# Mai ngā pouwhirinaki

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## The experiences of whānau caring for Māori tangata whaiora with traumatic brain injury in the Waikato

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# Ariā - Abstract

In Aotearoa today, Māori have a disproportionate experience of Traumatic Brain Injury (TBI) in the community and in prisons compared to non-Māori. Furthermore, Māori have higher mortality rates following TBI, and are more likely to have a prolonged stay in hospital then be discharged without community support services compared with non-Māori. Currently, many of the post-acute rehabilitation services are located in the Auckland region which causes undue pressure of whānau needs, finances, and work commitments for many whānau and individuals with TBI from the Waikato region. My research focuses on the experiences of whānau navigators experience of caring for Māori tangata whaiora with TBI in the Waikato region. Whānau navigators for this thesis refers to members of the whānau who have familial obligations of care. Within this thesis I consult and engage with whānau about post-acute rehabilitation services. This is a qualitative based research project, which draws upon narrative inquiry, and a Kaupapa Māori research paradigm. Documenting these experiences will provide empirical evidence to highlight the invaluable role whānau have within recovery and the value of whānau support. This research can be used to identify the dynamic needs of whānau and encourage the healthcare system to provide a service that is consistent with Kaupapa Māori health frameworks and practices which at present is non-existent. As a result, the project will help inform the development of a service model within TBI that can better reflect and support the needs of whānau and Māori communities, that is a locally derived practice and more applicable and appropriate for Māori. Mauri ora!

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*Mātou i heke mai i ngā kawai o Ohomairangi o Te Arawa, o Tainui.*
*Tui noa*
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# Kuputaka – Glossary

| Term | Definition |
|---|---|
| Kai | Food and drink |
| Kaimahi | Worker (s), helper, assistant, contributor, counsel, in some cases advocate |
| Kanohi kitea/Kanohi ki te kanohi | Face to face, in person, in the flesh |
| Kaupapa Māori | An approach that privileges the perspective and protocols of Māori |
| Kaupapa Whānau | People who do not necessarily have a genealogical relationship but who were seen as fulfilling that role for the TBI participant. Kaupapa Whānau participants can be non-Māori. |
| Karakia | Incantations, prayers, chants – karakia are used to invoke atua (ancestors and supernatural being with influence over particular domains) which enables people to carry out daily activities in union with atua Māori |
| Kōrero | To talk, discuss, converse, state |
| Mahi rangahau | Research, investigate |
| Mana | Status, prestige, influence, power, control, authority, charisma – Mana is inherited at birth by atua Māori and individuals become agents of mana throughout their lives |
| Mātauranga Māori | An ever–evolving foundational body of knowledge rooted in ancient Māori beliefs, practices, and ways of being |
| Rangahau Kaupapa Māori | A research approach that privileges the perspective and protocols of Māori |
| Roro pāmamaetanga | Traumatic brain injury |

| | |
|---|---|
| Te Ao Māori | The Māori world, including Māori practices, ways of being and relating with people, places, and the natural environment. |
| Te taha hinengaro | Mental and Emotional wellbeing, also mind, thought, intellect, consciousness |
| Te taha tinana | Physical body and realm |
| Te taha whānau | Family and social connections |
| Te taha wairua | sometimes translated as the spiritual dimension of wellbeing, profound connection, uniquely Māori |
| Te Reo Māori | The Māori language |
| Te whara o te roro | Traumatic brain injury |
| Tikanga Māori | Māori cultural protocols, and practices, this reflects culturally embedded ways of enacting processes that are just and fair. Important to note that tikanga varies across regions, tribes, and within subtribes. |
| Tino rangatiratanga | Sovereignty, self–determination, autonomy, self–governance, control, power. This reflects the notions of the right to exercise authority and retain independence. |
| Whakapapa Whānau | People who are genealogically linked either by blood, marriage or romantic relationship |
| Whānau | Immediate and extended family |
| Whanaungatanga | Processes of making relational links - built on identifying and positioning oneself and others in relation to another within shared relational networks |
| Tangata whaiora | People/person seeking wellness |

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## Te mahi rangahau: research focus

### *Aims and purpose*

This thesis explores whānau (immediate & extended family) and their experience with caring for Māori tangata whaiora (person seeking wellness) with traumatic brain injury (TBI). I will explore and consider how whānau in the greater Waikato region care for, and support Māori tangata whaiora with moderate to severe TBI, as well as whānau experiences of TBI services in this region, with an emphasis on post-acute rehabilitation services.

The partners, parents, tamariki (children, kids) and wider whānau network can be hugely impacted immediately after the TBI event, and the long-term outcome of the mental well-being for the whānau can be strenuous, and in some cases more severe than the Māori tangata whaiora with the TBI (Lavelle Wijohn, 2017). Furthermore, because Māori have diverse health needs it can be hugely difficult for whānau to navigate and manage the healthcare systems and rehabilitation services that fail to respond to the cultural needs of Māori, which can contribute to ongoing stress and anxiety for whānau and their Māori tangata whaiora (Jansen et al, 2008). This research project is important for the Māori health sector as information explored and shared by whānau might contribute to reviewing and developing new or alternate practices that support whānau living well, whilst supporting Māori tangata whaiora.

Within Aotearoa, Māori experience inequities in access and outcomes in health services, structural critique over failures within existing systems remain prevalent as cultural identity remains invisible (Dudley et al., 2014). By seeking to understand the whānau experiences of the healthcare system, inclusive of post-acute rehabilitation services, this informs understanding of structural determinants of health inequities, that can in turn support the betterment of quality healthcare that is sustainable. As a result, this reduces the unequal distribution of quality healthcare (Palmer et al., 2019). Currently, there is very limited research on Māori with TBI in the Waikato, and even fewer studies involving their whānau (Lakhani et al., 2017; Lavelle Wijohn, 2017).

To understand health, educational, social, political, and economic disparities between Māori and Pākehā (New Zealand European) in the context of Aotearoa, it is imperative to acknowledge and reconcile the initial and ongoing impacts of colonisation. Qualitative exploration of how socioeconomic, political, and public policies influence Māori experiences of health services and programs could inform a broader range of structural policies to address health inequities (Jansen et al., 2008; Palmer et al., 2019). Therefore, this mahi rangahau (research) is significant and needed as it seeks to give voices to whānau of Māori tangata whaiora with TBI, and understand their abilities and lived experienced in how they live their lives. Without this mahi rangahau, many of these whānau would otherwise be overlooked in research and academia. Additionally, this mahi rangahau seeks to demonstrate an effective way of conducting rangahau that has direct relevance to the community of concern. By building relationships throughout the Waikato, with a variety of whānau and with the support of local brain injury services.

## Roro pāmamaetanga: Definition of Traumatic Brain Injury

TBI, referred to in Te Reo Māori as roro pāmamaetanga or more commonly as te whara o te roro (Elder, 2012), is a non-degenerative, non-congenital injury to the brain from an external force that can lead to permanent or temporary impairment of cognitive, physical and psychosocial functioning (Carroll et al., 2004). Within Aotearoa, the Accident Compensation Corporation (ACC) defines TBI as a change in function of the brain, or other evidence of brain pathology, caused by an external force (Accident Compensation Corporation, 2017; Carroll et al., 2004). TBI can be caused by a physical blow, shake or jolt to the head (or body), or a penetrating injury, that disrupts the normal functioning of the brain of a tangata whaiora.

The severity of TBI is measured by the length of the initial period of confusion (post-traumatic amnesia) and the degree of reduction in consciousness, generally measured by the Glasgow Coma Scale (GCS). The GCS measures the severity of TBI within 48 hours of the injury, then measures scores based on severe TBI (3-8), moderate TBI (9-12) and mild TBI (13-15) (Smith et al., 2017). Additionally, the GCS includes the length of time the individual has lost consciousness, i.e., over 24 hours (severe), over 30 minutes (moderate) and anything less than 30 minutes is classified as mild (Elder, 2012). Overall, the impacts of a TBI can be short term or long term, for example a mild TBI, can be relatively non-permanent and most people experience full recovery within 3-12 months (Carroll et al., 2004; Theadom et al., 2015), however for moderate to severe TBI, effects can be life long and will be the focus of this thesis (Barker-Collo et al., 2015).

The complexity of TBI is evident and can cause physical, behavioural and cognitive changes in an individual. The physiological symptoms can range from vomiting, dizziness, nausea, headaches, blurred vision, sensitivity to lights and/or noises, as well as a tangata whaiora struggling to balance (Smith et al., 2017). Moreover, tangata whaiora can experience behavioural and emotional changes, these include changes in patterns of anxiety, irritability, lethargy, tiredness, and sleep. Whereas cognitive changes include the tangata whaiora having difficulty concentrating on tasks, memory impairment, and decreased organisational skills (Simpson, Mohr, & Redman, 2000). With further changes that contribute to increased risk-taking behaviour as well as lack of inhibition (Simpson et al., 2000). The ongoing impacts of TBI can affect the quality of life of a tangata whaiora and their whānau, as they are less likely to live independently, maintain relationships and return to educational or vocational activities.

## Aotearoa (New Zealand) research

In Aotearoa (New Zealand), there are an estimated 36,000 new brain injuries per year from both TBIs and stroke (Accident Compensation Corporation, 2017). Of all TBI's, 5% are considered moderate to severe. This percentage is estimated to be between 1200-1500 tangata whaiora who suffer moderate TBI's, and 1750 tangata whaiora who suffer severe TBI's each year (Accident Compensation Corporation, 2017; Feigin et al., 2013). Of these results, males were approximately two times more likely than females to suffer moderate to severe TBI, which is reflected throughout this mahi rangahau, as mainly male tangata whaiora were recruited.

Research conducted within Aotearoa suggest that for moderate to severe TBI amongst the general population, the majority are caused by falls and road crashes (39% each), followed by assaults (14%) with a smaller number as a result of exposure to force (4%) (Feigin et al., 2013). Similarly, international data suggest that the incidence of TBI within indigenous populations is higher than that of the majority population, for Māori rates are more than three times those of non-Māori, however the increased risk of TBI for Māori compared to non-Māori is not yet clear (Feigin et al., 2013; Barker- Collo et al., 2012; Theadom et al., 2015). Although there is no significance risk difference in sustaining a TBI between rural and urban communities, rural populations were more than twice as likely to sustain a moderate to severe TBI than urban populations (Feigin et al., 2013). This research identifies the existing risk factors within Waikato District Health Board (WDHB) as a largely rural community with a high population of Māori compared to any other DHB.

Due to Māori having a higher risk of suffering a TBI than non-Māori, they are also more likely to suffer poorer outcomes, and their whānau may experience a greater burden from the TBI (Jones et al., 2020; Te Ao et al., 2014). Greater prevalence of TBI and the breadth of potentially adverse outcomes may affect partners, neighbours, friends, whānau, or other relatives who take on additional roles to support the tangata whaiora and whānau unit. Whānau members may not adjust well to required changes (Marsh et al., 2002; Simpson et al., 2000) and disruptions to their daily routines and social, vocational, and recreational activities (Nonterah et al., 2013), however whānau are imperative to long term recovery and wellbeing of tangata whaiora throughout their rehabilitation journey (Lakhani et al., 2017). It is clear that the burden of TBI in Aotearoa is substantial and linked to other health and social factors not only for Māori tangata whaiora but also their whānau. The role of whānau in the rehabilitation of tangata whaiora is grounded in nuanced understandings within whānau systems that provide a safe environment for the ongoing support of tangata whaiora and their collective wellbeing (Durie, 1997; Moeke-Pickering, 1996).

### Ngā ara hauora: Pathways of care

The rehabilitation pathway may look slightly different for each tangata whaiora and their whānau, however, a typical pathway begins from the injury event. After the injury the tangata whaiora is transported to the hospital and will remain in the emergency care unit until moved to in-patient care. The tangata whaiora will then remain in care until medically stable. Those with moderate to severe TBI are engaged in rehabilitation before being discharged into the community.

For whānau who are supporting their tangata whaiora with high medical, cognitive and behavioural needs, often the tangata whaiora may insist on supporting themselves, however, can become quite aggressive or irritated and in more extreme cases they may need to be restrained for the safety of themselves, and those caring for them. This experience can be distressing for both tangata whaiora and whānau. The entire healthcare system, from site of injury to rehabilitation can be a foreign environment, the cultural barriers can also limit the capacity of whānau to engage with services and support their tangata whaiora (Dudley et al., 2014; Durie, 2001; Jansen et al., 2008; Lavelle Wijohn, 2017). There are three main barriers within the healthcare system, the first is the greater need for Māori healthcare professionals and Kaimahi (Lavelle Wijohn, 2017). Whānau will often interpret behaviours based on their own lived experiences of tangata whaiora, as well as their experience of the healthcare environment, therefore, for Māori and individuals who do not identify with the dominant Pākehā worldview, there is greater likelihood of cultural alienation. The second is the copious amounts of time spent away from the vocational responsibilities of whānau, which in more transient circumstances impact how engaged whānau are able to be with services and ultimately the on-going care of their tangata whaiora (Fleminger & Ponsford, 2005; Rolland, 1999). For example, if whānau members need to return to work to support their household and other whānau roles. Thirdly, the continuous changes occurring to the tangata whaiora due to the TBI, also impact whānau members. As whānau may not always be equipped on how to deal with these changes, such as the ability to de-escalate situations where tangata whaiora are more irritable. As a result, this mahi rangahau intends to identify current barriers and enablers of good quality care and opportunities for improving services. I expect this approach to also facilitate discussion of matters of most concern to whānau carer participants.

## Māori models of health

Within Aotearoa, Māori have been forced to assimilate to non-Māori ideologies of health that is primarily based upon the biological model and that are exclusive of values, beliefs and ways of being that are important to Māori. Māori health models highlight the need for balance between individuals, their whānau, cultural heritage and environment, thus reflecting a strengths-based approach towards affirmative change (Johnson et al., 2013). This means Māori health is more than physical or mental illness. Health is interconnected with other people and the environment (Rua et al., 2017). If whānau, for example, are disconnected from their cultural practices and identity, this can create social and cultural displacement, which can result in negative effects on a person’s wellbeing (Jahnke, 2002).

Māori health models such as Te Whare Tapa Whā (Durie, 1985) and Te Wheke (Pere, 1982) use a combination of interconnection and incorporation of whānau, hapū (sub-tribe) and iwi (tribe) that are central to Māori well-being (Hickey, 2008). For many Māori communities, health is a holistic concept that incorporates social, environmental, biological, cultural and spiritual dimensions. All of which involves the interconnection of relationships and with individuals who others can gain support and reciprocity. For example, using Te Whare Tapa Whā which describes waiora (health) in four parts, this includes, te taha hinengaro (cognitions), te taha whānau (family), te taha tinana (physical), and te taha wairua (spiritual) (Durie, 1985). To assess a TBI, a neuroscientist may consider the locations and extent of tissue damage (a pure focus on te taha tinana), or perhaps also consider cognitive and emotional functioning (tapping into te taha hinengaro) but without a more holistic framework, the dimensions of wairua, and whānau in this instant could be overlooked which can be detrimental to the care and support needed to recover (Dudley et al., 2014). Therefore, from a holistic Māori perspective, the incorporation of whānau is necessary to support the individual who has TBI to ensure appropriate care (Elder, 2015). Within Māori health models the iteration and importance of whanaungatanga or positive and relational networking, specifically with their children, partners, siblings, and parents (Bishop, 2005; Durie, 1998) has been confirmed to be more important to Māori than to other groups in Aotearoa for life satisfaction.

It is crucial for government agencies, policy makers, and service providers to use Māori health models to provide Māori communities with equitable opportunities to care. As a result, this will promote active participation in services that are inclusive and appropriate to Māori cultural values (Dudley et al., 2014). Thus, a concern is raised as, the largely individualistic focus of most rehabilitation delivery is particularly inappropriate for people with a whānau-centred way of being. A current Māori model that aims to enhance the mana (status, prestige, influence) of whānau in a whānau-centred approach within TBI is Te Waka Oranga Model (Elder, 2015).

### *Te Waka Oranga*

The Te Waka Oranga model (see ***Figure 1***) of health challenges the current Eurocentric position of care and rehabilitation relative to the marginalised positions of Indigenous knowledge (Elder, 2015; Elder, & Kersten, 2015). This model of health has been developed specifically for the assessment and treatment of TBI and to be used by Kaimahi (workers) when dealing with Māori and non-Māori tangata whaiora alike. The model described, locates whānau within their own culturally determined knowledge systems and optimising their integral role in the delivery of culturally required interventions, the recovery experience will be enhanced, and they will feel a greater sense of ease and self-determination in the process of their own healing. Te Waka Oranga priorities the understanding of the significant wairua component of TBI and sees whānau knowledge alongside the medical and rehabilitation knowledge (Elder, 2017). The process of bringing together whānau knowledge, skills, and feelings, with health workers' knowledge, skills, and feelings in the context of identifying recovery goals, to collectively improve the experience of recovery. As a result, this improves the outcomes for whānau using Te Waka Oranga.

### What is whānau?

Whānau is defined for the purposes of this mahi rangahau as a foundational unit of contemporary Māori society (Mckenzie, & Carter, 2010; Smith, 2012). Visible in that the whakapapa (genealogy) forms the basis of whānau, and that these relationships are: intergenerational; shaped by context; given meaning through roles, responsibilities and relationships of mutual obligation (Durie, 2019; Kruger et al., 2004; Kukutai, & Webber, 2017.) Throughout this mahi rangahau, the conceptualisation of whānau is broken down into two categories, the first, is Whakapapa Whānau and the second, is Kaupapa Whānau.

Whakapapa whānau are individuals who are linked by a common ancestor or by marriage, whereas Kaupapa whānau are individuals who are connected to fulfil a common purpose or goal (Lawson-Te Aho, 2010). Within this mahi rangahau, Kaupapa whānau more specifically are identified by tangata whaiora as someone who has been a part of their rehabilitation journey either from injury event, hospitalisation, rehabilitation, and back into community over a long period of time, these individuals can be made up of friends, colleagues, and kaimahi (Lawson-Te Aho, 2010; Mikahere-Hall, 2020). Current literature suggests that many whānau units centre around both the traditional understanding of whakapapa whānau as well as the contemporary understanding of kaupapa whānau (Cram & Kennedy, 2010; Lawson-Te Aho, 2010; Moeke-Pickering; 1996). In this way, Māori are able define and acknowledge kinship networks within the context of Te Ao Māori (the Māori world view) as a site of healing and a valuable resource for flourishing.

For Māori, relationships play a larger role in life satisfaction, supporting the importance of whanaungatanga in te ao Māori. Whanaungatanga, is an intrinsic aspect of Māori culture, values and prioritises interdependence with others to strengthen bonds of kinship, which in turn strengthens the individual (Smith, 2012). Moreover, Durie (2013) notes that despite the many understandings of whānau, key characteristics can be identified, namely: shared responsibility; reciprocity, mutuality, interdependence; collective identity; and cultural practice.

It is important to note that Māori forge their identities within the settler colonial society, but many are also influenced by and remain anchored in Te Ao Māori, and iwi ways of being. In this way, the diversity that exists in relation to the extent and frequency of Māori engagements with Māori cultural practices (Durie, 2006), as well as the diversity and combinations of a variety of non-Māori family members and whakapapa within Māori whānau are important in recognising Ngā Matatini Māori - diverse Māori realities (Durie, 1995a).

### *Ngā Matatini Māori: the diverse Māori realities*

Acknowledging and recognising Ngā Matatini Māori - the diverse Māori realities (Durie, 1995a) of whānau in Aotearoa, enables active participation and engagement from whānau within a Te Ao Māori perspective. The multifaceted and culturally eclectic experience and nature of whānau Māori that make up Whakapapa whānau and Kaupapa whānau who share experiences and values, remain the network of support and safety for Māori tangata whaiora. Much of the diversity in whānau are variable due to the access to Te Ao Māori that result in variable outcomes (Durie, 1995a, 1995b). For cultural markers of Māori identity, such as the ability to speak Te Reo Māori (Māori language), having strong hapū or iwi connections, having understanding of Te Ao Māori inclusive of customs and practices, are seen as pertinent to being Māori (Houkamau, & Sibley, 2015). However, fails to recognise the impacts of colonialism and the access to aspects of Te Ao Māori as mentioned above (Durie, 1995b). Furthermore, the concept of whānau through the lens of Ngā Matatini Māori gives voices to different sections of Māori communities, like whānau members who do not have Whakapapa Māori, but are identified as Whakapapa whānau or Kaupapa whānau (Smith, 2012). The pragmatic function ensures all whānau members are rightfully acknowledged and included in mahi rangahau while keeping Māori values central to this project. This ensures whānau voices and narratives are able to shape and influence this mahi rangahau.

### *Challenges for whānau carers*

A systematic review of 62 studies of predominantly moderate to severe TBI samples revealed widespread evidence of three main challenges that whānau may face while looking after their tangata whaiora with TBI. The main factors that reported a consistent negative outcome were: high levels of caregiver burden; poor family functioning; and poor mental health and high levels of whānau carer emotional distress (Baker et al., 2017; Knight et al 1998). These findings are consistent with Aotearoa based literature (Jones et al., 2020). Much of the cause of emotional and cognitive burden experienced by whānau carers is due to the difficulties tangata whaiora face with executive functioning caused by the ongoing impacts of the TBI, these include behavioural management, coping skills, and reintegration back into 'normal' life (Baker et al., 2017). For many whānau carers, they will support their tangata whaiora throughout the rehabilitation pathway, subsequently tangata whaiora may become dependent on their whānau. Whānau members often support transitions between services, and back into the community which can be stressful and demanding times, these can have impacts on the wider whānau context and lead to relationship breakdowns (Armstrong et al., 2019; Baker et al., 2017; Lavelle Wijohn, 2017). Moreover, the reliability taken up by whānau carers for their tangata whaiora is often to liaise between healthcare professionals and as well as financial insurance organisations, such as ACC, additional to the ongoing practical treatment of rehabilitation (Baker et al., 2017).Many of the identified whānau carers in the existing literature are either partners or parents who support their tangata whaiora, but this can cause stress for themselves, due to the increased responsibility and lack of support from services.

Further research indicates that being a carer for tangata whaiora during these times can lead to greater concerns for their own emotional state, including increased emotional distress, anxiety, depression, and caregiver burden as well as unmet whānau needs (Arango-Lasprilla et al., 2010; Doser & Norup, 2016; Knight et al.,1998). Caring for tangata whaiora with TBI can also be associated with an increase in health problems, such as headaches, fatigue, and back pain (Berglund et al., 2015; Jones et al., 2020; Kreutzer et al., 2009). As a result, poor well-being among whānau carers may be associated with poorer recovery of tangata whaiora with TBI (Jones et al., 2020), this is important as supportive whānau carers facilitate better recovery for tangata whaiora (Elder, 2017). These associations, highlight the value of understanding the nuanced well-being and lived experience of whānau carers to influence change within this mahi rangahau.

## Whakarāpopototanga – summary

This mahi rangahau will explore whānau carers and their experience with caring for Māori tangata whaiora with TBI, further research will identify how whānau in the greater Waikato region care and support tangata whaiora with moderate to severe TBI, with an emphasis on post-acute rehabilitation services. The primary aims of this mahi rangahau is to identify and understand whānau experiences of the current rehabilitation pathway. It is intended that the focus will be on the post-acute rehabilitation services, however this mahi rangahau will support whānau carers to report their experiences of the whole pathway of care i.e., from the site of trauma, to Emergency care, in-patient care, to rehabilitation, and in the community. Furthermore, whānau will be able to talk to current barriers and enablers of good quality care and opportunities for improving these.

The analysis of the literature presented in this chapter has explored the size and shape of Māori and TBI, and has reviewed the wider international literature related to cultural factors and TBI. There is clear evidence of over representation of Māori in populations of TBI. However, what is striking is the paucity of published research that focusses on Māori at the highest risk of TBI. The absence of specific research exploring aspects of TBI for this group and their whānau is a significant gap in the current literature. It is clear that the number of Māori tangata whaiora and whānau carers who are impacted by the ongoing and lifelong challenges of TBI are high, and that there is a need to explore this area. The role of Māori models of health and Te Ao Māori will ground and guide this project as these systems inform the process and content of this mahi rangahau.

The utilisation of Rangahau Kaupapa Māori methodologies is required so the process of investigation remains culturally safe. The next chapter expands on these ideas, describing the methodology and methods taken in exploring the uncharted waters of whānau and their experience with caring for Māori tangata whaiora with TBI.

# Upoko Tuarua - Chapter 2

# Ngā huanui i whāia: Methodology

In this chapter, an exploration of the philosophical understandings of this mahi rangahau project, theoretical considerations in the construction and dispersal of knowledge, researcher conduct, and ways to mitigate potential issues will be highlighted. Further, this chapter will position Māori approaches to knowledge and research, by considering how this project has produced knowledge that is grounded in subjectivities that highlight the complexity of being Māori in a colonised world with the use of qualitative tools and Kaupapa Māori research that speaks to the importance of conducting research that is responsive, relational, and respectful.

This thesis is also linked to an earlier University of Auckland research project led by Dr. Tai Kake (Auckland University), titled, 'The experiences of Māori with Traumatic Brain Injury and their whānau in the Waikato region with post-acute rehabilitation services' – A Kaupapa Māori research project which looks at Māori tangata whaiora, whānau and service providers experiences of the TBI pathway. This Auckland University project focused upon improving the quality and accessibility of health services for Māori with TBI. I was employed as a research assistant tasked with interviewing Māori tangata whaiora, whānau and service stakeholders in the Waikato region. I was also involved in the analysis and presentation of the findings alongside Dr. Tai Kake. With this experience in mind and with support of Dr. Tai Kake, my thesis will extend upon the themes of whānau and draw from some of the stories and information collected throughout the project in more depth and detail.

## Kaupapa Māori theory and methodology

Kaupapa Māori research has been employed as a mechanism of resistance as well as a methodological strategy for research. As research is formulated, developed, and then carried out by Māori, this ensures the issues and needs of Māori are the focus and outcomes of research (Pihama et al., 2002; Smith, 2012). Kaupapa Māori methodologies provide a philosophy of being and acting Māori, which as researchers, we can align with research motivations and objectives. Further, Kaupapa Māori research centres Māori philosophy and principles, by ensuring the legitimacy and validity of Mātauranga Māori (culturally embedded knowledge) to promote the amelioration of Māori beliefs, practices, ways of creating meaning, and the fight for autonomy over our own wellbeing, and agency over our own lives (Smith et al., 2016). The underlying methodologies of a Kaupapa Māori approach support critical theory in that they are both an analysis of existing power structures and social inequality (Smith, 2012), thus enabling structural analysis that creates scope for practice, and understanding the intertwined relationship between political action and analysis (Smith, 2012).

Kaupapa Māori methodology operationalises itself in the concepts of tino rangatiratanga, (sovereignty, self-determination, governance, autonomy, & independence; Pihama et al., 2002), and tikanga Māori. This offers guidelines which are acknowledged throughout all phases of research (Bishop, 2005; Smith, 2012). Tino rangatiratanga and Tikanga Māori promotes the advancement and development of Māori flourishing which creates a strengths-based approach to conducting research as opposed to a deficit focused approach (Cram, & Mertens, 2016; Eketone, 2008). This is crucial in mitigating the political context of unequal power relations between Māori and Pākehā in interpersonal, institutional, and Western social structures. By rejecting the ongoing deficit-based portrayals of Māori and ensuring a commitment to highlighting the struggle in promoting critical consciousness, engagement with, and confronting of dominant Western structures (Cram, & Mertens, 2016; Durie, 1997), this then frames the research in a way that highlights the natural strength, diversity, and mana associated with Māori whānau that participated in the interviews within this study. Hence, utilising a Kaupapa Māori framework ensures power and control is grounded in Māori cultural notions and understandings, so that a Māori-centred agenda is emphasised. After the right to control the agenda of research is established, then Māori worldviews and ideologies can become the recognised, and accepted norm within Aotearoa. Moreover, Kaupapa Māori methodologies and approaches are grounded in seven practices that will guide this mahi rangahau, these include aroha (giving love and respect); manaakitanga (sharing, hosting and being generous); mana (to show respect), mahaki (to demonstrate humility in the sharing of knowledge and building trust and dignity); titiro, whakarongo, kōrero, (look, listen and then speak); kia tūpato (be cautious and keep safe) this is important both culturally and politically and be reflective of the influence and interaction with all those involved in this mahi rangahau; and Kanohi kitea (meeting face to face, in person, and in the flesh; Pipi et al., 2004).

In addition, Kaupapa Māori methodologies utilises whanaungatanga (Bishop, 2005; Durie, 1998) as central to the collection of data within this study. Whanaungatanga acknowledges both the individual and collective members of the community as being pivotal to the development of Māori research as a whole (Mane, 2009). Within this research, whanaungatanga has been evident throughout the whole process of determining the sample, recruitment of participants, and interview styles.

This research project seeks to move beyond the constraints of the dominant western research structures within psychology that is largely descriptive and quantitative, as dominant psychology research isolates and decontextualises individual data points, in the absence of conceptualising ways forward (Masters-Awatere & Nikora, 2017). By utilising an interdisciplinary lens to gather and disseminate understandings of the lived realities of whānau, who have volunteered to gift their knowledge and expertise, and present detailed descriptions of their journey and the journey of their Māori tangata whaiora. This project strives to position Māori ideologies and solutions to anchor ideas of informed and guided systems of practice. The aims of this project include providing space in which whānau carers are able to share their lived experience and provide insight into the challenges and reimagine solutions for their Māori tangata whaiora that better supports them and their rehabilitation pathway.

Lastly, due to the consistent negative portrayal of Māori in academia and media, this project seeks to increases the amount of cited research that centres whakapapa in Indigenous understandings as an extension of relational knowledge. Therefore, recognising relationships that continuate whanaungatanga. By consolidating existing Mātauranga Māori, and Kaupapa Māori research, this then contributes to the futures we desire (Burgess et al., 2021). Due to the Kaupapa Māori approach and centrality of Māori epistemologies within this mahi rangahau, literature and academia that challenges the valid beliefs, practices and understandings of Te Ao Māori will not be referenced as a refusal to the dominate colonial powers that keep Māori voices silent (Burgess et al., 2021; Smith et al., 2018).

### Rapunga kōrero: Narrative inquiry

This thesis draws upon a narrative inquiry within a broader qualitative kaupapa Māori research approach in order to understand the experiences and everyday relational practices of my research participants within context and overtime (Clandinin, & Caine, 2013). The narrative inquiry style of research is concerned with the lived realities of the people concerned, and their engagements with the world around them (Ware et al., 2018). The use of this tool highlights the need for context-sensitive information about the whānau life experiences with relation to their narrative stories which is paramount in qualitative data collection and as a result allows for ‘rich’ or ‘thick’ descriptive accounts (Rua et al., 2017) of whānau rehabilitation journeys with their Māori tangata whaiora. The Kaupapa Māori orientation of this mahi rangahau integrated a variety of qualitative elements to encourage open dialogue with whānau carer participants. For example, group narrative interviews allowed opportunities for whānau carer to discuss meaningful and nuanced stories about their lived experiences, as well as supporting their Māori tangata whaiora in the interview space, resulting in rich accounts of their knowledge and expertise, and present detailed descriptions of their journey and the journey of their Māori tangata whaiora (Bishop, 1996; Rua et al., 2017). These interviews provided a way of exploring the personal narratives in response to interview questions. Further, the semi-structured style of interviews ensured there was flexibility in seeking clarity around answers that in some cases were ambiguous or unclear and ensured there was time for supplementary questions when needed (Jones et al., 2010). This process safeguarded the mana of whānau carer participants and ensured their authentic stories were told and understood accurately.

Within Indigenous cultures, and specifically Māori communities, stories are a common repository of knowledge and promote the process of knowledge retention. The use of oral tradition and narrative inquiry to express awareness, understanding, and experiences as Māori orient this project within a Kaupapa Māori paradigm (Ware et al., 2018). The purpose of Narrative inquiry is to understand and create meaning out of the dialogue, discussions, and participation in the lives of whānau carers (Clandinin, & Caine, 2013).

As a kaupapa māori researcher, recognising the centrality of whanaungatanga among whānau carer participants and myself provides insight into the multi-layered context, histories, and meaning making. Narrative inquiry aims to engage with participants in the field, by creating field notes, that eventually contribute to research texts while still maintaining ethical responsibilities and relationships with whānau carers (Clandinin, & Caine, 2013; Ware et al., 2018). Further, manaakitanga principles are utilised throughout as to ensure the safety of whānau carers and their Māori tangata whaiora, for example, following up on the safety of whānau carers and their Māori tangata whaiora, and assisting with any services connections they may need in that moment both during and after researching. Additionally, the field notes collected reflect multiple stories, moments that were not picked up on in conversation such as behavioural cues and gestures that enriched their stories and the data set.

Indigenous methodologies such as Kaupapa Māori theory, use tools such as narrative inquiry and qualitative research to draw on ways of creating meaning. These approaches privilege Indigenous voices, analysis, material, and knowledge with a variety of tools and methodologies to actualise these experiences of participants (Smith 2005).

### Uaratanga rangahau: Axiology

Axiology permits researchers to investigate the role their own values have within the research project (Cram, 2017). This project considers the intrinsic value that is informed by my subjective ideologies and ways of creating meaning as an Indigenous wahine of dual Māori and Pākehā heritage and as a researcher. As a result, this then has informed specific axiological considerations for what is deemed imperative and ethical throughout this mahi rangahau, such as, identifying and acknowledging the mana of all those involved, and its ability to reshape and reimagine (Ormond, 2019). The axiological approach within this mahi rangahau highlights the importance of research questions that value and honour the lived experiences and qualitative recounts of daily life over quantitative depictions that diminishes the diverse ways of creating meaning and ways of being as Māori (Smith, 2012).

To further understand the axiological perspectives of this project, it is first important to identify my reasons and values for conducting this mahi rangahau, as this ultimately impacts the methods used, questions asked, and ways meaning is created from the information I am cognisant of. As an Indigenous wahine of dual Māori and Pākehā heritage living in a colonial context, aspects of this experience is interwoven with how I create meaning to the world around me. Within my whānau, we experience the world through a Māori worldview, as my parents, siblings and myself speak and understand Māori and were brought up on the Marae, through Kura Kaupapa Māori and Tikanga Māori. Therefore, it is important to dispute the deficit-based descriptions of Māori in media and academia. To elaborate, my upbringing and Indigeneity positions me within an understanding of mana, and conducting mana enhancing research for all those involved. By respecting and recognising the intrinsic values of community and individual lives, ways of being and experiences, this qualitative approach reflects the importance placed on understanding complicated and nuanced narratives. Researching alongside my supervisors, and whānau carers, who are recognised as knowledge bearers, and collective owners of narratives (Moreton–Robinson, & Walter, 2009).

The current mahi rangahau seeks to place significant value on the depth of knowledge that is shared within whānau and community context across a diverse range of whānau carers, from rural and urban settings, some of which have Māori and Non-Māori heritage, as they were identified as whānau members of the Māori tangata whaiora themselves. By recognising Ngā

Matatini Māori - the diverse Māori realities (Durie, 1995a) of whānau in Aotearoa, this research has enabled participation of whānau, here used to refer to Whakapapa whānau and Kaupapa whānau who shared experiences, advice and values. The network of support and safety created within these spaces ensured engagement and participation rooted within Te Ao Māori. Within this mahi rangahau, research questions intended to allow whānau carers to explore for themselves the barriers within services, experiences of rehabilitation, and their role in supporting their wider whānau and Māori tangata whaiora on their journey. Moreover, the lived experience, and whanaungatanga shared in material and research interactions reflect the community discussions and engagement that originate from whānau narratives which strives to be responsive to their identified needs.

The axiological perspective within this mahi rangahau endeavours to provide informed solutions from meaningful discussions to overcome barriers within the health sector and ensure recommendations to responsive and appropriate care for whānau and Māori tangata whaiora with TBI.

### Ngā kōpiri: Limitations

Despite the value this mahi rangahau possesses towards improving and understanding the experiences of whānau carers within the TBI care pathway, few limitations are present. These limitations are constituted areas of future mahi rangahau to continue the progression of knowledge towards flourishing and the futures we as Māori desire.

Due to the on-going impacts of Covid-19 from the year 2020-2022 this has halted and limited the type of data that could have been collected in a timely manner for the Master's Thesis requirements. Follow up interviews were intended and therefore a larger sample size, however this unable to be carried out due to the time constraints and on-going impacts of Covid-19. Interviews were limited due to Lockdown-level-4, and further nation-wide restrictions throughout this time period. This inhibited kanohi kitea as a necessity to conduct appropriate Kaupapa Māori research for vulnerable communities like these, especially with the increase in uncertainty for many whānau during these periods.

# Upoko Tuatoru - Chapter 3

# Te tukanga: Method

This Master's thesis is completed in line with Kaupapa Māori methodology, a specific approach that is responsive to our colonial contexts, and the mana of the intended research audience and with all those involved. This mahi rangahau aims to identify the experiences of current TBI service provisions, as intended the focus will be on post-acute rehabilitation services, however, our approach will support participants to report their experiences of the whole pathway of care i.e., from the site of trauma, to ED, in-patient care, to rehabilitation, and in the community. Identify current barriers and enablers of good quality care and opportunities for improving services. Facilitate discussion of matters of most concern to participants. Assess the cultural responsiveness and feasibility of our proposed methods with participants. Findings from this process can be used to construct interview prompts, survey questionnaires, and recruitment/sampling procedures for a larger proposed study. Furthermore, by legitimising whānau carer's experiences as knowledge bearers (Smith et al., 2016) this project hopes to centre whānau narratives at the forefront. As outlined in the methodology, this mahi rangahau hopes to provide a foundation for providing contextual, compassionate, and nuanced accounts of the lives of whānau carers, and practice. As a result, whānau carers are recognised as experts within their own mana, and Kaupapa Māori theory attempts to rebalance the power dynamics between participants and researcher. This chapter is broken into two sections, the first will focus on the participants, recruitment processes, and the research ethics. The second section outlines the analysis process used, and dissemination of research and findings.

## Āhuatanga patapatai: Whānau participants interviews

### *Recruitment and participants*

Recruitment of participants occurred through the Midlands-trauma register as a database for all individuals who suffered a TBI within the Waikato region, a letter was sent out with support from Midlands-trauma on behalf of the University of Auckland TBI project. This process only yielded one participant; therefore, other methods were utilised to ensure engagement. Secondary supervisor, Dr. Tai Kake (Auckland University), and myself presented at the Waikato Brain Injury Association conference in 2019 to gain input from on the project and gain connections within TBI service providers. From this, a list of appropriate TBI related support services within the Waikato region were identified and contacted to recruit and discuss potential suitable participants. Managers and administrators identified eligible candidates and distributed research information sheets to Māori tangata whaiora. Eligible candidates needed to meet the following criteria: Māori, aged 16-65, living within the Waikato catchment-region, and had a moderate-severe TBI within the past 20 years. From this point, Māori tangata whaiora were able to nominate their own whānau members who they believed would be most appropriate and applicable to them and the research project. Whānau members did not need to be of Māori decent and were included under Ngā Matatini Māori (Durie, 1995a). Furthermore, a combination of people living in urban and rural residences were recruited to ensure a broad perspective from the lived experiences and unique challenges faced by living rurally and within urban settings.

Individuals who were interested in the interview communicated with their administrator or manager from their respective service providers, who then passed on their contact details to myself as the researcher. I then made direct contact with each TBI participant and their chosen whānau participants either by phone, text message or email to initiate communication. Phone calls were then made to each participant, as a screening process needed to occur to ensure the project was appropriate for them and our criteria. At each TBI service provider, various whanaungatanga meetings were held with the different participants from the respective service providers to practice kanohi kitea, and manaakitanga principles with all Māori tangata whaiora and whānau participants.

After the phone call screening process with potential participants, a whanaungatanga meeting was held at the services to introduce myself and the project, this allowed participants to bring their whānau if they wanted, to meet other Māori tangata whaiora, which created an inclusive environment for potential participants to ask questions and get a feel for the research process before committing. These initial interviews ranged from an hour to two hours depending on how many people arrived, and how many questions they had. In this process it was very much led by participants and facilitated by myself to guide and support their curiosity. Kai was also provided at each physical meeting as a form of koha for their time and interest.

The main focus of this study was to understand the experiences of whānau participants in caring for their Māori tangata whaiora with TBI. Five whānau participants (n=5) across five different whānau were formally interviewed face-to-face once, these interviews ranged from 1 hour to an hour and 40 minutes. The criteria for selecting whānau participants were by the choice of the Māori tangata whaiora who identified as Māori, this then demonstrated the Ngā Matatini Māori (Durie, 1995a), and the diversity of Māori whānau. A total of four whakapapa whānau and one kaupapa whānau took part, two were Māori, two were Pākehā, and one was of Samoan decent. Three were female, and two were male, the majority of whānau participants were in the age range of 35-45 years, with small numbers represented in the remaining age categories of 45-55 years, and 55-65 years. At the time of the interview, participants lived in South Waikato, and Central Waikato.

**Table 1.**

*Whānau Carer Participant and Demographics*

| | Whānau 1 | Whānau 2 | Whānau 3 | Whānau 4 | Whānau 5 |
|---|---|---|---|---|---|
| **Ethnicity** | Māori | Māori | Pākehā | Pākehā | Samoan |
| **Sex** | Female | Female | Female | Male | Male |
| **Relationship to Māori Tangata whaiora** | Sister | Partner | Partner | Father | Kaupapa whānau |
| **Iwi** | Tūhoe, Ngāti Awa | Ngāti Kahungunu | | | |
| **Age range** | 35-45 | 35-45 | 45-55 | 55-65 | 35-45 |
| **Employment status** | Y | Y | Y | Y | Y |
| **Tangata whaiora pseudonym** | Maehe | Kauri | Rimu | Pūriri | Kōwhai |

### *Procedure and processes*

Once potential whānau carer participants were identified by the Māori tangata whaiora, a Participant Information sheet (see **Appendix A)** to ensure whānau carer participants were fully informed and aware of the scope of the mahi rangahau as well as support services available to them should they need. Whānau carer participants were then provided consent forms (see **Appendix B).** The interviews were conducted in the English language with the option of Te Reo Māori, additionally karakia was always offered and an option was provided for the participant to do karakia or for myself as the interviewer to do karakia in Te Reo Māori. Each whānau were interviewed once with an option of follow up interview if they preferred. No formal follow-up interviews were conducted, however, after the formal interview process the participants were given a timeline on when their data would be available to view if they would like to add or remove any comments, all whānau participants have remained involved throughout offering additional input and consultation on process via email, text, phone call, and in person conversations. A summary of the outcomes of the research will be sent to individuals who identified they would like a summary. Following on, the semi-structured interview process began. Two digital Dictaphones were used to audio-record the interviews. Written field notes were taken in addition to the interview process by the researcher throughout the interviews, this provided another source of information to the data set. Formal interviews took between an hour to an hour and 40 minutes. Once ethics approval was accepted by Waikato University whānau carer participants were provided with another consent form (see **Appendix C**) pertaining to the use of data for the purpose of this Master's Thesis under Waikato University.

### *Semi-structured interviews*

Interviews were an opportunity to explore in more depth the experiences of whānau participants and the strengths and challenges they faced in trying to support their Māori tangata whaiora. Kanohi kitea was utilised with participants throughout the recruitment and interview processes, this facilitated whanaungatanga, which fostered the strengthening of relationships (Smith, 2012). In keeping with the Kaupapa Māori approach of the larger project 'The experiences of Māori with TBI and their whānau in the Waikato region with post-acute rehabilitation services', the interview was conducted in a natural conversation style (Dahlberg & McCaig, 2010). The style allowed respondents to say as little or as much as they wanted, for the sake of individual relevance (Breakwell et al., 2006). The questions were not always strictly adhered to because the conversation would often generate other questions that were not included in the interview schedule. Generally, all the interview questions were asked because each topic in the interview schedule addressed relevant information for this study.

Face-to-face engagement with all participants allowed for a more nuanced account of experiences to emerge (Jones et al., 2010; Dahlberg & McCaig, 2010) and an opportunity to prompt for culturally specific strategies whānau participants might have engaged with. During the interview process, whanaungatanga was established, with an option of karakia (incantation, chant, prayer), followed by kai (food), and kōrero (discussion). Participants were provided with a printed information sheet additional to previous email and phone engagements about the study before signing the consent form. The demographic forms were completed after the consent was signed. The interviewer then further discussed some conversational topics that may be covered throughout the interview (see **Appendix D).** These included: site of accident, timeline of events, experiences of services, post-acute rehabilitation services, identify issues around access and potential barriers, changes and improvements associated with service provided, as well as cultural considerations. Audio-recorded interviews were completed at a time and place suitable for participants. Interviews were often held in participants' own home, in turn promoting open and comfortable sharing, and in Service Provider facilities. After the interview process, participants were offered koha to the value of $40 for their time and stories shared.

### ***Research Ethics***

Ethics approval for the whānau participants interviews was obtained by the University of Auckland from the Health and Disability Ethics Committee on 30th April 2020, ref: 19/NTB/53/AM01. Consequently, I sought and received an ethics approval from the University of Waikato Human Research Ethics Committee on 20 May 2020 as the institution responsible for this thesis to seek permission to use whānau data that drew on their in-depth lived experiences from whānau participants.

This research was guided by, and strictly adhered to the ethical regulations set by the University of Auckland from the Health and Disability Ethics Committee and University of Waikato Human Research Ethics Committee. The key principles in the *Human Research Guidelines* are as follows:

- obtaining voluntary informed consent
- respecting the privacy of participants, along with explaining the limitations to privacy
- using methods that are culturally appropriate to the sample population

Furthermore, the *Code of Ethics for Psychologists Working in Aotearoa/New Zealand* (New Zealand Psychological Society, 2002) has been used to inform this research design.

### *Informed consent*

The Code of Ethics for Psychologists Working in Aotearoa principle 1.7 outlines the responsibility of the psychologist to gain explicit informed consent from any participants in research. An information sheet was provided to participants outlining the purpose, aims, objectives and the requirements of the research (see **Appendix A**). The information sheet confirmed participant and researcher expectations as well as explained that their participation is voluntary. Each participant read or had read to them the details of the information sheet before signing the consent form. Participants were informed of their right to withdraw or change any information they have provided to the researcher, until September 1st 2020.

### *Privacy of participants*

All participant's privacy is protected through the implementation of anonymity. This is achieved by redacting information about the participant which could be potentially identifiable, such as, names, locations and job positions. Identifiable information was redacting from the interview transcriptions and the final report to ensure the identity of participants remain anonymous. There is a possibility that participants may be identified through participant responses which could potentially be linked to them; however, any risk of a breach to privacy was explained to all participants in this research in depth (prior to interviews and via the information sheet and consent forms). Non-anonymised data such as audio recordings, consent forms, and participant contact information is only accessible by the researchers and participants upon request.

### *Data storage*

Electronic audio files from semi-structured interviews were password protected on an electronic device. Consent forms (hard copy) and contact information are kept in a locked filing cabinet in a swipe card entry only research lab, only accessible by myself. The anonymised data was made available to the supervisors of this mahi rangahau in the event they wish to access it for the purposes of the Master's Thesis. All information collected during this research will be stored in a manner that safeguards the privacy and confidentiality of whānau participants.  This information will be stored for a period of ten years. This time period is required by the New Zealand Health Information Privacy Code 1994.

## Tātaritanga: data analysis

### *Transcription and coding*

To maintain the mana of whānau carer participants all interviews were transcribed in full by myself. Once initial transcription had been completed, these interviews were then edited as quality checks to remove repetition, hesitation, or stammering all of which are naturally occurring in verbal conversational style but can be misinterpreted when written and read. These interviews were transcribed and then coded using an inductive and deductive process to identify the salient themes within each transcript.

Analysis of the data was achieved by listening to audio recordings, transcribing audio-recordings verbatim, quality checking transcripts, re-listening to audio-recordings with the project lead, and verbal discussion occurring throughout, followed by reading and coding the transcripts to identify the underlying salient themes and subthemes across the dataset (Braun & Clarke, 2006), all of which were relevant to the whānau participants lived experience and the research project. Codes were developed using Braun and Clarkes (2006) thematic analysis method, following a recursive process to further examine each transcript multiple times. Key words and concepts were initially recorded in excel as "subthemes" and liked to quotations in the transcripts. These were grouped together following further reflection into "main themes" mind-maps, and participant profiles were used to assist and make clear the relationship of the codes and themes through various visual presentation of codes/themes. Consensus of coding and theory building by supervisors were utilised, which resulted in final themes, subthemes and definitions of these theme to have more detailed and specific understanding of the broad concepts previously identified.

Once independent coding, themes and subthemes were identified, the researcher and the project lead compared and contracted similar and differing themes until a consensus and main themes and names were agreed upon. This was important to seek secondary input in finalising the themes and subthemes, as two Māori researchers, it is imperative to consider different types of communication as whānau Māori have a unique cultural style of communication, for example their language, voicing, intonation, and body language is subtle, and may be important to the interpretative process.

Once this process had been completed, and to maintain the whanaungatanga between myself and the whānau carer participants, transcripts were returned, however participants did not have to further analyse and check their data if they did not wish to. As a result, after the main themes had been identified a selection of quotes belonging to whānau carer participants were sent and requested to be used within this thesis. These quotes have been edited further to provide more information and insight as well as maintain the integrity of whānau carer narratives as well as comprehensive readability.

The initial codes identified among the whānau participants transcripts consisted of separating the most common statements across each of the whānau participants. The majority of whānau participants reported on the challenges of caring for Māori tangata whaiora long term, the lack of education and involvement around TBI, the lack of support for whānau, the barriers of traveling to health services, relationship and familial pressures after TBI incident, fragmented service provisions, cultural concerns, and the continued responsibilities on whānau as the navigator for their vulnerable Māori tangata whaiora within services.

## Thematic analysis

Transcriptions were analysed through the process of thematic analysis. This process requires the researcher to analyse reoccurring themes and experiences throughout the whānau narratives (Braun & Clarke, 2006). Once transcripts, quality checks, participant checks, codes, themes and subthemes were systematically agreed upon by the researcher and the project lead, key themes were then established from the existing codes, reviewed and refined into topics of interest reflective of participant responses and research objectives. Furthermore, peer review of ingoa Māori (Māori names) of themes and codes with Māori cultural advisor, and lawyer (T. Silveira, personal communication, December 10th 2021) were used. As a result, three main themes were produced which are, first Ngaukinotanga: Trauma, with the subthemes of, Injury to the whānau, separation, loss, aggression and risk. Second, Kaiurungi Whānau: Whānau Navigator, with the subthemes of, navigating health and other system challenges, whānau navigators as a repository of memories, whānau navigators as a function of healing. Thirdly, He Piere Ratonga: Service issues and challenges, with the subthemes of, complexity and fragmentation of the healthcare system, inflexibility of services and lack of information provided, and limited cultural responsiveness to Māori health within Pākehā clinical settings.

## Dissemination of research and findings

The final thesis will be submitted to the University of Waikato School of Psychology for marking. The University of Waikato will hold full ownership of the final thesis. I will also request the right to forward an electronic or hard copy summary of results to any whānau who have indicated (on their consent form) that they would like to see the final outcomes of this mahi rangahau.

I will retain full ownership of the data collected (audio recordings, field notes and interview summaries) and not include this as a provision with the report, to ensure the full privacy of participants and the information they provided.

# Upoko Tuawhā - Chapter 4

## Ngaukinotanga: Trauma

This chapter speaks to the theme of Ngaukinotanga - Trauma experienced by whānau carer participants. Whānau carer participants discussed the experiences they, and their Māori tangata whaiora have had with the healthcare system and the rehabilitation pathway. Many whānau spoke about the deeply distressing and emotional shock they experienced when the TBI event occurred, as a result, this sense of distress and shock continued throughout their entire pathway of care, from injury event, hospital care, rehabilitation, and returning back into the community. Furthermore, the points discussed in this chapter consider how this Ngaukinotanga - Trauma is sustained through three subthemes, - *injury to the whānau, separation, loss,* and *aggression and risk.*

Throughout this chapter analysis of whānau narratives which discuss the immense trauma associated with a TBI, and how this impacts the wider whānau network as an *injury to the whānau* unit either by whānau members witnessing the TBI event, or the initial aspect of finding out. Next, the *separation* of whānau and Māori tangata whaiora either physically or emotionally deprived and hindered the ability of whānau to have daily or more regular contact with their Māori tangata whaiora. This context pushed whānau into spaces of *loss,* as they witnessed cognitive, functional, emotional and physical changes within Māori tangata whaiora, which for some whānau, was akin to the death of that person. As in some cases tangata whaiora were unable to "be" the person they once were, before the injury, due to changes in personality, leading to relationship breakdowns (Kieffer-Kristensen et al., 2011; Tiar & Dumas, 2015). These changes in personality often lead to *aggression and risk*, where the tangata whaiora develop problems with impulse control, agitation, aggression and/or illicit drug use. The changes that occurred in our predominantly male Māori tangata whaiora population identified the increased risk of harm for vulnerable whānau e.g., children, female partners, siblings, and elderly parents.

These themes and subthemes encapsulate the importance of whānau experiences and the purpose of this mahi rangahau. Further, this chapter will reflect upon whānau experiences of supporting Māori tangata whaiora and some of the major issues of concern.

### Injury to the whānau

Whānau carer participants spoke to the notion of '*injury to the whānau'* which is defined as whānau members either directedly witnessing the TBI event, or on becoming aware of it.

Throughout the whānau narratives, whānau participants spoke of how the immense trauma associated with a TBI impacts the wider whānau network as an *injury to the whānau.* Whānau participants clearly described the initial shock and distress associated to the injury event, as well as the ongoing and sustained trauma whānau and Māori tangata whaiora continue to endure today. Whānau participants reflected on the unpredictable nature of such an event and how nothing can prepare you for the changes that will persist for all involved.

In the following extract, one whānau participants spoke about the initial experience of hearing of the TBI event.

*"...I said "oh, I don't know what to do yup this has happened" and I was just like trembling you know and I couldn't even like think, I was just panicking..." (Whānau 3, Pākehā, Partner)*

The above extract describes the partner trembling and panicking and how her reaction to first hearing of a TBI event manifested in her own physical reaction similar to an injury. Literature suggest that the significant others of individuals with more severe TBI suffer greater psychological distress than those carers of tangata whaiora with less severe TBI (Arango-Lasprilla et al., 2010; Doser & Norup, 2016; Jones et al., 2020; Liu et al., 2015). Furthermore, whānau carers who are females were found to be at greater risk of stress-related health problems due to the TBI event (Knight et al.,1998; Li & Loke, 2013). The immense fear and uncertainty whānau can experience during this period is akin to an injury to the entire whānau unit.

Lastly, In the next extract, one whānau participant spoke to the experience of finding his son on the side of the road, and being the first at the scene. The father's experience of injury in this quote is highlighted as he has described having to change his clothes due to the amount of his sons blood on his clothing.

*"...yeah, I was heading home, and I found him lying on the road, so I called the ambulance... when he was on the road there was fair bleeding so I had to change my clothes to go back to the hospital..." (Whānau 4, Pākehā, father).*

The experience described by the father is likened to an injury, as the trauma associated with finding his son on the road, and the panic that occurs in not knowing if his tangata whaiora is alive (Abela et al., 2020; Foster et al., 2017).

Each extract provides a valuable snippet of the lived experienced of whānau participants and processing the sequence of events related to the TBI event. Further the whānau participants described witnessing in person the TBI event as it occurred to their Māori tangata whaiora, or learning about the TBI event that occurred to their Māori tangata whaiora. Both of which were described as similar experiences of distress. While witnessing and learning about these injuries, whānau carers have to simultaneously cope with the external demands of managing vocational and household responsibilities, and maintaining the needs of other whānau members, such as tamariki (Knight et al.,1998; Reid et al., 2016; Warren et al., 2016).

Research suggests that the distress experienced by whānau members can lead to lifelong psychological impacts (Warren et al., 2016). Therefore, whānau carers should be included in a component of comprehensive whānau-centred care (Boulton et al., 2013; Jutte et al., 2015; Knight et al.,1998; Mpofu et al., 2021). This will then encourage and attempt to develop and maintain a sense of hope for whānau carers (Kirk et al., 2015). The mechanisms of improvements for whānau over time cannot be determined from these extracts, however, for tangata whaiora with severe TBI these perceptions may change over time as whānau carers develop and improve their coping strategies to manage the on-going effects of caring for someone with a moderate to severe TBI (Knight et al.,1998; Marsh et al., 2002). It is relevant to consider that these improvements can also be reflective of the rehabilitation progress of the tangata whaiora over time.

Within this subtheme, narratives affirmed the diversity of Ngaukinotanga - trauma experienced by whānau through the TBI event and the way these experiences are navigated and given meaning through *injury to the whānau*. The insight by whānau carer participants explored their ability to witness and learn about the TBI event of their Māori tangata whaiora, as well as their strength to simultaneously cope with the uncertainty involved by maintaining hope and resilience as a possible protective factor.

## Separation

A number of whānau carer participants spoke to the notion of '*separation'* which can be understood as the physical, and or emotional separation of whānau carer participants from their Māori tangata whaiora. This physical separation for some whānau includes, whānau members living in rural tribal lands, and Māori tangata whaiora living away from whānau support in larger urban settings. This physical distance meant that whānau were less likely to engage in particular services due to physical separation and distance, thereby feeling unable to support their Māori tangata whaiora through daily or regular healthcare needs.

In the following two quotes, one whānau carer participant spoke of the emotional and physical separation felt by whānau and Māori tangata whaiora. This whānau member describes the initial experience of separation at the hospital, and the second experience of separation at ABI in Auckland, which was roughly one hour and forty minutes to two hours away from their home in the Waikato.

*"…You (tangata whaiora) had drugs and pain, just everything was quite not so good. You didn't wanna be there (at rehabilitation service) and you were angry, and you were sad, and when people had to leave it was quite tough going…" (Whānau 3, Pākehā, Partner)*

*"…I missed part of it (rehabilitation), but I couldn't live all your week with you…" (Whānau 3, Pākehā, Partner)*

The experience of separation in the above two quotes, highlights the impact physical separation has toward emotional separation of the tangata whaiora. The physical and emotional separation in these quotes can be understood within Te Whare Tapa Whā, as te taha hinengaro, and te taha tinana, as well as te taha whānau which are of equal weight and importance with the fourth component, te taha wairua, (Durie, 1985; Pitama et al., 2007). The Māori model of health and holistic framework encompasses Mātauranga Māori with the utilisation of all four components of Te Whare Tapa Whā which are crucial in considering the health and rehabilitation of tangata whaiora and whānau. Moreover, research suggests that the partners of tangata whaiora still have to take care of home and whānau responsibilities (Warren et al., 2016), therefore are not able to "live all week" with their tangata whaiora. For example, whānau carers are still needed to look after their tamariki and ensuring bills are paid. However, the more time whānau spend away from these responsibilities to take care of tangata whaiora, the greater the impact on wider whānau and the inability for whānau carers to support their tangata whaiora (Fleminger & Ponsford, 2005; Rolland, 1999). Interestingly, for parents of a tangata whaiora child, a greater focus on the needs of the child was a little easier comparative to a partner who is caring for their household, tamariki and tangata whaiora (Buhse, 2008).

Lastly, In the next two extracts, two whānau carer participants spoke about being separated from important whānau members at initial TBI injury event and in long-term care. The first quote describes the distance between the rehabilitation service for important whānau members who were unable to travel the distance. Additionally, the second quote, also describes the distance between services and whānau residence, which for this tangata whaiora is up to four hours one way.

*"…he (tangata whaiora) did say to me one day, "it's nice seeing you but it would be nice to see someone else" *all laugh*. But because he lives (in rehabilitation at the time) so far away, none of his family could go and visit him…" (Whānau 2, Māori, Partner)*

*"…majority of his whānau live in Hasting so, she's (mother of Māori tangata whaiora) always welcome to come but there's circumstances that didn't allow her to get here…" (Whānau 5, Samoan, Kaupapa)*

The intricate dynamics experienced by whānau participants are in some cases insurmountable, and meant whānau were not able to physically support their Māori tangata whaiora, especially over a long period of time. For the wider whānau in both extracts, financial limitation with regards to transportation and distance travelled appears to be a perpetuating factor in the separation experienced. For many Māori whānau living in rural or small-town communities, there is limited accessibility to services due to barriers such as financial, transport even if services are known to them (Stats NZ Tatauranga Aotearoa, 2020). However, Māori who live in larger urban cities are more likely to be isolated to extended whānau networks

(Reid et al., 2016). These findings suggest a greater need for services that are local and encompassing of whānau-centred healthcare.

Each extract affirms that the physical separation of whānau and Māori tangata whaiora directly impacts on the emotional support that is needed, leading to emotional separation. As a result, whānau members are unable to check in as regularly or at all on how their tangata whaiora is feeling, progressing, and their overall wairua. Furthermore, depending on the stage of rehabilitation and healing the Māori tangata whaiora is at, the Māori tangata whaiora may not have access to digital devices due to sensory and cognitive stimulation, impairment and fatigue. As a result, whānau have essentially been severed from the inclusion of supporting and healing their tangata whaiora which is paramount in the rehabilitation pathway (Elder, 2017). Moreover, the extracts show the amount of involvement of whānau in rehabilitation varies due to physical separation, these whānau describe their feelings of uncertainty, and consternation as well as missing out on general care for their tangata whaiora. The sometimes-limited ability for whānau to physically be there for their tangata whaiora reflects the absence of Te Ao Māori and Māori models of health utilised within the healthcare system, as these tools would have otherwise helped to promote active engagement from whānau within a whānau-centred approach (Dudley et al., 2014; Elder 2017).

### Loss

A number of whānau carer participants spoke to the notion of '*loss'* where whānau speak to the deterioration of cognitive and physical functioning of tangata whaiora due to TBI. In addition, the notion of loss is akin to the loss of tangata whaiora. The shift in dynamics in relationships due to the affective cognitive, and functional changes in Māori tangata whaiora can lead to relationship breakdowns, which increases the pressure put on whānau to adapt to the new norm, and can be more difficult depending on the nature of the relationship between the Māori tangata whaiora and whānau member (Baker et al., 2017). For example, between a whānau member who is the father and a Māori tangata whaiora who is the son, a whānau member who is the female partner and a Māori tangata whaiora who is the male partner, a whānau member who is the child and a Māori tangata whaiora who is the father, a whānau member who is the sibling and a Māori tangata whaiora who is the brother, these examples are representative of the sample population with almost all Māori tangata whaiora identifying as male. The connections shared between the whānau and the Māori tangata whaiora deepening on the relationship can increase risk for vulnerable whānau such as tamariki, female partners, siblings or elder parents.

In the following quotes, two whānau carer participants spoke about the ongoing changes in the lives of Māori tangata whaiora and whānau due to the evolving TBI over time.

*"…you don't actually realise how different someone with a brain injury is and what to expect. It's been a lot of learning over the entire, over the past 4 years aye…because it changes, it [life] doesn't stay the same…" (Whānau 2, Māori, partner)*

*"…especially with the vision he's never ever gonna be able to drive again, when he explained it, it was quite shocking, the vision that he's got. I've seen him at home, and he'll just walk along and he'll walk straight over the coffee table or something you know. I get worried sometimes if he's out on the step having a cigarette, and I get worried so I keep looking out that he doesn't walk over the steps, things like that. Like with rehab I can see its gonna be fairly limited to what he can sorta achieve or do…" (Whānau 4, Pākehā, father).*

In the below extract, this whānau participant reflects upon his son's focus on getting on with a party life and not understanding the limitations of his TBI and the support he needs to recover. The affective cognitive, and functional changes in this tangata whaiora means he needs long-term residential care which his farther is unable to provide.

"*…His vision of the world is coming back home and its one big party, just getting drunk, he doesn't know what the real world is like, he says to me, he shouldn't be here (at this service), and I know he shouldn't, but what he can't see is he needs a certain amount of support at this stage, to function to live, he can't just be dumped on my door step while I'm working…" (Whānau 4, Pākehā, Father).*

In the below extract, one whānau carer participants spoke about the strain in relationships due to the TBI event. The challenge in supporting tangata whaiora can be overwhelming, and in this instance was left to one person to step up.

*"…his brother couldn't see him; his best mate just couldn't see him like that…they (other whānau and friends) just found it really difficult which is kinda where I came in because that's why I did what I did, even his mum found it difficult to see him like that so I took care*

*of a lot of things, and left his mum there to process everything that was happening…"*
*(Whānau 2, Māori, Partner)*

For many whānau the experience of loss and worry in their daily lives after the TBI event are difficult to process. The changes in relationship due to the TBI event can have profound effects as whānau and tangata whaiora can feel disconnected from their previous lives (Levack et al., 2010). Analysis of these quotes highlight that whānau may feel relief that their tangata whaiora has survived the TBI event, however are often left with feelings of constant worry for their tangata whaiora, and for what is to come in the future (Lavelle Wijohn, 2017). The extracts provide insight into the range of loss experienced by whānau carer participants, and the changes in the lives of tangata whaiora and whānau as a result of the TBI.

Furthermore, the increase in care needed by whānau to support their tangata whaiora, particularly the parent-child dynamic has caused increased pressure and change on relationships, and in one example, the whānau members refusing to "see" their tangata whaiora.

These experiences are highlighted in more detail in current literature that describes "ambiguous loss" as whānau experience ongoing distress, worry, grief, for who the tangata whaiora once was, and "ambiguous loss" is an experience that is compounded over a lifetime as whānau feel guilty or are unable to maintain relationships with tangata whaiora (Kreutzer et al., 2016). Moreover, the tangata whaiora and whānau can continue to experience "ambiguous loss" and grief as they see friends and whānau networks achieve milestones throughout their lives, some milestones tangata whaiora may not ever be able to achieve due to their injury or will achieve goals and aspiration that are different to their intended path (Bruce, & Schultz, 2002; Kreutzer et al., 2016). These experiences of "limited" lives described by whānau carer participants challenge tangata whaiora and whānau to reconstruct their identify by accepting the current circumstances and learning pathways to establish new goals, aspirations and desires (Gracey et al., 2009; Elder, 2017; Yeates et al., 2008; Ylvisaker et al., 2008). In this way, supportive whānau carers facilitate recovery for tangata whaiora (Elder, 2017).

### Aggression and risk

A number of whānau carer participants spoke to the notion identified as *aggression and risk* in caring for or supporting tangata whaiora. Within this subtheme, the definition can be understood by the changes in personality often leading to *aggression and risk,* where the Māori tangata whaiora developed problems with impulse control, agitation, aggression and/or illicit drug use. The quotes below reflect upon how changes in tangata whaiora post TBI has seen an increased risk of harm to whānau, including children, female partners, siblings, and elderly parents. Conversely, whānau carer participants discussed how Māori tangata whaiora can in the same breath be at risk themselves and be vulnerable to others attempting to take advantage of them due to their TBI.

In the following quote, one whānau carer participants spoke about the vulnerability experienced from others around the Māori tangata whaiora, particularly the whānau, in this instance their tamariki. This whānau member describes previous situations that their tamariki were at potential risk of harm due to the changes in personality caused by the TBI. In addition, this quote also highlights the aggression expressed by the Māori tangata whaiora that was not previously there due to the TBI.

*"…so, we've had incidences with the kids where somethings irritated him (tangata whaiora) and then he's ended up emotionally abusing the kids being really forceful, just forceful towards the kids and we had a couple of police investigations as a result…its quite a difficult thing because the police come from a criminal perspective whereas we're like actually it's not because he's an abusive person naturally it's because he's got a brain injury so he's got impulsivity…" (Whānau 2, Māori, Partner)*

In the above quote, the changes in aggression, impulsivity and agitation as described by this whānau member, are consistent. Literature state that the prominent aggressive traits for tangata whaiora after TBI are impulsive verbal aggression and anger (Dyer et al., 2006; Pitman et al., 2015; Ferguson & Coccaro, 2009). Similarly, many changes in personality, specifically for aggression that is predominantly verbal, can further develop into physical aggression to self, others or objects (Walker et al., 2010). The dysregulated behaviour of threats and violence increases over time from 15 percent at one year post TBI, to 54 percent at five years post TBI (Kreutzer et al., 1995).

Further, the whānau member identifies the lack of knowledge and awareness within state services, such as the police in dealing with the entire whānau unit. Here, police services isolate situations and individuals, whether it be tamariki, tangata whaiora, or whānau to perpetuate the Eurocentric and person-centred approach rather than the whānau-centred approach, which would have otherwise identified and established the care-needs of the entire whānau, including the tangata whaiora to provide more appropriate support (Mpofu et al., 2021).

In the following two quotes, one whānau carer participant spoke about the constant worry he has for his son, the Māori tangata whaiora being more vulnerable to others, in particular, others taking advantage of them as well as his son's current reality due to his TBI.

*"…I won't cope with that, its sorta happened before, it's just that when someone is vulnerable it seems to attract all the low life's, you know? These ones were hitting him up saying he'd got dope off them when he hadn't, trying to get you know? (Get money off him). So, he's not in control of his money. His sister is. he has money in the bank which is great, but these sort of things that Pūriri (Māori tangata whaiora) doesn't realise because he's never worked or he's got no idea about that sort of thing, life's not just lying around, until your mates turn up having a beer… I've said to him, that he's got to help himself because you can't sit back and just do things that you enjoy doing. That's where he's stifled progress a little for himself since he's been here (long term rehabilitation service) ..." (Whānau 4, Pākehā, father).*

The vulnerability highlighted in the above whānau narratives emphasises the cognitive impairment that is sustained either by the memory, attention, or comprehension of the tangata whaiora which has been impacted due to the TBI. This quote highlights the willingness of whānau to holistically support their tangata whaiora, and maintain their best interests, in this instance by giving financial responsibility to the sibling of the tangata whaiora so that he is not being taken advantage of. This tangata whaiora sustained his injury during his early adolescents, and has had his TBI for nearly 20 years, the perception of the world Pūriri lives in is reflective of his experiences prior to the TBI. As a result, the tangata whaiora does not have understandings of financial or vocational responsibilities due to his developmental level, which is still of an early adolescent (Arnett et al., 2013). The experiences make tangata whaiora more vulnerable to "low life's" as he has not been able to experiences and develop his social, cognitive and independent functioning (Hoofien, 2001). Furthermore, the whānau member recognises the need for the tangata whaiora to get a job, however literature suggest that there is considerable job instability following a TBI (Hoofien, 2001), and tangata whaiora who are able to get jobs struggle to maintain jobs for a prolonged period of time due to the TBI (Asikainen et al., 1998).

The same whānau member further discuss his experience of being cautious about the social groups his son is associating with, as many attempt to exploit him due to his TBI.

*"…I have to be careful, who he's with, because a lot of them, people tend to take advantage, rip him off or takes his tobacco, and he's forgotten where he's put it, but they've stolen it and I'm more concerned that he's gonna fall over somewhere, you know, he's just vulnerable to anyone out there…" (Whānau 4, Pākehā, father).*

Whānau carers often describe feelings of being watchful and protective of their tangata whaiora with TBI, as this attempts to ensure they avoid being taken advantage of (Kratz et al., 2017). An example described by this whānau member is the cognitive impairment suffered by this tangata whaiora, which is his ability to retain and remember information. For many tangata whaiora with TBI their memory loss worsens over time (Smith et al., 2017; Wasserman, & Mion, 2018). The deterioration of te taha hinengaro for tangata whaiora is confronting as parent carers can feel concerned for the future of their tangata whaiora, and who will provide for them once the whānau member is gone (Allen et al., 1994).

In the following quote the whānau carer participant is speaking to her brother, the Māori tangata whaiora, and myself as the researcher and interviewer.

*"…they rang me to ask and come and collect you (tangata whaiora) because they just thought that you weren't the kind of person that they wanted there. Which was sad, it was just because of his head injury and a lot of the young girls that were traveling Backpackers just thought he was creepy because he'd just stand there and stare, not that that's what he does but he'd stay in the lounge, the communal lounge all day. They found him intimidating because of the way he looked, but he's a big softy. Because of the way he looked and his behaviours, management didn't want him there anymore even though we were paying more for him to stay there. So that was frustrating, because then I didn't know what to do with him, because my husband was like he's not coming back here. So, it was frustrating. I wasn't really too sure what to do…" (Whānau 1, Māori, Sister)*

In the above quote, this whānau member describes an example of behavioural changes that occurred in the tangata whaiora due to the TBI. The consequences of behavioural changes as highlighted in this quote impacts the ability for tangata whaiora to communicate and engage with others socially (Warren et al., 2016).

It is evident the existing risks and vulnerabilities faced by whānau remain uncertain, as vigilance is needed, however there is no identified timeframe for how long this will impact tangata whaiora and the whānau. The dependency on whānau limits tangata whaiora independence, nevertheless is crucial in ensuring tangata whaiora and others are safe. Further, many services, and communities are relatively unaware of the injury sustained by the tangata whaiora, as it is not always obvious or visible which can lead to misunderstandings or tangata whaiora becoming targets as identified throughout the whānau narratives. The extracts provide insight into the range of aggression and risk experienced by whānau, and offer potential solutions around education, discussion and compassion when dealing not only with tangata whaiora with TBI but their whānau context.

### Whakarāpopototanga – summary

Within this chapter, narratives affirmed the complexity of Ngaukinotanga - trauma experienced by whānau through the TBI event and the way these experiences are navigated and given meaning. All of which described the significant impact on how whānau carer participants understand themselves, their Māori tangata whaiora, the healthcare system, and their future. The subthemes, *injury to the whānau, separation, loss, aggression and risk,* forged discussion on pathways and possibilities aimed at identifying current issues within the system, and contributed to the healing and recovery of whānau and Māori tangata whaiora throughout the TBI pathway.

Key analysis from each subtheme, identifies commonalities whānau are likely to experience due psychological distress, which is exacerbated if whānau members are female. These findings are also linked with wider whānau responsibilities which are more prominent if the whānau member is the partner, compared to the parent relationship. Moreover, the establishment and utilisation of Māori models of health ensures whānau-centred approaches which will promote active engagement by whānau within the healthcare system.

The role of identity for whānau and tangata whaiora is identified as well as the concept of "ambiguous loss" as whānau attempt forge new pathways, and the need for greater knowledge and information sharing amongst services and social networks. The

Particular emphasis on the changes in cognitive, behavioural and social functioning leading to aggression, impulsivity and agitation which was found to become worse over time for tangata whaiora. Comparatively, tangata whaiora were also likely to be exploited due to the impacts of their TBI, which in turn meant whānau were more watchful. Lastly, chapter discussed the changing dynamics and relationship between whānau members and tangata whaiora, and the ever-evolving nature of the TBI, as well as the challenges and ways whānau manged throughout.

The next chapter expands on the notion of Kaiurungi whānau – Whānau navigators, as the chapter discusses subthemes in exploring the role of whānau as navigators within the pathway of care for tangata whaiora.

# Upoko Tuarima- Chapter 5

## Kaiurungi Whānau: Whānau Navigator

This chapter speaks to the theme of Kaiurungi whānau – Whānau navigator experiences by whānau carer participants. The notion of Kaiurungi whānau – Whānau navigator, involves the leadership, support, coordination, and advocacy, role provided by whānau during the care of tangata whaiora from hospitalisation, to rehabilitation, and back into the community.

Throughout this chapter analysis of whānau narratives which discuss whānau carer participants nuanced and diverse lived experiences within the rehabilitation pathway, and how these experiences have informed their interactions with these services as a whānau navigator. These understandings were situated within three subthemes, - *navigating health and other system challenges, whānau navigators as a repository for memories,* and *whānau navigators as a function of healing.*

The first subtheme, *navigating health and other system challenges,* is described by whānau as their difficulty in *navigating health and other system challenges*, where whānau member/s had to assist the Māori tangata whaiora in navigating the labyrinth of the health system and ensuring access and necessary care. Thus, anchoring the care for Māori tangata whaiora when services and health professionals were without support and care. This chapter will highlight how whānau spoke to the ways they stepped in to assist Māori tangata whaiora to navigate the complexity of the healthcare system, to problem solve, to access necessary care, and to plan for a sustainable recovery.

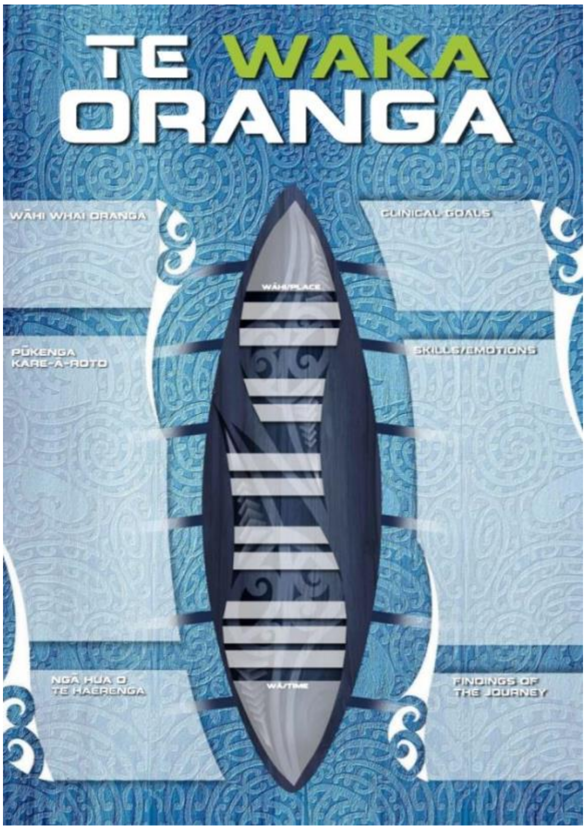
In the second subtheme, this chapter will reflect upon whānau navigators as a *repository of memories* for Māori tangata whaiora, due to the loss of cognitive functions such as memory.

Whānau became a source of memories for Māori tangata whaiora and assisted Māori tangata whaiora to navigate events that occurred prior to, during and after the TBI event.

Finally, the last subtheme that will be further analysed, identifies the wider whānau unit as an important aspect and emphasised *whānau navigators as a function of healing.* There is a collective understanding as the whānau unit both provides healing and requires healing. As a result, the function of healing within this thesis is linked to whānau navigators' ability to be compassionate and competent throughout the rehabilitation pathway (VanKatwyk,1997). The Māori tangata whaiora and the whānau themselves requires healing as they too experience stress in navigating the system, and uncertainty during the care of their Māori tangata whaiora due to the changes occurring in their own lives and how they manage these changes.

This chapter also seeks to centre Indigenous knowledge of care by drawing upon the Māori health model, Te Waka Oranga (Elder, 2015) and the role of Kaiurungi whānau – Whānau navigators within this model. The model centralises Whānau, whānau Mātauranga (family knowledge systems) as well as the importance of social relationships as essential to the recovery outcomes for tangata whaiora with TBI (see ***Figure 1***).

**Figure 1.** *Te Waka Oranga model developed by Elder (2013)*



*Note:* Te Waka Oranga Māori model of health

## Navigating health and other system challenges

Whānau carer participants described their willingness to step into the whānau navigator role to assist their Māori tangata whaiora by guiding them through the uncertainty of the health system, and ensuring they have access to necessary care, which ultimately helps throughout the recovery process (Elder, 2017). Aspects within the whānau navigator themes and subthemes describes the pressures associated with this role as immense, and time consuming. Regardless of the existing and increased pressure whānau had, whānau carer participants ensured they were able to address the issues that arose within the healthcare system to support their Māori tangata whaiora and advocate for them when services lacked culturally responsive care, especially for Māori.

In the two following extracts, whānau carer participants spoke of some examples when they were needed to help navigate their tangata whaiora within the healthcare system. The first extract describes the lack of support and understanding provided by the healthcare system, and identifies a gap that Māori tangata whaiora and whānau needed more information and communication to occur between the healthcare system and themselves.

"*…Yeah, the social worker, in the very early stages, coming over home would have been quite ideal because we didn't get it (social worker support) until a bit later… It was just a little bit late, because we didn't think it was necessary later on because - we'd already like lived for 3 months, 4 months without that (support) so had to – try and figure it out…"(Whānau 3, Pākehā, Partner)*

Following on, the "it" described by this whānau carer participant is the support provided by services, specifically the social worker. The quote then discusses how aspects that would have otherwise been uncomplicated, are now more complicated due to the TBI. For example, the ability, or lack of ability for tangata whaiora to remember to attend appointments, which appointments these are, where these appointments are, who these appointments are with, and what is needed by the tangata whaiora for these appointments. All of which are highlighted further in the following quote from the same whānau member.

*"… Mm I'd make sure you're not missing the crucial appointments and things that you want to do, it's kind of a forecasting board and an appointment board and that sort of thing…" (Whānau 3, Pākehā, Partner)*

This whānau carer participant spoke of the ways in which she had to "figure out" how to support her tangata whaiora by herself without Kaimahi support, and that by the time Kaimahi were finally involved it was too late. These experiences of rehabilitation after being discharged back into the community align with research conducted by Wepa and Wilson (2019), where whānau resolve to endure the healthcare system because due to their need to support tangata whaiora. By whānau members taking agency in the healthcare journey, they aided the endeavour of tangata whaiora to remain involved in the right healthcare and recover (Wepa & Wilson, 2019). An example she discusses is around ways in which she is able to help her Māori tangata whaiora navigate his appointments. The use of a forecasting and appointment board at home, helps to document the important dates he'd need to attend over the week and month, so that each part of his day is set out, and the Māori tangata whaiora is able to have a clear recovery plan in place. As the whānau navigates these spaces and uses these tools, this ensures the Māori tangata whaiora is aware of meetings, group and individual sessions, therapy, and any other important appointments that are ahead. Pragmatically, whānau assist in these actives within the healthcare system which according to literature enhances the collective wellbeing of whānau and tangata whaiora (Lyford, & Cook, 2005; Pitama et al., 2007). As a result, both extracts together emphasise the role whānau play in advocating, leading and providing wrap around support to navigate the healthcare system with their tangata whaiora. Furthermore, these two quotes highlight the limited support provided while in the community for whānau and tangata whaiora after the TBI event.

In the next quote, another whānau carer participant reflects upon her role in navigating the healthcare system with her partner. These quotes will be further analysed using Te Waka Oranga (Elder, 2015).

*"…we (whānau member and tangata whaiora) will utilise the couples (therapy) sessions. It's not just for us (whānau member and tangata whaiora) to discuss things that are happening between us, it's actually (for me) to give the therapist more information because sometimes he'll (tangata whaiora) be like "ah everything's really good," and he won't say "I've got this police investigation sitting there, my partner is losing her shit and I haven't seen the kids for*

*months" but its "ah I'm good" you know? He misses out information. So, I'd say to the therapist "No, this is happening, this is happening, this is all the things I've picked up this week, this is where his fatigues at" so I fill in all the gaps…" (Whānau 2, Māori, Partner)*

This whānau carer participant spoke of her role in filling in the "gaps" of communication between tangata whaiora and clinicians. Within Te Waka Oranga, the conceptualisation of a waka with whānau as paddlers on one side of the waka, and on the other side, Kaimahi. This sets up Stage 2: Te Haerenga o te Waka Oranga (Elder, 2015). Stage 2 describes the launching, sailing and arriving phases of the rehabilitation pathway. Highlighted here, whānau collaborate with tangata whaiora and Kaimahi to share whānau Mātauranga, specifically skills, knowledge, and high-quality communication (Elder, 2017). This process anchors the needs of the tangata whaiora within the healthcare system. Further analysis of this quote identifies the whānau members own struggles while caring for her partner. The many pressures faced by whānau, especially carers, as described in more detail in *injury to the whānau*, where managing vocational, household responsibilities and the needs of other whānau members, like their tamariki can be taxing (Warren et al., 2016). Te Waka Oranga model allows space for whānau to divide up different parts of the rehabilitation pathway into shorter journeys, as Wā (time) is highlighted in the model to allow for more flexibility when thinking about the Wāhi (place or destination) to make the journeys and Wāhi whai oranga (goals) achievable (Elder, 2017). The actions of whānau members and their resilience in the face of challenging situations, highlights the support that exist within whānau to navigate the healthcare system for their tangata whaiora as events continue to unfold, whether these be positive or negative (Wepa & Wilson, 2019).

Lastly, in the next quote, one whānau carer participants spoke about the coordination and advocacy role provided by the whānau member, their mother, and her ability to advocate for her son with the TBI throughout his recovery.

*"…yeah, lots of physio because Maehe (Māori tangata whaiora) couldn't walk at all really, he had to pretty much learn how to feed himself again, all that stuff, toileting, he couldn't do any of that stuff himself and my mum stayed with him 24/7 she practically lived there (at the hospital) and our mum was real hands on and demanding, like she was, if something wasn't getting done, she'd make sure it got done…" (Whānau 1, Māori, Sister)*

The extract above describes how Maehe's mother, ensured he was advocated for by staying with him 24/7, ensuring staff were taking care of him, (toileting, showering etc), her role in navigating the health system for him meant his needs were met. Here, the mother actively changed aspects of her life, for example her continuous availability for her son to manage and accept the changes and difficulties after the TBI (McPherson et al., 2018). A potential purpose behind needing 27/4 advocacy is that while tangata whaiora are in ICU, they endure unfamiliar and painful medical procedures, and in these instances can have significant barriers with communication due to their injuries (Warren et al., 2016). Therefore, the whānau member is willing to assist their tangata whaiora in accessing necessary care and to plan for a sustainable recovery (Boulton et al., 2013; Wepa & Wilson, 2019). The tangata whaiora is being looked out for and having someone help drive the process of care, rehabilitation and successful treatment (McPherson et al., 2018). Furthermore, this particular tangata whaiora was in his early adolescence at the time of his injury, which meant the mothers role in supporting him was more prevalent as seen in the above quote.

Although the exact type of whānau support varied from whānau to whānau, most whānau carer participants discussed that whānau were relied upon for help to drive the process and navigate the healthcare system. These were especially prevalent during difficulties faced by Māori tangata whaiora, particularly in the early stages of the rehabilitation pathway. Additionally, whānau support was highlighted as being a vital resource to Māori tangata whaiora in managing the changes and difficulties after their injury.

### Whānau navigators as a repository of memories

Due to tangata whaiora losing of cognitive functions such as memory, whānau carer participants become a *repository of memories* for the Māori tangata whaiora post TBI event. Throughout the whānau narratives, whānau carer participants described the unique theme of *whānau as a repository of memories* as a function of memory retention, memory recall and storytelling, thus assisting and supporting Māori tangata whaiora in their healing. For example, Māori tangata whaiora would touch their whānau member, or look to them in times of uncertainty and memory loss throughout the pathway of healing, inclusive of post-acute, hospital, rehabilitation, community care, and witnessed during the interview process, this theme will be analysed further in the extract below. The physical expression of help from whānau toward Māori tangata whaiora when they are attempting to piece together their thoughts, experiences and distinctive stories was reassuring for Māori tangata whaiora as they were guided and supported throughout their rehabilitation journey by their *Kaiurungi whānau - Whānau navigators.*

To reflect upon the way whānau supported tangata whaiora, I will draw upon my field notes from two whānau carer participants which characterised their role in supporting tangata whaiora.

*"…throughout the interview Rimu (Māori tangata whaiora) would look at his partner when he'd forget stuff, or touch her hand (on the table) to reassure him – ground his story/thoughts and she'd be able to fill in the gaps and support him (talking to each other to find story then to me) …" (Field note 18/12/19 - Whānau 3, Pākehā, Partner)*

*"…Kauri (Māori tangata whaiora) would look to whānau like "this is right aye?" as a way to seek re-assurance from whānau member to support Kauri especially when he'd forget some aspects or get side tracked. The whānau member would guide him back and help him remember – also piece together the puzzle…" (Field note 17/12/19 - Whānau 2, Māori, Partner)*

These two field notes illustrate that whānau are supporting tangata whaiora to recall stories and narratives in a way that maintains the mana of the tangata whaiora post TBI. Here, whānau support tangata whaiora to gain mastery over their responses and make meaning of their experiences. This is part of whānau being navigators of the healing process by supporting tangata whaiora to articulate their own experiences with support and reassurance. The reassurance gained through the process further supports the notion of *whānau are a function of healing* for Māori tangata whaiora, as whānau respectfully and accurately presented and supported the presentation of their own stories and experiences of the healthcare system alongside their Māori tangata whaiora (Elder, 2012).

In the next quote, one whānau participant describes her experience of being a sounding board for her Māori tangata whaiora as he shares his opinions and thoughts.

*"…He'd (tangata whaiora) just use me as a sounding board though, you'd (tangata whaiora) say how busy he was "oh I've got all these things" but we understood that that was your*

*condition at the time so we'd just focus on what they've got you doing, and we'd see all these you know, routines…" (Whānau 3, Pākehā, Partner)*

It is clear that whānau are important in supporting Māori tangata whaiora to articulate their lived experience through touch, and helping with memories or everyday routines. By whānau carer participants not talking about tangata whaiora, or for them, but instead with them, highlights precise care and consideration whānau provide in enabling tangata whaiora to be the authors of their story, from an intrinsically Māori perspective. The practices and observations of whānau as illustrated here, whether they are aware or not is consistent with Te Waka Oranga (2015). Within Te Waka Oranga, the whānau Mātauranga is activated through the repository of memories within whānau navigators as they enable mana enhancing processes, these concepts of co-storytelling and collaborative kōrero paki (to tell stories) construction are values and beliefs grounded in Te Ao Māori (Elder, 2012; Smith, 2012). The relationship whānau Mātauranga has on the direct effect of mana of the tangata whaiora, whether by touch, supporting with memories and recall, or active listening as sounding boards all attend to the wairua needs of the tangata whaiora (Elder, 2012). The wairua element is essential in improving recovery and the diverse cultural and clinical needs of tangata whaiora (Elder, 2012, 2017).

## Whānau navigators as a function of healing

A number of whānau carer participants spoke to the subtheme identified as *whānau navigators as a function of healing.* Whānau carer participants discussed the importance of whānau, with an emphasis on the collective needing to be considered as the unit that both provides healing and requires healing. To consider how whānau are part of the healing process, the Te Waka Oranga (Elder, 2013), is further utilised, more specifically the emphasis on stage 1 Hoe tahi: paddling as one, and later on with stage 2 Te Haerenga o te waka: launching, sailing, and arriving.

At Stage 1 Hoe tahi, whānau, Māori tangata whaiora and kaimahi can establish their own ground rules of their individual Waka Oranga, as well as identifying all the people involved in paddling the waka to the agreed destination. Within the model, each paddle has a skills side and an emotional side. Cultural concepts imbedded are inclusive of consideration of head and brain as tapu, the impact of injury on wairua of the Māori tangata whaiora, as well as the whānau and the whakapapa. Further, there is acknowledgement of the place where rehabilitation is taking place (e.g., a long way from the marae) (Elder, 2012).

In the below extract, one whānau carer participants spoke about the challenges faced by other whānau members who were not able to be part of the healing process or waka journey for their Māori tangata whaiora. In this instance, the partner had to assume the main Kaiurungi whānau – whānau navigator role and function as way of healing for her partner.

*"…his brother couldn't see him; his best mate just couldn't see him like that…they (other whānau and friends) just found it really difficult which is kinda where I came in because that's why I did what I did, like even his mum found it difficult to see him like that so I took care of a lot of things, and left his mum there to process everything that was happening…" (Whānau 2, Māori, Partner)*

Within this quote the partner is identified as the main whānau navigator, where she is able to assist and establish the ground rules of how the rehabilitation pathway will go for her tangata whaiora by "taking care of a lot of things." This stage in Te Waka Oranga identified as Stage 1 Hoe tahi, establishing roles, relationships with whānau, tangata whaiora as well as clinicians. If the appropriate people are involved immediately the waka journey is better reinforced (Elder, 2012). Research by Wepa and Wilson (2019) identified the presence of whānau alleviates any emotional and wairua fatigue that may be associated with the rehabilitation journey.

As discussed previously in the notion of *injury to the whānau,* not all whānau are able to be supportive and be a part of the waka journey. The strain the TBI injury can cause to other whānau is too much for them, and therefore they require healing themselves. It is important to consider that this can exacerbate the pressure put onto the partner as identified in the notion of *navigating health and other system challenges*.

In the next extract, one whānau carer participants spoke about the sustained support and care provided by the kaupapa whānau in collectively guiding the waka towards healing. The kaupapa whānau participant touches on values within stage 2 Te Haerenga o te waka: launching, sailing, and arriving by collaboration, skill sharing and high-quality communication and connection between himself and his Māori tangata whaiora. At Stage 2, there is a focus on implementing the agreed processes in 'hoe tahi' into action for the rehabilitation journey.

Complementary to this, the kaupapa whānau identifies that "too many decisions" without help is inordinate, hence dividing up the overall rehabilitation journey into shorter journeys provides flexibility within Te Waka Oranga (Elder, 2012).

*"...just the continuous support (the kaupapa whānau provide), so he can make good decisions, if Kōwhai (Māori tangata whaiora) was left too long, and left too long to make too many decisions on his own then it's just overwhelming, so just breaking it down, having someone always there, and be able to help him do that, and I saw that that's what was needed..." (Whānau 5, Samoan, Kaupapa)*

Highlighted in this quote, is how kaupapa whānau, who is a support worker in the long-term residential service is able to identify and breaking down the needs of the tangata whaiora. The breakdown of goals and targets of the rehabilitation journey makes treatment and recovery more sustainable and achievable for tangata whaiora and whānau (Elder, 2012).

Lastly, in the next extract, one whānau carer participants spoke about being empowered to sit alongside clinicians to collectively guide the waka towards the agreed destination.

*"...We were doing the journey there with you (the tangata whaiora) but it doesn't mean to say that I'm meant to be a therapist myself but I had to learn...When did we have that first medical meeting? we'd had a couple of those big meetings where everybody had their say on how Rimu was progressing so I appreciate those were like round table's..." (Whānau 3, Pākehā, Partner)*

In the above quote, the clinical team is described as sitting in a whānau space identified as the "round table" and within Te Waka Oranga is likened to a team of paddlers working together to move the waka, forward (Elder 2015).

### Whakarāpopototanga – summary

Within this chapter, whānau narratives covered the role of Kaiurungi whānau – Whānau navigators with the notion of *navigating health and other system challenges, whānau navigators as a repository for memories,* and *whānau navigators as a function of healing.* The concepts of Te Waka Oranga (Elder, 2012) were outlined across multiple dimensions of individual and collective wellbeing and social relations, providing linkages to how whānau can utilise Te Waka Oranga as a tool to navigate the healthcare system as a way to centre Te Ao Māori, and also to emphasise a whānau-centred approach.

The three subthemes in this chapter highlighted whānau navigators as a protective factor for tangata whaiora. The role of whānau Mātauranga in driving the process of care (McPherson, 2018), the ability for whānau to problem solve, and advocate for their tangata whaiora was also evident throughout the extracts. The connections between tangata whaiora and whānau was identified as a source of support and strength. Furthermore, the whānau space was an important coping strategy in navigating the rehabilitation pathway with the changes and challenges that arose (Wepa & Wilson, 2019). In this mahi rangahau, the changes and challenges for tangata whaiora were minimised by their whānau member due to their support strategies.

Whānau endeavoured to assist and manage the collective wellbeing, driven by their ability and responsibility to care for their tangata whaiora. The highlight of whānau is this chapter is their capacity towards navigating and engaging with the healthcare system and receiving quality care for their tangata whaiora. Further analysis of the healthcare system will be discussed in the following chapter.

The next chapter expands on the notion of He piere ratonga – Service issues and challenges, as the chapter discusses subthemes in exploring the complexity, and fragmentation of the Pākehā clinical settings for whānau carers.

# Upoko Tuaono- Chapter 6

# He Piere Ratonga: Service issues and challenges

This chapter speaks to He Piere Ratonga - service issues and challenges experienced by whānau participants when engaging these services from the time of the TBI event through to the hospital (ED & in-patient ward), to post-acute rehabilitation, and then back into the community for ongoing recovery. In reflecting upon these challenges, this chapter will consider how the following issues; *complexity and fragmentation of the health system; inflexibility of services and lack of information; and limited cultural responsiveness to Māori health within Pākehā clinical settings.*

## Complexity and fragmentation of the health system

The notion of *complexity and fragmentation* is defined as a difficulty in accessing necessary care, and to plan for a sustainable recovery. In this section, complexity of the healthcare system is referred to the distress and difficulties faced by whānau due to navigating this system. Similarly, when referring to the healthcare system as fragmented, it is defined as the inconsistency with co-ordination and delivery of care between Kaimahi, service providers, and whānau. Often these concepts overlap where whānau experience a fragmented healthcare system that makes navigating it complex and distressing. The following quotes reflect such issues.

*"…the ambulance drove him to my house instead of to the hospital, which was just around the corner which I just thought was ridiculous! …I asked them if they can take him to hospital and if I could come with him, but they were still asking questions like if it was just drugs or something but he was moaning and not really responsive, and so from there we went to the hospital…" (Whānau 1, Māori, Sister)*

Highlighted in this quote, whānau describe the fragmentation of the ambulance services in the transition to the hospital, furthermore this whānau member states the unnecessary difficulty in getting her brother to access necessary care.

Literature suggests that for TBI the transitions between hospital, to rehabilitation and back into the community can be stressful, especially for whānau (Piccenna et al., 2016; Turner et al., 2010). However, in the above quote, whānau describe a distinct delayed response to the TBI event by ambulance services. For Indigenous people who are facing uncertain diagnosis, evidence shows they are more likely to be susceptible to inadequate or delayed medical intervention compared to non-Indigenous communities (Theunissen, 2011; White et al., 2010).

In the next two quotes, one whānau member describes the complexity and differences with healthcare professionals and healthcare providers in in their approaches to support whānau.

*"…A couple (of healthcare professionals) that were involved I just got no time for. I myself just think they're idiots, they (healthcare professionals) don't know what they're talking about as far as I'm concerned… the ones I tended to listen to was the care-givers, and they're not recognised and they've got more clue than all these other ones, they (healthcare professionals) told me that because of the result of his accident that there's a good chance he could get into dope, cigarettes, alcohol, you know the whole lot. One of the psychologists, I said to him, I was having a problem with Pūriri (Māori tangata whaiora) getting into this dope and he said to me "oh, that's a family issue." Some of these idiots, they had in place actually put us back probably two years…" (Whānau 4, Pākehā, Father).*

*"…The biggest thing originally, was that he had the wrong people involved you know? That's where a few of these care-givers are really underrated because they haven't got titles to their names, but they're on the cold-face, and to me they've got more clue than these so-called*

*psychiatrists, and all these other ones. They could see what was going on from the word go, but they're so underrated and it was just the wrong people..." (Whānau 4, Pākehā, Father).*

The healthcare professionals and healthcare providers were inconsistent in their approaches to support whānau, the changes in personnel and the limited communication between them meant whānau were without a recovery plan. As a result, these unnecessary complexities interfered with progress and recovery. This pushed whānau into uncertain environments, where their tangata whaiora were without care. These findings are of concern as Māori are less likely to be referred to specialist treatment and more likely to be discharged from hospital and rehabilitation services compared to non-Māori, despite Māori having higher rates of morbidity and disease (Ellison-Loschmann & Pearce, 2006; Wilson & Barton, 2012).

Conversely in the following quote, one whānau member echoes the sentiment of inconsistency with changes in personnel, however identifies that once the right people were involved in the delivery and co-ordination of care, these experiences were alleviated.

*"...I think the first one, we had a case manager for the first 4 weeks and then we'd have a different short-term person, but then when it's established that it's a long-term traumatic brain injury then they put you onto the long-term manager, so it's a system, I see it as a system. I didn't even think that we'd be face to face honestly with ACC, my thoughts were I wouldn't even thought to see somebody, I thought it would always just be communications, I just thought this is a big conglomerate, ACC you're just gonna be communicating with them and there not gonna be too interested in you as a person just processes, and processing cases and things, that was my thoughts, so when we'd had finally met the manager (name redacted) we (whānau member and tangata whaiora) found her to be a very personable women and very interested and concerned..." (Whānau 3, Pākehā, Partner)*

Whānau narratives show that the experience with health and ACC personnel varied, however were overall inconsistent and fragmented in their approaches. This is evident due to the many changes in personnel, and the appeared limited communication between them or an agreed plan of care. Whānau found this to be confusing and upsetting. Improvement in care co-ordination across care transitions are needed to ensure continuity of care and integration of support (Kirk et al., 2015).

As healthcare professionals and service providers facilitate or obstruct progress, whānau narratives described the importance of others as being helpful in enhancing either positively or negatively the treatment and recovery of tangata whaiora. Here, it is evident that the recovery within TBI is a social and relational process (Douglas, 2015). Many of the whānau narratives spoke about the social workers, and case managers that had a positive impact on their recovery. These narratives align with findings by McPherson et al (2018), where Kaimahi are praised not due to their clinical or medical expertise and accolades, but due to their personable and caring nature in how they treated tangata whaiora. Further analysis suggests that healthcare professionals should avoid assumptions about potential matters of concern to whānau. Instead, they should ensure treatment is cohesive and based on the care-needs of the tangata whaiora and whānau as a whole (Bright et al., 2015). Lastly, medical treatment is identified as an important part of recovery for tangata whaiora, however within the community stages, alongside positive long-term case managers and social workers is where the most significant support needs to occur, as tangata whaiora and whānau navigate the changes in their lives (Riley et al., 2015).

### Inflexibility of services and lack of information provided

In this section, *inflexibility of services* is referred to the ridged process of care by Kaimahi and service providers that are described as difficult to deal with. Similarly, when referring to the *lack of information provided*, this is referred to the services, processes, and problems whānau were experiencing. These two concepts often overlap, and will be reflected in following quotes.

*"…it was really hard, and I think that's why mum and dad- I think they fought with ACC for nearly 10 years…" (Whānau 1, Māori, Sister)*

*"…I was at Uni at the time (studying), and I was tutoring at Uni (working), so I covered that myself not ACC (travel costs to hospital and ABI)…It was a pretty weird situation though, so I wouldn't have expected ACC to pay for me either because at the time we weren't together…it is (quite a bit of money) I was paying board, paying rent, paying petrol, paying for him…" (Whānau 2, Māori, Partner)*

Highlighted in the above two quotes are whānau recounts of the inflexibility of services, the first quote describes the whānau members parents battling with ACC to get cover for their son who suffered the TBI. To contextualise this quote, ACC initially refused to cover the medical and rehabilitation costs as they did not recognise the injury of the tangata whaiora as a TBI. The second quote highlights Kaimahi and service providers focussing solely on the tangata whaiora with TBI, and did not offer financial support for kaupapa whānau. This whānau member also touches on some of the financial pressures she had to endure. It is important to recognise that  the experience of TBI does not occur in isolation, as the lives of whānau also change (McPherson et al., 2018). Moreover, the Eurocentric and person-centred approach by Kaimahi and service providers meant kaupapa whānau were not able to receive adequate financial support, whānau were left traumatised by the changes in their own life, and the lasting immense effect of the TBI event. The Eurocentric values position TBI and the experience of trauma as an individual event, which inhibits the ability for whānau to engage in meaningful relationship building within the healthcare system (Dudley et al., 2014; Gilchrist, 2017). Further analysis of Te Whare Tapa Whā (Durie, 1985), identifies the need for te taha whānau to be recognised as part of the healing process for tangata whaiora as a significant aspect in the conceptualisations of health and wellness. The inflexibility of healthcare professionals and services meant tangata whaiora were without adequate support.

In the next quote, this whānau member describes the lack of information provided to her in terms of the severity of the injury over time, as well as the continuous impacts this will causes for her partner.

*"...somebody said a year, 2 years, so you just gotta get on the journey and see how long it'll take you individually, because every brain injury is different, even though we knew from the outset that you (tangata whaiora) had hearing loss but we didn't know that It was permanent... That he had cerebellum damage..." (Whānau 3, Pākehā, Partner)*

In the next quote, the same whānau member describes being given "paper work" to look over and read up about in regards to TBI. However, states that these resources weren't helpful at this point in time, as it was presented in a fragmented manner relative to the rehabilitation pathway of her partner.

*"...But I was just believing him (tangata whaiora), oh "I'm gonna be back to work in 2 weeks" ... I could have been given a lot of info about head injuries but I think it just had to be given in time with the recovery process, because he would go to those sessions and he'd get a lot of paper work, and even now he'd go back and read the paper work, but it would be*

*useless because I'd look at it and think, I knew a lot of stuff but it wasn't in conjunction with internalising it, it was just some paper work information…" (Whānau 3, Pākehā, Partner)*

The uncertainty for whānau to not know the outcomes and extent of the TBI shows healthcare professionals and services providers absence of plan for the future (Riley et al., 2015). Here, whānau are believing everything will return to normal, which is more difficult when the uncertainties and expectations of the TBI are relatively invisible to others (McPherson et al., 2018). Whānau need assistance from services that are realistic, and personalised to their specific situation.

Similarly, in the following quote, another whānau member also describes his experiences of receiving reports from ACC that were too technical or clinical for him to understand.

*"… He's had quite a few different assessments…Like some of the reports, I just about had to go to medical school to even understand it. ACC have done a few follow ups to see if he's progressed or gone backwards. There was a real issue with 1 (assessment) that at some stage with his memory, could be an early stage of dementia…" (Whānau 4, Pākehā, Father).*

The subsequent *lack of information provided* to whānau throughout the rehabilitation pathway was described as limited and too technical or clinical for whānau to understand. Additionally, the information that was provided was presented in a fragmented manner.

Literature suggests that for Māori tangata whaiora and whānau who are facing uncertain diagnosis in Pākehā healthcare systems, inappropriate and inadequate information provision inhibits whānau from knowing what questions to ask (Graham, & Masters-Awatere, 2020). Despite whānau having access to information, either as pamphlets, or reports, the information was not always explained, as information sharing seems to be dependent on Kaimahi availability, willingness, and knowledge to engage with whānau (Graham, & Masters-Awatere, 2020; Slater et al., 2013). Within these findings, it is unclear if Kaimahi were too busy to provide information, or unaware of services in assisting Māori tangata whaiora and their whānau, however whānau were still left with limited support throughout their rehabilitation pathway. The healthcare services would have benefitted from having a simple coherent overall description of the assessment, treatment, and rehabilitation pathway of the TBI, preferably tailored to the tangata whaiora.

In the next quote, this whānau member alludes to the disappointment in the service provisions for his son, stating he has regressed.

*"...far as I'm concerned, they (healthcare professionals) didn't have a clue and in the mean time when we got the right people in place, we started making progress, but we lost time and he went backwards and there's ground that we didn't regain, you know? ..." (Whānau 4, Pākehā, Father).*

Throughout these whānau narratives, the inflexibility of services and the lack of information provided made managing the impact of TBI complex. Whānau were between decisions of challenging and accepting aspects of the rehibition journey (McPherson et al., 2018). As whānau members described a combination of "getting on with the journey," not "expecting" too much from services and getting the right people in place. A finding from similar whānau carer experiences within TBI is the resilience associated with long-term outcomes due to the ability for whānau to navigate accepting and challenging treatment (McPherson et al., 2018; Wepa & Wilson 2019). Furthermore, this finding may be something healthcare professionals and services have capacity to enhance in their advice to tangata whaiora and whānau.

## Limited cultural responsiveness to Māori health within Pākehā clinical settings

In this section, *limited cultural responsiveness to Māori health within Pākehā clinical settings* is referred to as the experience of the clinical world as an alien culture. The needs of Māori in care were not being adequately met by health professionals and healthcare providers, these experiences will be highlighted in below.

This whānau member describes the Western healthcare system and the limited Māori cultural responsiveness throughout. Here, the tension between the diverse Māori cultural needs of tangata whaiora and the whānau member is present. The lack of involvement and consideration towards the wider whānau unit limited connection those whānau members needed to engage within services to support their tangata whaiora.

*"...the services that he got were very westernised, there was a touch of Māori tradition but not a lot, but he was able to cope because at that point he wasn't able to immerse himself*

*in his Māori culture, whereas his mum she very much does immerse herself in Māori culture and is involved in the marae. I think that she actually needed that (Māori cultural) support and I think that would have helped her connect better with the services, because she stayed quite detached and she did her best to function within that sphere. If there was a bit more of a Māori element it would have created more of a connection with her, because she wasn't connected with the service, so she would have been able to participate more…" (Whānau 2, Māori, Partner)*

The same whānau member also recounts the uncertainty in navigating the clinical space, and feeling lost due to the limited cultural responsiveness. As a result, whānau are forced to navigate the clinical space alone or disengaged from the system.

*"…for his mum no one knows what it's like to deal with this type of injury unless you've been through it before, so you can feel really lost within the system and I think for me watching his mum, she was really hovering with no real routes*

*(interviewer:)* ***like there wasn't any sort of connection or entry point for her into the service?***

*Yeah, she just sat back and just watched and then did her own research in the library to try and understand what was going on. All she sees is doctors and nurses talking, medical talk, so she doesn't know what they're talking about, so I think that she could have really done with that or just Kōrero with someone, it would have helped…"(Whānau 2, Māori, Partner)*

In these above quotes, this whānau member gives examples as to depth and breadth of experience whānau go through. The limited responsiveness to Māori and the cultural disconnection for Māori within Pākehā clinical environments is for some whānau insurmountable. To minimise these tensions, greater understanding amongst healthcare professionals and healthcare providers alongside Māori healthcare professionals will mediate these experiences (Cameron, 2018). Furthermore, support can be gained within Kaupapa Māori providers (Boulton et al., 2011). The same whānau member identified the experience of "loss" due to the lack of cultural support, these narratives are echoed in other indigenous communities when accessing care for their children within Western systems (Dalach et al., 2021). The apparent cultural clashes felt by this whānau in the absence of Mātauranga Māori is congruent with the lack of specific information about how to facilitate culturally responsive care with Māori (Stevenson, 2018). Furthermore, the cultural dynamic of diversity between the parent-child relationship identifies the differing Māori cultural needs of tangata whaiora and whānau members (Durie, 1995a). This complex relationship can be mediated by Kaimahi providing a cultural bridge between tangata whaiora, the whānau members and the services (Cameron, 2018). Offering "Kōrero" and insight with whānau as well as the use of Te Reo Māori to enhance understanding, will maximise the care of whānau and tangata whaiora (Pitama et al., 2014).

Further to the points raised above, a culturally responsive health service would incorporate whānau as a significant part of the rehabilitation process. At the moment, the health system focuses on the individual as a decontextualised being which transgresses Māori cultural notions of health and wellbeing. For the following quote, this whānau member talks about the importance of having kids and partners as part of the care plan within and outside of the health system.

*"…I do think if a Māori influence was incorporated within the service that the kids would have been covered, because its more community focused in Māori tradition, whereas in western its individual… I mean of course we want them to focus on them (tangata whaiora) but it's very tunnel vision and they don't take into consideration that a person doesn't heal, if we weren't there with him... I have people say to me "if you weren't there with him- I'm not sure he'd be where he is today…" (Whānau 2, Māori, Partner)*

This particular narrative speaks to the importance of whānau-centred approaches within services. This quote reflects the metaphor "tiakina te pā harakeke" which describes the emphasis on parents, whānau, hapū and iwi involvement throughout the care and protection of tamariki (Pihama et al., 2014). This metaphor for whānau is better understood as Te Rito (young centre shoot) which is likened to a tamaiti (child) growing between the support of Te Awhirito (parent shoot) on either side (A. Silveira, personal communication, nd (expert weaver); Pihama et al., 2014). Additionally, the notion 'Pā harakeke', is an expression through Te Ao Māori and the metaphorical relationship to all whānau members, which is highlighted in the above quote as the partner provides healing for her tangata whaiora. This concept provides cultural representation and understanding of the essential role of whānau within Te Ao Māori. Within this quote, the whānau member describes positive impact Te Ao Māori me ōna tikanga would have had on her entire whānau if it were included in the care pathway.

In the next quote, one whānau carer participant, stated that having access to Māori cultural support/Te Ao Māori me ōna tikanga within the system was non-existent to Māori tangata whaiora and whānau members.

*"…I don't think they did, no, (have access or opportunity for Māori cultural support) they didn't really have those kinds of things in place…" (Whānau 1, Māori, Sister)*

The above quotes about a lack of Māori cultural health approaches and support reflects the dominant Western cultural paradigms, like individualism, that permeate the healthcare system (Hyslop, 2018). The individualised focus within the healthcare system has created a cultural context that marginalises Māori health approaches which can compromise the role of the whānau within the healing process. The Western medical and disease-oriented model, clashes with the holistic and preventative Māori models of health, and as result whānau and non-Māori clinicians have differing perspectives on the care-needs of tangata whaiora (Wehipeihana et al., 2020).

Within these extracts, whānau spoke to the ways they felt and experienced these cultural collisions. In their experiences, often these barriers could be resolved if aspects of Te Ao Māori me ōna tikanga were operationalised throughout all levels and aspects of the healthcare system but would demand significant work to ensure appropriate integration occurred at all levels of the healthcare system, inclusive of clinical practices and beliefs. However, requires effort by Māori practitioners, this then creates expectations that Māori staff are required to patiently educate their Pākehā and Non-Māori counterparts to facilitate change within concepts that stem from understanding Te Ao Māori me ōna tikanga (Watson, 2019). The dominant Western cultural paradigms are positioned as unsafe for whānau and Māori tangata whaiora as it maintains the assertion and authority of colonial process and structures (Te Momo, 2015).

To operationalise Te Ao Māori me ōna tikanga ensures respect and validation of Māori beliefs and values, this then strengthens the ability for whānau to connect more closely with their own healing process (Elder, 2012). The research suggests that clinical validation of Te Ao Māori me ōna tikanga would also ensure whānau and Māori tangata whaiora are actively engaging in recommendations with more certainty due to this mana enhancing process (Elder, 2012, 2017). In contracts, if the healthcare system and healthcare professionals have limited potential to support and understand the needs of whānau and Māori tangata whaiora to access concepts, values and beliefs within Te Ao Māori me ōna tikanga or invalidate this need, then it could compromise the whānau ability to completely access and express their own defined healing needs within Te Ao Māori. As a result, whānau are being pushed out of, and distanced from their own Māori cultural resources, as whānau are instead using time and energy to manage their current negative experience of the healthcare system instead of caring for their Māori tangata whaiora due to no fault of their own.

## Whakarāpopototanga – summary

This chapter presented He Piere Ratonga - service issues and challenges experienced by whānau participants when engaging with healthcare services. The notions of; *complexity and fragmentation of the health system; inflexibility of services and lack of information; and limited cultural responsiveness to Māori health within Pākehā clinical settings* were highlighted in-depth.

The first subtheme, *complexity and fragmentation of the health system* identifies the delay in treatment and poor co-ordination and communication between healthcare professionals which impeded the recovery of tangata whaiora. The second subtheme, *inflexibility of services and lack of information* identifies the Eurocentric and person-centred approach of the healthcare system that was not infusive of care for all whānau members, particularly tamariki. The third subtheme, *limited cultural responsiveness to Māori health within Pākehā clinical settings* identifies the alien culture ceased whānau members from engaging within the system, which ultimately meant they were not able to support their Māori tangata whaiora as much as they would have if Te Ao Māori me ōna tikanga were integrated.

The proposed mediating factor is for the healthcare system and healthcare professionals' ability to both acknowledge Te Ao Māori me ōna tikanga and support the whānau to engage throughout the rehabilitation pathway. Seeking to actively acknowledge and support whānau and Māori tangata whaiora with the utilisation of Te Ao Māori me ōna tikanga, as cultural resources is intended to improve the outcomes, participation and engagement for Māori tangata whaiora and whānau members.

Through the health professionals and healthcare providers *limited responsiveness to Māori* the needs of Māori in care were not being adequately met. Some services incorporated elements of Te Ao Māori, but overall, the approach was fragmented, under-resourced, and cultural practice and beliefs were not integrated within routine clinical practice, clinical environment or represented at senior management level.

The whānau described the sense that the clinical world was alien to them; having different values and a different medical language that was hard to understand. Whānau identified their experiences of being Māori within the clinical world meant they were not understood, and would have to leave their culture at the door. Whānau highlighted the importance of this understanding of who they are as Māori as central to their experience of recovery. There was a sense of an disconnect between whānau and professionals. Solutions for the reduction of these barriers included use of Te Reo Māori me ōna tikanga (Māori language and protocols) and professionals actively demonstrating respect for Māori values and needs. These understandings highlight the importance of genuine engagement by healthcare professionals and healthcare providers with Te Ao Māori, and making visible the normative, default cultural assumptions that maintain existing barriers to appropriate care.

The next chapter discusses the clinical implications and recommendations based off of this mahi rangahau.

# Upoko Tuawhitu - Chapter 7

# Kupu taunaki: Clinical implications and recommendations

This thesis has presented a piece of rangahau that has used a Kaupapa Māori approach to understand the experiences of diverse whānau navigators caring for their Māori tangata whaiora. Before this, there was little research that explored diverse whānau Māori experiences of TBI in the healthcare system, and therefore little comparative literature on the topic.

Whānau were interviewed to understand their experiences of current TBI service provisions with a particular focus on post-acute rehabilitation services. Whānau identified barriers and enablers of good quality care for their Māori tangata whaiora as well as opportunities for improving TBI health services. This chapter will explore the clinical implications and recommendations based on whānau narratives as presented below. Within my analysis of whānau narratives, three key overarching themes emerged, Ngaukinotanga – which identified the experience of trauma; injury to the whānau, separation, loss, and aggression and risk. The second theme, Kaiurungi whānau – which reflected upon whānau being healthcare navigators; navigating the healthcare system and other system challenges, whānau navigators as repositories for memories, whānau navigators as a function of healing. The final theme for this thesis included, He Piere Ratonga - which considered the experience of whānau with service issues and challenges; complexity and fragmentation of the health system, inflexibility of services and lack of information provided, and lastly, the limited responsiveness to Māori cultural health models and ways of engaging.

## Services guided by Te Ao Māori

To support and improve TBI services for whānau, it is recommended that engagement is guided by Te Ao Māori me ōna tikanga. By implementing mana enhancing process, whanaungatanga, and Mātauranga Māori to facilitate cultural connection as well as working alongside whānau will ensure the care-needs of tangata whaiora and whānau are met (Douglas, 2015; Dudley et al., 2014). As a result, whānau and Māori tangata whaiora are able to be have positive experiences within services. Therefore, assessment, formulation, and intervention is completed with engagement from whānau alongside Māori tangata whaiora that is responsive to their clinical and cultural needs (Elder, 2012, 2017).

Drawing on Te Whare Tapa Whā (Durie, 1985), Te Waka Oranga (2013) and other Māori cultural models of health and assessment, acknowledges the holistic perspective that Te Ao Māori has. For example, using all elements of Te Whare Tapa Whā ensures tamariki and whānau are recognised within rehabilitation as described by whānau narratives. Using Te Waka Oranga which identifies the expertise whānau have in navigating the healthcare system alongside clinicians toward an agreed upon plan and goal. These tools that are grounded in Mātauranga Māori ensures relationships and care between services and whānau are relational (Douglas, 2015). This consequently supports whānau to make sense of their experience through a safe and responsive environment, without feelings of loss, or isolation (Cassim et al., 2021). Furthermore, facilitating opportunities for whānau and Māori tangata whaiora to connect and reconnect with the familiarity of Te Ao Māori in services ensures they are safeguarded to heal and feel empowered within their own experience (Hokowhitu et al, 2020; Hunter, & Cook, 2020; Owen et al., 2016). Considering the importance of Ngā Matatini Māori (Durie, 1995a) and the cultural diversity of whānau and Māori tangata whaiora, this then enables individual care plans for each whānau that is specific to their current circumstances and their specific TBI journey.

Based on the whānau narratives, the transition for TBI services from individual-oriented care to whānau-centred care is recommended. Ultimately, these service providers are recommended to work alongside Māori Kaimahi and whānau carers to ensure mana enhancing process and whanaungatanga are followed from the outset. Whānau are recognised as a function of healing the collective wellbeing, as well as requiring healing themselves. Therefore, providing support to whānau will intern provide support for tangata whaiora. As described in the whānau narratives, whānau carers support their Māori tangata whaiora in the days that lay ahead. For example, before and after sessions, transitions between services, beyond service contact, and everyday routines. So, inviting their perspectives in decision making, planning and treatment ensures best practice is provided. The whānau-centred and strength based collaborative approach seeks to promote the amelioration of Māori beliefs, practices, and ways of creating meaning (Smith et al., 2016), which empowers whānau and Māori tangata whaiora to fully engage in their own pathway of care.

In this approach, Kaimahi are able to employ their clinical skills and knowledge alongside the lived experiences of whānau. With the use of active listening, reciprocal kōrero and whanaungatanga, whānau carer voices can be heard (Durie, 1997; McIntosh, 2005). The whānau-centred and strength based collaborative approach empowers whānau and their Māori tangata whaiora to express tino rangatiratanga, thus foregrounding the desired direction for the pathway of care that is congruent to their values, beliefs, and practices within their whānau Mātauranga (Eketone, 2013; Elder, 2012, 2017). Recognising and implementing the whānau-centred and strength based collaborative approach, Kaimahi will have opportunities to regularly seek and ask whānau how they are managing with care, and being able to connect them with resources and information they need. Such as self-care strategies, respite, therapy and Kaimahi to kōrero with. The practical interventions in the context of ongoing therapeutic relationship with whānau ensures emotional burden and tiredness can be alleviated if whānau are encouraged to seek respite (Knight et al., 1998). The active listening reduces the worry experienced by whānau, and the facilitation of kōrero alleviates the possible tensions that may arise in the future (Knight et al., 1998).

To safeguard sustainable engagement with whānau and therefore Māori tangata whaiora with TBI service providers, Te Ao Māori practices, beliefs and ways of creating meaning need to be embedded within each service at all levels. For example, training, policies, processes, and sector culture. Kaimahi within service providers remain agents of change and an anchor of cultural and clinical responsiveness to care and experiences for whānau. It is necessary that Te Ao Māori and Kaupapa Māori perspectives and approaches are prevalent throughout services, this then creates a competent workforce that appropriately serves the needs of Māori in Aotearoa.

# Upoko Tuawaru- Chapter 8

# Kōrero whakatepe: Future research and concluding comments

This mahi rangahau has contributed to the pool of academic literature related to TBI, whānau carers and Māori health. Many questions were presented around the constraints created by Western systems and culture that directly impact and inform the lived experiences of whānau carers, wider whānau networks and their Māori tangata whaiora. In seeking to answer how whānau experience the pathway of care, how barriers may be navigated, whānau carers discussed links between the Western systems, current contexts of practice, services providers and the whānau carer's role in continuing to supporting the recovery of their Māori tangata whaiora in the past, present and future. Similarly, this mahi rangahau has involved Kaupapa Māori approaches, and a Te Ao Māori centrality to collect narratives, histories and experience to comprise the breadth and depth of kōrero paki drawn on by whānau carers. In an attempt to encourage Kaimahi and services providers to act within the realms of kaupapa whānau and offer more adequate and appropriate care for Māori communities within Aotearoa.

Throughout this thesis, the learnings and production of knowledge has given rise to individual growth, and further development as a Kaupapa Māori researcher and Indigenous academic. Many of the principles and values drawn from Te Ao Māori have been informed through engagement with participants, supervisors, colleagues, and the literary ventures of previous generations of Māori. The bearers of Mātauranga Māori remain within hapū, iwi, and whānau Māori. Therefore, the intergenerational transmission of this Mātauranga Māori has ensured this project was able to be completed and will further enable future generations to work towards the futures we desire.

## Mahi rangahau o te apōpō: Future Research

Areas of further exploration for this mahi rangahau include, the design, creation and execution of a similar study with greater sample size. This will contribute to more breadth and depth of knowledge in this field, and the lived experiences of whānau carers, Māori tangata whaiora and service providers. Moreover, the development of online forums, pages and community groups for whānau carers would be an essential tool to ensure community support and shared resources. Alternatively, creating training programs that informs service providers and Kaimahi on the combination and utilisation of culturally and clinically responsive care. This could be implemented in research by using a collaborative approach alongside iwi, hapū and Māori organisations which can offer another dimension of depth and understanding to better support the needs of whānau and Māori communities alike. Furthermore, creating locally derived and responsive services will create environments where Māori Kaimahi are better placed to serve their communities (Te Momo, 2015; Watson, 2019).

In addition, research could focus on the experiences of whānau caring for tangata whaiora with TBI and factors that influence the care from a strength-based perspective as opposed to a deficit focus. Literature related to the deficit focus of service providers, Kaimahi and rehabilitation may perpetuate the lack of engagement amongst Māori communities.

This mahi rangahau looked at the experiences of whānau carers of Māori tangata whaiora post TBI (between 1-10 years since injury), future research could look into a longitudinal study of Māori experiences over time. This will examine how the lives of whānau and tangata whaiora have changed from each point of care. Furthermore, a particular area of interest could be around the transitions from site of injury to hospital, to rehabilitation, back home, and in some cases to residential rehabilitation services. Alternatively, research could focus on the experiences of whānau caring for tangata whaiora with TBI and factors that influence the care from a strength-based perspective as opposed to a deficit focus. Literature related to the deficit focus of service providers, Kaimahi and rehabilitation may perpetuate the lack of engagement amongst Māori communities.

### Whakarāpopototanga: summary

The aims of this project included providing space in which whānau carers are able to share their lived experience and provide insight into the challenges and reimagine solutions for their Māori tangata whaiora that better supports them and their rehabilitation pathway.

Overall, the findings from this mahi rangahau suggest that whānau carers an intertwined with the healing and collective healing of Māori tangata whaiora and are the bridge between service providers and Māori tangata whaiora. Although the data describes the need for change and that the lack of cultural inclusion, wider whānau support and the need for whānau-centred care, there is still hope for the future.

The perpetuation of current systems to TBI service provision may likely lead to continued poorer health outcomes, disengagement, and overall absence of support for whānau and Māori communities. This mahi rangahau has highlighted the importance of whānau inclusion, and recognising the differences amongst Māori whānau and the crucial role whānau play in navigating the healthcare system. By implementing policies that govern the healthcare system and Te Ao Māori me ōna tikanga, it is intended that better outcomes will ensue. These better outcomes will derive from new pathways that are inclusive of Mātauranga Māori, Te Ao Māori me ōna tikanga but also allow space for new, appropriate knowledge systems and practices to create partnership between Māori and Pākehā worldviews (Royal, 2009).

The contribution, time, effort, and themes identified throughout this mahi rangahau is encapsulated in the following whakataukī (Māori proverb) which will close this thesis.

*Mā te whiritahi, ka whakatutuki ai ngā pūmanawa ā tangata –*
*Through the weaving together of people, we realise potential*

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# Appendix

## **Appendix A** - *Participant information sheet*

| | | | |
|---|---|---|---|
| Study title: | *The Experiences of Māori with Traumatic Brain Injury and their whānau in the Waikato region with post-acute rehabilitation services* | | |
| Locality: | **Waikato** | Ethics committee ref.: | **19/NTB/53.** |
| Lead investigator: | **Dr Tai Kake** | Contact phone number: | **027-227-1941** |

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He aha te mea nui o te ao, he tangata, he tangata, he tangata
*What is the most important thing in the world? It is people, it is people, it is people.*

Kia ora. Nau mai, Haere mai. You are invited to take part in a research project on the experiences of Māori with Traumatic Brain Injury and their whānau in the Waikato region. We are interested to hear from you and your whānau about your experience of the health services you received for your brain injury. How were these services for you? and for your whānau and whether your experiences were good or bad, and how you think they could be improved, particularly for Māori.

Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the research at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the research, what your participation would involve, what the benefits and risks to you might be, and what would happen after the research ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this research. Before you decide you may want to talk about the research with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this research, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep. We will request your permission to audio-record the interview we have with you but you can still participate if you do not want to be recorded.

This document is 7 pages long, including the Consent Form. Please make sure you have read and understood all the pages. Haere mai.

### What is the purpose of the study?

Tēnā koe, kia ora. The purpose or kaupapa of this research is to explore and understand the experiences of Māori with Traumatic Brain Injury in the Waikato region and their whānau of the health services they received for this injury.

Our main goal is to use this research to improve health services in the Waikato for Māori with traumatic brain injury. We will provide a report on the research to the Waikato DHB and ACC so they can use it to improve the services.

This research is the first step in developing a larger project that is looking at how Māori experienced these services when they had a traumatic brain injury. The research is being funded by the University of Auckland.

The research is led by Dr Tai Kake (Auckland University), a Māori researcher based at the Waikato Hospital Clinical Campus of Auckland University. If you decide to participate, you can choose to be interviewed alone or you could be part of a group discussion with other people who have had a traumatic brain injury. It’s your choice and completely voluntary.

If you choose to participate you will be interviewed by a Māori researcher. Her name is Maia Silveira. Her contact number is: 021-160-0497. You can choose to be interviewed in English or Māori. The interview or group discussion could take about an hour or two hours but it depends on what you are comfortable with. We will ask you questions about your experience of the health services you received when you had a traumatic brain injury. We are particularly interested in the rehabilitation services you received, but please feel free to tell us about your whole journey and experiences.

This research project has received ethics approval from the Health and Disability Ethics Committee at the Ministry of Health. The reference number for the research is: 19/NTB/53.. Contact details for the ethics committee are:

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

### What will my participation in the study involve?

You have been chosen to participate in this study because you are Māori, live in the Waikato region, and have a whānau member who had a traumatic brain injury in the past 5 years. If you agree to participate we will then contact you to organize a time and place that is suitable for you to talk or kōrero with you. You can choose to be interviewed alone or as a part of a group of other whānau who also have a family member with a brain injury. We will provide an information sheet about the research and request that you sign a written consent form before taking part in the research.

If you agree to participate, we will offer you karakia before starting the interview process. We expect that the interview and kōrero will take about an hour but this will depend on the kōrero and what you are comfortable with.

The interview can take place at a venue that you prefer or at the Waikato Hospital clinical campus, Pembroke Street, Hamilton. For the group discussion, the venue will be at Waikato Hospital clinical campus. We will request some standard information such as for example, age, employment status, whether you are single or partnered and have children.

The discussion or kōrero will be mainly about your experience with the health services your whānau member had for their brain injury and how you found these services from your viewpoint. All this information will be treated with confidentiality and to safeguard your privacy we will keep your name and contact details separate from the information and experiences you share with us. We will request your permission to audio-record the interview we have with you but you can still participate if you do not want to be recorded.

### What are the possible benefits and risks of this study?

The results from this research will contribute to a larger project that could be used to improve the quality and accessibility of services for Māori with traumatic brain injury.  This is why we are really interested to hear how you think these services could be improved, and any difficulties or problems you may have experienced.

There are minimal risks for your participation in this research and this will have no impact on the services you currently receive. All your comments and kōrero will be confidential, and will not be provided to anyone without your consent and written agreement.

### Who pays for the study?

The cost of this research is being paid for by the University of Auckland. We will offer you a $40 voucher to thank you for your participation in this research project. We will also offer you kai, tea/coffee and a biscuit.

### What if something goes wrong?

This research project only requests that you engage in a face-to-face meeting with the researcher for a discussion or kōrero about your experiences with services for traumatic brain injury. It is very unlikely that you would be injured during this process.

In the unlikely event you were injured in this study, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at work or at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery.

### What are my rights?

Your participation in this research is voluntary and you can withdraw from it when you choose to.  If you choose to withdraw, this will have no impact on your access to health care and any treatment you are receiving. All your information will be treated confidentially and your privacy will be respected. You have the right to access the information that has been collected about you if you request this.

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

We expect that the research will be completed by May 2020. We will provide you a written summary of the main findings from the study in plain English or in Te Reo if requested. We will also provide an oral presentation of the main findings and the opportunity for to answer your questions and kōrero. We will advise you of the date and venue for this presentation.

All information collected during this research will be stored in a manner that safeguards your privacy and confidentiality. This information will be stored for a period of ten years. This time period is required by the New Zealand Health Information Privacy Code 1994.

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

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

*Dr Tai Kake, Lecturer Auckland University (Waikato Hospital Clinical Campus)*
*Telephone number: 027-227-1941*
*Email: t.kake@auckland.ac.nz*

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

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

For Māori health support please contact :

Te Puna Oranga Māori Health Service, Waikato DHB
(07) 8343628 or Research (research@waikatodhb.health.nz)

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

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

## **Appendix B** - *Participant consent form*

Consent Form for participation in research on:

*The Experiences of Māori with Traumatic Brain Injury and their whānau in the Waikato region with post-acute rehabilitation services*

*An interviewer is available if you wish to kōrero Māori*

**Please tick to indicate you consent to the following**

| | | |
|---|---|---|
| I have read, or have had read to me in my first language, and I understand the Participant Information Sheet. | | |
| I have been given sufficient time to consider whether or not to participate in this study. | | |
| I have had the opportunity to use a legal representative, whānau/ family support or a friend to help me ask questions and understand the study. | | |
| I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet. | | |
| I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care. | | |
| I consent to the research staff collecting and processing my information, including information about my health. | | |
| I consent to an individual interview | Yes ☐ | No ☐ |
| I consent to my individual interview being audio-recorded | Yes ☐ | No ☐ |
| I consent to participating in a focus group interview or hui and I understand that this will be audio-recorded. | Yes ☐ | No ☐ |

| | | |
|---|---|---|
| If I decide to withdraw from the study, I understand that I may withdraw all the information I have provided up to the point in time that I have withdrawn. | | |
| I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study. My name and contact details will be stored separately from the information I provide during the interview. Any information I provide will be stored in a locked cabinet in a lockable room. Only members of the research team will have access to this information: Dr Tai Kake, Prof Matthew Parsons, Maia Silveira, Prof Paul Rouse, Dr Cameron Walker, and Sean Mathieson. | | |
| I understand the compensation provisions in case of injury during the study. | | |
| I know who to contact if I have any questions about the study in general. | | |
| I understand my responsibilities as a study participant. | | |
| I wish to receive a summary of the results from the study. | Yes ☐ | No ☐ |

## Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature: Date:

## Declaration by member of research team:

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

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

| | |
|---|---|
| Researcher’s name: | |
| Signature: | Date: |

## **Appendix C** - *Participant Masters consent form*

| | | | |
|---|---|---|---|
| Study title: | *The Experiences of Māori with Traumatic Brain Injury and their whānau in the Waikato region with post-acute rehabilitation services* | | |
| Locality: | **Waikato** | Ethics committee ref. | **19/NTB/53** |
| Lead investigator: | **Dr Tai Kake** | Contact phone number: | **027-227-1941** |

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He aha te mea nui o te ao, he tangata, he tangata, he tangata
*What is the most important thing in the world? It is people, it is people, it is people*.

Kia ora. Nau mai, Haere mai. Thank you for agreeing to participate in this research as a whānau of a person with traumatic brain injury. We really appreciate the time you have taken to share your experiences. We are now seeking your consent for the information you shared to be part of a Masters thesis project by Maia Silveira to be done at Waikato University. Your involvement in this project is completely voluntary and will not affect your access to health services.

All your information will be made anonymous to protect and safeguard your confidential information. The focus of Maia's thesis will be on the experiences of Māori whānau of people with traumatic brain injury. The thesis will be supervised by Dr Mohi Rua at Waikato University and Dr Tai Kake at Auckland University.

If you agree to take part in this research, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both this Information Sheet and the Consent Form to keep.

This research project has received ethics approval from the Health and Disability Ethics Committee at the Ministry of Health. The reference number for the research is: 19/NTB/53
Contact details for the ethics committee are:
Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

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

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

*Dr Tai Kake, Lecturer Auckland University (Waikato Hospital Clinical Campus)*
*Telephone number: 027-227-1941*
*Email: t.kake@auckland.ac.nz*

*Dr Mohi Rua, Māori Psychology Research Unit, Waikato University*
*Telephone number: 07-856 2889, Extn 9213*
*Email: mohi.rua@waikato.ac.nz*

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

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

For Māori health support please contact :

Te Puna Oranga Māori Health Service, Waikato DHB
(07) 8343628 or Research (research@waikatodhb.health.nz)

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

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

## Consent Form for participation in research on:

### *The Experiences of Māori with Traumatic Brain Injury and their whānau in the Waikato region with post-acute rehabilitation services*

*An interviewer is available if you wish to kōrero Māori*

Please tick to indicate you consent to the following

| | | |
|---|---|---|
| I agree for my interview information to be used for a Masters Thesis by Maia Silveira at Waikato University | Yes ☐ | No ☐ |
| I have been given sufficient time to consider whether or not to agree to this use of my information | | |
| I understand that I can decline to have my data used as part of the Masters Thesis without withdrawing from the Research Project | Yes ☐ | No ☐ |
| I understand that I may withdraw my consent for the use of my data in the Masters Thesis by September 1st 2020 without this affecting my involvement in the Research Project | Yes ☐ | No ☐ |
| I have had the opportunity to use a legal representative, whānau/ family support or a friend to help me ask questions and understand the study. | | |
| I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet. | | |
| I understand that my data will be transferred from Auckland University to Waikato University. This data will not include my name or contact details and so my privacy will be protected. The data will be transferred in a password protected file using a secure transfer system. | Yes ☐ | No ☐ |
| I understand that the Masters Thesis will be publicly available for an indefinite period, however my personal information will not be shared with the public | Yes ☐ | No ☐ |

| | | |
|---|---|---|
| I know who to contact if I have any questions about the study in general. | | |
| I wish to receive a summary of the results from the Masters Thesis. | Yes ☐ | No ☐ |

## Declaration by participant:

I hereby consent for my information to be used as part of a Masters thesis by Maia Silveira at Waikato University.

Participant’s name:

Signature: Date:

## Declaration by member of research team:

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

I believe that the participant understands the Masters research project and has given informed consent to participate.

Researcher’s name:

Signature: Date:

## **Appendix D** - *Interview schedule*

*The Experiences of Māori with Traumatic Brain Injury and their whānau in the Waikato*

Participant code:

| | | | |
|---|---|---|---|

**Please record participant name in Study Key chart**

### Focus Group Interview Guide: Whānau Participant

Location:

Interviewer:

Date:

Start time:

End time:

Ethnicity:

Which ethnic group do you belong to?
*Mark the space or spaces which apply to you.*

- ○ New Zealand European
- ○ Māori
- ○ Samoan
- ○ Cook Island Maori
- ○ Tongan
- ○ Niuean
- ○ Chinese
- ○ Indian
- ○ other such as *DUTCH, JAPANESE, TOKELAUAN.* Please state:

Iwi:

DOB:

Gender identity:

Relationship status:

Employed/Unemployed:

Te Reo or English hui:

## Introductions/Mihimihi

- Kia ora tātou (or Tēnā tātou)….my name is…..and I will be the facilitator today for this group kōrero about whānau experiences of services for brain injury in the Waikato. I want to thank you all for coming today.
- Establish whether the participant/s would like to start with a karakia and whether they would like to kōrero in English or Te Reo Māori
- Offer Karakia
- Whakawhanaungatanga, provide the opportunity for each participant to introduce themselves. Lay out name cards and explain that you are doing this to help us remember each other's names
- Information sheet-kōrero, explain the discussion topic and process, seek to address any questions, reassure
- Please ask the participant how they found the information sheet: record any feedback
- Consent form: complete signing and dating
- Confirm contact details
- Present guidelines for the group discussion:

1. We are interested to hear from everyone
2. There are no right or wrong answers, only different points of view
3. We're tape recording the hui because it can be hard to keep up with writing down everyone's kōrero. The recording and notes are confidential and we will not use your names in any of our research reports.
4. Can we please try to have one person speaking at a time
5. We're on a first name basis
6. You don't need to agree with others, but you must listen respectfully as others share their views
7. We ask that your turn off your phones
8. My role as facilitator will be to guide the discussion

**NB. The prompts below are just suggestions or reminders for the interviewer, and do not necessarily have to be used as written, and the sequence can also be changed as you**

**deem appropriate. Please offer breaks, reassurance, and support to the participant/s if they appear tired or distressed or struggle to recall events, or they request a break. Offer tea and coffee/biscuits/water when appropriate. Refer participants to toilets and describe building evacuation procedures.**

### Question Prompt 1 (please modify as appropriate):

Kia ora koutou. You have been chosen for this group kōrero because you all have a whānau member who suffered a traumatic brain injury when they were living in the Waikato region and because you are Māori. I want to acknowledge this is a challenging topic to discuss and if at any point you need a break or some support please signal to me and I will help you. The hui will probably go for one to two hours but this will depend on the kōrero and what you as group would like to talk about. Please feel free to ask me any questions you might have throughout this hui. Does anyone have any questions?

So I thought I would start us off by asking “How was it for you as whānau in supporting your loved one when they had a brain injury?”

### Question Prompt 2 (please modify as appropriate):

Would someone like to tell the group about your experience of the services your whānau member received when they had a brain injury? (Try to get a sense of the timeline of events from the injury and the services used. The services can include those present at the site where the participant was first treated e.g ambulance, to the emergency department, to in-patient, discharge from hospital through to rehabilitation and the community, GP.)

### Question Prompt 3 (please modify as appropriate):

**Consider using the prompt below if the participant does not discuss their experience of rehabilitation as a whānau member in Auckland**

Did you have to travel to Auckland to support your whānau member for any treatment/rehabilitation? (If yes) Can you please describe your experience of this? What was it like for you? For your family/whānau?

### Question Prompt 4 (please modify as appropriate):

Are there any particular things about the services and treatment your whānau member received that you feel could be improved? Or changed? Are there any cultural considerations that you feel should be taken into account? Were there positive things about the services and treatment your whānau member received that you would like to talk about? What do you think is the most important thing to change?

### Question Prompt 5 (please modify as appropriate):

Is there anything else you as a group would like to talk about regarding your experiences with the services and treatment your whānau member had their brain injury? Anything you feel we have not covered?

Is there anything about the process today that you feel we could have done better? Do you have suggestions how we could improve the process?

## Ending interview/Kua mutu

Kia ora tātou. Thank you again for sharing your experiences with the group and me. We really appreciate this and acknowledge that recalling these experiences can be challenging. Your comments will be included in a report that we will present to ACC and the Waikato DHB in the hope that it may lead to some changes in the services for people with Traumatic Brain Injury in the Waikato. I want to again reassure you that your names will not be used in any of our reports and the information you have provided us will be treated confidentially.

Would you like to end with a karakia?