy by Māori whānau coping with **discrimination**.

Table 2: Early memo about constant comparative analysis: 5/06/2013

Field notes

In addition to gathering data from interviews, field notes were taken to capture my thinking, assumptions, experiences and knowledge as the data was collected (Birks & Mills, 2011). Glaser (1978) recommended keeping field notes and memos separate so that the researcher can distinguish raw data from analytical abstractions. For example, confusion may arise where a document may contain data at different stages of theoretical abstraction, and theorising from field notes instead of memos may add to this confusion (Corbin & Strauss, 2008; Montgomery & Bailey, 2007). I recorded the field notes immediately after each interview and these were in addition to the transcribed recordings. An example of an early field note is provided below (see Table 3), where whānau shared information on how negative the experience was for them and their whānau while engaging with healthcare services.

Many negative experiences emerging so far. I must remember to code for processes, actions and meanings as opposed to topics and themes. Under what conditions is this occurring? How are the whānau managing this situation and what are the consequences of how they manage this process of engagement?*A lot of our Māori, especially our older ones, they're pretty good, you know, they still see the doctor as god. Being judged because you're Māori.Being punished because she DNA'd (did not attend) last time – given the last appointment.*

Table 3: Field note on negative experience for whānau 3/04/2013

From this field note, I was able to develop an analytic memo to begin to develop codes related to *being treated badly* and *having a bad experience* (see memo dated 10/11/2013, Table 4).

Memoing

In addition to using the constant comparative process during coding and analysis, Glaser (1998) also recommended the use of analytic memos to capture and track conceptual ideas and to document the researcher's thoughts about the emerging theory. Memos are not intended to describe the social worlds of the researcher's data, instead they 'conceptualise' the data into a narrative (Lempert, 1996). Memos are the analytical locations where researchers are most fully present (Charmaz, 2002). Furthermore, Charmaz noted that memos are where the construction of theory occurs and allow the whānau and the researcher to co-construct their voices. Memos cannot pretend to offer universal knowledge, but instead must acknowledge the situational limits of the researcher. Memoing for me, distinguished what was raw data from my analytic assumptions during the research process.

Writing successive memos throughout the research process, assisted with the analysis and conceptualisation of ideas (Charmaz, 2014a). Memos established an audit trail for me and provided a bank of ideas for discussion with my supervisors, as well as a focus point to refine my theoretical sensitivity towards conceptualising the emerging codes and categories. Theoretical sensitivity is identified by Glaser and Strauss (1967), as an important attribute when the researcher needs to read widely and be sensitive to what theory actually is. Developed by Herbert Blumer (1954), the term 'sensitising concepts' represents abstract notions that "lack precise reference and have no benchmarks which allow a clean-cut identification of a specific instance" (p.7). To increase my theoretical sensitivity and raise a code to a category, I began to write narrative statements in memos that considered each of the following activities: (a) defining the category; (b) explaining the properties within the category; (c) specifying the conditions under which the category arose, was maintained and changed; (d) describing its consequences; and, (e) relating the category to other categories (Charmaz, 2014a).

The categories then led to explanations of the process and predictions concerning these categories. Each of these action-focused memos were integrated throughout the study and provided an audit trail of my rendering of the data and analytic insights. The following excerpt is an advanced memo that extended my thinking from the initial field note in Table 3. This memo further explored the code *having a bad experience*.

How, after 174 years (since the signing of the Treaty of Waitangi), can health professionals not know how to engage with Māori whānau? I'm trying to answer that question by explicating some conditions under which a health professional might remain unaware. Under the condition that cultural safety is part of the nursing and other curricula for undergraduate health programmes and part of the requirement to maintain an annual practising certificate (hence the expectation that New Zealand registered nurses and health professionals are aware of how to engage with Māori); the potential consequence is that Māori whānau engagement with healthcare services is considered a priority. Under the condition that some health workers may not be educated on how to engage with Māori, and may only undergo a brief introduction to the context of New Zealand, the potential consequence is that Māori whānau engagement with the healthcare service is not a considered a priority.

What other conditions are there that I haven't considered? Racism? A sense of colonial superiority over Māori? As a category, *having a bad experience* portrays whānau wanting the right care for their loved one despite the many negative experiences during this process. I was sensitising myself to potential patterns in the data which lead me to the question: is it the behaviour of health workers that needs further examination together with relationships with whānau?

Table 4: Advanced memo on having a bad experience 10/11/2014

One of the areas that makes grounded theory different to other qualitative approaches, is that less of a focus on the description of the experiences of whānau is provided (Glaser, 1998). Rather than providing an almost verbatim portrayal of people's narratives, grounded theorists stress identifying patterns of behaviour or actions taken by the whānau. The actions, events and stories are then fragmented to assist with theory development and whānau stories are integrated to illustrate an analytic point rather than a complete narrative (Charmaz, 2014a).

The advanced memo in Table 4 depicts the mechanism to support this process as it brought in raw data and helped make comparisons between data, codes and categories. Fracturing of the data enabled analytic ideas to emerge that explained the consequences of actions (prioritising Māori whānau engagement) and the conditions that contributed to changes occurring (undergraduate education). The fractured data has then been presented as an interpretive rendering and co-construction of what the whānau said and my examination of the data. The rendering aspect of this memo is where I became present and contributed to the narrative space between myself, the whānau and the reader.

Theoretical sampling

Purposive sampling was used in the beginning of the study. This type of sampling implies that whānau have knowledge of the phenomenon being studied (Holloway, 2005). Initially, purposive sampling took place when whānau were selected because they could provide data relevant to the

study. The use of pānui that contained te reo Māori (Māori language) and imagery, engaging Māori liaison services and word-of-mouth, assisted in purposive sampling. As the theory began to emerge, theoretical sampling was then included, where analysis of the data informed sample selection (Glaser & Strauss, 1967). The goal of theoretical sampling is purposive sampling. The researcher's goal is not the representative capture of all possible variations, but to gain a deeper explanation of the emerging analysis and to facilitate the development of analytic frames and concepts (Glaser & Strauss, 1967). Theoretical sampling can be viewed as a technique of data triangulation: using independent pieces of information to get a better fix on something that is only partially known or understood (Denscombe, 2007). The following advanced memo is an example of how I engaged in theoretical sampling.

I theoretically sampled **being Māori** by investigating the literature and continuing with the constant comparison process and reviewing my substantive codes that related to the conceptual categories. I reflected on my starting points and continued immersion in this study as a social actor and to have a constructivist assumption.

As a researcher I became immersed and subsequently found my views challenged and changed. Like the studied phenomenon, the research process itself is never neutral or without context. It too, is an emergent social construction. I needed to maintain a constructivist view, not just of the data, but also of my own position.

I have located my study in the substantive area of **Māori whānau engaging in healthcare** and this perspective has kept whānau at the centre of attention. As a result I have taken into account how engaging with healthcare services has affected whānau lives as they have **taken control** of the process of engagement and **survived the experience**.

Table 5: Advanced memo on theoretical sampling 05/06/2014

Coding

To meet Charmaz's (2014a) criteria for analysis (fit and relevance), coding word-by-word and line-by-line was utilised. Each of these types of codes comprised the initial phase of coding which made relationships between whānau implicit processes visible. Charmaz (2014a) identified three types of in vivo codes: general terms that everyone knows (for example, *rapport building*, which means the ability of the health professional to build a relationship with the patient); innovative terms that whānau captured (for example, *we-dentity* where Māori spoke as a collective and used the term *we* as opposed to *I*); and, insider shorthand terms (for example, healthcare providers or workers – HCPs). In this study, all three variants were used where in vivo codes became integrated later into emerging categories and theory. The codes were drawn directly from the whānau spoken words

included *having a bad day,* and *going to get better*. According to Charmaz, focusing on the whānau experiences as a source of conceptual analysis fosters theoretical sensitivity (the ability to see relevant data), because the words "nudge us out of static topics and into enacted processes" (p.136).

Initial coding

The coding procedure of Charmaz's constructivist grounded theory utilises two stages, namely initial and focused coding (Charmaz, 2008). The goal of initial coding is to remain open to possible theoretical ideas, assumptions and tacit or implicit actions and meanings (Charmaz, 2014a). During initial coding, I employed Glaser's two key questions: "what is the chief concern of whānau?" and "how do they resolve this concern?" (Charmaz, 2008, p.163). Data was then coded by actions and potential theoretical cues emerging from these two questions, rather than coding for themes. Coding for themes would have likely reflected an outsider's rather than an insider's view (Charmaz, 2014a). Coding for actions helped me stay close to the data and preserved the integrity of the whānau experiences. My initial coding of the transcripts utilised Charmaz's (2006) gerunds as well as in vivo codes to encompass the language of the whānau and expose what was happening within their actions (see Table 6).

Transcript	Properties	Initial Coding
Yeah, definitely, there's a definite link, because with that condition there's, as I said, you're that debilitated that you actually can't contribute or you're not participating in a lot of whānau or work activities that you normally would be. So to me, the cultural and spiritual wellbeing was impacted upon because of the engagement with my whānau, and I couldn't be a full participant in whānau activities. So when they would want to go to the holiday camp or something like that, I had to sit back and think about – oh cripes, that's not going to be comfortable, I won't be able to stand that, so I would withdraw from that. (Participant 1).	Reduction in participation (*frequency*) Wanting to fully participate (*degree*) Assessing level of pain before committing to whānau activities *(type)*	Externalising condition Being debilitated Moving away from participating less in whānau and work activities Impacting on cultural and spiritual wellbeing Holding back Couldn't be a full participant Withdrawing from whānau activities

Table 6: Initial coding of transcript

Table 6 provides an example of how I engaged in initial coding from my first interview with a whānau member. Her description of chronic ill health impacting on whānau activities revealed properties such as frequency, degree and type. Strauss and Corbin (1998) defined a property as a "characteristic of a category, the delineation of which defines and gives it meaning" (p. 101). The components of the property helped qualify the *frequency* of the health condition impacting on whānau activities, the *degree* of withdrawal from whānau activities, and the *type* of activities that would be comfortable or not for her, due to the levels of pain. The initial codes of *being debilitated, impacting on cultural and spiritual wellbeing,* and *withdrawing from whānau activities,* were in vivo codes arising from the participant's own words. The basic social process for this whānau member was *living with a chronic condition* and the consequence was *withdrawing from whānau activities*, which *impacted on the cultural and spiritual wellbeing.*

When I began the initial coding of categories, I engaged in line-by-line coding which means naming each line of the written data (Glaser, 1978). Line-by-line coding forces a real intimacy with the data, as it helped me to be free of pre-conceptions, remain open to the data and see nuances in it. This type of coding, helped to identify implicit concerns as well as explicit statements (Charmaz, 2006, 2014a). Thirty initial codes revealed implicit concerns about diminishing roles in the whānau. Explicit statements included concerns about the behaviour of health professionals (mostly, although not solely, doctors) impacting on the whānau spiritual and cultural wellbeing.

Negative meanings & actions	Neutral	Positive meanings & actions
Having a bad doctor	Having whānau	Getting the right care
Having different doctors	Māori speaking as a collective	Being thankful
Feeling embarrassed	Managing	Having hope
Getting fatigued	Using the internet	Getting advice
Making complaints	Asking what's happening	Taking control
Regretting		Feeling lucky
Impacting on spiritual welfare		Rapport building
Impacting on what a person can do		Having choice
Feeling frustrated		Having empathy
Making complaints		Receiving culturally safe care
Being shocked		
Being scared		
Assuming		
Diminishing role in the whānau		
Waiting		
Being subject to racism and discrimination		

Table 7: Initial coding of categories

To make some sense of the categories, I placed the codes on a continuum with 'negative meanings and actions' on the left-hand side of Table 7. In the middle column, I labelled the heading 'neutral', and included codes that related to the descriptions of experiences that were neither positive nor negative. On the right-hand side, I placed codes that were identified as giving 'positive meaning and actions' for the whānau. The codes needed to be related to each other, otherwise all I was doing was labelling a phenomena and not building a theory. My preliminary table with the headings: negative meanings and actions, neutral, and positive meanings and actions, became the first step towards making relationships between the codes. I could have remained at this stage and indulged in what Glaser (1992) called 'conceptual description'. For the purpose of theory building, however, I needed to continue to link the codes using relationships. Further discussion on how I linked the codes is provided as part of Figure 1 later in this chapter.

Another component of the coding process I engaged in, involved the use of in vivo codes where whānau talked about *having whānau*, *being scared* and *feeling whakamaa (vulnerable)*. Identifying a process, or 'basic social processes' used by the whānau is often described as a feature of grounded theory (Glaser, 1978). Moreover, Charmaz's (2006) emphasis on action also assisted with identifying relationships evident in the study. As the substantive area of this study was *Māori whānau engaging with healthcare services*, the emphasis on actions and processes was important as whānau moved through major phases of connecting with the health system. Analysing the processes, therefore, helped develop initial codes and the relationships between them.

Other prompts involved notes placed on my computer that asked: "what category does this incident indicate?" and "from whose perspective?" (Charmaz, 2006, p. 47). These questions assisted with sorting and theoretical coding, which occurred simultaneously from the first interview and continued throughout the study. I sorted by code and wrote about each with my prompts constantly in view of the computer. This was an exercise in finding out what I knew and what I did not know. I eventually found that my initial coding needed to involve more conceptual descriptions of the data. For example, I used the word *having* several times when naming codes such as *having a bad doctor* and *having whānau* and *having hope*. I did not notice this occurring until I placed the codes within Table 6 and considered a more analytic term than *having*. After a discussion with my supervisor and reading Urquhart (2013), it was agreed that descriptive codes were a necessary first stage of an analytic code that would then help me to theorise. Therefore, the term *having,* was an acceptable term to assist with my thinking.

As I progressed and became more conceptual in my thinking, I was not simply coding from what the whānau said. The more tacit meanings or unspoken words required thought to distinguish between what people said and what they did. During this phase, I did not always reproduce the whānau use of terms. I investigated the implicit meanings and then examined how people constructed and acted upon these meanings. In doing so, I unpacked the terms to not only give an opportunity to explain the implicit meanings and actions but to also make comparisons between the data and emerging categories. The codes were now prepared for the next phase of focused coding.

Focused coding

Charmaz's (2014a) focused coding approach, provided a level of abstraction that helped determine which codes became categories that could be linked with relationships. "Through focused coding, you can move across interviews and observations and compare people's experiences, actions, and interpretations" (p.138). Focused codes are more directed, selective, and conceptual than word-by-word and line-by-line coding (Glaser, 1978). The process involved analysing the most significant or frequent initial codes and examining what was similar while bringing together codes to integrate and organise the data. Theoretical integration began with focused coding and proceeded with subsequent analytical rendering of the data.

I engaged in focused coding by examining the initial codes and comparing people's experiences, actions, and interpretations. I began to develop seven substantive codes from the focused coding process, which were then reviewed and compared constantly with each other. I reflected on my starting points and continued my immersion in this study with a constructivist assumption lens. As a researcher I became immersed and subsequently found my views challenged and changed. Like the studied phenomenon, the research process itself is never neutral or without context. It too, is an emergent social construction. I needed to maintain a problematic view not just of the data but also of my own position. I have located my study in the substantive area of *Māori whānau engaging in healthcare* and this perspective has kept whānau at the centre of attention. As a result, I have taken into account how engaging with healthcare services has affected whānau lives as they have been *struggling to be involved* and have *survived the experience*. Table 8 provides an example of how I used focused coding when a participant discussed his reaction towards a doctor's behaviour.

Transcript	Focused Coding
Unfortunately for me [name] came and because they were all concerned about you know what, what's happened to me [health condition]. Anyway I go in there, and the doctor says, Oh yeah, got a problem! what I found was culturally insensitive, that I'm Māori of the age where Māori males don't live very long [being judged]. He made reference to that and the operation would only last for ten years. I felt for me it was a good investment in me and I couldn't say anything else [being silenced]. The doctor wasn't worried about my quality of life [worrying]. I left there really pissed off, really angry. (Participant 3).	Knowing what's happening (tacit meaning) Being a Māori male and not living long – being judged Being silenced Being angry Worrying that doctor wasn't worried about him Feeling fed up

Table 8: Example of Focused coding of transcript

The focused codes of being judged, being a Māori male, being silenced, being angry, worrying that the doctor was not worrying and feeling fed up, were compared with other transcripts that also revealed similar reactions towards healthcare workers' behaviour. The most significant and frequent initial codes were now at the stage to be rendered into focused codes. Table 9 depicts the six focused codes that emerged from the 30 initial codes. A discussion then follows on how I arrived at three of the six focused codes, using memos and constant comparative analysis.

Category	Focused codes	Initial codes
Being Māori	Being Māori	Speaking as a collective or we-dentity, not doing anything on our own, being relationship focused Includes whānau – providing support, acting as interpreters, acknowledging whānau members & responsibility
Struggling to be involved	Having a bad experience	Having a bad doctor, having different doctors, lacking coordinated care Being silenced, impacting on spiritual welfare & what a person can do, feeling frustrated, being shocked, being scared, feeling whakamaa (vulnerable)
	Having to ask questions	Wondering about whānau, lacking information, assuming you'll be told, asking for plain English information, asking why, encouraging others to ask questions, getting advice
Surviving the experience	Having hope	Hoping treatment works, assuming they know what they are doing, hoping for empathy
	Feeling lucky	Getting the right care, getting an appointment, having a good consultant, having whānau support, being thankful
	Taking control	Seeing the person that makes a difference, managing health & wellbeing, making the health professional be bothered

Table 9: Example of Focused codes

Being Māori

The initial codes of *speaking as we, a collective*, *including whānau* and *being de-centred"* emerged as a focused code I termed *being Māori*. Since *being Māori* is a significant social act, I started to explore the code both conceptually and by location in the data. I noted that when whānau discussed components related to *being Māori*, it was within the context of larger sociological issues. When discussing their own health issue, whānau would frame their personal experience with how Māori collectively were experiencing similar health concerns.

> *So I think there is some work to be done on really making an effort to prioritise Māori healthcare experience through the way that we fund, look at the waiting lists* (Participant 1).

> *…but I was very interested in what they were saying though. Majority Pākehā, 20 in the support group, 3-4 Māori – looking at that, because obviously Māori are suffering but they are not being engaged in those groups. So I just think to myself – how many whānau are out there that are suffering?* (Participant 2).

The cultural narratives captured in these two transcripts and others in the study revealed sensitivities between a participant's personal story and the public issues on Māori health inequities. I used this tacit knowledge to ask questions of the data (Belenky, Clinchy, Goldberger, & Tarule, 1986). The transcripts reflected more than whānau narratives as they allowed me to see events from different viewpoints, namely, the meso perspective of health inequities for Māori and the micro perspective of Māori whānau engaging with healthcare services. I asked *why do Māori speak as a collective in this manner?* The following extracts from transcripts exemplify this question and properties of the category *being Māori*.

> *We don't do anything on our own* (Participant 1).
> *We are just worrying about whānau being cared for* (Participant 4).
> *We are having to arrange whānau to come and be with the patient* (Participant 6).
> *All Māori do that – making sure someone's checking up on them* (Participant 8).

Initially I considered that speaking as *we as Māori* or *we as whānau* was a way of informing people about their illness, by remaining separate from themselves. According to Charmaz (2006), people can "separate their bodies and their situations as a way of decreasing emotional risks and allowing greater control over emotions and over others' responses, and over possible labels" (p. 160). However, the data did not convey social processes of controlling emotions over others' responses. I followed the lead in the data to examine what was going on with this phenomenon and undertook theoretical sampling of the literature to discern not so much what I was 'looking for' (that is, preconceived ideas) in the data, but to help to determine what I was 'looking at' (that is, what could this be?). At no point did I deliberately look for collective 'speak' in the data, and I kept an open analytic stance to avoid forcing conjectured assumptions and theoretical claims, and allowed the data to dictate.

The following literature sensitised me to the potential answers as well as to processes in the narratives. I examined literature that ranged from focusing on the discourse of how Māori used the term *we* and Māori models of engagement for working with Māori in therapeutic settings. I eventually distilled the literature in relation to the research process. For example, Wilson (2004) developed the Te Kakano model where Māori whānau and kaupapa are kept at the centre. The use of a Māori-centred approach in this model, informed grounded theory and allowed for what was important for the whānau to emerge from the data. Whānau in Wilson's study talked about Māori concepts in reference to their collective orientation and resisted talking about themselves as individuals, preferring instead to make reference to 'Māori women'. To this end, Māori women in Wilson's study tended not to promote themselves, but instead positioned themselves collectively among others.

Moreover, Edward's (2009) PhD captured the dynamic '*I am because we are'*, which is referred to as '*we-dentity'*. Edward's study is consistent with Davey and Dwyer's (1984) assertion that the Māori world view is de-centred whereby the universe is viewed as dynamic, complex and continuous with no one centre. Within this paradigm, human beings are not the centre of consciousness and knowledge. From a communication stance, Durie (2003) argued that Māori attempt to find meaning in bigger pictures and higher order relationships. Durie examined the use of metaphor which is commonly used by Māori, as it avoids a focus on the individual and positions the person within a broader context as members of whānau, hapū (sub-tribes) and iwi (tribes).

Durie (2003) argued that Māori generally shun directness, preferring a type of communication that alludes to, but does not necessarily focus on, a detailed point. This peripheral approach can be

confusing to those that prefer a linear method of communication which is more direct and to the point. The term 'centrifugal' is used by Durie to describe this emergent approach, where the topic of conversation is discussed indirectly. Through dialogue around the topic using imagery and metaphors, one eventually arrives at the centre of the topic. Therefore, *being Māori* as a category, was a broad and abstract category combined with my experience of being Māori contributing to my theoretical sensitivity. The category *being Māori* then served as a heuristic device as I continued to ask the questions: 'what is the data a study of?' and 'from whose perspective?' (Charmaz, 2014a).

Having a bad experience

When I started coding *having a bad experience*, I reflected on how the participant's perspective dominated their interpretation of this experience. Thomas and Thomas' (1928) theorem states that "If situations are perceived as real, they are real in their consequences" (cited in Clare, 2005, p. 7). My reading of the data, was that whānau actively presented to healthcare services. However, *having a bad experience* was perceived as real and was real in the consequences for whānau.

Furthermore, I was struck by several instances where whānau experience was negative despite the narrative that the whānau only ever wanted to be positively engaged with their loved one's healthcare. I coded this phenomenon by naming it *having a bad experience*, so I could analyse its characteristics and relationships within the code and other codes. In grounded theory, a title for a code evokes a constellation of impressions and analyses for the researcher. I coded several negative experiences within *having a bad experience* and I asked myself questions about it, reminding myself of the limits of the data (specifically, it was the account of the whānau and the whānau perceptions from up to 12 months previously, so recall and emotions may have changed over time). I began to look for reasons for *having a bad experience*. That is, how the conditions for *having a bad experience* began to emerge with *having a bad health worker, having different doctors, lacking coordinated care, being silenced, impacting on spiritual welfare*, *feeling frustrated, being shocked, being scared*, and *feeling vulnerable*. The consequence of *having a bad experience* was mistrust and at times whānau dis-engagement with the healthcare system. An analytic memo dated 10/11/2013 (Table 4) provided earlier in this chapter, further explores the code *having a bad experience*.

Having to ask questions

Asking 'why' questions is what Charmaz (2008) argued, is a form of constructionism. My interpretive thoughts were always another source and form of data. Grounded theory engages both 'why' questions with memoing and 'what' and 'how' questions with initial and focused coding and the use

of gerunds. "A social constructionist approach to grounded theory allows for the 'why' questions while still preserving the complexity of social life" (Charmaz, 2014a, p.109).

The following initial codes were developed into the focused code, *having to ask questions*, namely: *wondering about whānau, lacking information, assuming you'll be told, asking for plain English information, asking why, encouraging others to ask questions, getting advice,* and *being told in a foreign language*. I needed to consider what the conditions, actions or processes were for the whānau, the problems that arose and the consequences of solving the problems. Asking questions appeared to be about an action or process that was encouraged by health professionals so that information could be correctly conveyed to patients. I re-examined the transcripts and noted that the whānau did not view asking questions as a positive action or process. To that end, the clustering of similar codes ascribed negative meaning to the act of *having to ask questions, wondering about whānau, lacking information, assuming you'll be told* and *asking for plain English information.* Drawing on a symbolic interactionism perspective, I considered how ascribing meaning by the whānau extended to studying emotions and how they entered the analysis (Charmaz, 2014a). For the whānau, the emotions contained within their actions or processes consisted of energy-sapping activities such as *having to ask questions*. For the whānau, *having* to ask questions as opposed to just *asking questions* emphasised being reactive. The conditions under *having to ask questions*, were mostly negative. If the engagement process was a positive one, then there would be less questions required. The consequence of this negative process resulted in negative reactions, as the whānau would often have to ask the same question more than once to different people.

Use of semantic relationships

Once I developed the categories *being Māori, struggling to be involved,* and *surviving the experience* (see Table 9), I began to relate the categories to each other, otherwise all I was doing was labelling a phenomena and not building a theory. I could have remained at this stage and indulged in what Glaser (1992) calls 'conceptual description'. For the purpose of theory building, I used Spradley's (1979) semantic relationships to determine which categories where characteristics of other categories (see figure 1). I was mindful not to force relationships between the categories, as they had not reached saturation point at this stage of the study. As part of the rendering process some of the focused codes merged into categories and others remained as codes. Resisting the inclination to make causal relationships, also helped to keep an emergent focus and an open mind. Therefore, few of the categories did not emerge as causal, therefore, utilising 'helps with' and 'becomes part of' enabled the next level of analysis to remain provisional and temporary in preparation for further

rendering of the data. The use of semantic relationships identified *being Māori* helped with *surviving the experience* and became part of *struggling to be involved*. The behaviour of health workers also impacted on relationships with whānau and resulted in *struggling to be involved*. Once I linked the codes with the relational statements, I was able to illustrate the properties within the categories and the emerging processes. The following discussion explains how I considered the relationships between each category.

Being Māori

As I considered the relationships between each category, *being Māori* was a statement of being as well as a social process that could paradoxically, hinder or help engagement with healthcare services. Whānau identified *being Māori* before they entered the healthcare services and *being Māori* also became a contributing factor during their engagement. Therefore, I related *being Māori* as being a generic process as opposed to a single basic process that helped with *surviving the experience*. I considered Charmaz's (1983) earlier studies of people experiencing chronic illness, where she could not define a single basic process that unified everything she was learning. Glaser promoted a single basic social process to resolve core concerns, although Charmaz believed that collapsing multiple different processes into one would be over-simplifying the complexity of the situation. For Charmaz, people experienced many different processes, ranging from learning to live with chronic illness, to experiencing time in new ways, to recreating or re-establishing a self they could accept. Ultimately, Charmaz wrote about all of these processes and developed a theory that explained the complex variations of experiencing major illness.

As a consequence, instead of a basic social process Charmaz (2014a), referred to generic processes that cut across different empirical settings and problems, and that could be applied to varied substantive areas. *Being Māori* emerged as a category and a generic process which contributed to drawing on a collective sense of *we-dentity* to address health concerns. *Being Māori* was a concept identified in Baker's (2008) grounded theory of *Te Arawhata o Aorua – Bridge of two worlds*. Baker's research on Māori mental health nurses' experience of dual competencies, considered *being Māori* as part of the philosophical foundation for the whānau practice. *Being Māori* was considered both a statement of positive cultural identification and a process towards improving Māori health.

Relationships with whānau

In this study, data emerged that situated the healthcare context on the individual patient and their health issue. *Relationships with whānau* did not emerge as a concern by healthcare services, when engaging with whānau. What did emerge, however, was a concern about the behaviour of

healthcare workers *impacting on* the *relationships with whānau*. All of the whānau stated that they knew engaging with healthcare services would always come with an experience. As a member of a collective, they were at times, unaware of how much the experience, good, bad or indifferent, would impact on their *relationships with whānau* and result in *struggling to be involved.*
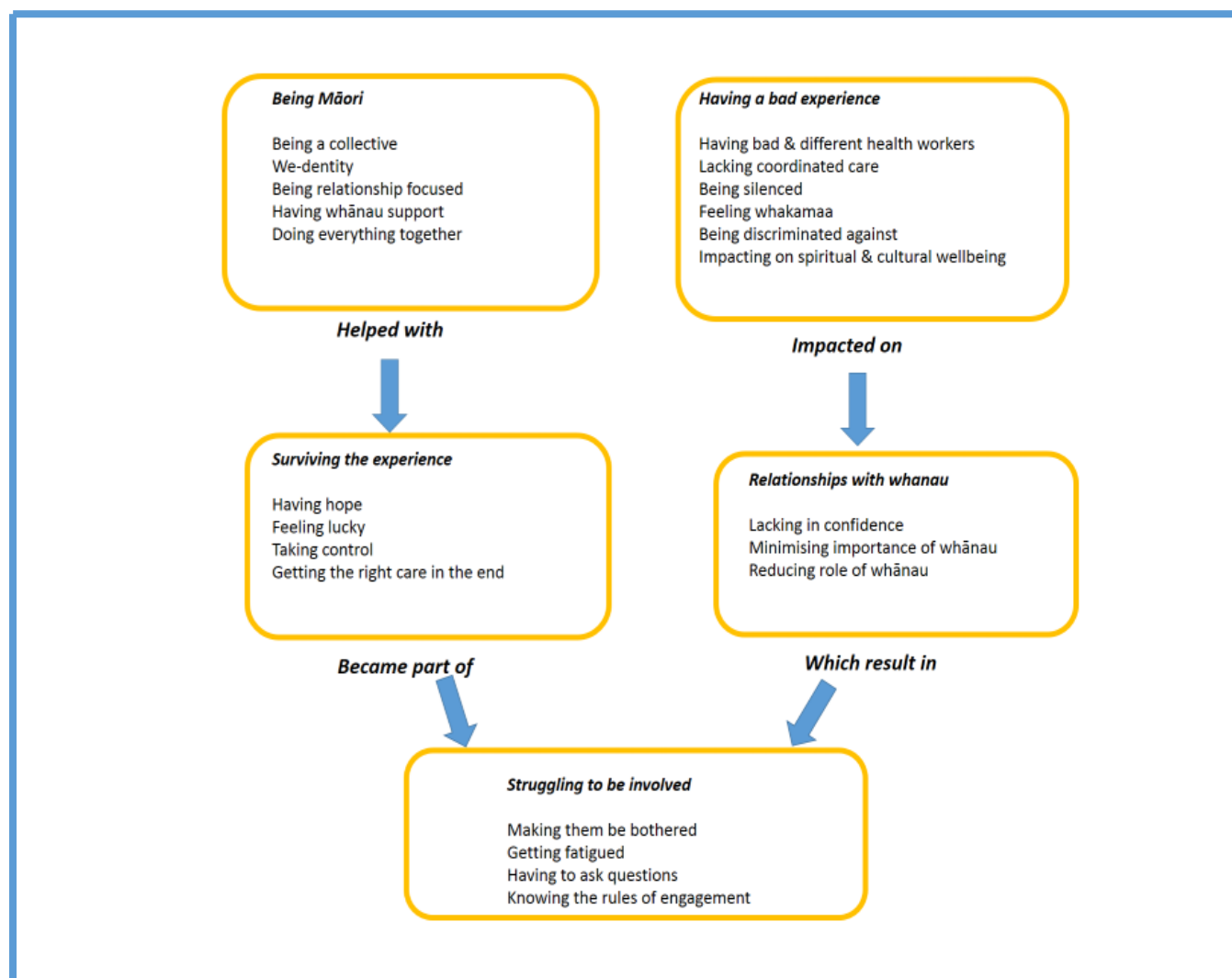
Figure 1: Relationships between categories

Struggling to be involved emerged as social psychological problem for the whānau. I reviewed the properties within this category, interviewed whānau and read literature for more information about *struggling to be involved*. I analysed the new data and then compared new substantive codes with the existing codes and asked "what are the similarities?" and "what are the differences?" As I performed constant comparative analysis, I became more aware of how the whānau managed *struggling to be involved*. Whānau discussed certain strategies that were included, becoming part of *surviving the experience minimising the importance of whānau*. I wrote an advanced memo to assist in developing my analytic insights at this stage of the study (see Table 10).

Table 10: Advanced memo about struggling to be involved 10/07/2014

Struggling to be involved and ***surviving the experience*** are two categories that have emerged. Is ***struggling to be involved*** a conceptual category or a property of another conceptual category such as ***surviving the experience***? How significant is ***struggling to be involved*** in the context of healthcare? Are there similar situations when a struggling response has implications for relationship building?

I theoretically sampled my next data source – someone that could tell me about the connection between ***struggling to be involved*** and relationship building. I began to understand why ***struggling to be involved*** might be so critical to relationship building. The informant, an expert on health literacy, explained how some whānau were trying their best to be involved with their whānau member's healthcare experience, but were perceived to as a threat by the healthcare workers. The exuberance of a whānau I interviewed, who helped with personal cares, was perceived as 'we take care of our own – leave us alone'. The whānau were communicated with less and less during their loved one's time in hospital.

Surviving the experience

Constant comparison of codes, memos and categories gave greater precision to the term *surviving the experience. Surviving the experience* became part of a series of social processes: 'processes' not in the sense of stages or phases, but denoting change over time in patterns of action or interaction and in the relationship to changes in conditions. For example, I became aware that whānau had to learn how to navigate the healthcare system by making and attending appointments and, in some instances, operating technology at home. There was now not just a physical unfolding of disease for some of the whānau, but the total organisation of work done with whānau over the course of the disease, together with the impact that the consequences of the disease had on the lives of the people involved whānau and health workers. There was an intertwining of the process within healthcare service engagement. Whilst reviewing *surviving the experience,* I found interwoven within the codes – giving them shape, were multiple moments of engagement: ward, machine, medical speciality, hospital, staff, whānau and the patient. These moments were linked in complex ways with each other and became part of *struggling to be involved* (Figure 2)*.*
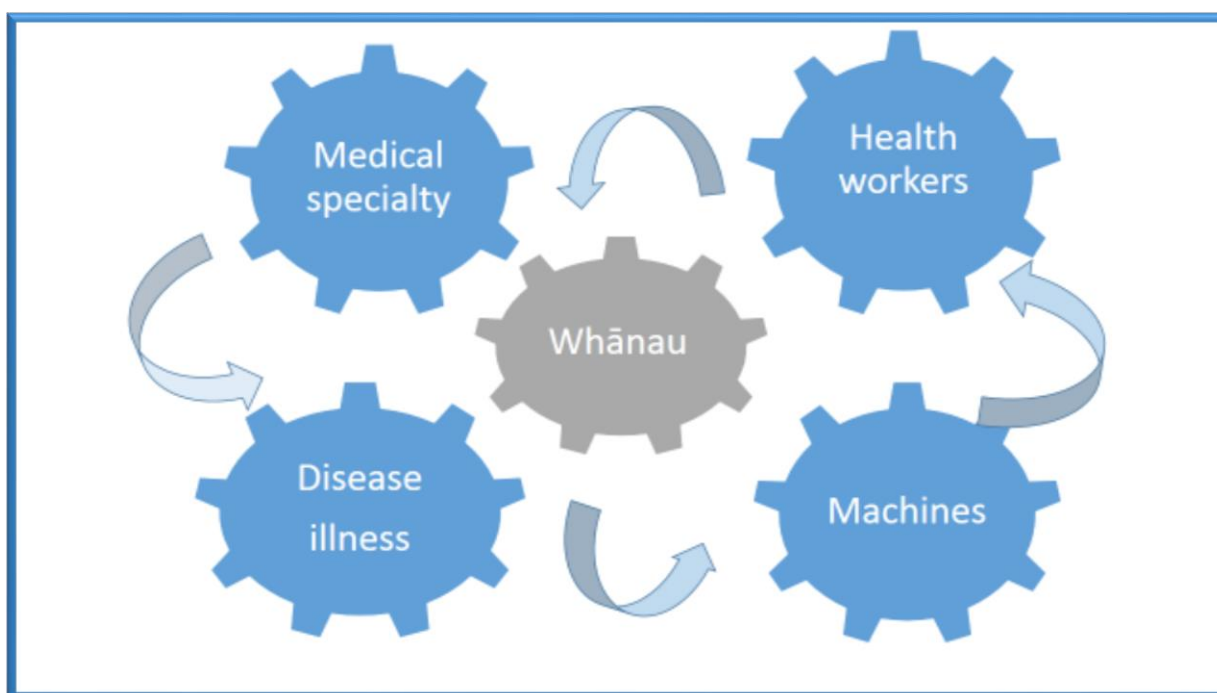
Figure 2: Multiple moments of engagement for whānau within surviving the experience

Developing the substantive theory

The multiple moments of engagement for whānau in Figure 2 impacted on their relationships with each other and their spiritual and cultural wellbeing. The processes of engagement consisted of what Charmaz (2014a) considers to be the unfolding of temporal sequences, which may have identifiable markers with clear beginnings and endings and benchmarks in between. The temporal sequences in this study, were linked in a process and lead to change for the whānau (generally speaking, from diagnosis to treatment and discharge) and they developed stronger connections with whānau to support their loved one. Thus, single events became linked as part of a larger whole and although the whānau reported never feeling quite the same again, their collective sense of identity and support helped ameliorate health concerns during and after the process of engagement with healthcare services.

As part of the constant comparative process, I went back to one of my earlier memos where a participant discussed how her mokopuna (grandchildren) alleviated the pain of her condition after having surgery (see Table 1). This memo connects a single event (having surgery), to being part of a larger whole and collective support system (*being Māori*). Several other whānau with mokopuna, provided similar accounts of how the spiritual and cultural impact of struggling to be involved with healthcare was ameliorated with the positive aspects of *being Māori,* in this instance, maintaining contact with mokopuna.

Table 11: Early memo about having whānau support: 12/09/2013

Participant 2 talked about Always doing nothing, trying to conserve energy and alleviating the pain. Her daughter would come and offer to take her to town. She felt like an old woman, but having the daughter bring the mokos, was how the daughter helped lighten her spirit. She didn't have to do anything for them, they just uplifted her. Having whānau support helped the participant culturally and spiritually. It wasn't just about helping with housework. Her spirit was becoming healed, just by being around her mokopuna.

Member checking

According to Charmaz (2014a) member checking refers to taking ideas back to research whānau for their confirmation. As another form of theoretical sampling, Charmaz supported member checking as a way to show increased conceptual precision so that ideas could be followed up. To assist with co-construction of the data, this technique enabled the gathering of further information to elaborate on emerging categories. The transcripts were returned to the whānau for checking and they agreed with what was written. I returned again to check my initial codes with the whānau, asking about an emerging category: *struggling to be involved*. I presented this emerging category to the whānau as I considered the issue or problem that was central in their lives. I located my interpretation within the context of whānau struggles with the behaviour of healthcare workers, discrimination, and the lack of clear information that they encountered.

Researcher reflexivity

In grounded theory's debut (Glaser & Strauss, 1967) and in Glaser (1978), Strauss (1987), and Strauss and Corbin's (1990, 1998) expansion work, the researcher – as a research instrument – was presumed to be the neutral knower. The positionality of researchers in the research process was absent. In contrast, Charmaz (2014a) argued that the researcher's subjectivity provides a way of viewing, engaging, and interrogating data. When the researcher asks analytic questions of the data, this is where the grounded theory derives its strength, and instead of leaving analysis to the coding stage, researchers can raise their main categories to concepts throughout the research. Moreover, Charmaz (2014a), argued that through constructivist grounded theory, 'insider' research aims to see the world as research whānau, from the inside. The goal is not to replicate their views or reproduce their experiences in the researcher's life, but to try to enter their settings and situations as much as possible. Seeing research whānau lives from the inside, often gives a researcher otherwise unobtainable views. Outsiders hold limited, imprecise, or erroneous views about the world under study.

As a Māori researcher, Pihama (2011) recommended being grounded in yourself. Being Māori is an inseparable part of who I am and how I operate. As an insider, the whānau who were also Māori, trusted the intentions of my research. Various authors have argued that being a Māori researcher is a critical element of Kaupapa Māori research (Bishop, 1996; Pihama 2001; Smith, 1997). As the author of this research, being Māori is never clear-cut, and like culture, it is dynamic, contextual and situated. For example, Kaupapa Māori research does not position the researcher as a tuakana or knowledgeable older person. Rather, it is more a mutual recognition of supporting roles and relationships (Rameka, 2012). As I was connected to the whānau through whakapapa or community association, I would maintain my relationships long after the study was completed. In doing so, the whānau were supporting me by volunteering to be in the study, as they were an integral part of the journey towards completing this PhD. The whānau were also vested in me as a person, colleague or relative. The reciprocal nature of our relationships pre-dated this study and would endure after its completion.

Similarly, Kaupapa Māori research must benefit Māori in its intent, process and outcome, where the most important imperative is the preservation of the mana (dignity) of the whānau (Smith, 1997). In this study, I received regular cultural supervision from my kaumātua, Turoa Haronga. With his guidance and wisdom, I maintained the cultural safety of the whānau by providing regular updates on how the study was progressing. In a few instances, the whānau requested a copy of their interviews to be retained as a legacy for their whānau. This request was humbling for me, as it indicated a high level of trust by the whānau in sharing their interview with whānau.

Another strategy to assist with analysis that is recommended by Glaser (1998), is peer debriefing. The role of a peer debriefer is to ask probing questions of the researcher and to help search for alternative perspectives and explanations (Baxter & Eyles, 1997). My attendance at a monthly grounded theory group, helped me identify ungrounded assumptions prior to commencement and during the study, thereby stopping the creative mind from being a conjecture mind (Glaser, 1998). Insights provided by the group were invaluable, as my isolation, both geographically and intellectually within my home town, would have limited my perspective otherwise. For example, I shared a transcript from one of my early interviews with the group to assist with initial coding. Each member of the group provided their interpretation of initial codes which revealed cultural assumptions that were different to my own. As the only Māori member of the group, I was challenged by some of the codings that revealed a different cultural understanding of the participant transcripts. I discussed this situation with my supervisor and came to the conclusion that I needed to

make my codings explicit for a general audience, as I could not expect only Māori readers to be interested in this study.

Ethical approval

Ethical approval was provided by the Auckland University of Technology Ethics Committee (AUTEC12/283) (Appendix 1). An information sheet (Appendix 2) and consent form (Appendix 3) were completed so whānau were fully informed of the study and their rights, should they want to be involved or withdraw. In formulating my ethical protocol, I used the Health Research Council's (2008) *Guidelines for Researching with Māori* and *Te Ara Tika Guidelines for Māori Research Ethics (2010)*, as all of the whānau were Māori. Both documents provided guidance on the importance of improving Māori health through the involvement of Māori as whānau. A key objective identified by the Health Research Council was to enable Māori to identify their own health needs. I believed that this study would support this objective through the co-construction of data with Māori whānau and would assist in maintaining their cultural safety during the research process.

Pickering and Anderson (2012) also recommended that the researcher is not too intimately connected to a clinical area, as they may overlook important aspects of the experience of the whānau, take information for granted, or analyse data from their own experience. For this study, I was not in a role where I offered clinical services to patients and so I did not anticipate a conflict of interest. To gain informed consent, whānau were invited to participate because someone knew about the study and had mentioned it to them, or gave them a pānui (public notice) containing my contact details (Appendix 4). Alternatively, whānau contacted me as the researcher, directly after seeing the pānui. If they were interested in participating in the study, an information sheet was provided and I discussed the content with them. The information sheet explained what the study involved and invited people to take part with an explanation of the expectations of whānau (for example: the interview length, digital recording of the interview and rights). All whānau were informed of the right to withdraw from the study up until two weeks after the interview. When the whānau questions had been satisfactorily answered, they were asked to sign a consent form (Appendix 3).

To meet the confidentiality requirement, whānau were allocated a pseudonym so that the information they gave could not be directly traced to the person or whānau. The transcriptions of the digital recordings were checked for accuracy and all identifying features were removed or changed (for example: names, organisations and locations). Whānau were also asked to agree to not

sharing or discussing the contents of the interview with others who were not present at the interview. The digital recordings and hard copies of interviews were stored in a locked filing cabinet in the Taupua Waiora Centre for Māori Health Research at AUT University, separate from the consent forms, which will be destroyed six years after the study is completed.

Criteria for evaluating grounded theory

The criteria for evaluating grounded theory depends on who forms them and the purpose he or she invokes (Charmaz, 2014a, p. 337). While Glaser (1978) recommended fit, work relevance and modifiability to gauge how a theory is constructed, Charmaz (2014a) preferred credibility, originality, resonance and usefulness as criteria for evaluating grounded theory. *Credibility* was assessed according to the methods used within the study and whether there was enough evidence for the reader to agree with my claims. The gathering of data from multiple sources such as interviews, field notes and reflexive memos assisted with credibility, by providing an audit trail of the various steps from raw data to analysis and interpretation. In particular, staying close to the data with initial, line-by-line, in vivo and in vitro coding facilitated the co-construction of a grounded theory that reflected the processes whānau used while engaging with healthcare services. *Originality* was determined with new insights gained and the challenge of current concepts, ideas and practices. Research with Māori whānau as a collective during the process of engagement with healthcare services has not been previously reported. The conceptual rendering of data and emerging theory provides fresh insights and a significant contribution to a change in practice for healthcare workers in the future. *Resonance* considered meaning for the whānau and insights into the taken-for-granted nature of their actions. Revealing the meaning of the whānau experiences through the co-construction of codes and emerging theory was achieved through full saturation of categories. *Usefulness* was achieved by offering interpretations that whānau could use in their everyday lives. Paying close attention to the meanings and actions of the whānau ensured the practicality of the theory and the continuation of further research to contribute to social justice outcomes.

Chapter Five discusses the findings of the study. At this point, theoretical sampling, constant comparison of data, categories and sub-categories begin to emerge. The following chapter explores relational statements contained in memos. The refining of categories identifies gaps in the data and the saturation of the emergent categories. Further theoretical sampling contributes to the development of the grounded theory.

Conclusion

Within this chapter, I have summarised the research methods used in this study and explained how I operationalised the methodological intentions discussed in chapter one. I have explained the methods used to examine the substantive field of Māori whānau engaging with healthcare services. Charmaz's constructivist grounded theory informed by Kaupapa Māori, has distinguished how people make meaning in their social worlds and interact within them. The subjective positioning of the researcher as one of the key elements of the constructivist approach, has been integrated into the method to explain how data is collected and analysed in collaboration with whānau. The next chapter presents and explains *Struggling to be Involved: A grounded theory of Māori whānau and health service engagement.*

CHAPTER FIVE: FINDINGS / TE AO MARAMA

Introduction

This study aimed to generate a theoretical explanation of the processes Māori whānau used when engaging with healthcare services. The findings of this study are presented as two sub-categories: *being Māori* and *surviving the experience,* which form the substantive theory **Struggling to be Involved: A grounded theory of Māori whānau and health service engagement** (see Figure 3)**.** The categories are presented together with an explanation of how each emerged from the data. The categories and processes are explained with clarification of the properties and examples illustrate the components of the properties with excerpts from the whānau.

Struggling to be Involved
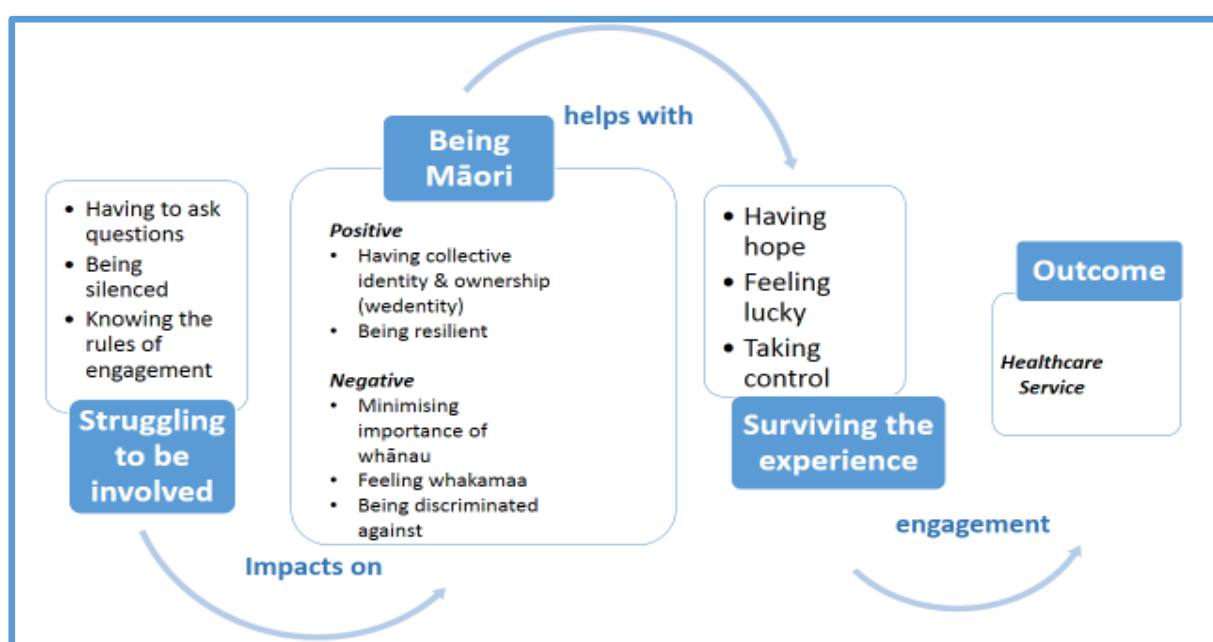
Figure 3: Theory overview diagram: Struggling to be Involved

Struggling to be Involved explains the difficulties whānau encounter to obtain health services. **Struggling to be Involved** emerged as a category as well as substantive theory as it explains how Māori whānau actively draw upon their collective identity and supports to address their health concerns. Many attempts were made by whānau to be an active contributor on the healthcare journey. The physical and spiritual wellbeing for whānau was at times strained, as the continual struggle weakened their energy and resolve to continue with treatment. *Knowing the rules of*

*engagement, being silenced a*nd *having to ask questions* were processes that contributed towards *struggling to be involved*. A discussion of each process and their contributing properties follows.

Figure 4: Process overview – knowing the rules of engagement

Knowing the rules of engagement

Conditions that contributed to the whānau not *knowing the rules of engagement* were *having a bad experience* and *getting the right care in the end* (see Figure 4). Whānau initially believed they understood the rules based on previous experiences or assumptions about how the service would meet their needs. This experience contributed to a sense of confidence to navigate through the health system and they would be *getting the right care in the end*. However, dissatisfaction soon emerged where the reality of mis-information, lack of information, racism and a lack of connection with the service became the norm. *Knowing the rules of engagement* became a process towards getting to know the rules as well as a milestone of *knowing the rules* and *acting on them*. *Knowing the rules* did not occur as a one-off event during the initial phases of healthcare engagement, rather, the process occurred whenever whānau encountered treatment for an acute health concern or long-term health condition(s).

A property of *knowing the rules of engagement* was *having a bad experience,* which emerged from negative encounters with health workers. The construction of *having a bad experience* formed part of not *knowing the rules* such as attendance at multiple appointments on different days. Various appointments with specialists, X-rays, scans and other treatments affected whānau resources to support being present on the correct day and time. Motivation to continue further engagement with health services was eroded over time due to continuous changes to information and the lack of

empathy demonstrated by health workers. Conditions such as the complexity of the health system confronted whānau pre-conceived beliefs that engagement would be a straightforward process. For example, whānau had to learn to *be a patient*, which involved coming to accept that the ever-changing rules about healthcare were never quite within their grasp.

> We didn't know what we didn't know. We fumbled along as we went. Wish we were told earlier, it would have saved a lot of time and energy. (Participant 16).
> No-one tells you what's going to happen. It's like there are these unwritten rules that you have to guess. They [health workers] know the rules because they are in it every day. Just doesn't seem right.(Participant 9).

The properties of not *getting the hellos and goodbyes right* contributed towards *having a bad experience*. The whānau held in their memories permanent snapshots that encompassed the entire health engagement journey. Many instances of the snapshots were of front-line staff that were irritated at being interrupted by the whānau presenting to them. First impressions were considered to be very important by the whānau and the protracted period of appointments and treatment regimes was made bearable if the front-line staff provided a more welcoming service. Whānau felt vulnerable during appointments and would retain the emotional reaction to a good or bad hello to the extent that it would affect their spiritual and cultural wellbeing for some time afterwards.

> It's like I had to drop my identity the minute I stepped into the waiting room. The receptionist was busy typing on her computer and seemed really annoyed that I was there. She made me wait a while before she put her head up to acknowledge me. My wife kept whispering to me to keep calm. I had just finished driving around for 20 minutes to find a park and then I had to deal with this person. She didn't care about me, the computer was more important to her. (Participant 15).

Participant 15 recalled in great detail *having a bad experience* with a front-line staff member. The emotion conveyed was still vivid for him despite the event occurring almost 12 months previously. *Getting the right care in the end* as a property of *knowing the rules of engagement* meant the whānau were resigned to eventually receiving results or diagnosis despite *having a bad experience*. A sense of fatalism emerged where the whānau believed if they kept tolerating *having a bad experience* then they would be *getting the right care in the end*. The energy-sapping process of *understanding what is happening* became eroded over time, so *getting the right care in the end* occurred as a one-directional process with minimal input from whānau. *Getting the right care in the*

end was a management strategy to bring about a sense of hope for the whānau where the end point was surgery and freedom from pain or medication for a chronic health condition.

When whānau were not provided information in a timely manner, they took action towards u*nderstanding what is happening*. This process involved re-establishing contact with the health worker about results and diagnoses, or seeking information during a consultation. Whānau would first consult with their members with a hui (a gathering) to determine the best solution for them going forward. If the health worker allowed the participant to speak uninterrupted within the first few minutes of the consultation, then they felt as if they were being understood. However, if the health worker interrupted the flow by looking constantly at the computer, or remained standing for example, then the person felt rushed. Their anxiety levels were raised, causing distress in trying to correctly convey any health concerns or issues and resulting in not *getting the right care in the end*. Conditions associated with *understanding what was happening* included the consultation fee and transport to appointments. Reliance on whānau members to provide transport and share their health experiences helped ameliorate this condition as well as the use of the internet to research health concerns. The use of the internet minimised the financial costs associated with appointments with a health worker as well as helping whānau to gain a sense of control over *understanding what was happening.*

> Dr Google is great! I looked up why I was feeling so tired all the time.
> I saved the information on my phone and took it to the GP. And sure enough,
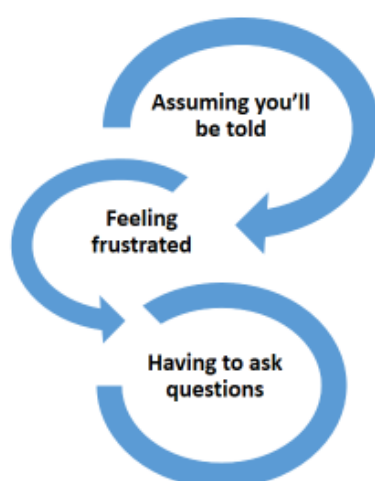> I was low on iron. (Participant 18).

Figure 5: Process overview – having to ask questions

Having to ask questions was difficult for the whānau as they navigated through the health system while *feeling frustrated* and *assuming you'll be told* (see Figure 5). The conditions for *having to ask questions* arose when whānau reacted negatively to the behaviour of the health worker. *Having to ask questions* was distinguished from *asking questions* as it implied extra effort by the whānau to gauge further information that was not forthcoming during the initial engagement phase with the health worker. For example, one participant reminded a health worker that a procedure carried out with a whānau member was an everyday occurrence for the worker and not for the participant. The lack of explanation about the procedure caused a lot of anxiety for the whānau member.

> We thought the doctor was actually going to do the explaining. I
> started asking more questions, I said You know, she's scared. Yeah
> you do this every day but she doesn't. (Participant 12).

Asking more questions conveyed the lack of clarity of information provided by the health worker. A participant wanted reassurance that the health worker was listening to their concerns and was not just focused on the task at hand but also on the whānau member's welfare. The lack of empathy conveyed by the health worker and a lack of information emerged as conditions for *having to ask questions* for another participant.

> Well, yeah the clinician was really cold at first. I got to a
> point where I said, Look, I want to know what you're doing.
> What's that? Why are you marking her? I said, Look, I know
> she's the patient but you need to look at me too.
> (Participant 18).

The whānau allowed for time in their day to attend appointments with health workers so that they could discuss their concerns and conditions. Regardless of the outcome, having questions answered to the whānau satisfaction emerged as an important consideration during the engagement process. Some questions were asked during the appointment with the health worker as part of the decision-making process on treatment options. Other questions did not arise until after the appointment had concluded and whānau had discussed a way forward with a hui with close members. Many of the whānau believed they were not encouraged to ask questions during the appointment, or had not considered asking questions until after they had reflected on the encounter.

> It wasn't until I got home that I wished I had asked more
> questions. Because I'm a mum, am I supposed to already
> know these things? Would have felt silly asking at the time.
> (Participant 7).

Tears, anger and sometimes laughter were responses to *feeling frustrated* or *hōhā*. Whānau support provided a repository for *feeling frustrated* so that the emotional highs and lows associated with healthcare engagement could be shared among the members. The range of emotions associated with *feeling frustrated* was expressed in various ways such as crying to release pressure and tension. Crying was also a way to release anger; otherwise holding in the tension could have contributed to further illness. Releasing tears helped with self-cleansing of the spirit and the mind, washing away the negative energy that had built up inside, making way for new energy.

> I wasn't afraid to cry. The fear really hits you. That's what
> you feel first, then it's anger and frustration. I felt
> betrayed by my body and by the people I thought would
> help heal my body. (Participant 5).

Feeling frustrated was associated on a pragmatic level where attendance at multiple appointments was coupled with a lack of answers to questions on health conditions. Focusing on the outcome and not the obstacles became more difficult to manage the longer the interactions with health workers continued.

> Expectation is the mother of frustration. After
> going to 20 different appointments with no
> answer to my questions, I had lots of frustration
> to go around! (Participant 2).

Assuming you'll be told was a condition that whānau associated with expecting the health worker to be fully conversant with their medical history and how to provide treatment. When there were time delays with receiving information on a diagnosis, a*ssuming you'll be told* was a process that contributed to being optimistic.

> We kept waiting for some news. We assumed
> we'd get told sooner. These days it doesn't take
> that long to find out if you're going to live or die.
> (Participant 13).

Assuming you'll be told fulfilled the whānau need to know information and replaced the need to communicate further with health workers. When the whānau did receive information and they did not understand it, they made assumptions about what the information meant to them. At times, the whānau made assumptions because they did not feel able to ask questions. Interestingly, the consequences for some of the whānau involved becoming advocates by encouraging others to ask

questions about their treatment. Sharing *feeling frustrated* and *assuming you'll be told,* became a catalyst to educating whānau and other patients about how to ask questions about their care.

> After seven weeks, I figured out how it all worked and helped other patients become more aware about the services. Like there's no effort to telling them, *Did you know you can get this, this and this sort of service on discharge?* I think too, what's needed for our whānau here is advocacy you know. Someone that would work on their behalf because even though they've got a social worker, I don't think she does a good job to tell you the truth. (Participant 6).

Figure 6: Process overview – being silenced

Being silenced meant not having a voice and not being heard whether questions were asked or not during the process of *making a complaint* and *being discriminated against* (see Figure 6). There was a belief that health workers would doubt explanations of whānau situations or minimise their anxiety about health concerns. The conditions that contributed to *being silenced* included past and current experiences of systems that were not culturally responsive to Māori. Identifying as Māori was integral to *being silenced* as residual trauma from being silenced as a child, as a youth and as an adult had a cumulative effect. Experiencing marginalisation and *being discriminated against* within the education, justice and welfare system throughout life contributed to *being silenced* as a matter of course within the health system. *Being silenced* meant that inaction would minimise further the

negative effects of culturally unresponsive services to Māori. The sense of powerlessness and the potential for reprisal from staff was a common reaction based on fear.

> I didn't want to rock the boat; I was afraid to
> ask anything in case they were going to ignore
> me. (Participant 20).

One whānau member, however, took action against *being silenced*. She resided in a small rural community with a high Māori population. Many years of managing a chronic health condition gave her the motivation to support patients by listening to what was happening to them and becoming their advocate.

> Aunty fell out of the wheelchair and I rang the nurse to
> check on her. Aunty said I'm alright, but she wasn't.
> They're too whakamaa (embarrassed) or they don't
> want to put the doctor out. (Participant 12).

Making a complaint whether it be real, perceived or intended emerged as a reaction to a service that did not meet the expectations of the whānau. Often *making a complaint* required questioning whether the behaviour of the health worker warranted a complaint. Fearing services would be negatively affected or withheld and racial stereotyping were underlying concerns with *making a complaint.*

> They [health workers] would be thinking a Māori
> making a complaint would automatically mean the
> services would be labelled racist. (Participant 15).

Conversely, whānau also believed that Māori did not normally complain as they were *being thankful* for receiving a health service at all.

> Māori aye, they don't like to complain, they like to
> say no no, I'm OK. (Participant 2).

Summary
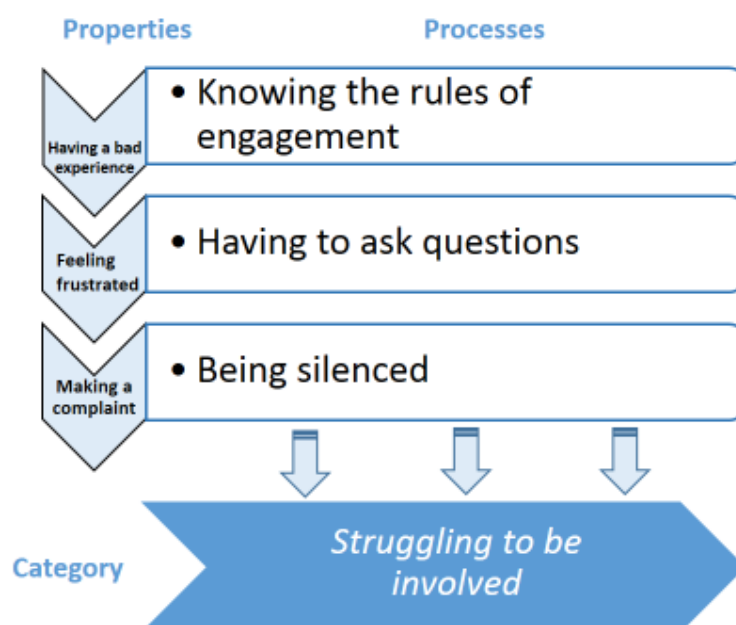
Figure 7: Category overview – Struggling to be involved

Figure 7 provides an overview of the category *struggling to be involved.* One of the key processes that whānau underwent was *knowing the rules of engagement*. Retaining emotional responses to the property of *having a bad experience* were so strong that whānau were able to recall them in great detail 12 months after engagement with a health service. The initial level of confidence with the health system quickly became eroded with not *knowing the rules of engagement*. Lack of information, racism and lack of connection with health services were identified as barriers to *knowing the rules* and *acting on them*. *Having to ask questions* meant becoming fatigued with the continual questioning of procedures and treatments to gain clarity for a whānau member's welfare. *Feeling frustrated/hōhā* meant finding a way to release built up emotions in a healthy way with whānau support providing the avenue for this to occur. Whānau provided a cultural and spiritual outlet for negative feelings resulting from the negative behaviour of health workers. *Being silenced* meant not having a voice after *making a complaint* either to whānau or health services. The turmoil whānau went through to consider *making a complaint* was of major concern as there was a perception on the one hand, that Māori did not like to complain and on the other hand, when they did take action, the health workers would be labelled as racist. *Struggling to be involved* impacted on the next category *being Māori* to the extent where the whānau, on the one hand, used their collective resources as Māori to remain engaged with health services, and on the other hand, faced discrimination for taking such action. An explanation of the category *being Māori* now follows.

Being Māori – positive processes

Paradoxically, the category *being Māori* contained both positive and negative properties. Properties that emerged as positive protective factors had a moderating effect on navigating through the health system and included *having collective identity* or *we-dentity*, which formed, *having collective ownership* and *being resilient* (see Figure 8). Each of these properties contributed to the physical, spiritual and cultural wellbeing of the whānau as they worked collaboratively towards a common goal.

Figure 8: Process overview – being resilient

The properties of *having collective identity or we-dentity* were interconnected and often overlapped. For example, the *simple things* noted by Participant 11 such as brushing another patient's hair produced a positive emotional, psychological and cultural experience for the participant and patient.

> Well she was 79 at the time this lady and it was so sad because no one came and visited her. All she wanted was her hair brushed and so I went over and brushed her hair and she was so much happier and they're just simple little things, but we're lucky as Māori if we got whānau that look after us, but there's a lot of people that don't have that awhi. It's just simple little things I reckon. (Participant 11).

Making a connection as part of the participant's cultural identity was not provided by the health worker. As a consequence, the participant ameliorated her lack of connection with the health worker by taking action and utilising her cultural practice of *providing support* or *awhi* to another patient.

Participant 3 took action by *having collective ownership* of her grandmother's living situation by moving her to her mother's house where she also resided after a hui with the whānau.

> She was in hospital, I walked in and said I'm moving you home!
> And she said, I'll be alright, and I said, Too bad, I'm moving you
> home, and I walked out and moved her home to mums.
> (Participant 3).

This participant identified the distress conveyed by her grandmother despite her statement of "I'll be alright." A range of factors contributed to the participant's actions such as the grandmother's failing health and lack of support within her previous residence. The whānau accepted the decision made by the participant, which provided beneficial consequences in the positive terms such as *getting to know whakapapa* (genealogy) and *providing wairua* (spiritual wellbeing) within the whānau. All of the processes indicated the positive role of the kaumatua or elder that helps to enrich the lives of whānau as they are recognised as knowledge holders of Māori tikanga (tradition) and practices (kawa).

Having collective identity or we-dentity and *ownership* meant the collective consciousness of the whānau enabled each participant to share responsibility for his/her actions within the context of the collective. This corporate sharing of tasks and interests achieved the purpose of attaining family goals as well as the continuation of the whānau imperative to survive. Involving others in healthcare practices and other daily activities (childcare, transport, care of the elderly) became a way of life for the whānau while alleviating anxieties about disease, pain, suffering and death. Participant 17 conveyed how the whānau took collective responsibility for her spiritual wellbeing by allowing the mokos (grandchildren) to stay overnight at her house.

> My daughter would come and offer to take me to town or something
> like that. I felt like an old woman, but it was really helpful though. She
> would have the mokos (grandchildren) there, or Can the mokos come
> and stay Mum? and that was her way, it just lightens the spirit. Having
> them there lightens the mood, not that I had to do anything for them,
> because my husband was OK with that and realised that the mokos do
> lift you up. (Participant 17).

Regular involvement and consideration of the *we* or the collective when an individual was encountering life events enabled the whānau to take action and provide a buffer for the person. Such

actions provided a moderating effect, which prevented internalisation of emotions resulting in mental distress. Individual wellbeing, therefore, equated to whānau wellbeing as the individual originates from the collective.

Being resilient

Being resilient emerged as a positive process within *being Māori.* Resilience was an action-oriented process as a response to an adverse health event or several events over time. The whānau developed skills to cope with the event(s) as they occurred and did not leave all the decision making to the member directly affected by a health condition. The decision-making process as a collective activity involving several hui at times with members, ensured a greater sense of control and contribution towards achieving positive health outcomes.

> I don't think I would have coped without my whānau helping me decide to have chemo. It just helped take the stress of having to make a decision. I would have kept it to myself otherwise and not done anything. I wouldn't be here today for sure. (Participant 8).

Learning from the health event(s) and the sharing of the lessons with the whānau contributed towards *being resilient*. Instead of asking "why me?", the whānau drew on their collective sense of we-dentity by finding out about similar experiences encountered by whānau members.

> First thing I thought was *oh my goodness, Uncle* (name) *got it as well*! He died of it of course. He never liked going to the doctor. Aunty (name) was always taking him to the doctor. It was too late in the end. Not too late for me. Mum's going to see her for me. (Participant 12).

The whānau did not always approach whānau themselves, some preferring to have an older member make the approach on their behalf, particularly if the learning was from someone of an older generation. As Māori are over-represented with health conditions in New Zealand, every person in this study knew of a member that had experienced a similar health condition to them.

Being Māori – negative processes

The sub-category of *not being understood* meant *minimising the importance of whānau*, *feeling whakamaa*, and *being discriminated against* (see Figure 9). *Not being understood* meant that there was a very big difference between *being heard* and *being understood*. *Being heard* was not simply

about the transmission of information from whānau to the health worker, but was also about receiving, understanding and showing comprehension of the information by the health worker in a culturally responsive manner. The importance of understanding who the whānau were as Māori was central to their experience of recovery.

> Māori like to have a relationship with people aye before
>
> they trust them, and so once they [health workers] get to
>
> know them, things just flow. (Participant 17).

Figure 9: Process overview – not being understood

Feeling understood meant a connection with the health worker, whereas feelings of *not being understood* meant disconnection with the health worker and health service.

> It felt like this big gap between myself and the nurse. Knowing
>
> someone takes a bit of effort. It was like she didn't want to try to
>
> get to know me and understand why my whānau wanted to
>
> have karakia (prayers) with me each evening. That made me
>
> very sad. I just wanted to get out of there [the hospital] as soon
>
> as I could. (Participant 16).

Not being understood was a condition that acted as a barrier to initial engagement with health workers. The actions of the health workers contributed to ongoing barriers to communication, which

involved *filling in the gaps with their imaginations*, and *creating a person in their minds that did not actually exist.*

> It takes time to get to know someone and then understand that person. Understanding isn't knowledge alone. Understanding is knowing and being able to relate – it's being able to comprehend the logic that is behind the actions of the person.

Not being understood created a disconnection between learning cultural knowledge and implementing skills such as *being able to relate*. The negative behaviour of the health workers was identified as a skills gap between the construction of *having knowledge* to engage with Māori and the willingness or competence to enact such knowledge. *Filling in the gaps* implies a fear about appearing incompetent when providing a health service to Māori. *Filling in the gaps* can mask a skills gap where the health workers would rather take *inaction* and look for reasons to wait for more information, options, and more opinions than risk being labelled incompetent. The construction of this situation paradoxically creates a health worker that is not culturally responsive to Māori whānau.

Being discriminated against

Stigma associated with *being Māori* meant that whānau were unfairly stereotyped by the healthcare service as being 'at risk' in some way. Participant 5 believed that if the healthcare service got to know her and her whānau, then the engagement process would have improved.

> Yeah, I did kind of feel that because we were a Māori family and we lived in a low socio-economic area that we were stereotyped and, because there's lots of really good families who work there, we're not all transients picking apples. (Participant 5).

Being discriminated against emerged from the property *having a lower quality of care* resulting in less options being given for treatment, longer waiting times and a less friendly service. If it were possible for the whānau to conceal *being Māori*, by making the interactions more anonymous and impersonal through the internet for example, then they would have taken this option. However, the internet deprives whānau of the preference of *not being discriminated against* – the opportunity to be treated fairly, respectfully, and as a welcome and valued patient, precisely as a Māori, rather than as an anonymous, raceless, sexless, faceless e-mail address on a computer screen.

> We felt that if she was a white male having a heart attack, she would have been sent to Auckland straight away for surgery. That's what happened to my boss. But instead, she was told to go on medication for the rest of her life. (Participant 14).

Being discriminated against was predicated on *being unfairly treated* where for example, Participant 14 tacitly expressed the unfairness of surgery being offered to a white male and a conservative medication regime being offered to her whānau member. Whilst discrimination was a condition identified in this situation, the participant did not take action as a victim of discrimination, although it did highlight the roles of health workers as perpetrators of discrimination, or observers of, or whānau in, a system in which discrimination occurs. *Being discriminated against* because whānau were Māori meant *feeling fatalistic* and wondering *what's the point anyway?*

> She said to me, Because you're Māori you're more likely
> to get gout. So I thought, what's the point of taking
> medication, I'm going to get it anyway. (Participant 7).

The conversations held by health workers that started with "because you're Māori" meant that the whānau could not contribute to any beneficial treatment options. Instead, the resulting behaviours as a consequence of *being discriminated against* were less adherence to medication regimes and poor health outcomes.

Feeling whakamaa

Older whānau members (kaumātua) emphasised *feeling whakamaa* as a condition from journeying through the health system. *Feeling whakamaa* meant *being embarrassed, shy* or *ashamed*. The kaumatua were conscious of *being at a disadvantage* as a property of *feeling whakamaa* and the consequence of taking action to ameliorate the situation.

> I felt whakamaa when I had the X-ray – they didn't cover me
> up. There were plenty of people going past in the hallway. I
> had to say a karakia to settle myself afterwards.(Participant
> 14).

Younger whānau members used tacit statements to reveal the implicit meaning of *feeling whakamaa.*

> We just felt stink, the way we were treated. It was
> shameful how we were growled at when we turned up.
> Yes, we were late, but at least we were there!
> (Participant 6).

The *feelings of whakamaa* suggested degrees within this process where the kaumatua were able to label the feeling as either embarrassed, shy, ashamed or *being at a disadvantage*. With the

experience of being immersed in Māori culture, the kaumātua developed strategies to counter whakamaa such as *having karakia* and *having whānau support.* Whakamaa in relation to Māori situations such as uncertainty on a marae (place of gathering) or transgression in behaviour required certain karakia to be performed so that balance could be restored. Whakamaa in relation to a Pākehā setting such as a hospital, however, raised the level of uncertainty for the kaumātua. Notwithstanding, their ability to draw on their life experiences contributed to strategies to reduce the feelings of whakamaa ranging from *having karakia* to *having whānau support.* The degree to which the younger whānau encountered feelings of whakamaa suggested a more heightened degree of *feeling whakamaa*. The lack of Māori situations to draw from, where uncertainty about situations could be applied to Pākehā situations, were limited for many of the younger whānau. The sustained or chronic *feeling of whakamaa* was present at a higher level of emotional distress than the kaumātua. Younger whānau *feelings of anger and frustration* towards health workers, therefore, emerged as *feeling whakamaa*.

Minimising the importance of whānau

Minimising the importance of whānau meant individualising healthcare at the exclusion of whānau members. The presence of whānau during consultations was an uncomfortable experience for the health workers. Despite whānau consenting to their whānau being involved in some way with their treatment, the reluctance demonstrated by the health worker to welcome their involvement was overwhelming. The member receiving healthcare would not always be the person taking responsibility for medication regimes (such as the case of a kaumātua). One or more of the whānau would take on this role instead.

> It might be her role as the patient to receive treatment,
> but it was my role as whānau to support her.(Participant
> 12).

Whānau were a resource that would help with ensuring information was understood rather than being a hindrance to what the health workers wanted to occur.

> It's like they [health workers] think we're too dumb to
> know how to help or we're going to make it worse or
> something.(Participant 6).

Minimising the importance of whānau was a superficial acknowledgement that whānau existed but only in a cursory way. Health workers talked about whānau involvement but did not actually know

how to engage and then mobilise whānau in a practical way that could be sustained to improve their member's health and wellbeing.

> We kept saying that all of his daughters were there to help with his cares. The staff just kept avoiding us and seemed intimidated by us coming in to help. In the end, they only checked on him when we asked them to. (Participant 1).

Participant 1 was part of a large whānau that helped with the daily bathing and changing of clothes of her father in hospital. The whānau mobilised themselves to care, as best they could, for their father. The health workers unfortunately missed an opportunity to engage with the whānau to discuss other aspects of their father's care. The disconnect between health workers and the whānau meant that the whānau were visible and present during their father's stay in hospital, but their role was minimised with very little meaningful discussions occurring on his health condition.

Summary
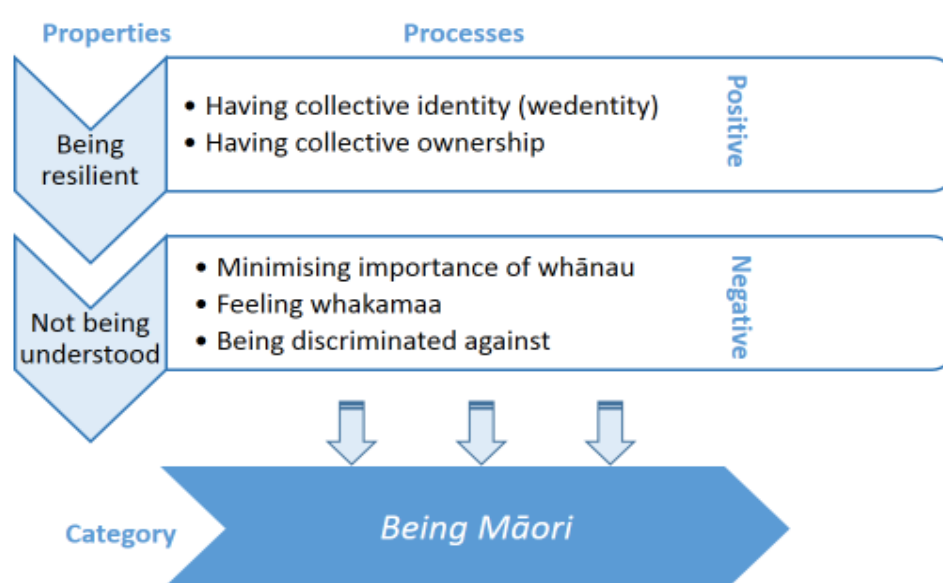
Figure 10: Category overview – being Māori

Figure 10 provides an overview of the category *being Māori*. Positive processes were used by whānau to mitigate *struggling to be involved* with *having collective identity or we-dentity*, *having collective ownership* and *being resilient*. The complexity of navigating through health services for an individual was minimised with the implementation of whānau support strategies. On a pragmatic

level, whānau used their collective identity and ownership to assist with daily tasks such as travel to appointments or accommodation of kaumatua that were becoming frail. On a spiritual level, whānau provided a culturally safe place to be and act as Māori. The emotional and spiritual fatigue experienced by whānau through *minimising the importance of whānau*, *feeling whakamaa*, and *being discriminated against*, were alleviated through membership status within a whānau. Each participant's personal wellbeing and identity were closely connected to the health and wellbeing of the collective. Despite the dichotomy associated with *being Māori,* the tension between the positive and negative processes did not prevent whānau achieving an outcome from healthcare engagement. In reality, *being Māori* helped with *surviving the experience* during healthcare engagement.

Surviving the experience

Surviving the experience captured a positive psychological state of being while journeying along the continuum of healthcare engagement. Various emotional and spiritual processes within *surviving the experience* included *having hope, feeling lucky* and *taking control*. The properties within each of the processes were derived from the negative experiences associated with not knowing what the health outcome would entail. The only certainty was that a health outcome would occur with little or no influence from the whānau. An explanation of the category *surviving the experience* now follows.

Figure 11: Process overview – having hope

Having hope

Having hope meant having the desire and confidence that events would turn out for the best. Figure 11 provides an overview of *having hope* and the properties *hoping treatment works* and *hoping for empathy*. Despite the challenging experiences with the health system, inner guidance was channelled through *having hope*. The whānau journeyed through numerous transitions when engaging with the health service; for example, *receiving a diagnosis, undergoing tests, having many doctors, waiting to be told, receiving treatment,* and *recovering from treatment*. The main concern from multiple engagement moments with healthcare services was the feeling of fear that the health workers did not know what they were doing. This fear was ameliorated by the process of *having hope, hoping for the best*, and *having regular karakia (prayers) with whānau.*

> Our whānau had hoped that he [the patient] would be treated with respect. He had a sign above his bed that said he was deaf in the right ear, blind in the left eye. They would yell at him as if he were totally deaf. He would tell them he was only deaf on one side. He would just turn off and not communicate. They just see deaf or hearing impaired. He said one time I'm not in the next paddock. (Participant 3).

Having hope was distinguished from wishful thinking, which has no power to bring anything to pass. The biblical focus on *having hope* was evident as *having faith in God* implied hope was connected to the actions of a higher being that could change circumstances such as *receiving treatment* or *receiving a diagnosis. Dealing with things that could not be seen* was a property of *having hope* and a test of one's faith in God when events were not positive for the whānau. To achieve a positive outcome *having hope* and faith in God placed the expectation beyond the whānau control. If the outcome was not positive then it could be reconciled as being God's will and actions by the whānau who could be taken to minimise blame on the individual.

Hoping treatment works emphasised imagining an acceptable future as a way of enabling the whānau to discover hope. The condition of a medicalised view created restrictions on what possibilities were regarded as a successful outcome. The risk-averse nature of the health system does not include hope as a quantifiable outcome measure, therefore, the lack of support provided to patients to enable hope refers to restrictions on possibilities for the whānau. *Hoping treatment works*, therefore, limited the whānau hopes for something else that was of value to them in their lives. The focus became all-encompassing on treatment outcomes. Success was *having treatment first* and *having treatment that works* was an added bonus. *Hoping treatment works* downplays the

possibility of hope being realised in favour of emphasising its uncertainty and the possibility of disappointment.

There was a related risk of embarrassment or whakamaa if whānau verbalised *hoping treatment works*. If hope was not realised then the consequence was the perception that others would disapprove of the participant having hope in the first place.

> We put a lot of emotional and spiritual energy into going
> through all that treatment. We know there's no magic bullet,
> just hope.(Participant 4).

By limiting the sharing of *hoping treatment works* to certain whānau members who the participant depended on for care, or whose opinion was valued, helped create intimacy with them and strengthened their resolve to continue with engaging in the health system. *Hoping for empathy* meant that the whānau felt vulnerable during the process of engagement with healthcare and wanted to create a relationship and connection with the health worker. *Hoping for empathy* was more than just a feeling, it was an emotional attitude towards the health system and the health worker represented the face of this system. Given the complexity and sheer volume of information and treatment for the whānau, the ability to filter out some of this complexity was helped with *hoping for empathy*. This action-orientated property was not internalised as an emotion as it included making use of available opportunities and resources and/or relying on whānau members.

Hoping for empathy was understood by whānau as they shared the same values and beliefs as the whānau so the role they played in assisting them continued over the period of engagement with the health system. Health workers have a great deal of knowledge and experience with illness and injuries and possible solutions. *Hoping for empathy* was not an expectation expressed when information was shared in a caring manner, especially with whānau that were struggling to come to terms with their illness or injury. *Hoping for empathy* was an interactive process in which health workers could be intimately involved or not. If the health worker assisted the participant to cope with their situation, *hoping for empathy* did not emerge. If empathic responses were not provided by the health workers, then *hoping for empathy* emerged with negative consequences such as a disconnection with the health worker and health system in general.

> We hoped that by telling our story about our concerns
> then there would be someone to hear us – truly hear us.
> A place that doesn't hear our stories is a place that
> doesn't allow us to hope. (Participant 14).

Feeling lucky

Feeling lucky meant obtaining healthcare as a matter of good luck as opposed to a matter of good timing and decision making by health workers. *Being thankful* and *being optimistic* were properties of *feeling lucky* (see Figure 12). Getting specialist appointments by chance or having a procedure sooner than whānau thought, were examples of *feeling lucky*. Participant 18 expressed *feeling lucky* for having a doctor that was known by Māori to show empathy with, and encouraged questions from patients.

> We asked if we could have Doctor [name] but they said there's a team of them but we were lucky we got that doctor. We heard that some of the other doctors were very cold, but we were thankful we had Doctor [name]. He asked all the time Do you have any questions? I was just really thankful. And now I can see why a lot of our Māori women wanted him as surgeon. (Participant 18).

Figure 12: Process overview – feeling lucky

Participant 20 told how *feeling lucky* was attributed to being connected to the community as they helped her adjust to living at home after surgery. She qualified her statement, however, by saying that support was provided due to her own resourcefulness as opposed to the health service.

> I couldn't cook and I've got two children and live on my own, I was just really lucky with our community for the first two weeks when I got home. One person would make me a meal for the whānau because I couldn't even do those things. I had no energy. There's none of that set up for people when they are discharged. (Participant 20).

Feeling lucky was a positive action associated with achieving certain milestones such as *getting an appointment, having a good consultant,* and *having whānau support.* Having some type of action occur as opposed to *waiting for an appointment or good consultant*, meant that the whānau were no longer in a holding pattern and their emotional energy was released as *feeling lucky*. Receiving a diagnosis meant that the whānau were *feeling lucky* and the treatment process could commence with an eventual result in sight. *Feeling lucky* was closely linked with *feeling blessed* as whānau completed treatment and took joy in living each day. *Feeling lucky* arose from spiritual actions when whānau engaged in karakia as part of *having hope*. *Feeling lucky* to have learned from the experience of healthcare engagement was then shared with whānau members, so that future concerns could be mitigated.

Being thankful reduced the negative emotions associated with frustrations with the health system. Rather than holding on to being resentful and angry at delays for example, *being thankful* was a strategy to help the whānau maintain their emotional and spiritual wellbeing. *Being thankful* occurred once the whānau neared the end of their healthcare journey or achieved a major milestone during the journey. *Being thankful* involved giving thanks to whānau members for their emotional, practical and spiritual support. Recognising *being thankful*, even during the worst times of poor health, helped whānau members to also consider *being thankful* and to focus on improving their own health and wellbeing. *Being thankful* helped improve relationships with whānau as positive communications helped draw people closer together. The more they sought to keep acknowledging each other's contributions to supporting the collective, the more reciprocal appreciation was demonstrated.

> We were just thankful it was almost over. Our whānau could rest for a while to gather strength for the next stage of treatment. (Participant 2).

Being optimistic

Being optimistic meant looking for the best in the participant's situation and expecting good things would happen. Despite conditions such as ill health, injury or disease, *being optimistic* meant believing things would turn out well. Whānau believed their own actions resulted in a positive outcome and that they were responsible for their own happiness regardless of their state of health. They viewed bad events such as delays in treatment or receiving a poor diagnosis as events outside of themselves. Having positive self-talk and karakia contributed towards *being optimistic*, as these actions provided an outlet for the sharing of thought processes to whānau. Anticipating the best

possible outcome helped as a coping strategy and attributed less significance to stressful events such as undergoing surgery or invasive treatment.

> I may not be able to do as much as before [the
> surgery], but I'm still going to make it to my
> mokopuna's birthday. (Participant 8).

Taking control

The conditions within the healthcare environment were foreign and hostile to whānau engagement. A range of positive, action-orientated responses to such conditions involved whānau *taking control* by *managing health and wellbeing and making them care* (see Figure 14). A consequence of these actions included a better understanding of the participant's health condition and/or treatment and greater satisfaction with the health service provided.

> Two years ago I went in for my first cancer operation. I was
> only in there a week and they said, You're going home and I
> said, No I'm not. (Participant 12).

Taking control meant that the whānau felt more optimistic about their situation by making choices about each phase within the healthcare journey.

> It's not that being positive was going to solve my health issue,
> it's just that it helps make the difference between coping and
> giving up. (Participant 4).

Taking control worked in conjunction with the whānau sense of wairua or spiritual wellbeing as it provided energy and a sense of purpose for the whānau, which became self-fulfilling. *Taking control* became a source of inspiration and hope beyond the confines of the whānau health condition. Rather than being resigned to being a victim of the health concern or health system, *taking control* enabled whānau to focus their efforts towards possibilities and think creatively past their initial problems.

Managing health and wellbeing

Whānau were actively *managing health and wellbeing* together throughout the healthcare journey. Maintaining a sense of control by developing health literacy practices was an example of *managing health and wellbeing*.

Keeping a diary as a memorabilia for whānau, a day-to-day record of everything that was happening, a way to keep track of any changes with dad's health condition, and a way to record conversations in medications and treatment, helped us when the doctors didn't do what they said they would do. (Participant 1).

A breakdown in communication was a common occurrence between whānau members and health workers. Keeping a diary performed a function towards *managing health and wellbeing* by increasing the visibility of information that could be shared from participant to whānau and from whānau to health worker and back to the participant and whānau (see Figure 13).
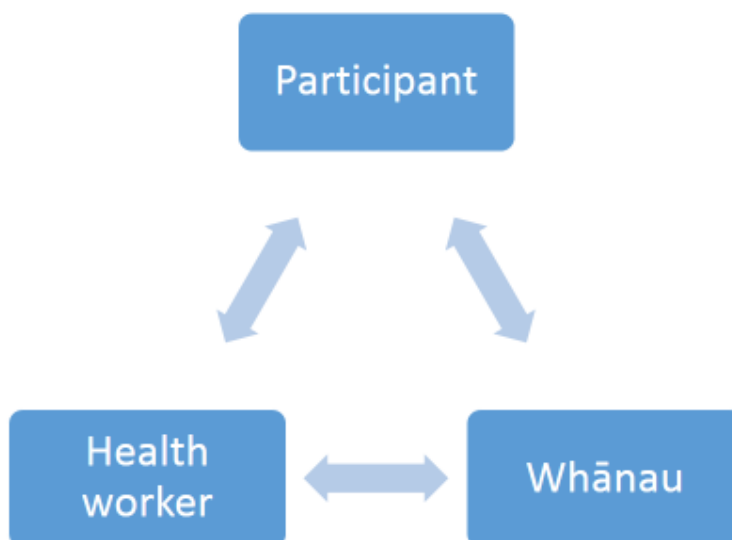
Figure 13: Health literacy practice overview – managing health and wellbeing

Managing health and wellbeing improved communication between the participant and health worker and allowed for more engagement in the healthcare process. As a consequence of *managing health and wellbeing*, the health status of whānau became more visible for the whānau. A feedback loop was created where whānau had a 360-degree view of their health journey, which was not present before the use of health literacy practices such as the diaries. Individual decision making was closely linked to, and depended on, the collective. As part of *managing health and wellbeing*, when decision processes were familiar to members of the whānau, they were more likely to engage as they had a greater sense of knowledge and thus control of the processes, and they felt more able to contribute meaningfully to achieving aspirations for their member's health. Whānau decision making was a key component to *managing health and wellbeing* as it afforded security, comfort and

reassurance about what to do next for the whānau and that the right thing would be done in the interests of the participant and whānau.

Figure 14: Process overview – taking control

Making them care

Making them care maintained engagement with health workers when whānau perceived the health worker did not care about their situation.

> They needed to treat her like she was your mother
> and treat the man like he was your father, that's all I
> ask, you know. (Participant 17).

Making them care required a relentless approach to ensuring information flow was constant, uninterrupted and health workers valued the participant. A health worker that was knowledgeable about the participant and their values as Māori was equally important as meeting medical objectives. *Making them care* meant taking action so the health worker understood the whānau imperative of collective decision making. If participants attended appointments on their own they were often 'brushed away' and treated 'like a number and not a person'. Whānau struggled with some difficult medical decisions at times, and this process was alleviated when health workers took the time to find out what really mattered to them and their whānau. *Making them care* became a shared responsibility where the participant focused on their wellbeing and the whānau focused on health workers providing the best care for their loved ones.

> Clarifying answers from the health workers, checking and re-
> checking information, and saying I don't know the medical
> term – be really simplistic with me achieved the purpose of
> *making them care*. (Participant 11).

Summary

Figure 15 provides an overview of the category *surviving the experience,* which became a process and an outcome of health service engagement for whānau. Despite the many negative experiences encountered during the healthcare journey, the whānau took action to survive the journey and make it to the other side. The other side in this instance was obtaining a health service. *Having hope* was imbued with spiritual connections to actions where the whānau imagined an acceptable future based on their faith in God. Conditions such as medical restrictions on *hoping treatment works* were overcome as different management strategies reduced uncertainty and the risk of embarrassment or whakamaa. *Hoping for empathy* was a response to culturally unresponsive health workers lack of relationship-building actions towards the whānau.
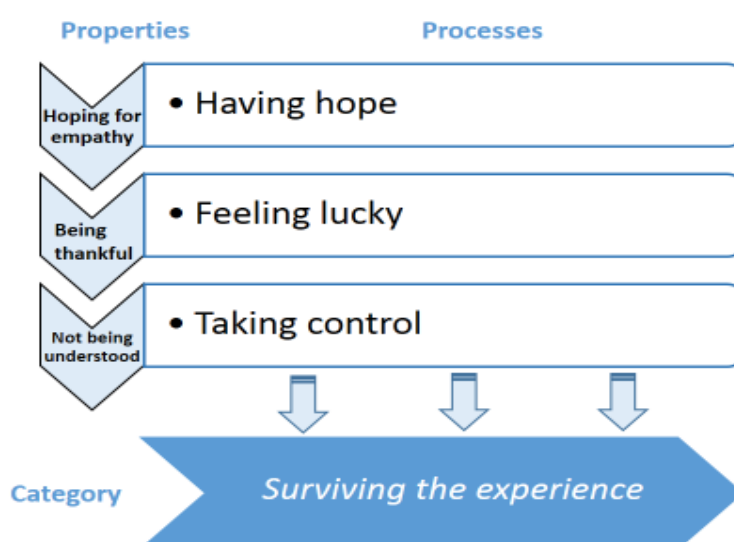
Figure 15: Category overview – surviving the experience

Each time this occurred, whānau assisted with providing empathy as part of their role to provide support for their loved one. *Feeling lucky* occurred when whānau achieved a milestone during their healthcare journey when they did not expect it to take place. Being connected to the community contributed to *feeling lucky* where whānau received assistance from whānau in pragmatic terms, such as making meals and making home visits. *Being thankful* released negative emotions and maintained emotional and spiritual wellbeing. The reciprocal nature of *being thankful* enabled positive communications with whānau to grow and drew members closer together. *Being optimistic* attributed less significance to stressful events by anticipating the best possible outcome. *Being optimistic* involved having positive self-talk and karakia as an outlet for sharing concerns and fears with whānau members. *Taking control* meant making choices within each phase of the healthcare

journey. With the support of whānau, *taking control* became the responsibility of the collective to obtain information so informed decisions could take place.

Managing health and wellbeing became a positive response to being managed by the health system. Active participation by whānau became the norm, especially when the illness or treatment occurred over an extended period. *Managing health and wellbeing* meant that whānau adapted positively to ongoing interactions with health workers and treatment regimes. The positive actions included health literacy practices, which performed the function of increasing understanding of the health information and communication process between the participant, whānau and health workers.

Conclusion

In this chapter, the substantive theory **struggling to be involved** has been explained. The sub-categories – *being Māori* and *surviving the experience* – have been presented together with an explanation of how each emerged from the data. **Struggling to be involved** emerged as a category and substantive theory as it explains how Māori whānau actively drew upon their collective resources and identity to address health concerns. **Struggling to be involved** impacted on whānau throughout their engagement with health workers and the health system in general. The impact, however, was both positive and negative for the whānau as the complexity of *being Māori* created a dichotomy of circumstance. The tension within the category *being Māori* created resilience for whānau. On the one hand, active whānau engagement provided the opportunity for protective factors to surface as a response to culturally unresponsive health workers; whilst on the other hand, *being Māori* resulted in barriers that minimised the role of whānau. Nevertheless, *being Māori* ultimately *helped with* the category and process of *surviving the experience*. As an outcome of healthcare engagement, *surviving the experience* enabled whānau to receive a healthcare service even though the healthcare service was not culturally responsive to Māori whānau.

Chapter six now follows with a discussion of the key findings of this thesis. This chapter will interpret and locate the findings within existing literature. Implications for future practice utilising the substantive theory and its properties will be discussed. Health policy that directly affects Māori whānau will be examined and improvements offered that consider the usefulness of the theory. The originality of the theory will be determined to offer new insights within cultural safety and competence education. Credibility and resonance will simultaneously be tested to gauge whether the amount of evidence within the theory is sufficient and relatable to the reader. Finally, further

research in the area of Māori whānau engagement will be proposed so that an original contribution of knowledge in this critical area of health can be developed.

CHAPTER SIX: DISCUSSION AND CONCLUSION / WHAKAKAPI
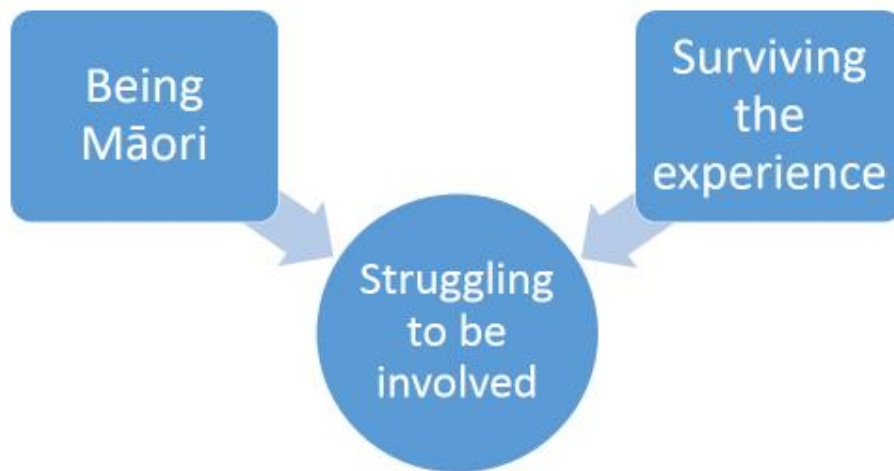
Figure 16: Substantive theory: Struggling to be Involved

Introduction

The findings of this study revealed the processes initiated by whanau to navigate through the health system. *Being Māori* and *surviving the experience* emerged as sub-categories within the theory of **Struggling to be Involved**. The theory of **Struggling to be Involved** explains how Māori whānau mobilise each other through a range of strategies to provide support during healthcare engagement. Drawing the components together indicated the need for a theory that offered a flexible framework within which Māori whānau can receive a health service that is culturally responsive to their needs. The theory of **Struggling to be Involved** meets those criteria. It contributes to making effective use of existing knowledge and identifies the gaps within such knowledge to support the health system's responsibilities to provide equitable healthcare. This chapter examines the findings about whānau engagement with healthcare services presented in Chapter Five and locates the findings within existing literature. Implications for health workers, policy makers and education providers are recommended. The limitations of the study are then deliberated with a critique of the rigour of the research process, and the thesis concludes by reviewing the aims of the thesis and identifies how the theory can be related to whānau better engaging in healthcare services in the future.

Struggling to be Involved and the literature

Given the persistent health inequities Māori endure, this research gained insights into what is happening for Māori and their whānau, and how they keep culturally and spiritually safe when they engage with health services. This led the researcher to ask what is happening with Māori *whānau when they engage with health services?* **Struggling to be Involved** provides an explanation of the social processes Māori use to ameliorate the ongoing disconnection that exists between healthcare providers, patients and patients' whānau (Egan et al., 2014). Charmaz's (2006, 2014) constructivist grounded theory assisted with considering how and why Māori whānau construct meanings and actions when engaging with health services. This approach meant more than looking at how Māori whānau viewed their situations; it also acknowledged the interpretive work that the whānau did to keep culturally and spiritually safe. Kaupapa Māori informed the research process, particularly with regard to consultation, data collection, and dissemination of the findings. As a Māori researcher and of Ngāti Kahungunu descent, I was connected to the whānau through whakapapa. Therefore. this commitment to the whānau sustained a drive to ensure all aspects of the research process were culturally safe.

The health literature associated with whānau **Struggling to be Involved** within New Zealand and internationally was not evident. The few studies that did emerge focused on Māori mental health consumers and nurses (Fourie, McDonald, Connor, & Bartlett, 2005; Jeffrey, 2005), and Māori as whānau in research (Cram & Kennedy, 2010; Durie, 2004b; Edwards, McCreanor & McManus, 2005). None of the research examined how Māori whānau struggled to be involved in their healthcare. The following review, therefore, examines the salient components of the theory **Struggling to be Involved,** which are located within existing literature.

Accepting the whānau collective

Wilson (2008) noted that a culturally appropriate health service was contingent on the inclusion of client's cultural beliefs and practices into intervention plans. Webb and Shaw's (2011) study on Māori use of organ transplants noted that most healthcare workers did not consider the whānau collective and cultural beliefs during the engagement process. The findings from **Struggling to be Involved** explains the importance of cultural worldviews to Māori whānau when engaging with healthcare services. Mutual obligations to other whānau members, especially those in need, is consistent with Durie's (1995) view that health is considered an inter-related phenomenon rather than an intra-personal one. Understanding occurs less by division into smaller and smaller parts. The wider conception of health and how it was related to whānau needs was evident in the findings in this

study. The term *pono na* (to present or to balance what has been offered between two sides) was discussed by Atareta Poananga (1998). *Pono* is to be true and honest, a meaning associated with the concept *tika*, to be right and proper. The principles of tika and pono are part of the decision-making process exacted in some form to re-assert the balance and bring rangimaarie or harmony to the community. Metge (1995) also noted rules around reciprocity, that oblige the recipient to give, not what has been received, but what could be incrementally more; that the return could be delayed months, years or generations later; that the return should be different in kind; and that the return does not have to be made to the giver, but could be made to the group that they belonged to or their descendents. Accepting the whānau collective as an entity and a process, especially when making healthcare decisions, is imperative to supporting positive health outcomes for Māori.

Incorporating whānau decision making

Struggling to be Involved encompasses factors whānau took into account when deciding to engage in each phase of their healthcare journey and the timing of when this should happen. Facilitating the decision process for whānau at the time that was right for them is a key component within **Struggling to be Involved**. Whānau decision-making processes ensured culturally specific tikanga (protocols) would be robust and enduring for the participant. As a consequence of whānau decision-making processes, health literacy practices were initiated to ensure the whānau were kept culturally safe and the whānau story or pūrākau was not lost. A discussion on each strategy and its location within existing literature now follows.

Whānau hui

Hui means to gather, and Māori gather for many purposes (Salmond, 1976). One is to "consider issues and make decisions about matters affecting whānau members" (Love, 2000, p.20). As Love (2000) elaborates, hui gather together people who matter, who can provide information and resources, who can show leadership and a pathway forward, and who can support outcomes. Through the process of hui, whānau in this study sought inclusion, respectful listening, the expression of views and the reaching of consensual outcomes.

Many of the whānau did not always speak during whānau hui, although their silence did not mean they agreed with what was said. If a consensus was not reached, then whānau members deferred to the leadership and seniority exercised by kaumatua (elder members). At times, disagreement would continue and some members withdrew from the hui to protest or avoid conflict. All whānau hui included a spiritual dimension, in which karakia (prayers) invoked the presence of ancestors to guide

the decision-making process. The construction of whānau decision-making processes meant that the members could gather when confronted by crises such as a health concern and live and know the reality of the Māori world by participating in it (Salmond, 1976).

A unique feature of **Struggling to be Involved** is the use of whānau hui, which are forums where health issues can be deliberated and actions agreed upon through consensus decision making within the whānau. Whānau hui were traditionally forums where Māori made critical decisions that influenced the mobilisation of community networks and resources especially with regard to tangi (funeral and grieving) proceedings (Nikora, Masters, & Te Awekotuku, 2012). Today, Māori continue to use whānau hui to include a broader range of activities that require input, from birthdays through to land acquisition. Māori decision-making styles are complex and are often a mystery for many outsiders, who can be baffled at how and why Māori arrive at the decision they do (Ritchie, 1992). Durie (2001) and Metge (1995) offer an explanation of the culturally prescribed roles and responsibilities of different whānau members during decision-making activities.

The younger members of the whānau (called teina) have a responsibility to support the decisions of their elder siblings (tuakana), and to ensure that they are all genuinely representing the plans of the whānau rather than their personal interests. While this is the general pattern, sometimes younger whānau members also fill leadership roles, particularly if the tuakana cannot meet their responsibility or if the teina demonstrates leadership qualities. When groups of extended whānau gather, everyone has a place, a duty and a responsibility. Descendents can rightfully claim membership in those whānau of both their parents, adding confusion and complexity (Sinclair, 2001).

According to Tupara (2009), the four elements of whānau decision processes include: hui (gathering of people to discuss issues face-to-face), rangatiratanga (the ability of whānau to exercise their autonomy in decision making), manaakitanga (valuing each other's contribution to the decision-making process) and kotahitanga (unity and collectivity). As Māori constructs, each emphasises the collective nature of whānau decision-making processes. Tupara's (2009) research noted, however, that greater emphasis was placed on the process of decision making than actual decisions. For the whānau in this study, there was an equal amount of emphasis on the decision-making process and the outcome because the outcome involved medical procedures and treatment that could not be avoided. A commitment to collective resolve, therefore, was a key process commonly emphasised by the whānau. Whānau decision making as a component of **Struggling to be Involved** explains the processes Māori whānau use towards achieving a healthcare service.

Health literacy practices

Struggling to be Involved contributes to knowledge by demonstrating how Māori whānau use their own resources to solve problems. Conditions that contributed to the whānau needing to draw on their own resources included health workers' perceptions that the whānau were actively undertaking negative actions against achieving healthy outcomes. Three particular actions were expressed during theoretical sampling with experts in the field of health literacy was that they were not doing the right thing; they were not taking the right medicines; and, they were not losing weight (personal communication, September 13th, 2013). The consequence was that the health workers were not checking to see if the whānau understood them. As chronic conditions become more prevalent in New Zealand particularly for Māori, the need for patients to be able to interpret health-related information becomes increasingly important. Despite efforts being made in this area, healthcare providers correlate an increase in patient visits to 'non-compliance' (Workbase, 2013). Research from a patient point of view, however, noted that Māori were compliant. Issues stemmed from the healthcare providers' actions where Māori were less likely to be offered a choice of appointment, be seen on time, and were communicated with less than non-Māori (Jansen, Bacal, & Beutow, 2011).

Although multiple patient visits for the same issue may seem to indicate noncompliance, they may also be due to the fact that the patient does not understand the information provided. **Struggling to be Involved** minimises health literacy issues for Māori whānau by providing strategies to support the health worker to remove barriers for the patient to access and process health information. Research by Jansen et al. (2011) supports the theory of **Struggling to be Involved** because regardless of the patients' health literacy levels, whānau support reduced anxiety for the whānau as they navigated through the health system.

Despite negative perceptions about the whānau actions noted by Workbase (2013) and Jansen et al. (2011), closure to any conflict from health providers is a common goal for whānau within **Struggling to be Involved**. An example of how whānau reduced such conflict involved health literacy practices. Health literacy is defined as "people's knowledge, motivation and competencies to access, understand, appraise and apply health information to maintain or improve quality of life" (Kickbusch, Pelikan, Apfel & Tsouros, 2013, p.4). Although the whānau did not refer to their actions as health literacy, they carried out important elements of this process. They obtained information that was relevant to them; processed the information and understood the information; then made informed decisions.

Health literacy is a relatively new concept as it links levels of literacy with the ability to interpret and act on health information, and is now an area of study in its own right. The term health literacy originated in the United States of America (USA) during the 1970s from a patient-deficit model where the patients were positioned as a risk. The American Medical Association wanted to change this perception and in 1995 noted that health workers also had a role in improving service delivery. Over the next ten years, the Institute of Medicine published *A Prescription to End Confusion* with the aim to change the way the health system approached health literacy (National Research Council, 2004).

In the USA, patient portals have been developed that are geared toward health workers to help them access information quickly for patients so they do not make a treatment error. Some places in the USA have developed patient portals where people can log on, find out their information such as results and take appropriate action. A report published by the California Healthcare Foundation found that health workers transferred entire medical notes into the portal (Emont, 2011). An issue with this system was the health workers were not summarising information in language that was understandable for the patient. Instead, the over-riding concern was that law suits would be submitted if the information was over-simplified into lay language. In New Zealand, the Ministry of Health (2014c) launched a campaign to raise awareness of the benefits of patient portals. The portals were launched in Auckland in 2014 and GPs throughout New Zealand were expected to inform patients about this service. Patients need to first discuss this option with their GPs so they can access their medical records, book appointments and order repeat prescriptions (Ministry of Health, 2014c). The literature is yet to be developed on how the issues identified in the USA could be mitigated in New Zealand.

Literature about Māori concerns and health literacy includes the Ministry of Health's *Kōrero Marama* (2010) report. The report noted that Māori had lower health literacy skills than non-Māori across all income levels. Functional literacy was not explicitly noted as a contributing factor towards low health literacy for Māori in the report. Functional literacy involves long-term learning which may be challenging for patients with low literacy because, as a group, individuals with low literacy levels have a lesser degree of background knowledge and working memory compared with individuals who have higher levels of literacy (Wolf et al., 2009). Rosemary Knight's (2006) report commissioned by the New Zealand Pharmacy Guild, noted this issue and recommended working on improving functional literacy to include "social skills, the ability to set and realise personal goals, critical analysis of options, making informed choices, problem solving, numeracy, and coping effectively with change" (p.1).

A strong perception from the literature and also this study is that the health workers' focus is on patients not being able to understand and not asking questions. **Struggling to be Involved** changes the focus from the patient not being able to understand, or not asking questions, to the health worker accepting the patient as a member of a whānau and utilising this natural resource and strengths within the collective to improve health literacy. Interventions offered in the literature are in the early phases of development, albeit in a disparate manner. One intervention offered by the New Zealand Guidelines group supports leveraging off community pharmacists and community nurses as the first port of call for people seeking health advice. The 'teach-back' method has been promoted and involves three steps: The first step is to find out what people know, then secondly building on key understandings, and thirdly, teach back (see Figure 17). Teach-back is promoted as an iterative communication strategy in which the healthcare provider checks for comprehension by asking patients to repeat, in their own words, and what they need to know or do. If there is a gap in patient understanding, the healthcare provider can then review the information again (Namratha, Malli, Larsen, & Baker, 2011).
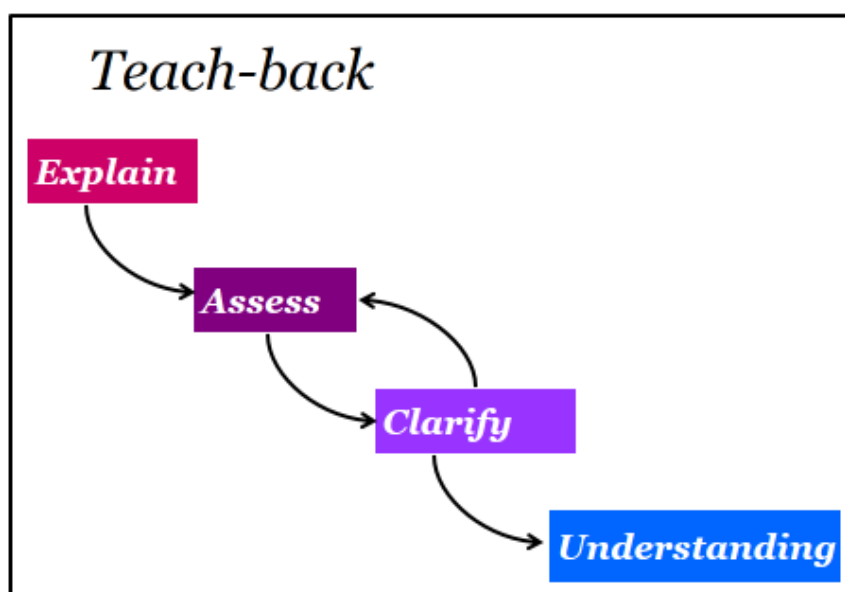
Figure 17: Teach-back method

The teach-back method, noted in Figure 17, is promoted as a way to engage patients so that they can improve their health literacy. There have been some drawbacks noted in the literature as it does not improve knowledge retention among whānau or literacy retention at two weeks (Namratha et al., 2011). The authors recommend health workers actively engage patients in long-term learning to improve the retention of health information. For example, instead of asking "Do you understand?" or "Do you have any questions?" which invariably leads to the answer "No", it is recommended the

questions include "Tell me what you've understood about this medicine?" or "I want to make sure I have explained your medicine clearly, can you tell me how you think you will take this medicine?" The focus then becomes on "need to know" and "need to do" for the patients. The findings in this study did not reveal that the teach-back method is being implemented for whānau. This begs the question, why is teach-back not working for Māori?

One reason associated with teach-back not working for Māori is provided within a report on health literacy in the USA (Berkman et al., 2004). The report emphasised bringing a family member to medication appointments to improve health outcomes for the patient and noted two things that the role of family could implement. The first is that family helped ensure that questions were asked by the patient in the first place, and second, the family member had a role helping the patient to remember what was discussed (Berkman et al., 2004). For the whānau in this study, involving whānau in appointments more often than not, was met with resistance by health workers. The use of notebooks and diaries provided by whānau assisted with remembering discussions with health workers if they were prevented from attending appointments. The report by Berkman et al. (2004) supports the theory **Struggling to be Involved** where whānau involvement can assist with acquiring, interpreting and acting on health information with, and for, their member.

The Health and Disability Commission has made an attempt to reduce health literacy issues, albeit from a captured population group residing in residential care. The Health Passport was launched on 1st July 2013 to all district health boards (DHBs) to provide information about patients to health workers (Health & Disability Commission, 2013). Literature on the Health Passport revealed that it was developed in the United Kingdom (UK) in the 2000s as a document held by a person with a disability or their carer, which they gave to providers when they entered hospital. The record of their health condition and medications was held on the passport and each consultation was added in. There are no evaluations of the passport to determine its success and how it might be improved (Ridgeway Learning Disability NHS Partnership, 2008).

In New Zealand, the passport was piloted at Capital and Coast and Hutt Valley DHBs in 2011.The Health Passport has now also been established at Waitemata and Waikato DHBs. The Health and Disability Commission is working with other interested DHBs to implement the initiative (Ministry of Health, 2013c). There have been no evaluations of the effectiveness or uptake of the passport in New Zealand. The passport focuses on disability, mental illness, chronic illnesses and deafness. There are three versions: an A4 format with pictures or without pictures, and A5. The passport is available free online to consumers or at a cost of $1.50 each for providers in a pack of 50. It is targeted at patients

staying overnight in a tertiary hospital and is a communication tool on 'how you can support me'. The whānau in this study did not have any knowledge about the existence of the passport as it has not been used in Hawke's Bay.

The health literacy practices that the whānau used such as notebooks and diaries were read by the health workers, but they did not enter information with the exception of one social worker who wrote a narrative about how the patient received support from social services. The usefulness of the passports may be of some benefit to Māori whānau in the future as part of **Struggling to be Involved**. However, the top-down approach demonstrated through the DHB-initiated rollout of the passports is not cognisant with the findings in this study, which indicated actions were whānau-initiated.

Figure 18 provides an overview of the complex, disparate and growing landscape of health literacy within New Zealand (Health & Disability Commission, 2013; Health Quality & Safety Commission, 2015: Knight, 2006; KPMG, 2013; Ministry of Health, 2011b, 2013b, 2014c, 2015; Namratha et al., 2011). Various focus areas include initiatives by DHBs, the government as well as education programmes and approaches recommended by institutions and organisations involved in health. The circular arrow in the centre of the figure indicates the evolving connection between each quadrant that occurs at times from the literature. Despite this, each focus areas appear to function as silos and are not connected across each domain. Not all of the areas are discussed in this thesis, however, a discussion on some of the key initiatives now follows.

One organisation that is taking action to reduce health inequities for Māori (see Figure 18) is called Workbase Trust then latterly, Healthliteracy.co.nz. Considered as the lead provider for the government, Workbase Trust focuses on improving the health literacy practices of health workers when engaging with Māori (Ministry of Health, 2013c). Workbase Trust conducted a literature review in 2013 for providers of health services and found that research in the USA by Zarcadoolas, Pleasant, and Greer (2006) supported the development of cultural literacy. As a component of health literacy, cultural literacy involves the presentation of information that is aligned to the beliefs, customs, and world views of diverse individuals (Workbase, 2013). Zarcadoolas et al. (2006) promote cultural literacy as having equal importance to the other domains of health literacy. Three of the remaining domains include fundamental literacy (knowledge of reading, writing, speaking and numeracy), scientific literacy (the skills and abilities needed to understand science and technology) and civic literacy (the awareness of public issues and participation in critical dialogue). The authors argue that the combination of these components provides a model for improving health communication and education.

After examining this research, the term cultural literacy did not appear to be different to cultural competency. According to DeWalt, Callahan, Hawk, Broucksou, and Hink (2010) learning about patients' ethnic backgrounds, cultural beliefs and religions, and the ability to apply this knowledge to shape the health encounter, shows cultural competence and enhances patient-centred care. The focus from DeWalt et al.'s (2010) description of cultural competence remains focused on the health worker learning about the culture of people receiving the service and not on the health worker's own beliefs, customs and world view and how each may impact on their practice. Nevertheless, the term is an interesting one as the findings are similar to the theory **Struggling to be Involved**. Development of the concept cultural literacy has merit as it locates culture as a key component of health literacy; however, the literature does not suggest that it becomes the prime focus and the risk is that other health literacy domains may be privileged by the health worker over culture. The only other New Zealand literature that discusses cultural literacy is research by Parton (2015) who recommends culturally appropriate health literacy assessment tools be developed for Māori women and whānau. This targeted approach includes inter-generational factors that affect the decision-making process for Māori whānau. With so many initiatives in existence before this study commenced, one would expect the whānau to be familiar with them. This was not the case as the findings from this study confirm the disconnect between health workers' approaches and whānau experiences. The health literacy landscape that has emerged from the literature portrays a top-down process from providers of health services and education, which may be changed with a whānau-up strategy contained within the theory **Struggling to be Involved.** The role of the health worker continues to be imperative for positive changes to occur for Māori whānau. The literature and findings from this study revealed many instances where the health worker has maintained control of the quantity, quality and dissemination of information with limited benefit for Māori whānau. Re-orientating the priorities from the health worker towards the whānau is a step towards reversing this situation.

Use of storytelling or pūrākau

The whānau came to see their health workers during some of the most intense and vulnerable moments of their lives. They trusted the health workers with translating clinical information and test results into explanations and treatment options that made sense. The importance of meaningful communication was clearly articulated within the findings of this study and as such, the majority of communication was expressed by non-verbal body language. For example, reassurance that the health worker was listening through appropriate eye contact (as opposed to gazing at the participant), even if he or she was multi-tasking, was an important indication that showed they cared. In February 2015, a major provider of health education in the USA surveyed 3000 consumers from the USA, the UK, and Germany (Nuance, 2015). The survey gained insight into the overall

patient-physician experience, patient engagement and behaviour, and patient awareness and preferences for technology. Of the respondents, 73% identified "time for discussion" as an area physicians could not ignore and 66% identified "non-verbal communication" as the second highest priority area (Nuance, 2015, p.14).
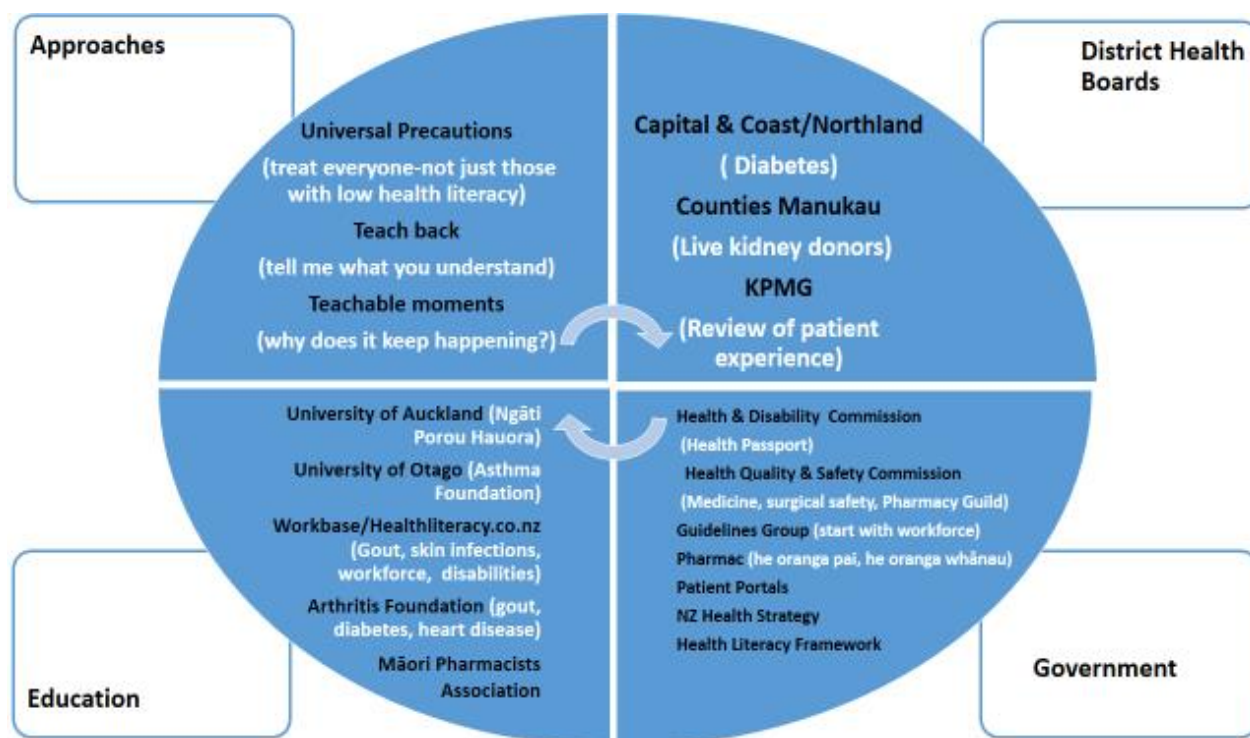
Figure 18: Health literacy landscape in New Zealand

Regardless of the outcomes, **Struggling to be Involved** encompassed proactive steps by whānau to ensure the health worker knew their patient story. With conditions such as the many moments of engagement with the health system, often the story got lost and the participant became a collection of unconnected data. Unconnected in the sense that information was stored about the whānau in various databases (GPs, pharmacists, hospital), without an overall narrative on the participant's current health situation. Consequences involved the next attending health worker either asking the same questions that were asked within previous encounters or not asking anything at all, giving the impression of not caring. The whānau response was frustration expressed as an unnecessary waste of time.

Storytelling is a part of life and is intrinsic to most cultures. At the most basic level, telling the story is a means of transmitting ideas and information about an experience from one person to another. Key events would be told as a story so the person hearing the story could remember and recall the account for others to learn from. Telling the story from the participants' point of view can provide the opportunity to gain deeper understanding of one's experiences and oneself and is the most common strategy utilised in understanding context and meaning making (Cox, 2001). From a symbolic interactionist point of view, telling stories helped the whānau construct the meaning of receiving bad news such as a diagnosis, to try to make sense of what happened by talking with whānau. When you tell a good story, you can frame important messages in ways that make them memorable for your listeners. One reason that purposeful storytelling works as part of **Struggling to be Involved** is because it brings across factual information along with a human interest perspective, drawing upon emotions. The effectiveness of telling the story meant that whānau could tackle any health problem despite knowing how the real world works. Once inside the story, the whānau felt a sense of connection with the health worker transporting them inside the story and getting their point across.

The majority of literature on storytelling in health remains focused on the health worker telling stories to gain compliance from patients. For example, in the USA storytelling is considered an effective intervention for patient engagement (Day, 2009). Telling the right story at the right time, can help a patient understand the importance of adherence to a treatment plan. Hence, storytelling can be beneficial for both teaching and motivating change (Osborne, 2008). Sometimes the tables are turned and the health worker needs to hear stories from the patients (Restrepo & Davis, 2003). To hear these stories, health workers must remain open to taking the time to listen. Key components to note are characters, actions (or inactions), settings, and messages. Restrepo and Davis (2003) argue that the patient's cultural perspective regarding health becomes more real as the health worker listens to the patient's story. In this way tolerance, empathy and culturally responsive care can be augmented by storytelling.

Telling the person's story as part of **Struggling to be Involved** helped them to heal by enhancing their ability to understand and cope with the disease or trauma, or improving their symptoms. Health workers may be unable to take away the pain and grief that patients and whānau experience, however, they can listen to their stories of illness or grief. Sharing the story of loss and finding someone to attentively and empathetically listen may be integral in the recovery process (Neimeyer, 2001). For Māori, pūrākau refers to stories as one form of Māori narratives that originate from oral traditions Other narrative forms include moteatea (traditional song), whakapapa (genealogies),

whaikōrero (speechmaking) and whakataukī (proverbs) (Lee, 2005). As an oral tradition, pūrākau continues to provide a cultural lens through which stories can be told. Pūrākau enables stories to convey messages, embody experiences and keeps cultural notions intact for Māori whānau.

The word pūrakau translates to the roots or the base (pū) of the tree (rākau) where in Māori language, words that relate to the imagery of trees reflect the cultural understandings of social relationships and inter-connectedness with each other and the natural environment. Pūrākau portrays an effort to paint the picture of the experience and engage with the audience in culturally relevant ways. Pūrākau encourages the transfer of knowledge and provides meaning for elements of emotion and wairua to be conveyed. Doctors Paratene Ngata and Rawiri Tipene-Leach, promote elements of pūrākau in a medical setting. Involving whānau in the storytelling and reflecting back their story to incorporate clinical information into a management plan is promoted. Dr Ngata and Dr Tipene-Leach stress that effective communication is not the ability of the GP to tell the story from a clinical perspective, but to listen to the story from the patient and their whānau to support a positive health outcome (Best Practice, 2015).

Listening requires maintaining an active presence, empathy and an openness to listening to the person telling the story – something difficult to do in our fast-paced health system. Health workers receive little training on how to deal with patients' grief, therefore, they may unknowingly erect barriers to a patient telling their story of loss, trauma or illness. If the sharing experience is difficult for the storyteller, it may impede the healing process. Health workers have a responsibility to the public to ensure that they are able to understand what they need to do to obtain healthcare needs. **Struggling to be Involved** can guide health workers in selecting an appropriate approach for Māori whānau through the use of storytelling or pūrākau.

Having hope

The gap between healthcare providers connecting positively with Māori whānau at an institutional level was of special significance in this study, as the whānau continually sought out their own natural resources to fill the gaps. **Struggling to be Involved** sustained whānau ability to hope as it could not be sustained by them as individuals. Utilising inter-dependence between whānau members as a way of *having hope* was a key strategy to remain engaged with healthcare services. The Māori term for hope is tūmanako. A well-known proverb states that with faith (whakapono), hope (tūmanako) and love (aroha), handed down by the ancestors, then the people and the land will be well. *Having hope* is strongly connected to wairua (spiritual wellness) and it is the affirmation and confirmation that

comes from having hopefulness mirrored back in empathic responses from other whānau members. As a component of health and wellbeing for Māori whanau (particularly within the te whare tapa wha model discussed in Chapter Two), having hope remains a process that is enacted to keep whānau members culturally safe.

The literature on hope in healthcare is limited with no research in existence in New Zealand. Holtslander's (2007) constructivist grounded theory of hope described the main concern was losing hope when losing a family member during palliative care in Saskatchewan. Losing hope then started the process of searching for new hope which was a positive response to counteract the grieving process. The study highlighted the need for support to caregivers of palliative cancer patients as they were at a heightened risk of regressing to losing hope. The study did not, however, highlight the support provided by family members and the focus of hope was for the whānau doing activities for themselves as a management strategy to search for new hope. Research in Australia asked how doctors might instil hope with incurable cancer patients (Hagerty, Butow, Ellis, et al., 2005). Ninety-eight percent of patients wanted their doctor to be realistic, provide an opportunity to ask questions, and acknowledge them as an individual when discussing prognosis. Doctor behaviours rated the most hope-giving included offering the most up to date treatment (90%), appearing to know all there is to know about the patient's cancer (87%), and saying that pain will be controlled (87%). The majority of patients indicated that the doctor appeared to be nervous or uncomfortable (91%), gave the prognosis to the family first (87%), or used euphemisms (82%) that did not facilitate hope. Factor analysis revealed six general styles and three hope factors. The most strongly endorsed styles were realism, individualised care and the expert/positive/collaborative approach.

Struggling to be Involved fills a gap in the limited research by contributing to a body of knowledge that supports Māori whānau to have hope while engaging with healthcare providers. Given the types of situations encountered in healthcare, and given that for many people health is an important good, it would seem that assisting Māori whānau achieve a variety of potential or acceptable futures would be one way of enabling them to discover hope. This may be particularly important if a cure or restoration to their former health or functioning is not possible. Finding ways to live life well with an illness or injury requires imaginative approaches to how successful outcomes such as a treatment are understood (Simpson, 2004).

Given that healthcare providers occupy an established social position for help and support of persons who are ill or injured, patients pay particular attention to what these healthcare providers do and do not say. Patients also notice the way providers respond to questions or comments relevant to particular hopes, even if that hope is not shared with the healthcare provider (Barnard, 1995). For example, off-hand comments from a health worker about another patient with the same illness at times affected whanau members' levels of hope. Whānau in turn limit the information shared with health workers for fear of the same experience happening to them.

Healthcare providers have the ability to control access to treatments and other forms of assistance, and many patients will rely on them to support their hopes. Hopes cannot be sustained by a patient alone or pursued by a patient alone. The support, or lack thereof, by healthcare providers can be a determining factor in a patient's ability to hope. It may not only be difficult for a patient to discover hope, but also to continue to have hope, especially if what is hoped for differs from the information and messages he or she receives from the healthcare providers (Simpson, 2004). One concern, however, that arises from drawing attention to the hopes of vulnerable patients is that healthcare providers may perceive a dilemma between hope and the need to protect patients. While there are situations in which patients do need to be protected, such as research participation, what is not clear is the protection that is required to maintain patient hope. Paternalistic interventions for the protection of those who are vulnerable with respect to their hopes is a reason for concern. Protecting the vulnerable could be interpreted as implying that healthcare providers should promote certain hopes for patients as a way of protecting them from the truth thereby making things easier on them. The following quote by Susan Sherwin illustrates this point.

> Because paternalism aims for the patient's good, it is recognised as a well-intended action, but its actual achievement in bringing about the best consequences is in doubt, because it is the physicians' – rather than the patient's – perception of the patient's good that is decisive. (Sherwin, 1992, p. 138).

In this study, stressing the vulnerability of Māori whānau with respect to their hopes made it more likely that healthcare providers assumed they knew what was best for them. This action in turn fostered what the healthcare providers believed to be the 'appropriate' hopes for Māori whānau. The end result was the provision of a culturally unresponsive service which minimised hope defined by Māori whānau themselves.

Moments of engagement

Multiple moments of engagement were a feature of whānau experiences (Methods chapter, Figure 2). Living with chronic health conditions involved many instances of engagement which did not always involve a health worker. The whānau noted 'Dr Google' as an option that they engaged with initially prior to seeing a health worker in person. Finding out about their health condition on the internet was common practice which is consistent with literature that supports the 'expert patient' model where people with chronic health conditions understand their condition better than their GP (National Health Service, 2015). In the UK, the expert patient programme supports people to manage their condition and treatment by partnering with healthcare professionals, being realistic about how their condition affects them and their family and it uses their skills and knowledge to lead a full life (National Health Service, 2015). Rhetoric surrounding the expert patient exists; however, programmes such as those from the UK currently do not exist in New Zealand (Flanagan, Moffat, Healey, & Moffit, 2014: Ministry of Health, 2012).

Talking to whānau helped the whānau consider information and options before, during and after engagement with a health worker. Whānau that were treated for a one-off health condition such as an accident, also reported multiple moments of engagement such as talking to someone on the phone about their condition, being assessed in an emergency department by the administrator and registered nurse, through to further assessment and treatment by different doctors and health professionals. Engagement was considered to be complex and varied with whānau, health workers, machines and the illness or disease. The lack of positive connection with a health worker contributed to whānau believing that their behaviour was to follow instructions without question and become compliant. **Struggling to be Involved** became a balancing act for the whānau as they did not want to be perceived as non-compliant with *having to ask questions* which resulted in *being silenced*.

A review of NZDHBs processes for measurement of patient experience was conducted in 2013 (KMPG, 2013). This review demonstrated that while some DHBs had consumer involvement strategies and policies for feedback as well as a complaints management system, most DHBs had consumer initiatives at individual ward, department or service level, that were not embedded into a DHB-wide framework. The revised New Zealand Health Strategy also indicated that patient engagement and feedback was sought by the government to change the name 'consumer' to 'people' (Ministry of Health, 2016). Five strategic themes are promoted within the draft strategy including: people powered, closer to home, value and high performance, one team and smart system with the over-arching goal being for all New Zealanders to live well, stay well and get well.

The promotion of direct engagement of people with the health system through patient portals and tele-health is also recommended in the strategy (Ministry of Health, 2016). GP practices will pilot patient portals, which provide real-time information and have an added bonus of reducing administration time. Māori are identified within two of the strategic themes. The *people powered* theme supports the New Zealand Māori Health Strategy, He Korowai Oranga, where the focus is on pathways to care that meet people's immediate and future needs. Moving to a stronger customer-focused approach is important within this theme although the term people is preferred to customer. *Closer to home* theme promotes more home-based services which Māori models of health and wellbeing are aligned. The significance of this theme addresses an issue where Māori are unable to access primary health care services due to cost. The *value and higher performance* theme includes the New Zealand Triple Aim Framework which has the goal of reducing inequities (improved quality, through safety and experience of care, improved health and equity for all populations, and best value for public health system resources) (Ministry of Health, 2011b). The Framework identifies the intention to remove infrastructural, financial, physical and other barriers for Māori, Pacific and people with disabilities. The strategy does not, however, state if the Triple Aim Framework has been evaluated since its inception in 2013.

Being resilient

Struggling to be Involved contributes to explaining how the whānau developed positive responses by *being resilient*. Having insight into their situation such as not accepting the service if it was not meeting their needs, refusing to give up, generating clarity to help solve problems, all contributed to *being resilient.* Other important processes included finding solutions to problems, having a sense of personal and collective identity, adherence to cultural practices, values and beliefs and building confidence by achieving success in one area which enhanced feelings of wellbeing and coping skills.

Definitions provided by various authors on resilience focus on being able to cope with and overcome difficulties and in the process, becoming strengthened by these difficulties (Grotdber, 2003: Rutter, 1985: Werner, 1993). A focus on competencies and positive outcomes, rather than on negative ones is also discussed in the literature (Collins, 2010; DeHann, Hawley, & Deal, 2013; Luthar, Cicchetti, & Becker, 2000). The lack of agreement on a definition of resilience, therefore, supports the notion of resilience being perceived as a risk factor in one circumstance and a protective factor in another (Ungar, 2004). In New Zealand, the limited literature on resilience for Māori has had a focus on Iwi (tribal group) responses after the Christchurch earthquake as opposed to whānau collectives engaging in health (Kipa, Potangaroa, & Wilkinson, 2011; Lambert, 2014). Collin's (2010) study,

however, of teenage mothers found that resilience for Māori referred to positive outcomes in the face of adversity, rather than to positive adaptation in general.

Luthar et al., (2000) argued that people who do not respond positively to adversity are blamed for their lack of resilience. Furthermore, the effects of discrimination and racism on health cannot be underestimated. Harris et al., (2006) argued that interventions to improve Māori health and reduce inequalities need to take into account the effects of racism as Māori were ten times more likely to report instances of racism when dealing with a range of services including healthcare. Although Harris et al. (2006) did not identify resilience as a protective factor for Māori, there was an emphasis on healthcare providers to recognise the effects of racism when reducing inequalities in health. The American Psychological Association's (2008) *Task force report on resilience and strength in African-American children and adolescents,* have made some traction in this area, and recommended a paradigm shift from an emphasis on risk to exploring the complex interactive process of resilience. The report recognised the effects of racism on African-American children and youth and re-framed their negative behaviours (such as acting out to authority figures) as protective actions to demontrate that they were not being heard by helping agencies. The behaviours were then considered to be part of how this group demonstrated resilience in a racist society. Responses recommended included a change in behaviour by authority figures to children and youth. A range of peers, families school and community groups were included in the implementation of this project.

The term, resilience, involves labelling people and to a degree can be considered as romanticised. In particular, it implies people have the freedom and agency to negotiate their own lives in the face of adverse circumstances. What the literature has revealed is that one of the main limitations with the concepts is that that there is a potential trade-off between resilience and wellbeing. In other words, one can be poor and unwell, but resilient (Bene, Godfrey-Wood, Newsham & Davies, 2012; Manyena, 2006). An already marginalised household for example, may have to cope with the rise in rent and therefore move to a cheaper but less desirable neighbourhood with high crime. The family have demonstrated resilience by adapting to their financial costs by paying less rent, but to the detriment of their wellbeing as a family. **Struggling to be Involved** supports Luthar et al.'s (2000) findings that whānau were *being discriminated against* as part of their healthcare journey by being labelled defeatist or fatalistic. The whānau considered themselves to be resilient otherwise they would not have survived the experience of healthcare engagement.

Another New Zealand-based research project called *Facilitating Whānau Resilience through Māori Primary Health Intervention* tested the hypothesis that primary health approaches in Māori settings

have the ability to assist whānau to increase their resilience by supporting them in finding resources that sustain their wellbeing in culturally meaningful ways (Boulton & Gifford, 2014). Initial results revealed that the more resilient whānau had greater access to natural resources including whānau, friends and links to their marae. Although the results from the Boulton & Gifford's study appear positive and support my study's findings when natural resources including whānau are used, it does not explain how whānau could be supported with *being resilient* in all healthcare environments. **Struggling to be Involved** does however explain how whānau draw on their support systems from a range of healthcare settings including primary healthcare and tertiary care. Nishiol, Chujo, and Kataoka (2015) utilised grounded theory to develop a model of functional perpetual resilience in their study of Japanese adults with type 1 diabetes. Functional perpetual resilience emerged as a core concept where patients progressed through five stages of developing resilience to face adversity. Nishiol et al.'s (2015) findings support the theory of **Struggling to be Involved** in which resilience was a changing construct that resulted in the greater emotional stability associated with *being Māori*. **Struggling to be Involved** contributes to understanding how Māori build resilience to manage their health issues through proactive efforts to involve whānau in decision-making processes.

Summary

The findings about whānau engagement with healthcare services have been located within existing literature. Salient components of the theory **Struggling to be Involved** have been examined incorporating whānau decision making, namely the use of whānau hui, health literacy practices and storytelling or pūrākau. Whānau decision-making processes cannot be stated enough as they are integral to being Māori, surviving the experience and struggling to be involved. Having collective identity (we-dentity), collective ownership and a commitment to the collective resolution of health issues is a unique process indigenous to New Zealand, which in turn supports the uniqueness of the theory **Struggling to be Involved**. Utilising inter-dependence between whānau members as a means of having and discovering hope or tūmanako is expressed within a spiritual lens. The whānau imperative defines, determines and drives hopes, which in turn reduce the risk factor of role minimisation of the whānau unit. Protective factors then become enhanced which offer ways to continue discovering hope for the whānau. Moments of engagement exist regardless of time or place and feature within one-off health encounters through to multiple encounters associated with chronic health conditions. The rhetoric surrounding the expert patient is yet to be realised within New Zealand insofar as engagement is currently framed as being noncompliant. Being resilient remains an enduring feature of Māori whānau despite many generations of colonisation. Being resilient within

this study comprises the same elements from similar studies in New Zealand and internationally where access to natural resources such as whānau, provides a culturally meaningful solution to healthcare issues. A discussion on the implications and recommendations from the findings of this study for health workers, policy makers and education providers now follows.

Implications of this study

To date, the investigation of Māori whānau engagement with healthcare services has been limited. The results of this study informed the development of the theory **Struggling to be Involved**. The theory captures Māori whānau management processes being constructed from a sense of connectedness and collective identity or we-dentity, through a shared purpose. Positive mediating factors on Māori whānau engagement include *being Māori* and *surviving the experience* involving conscious engagement through whānau decision-making processes. Revealing Māori whānau management processes in relation to healthcare engagement provides a portal through which health workers and policy and education providers can further investigate the integrity of whānau engagement at a systems level.

The findings of this study contribute to explaining how Māori whānau manage to keep spiritually and culturally safe while engaging with healthcare services. The theory of **Struggling to be Involved** provides a vehicle for assisting these actions to be implemented so that the health system can improve engagement with Māori whānau. When considering these implications it is important to clarify that the theory has been constructed for use by Māori whānau primarily and then those who support them such as health workers, providers, policy makers and educators. The theory was developed to explain how Māori whānau managed to navigate through the health system and the influences of natural resources to support their healthcare journey. **Struggling to be Involved**, therefore, provides a tool for working *with* Māori whānau to assist them with receiving the best healthcare possible in New Zealand, as they deserve no less.

Implications for health workers

New Zealand's Health Quality and Safety Commission developed a co-design programme in 2012 with the goal of providing opportunities for consumers and providers to work together on projects to improve service delivery. The programme is based on a similar programme developed in the UK and has been applied in England, Canada, the USA and New Zealand (Doyle, Lennox, & Bell, 2013). In 2015, the programme was evaluated and the findings revealed that engagement approaches needed

to be tailored, there was no 'one right way' of approaching consumers, and consumer engagement was value driven and highly personal (Hayward, 2015). The goals of the programme were to improve quality, safety and the experience of care and to increase the engagement of consumers in decision making about the services they use, and to increase consumer literacy and capture consumer experiences.

The Health Quality and Safety Commission produced resources on consumer engagement titled *Engaging with Consumers: A guide for District Health Boards*, which highlights the benefits of consumer engagement, communicates principles of consumer engagement and provides advice on facilitating consumer engagement in healthcare organisations (Health Quality & Safety Commission, 2015). The guide provides information for health workers to improve engagement with consumers during their healthcare journey. The guide does not, however, explain specifically how Māori whānau can be supported to do the same. **Struggling to be Involved** could be used as a tool to reducethis gap, as it prioritises Māori whānau during the healthcare engagement process.

It is important that health workers use their clinical, administrative or assessment skills to enhance whānau wellbeing; however, it is the whānau who ultimately decide to incorporate any recommendations to support the cultural and spiritual wellbeing of their loved one. Understandings learnt from **Struggling to be Involved** can be used to facilitate positive interactions between health workers and Māori whānau. The findings of this study identify three key messages for all health workers who provide services to Māori whānau. The three key messages are: 1) to accept and support the identity of Māori patients as members of Māori whānau; 2) to accept and support the importance of whānau in decision making; and 3) to ask what are your goals for me? A discussion of each key message now follows.

Accept and support the identity of Māori patients as members of Māori whānau
To enhance the likelihood of health information being understood and implemented, effective health workers need to first seek out information that is important to the whānau member. If information is gained solely from the person receiving healthcare then it will be less informative and comprehensive than if the whānau were involved in this process from the outset. *Minimising the importance of whānau* will become the likely outcome, potentially negating further engagement processes from occurring. The language and behaviour of the health worker needs to change to where the person is considered to be part of a collective at all times and that collective is the whānau. The term whānau member is, therefore, preferred to patient. Re-interpreting the cultural lens worn by the health worker will assist with understanding how Māori whānau are **Struggling to be Involved**. A re-

imagining of the Māori patient as someone that comes from a whānau that follows the whānau imperative of *surviving the experience*, is the starting point to truly demonstrate engagement.

As previously discussed, Doctors Ngata and Tipene-Leach provide relevant and specific advice to embrace the role of the whānau along the healthcare journey. Once the health worker has decided that the whānau are crucial to achieving positive health outcomes for their loved one, then the healing process can begin. The health worker simply needs to make the decision to see the person as an inter-dependent member of the collective first and foremost. To enable learnings to be implemented from **Struggling to be Involved**, the decision to view and treat the person as a whānau member requires commitment. Once the decision is made then the health worker is in a position to support whānau decision making as a tool to progress effective health outcomes for the whānau member.

Accept and support the importance of whānau in decision making

Struggling to be Involved explains how Māori whānau mobilise each other through a range of strategies to care for each other during healthcare engagement. **Struggling to be Involved** offers a theory within which Māori whānau can receive a health service that is culturally responsive to their needs. Supporting the whānau decision-making process is a culturally responsive strategy that enables deliberation and actions to be agreed upon through consensus. Whānau decision making is identified as a collective ambition (Tupara, 2009). The nature of whānau and the processes they employ are culturally determined to reflect a Māori concept of wellbeing or hauora. Comparing a Western and whānau decision-making process is problematic and does not serve the purpose of enhancing health outcomes for the whānau. However, accepting that it occurs is a decision-making step for the health worker who can then take action. Whānau decision-making processes are a mechanism for socialisation, and allow for the internalisation of Māori practices and values to be enacted. A hui is the most common way for whānau to make decisions.

The health worker's role is vital in facilitating whānau decision making in several ways (although it is not limited to the following). First, if a whānau member tells the health worker that they need to have a whānau hui to discuss the decisions related to their concern then the worker must not create barriers to this occurring. For example, interrogating the whānau member about why there is a need for a whānau hui is not conducive to assisting whānau, although it may appear as a simple line of enquiry from the health worker's point of view. Acceptance is required that whānau hui is a cultural practice that may occur, with or without the permission or knowledge of the health worker. Whānau members who have intimate knowledge of health conditions over many generations may come

forward with vital information during a whānau hui, uncovering unknown familial information. The development of new knowledge or mātauranga can, therefore, occur during whānau hui. The whānau then have an opportunity to preserve knowledge about a familial or genetically-based health condition, for example, for the betterment of future generations.

Second, the health worker is not required to attend whānau hui, however, they can assist with the discussion by providing information in lay language for the hui to consider. The benefit of engaging with the whānau hui albeit from an information-providing stance is a short-term investment for the health worker with long-term gains in terms of health outcomes. As part of the initial engagement phase, the health worker may suggest whether a whānau hui is going to occur as part of the decision-making process. Broaching the subject demonstrates an openness to the process even if the whānau member has not raised the topic themselves.

Third, encouraging storytelling or pūrākau from the whānau member as a result of him or her attending a whānau hui shows an interest in supporting a positive health outcome. Listening attentively to the story assists with the whānau member feeling they are being heard and that their story is not forgotten. Recalling previous stories provided by the whānau member as an opening to an initial discussion conveys confidence and competence in culturally responsive care by bringing the past into the present. Re-connecting past events with the present is seen by Māori whānau to be part of effective communication and demonstrates a deeper understanding of cultural frameworks of knowledge.

Facilitating whānau engagement in decision making requires an enabling environment to be developed for both the health worker and whānau member. Accepting that whānau hui will occur regardless of a health worker's intervention, provides meaningful engagement with a whānau member. Utilising the whānau hui as an engagement tool to improve health outcomes is efficient and effective as: 1) it demonstrates a culturally responsive approach by embracing whānau models of decision making; 2) it improves effective communication and engagement with whānau to gather relevant health information that may not be attained otherwise; 3) it provides a more efficient use of time to front-end load the assessment process so that less time is spent with ongoing follow-up interventions; and 4) it recognises the value of a whānau-determined process that meets the whānau imperative as well as the clinical or administrative imperative of the health worker.

Ask what are your goals for me?
Healthcare workers can often believe that Māori whānau already know how to navigate through the

health system. This is mostly likely to occur if the whānau member presents with a chronic health condition. Assumptions are then made that the person already knows about treatment regimes, appointments or health information. Supporting a culturally responsive approach involves less talking and more listening. The behaviour and attitudes of health workers impact on the behaviour and attitudes of people to whom the workers are providing a service. If a whānau member is presenting on a regular basis with little improvement in their health, then this can be interpreted as the service not being culturally responsive. To remedy the situation, a simple yet effective approach is offered. The approach involves asking "what are your goals for me?" The following story epitomises how a culturally responsive service was provided for a kaumātua (elder) who regularly presented to hospital for a chronic health condition.

The experience allowed Jessie to comment on what she wanted to achieve during her stay in hospital without her having to react to the healthcare worker's goals. The health worker also achieved his objective of assessing Jessie's level of understanding about her condition and to prepare for receiving whānau members that would arrive at some stage. The sharing of the health worker's goals after Jessie shared her goals, facilitated partnership between them both and ensured positive engagement for the rest of Jessie's time in the hospital. Jessie also 'enjoyed' her experience in hospital as she felt her needs were attended to and she was not going to 'bother' the nurses. The overall outcome was a change of focus from *what is the matter with this person* to what matters to this person. The whānau member together with the healthcare worker defined what the right care was and it was executed while maintaining Jessie's cultural integrity. Jessie also presented less often to hospital and began to better manage her health condition. A shortened version of Jessie's story follows:

Healthcare worker:	Kia ora (cultural greeting). My name is …… and I'll be your nurse until seven pm tonight. What would you like me to call you?
Jessie:	Kia ora. Jessie will be fine.
Healthcare worker:	Thanks Jessie. Can you tell me what are your goals for my shift?
Jessie:	I'd like help with going to the toilet and help with taking my pills and I'm expecting my whānau to visit.
Healthcare worker:	That's great. I have some requirements for you as well. I need to check your bandage every two hours and take your blood pressure. I'll write our shared goals on the whiteboard behind you so we don't forget and if another nurse attends to you then you won't have to repeat yourself. Sound ok?
Jessie:	Sounds great.

Jessie was the most satisfied she had ever been during her many moments of engagement with healthcare services (personal communication, December 10th, 2015). One health worker's actions and approach had the following outcomes:

1) Jessie did not have to ring the bell once during her entire stay in hospital as her medical situation and requests for assistance were made visible to the staff in a language that was understandable by her as the patient, the health worker and visiting whānau.

2) The healthcare worker greeted Jessie in a culturally responsive way with *Kia ora*. The healthcare worker introduced himself and asked Jessie what she preferred to be called. Some people prefer Mr or Mrs. In this instance Jessie preferred to be called by her first name.

3) Instead of the healthcare worker telling Jessie what was going to happen to her, he asked Jessie what her goals were first.

Implications for healthcare providers

Supporting hope

Just as health workers are encouraged to re-imagine Māori whānau members as part of a collective, so too are healthcare providers encouraged to re-imagine new approaches to providing hope for them. Attending to patient hope in an ethical manner requires: a) an acknowledgement of the vulnerability that accompanies the hope of whānau members; b) an appreciation that this vulnerability can take different forms as discussed previously; and, c) consideration of vulnerabilities affecting the ability of whānau members to hope.

Future work on the role of hope in healthcare should consider how and in what ways healthcare providers can best attend to patients' hope in light of these different vulnerabilities. For Māori whānau, hope or tūmanako is closely linked to wairua or spirituality. Although there are some perceived difficulties with including spirituality in assessment and treatment processes, the inclusion of hope or tūmanako can be less problematic. Healthcare providers can support staff to engage in conversations of hope as it is a topic most relatable to Māori whānau. For example, gauging a whānau member's perception about their future and ongoing events in their life is one way of linking their hopes with anticipated outcomes about their life. The vulnerabilities that accompany hope can then be identified and appropriate action taken with the whānau to address their concerns. The term hope can be made discrete to the whānau member when this engagement process occurs, just as in the same way that health literacy is a term that is not used directly when discussing such practices with patients.

Implications for policy makers

Policy plays an important role in shaping environments that affect Māori whānau. The following implications and recommendations for policy makers focus on whānau and aim for integrated whānau-based experience indicators and cultural literacy assessment tools that focus on the naturally occurring and internal assets of whānau.

Develop whānau-based experience indicators

Jansen, Bacal, and Crengle's (2008) study used experience-based, rather than satisfaction-based questions to explore low engagement with GP services. Satisfaction-based questions do not reflect true attitudes (i.e. Māori are reluctant to be seen as rude or critical) and may reflect an acceptance of inequalities (e.g. satisfaction is reported as high because expectations are extremely low). By inquiring about experiences, people's responses can be compared to best practices and assessed more objectively. Jansen et al. (2008) found that Māori have a cultural tendency to be *noho whakaiti* – to not cause a ruckus – and so they may not appear worried, upset, or assertive to staff in the face of an urgent health need. Despite years of government programmes to reduce health disparities for Māori, they are still reporting that they are less likely to be offered choices with healthcare or to be seen on time and within their preferred timeframe. These findings suggest additional work is needed to align Māori experiences of health with those of non-Māori. Whānau-based experience indicators have been highlighted in this study that would assist policy makers to develop the indicators further. Utilising the co-design methodology recommended in the government's revised New Zealand Health Strategy would achieve this recommendation by involving Māori whānau as design partners.

Develop cultural literacy assessment tools

The abundance of literature in health literacy noted in this study revealed a top-down approach from government, policy makers, health workers and educators to Māori whānau. A whānau-up approach is recommended which includes Māori whānau in the development of health literacy resources. The *Three Steps to Better Health Literacy* resource developed by the Health Quality and Safety Commission in 2015 that targets pharmacists, is an example of where cultural literacy could be augmented. For example, the resource proposes that the pharmacist asks the patient questions about what they already know about their health condition and reinforces the teach-back method. The resource does not, however, include whānau as part of the engagement process and is individually focused on the patient alone. The inclusion of whānau within the resource would engender more comprehensive answers and improve the cultural literacy of the pharmacist.

The integration of information on how to ask the whānau questions about their member's health with the person present, is preferred to a separate cultural literacy resource as it costs less to produce and integrates the change in focus as part of best practice. A roll-out of the integration of cultural literacy assessment tools into the health literacy framework would also achieve the goal of integrating whānau involvement and decision making on a wholesale level in New Zealand (Ministry of Health, 2015a).

Implications for health education providers

Literature such as Beutow, Adair, and Coster (2003) support a finding in this study that providers of healthcare services need to receive appropriate training so they can communicate safely and effectively with Māori while addressing their needs. Chapter two examined a range of culturally responsive models that attempt to reduce Māori whānau health disparities. Each model is tailored to the corresponding occupational group such as medicine, occupational therapy, psychology, physiotherapy, psychology, osteopathy, midwifery and nursing. Each profession requires a different lens to deliver key messages such as cultural safety, cultural competence, patient-centred care and cultural responsiveness. Regardless of which approach is taken, the outcome requires the best service to be delivered to Māori whānau, as they deserve no less. The Meihana model is consistent with the findings of this study as it supports Māori whānau decision-making processes. Although the model is framed as a medical intervention, the components of the model support cultural competency and cultural safety for Māori patients and their whānau. The model integrates the hui process which is important to Māori whānau as a finding within this study. The model provides assessment tools on history taking which account for racism, colonisation, migration and marginalisation. Māori beliefs and values are augmented with personal health indicators which are important to the person receiving care. One recommendation to extend on the success of the Meihana model is to include historical trauma as an indicator alongside colonisation and racism as trauma can become embodied as physical, spiritual and psychological symptomology within generations of whānau members**.**

For non-clinical personnel, an equally effective educational approach is required. Getting the hellos and goodbyes right is a finding within this study where front-line staff can have the most influence with Māori whānau. In a general setting, smiling as an example of getting the hello right, indicates a desire to connect with others and to continue the interaction. In this study, smiling as part of saying hello indicated a good service in comparison to an encounter where the expression suggested a lack of desire to continue the interaction. Customer service training is an opportunity to increase general

skills and competencies for front-line staff when engaging with patients. The training would, however need to be supplemented with Māori whānau-based storytelling or pūrākau so that the quality of the service encounter achieves more than simply putting the whānau member in a good mood. Building emotional and cultural intelligence will achieve the goal of providing a quality service and support satisfaction with the overall encounter for Māori whānau.

Limitations of the study

The participant group in this study was small (n=20) and is, therefore, suggestive of processes being used by New Zealand Māori whānau rather than being definitive. Studying a larger group from a wider geographical area would provide data to develop and add diversity and complexity to the categories and processes constructed at this point. Caution is advised in generalising the findings beyond the whānau involved in the study.

Recommendations for further research

Policy makers, educators and health professionals were included as key informants, particularly when theoretical sampling occurred. These informants, however, were not selected in their own right as contributors towards the engagement process with Māori whānau. The research did not intentionally intend to seek out this group, however, research that specifically targeted their perspectives would add insights with the potential to enhance their practice, policy development and education programmes associated with Māori whānau engaged with healthcare services.

An important finding in this study was that the collective identity (we-dentity), ownership and decision-making processes supported resilience for the whānau. Māori whānau provided the immediate groupings responsible for the care of their members. Māori whānau also have considerable potential to influence the health of their members. The natural resources that Māori whānau access strongly influence their ability to provide care and wellbeing with all systems beyond health. Research that extends how Māori engage with other systems such as social services, housing and justice is an area highlighted for potential exploration.

Although the impacts of colonisation have been documented and research has found an association between racism and health, there is also limited research on exploring the relationship of historical trauma on Māori whānau health and wellbeing within areas such as social services, housing and

justice. The role of each sector and how each can facilitate whānau decision making can contribute knowledge and improve Māori whānau status within the respective areas.

Review of question and aim

The research question for this study was : *what is happening with Māori whānau when they engage with health services?* The study aimed to generate a theoretical explanation of the processes Māori whānau use in health care services to have their cultural and spiritual needs addressed. **Struggling to be Involved** has emerged as the theory to explain what was happening for Māori whānau during healthcare engagement. The process of generating the theory was continuously informed and guided by Kaupapa Māori, particularly with regard to consultation, data collection, and dissemination of the findings. I used Charmaz's (2006, 2014) constructivist grounded theory to consider how and why Māori whānau constructed meanings and actions when engaging with health services. With constructivist grounded theory the review of the question and aims is discussed more extensively by discussing the rigour of the research process which now follows.

Rigour of the research process

Constructivist grounded theory offers explicit analytic guidelines, ways of seeing data, control over the research process, and the promise of a completed project (Charmaz, 2012). **Struggling to be Involved** is the culmination of a completed project that used grounded theory for studying processes and it is also a method in the process (Charmaz, 2009). This method presented different theoretical perspectives with a focus on various levels of analysis, objectives and an area close to the researcher's heart, and that is Māori health. Using Charmaz's (2014a) criteria of credibility, originality, resonance and usefulness, the robustness of the process involved in this study has been referred to in the methods discussion in chapter four. Nonetheless, further discussion of how this study met the criteria will now be provided.

Credibility

Credibility as a criteria of rigour is met when the researcher has presented enough evidence to support their interpretation. The rich description offered in this study and the variation of social patterns explained how the theoretical categories provided data to substantiate the claims made. Where possible, the whānau words were used in the theory and to document the researcher's personal ideas through the use of memos. Transparency was enhanced with a discussion on the researcher's location as a Māori researcher being connected to the whānau through whakapapa

(genealogical links), which in turn allowed the reader to understand the thesis from the researcher's cultural lens. Ultimately, the credibility of this study can be judged by the depth of the substantive theory.

Originality

Originality is measured where the theory offers new insights or extends current concepts. There is very little health research which documents the experience of Māori whānau during healthcare engagement. The research that does exist focuses on the individual whānau member first and foremost and whānau are supplementary to the findings. This research is significant as it contributes to a very small area of research that has utilised constructivist grounded theory and Kaupapa Māori. Given the increasing health disparities endured by Māori whānau, this research provides new insights that have not been considered previously.

Resonance

Resonance questions whether the end product makes sense to whānau and whether the categories portray the fullness of the studied experience. The findings of the study captured the taken-for-grantedness of the whānau management strategies when engaging with healthcare services. Member checking assisted with revealing the meaning of actions identified by whānau, either tacitly or through in vivo codes. This process involved taking initial codes back to them for clarification or theoretical sampling. The co-construction of codes, which contributed to full saturation of the categories portrayed the fullness of the whānau experience.

Usefulness

Usefulness asks if the study offers interpretations people can use in everyday worlds. I have endeavoured to: a) generate a theory which both reveals insights into whānau decision-making processes as they struggled to be involved in their healthcare journey; and b) provide a foundation for future research. This theory identified significant barriers that Māori whānau encountered during interactions with the health system. Given the continuing failure of established interventions to reduce Māori health concerns, this research adds new knowledge at a time when it is desperately needed. This study demonstrates the importance of recognising the role of Māori whānau during healthcare engagement and reveals the critical mismatch between what Māori whānau want, versus what actually happens for them during healthcare interventions. This research makes a new contribution to existing health science literature and the findings have the potential to change Māori whānau experiences and health outcomes in the future as what is currently happening for Māori whānau, is not working for them.

Conclusion

This thesis provides evidence that the New Zealand health sector, health legislation and policies are largely unfavourable for guaranteeing whānau engagement in decision processes. Yet, whānau decision making is an overall objective of the government's *Māori Health Strategy: He Korowai Oranga*, to reduce inequalities in health between Māori and other New Zealanders. The whānau in this study have contributed some of their whānau decision-making experiences to the construction of a theory, which seeks to explain how they engage with healthcare services. Each participant had a health history that was unique to them yet there were commonalities in their patterns of **Struggling to be Involved.** Having to ask questions, being silenced and knowing the rules of engagement were the patterns that created emotional responses from becoming fatigued with discrimination. Whānau provided the spiritual and cultural outlet for the negative conditions that arose from the behaviour of health workers.

Struggling to be Involved was a core process and the substantive theory as it impacted on *being Māori* and surviving the experience of healthcare engagement. Paradoxically *being Māori* contributed to negative and positive processes for the whānau. Negative processes included minimising the importance of whānau, feeling whakamaa and being discriminated against. Fortunately, the positive processes provided protective factors, as the whānau were able to draw on their collective identity (we-dentity) and collective ownership of their whānau member's health concerns. *Surviving the experience* became a process and an outcome of healthcare engagement for the whānau and their whānau. Making it to the other side by obtaining a health service (good or bad) was achieved by whānau taking control, feeling lucky and having hope through a range of management strategies such as health literacy practices and having karakia with whānau members.

The dynamic interactions of processes and perspectives comprising the theory demonstrate that Māori whānau are managing the healthcare of their members despite the health system within New Zealand. Although many families may encounter similar experiences to the whānau in this study, for each participant their experience was compounded by many discriminatory practices. They faced many challenges that other New Zealanders have the privilege of never experiencing. The challenges required them, therefore, to be continuously **Struggling to be Involved** in order to achieve a quality healthcare service, which should be the right of every New Zealander in the twenty-first century.

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APPENDIX ONE: AUTEC APPLICATION APPROVAL

**AUTEC
SECRETARIAT**

6 November 2012

Denise Wilson
Faculty of Health and Environmental Sciences

Dear Denise
Re: **12/283 Māori and whānau and their engagement with healthcare services.**
Thank you for providing evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC), and I have approved your ethics application for three years until 5 November 2015.
As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through http://www.aut.ac.nz/research/research-ethics/ethics. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 5 November 2012;

- A brief report on the status of the project using form EA3, which is available online through http://www.aut.ac.nz/research/research-ethics/ethics. This report is to be submitted either when the approval expires on 5 November 2012 or on completion of the project;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to whānau. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.
AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply within their.
To enable us to provide you with efficient service, we ask that you use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.
All the very best with your research,

Dr Rosemary Godbold
Executive Secretary
Auckland University of Technology Ethics Committee

APPENDIX TWO: INFORMATION SHEET

Information Sheet

Date Information Sheet Produced:
> 2 November 2012

Project Title
> Māori and whānau and their engagement with healthcare services

An invitation
You are invited to participate in a study which will explore how Māori and their whānau experience healthcare services. My name is Dianne Wepa. My hapū are Ngāti Pahauwera, Ngāti Hinepare and Ngāti Hawea. My iwi is Ngāti Kahungunu. I have been a social worker and tutor at the Eastern Institute of Technology (EIT) teaching nursing students in the area of cultural safety. I now work as a workforce coordinator with the Māori Health Service at Hawke's Bay District Health Board. I receive weekly cultural supervision from the kaumatua and kuia employed within the Service. I am a PhD student at AUT and would like to interview you and your whānau about your healthcare experience in the last 12 months. Participating in this study is entirely voluntary. Anyone who does choose to participate is free to withdraw at any stage prior to the completion of data collection.

What is the purpose of this research?
This research contributes toward my PhD qualification. The purpose of this study is to explain the process of how Māori and their whānau keep spiritually and culturally safe while engaging with primary and secondary health services. Information gathered from whānau will be used to assist health professionals to improve the services that are currently offered. A thesis, articles, presentations at hui and publications will result from this study which can be accessed by the public. At no stage will you be identified in any reporting of this study.

How was I chosen for this invitation?
You have been invited to participate because someone who knows about the study has mentioned it to you or given you a panui containing my contact details. You may have contacted me directly after seeing the panui.

What will happen in this research?
If you choose to participate, I will talk with you and your whānau to arrange a time and place for an interview. I am expecting most interviews will take approximately one to two hours, but some may take more while others may take less. You can stop the interview at any stage. During our discussion I will be asking you and your whānau to tell me about how your spiritual and cultural considerations were included during your healthcare experience. The interview will be audio-recorded so that later on I can analyse the information given. You will be given a copy of the transcript from your interview and will be offered a copy of the audio recording. I may also request permission to contact you again if I need further clarification or more detailed information. You are under no obligation to agree to any further contact.

What are the discomforts and risks?
Some of the topics you discuss with me may involve a difficult or unhappy experience that has affected the ways in which you manage your health and wellbeing. Talking about situations such as these may cause emotional discomfort for some people.

How will these discomforts and risks be alleviated?
If you become upset as a result of telling particular stories you do not have to continue. The interview can be paused or stopped according to your wishes at the time. I will spend time talking with you and your whānau to ensure that any immediate discomfort is addressed. If you or your whānau need any further assistance as a result of the interview I will be happy to provide information on the support services available.

What are the benefits?
There are several potential benefits for those who choose to participate. You have the opportunity to share your positive experiences when receiving a healthcare service that might assist other who have been through a similar situation. You also have the opportunity to give a first-hand account of any difficulties that you experienced, what contributed to them and what would of helped to address them. When this information is collated and analysed it will contribute to a theoretical explanation of how cultural and spiritual safety is managed by Māori and their whānau. This framework can then be developed to enhance health professionals work better with Māori and their whānau. You and your whānau will receive a summary of the findings of this research when it is finished, and an invitation to local hui where the findings will be presented. The benefits to me as the researcher are that I will gain a PhD and a better understanding of issues related to the cultural and spiritual safety of Māori and their whānau when receiving a healthcare service.

How will my privacy be protected?
All whānau will be allocated a pseudonym (false name) so that information they give cannot be directly traced to the person or whānau who gave it. Recordings and hard copies of interviews will then be analysed and then moved to the supervisor's office and stored safely in a locked filing cabinet. The data will be destroyed 6 years after the study is completed. Data and consent forms will also be destroyed after 6 years. Interviews will be held in a place that is comfortable to you and your whānau, ie in your home or in a meeting place of your choosing.

What are the costs of participating in this research?
There are no anticipated costs to you and your whānau except approximately one to two hours of your time. You will be provided with a koha to acknowledge the use of your time for this study.

How do I agree to participate in this research?
If you agree to participate directly before the interview begins I will ask you to read and sign a consent form that records your agreement as part of the study.

What do I do if I have concerns about this research?
Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor: Associate Professor Denise Wilson, dlwilson@aut.ac.nz ph: 09 921 9999 ext 7392

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Dr Rosemary Godbold, *rosemary.godbold@aut.ac.nz* , 921 9999 ext 6902.

Who do I contact for further information about this research?
Research Contact Details: Dianne Wepa, Dianne.b@vodafone.co.nz 021 748 678

Approved by the Auckland University of Technology Ethics Committee on 6 November 2012
AUTEC Reference Number 12/28

APPENDIX THREE: CONSENT FORM

Consent Form

Project title: **Māori and whānau and their engagement with healthcare services**

Project supervisor: Dr Denise Wilson

Researcher: Dianne Wepa

- I have read and understood the information provided about this research project in the I information Sheet dated 15/10/2012.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interview and that they will also be audio-taped and transcribed.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- I agree to take part in this research.
- I agree for my whānau to be involved in the interview as part of this research.
- I understand that I will be given a copy of the interview transcript.
- I wish to receive a copy of the voice recording (please tick one) : Yes O   No O
- I wish to receive a copy of the research report (please tick one): Yes O   No O
- I agree to being contacted by the researcher to discuss a further interview if required (please tick one): Yes   O   No O

Participant's signature: …………………………………………… Date………………………………..

Participant's name: …………………………………………………………………………………………

Participant's Contact Details:

………

………

Approved by the Auckland University of Technology Ethics Committee on 6/11/2012
AUTEC Reference Number: 12/283
The Participant to retain a copy of this form

APPENDIX FOUR: ADVERTISING FLYER

AUT
UNIVERSITY
TE WĀNANGA ARŌNUI O TAMAKI MAKAU RAU

Advertising Flyer

Māori and whānau and their engagement with healthcare services

Kia ora.

You are invited to take part in my PhD research project. I am interested in talking to Māori and their whānau about their experiences of healthcare.

I am interested in talking with you if you are:

- Māori,

- Have received a healthcare service within Hawke's Bay in the last 12 months,

- Have whānau that will also want to share this experience,

- Aged between 18 and 70 years, and

- Want to share your healthcare experience to help improve services for Māori

Please contact: Dianne Wepa
                    Phone/text: 021 748 678
                    Email: Dianne.b@vodafone.co.nz