

The experience of living with bowel cancer for Māori in Taranaki

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ABSTRACT

The title of this study is: *The experience of living with bowel cancer for Māori in Taranaki*. Research methods for this study have been adapted from research approaches collectively known as Kaupapa Māori. The study is also informed by Gadamerian hermeneutic interpretive methodology which unpacks the nature of how we understand and interpret. However, the lens through which understanding is expressed, is from a Māori worldview.

Ten Māori patients, diagnosed with bowel cancer were interviewed and their narratives analysed using Gadamerian hermeneutic methodology. The concepts of whakapapa, mauri and tapu were fundamental to the analysis process. Whakapapa in the context of this study examined the stories substance or origin about participant experiences and initial signs that not all was right with their health. The concept of mauri shed light on ways of experiencing bowel cancer that came to reveal how participant stories fell into one of three perspectives: mauri moe; mauri oho and mauri ora. Signs archetypal of mauri moe were evident where participant behaviours remained grounded in responses framed within the notion of mamae and its negative elements of neglect, hurt, pain, anguish, and sorrow. Mauri oho revealed distinct changes in behavioural patterns that signified an upsurge in motivation by participants who were committed to overcome their dilemma and be well again. Mauri ora signified actions that revealed successful outcomes when participants became highly motivated, felt good about their health and were committed to keeping good health. The concept of tapu was utilised to examine the underlying principal issues that determined participant existence in the present.

The findings showed that participants had no understanding of bowel cancer before they were diagnosed. Some participants experienced shame and embarrassment at the prospect of having to live the rest of their lives with a stoma. Recognition of tapu through the proper exercise of mana was an important factor in participant recovery. Violation of tapu through the wrongful exercise of mana also manifested as having negative effects on participant recovery. Based on the findings from this study the following recommendations for further research are proposed: a Kaupapa Māori action research study in conjunction with introducing the inflatable colon to the community working with a group of stakeholders to

educate Māori about bowel cancer and; a Kaupapa Māori action research study with a group of stakeholders to devise a treatment pathway that integrates the concepts of whakapapa, mauri and tapu when assessing Māori who present to healthcare providers with a suspected prognosis of bowel cancer.

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ATTESTATION OF AUTHORSHIP

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

Signed.....

Dated.....

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This study was approved by the Auckland University of Technology Ethics Committee (AUTEC) (ref no: 13/86 May 2013).

DEDICATION

To the participants and their whānau who gave of their time for this study so that
our tamariki, our mokopuna and future generations may enjoy the fullness of life
– in Mauri Ora

.

PROLOGUE

HE MIHI

*Ko Kurahaupo te waka
Ko Taranaki te maunga
Ko Taranaki te iwi
Ko Nga Mahanga a Tairi te hapū
Ko Puniho te marae
Ko Matanehunehu te awa
Ko David Te Raroa taku matua
Ko Poroaki Tahuaroa taku whaea
Ko Tom Ruakere taku ingoa*

*Kurahaupo is my canoe
Taranaki is my mountain
Taranaki is my iwi
Nga Mahanga a Tairi is my hapū
Puniho is my marae
Matanehunehu is my river
David Te Raroa is my father
Poroaki Tahuaroa is my mother
Tom Ruakere is my name*

MY STORY

I was raised under the korowai of Maunga Taranaki on rich fertile land in the small settlement of Warea and reflect here on the formative years of my upbringing including my years as a child while living for a time at Parihaka Pā and as a teenager at Warea. I discuss aspects of life on being raised on a dairy farm and attending a mainstream school at the small farming community of Okato. The story of Parihaka, since 1881, has grown in significance nationally and internationally. The legacies left by significant players on the political front in the late 19th century cannot be ignored. Because of its historical significance, I mention the infamous sacking of Parihaka Pā in 1881 by Government armed forces, led by the then incumbent Minister of Native Affairs, Captain John Bryce. I also mention the prophets of Parihaka, Te Whiti o Rongomai and Tohu Kākahi¹, both inspirational leaders of their people, and their subsequent imprisonment. I provide some background on the effects of colonial intervention on the people of Taranaki and the conceivable effects that those actions had on the health and wellbeing of Māori in the Taranaki region. I posit the belief that the loss of land had a significant effect on the mana on the Māori people of Taranaki, an outcome predicted by Te Whiti o Rongomai in 1881. Finally, this prologue is not only about knowing me as a person, it is also about knowing my whānau, my hapū, my iwi – and indeed, all the people who whakapapa to the iwi of Taranaki. When one understands the story of Parihaka we come to realise the effects that colonisation has had on the Māori people of Taranaki.

Timeless wisdom for the ages – Te Raukura

For the people of Taranaki Te Raukura² has special significance as it is the emblem that is unique to the people who have whakapapa links to Parihaka Pā in South Taranaki (Figure 1, p. xvi). Oral accounts tell us that the genesis of Te Raukura transpired when an albatross settled on the forecourt of Te Whiti's wharenuī, Te Raukura. As it took flight on its homeward journey, it shed a single feather. The feather was interpreted by Te Whiti and the people as a sign of peace, a legacy now perpetually engraved in the minds of the people.

¹ The Prophets of Parihaka

² The feathers of peace



Figure 1: Te Raukura – the three-feathered emblem

Retrieved 1 September 2016 from: <https://www.google.co.nz/search?q=parihaka+marae&biw>.

Devout followers of the prophets can be readily recognised by the white feathers often adorned in the hair as a plume of three white feathers. Te Raukura represents spiritual, physical, and communal harmony and unity, a symbol of the pacifist movement instigated by the prophets of Parihaka. It is a symbol of faith, hope, and compassion for all of mankind and the environment that we live in. The emblem encompasses the biblical reference of Luke 2:14 in the following passage:

*He whakororia ki te Atua i runga rawa
He maungarongo ki runga i te mata o te whenua
He whakaaro pai ki te tangata*

*Glory to God in the highest and on earth
Peace
Goodwill toward men. (Luke 2:14)*

My experiences as a very young boy living at Parihaka are encapsulated by memories of Te Whiti's whareniui, Te Raukura (Figures 2 and 3, pp. xvii-xviii). The forecourt was our place of playful battle where all the young boys sparred with bamboo sticks. Sadly, in 1960 Te Raukura was destroyed by fire along with the loss of life and many priceless artefacts.



Figure 2: Parihaka Pa in the early 19th century

Retrieved 1 September 2016 from: <https://www.google.co.nz/search?q=parihaka+marae&biw>.

In modern times the feathered emblem symbolises peaceful co-existence between Māori and Pākehā and reminds us all, of the passive resistance movement against land confiscation by the colonial Government of the time. It was Te Whiti's way of preserving the tapu and mana of the people who had been systematically stripped of their land and wealth. Both prophets find presence, both nationally and internationally, as their mana retains its' significance beyond the boundaries of Aotearoa/New Zealand through acknowledgement as the founders of passive resistance on a world stage.



Figure 3: Te Whiti o Rongomai's resting place

Parihaka Pā today. Te Whiti's final resting place only metres from the remains of Te Raukura (Te Whiti's House) which was destroyed by fire in 1960. Many priceless artefacts and memories were destroyed. The foundations of Te Raukura are in the background; and the forecourt (far left) was the place where we as youngsters fought our boy battles. It was not until years later that I realised the significance of that wharenui and the subsequent loss to the people of Parihaka.

Source: Private photo album collection

Suppression of historicity- what we were not taught at school

During the first days of the New Zealand wars on 29 March 1860 the British warship Niger stood off the coast of Taranaki, 25 miles south of New Plymouth, and hurled shells and rockets at the Māori mission station at Warea. The bombardment continued for two days and nights. A combined military and naval force was then sent overland from New Plymouth to complete the destruction and mop up any remaining resistance by the peaceful people of Warea, a community committed to the philosophies of Te Whiti o Rongomai and Tohu Kākahi of Parihaka. The force consisted of 1000 soldiers, marines and volunteers, along with supporting munitions including howitzers and field guns. That invasion was the precursor to a significant event in New Zealand's history – the unprovoked invasion of the peaceful settlement of Parihaka. It was an invasion deliberately planned and implemented by the New Zealand government under the leadership of the then Minister of Native Affairs, Captain John Bryce. I recall these events of the past as significant markers in our history that have had a major impact on

me personally. This has been a part of our history that has been suppressed for over 100 years but once revealed has found its way into the hearts and minds of many Māori and Pākehā alike. Slowly but surely the skeletons in the closet reveal themselves as we learn the facts of historicity and the place that Māori occupy throughout the continuum of that historicity. The revealing of such events and the ongoing impact of the resultant loss of Taranaki lands through confiscation has been a major factor on the wellbeing of Māori in Taranaki. Taranaki Māori have suffered immensely as a result of confiscation and one of the most significant effects is the appalling state of Māori health (Leung-Wai & Sanderson, 2010).

The legacy of inspirational leaders

Both Te Whiti O Rongomai and Tohu Kākahi were men of wisdom. They possessed great mana and were highly esteemed by the people. They made their mark in Taranaki because they would not yield to Western influences and fought for Māori rights to defend the whenua, the heart and soul of the Māori people. Their legacy remains to this day not only in New Zealand/Aotearoa but on a world stage.

A legacy with a difference

The invasion of Parihaka by constabulary forces left a permanent imprint on the minds of Taranaki Māori and is firmly embedded in the annals of New Zealand/Aotearoa history. The invasion was unjustified, unnecessary, and fabricated within the bowels of the parliamentary corridors led by Captain John Bryce. Unlike the prophets, Bryce's legacy was one of barbaric treatment of the people and the eventual confiscation of virtually all Māori land in Taranaki. In an editorial published by the New Zealand Herald on 13th November 2013 titled *150 years of great New Zealanders*, the editor noted that Captain Bryce's deeds would have him as a leading recipient for the New Zealander of the year 1881. On reflection, the New Zealand Herald³ takes a retrospective viewpoint by displacing Bryce in favour of Te Whiti o Rongomai and Tohu Kākahi as outstanding examples of Māori leaders who chose to negotiate a path through a difficult, dangerous and changing world. Today they are remembered as outstanding exemplars of moral and physical courage. For holding their nerve and remaining

³ New Zealand Herald 150 Years Special Edition November 2013

true to their convictions, under extreme provocation, they were the New Zealand Herald's choice for New Zealander of the year, 1881.

Growing up on the land

Perhaps a significant aspect of my formative years, being brought up on the farm in Warea, was the influence my mother had on members of my whānau. She was both a writer and a poet and possessed this seemingly insatiable hunger to learn more about Parihaka, the appalling events that led to the sacking of Parihaka and the arrest of its spiritual leaders. She was well known for her ability to write in both te reo Māori and English. On the home scene, she was better known as the phantom author of many school essays presumably written in collaboration with and for certain budding scholars within our whānau. The teachers at our college were on occasions bewildered by the sudden rise in standard of written essays submitted for marking. One of the poems composed by my mother was written to express her feelings and sadness about the sacking of Parihaka Pā in 1881. She was an avid follower of their philosophy of pacifism which history reminds us, concurs with the same philosophical teachings espoused by Mahatma Ghandi of India (1869–1948). I witnessed her on many occasions writing countless letters to the Editor of the Taranaki Daily News venting her anger and frustration of misreporting of events and, even worse, misinterpreting the philosophical wisdom of Te Whiti's and Tohu's words. For her the intent of the prophets' wisdom and those of the invading forces of Bryce in 1881 gives us all an insight to the paradoxical reality that existed in those times between Te Whiti and the Minister of Native Affairs Captain John Bryce. Te Whiti was determined to hold on to the land. Bryce was just as determined to take it away, by whatever means. Perhaps a poem she penned in the early 1960s, while I was still a student at high school, gives us all food for thought as we attempt to interpret the message she intended.

THE MOUNTAIN SAW IT ALL

Go and ask the mountain, he saw it all
 He saw their rise, he saw their fall
 Her saw the soldiers, one thousand strong
 Marching, marching, marching

He saw their bayonets gleaming in the sun
 He saw the marching feet rise and fall
 He heard the commander
 “Members of the company halt, attention
 Where is the enemy that we have come to slay?”

Only children, skipping – there to block their way
 Skipping, skipping, skipping as though they were at play
 While the women chanted, and sang all throughout the day
 Behind, the men sat in mute repose
 Arms folded – not a word

He saw Bryces’ army eager for the fray
 A sword flashed, a child’s scream fills the air
 Amongst the thicket, amongst the thorns
 A child’s cry - a new-born
 He saw the soldiers thwarted of their prey
 Slowly turn themselves about and slowly march away.

Poroaki Tahuaroa (My mother’s maiden and signature name)

There is no doubt that my mother’s influence and support throughout my high school years had a huge influence on my affinity to find a niche in the helping professions. Perhaps the most appropriate way of acknowledging her contribution to our upbringing is to work hard at being the best that we can be. Her efforts have benefitted us all and is now evident in many of her mokopuna as they strive to uphold her legacy by the way they conduct their lives in the present. My part in upholding the mana of my mother is to pursue a course of action that upholds those beliefs that benefit us as a family. That course of action, in my case, is to piece together a single part of the puzzle, along with others’ contributions, that will enhance the health and wellbeing of our people and especially the health and wellbeing of Māori throughout nga rohe o nga iwi katoa

o Taranaki⁴. That is, after all, what Te Whiti fought for when he so vehemently opposed the confiscation of the land. He knew only too well that without the whenua Māori would lose everything.

An awakening – the revelations of historicity

What has been truly extraordinary however, was the fact that we were not taught about the atrocities that took place in the very community in which our whānau and hapū have occupied for generations. Clearly, the colonial policy of Western indoctrination was firmly established and implemented. I have a direct whakapapa link to the people who were driven from their land at Warea, some of whom were driven to occupy the hinterlands⁵ at the foot of Maunga Taranaki and the bitterly cold winters of Otakau⁶. A number of our tūpuna died there through the hardship of having to survive the cold conditions and later, to the ravages of European introduced diseases, including the devastating flu epidemic at the turn of the 20th century (Lange, 1999).

The process of colonisation and past government policies of confiscation, assimilation, and integration resulted in major disruption to Māori cultural beliefs and tikanga.⁷ The effect of such policies has impacted immensely on the social, political, and economic status of Māori. Many Māori, therefore, attribute the loss of land to diminished tapu, impaired mana and the eventual onset of poor health.

Being disconnected - an outcome fabricated through acculturation

There is no doubt that the loss Māori customs has had a significant impact on the demise of te reo Māori in Taranaki. Māori values and concepts are foundational to Te Ao Māori and the loss of those values has contributed to a dearth of fluent speakers of te reo today. My own experience throughout my schooling years is testament to that. Speaking te reo Māori was forbidden in the primary school I attended. I have, throughout my school years, witnessed Māori students being punished for breaking that rule. Notable among those experiences were the occasions where I had to remain at school after hours, writing lines. The first line

⁴ Throughout all the tribes of Taranaki

⁵ Foothills and slopes of Maunga Taranaki

⁶ Otago

⁷ Custom

“I will not speak Māori at school” was always written by the teacher. Such punitive action was mediocre compared to others I had witnessed including boys being physically beaten by teachers – all because they rebelled and continued to break a rule that was cast in concrete. Attending school was something that all Māori students of my time spurned. If the truth be known, it would be fair to say that we spent more days absent from school because in those early days it was simply an institution that we all despised.

The snowballing effects of the loss of land meant not only the physical dislocation from the land but also, and significantly, the spiritual alienation of Māori to the whenua. Over time the impacts have exacted a great toll on Māori including traditional food gathering practices where traditional foods such as kai moana and greens such as pūhā and poroporo have been replaced by fast food outlets. There is little wonder then that there has been a significant rise in the chronic conditions associated with poor Māori health. The confiscation of Māori lands has struck at the very core of Māori spirituality, custom,⁸ and wellbeing. The position Māori currently occupy has been brought about by the effects of successive Government policies that have impacted immensely on the social, political and economic status of Māori.

As a young person, I was taught the fundamentals as a gatherer of food through traditional practices including the gathering of tuna⁹ and piharau¹⁰. Piharau was sourced mainly from Te Waiweranui, the main river which runs through the settlement of Warea. It is the area in which I was raised as a farmer’s son and is the area to which I have, over the years, aspired to return. The attack on, and destruction of Warea has distinct relevance for me personally – the small community of Warea was the stomping grounds of my boyhood years.

For a period prior to that I lived at Parihaka Pā. My memories of that experience are crystal clear over 60 years later. The most significant memory I have had of Te Raukura, Te Whiti’s house was analogous to that of a museum. Te Raukura was the home of priceless artefacts. The most memorable recollections for me were the rows of taiaha and other artefacts neatly arranged on the walls of Te Raukura. The great pity however, is written in the annals of history – Te Raukura

⁸ Tikanga

⁹ Eel

¹⁰ Lamprae

was destroyed by fire in 1960. Irreplaceable artefacts once revered by people, including visitors from abroad, were destroyed in the fire. The loss of Te Whiti's whare Te Raukura, was tragic and only served to further disenchant whānau who lived in and around the Pā. The people left Parihaka in droves to seek greener pastures elsewhere. The tsunami that Te Whiti had predicted had taken hold and the tide of change for the worse for Taranaki Māori was gaining momentum. The new reality set Māori on a disastrous slide to poverty, degradation, and humiliation. The invasion of Parihaka in 1881 and the experience that followed, I believe, has been a major contributor to the current state regarding health and wellbeing of Māori in the Taranaki region.

Loss of land, loss of tapu, loss of mana, loss of health

The process of colonisation and past government policies of confiscation, assimilation, and integration resulted in major disruption to Māori cultural beliefs and tikanga.¹¹ The effect of past Government policies has impacted immensely on the social, political, and economic status of Māori. Some academics attribute the loss of land to the onset of poor health for Māori. According to Riseborough (2002):

It was an axiom of the time that only by assimilating to the European culture could Māori survive, so destruction of the old way of life was held to be in Māori's own interests. The race was widely believed to be in a state of moral, spiritual and psychological collapse following defeat in war and the people were therefore thought to be ready and willing to accept European solutions to Māori problems when the people of Parihaka appeared to thrive in isolation from the European world ...the very laws of nature were perceived to be under attack. The only acceptable explanation for their behaviour was that they were suffering a mental epidemic. (pp. 219-220)

European solutions to Māori problems

The Business Economic Research Limited (i) Report (2010) showed that two-thirds of Māori who whakapapa to the Taranaki region live outside the Taranaki region. The report showed that across nearly all social and economic indicators, Māori are worse off than non-Māori in Taranaki and Māori tend to make up a

¹¹ Custom

significantly higher proportion of the population in the lower decile areas. Consequently, overcrowding has contributed to poorer health outcomes. Māori life expectancy is lower than for non-Māori. Māori males can be expected to live to 69, 8.3 years less than non-Māori. Māori females can expect to live to 73, which is 8.7 years less than non-Māori females. Māori infant mortality is at 10.1 deaths per 1,000 live births compared to 4.8 deaths per 1,000 live births for non-Māori. The Taranaki District Health Board spent \$9.9 million on Māori specific health services in 2008/2009. While this is a significant increase on the \$7.7 million spent on Māori specific health services in the previous year, expenditure on Māori specific health services is equivalent to 3.4 percent of the operational expenditure. That percentage was considered low when aligned to the targeted delivery approach and the health and socio-economic disparities discussed in the BERL report (Leung-Wai & Sanderson, 2010).

Locating self as researcher

Taranaki consists of eight tribes (iwi): Taranaki; Ngāti Ruanui; Ngā Rauru; Ngāti Tama; Te Atiawa; Ngā Ruahine; Ngāti Maru; and; Ngāti Mutunga. My roots are firmly established within the confines of Taranaki iwi which extends from Opunake in the south to Onukutaipari in the North. The small coastal community of Warea lies within the boundaries of Taranaki iwi - the whenua on which I was raised. While the previous narrative provides some understanding as to the reasoning behind my personal interest in research that focuses on Māori health, it has been necessary to inculcate an understanding of the contextual environment in which I was raised and the position I now find myself in. I was brought up in a coastal community of Warea on a small dairy farm (Figure 4, p.xxvi).



Figure 4: The family farm 1955

Source: Private collection

The land was our bread and butter and from my experience a source of sustenance for those people who lived in and around the marae¹². We, at least, had a few acres of land to grow crops and milk a few cows. The marae was the centre of wider social interaction between whānau within our hapū¹³ and was the central institution where we all went at times of tangi¹⁴ and major hui¹⁵ when important decisions needed to be made (Figure 5, p. xxvii). It was also the spiritual hub for our whānau as we had over the years become assimilated into Catholicism. The Catholic Mass was celebrated weekly at the marae and family members who practiced Catholicism also became influential political figureheads within our community.

¹² The hub of Maori societal upbringing

¹³ Sub-tribe

¹⁴ Funeral

¹⁵ Gathering



Figure 5: Puniho Pā

After my early experiences living at Parihaka, Puniho marae was the marae where I spent most of my boyhood and teenage years. Maunga Taranaki in the background appears as the backdrop to the marae. Puniho marae is situated approximately six kilometres north of Parihaka Pā on Taranaki's surfing highway 45.

Source: Private collection

I attended a mainstream school where management and teaching policies were mono-culturally structured. There was a vast chasm between the school environment and the community in which I was raised. The process of acculturation¹⁶ had found its mark in our community and in many of the educational institutions. We had inherited a firm grasp of the values and concepts that are Māori but the process of acculturation had pervaded our community leaving a dearth of fluent speakers of te reo Māori.

A shift from a rural to an urban environment meant a move away from the basic cultural principles and values of being Māori. Throughout the ensuing 10 years I experienced life as an urbanised teenager and for a period I became a student at university. A return to dairy farming in the 1979 signalled the beginning of a new

¹⁶ To be immersed in another culture

phase in my life, a life that recaptures the essence of what it is to be Māori and what it means to be back working the whenua. This was to have a significant effect on the person I would become.

Locating self in relation to others

A return to the community in which I was raised meant pursuing a pathway centred in the helping professions. Assisting other Māori families through sport led to success at community level. A step up as a statutory social worker in the community brought awareness of disparate engagement practices in social services. Taking on new challenges meant taking on challenges to reduce inequalities in health in Māori communities. The first step to meeting that goal was to complete a two-year Diploma in Social Work at the Auckland College of Education. I can still see the then Minister of Social Welfare, The Hon Jenny Shipley speaking to us and dishing out a stern warning that there would no place for practicing statutory social workers who were not qualified. It was a stance that I was fully in agreement with and it was the catalyst for my decision to travel to Auckland to get such a qualification. Studying for and graduating with a Diploma in Social Work in 1995 was the first step of my journey. In 2005, I completed the Post Graduate Diploma in Public Health at Massey University and in 2010, I graduated with a Master of Health Sciences Degree at Auckland University. I have continued this journey that has enabled me to acquire the necessary knowledge where I now teach others in the field of healthcare practice. The academic part of my journey will end at the completion of this thesis. Of greater significance however, is the need to convey the findings of this study to the Māori people of Taranaki who have withstood the challenges of confiscation through Government policies of the 19th century (Dow, 1999). The findings of this study will, therefore, be presented initially to the people who have made this study possible – the participants and their families. Proliferation beyond that will become the responsibility of health and educational providers. Over the last 22 years I have learnt how to express and communicate my knowledge in the practice of social work. I am cognisant of my own position and prejudice as Māori and this research project will be orientated toward understanding the stories that elucidate a clear message of what it means for Māori whānau who have been afflicted with bowel cancer.

In conclusion, this story is not just about me. It is also about the realities and experiences of my parents, my grandparents and all those before them. Conceivably, my story may well be the same story that lies hidden in the memories of other families in Taranaki. All 10 participants in this study are connected through whakapapa to Taranaki iwi. All 10 participants have a powerful connection to the events that took place at Parihaka in 1881. Their tupuna were part of the events of 1881. This story is about them as well. With that in mind I am hopeful that my story will serve as a foundation to understanding the ensuing chapters of this thesis and the reason why I have chosen to do a study on the experiences of Māori whānau who have been afflicted with bowel cancer.

CHAPTER ONE: CONTEXT OF THE STUDY

1.1 Introduction

This study is about *the experience of living with bowel cancer for Māori in Taranaki*. As the prologue has indicated, Taranaki is my maunga, Taranaki is my iwi, Ngā Mahangā a Tairi is my hapū. My concern begins with my people. This chapter provides a background to the study including the reason why, in the first place, a study on bowel cancer was proposed for Māori. A comprehensive background of the approach to healthcare in Aotearoa/New Zealand is highlighted through legislation in the form of the New Zealand Health and Disability Act, and Government policy including the updated New Zealand Health Strategy and He Korowai Oranga, the refreshed Māori Health Strategy launched in 2015. I contend that the dilemma that bowel cancer poses to the nation, and indeed Taranaki Māori, is serious. A transformative approach is factored into the feasibility of creating improved awareness of bowel cancer in Taranaki. Māori demographics, the status of Māori health, and bowel cancer management for Māori in Taranaki is also discussed. Throughout this thesis I refer to numerous words and terms in te reo Māori. In keeping with the context of this study a glossary of Māori words and their meanings is included in appendix A.

1.2 The Approach of the Study

This study sought to enable participants to tell their story about living through the experience of bowel cancer, in a manner congruent with Kaupapa Māori. The writing of Atkinson (2001) influenced my thinking:

Stories illustrate the three-fold complexity of every life story. First is the stories substance or origin, which relates to the “who am I” question? Second is the stories construct, which answers the “How am I” question and third is the story’s meaning, which answers the “Why am I” question. (p. 133)

I contextualised the “who am I, how am I, why am I” questions to concur with the concepts of whakapapa, mauri, and tapu.

Who am I? (The realm of whakapapa)

The realm of whakapapa, assumes the genealogical position of participant’s existence in the world as Māori. Whakapapa in the context of this study is also

about the stories' substance or origin about the participants' experiences and initial signs that not all was right with their health, the anxiety of not knowing, and the trauma of a diagnosis that has the potential to threaten one's very existence. Knowing the person thus provides a platform to one's existence in terms of mauri, in 'the now'.

How am I? (The realm of mauri)

Mauri holds a central place in informing Māori, how and why our lives take the form they do. It imbues Māori thinking, knowledge, culture and language. We are born into this world in mauri ora. We grow up in a world where the dynamic interchange of mauri dictates how we are feeling. At times, we face critical moments in our growing up in this world. A judicious moment can lead to gratitude, a vulnerable moment to despair. We become a product of those moments created by the choices we make in life. We exist in tapu and the choices we make can determine the way we interact with the rest of the world.

Why am I? (The realm of tapu)

Tate (2010) stated that every person has his or her own intrinsic tapu. How we conduct our lives can impact the sanctity of one's intrinsic tapu. The sanctity of our intrinsic tapu throughout life can be diminished, enhanced, and/or restored. I assert that the dynamic movement of the tapu of a person can impact on the mauri of a person, that is, to impact the life principle or vital spark¹⁷ of a person.

The stories within this thesis and the analysis that follows goes wider and beyond the bowel cancer itself. The notions of whakapapa, mauri, and tapu, as described, above guide thinking and analysis. The approach of this thesis is Kaupapa Māori. Further, insights drawn from the writing of Gadamer (1960) inform the hermeneutic manner in which my interpretations were made. Nevertheless, my lens was Kaupapa Māori.

What is Cancer?

Cancer is a chronic condition that has been in existence throughout history. Evidence of cancer can be found among fossilized bone tumours that date back millions of years, in mummified remains of humans discovered in ancient

¹⁷ Mauri as defined by Best (1934)

Egyptian burial sites, and writings encrypted from ancient manuscripts (American Cancer Society, 2012). The Greek physician, Hippocrates (460–370 BC) is regarded to be the founder of the concept and meaning of cancer in which he ascribed the formation of ulcer forming tumours as carcinoma. Greek physicians likened carcinoma to the tentacles of a crab – presumably because the spread of cancer was observed to affect other organs of the body in crab like fashion. Celsus, a Roman physician, later ascribed the Latin definition as cancer which remains to this day. Internationally, cancer has become one of the most common causes of mortality. A worldwide review on incidence, mortality, and prevalence of cancer provides an indication of the enormous burden of cancer worldwide (Parkin, Bray, Ferlay, & Pisani, 2005):

The most commonly diagnosed cancer was lung (1.35 million), breast (1.15 million), and colorectal (1 million); the most common cause of cancer deaths is lung cancer (1.18 million deaths), stomach cancer (700,000 deaths), and liver cancer (598,000 deaths). The most prevalent cancer in the world is breast cancer (4.4 million survivors up to 5 years following diagnosis). (p. 74)

The review by Parkin et al (2005) provides interesting data on global statistics for age standardised incidence rates of colorectal cancer. The combined standardised incidence rate of bowel cancer for males in New Zealand and Australia, is 48.2/100,000, which puts New Zealand among the highest incidental rates of colorectal cancer worldwide. North America follows closely with a standardised incidence rate of 44.4/100,000. There appears to be a rise in bowel cancer mortality rates among Māori over the last two decades, this despite data on the prevalence of bowel cancer among Māori being only half that of European New Zealanders (Dickson, Cunningham, & Parry, 2010).

Understanding Bowel Cancer

Bowel cancer is also referred to as colorectal cancer. Cancer tumours of the colon is referred to as colon cancer and a cancer tumour that develops in the rectum is called rectal cancer. Colorectal cancer occurs when some of the cells that line the colon or the rectum become abnormal and propagate out of control. The abnormal growing cells create a tumour to form the cancer.

Why a Study on Bowel Cancer?

A significant motivating factor for me to do a study on bowel cancer was the experience I had as the Māori coordinator on the '*Bowel screening programme*' at the Waitemata District Health Board (WDHB). My experience over a 14-month period was one of witnessing many Māori turning their backs on the programme. A significant barrier to participation in the programme for Māori was the immuno faecal occult blood (iFOBT) test¹⁸. That process is challenging from a cultural perspective and does nothing to instil confidence for Māori who are ambivalent to take the test in the first place. Other significant factors were Māori transience and poor literacy about chronic ailments that many Māori experience (Ministry of Health, 2010). A significant factor for me was that Māori have very little conceptual understanding of what bowel cancer is and that early detection of the disease can prevent a painful existence. As the Māori coordinator for bowel cancer in the community I was privy to many conversations with eligible participants. The overriding factor that shocked me most was the number of young Māori men who had been diagnosed with Dukes 4¹⁹ bowel cancer. It was the trigger that gave me reason to find out more about this terrible disease and in doing so forge new ways and means to combat what I can only describe as another chronic disease poised to threaten the health and wellbeing of Māori.

My involvement on the Bowel Screening Project at WDHB provided a significant step up in my own awareness about bowel cancer. The realisation that I was of the age where bowel cancer was most prevalent proved to be the catalyst for me to find out more about why our people were so resistant to taking the test and, even worse, to talk about it. The point I make here is that I wanted to talk about it because I wanted to know more about it. Prior to my involvement on the screening project I was, in effect, among the masses who did not care about what a bowel was let alone know about the intricate and finer details of what caused bowel cancer.

A comprehensive review of the literature convinced me that a study on Māori whānau was necessary. Many of the issues that surfaced in the literature had

¹⁸ A test to analyse whether there are traces of blood in samples of human faeces

¹⁹ The stage where the only options are invasive surgery and/or therapy including chemotherapy and radiotherapy

relevance to Māori whānau and the idea of doing a study on Māori whānau gained momentum. It soon became evident that the study would need to be done among my own people in Taranaki. Gaining the consent and approval of the people was essential and that meant taking the study back to Taranaki to gain the approval of the people. The study was presented to Te Kaunihera O Te Atiawa Nui Tonu²⁰ on 23 April 2013 where it received unconditional support including support from health professionals from the Taranaki District Health Board and Tui Ora Primary Health Organisation.

More recently, my work on a pilot project at Auckland District Health Board (ADHB) provided further impetus to proceed and complete a study on bowel cancer. Under the auspices of Government's '*Faster treatment for cancer*' programme the project that was funded by the Ministry of Health was instigated to reduce numbers of DNA²¹ for patients who were deemed as 'high suspicion of cancer – not yet diagnosed'. Māori DNA rates are extremely high across the board in all departments and Māori referred to ADHB for 'First Specialist Assessments²²' is abysmal. Some of the Māori patients I worked with had been admitted to hospital with suspected complications associated with the bowel, which ultimately led to a diagnosis of bowel cancer. These people were familiar with the other cancers we speak of daily, but they had no knowledge of bowel cancer.

Dame Tariana Turia's assertion that there needs to be a clear focus on developing strengths within whānau to facilitate change from within is highly relevant to this study (Ministry of Social Development, 2010). Taking the kino,²³ that is, the causal factors associated with bowel cancer to the people is, in my view, a much more effective way of conveying that message. One of the prime reasons for this study is to learn from the stories of Māori who have experienced bowel cancer in their lives to increase awareness of bowel cancer amongst Māori.

²⁰ Kaumatua group

²¹ Do not attend

²² Auckland District Health Board Oncology, 2015

²³ Root causes

1.3 Background

Researching Māori Health – The Reason Why

The New Zealand Health and Disability Act (Ministry of Health, 2016b) established the foundation for a clear pathway for health strategy in Aotearoa/New Zealand. The updated New Zealand Health Strategy (Ministry of Health, 2016a) refreshed the previous strategy developed in 2000. It was developed with the help of sector leaders, independent reports, extensive public consultation, and was informed by other Government programmes and initiatives. The Strategy has two parts:

- New Zealand Health Strategy: Future directions;
- New Zealand Health Strategy: Roadmap of actions 2016.

He Korowai Oranga, the Māori Health Strategy, provides the foundation for Maori health policy (Ministry of Health, 2015).

Māori experience poorer health outcomes compared to the non-Māori population and are, therefore, the priority group for this study. Consequently, He Korowai Oranga, which was updated in 2015, sets the overarching framework to guide the Government and the Health and Disability sector to achieve the best health outcomes for Māori. Key threads, directions, and pathways provide the foundation in which the synergy of Pae ora²⁴, Wai ora²⁵, and Mauri ora²⁶ culminate in the overall aim – Whanau ora²⁷. He Korowai Oranga thus becomes the window through which the health system recognises and addresses the principles of the Treaty of Waitangi.

As a health professional, I have an interest in Māori health research because it is known that the health system is failing Māori. Dow (1999) reminds us how past Government policies have impacted immensely on the social, political, and economic status of Māori (Dow, 1999). Historical accounts by Māori and non-Māori theorists and academics attribute the loss of land to the loss of mana and the eventual onset of poor health (Buchanan, 2009; Scott, 1975). Although successive Governments have acknowledged the existence of health inequities

²⁴ Healthy futures

²⁵ Healthy environments

²⁶ Healthy individuals

²⁷ Healthy families

in society, they have been reluctant to address the socio-economic determinants of health including access and use of health services and how those services are delivered. Hopefully, the updated Health Strategy launched this year (2016) will significantly improve the socio-economic determinants of health that impact upon Māori. The socio economic survey carried out by Business Economic Research Limited (BERL) in Taranaki paints a picture of disparate outcomes for Māori across all sectors of socio-economic position (Leung-Wai & Sanderson, 2010). The report, commissioned by the Taranaki District Health Board on the Socio-economic and Health Profile in Taranaki Māori revealed that:

While the economic profile suggests that Māori have significant assets and can be a key contributor to economic development in the region, this socio-economic profile suggests that there is a wide gap between Māori and non-Māori across a range of social and health indicators... Māori health status is poor. Similarly, Māori have poor outcomes across most socio-economic indicators. Direct spend on Māori health and participation by Māori in the provision on health is also low. (p. 2)

The socio-economic analysis in the BERL report highlights the stark inequities across a range of indicators that are reflected in the health outcomes where Māori have greater health issues. The report sends a clear signal that action is required to break this cycle of poor health and growing dependence on the health system.

Most Māori receive treatment in mainstream services where there is an overwhelming approach to biomedical intervention. The Whānau Ora initiative (Ministry of Social Development, 2010) is a key cross-government work programme jointly implemented by the Ministry of Health, Te Puni Kōkiri, and the Ministry of Social Development. It is an approach that places families/whānau at the centre of service delivery that requires the integration of health, education, and social services in the quest to improve outcomes for New Zealand families/whānau. The programme, which came into being in 2015, is about the recognition of Kaupapa Māori practices and how such practices should be incorporated into wider health care systems. I contend that many health professionals have little understanding of the Kaupapa Māori process and this has implications for future health care initiatives for Māori.

It appears that a significant contributing factor to the burden of chronic conditions for Māori has been urbanisation of Māori. For Māori, traditional food gathering

practices including gardening, hunting, and a reliance on kai moana²⁸ have been replaced by fast food outlets of convenience. Ferguson et al. (1995) studied the differences in intake of specific food plants by Polynesians and concluded that food intake may explain their lower incidence of colorectal cancer compared with Europeans in New Zealand. I contend that changes in traditional lifestyle influenced by colonial intervention has, over the years, been a major contributing factor in the gradual worsening in health status for Māori. Robson et al. (2010) in *Unequal impact II: Maori and non-Maori cancer statistics by deprivation and rural urban status*, shows that among the most destructive chronic diseases to afflict Māori is cancer.

Disparities in health for Māori remain a testament to Government's failure to address the prevalence of poor health that Māori experience. Came (2014) studied issues around the systematic existence of health inequalities between Māori and non-Māori. Her paper suggested that institutional racism had permeated public health policy making in New Zealand. She contends such racism is a contributor to health inequalities alongside colonisation and uneven access to health services. Rumball-Smith et al (2013) studied ethnic disparities in the quality of hospital care in New Zealand. Harris et al (2012) studied the pervasive effects of racism in New Zealand's healthcare system. In the context of this thesis however, discussion pertaining to anti-racism and decolonisation sits outside the parameters of this study. This study is focused on understanding the meaning of what it was to live with bowel cancer for Māori in Taranaki, of which racism did not overtly feature for participants.

We are reminded of the position that Māori occupy in Taranaki where the research for this study was conducted. The snowballing effects of the loss of land meant not only the physical dislocation from the land but also, and significantly, the spiritual alienation of Māori from the whenua²⁹. There is a plethora of historical evidence that supports the above analysis. Riseborough's book '*Days of darkness*', (2002) based on her PhD thesis on the Government and Parihaka: 1878 – 1884, provides a candid and revealing account of what Taranaki Māori could expect in the years beyond 1884 (Riseborough, 2002).

²⁸ Seafood

²⁹ Land

Māori Population – Taranaki

The BERL report showed that 15,798 Māori usually live in the Taranaki region. Its Māori population ranks 10th in size out of the 16 regions in New Zealand which equates to 2.8% of New Zealand's Māori population (Leung-Wai & Sanderson, 2010).

Demographics of Taranaki Iwi

There are eight tribes (iwi) in Taranaki. The following Table 1 (p. 10) shows the number of Māori residing in each iwi in 2009.

Māori Health Status in Taranaki

The socio-economic analysis in the BERL report (Leung-Wai & Sanderson, 2010) provides a clear signal that assertive action is required if we are to break this cycle of poor Māori health and growing dependence on the health system. Although statistics for bowel cancer are not provided, evidence from the BERL report paints a dismal picture for Māori health when we examine the prevalence of other major chronic diseases in Taranaki. The report makes specific reference to: cardiovascular disease; ischemic heart disease; cancer; diabetes; obesity; and asthma. The signs and symptoms of bowel cancer, screening tests, staging and treatments are overviewed in Appendix C. However, the focus of this thesis is to move beyond the medicalised view to ask of the experience itself. What is it like, to worry about disturbing changes in one's bowel habits, to find out one has bowel cancer, to go through the treatment and then to live with the ongoingness of this disease? These questions are considered through the cultural notions of what it means to be Māori.

Table 1: Taranaki iwi and currently resident Māori

Iwi	Currently resident in Taranaki
Te Atiawa	2,721 out of a total of 12,852
Taranaki	1,473 out of a total of 5,352
Ngati Ruanui	1,614 out of a total of 7,035
Nga Rauru	726 out of a total of 4047
Nga Ruahine	1,449 out of a total of 3,726
Ngati Mutunga	516 out of a total of 2,094
Ngati Tama	306 out of a total of 1,167
Ngati Maru	192 out of a total of 735

Source: Business and Economic Research (BERL) 2009

Bowel Cancer Management for Māori in Taranaki

Currently, there is no community management programme on bowel cancer education in Taranaki. Current intervention is limited to doctor/patient collaboration. Given time limits for appointments (usually 15 minutes) little is achieved in terms of addressing awareness and education issues pertaining to bowel cancer. This can have serious ongoing effects, particularly in instances where the disease has been missed or mistaken for something else resulting in serious implications for tumour propagation.

1.4 Summary

This chapter has presented the reason why a study on bowel cancer was proposed for Māori in Taranaki. Legislation in the form of the New Zealand Health & Disability Act, Government policy, and Whānau Ora were highlighted as the drivers of healthcare in Aotearoa/New Zealand. Cancer is a dilemma to the nation, particularly the prevalence of bowel cancer. Māori demographics, the status of Māori health, and bowel cancer management for Māori in Taranaki shows the urgency of addressing this issue. Finally, I provide an overview of the thesis, the roadmap. In chapter two I discuss the theoretical foundations of Te Ao Māori that underpin this study.

1.5 Overview of the thesis

In **Chapter One** I introduce the purpose and content of the thesis and provide a comprehensive background to the study including the reason why this study was proposed in the first place.

Chapter Two is divided into two sections. In section one a comprehensive description of the philosophical and theoretical foundations of Te Ao Māori are drawn from traditional myths and legends. In section two a series of Māori values and concepts are provided to articulate the various principles of living that constitute Te Ao Māori.

Chapter Three relates to subject literature of a current nature on bowel cancer and examines what other researchers have said about bowel cancer.

Chapter Four focuses on the Methodology of the study. It begins with an overview of the hermeneutic approach informed by Gadamer. Then the foundations of Te Ao Māori are presented as an interwoven collection of Māori concepts and systems that constitute Māori knowledge and Māori practices. In keeping with a Kaupapa Māori approach, research methods for this work have been adapted from current research approaches collectively known as Kaupapa Māori.

Chapter Five focuses on the story of doing the research. These methods call upon the philosophical aspirations expressed by other Kaupapa Māori researchers and academics which recognises the epistemological and ontological realities that are embedded in Kaupapa Māori. The interpretive process of hermeneutics further informs the method.

In **Chapter Six** I examine and interpret the stories of participants who displayed the archetypal signs of mauri moe framed within the notion of mamae and its negative elements of hurt, pain, anguish, and sorrow.

In **Chapter Seven** I analyse stories of participants experiences of moving beyond the behaviours that mirror inhibitors to progress, grounded in responses framed within the notion of hurt, pain, anguish, and sorrow. Mauri oho is considered a proactive state which alerts us to a definite shift in a person's behavioural patterns

that denote actions and expressions of activity, an awakening, a new beginning, a rebirth.

Chapter Eight denotes experiences of participants who were enabled to transition from behaviours archetypical of all states of being of mauri including mauri moe, mauri oho, and mauri ora. The culmination in mauri ora signals increased activity and awareness that comes from a high level of energy in which there is purpose for being.

Chapter Nine discusses both values and concepts that accentuate the prime focus of this thesis, to bring into focus the experiences of Māori participants who have experienced bowel cancer in their lives.

CHAPTER TWO: THEORETICAL FOUNDATIONS OF TE AO MĀORI

2.1 Introduction

In this chapter I discuss aspects of Te Ao Māori that form the foundation to the succeeding chapters to this thesis. In the first section of this chapter I outline a comprehensive description of the philosophical and theoretical foundations of Te Ao Māori, as drawn from traditional myths and legends. In doing so, I highlight important aspects within Māoridom that will appear in the writings of this thesis that constitute the cultural perspectives about what it is to be Māori. In the latter section, I present important Māori values and concepts to articulate the various principles of living that constitute Te Ao Māori.

2.2 Kaupapa Māori Theory

For this study to be congruent with participants who identify as Māori it is important that I lay a foundation of the theoretical notions that underpin the study. I turn now to those notions and begin with the genesis of Kaupapa Māori theory, Māori cosmology.

Māori Cosmology

Shirres (1997) suggested that traditionally Māori believed that the whole of creation is a dynamic movement – *I te kore, ki te po ki te ao Mārama* – out of the nothingness, into the night, into the world of light” (M. Shirres, 1997). According to Buck (1949) the theories concerning natural phenomena fall into two categories, the first being a popular version which was given to the public by expert genealogists and priests. The second, more select version, was said to have been held by an inner circle of priests who considered it too sacred to divulge to the common people. The cosmological narratives that underpin Māori theory involves teachings from two separate schools of thought. The first version constitutes the practical application of knowledge and consists of applying proper names to the phenomena of nature and arranging those phenomena into an ordered sequence likened to a genealogical table of human descent (Buck, 1949).

In this ontological framework, the first stage of the inception of the universe involved the nothingness or *Te Kore*. The second stage was a period of darkness,

Te Po. Buck (1949) postulated that some iwi had differing versions of how Māori portrayed *Te Kore* and *Te Po*. Such portrayal was, in his view, meaningful according to their interpretations. Each stage outlines the cosmological ages preceding the birth of the gods (Buck, 1949).

The second perception, the obscure version claims that 'Io' who possessed super-natural powers brought the existing world in its present form out of chaos and caused the gods to appear. Walker (1992) postulated that the periods *Te Kore*, *Te Po*, and *Te Ao Mārama* represent three different periods in which the universe developed. *Te Kore* and *Te Po* were periods that were succeeded by *Te Ao Mārama*, the world of light in which humans exist. In the creation stories the Sky Father Ranginui manifested as the male element and partner to Mother Earth Papatūānuku representing the female element. The evolvment of Ranginui and Papatūānuku purportedly took place during the period of *Te Po*. During that period Ranginui clothed Papatūānuku by covering her body with plants and vegetation. The manifestation of insects and reptiles appeared on the land and shellfish were established in the waters. This led to the union of Papatūānuku and Ranginui and the birth of their progeny. The myth brings forth an account where Ranginui clings to Papatūānuku, an act that left their children in a world of darkness (R. Walker, 1992). Remaining in a world of darkness became the source of conjecture among the brothers and after a period of consultation the brothers decided to do something about the union of their parents. The mythological account of events tells how the brothers decided to separate their parents thus allowing light into their world. Tawhirimātea³⁰ refused to be part of their plan and was excluded. Tāne-mahuta devised a strategy on how they would achieve their goal. His gladiatorial act of thrusting Papatūānuku and Ranginui apart by placing his hands on Papatūānuku and his feet against Ranginui severed the union of his parents. According to Buck (1949) the children of Ranginui and Papatūānuku took on specific roles within Māori mythology in the form of malignant spirits or gods. Each was given a specific area within the realms of creation:

- Tāne-mahuta, god of the forests and of all beings that lived and cohabitated within the domain of forests;

³⁰ God of the wind

- Tūmatauenga – the god of warfare;
- Rongomatāne, the god of cultivated food and peace;
- Tangaroa, the god of the ocean and all its creatures;
- Haumietiketike, the god of uncultivated foods and;
- Tāwhirimātea, god of the winds (pp 457-459).

An acceptance of the model prescribed by the Ranginui - Papatūānuku view of the universe has evolved to the extent that humans over time have aligned themselves with different spiritual powers. In Shirres (1997) view, it is from the spiritual powers that humans receive their worth, with intrinsic tapu from which power and mana can be ascribed (M. Shirres, 1997). Shirres assertion coincides with other modern-day theorists, among them Pa Henare Tate³¹, who agrees with the suggestion that humans receive their worth, with intrinsic tapu, from which power and mana can be ascribed. The personification of these gods or Atua is a distinctive aspect of the Māori worldview. Walker (1992) suggested that the relevance of Māori myth and tradition can be firmly applied to modern day contexts when dealing with issues that pertain to Māori:

Māori mythology and traditions provide myth-messages to which the Māori people can and will respond today. The stories of Māori myths are set in the remote past associated with the mythical homeland of Hawaiiki. They deal with the origins of the gods from the primeval pair Ranginui and Papatūānuku, the creation of the world and the origins of man and his institutions. (p. 170)

Buck's account (Buck, 1949) of the esoteric mythologies surrounding Tāne-mahuta's³² journey into the 12th heaven in search of nga kete tuatoru³³ and his search for the female principal introduces us to another aspect of Kaupapa Māori theory. Tāne-mahuta's journey saw him gain access to "nga kete wānanga"³⁴. His quest for knowledge sought to provide hauora³⁵ for all. The three baskets Tāne-mahuta sought were:

1. The *kete uruuru matua*, of peace, goodness and love;

³¹ Towards Some Foundations of a Systematic Maori Theology – PhD Thesis, 2010

³² God of the Forests

³³ The three baskets of knowledge

³⁴ Te kete uruuru matua [peace, goodness and love]; te kete uruuru rangi [prayers, incantations and ritual]; te kete uruuru tawhito [war, agriculture, woodwork, stonework, and earthwork]

³⁵ Wellbeing

2. The *kete uruuru rangi*, of prayers, incantations and ritual;
3. The *kete uruuru tau* (or tawhito), of war, agriculture, woodwork, stonework, and earthwork. (p 449)

His pursuit for the uha³⁶, carried out on behalf of his brothers, exemplifies the Māori philosophical approach of the desire to benefit all (Buck, 1949). Collective requirements and benefits are therefore the recurring motives for Tāne-mahuta's search. The notions of collective need, the requirement for a consultation process, collective accountability, and collective benefits are grounded in Māori attitudes to knowledge. This is evident in relation to the accessibility of knowledge and in the sanctioning, preserving and protection of knowledge for the wellbeing of the whānau and iwi. Makereti (1986) alluded to Māori philosophical thinking in the following expression:

The Māori did not think of himself, or do anything for his own gain. He thought only of his people, and was absorbed in his whānau, just as the whānau was absorbed in the hapū, and the hapū in the iwi. (p. 38)

2.3 Notions of Ontology, Epistemology, Axiology

Existing in the Māori world is significantly connected to the social reality that Māori have with the living and the non-living. The focus of the discussion among Māori is, therefore, premised with many relations and many connections. The creation mythologies within Māori folklore signify the connections with the living and non-living, with land, with the earth and with other beings.

Chilisa (2012) admirably captured the philosophical underpinnings of indigenous ways of knowing and doing when she defined the ontological, epistemological, and axiological notions when conducting research:

- Ontology is the body of knowledge that deals with the essential characteristics of what it means to exist;
- Epistemology enquires into the nature of knowledge and truth. It asks the following questions: What are the sources of knowledge? what can one know? how does one know if something is true?

³⁶ The female principle necessary for the creation of humankind

- Axiology refers to the analysis of values to understand better their meanings, characteristics, their origins, their purpose, their acceptance as true knowledge, and their influence on people's daily experiences. (p 21)

According to Chilisa (2012) indigenous knowledge plays an important role in the articulation of indigenous research methodologies. She asserts that indigenous knowledge's role in framing postcolonial indigenous methodologies can be summarised as follows:

1. Indigenous knowledge is embodied in the languages, legends, folktales, stories, and cultural experiences of the formerly colonised and historically oppressed;
2. Post-colonial indigenous knowledge systems can enable the researcher to use new topics, themes, processes, categories of analysis, and modes of reporting and dissemination of information not easily obtainable through conventional research methods;
3. Post-colonial indigenous knowledge's enable researchers to unveil knowledge that was previously ignored, enabling the researcher to close the knowledge gap that resulted from imperialism, colonization, and the subjugation of indigenous knowledge's;
4. Researchers can draw from indigenous knowledge systems to theorize about methods and research processes from the perspective of the cultures and values of the colonized 'Other' and those historically marginalized;
5. Indigenous knowledge-driven research methodologies can enable reclamation of cultural or traditional heritage, a decolonization of the captive and colonized mind and thought, protection against further colonization, exploitation and appropriation of indigenous knowledge, and a validation of indigenous practices and worldviews;
6. The colonized 'Other' can become the source of solutions to the challenges they face;
7. Indigenous knowledge-driven research methodologies can enable research to be carried out in respectful, ethical ways, which are useful and beneficial to the people;

8. The methodologies open space for collaboration between researchers and the researched as well as community participation during all stages of the research process (pp 99-101).

The ontological, epistemological, and axiological notions that Chilisa has defined in respect to indigenous peoples are important concepts that underpin this study. There is more to Kaupapa Māori than our history under colonialism or our desires for self-determination. I concur with the points that Chilisa raises – we have a different epistemological tradition, one that frames the way we see the world, the way we organise ourselves in it, the questions we ask, and the solutions that we seek.

2.4 Māori Narratives

The narrative or story that underpins Te Ao Māori is an essential component of knowledge building and manifestations of values into practices. In Māori philosophy, the malignant spiritual beings or gods are sources of knowledge and act as intermediaries to humankind. The heroic stories of Maui passed down through the generations give momentous accounts of Maui's heroism in his quest to overcome adversity. In one encounter, he deceived his mother by seeking the identity of his father against his mother's wishes. Finding his father validated his standing in the world. Although such philosophical notions are viewed as ancient they still exist in modern day thinking and practices for Māori (R. Walker, 1992).

Traditionalists who disagree with Christianity adhere to the supreme being, Io, and the malignant Gods including Tāne-mahuta, Tangaroa, Tūmataunga and Tāwhirimātea. The Christian belief accepts that Atua is the source of all creation (Tate, 2010). I personally interpret the malignant Gods in terms of the myth messages. A modern-day interpretation of a myth message in respect to Tangaroa for example would stress the importance of respecting the oceans and all the creatures that exist therein. Under the lore of tapu there can be controls and restrictions concerning safety. A violation of restrictions such as going to sea alone and ill prepared can culminate in a calamity.

The values practiced within my own rohe are based very much on the philosophy and teachings of Te Whiti o Rongomai and Tohu Kākahi of Parihaka, both highly influential prophets of the late 19th and early 20th centuries. Both prophets were

at the height of their powers when they were arrested and imprisoned by the New Zealand Government. The template for pacifism worldwide was seeded in the flourishing settlement of Parihaka under the leadership of both prophets in response to the illegal confiscation of Māori land. It goes without saying that the teachings of Te Whiti and Tohu have given the people of Taranaki identity through being in touch with reality linked to a philosophy of pacifism. They sought to protect the tapu³⁷ and mana³⁸ of the people and of the whenua³⁹. Their philosophy remains steadfast to this day. Their deeds reverberate throughout the length and breadth of Taranaki.

For Taranaki tradition, the karoua⁴⁰ are regarded as the repositories of all knowledge. It is a responsibility that comes with great mana and those empowered with such knowledge do not part with it readily. Protected knowledge given out randomly soon becomes common knowledge and once commonality has become the norm the source of original mana can be greatly diminished. Protected knowledge imparted unwisely could be abused and used inappropriately. A contemporary interpretation of abuse of such knowledge would be the deliberate formulation of policies and political action that are counterproductive to Māori advancement. The 99 years West Coast leases of prime Taranaki land drawn up over 150 years ago had a clause inserted which gave the incumbent farmers the right of renewal at the same peppercorn rental rates⁴¹ after the 99 year leases expired. All the lessor had to do was renew the lease. Although the lease rates have been amended in recent years Māori who seek land ownership are still required to buy back lease land to which they are the rightful owners, at current valuation prices.

The story of Maui in his quest to raise the North Island⁴² from the ocean and the slowing of the sun for the benefit of all humankind has consistent links to contemporary Christian beliefs about life and death. In his quest for immortality from Hinenuitepō, the goddess of the underworld, Maui, upon being discovered, was crushed between the thighs of Hinenuitepō. Maui's demise through death is

³⁷ Sanctity

³⁸ Authority

³⁹ Land

⁴⁰ Elders

⁴¹ 2 shillings an acre

⁴² Te ika a maui

thus linked to the eventual outcome of mortality for all humankind (R. Walker, 1992). The mythological template for Māori customs and their manifestation in how Māori lived their lives is a tradition that dates back, to pre-migration times. A belief in the supreme being, that is, 'Io' and the lesser malignant Gods, was a fact of life and foundational to what was real in the world for Māori. The passing on of tribal traditions was part of the social and educational template taught in whare wānanga⁴³. Knowledge regarding whānau and hapū links were the domain of the tohunga who was not only entrusted with such knowledge but who also ensured that such knowledge remained sacrosanct; thereby preserving the tapu of tribal whakapapa.

2.5 Māori Consciousness – The Māori Mind

Marsden (1992) suggested that the retelling of Māori history by describing events that occurred, and the heroes and villains associated with those pieces of history, is only one aspect of the Māori cultural set. He was deeply concerned with the lack of exploration of the inner consciousness of the Māori mind undertaken by Māori scholars. In his view, only an approach that describes the main features of the consciousness of Māori is acceptable. It offers a way of looking at what is regarded as real in the world for Māori (Marsden, 1992). Positivistic approaches built on abstract rational thought and empirical methods cannot grasp the true meaning of what it is to exist. What is necessary in Marsden and Henare's (1992) view, is a meaningful subjective approach that comes from within (M. Marsden & Henare, 1992). What Marsden and Henare attempted to demonstrate is that people must intimately understand more about themselves instead of taking for granted their Māoriness. People must, therefore, possess a sense of consciousness about what it is to be or to exist.

Sir Apirana Ngata presented the importance of maintaining a commitment to cultural enlightenment as a constant theme through his efforts to revive Māori interest in traditions in song and dance and above all, in the growth of Māori consciousness and self-confidence. For one to understand Māori consciousness one must draw upon and look further into the cultural basis for Māori. That course of action is reflected through Māori concepts such as tapu, mana, and mauri as a

⁴³ School of learning

way of delving further into the minds and hearts of people who adhere to and practice the principles of Te Ao Māori.

A response to Marsden's assertions on the concept of being and Māori consciousness has, in recent times, been the focus of two prominent Māori academics; namely, Tate (2010) and Pohatu (2011). Tate's PhD thesis, *Towards, some foundations of a systematic Māori theology* examines in great depth the inner being of Māori consciousness through the concepts of tapu and mana. Pohatu (2011) proposed that mauri be utilised as a window to rethinking human wellbeing. He asserted that mauri holds a central place in informing Māori, how and why our lives take the form they do. Pohatu proclaimed that mauri imbues Māori thinking, knowledge, culture and language with a unique cultural heartbeat and rhythm. Both Tate and Pohatu proposed approaches that are closely interlinked. I contend that 'tapu as being' or to 'exist', as postulated by Tate (2010), can significantly impact the behavioural patterns of the state of being of mauri proposed by Pohatu (2011). Māori philosophy did not exist independent to or disconnected from the various events and context in which Māori existed. Māori concepts form the basis of Māori tikanga, customs, worldview, and sense of being.

Te Reo Māori

The very essence of what is Māori and the activities that characterise being Māori are ultimately connected to the Māori language. It is the vehicle through which the essence of the Māori worldview is expressed. Language is integrated with culture and the two dimensions together serve as a foundation from which one might experience Te Ao Māori.

Whakapapa

Sir Apirana Ngata defined the literal meaning of whakapapa as the process of laying one thing upon another. The concept is not unique to Māori; however, what is unique is the way in which whakapapa is used to organise Māori society and the expression of identity. It is an expression of a person's whānau, his/her hapū and his/her iwi. The following example of my own links to whānau, hapū, iwi, and whenua is an illustration in point:

<i>Ko Kurahaupo te waka</i>	<i>Kurahaupo is my canoe</i>
<i>Ko Taranaki te maunga</i>	<i>Taranaki is my mountain</i>
<i>Ko Taranaki te lwi</i>	<i>Taranaki is my lwi</i>
<i>Ko nga Mahanga a Tairi te hapū</i>	<i>nga Mahanga a Tairi is my hapū</i>
<i>Ko Puniho te marae</i>	<i>Puniho is my marae</i>
<i>Ko Matanehunehu te awa</i>	<i>Matanehunehu is my river</i>

Wairua

Wairua is often interpreted literally as the spirit form of humankind (M. Shirres, 1997). The notion of wairua does not just concern people. The whenua, animals, birds, and fish are said to have wairua, as are the lakes and mountains. This understanding is consistent with the notion that when people depart this life the physical forms return to Papatūānuku⁴⁴ but the spiritual dimension travels the journey taken by Tāne-mahuta to the spiritual resting place for Māori; that is, to Hawaiiki nui, Hawaiiki roa, Hawaiiki pamamao. It is often heard in mihimihi at tangi when the departed is being given a final farewell message as they begin their journey back to Hawaiki:

*Haere e hoki i runga i o koutou waka
 Ki Hawaiiki nui
 Ki Hawaiiki roa
 Ki Hawaiiki pamamao
 Ki te hono i wairua*

*Go, return to your canoes
 to Great Hawaiiki
 to Long Hawaiiki
 to Hawaiiki of the Great Distance
 to the Gathering Place of the Spirits*

Wairua is conceptualised in modern times as an important component of a person's being. Durie (1998) stated that without spiritual awareness an individual

⁴⁴ The earth

can remain unhealthy for extended periods of time further exacerbating a chronic health condition (Durie, 1998b).

Tapu

The word 'tapu' has a broad range of meanings for Māori. H. W. Williams (1971) defined tapu from four different perspectives:

1. Under religious or superstitious restriction – a condition affecting persons, places, and things, and arising from innumerable causes;
2. Beyond one's power, inaccessible;
3. Sacred;
4. Ceremonial restriction, quality or condition of being subject to such restriction. (p. 385)

Buck, (1949) in '*The coming of the Māori*' referred to tapu in a general sense around the concept of sanctity:

The tapu of a chief is difficult to define, but it is probably best regarded as a form of personal sanctity. The Ariki (chief) inherited it...and he inherited the tapu observances which his family had created in previous generations. (p. 346)

Buck described tapu as a factor in the aetiology of mate aitua⁴⁵, an illness for which there is no obvious physical cause. Durie (2001) stated tapu was exercised as an agent for social control. In the absence of regulations and law enforcement processes, as we know them today, tapu enabled social systems to function because tapu was the platform on which law and order was maintained (Durie, 2001).

Marsden (1992) defined tapu primarily as:

...the sacred state or condition of a person or things placed under the patronage of the gods. The person or object is thus removed from the sphere of the profane and put into the sphere of the sacred. It is untouchable, no longer to be put to common use. (p. 117).

Marsden (1992) spoke of the untouchable sacredness of tapu of persons or things, and any disrespectful or irreverent abuse is tantamount to sacrilege, violating the law of tapu . In another sense, a tapu object may be classified as an accursed or unclean thing. The unclean element that constitutes the tapu can

⁴⁵ Unexplained Maori sickness

then be transmitted by contact or association and a person can be contaminated and polluted by it (Buck, 1949). Consequently, the existence of tapu restrictions does not depend on people's awareness of sites or objects that are tapu, they exist whether people know about them or not.

Shirres (1994) discussed intrinsic tapu and extensions of tapu. The tapu of the warriors when they went on a war expedition were extensions of the tapu of Tumatauenga⁴⁶. The tapu or restrictions placed on a mother when she is giving birth to a child, are extensions of the intrinsic tapu of the child and of the spiritual powers to whom the child has been dedicated. Similarly, the restrictions placed on the kūmara garden can be seen as extensions of the intrinsic tapu of the kumarā (M Shirres, 1994).

In pre-European times, sacred stones, mauri, were placed or buried in hidden locations to protect them from desecration. With the introduction of Christianity many Māori converted to the various faiths and adherence to the law of tapu was disregarded by many, resulting in the incursion into and desecration of tapu sites (Elsmore, 1989). In the mid-19th century (1850–1857) a movement known as the 'Kaingarara Response' was formed in the Taranaki-Whanganui region to overcome the consequences of desecration of wāhi tapu sites. The sole purpose of the movement was to remove the tapu⁴⁷ from known sacred sites as they were perceived as the cause of chronic illnesses rampant among the Māori population at the time (Elsmore, 1989).

The advent of colonisation meant new challenges for Māori and one of those challenges was the introduction of foreign disease. Introduced disease spread among Māori at an alarming rate. It was not until the early 1900s that the Spanish flu epidemic introduced by the early settlers was known to be the source. Lange (1999) believed the resurgence of the Māori race can be attributed to two Taranaki medical doctors, Te Rangi Hiroa (Sir Peter Buck) and Sir Maui Pomare. In 1919, Pomare put aside his Parliamentary duties to lead the fight against the Spanish flu. Both men served in Government appointed roles to alleviate the

⁴⁶ God of warfare

⁴⁷ Positive noa referred to by Shirres (1994)

burden of chronic illness that was endemic among the Māori population in the early 1900's (Lange, 1999).

Durie (1998b) considered the concept of tapu as a preventative measure as well as a cause of sickness:

A breach of tapu could lead to illness and even calamity on a widespread basis. The balance between tapu and noa was a dynamic one, moving to accommodate seasonal, human, and physical needs within a value system that was sufficiently holistic to accommodate health interests. Both noa and tapu had meaning for health, noa denoting safety, tapu protection. (p. 9)

I now consider the definition of tapu as advocated by Tate (2010), which is fundamental to the interpretation of participant stories in this thesis. Tate defined tapu as a concept that has three related perspectives:

- First, tapu is the restricted or controlled access to other beings – Atua, tangata and whenua;
- Second, tapu is being understood as 'being-in-itself', to exist;
- Third, tapu is 'being in relationships' with primary being⁴⁸ or with other beings, such that the relationships enhance, sustain, restore and empower those in relationship. (p. 32)

The first aspect, restricted or controlled access to other beings covers a broad array of scenarios of how Māori engage with each other, between tangata and tangata, how we engage with Atua, between tangata and Atua, and how we engage with the whenua, between tangata and whenua. Further extensions come into effect between people (tangata) and objects of special significance, taonga.

The second aspect, *te tapu i* as 'being-in-itself', proposes elements that qualify the essential nature of *te tapu i*:

- *te tapu i* is primarily being-in -itself;
- *te tapu i* encompasses existence;
- *te tapu i* is dynamically ordered towards totality and fullness and;

⁴⁸ Atua, tangata, whenua

- because of this, *te tapu i* is understood as source and fulfilment of all other tapu⁴⁹;
- From *te tapu i* emanate extensions of tapu (pp 50 - 51).

The second aspect of 'tapu as 'being-in-itself' acknowledges the reality that we must first exist for anything to be in relationship with or be restricted in access to other beings. The phrase '*te tapu i*' refers to the intrinsic tapu of a primary being be it Atua, tangata, or whenua. Tate (2010), therefore, proposed that the primary meaning of tapu is being, and while all three definitions denote different aspects of tapu, *te tapu i* embraces the primary meaning of all three. Thus, a holistic approach to being includes all three perspectives.

The third aspect, *te tapu o* is the tapu of being in relationship between existing realities, tangata and Atua; tangata and tangata; tangata and whenua. Tate (2010) says:

When beings come into relationship, this comes about by an encounter of one being with another. Māori give attention to the encounter itself and in the way, the encounter comes about, and thus to the quality of the encounter and to its consequences. In encounter, the relationship imparts some aspect or quality of being that is creative or productive, enhancing and empowering, from one to another. The process is two-way; one imparts while the other participates. One shares of while the other shares in. One gives while the other receives. All that one imparts and gives, and all that the other receives and participates in, is captured in the phrase, *te tapu o*. (p. 36)

Te tapu o is interpreted here as an aspect or quality of someone or something. It is not about an existing reality but rather it is something of or about an existing reality. The relationship is mutually enhancing, restorative, and empowering. An example of this scenario would be the doctor/patient consultation relationship. Such engagement process is applicable to all forms of consultation but particularly so for Māori who present with a suspected prognosis of bowel cancer.

Noa

The Williams Dictionary, (1971) of the Maori language defines noa as:

⁴⁹ Te tapu i must exist for all other forms of tapu to come into effect e.g. restrictions, relationships, etc.

1. Free from tapu or any other restriction;
2. Without restraint. (p. 222).

The term noa denotes a state of relaxed access where protective mechanisms or restrictions do not apply. Women, for example, were not allowed to enter a whare while it was under construction under the precept that the site was not only dangerous physically, but women the potential bearers of children, may experience harm or other type of calamity including punishment due to violation of tapu. Today the construction of wharehau is made noa after the building has been completed and the tapu has been removed. Women are then free to enter. The concept of noa is applicable to everyday situations for Māori and is an essential part of formal rituals and ceremonies that can involve the giving of food to manuhiri⁵⁰ after they have been welcomed to the marae through the formal process of powhiri⁵¹. The ritual of sprinkling water over the head and face after visiting the urupā⁵², is enacted to make a person noa. Today, Maori who seek healing from tohunga are subject to the same process of positive noa; that is, an intervention by tohunga to nullify the effects of harmful spirits that has affected a person's state of being.

Mana

According to Shirres (1994) mana means spiritual authority and power. People of eminence including Sir Apirana Ngata, Te Rangi Hiroa⁵³ and Sir Maui Pomare, are held in high esteem by their people because of their actions to improve the livelihood of their people by advocating in the Chambers of Parliament on their behalf. Te Whiti o Rongomai and Tohu Kākahi of Parihaka received the same respect from their people because they resisted the confiscations of Māori land sanctioned through the Chambers of Parliament. They are said to possess great tapu and mana. Their tapu and mana can never be extinguished, once attained it remains forever. It is mana that has been bestowed upon them by others for all time.

⁵⁰ Visitors

⁵¹ Formal welcome on to the marae

⁵² Cemetery

⁵³ Sir Peter Buck

Tate (2010) asserted that for something to have mana it must first have tapu; that is, it must exist in the first place if it is to have spiritual authority and power:

Mana is not of its own source because it comes into existence only when tapu comes into existence. Mana is rooted in tapu. It does not exist independently of tapu. Since mana is dependent on tapu, for existence, then tapu is the source of mana. It is from tapu that mana emanates. (p. 65)

In the word usage of mana, Tate (2010) highlighted 10 aspects of mana as:

1. Power;
2. Spiritual power;
3. Authority;
4. Influence;
5. Psychic force;
6. Control;
7. Prestige and status;
8. Manaaki;
9. Charisma;
10. Rangatiratanga. (p. 60)

Tate (2010) thus defined mana as:

...spiritual power, authority, and prestige and status. Once it comes into existence, which it derives from tapu as its source, it is either power in potentiality or power in operation. In its operation, it acts either to create or to produce (from existing sources), further beings with their own tapu. Each of these beings has, and exercises, its own mana, derived from its own tapu or from the tapu of others.

Mana is tapu centred. In every case, the mana deriving from tapu acts, to manifest, address, enhance, sustain, and restore its own tapu and the tapu of other 'beings' until the goal is reached of possessing tapu in its fullness. (p. 63)

The application of the above definition becomes evident when we consider our own professional experiences as health professionals working with Māori, young and old, who have been raised in environments that have been abusive and neglectful. As health professionals, we exercise our own tapu, and hence mana, when we enter the process of whanaungatanga to engage with our people, to be pono⁵⁴. We operate with the correct and rightful tikanga⁵⁵; that is, the right way

⁵⁴ Truth

⁵⁵ Rightful process

of doing things, which respects the tapu and mana of the people with whom we are engaging. The process is reciprocal as we are seen to engage with the person's interests at heart – what matters to them. We are then accorded the same respect as our own intrinsic tapu and mana is acknowledged. Within that process, we exercise our mana with integrity to manifest, address, enhance, sustain, and restore the tapu and mana of others.

A common misdemeanour, often made by health professionals when engaging with Māori in primary and secondary healthcare settings, is the lack of acknowledgement of Māori, the person. Such approaches fail to engage appropriately through whanaungatanga⁵⁶, which is essential if one is to engage in a meaningful dialogue. Such engagement practices by health professionals can leave patients confused and frustrated. It is not unusual for patients, more specifically Māori, to come out of consultations and admit they did not understand a word the doctor said.

Mauri

Best, (1934) in *'The Māori as he was: A brief account of life as it was in pre-European days'* defined the mauri of a person as:

...something that cannot leave the body during life. It is his life-principle, or vital spark, and so is sometimes referred to as mauri ora, or living mauri. (p 80)

According to Durie (1998b):

...all living things, including natural and physical resources, possess a mauri, a life principle or life essence. Distinctions between inanimate and animate objects are therefore blurred, because each is afforded a spiritual existence which complements the physical state. Nothing is lifeless. (p. 23)

Mauri is a special force, life principle, vitality or ethos of all things that is derived from Atua. Everything has a mauri including the whenua, animals, birds, forests, fish and, in some cases, items considered of cultural value (taonga) such as the Korowai⁵⁷ which can be handed down through many generations. The physical symbols that are imbued within mauri possess certain powers; for instance, the

⁵⁶ Proper relationship

⁵⁷ A special cloak that has significance to whānau in terms of tapu and mana

laying of the mauri stone for a structure at the commencement of a new building is an important process for Māori.

Pohatu's (2005) postulation of the concept of mauri in terms of human wellbeing⁵⁸ is another significant aspect of this study. He asserted that mauri holds a central place in informing Māori, how and why our lives take the form they do. According to Pohatu mauri imbues Māori thinking, knowledge, culture, and language with a unique cultural heartbeat and rhythm (T. Pohatu, 2011).

Whenua

The Māori philosophical viewpoint of whenua has two meanings namely:

1. The land which is symbolic of Papatūānuku, the Earth Mother, nurturer of mankind and secondly;
2. The placenta, a source of nourishment for the unborn child.

Māori place extreme importance on the whenua and despite almost 200 years of dislocation from the land, Māori remain attached to the whenua through whakapapa, despite no longer having legal title to the land. The following example illustrates the importance of whenua from a Māori viewpoint. The recent sale of whānau land on the open market has left a family saddened and somewhat in a state of shock. It was tantamount to the severing of the spiritual umbilical cord that connected that whānau to the whenua. It was the place where they were raised as children, as teenagers, as adults. The whenua remains in spirit but the physical dimension is merely a distant memory where aspirations for whānau who wish to return to the land may never to be realised. The sale in my view constitutes a violation of the intrinsic tapu of that whānau (*te tapu i te whānau*) and by implication the mana of the whānau (*te mana o te whānau*). The land possesses great tapu and mana for them as a family because it has been their faithful servant for generations in the form of sustenance for the whānau, sustenance at times for hapū and, to a lesser extent, sustenance for iwi. The concept of whenua for that whānau cannot find purpose and worth because they no longer have a place to stand and feel as though they are truly at home – on their whenua, their turangawaewae⁵⁹. To that end, as with many other whānau

⁵⁸ *Mauri: Rethinking Human Wellbeing* (Pohatu, 2005)

⁵⁹ Place to stand

throughout the motu⁶⁰, the tapu of the whānau has been diminished and the mana of the whānau impaired.

2.6 Māori Social Structures

The following account provides some understanding on how Māori society is structured and the dynamics of social organisation within whānau, hapū, and iwi.

Rangatira

Buck (1949) provided an in depth description of Rangatira through his account of attributes of chieftainship. The *Ariki* chiefs, by reason, of their exalted birth, were imbued with the two inherited attributes of tapu and mana. The mana of the chief carries the meaning of power and prestige. The first-born son inherited the power to rule and direct his tribe, but his mana lay dormant until it was given active expression on his father's death or other form of abdication. The mana of the chief was integrated with the strength of the tribe. According to Buck, it was not a mysterious, indefinable quality flowing from super-natural sources; it was basically the result of successive and successful human achievements. Buck asserted that the tapu of the chief is difficult to define, but it is probably best regarded as a form of personal sanctity. The *Ariki* inherited it through his senior lineage (*aho Ariki*), and he inherited the tapu observances which his family had created in previous generations. His people treated him with a respect which sometimes amounted to awe and trepidation. The term for trepidation or dread is *wehi* and high chiefs were sometimes welcomed with the greeting *haere mai te mana, haeremai te tapu, haere mai te wehi* (welcome to power, welcome to sanctity, welcome to dread).

Tohunga

In ancient Māori society tohunga acted as the mediums of the gods. Tohunga were experts in mātauranga Māori⁶¹. Qualifying terms were ascribed to them to distinguish specific areas of expertise. The expert carver was a tohunga whakairo⁶² and the tattooing artist was a tohunga tā moko⁶³. The experts in religious theory and ritual were graded in accordance with the class of god they

⁶⁰ Country

⁶¹ Maori knowledge

⁶² To carve

⁶³ Moko – to tattoo

served. Buck (1949) listed 10 priestly titles derived from various sources. The highest class of priests were termed *tohunga ahurewa* or *tohunga taua*; and the lowest, who exploited their fellows through fear, were termed *tohunga kehua*. *Tohunga matakite* were renowned for their powers to foretell the future, *tohunga kokorangi* read the stars, and *tohunga makutu* slew people by black magic. The high-class priests went through a difficult course in a proper house of instruction, in which their instructors were termed *tohunga pūkenga*⁶⁴. An entrance student was termed a *pia*, one in the next grade, a *taura*. Towards the end of the course, he became a *taura*⁶⁵ assisting the fully qualified priests in religious ceremonies.

Kaumātua

The use of the term *kaumātua* is the Māori term for elder. However, not all persons who reach the age of eligibility are referred to as *kaumātua*. The term is used more often to describe a person who has acquired certain leadership qualities where one possesses wisdom and the mandate to speak on behalf of the people. In Taranaki *kaumātua* is the term ascribed to older Māori men who have earned the respect of *whānau*, *hapū*, and *iwi*. The term *kuia* has the same respectful intonation for older Māori women.

Whānau, Hapū, Iwi

The smallest unit in Māori society is the biological family, which Māori term *whānau*, derived from *whānau*, to give birth. With each generation, the number of families increased and reached such numbers that the restricted term of *whānau* could no longer be applied to the group. The term *hapū*⁶⁶ was used to denote this extended family group for it expressed the idea of birth from a common ancestor and thus stressed the blood tie which united the families to encourage cooperation in active operations and in defence. The *hapū* expanded further in succeeding generations making it necessary for groups to separate from the original settlement and take up land in neighbouring localities. The term *iwi*⁶⁷ was brought into current use to include all the *hapū* descended from a common

⁶⁴ Intellectual, skilful

⁶⁵ Student

⁶⁶ Pregnancy

⁶⁷ Bone

ancestor and thus related to each other by a blood tie. In English iwi is denoted by the term tribe and hapū a sub-tribe.

Waka

Buck (1949) proclaimed that the great migration of the ancestral canoes⁶⁸ which came from Hawaiiki⁶⁹ is the most famous event in Māori history because all of the tribes of Aotearoa trace their aristocratic lineages back to the chiefs of the voyaging canoes which took part in conveying the third and last wave of settlers to New Zealand. For Buck, there is some conjecture as to the place of origin from where the Great Migration began its momentous journey to Aotearoa. Buck's analysis of the origin of departure was based on dialectical terminological analysis of the Pacific Island nation's language and the most likely points of origin in his opinion were Hawaii and/or Western Samoa.

Nga Tikanga Māori

The term tikanga stems from the word tika the literal meaning of which is correct. Tikanga Māori means to do things in a certain way in accordance with Māori custom. The basis of doing things the correct way manifests itself in the application of Māori knowledge and values. One such custom is the pōwhiri, a welcoming process for manuhiri where the concepts of tapu and noa are critical aspects for people who visit a marae for the first time. In terms of this study, participants were recruited from Taranaki. The prevailing tikanga was Taranaki, prospective participants were recruited by word of mouth and by flyers distributed throughout the community. Participants were interviewed in an environment where they were at ease and in most cases, this was done in their homes which meant face to face contact (*kanohi ki kanohi*). The observation of tikanga in this case was part of the engagement process where Māori were given an opportunity to make the appropriate connections to the researcher and, most importantly, identify where the researcher fits into their world. On occasions the protocol

⁶⁸ Waka

⁶⁹ Great Hawaiki, long Hawaiki, far distant Hawaiki

around engagement included mihimihi⁷⁰, whānaungatanga⁷¹, whakapapa kōrero,⁷² karakia⁷³, and kai hākari⁷⁴.

Marae and Papakainga

In earlier times the marae was regarded as the centre of Māori societal interaction. It was a place of belonging, a place where they could stand and feel at home. The change in Māori demographics over the past 50 years is reflected in the gradual exodus from the marae. The original concept, however, remains where there is a formal meeting house⁷⁵ and a whare kai⁷⁶. The marae has always been regarded as the centre where Māori discussed and made important decisions regarding whānau, hapū, and iwi tribal affairs. The critical consultative process in decision making for whānau, hapū, and iwi are usually discussed in this environment.

Manaaki and Kai

Manaaki literally means to enhance one's mana through the act of caring. This can happen on occasions where large groups have been welcomed onto the marae. It is the responsibility of the tangata whenua to ensure that the best possible care is afforded to manuhiri⁷⁷. It is also an occasion where the mana of tangata whenua can be enhanced. Alternatively, it can also be an occasion where mana can be diminished. The responsibility of upholding the mana usually falls upon a specific person who has been acknowledged by the whānau for her/his special talents including knowledge of tikanga Māori. Great efforts are undertaken to provide the best possible care for manuhiri. Tangata whenua know that by accommodating that requirement their mana can be greatly enhanced.

Whānaungatanga and Hui

Whanaungatanga is concerned with the practices that strengthen the kinship ties of whānau. The following example illustrates a typical occasion where

⁷⁰ Speeches

⁷¹ Linking of relationships

⁷² Reciting of family genealogy

⁷³ Prayer

⁷⁴ Kai/kapu ti

⁷⁵ The wharehau

⁷⁶ Dining room

⁷⁷ Visitors

whanaungatanga is practised in a Māori context. Over the past 30 years our whānau have come together on the family marae to be as a family and to strengthen whānau relationships through whanaungatanga. We have been blessed on occasions with the addition of new mokopuna which is a time for them to know the older children and cousins. It is also a time to discuss any new developments that may be of interest to the whānau. The hui usually extends out to for five or six days over the Christmas/New Year holiday break. One of the underlying reasons for the annual hui is to bring the whānau together in whanaungatanga. The hui presents an opportunity for those who may have experienced difficulties throughout the previous year to come closer to the whānau, thereby negating any sense of isolation. Hui conducted in such circumstances can produce amazing outcomes where whānau members in need are given support, especially in the current socio-economic environment. As a whānau we have witnessed many occasions where we have benefitted as a collective. While this scenario illustrates a way in which we, as a whānau, address issues that confront us, I make the point here that the concepts of whanaungatanga is fundamental to the Māori way of life. The concept of whanaungatanga is about coming together and celebrating achievements as a whānau and creating safety within the wider whānau network.

2.7 Summary

In this chapter I have positioned Te Ao Māori as the foundation to the succeeding chapters to this thesis. In doing so, I have highlighted important aspects within Māoridom that will appear time and again in the writings that constitute the cultural perspectives of Kaupapa Māori. A comprehensive description of the philosophical and theoretical foundations of Te Ao Māori were drawn from traditional myths and legends. Māori values and concepts, fundamental to this study, were discussed including the concepts of tapu, noa, and mauri which are given greater contextual relevance in the proceeding chapters.

CHAPTER THREE: A REVIEW OF THE LITERATURE

3.1 Introduction

The purpose of this literature review is to examine what other researchers have said about my topic of interest and to condense this into a synthesised argument. According to Davidson and Tolich (1999), a literature review needs a plan and a clear focus of what it is being reviewed, and seeks to answer the following questions:

- What have others said about this topic?
- What theories address this topic?
- What do these theories say?
- What research has been done previously?
- Do the results of the existing research agree with one another, or is there disagreement?
- Are there flaws in the existing literature?
- What are the gaps in the research? (p. 88)

A recent article by Smythe and Spence (2012) challenged the status quo regarding the assumption that there remains only one way to conduct a literature review. They argued that the manner of reviewing literature needs to be congruent with the research methodology. They used the example of doing hermeneutic research and how a hermeneutic literature review ought to be carried out. Both authors posited their argument on the premise that the key purpose of exploring literature in hermeneutic research is to provide context and provoke thinking.

There is a plethora of research internationally on the lived experiences of bowel cancer however, there is no known study on the lived experiences on bowel cancer for Māori. Walker (2008) explored Māori experiences of cancer in a general context and aimed to shed light on the causes of cancer inequalities for Māori. Significant among the findings was the involvement of whānau in the cancer journey as this facilitated a holistic approach to their wellbeing. Among the recommendations was the need to improve cancer services for Māori through better resourcing of Māori providers, more effective utilisation of systems navigators and inclusion of whānau in the cancer control continuum. In keeping

with the argument that Smythe and Spence (2012) portrayed, the review of literature has been conducted in a manner congruent with the perceived experiences of Māori who have been afflicted with bowel cancer. Bowel cancer is something that most Māori do not talk about or have very little knowledge of. I make the assertion that this study has potential to contribute to new knowledge on early detection and management of bowel cancer for Māori in Taranaki.

Literature pertaining to this review has been collated through various search databases including: Scopus; medical and health management databases; PubMed (<http://www.pubmed.gov>); Ovid; Google Scholar; Psych INFO; and EBSCO. Online searches have also been examined through the internet search engine 'Google' (www.google.co.nz) and Ministry of Health (<http://www.moh.govt.nz>) web pages. The following key words were used in the searches: bowel cancer and Māori; bowel cancer and indigenous; bowel cancer and recovery; health literacy and Australia; health literacy and New Zealand; Māori and engagement and health; Māori and engagement and pathways; Māori and engagement and bowel cancer; and World Health Organization and cancer. The Boolean operators 'AND' 'OR' and 'NOT' were used to scale down and limit the number of studies appropriate to the topics related to the research question.

Journal articles have been included in the literature for this review where material encompassed issues such as the dynamics of cultural engagement, cultural identity, epidemiological evidence, programme evaluation and health outcomes, health promotion, holistic care, Māori models of health and Māori research recovery programmes. Articles on qualitative research design have also been included as have all relevant published reports from the Ministry of Health. Books and supplementary literature focusing on Māori health care have also been part of this literature review.

3.2 The Prevalence of Cancer Worldwide

Internationally, cancer has become one of the most common causes of mortality. A worldwide review on incidence, mortality and prevalence of cancer (Parkin et al., 2005) provides an indication of the enormous burden of cancer worldwide. The review by Parkin et al. provided interesting data on global statistics for age standardised incidence rates for colorectal cancer:

Colon and rectum cancers accounted for about 1 million new cases in 2002 (9.4% of the world total), and unlike most sites, numbers were not so different in men and women. In terms of incidence, colorectal cancers rank fourth in frequency in men and third in women. The highest incidence rates are in North America, Australia/New Zealand and Western Europe. (p. 86)

A statistic worth noting, the age standardised incidence of colorectal cancer per 100,000 for Japanese males who emigrated to Hawaii was 49.3. For many observers, the Japanese diet is synonymous with a clean living and healthy society, where foods associated with healthy diet is common practice. The worldwide review by Parkin et al 2005., indicated that changes in environment for Japanese men had a marked effect on their dietary patterns which led to an unusually high incidence of colorectal cancer (Parkin et al., 2005).

A study conducted in the United Kingdom supports the above assumption where findings showed that a high intake of dietary fibre, especially cereal fibre and whole grains was associated with a reduced risk of colorectal cancer (Dagfinn et al., 2011). Although the study showed diets high in fibre act as a buffer to the onset of bowel cancer, the evidence collated by Parkin et al. (2005) is reflective of an industry in which processed foods commonly perceived as contributors to certain cancers are becoming the benchmark of diet patterns throughout the developed nations of the world. Perhaps more revealing are the statistics for the combined standardised incidence rate of bowel cancer for males in New Zealand and Australia, 48.2 per 100,000. North America follows closely with a standardised incidence rate of 44.4 per 100,000 (Parkin et al., 2005). Clearly, Parkin's review supports recent research in New Zealand where bowel cancer is a major contributor to mortality in New Zealand (Robson et al., 2010).

In the past two decades there have been a number of attempts to alleviate the burden of chronic diseases that exist within Māori society (Dickson et al., 2010; S. Hill et al., 2010; T. Walker et al., 2008). Diseases such as diabetes, cardiovascular disease, and chronic gout are some of the conditions to which I refer. The incidence and prevalence of bowel cancer among Māori whānau may well be much higher than current research reveals. There has been a rise in bowel cancer mortality rates among Māori over the last decade (Ministry of Health., 2015b), this despite data on the prevalence of bowel cancer among Māori being lower than European New Zealanders (Dickson et al., 2010).

The International Agency for Research on Cancer, the specialised cancer agency of the World Health Organization, provides an updated global view of cancer including cancer patterns, causes and prevention. The World Cancer Report series is recognised as an authoritative source of global perspective and information on cancer. The first volume appeared in 2003 and the second in 2008. The third volume in the series encompasses both established knowledge and recent research achievement. The World Health Organization (World Health Organisation, 2014) has released the following updated information on global cancer statistics. The most common causes of cancer death are cancers of:

- lung (1.59 million deaths);
- liver (745 000 deaths);
- stomach (723 000 deaths);
- colorectal (694 000 deaths);
- breast (521 000 deaths).

Cancers figure among the leading causes of morbidity and mortality worldwide with approximately 14 million new cases and 8.2 million cancer related deaths in 2012. The number of new cases is expected to rise by about 70% over the next two decades. Among men, the 5 most common sites of cancer diagnosed in 2012 were lung, prostate, colorectal, stomach, and liver cancer. Among women the 5 most common sites diagnosed were breast, colorectal, lung, cervix, and stomach cancer. Around one third of cancer deaths are due to the five leading behavioural and dietary risks: high body mass index; low fruit and vegetable intake; lack of physical activity; tobacco; and alcohol use. Tobacco use is the most destructive risk factor for cancer causing around 20% of global cancer deaths and around 70% of global lung cancer deaths. Cancer causing viral infections such as HBV/HCV (hepatitis B & C) and HPV (human papillomavirus) are responsible for up to 20% of cancer deaths in low- and middle-income countries. More than 60% of the world's total new annual cases occur in Africa, Asia, and Central and South America. These regions account for 70% of the world's cancer deaths. It is expected that annual cancer cases will rise from 14 million in 2012 to 22 million within the next 2 decades (World Health Organisation, 2014).

3.3 Indigenous Populations

Defining Indigenous

Indigenous communities, peoples and nations are those which having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories or parts of them (United Nations, 2014).

Indigenous Peoples

It is estimated that there are more than 370 million indigenous people across 70 countries worldwide. Practicing unique traditions, they retain social, cultural, economic and political characteristics that are distinct from those of the dominant societies in which they live. Spread across the world from the Arctic to the South Pacific, they are the descendants according to a common definition of those who inhabited a country or a geographical region at the time when people of different cultures or ethnic origin arrived. The new arrivals later became dominant through conquest, occupation, settlement or other means. Among the indigenous peoples are those of the Americas, the Inuit of the circumpolar region, the Saami of Northern Europe, the Aborigines and Torres Strait Islanders of Australia and Māori of New Zealand. These and most other indigenous peoples have retained distinct characteristics which are clearly different from those of other segments of the national populations (World Health Organisation, 2006).

Indigenous Peoples and Health Status

The health status of indigenous peoples throughout the world share similar traits. The First Nation and Inuit peoples of Canada for example have higher rates of chronic health conditions than other Canadians. The situation in other countries is similar where the Aboriginal people of Australia and New Zealand's own Māori population, share similar trends across most chronic health conditions. The health status regarding indigenous populations epitomises the position that indigenous peoples occupy in terms of their wellbeing (World Health Organisation, 2006).

3.4 International Perspectives on Bowel Cancer - Journeys of Emotion and Despair

The following literature focuses on stories and accounts of people's experiences of bowel cancer. Because of the chronic nature of bowel cancer much of the current international literature reflects what can only be described as journeys of emotion and despair. Factors associated with late presentation of cancer (Almuammar, Dryden, & Burr, 2010) focused on issues associated with delayed presentation of cancer reported by previous studies. Salient insights emanating from the review of numerous studies showed that there was a high correlation between patient delay to seek professional help and patient knowledge of cancer, stress, fear, and the nature of the disease. A study by O'Connor et al. (1990), *'Understanding the cancer patient's search for meaning'* focused on patients' perceptions immediately following diagnosis of cancer. The study portrays patients struggle to find meaning in their lives after being diagnosed with an illness that signifies likely and impending death. Two factors of note to emerge from the study were a strong commitment and belief in faith and the importance of ongoing social support (O'Connor, Wicker, & Germino, 1990). Taylor (2001) too described an account of the experience of being diagnosed with colorectal cancer. The objective was to understand a specific experience and uncover the meaning and the trauma of being diagnosed with bowel cancer. One of the most poignant themes, 'feeling on your own', provides the reality of what it is like to be diagnosed with bowel cancer (Taylor, 2001). A similar study by Moene, Bergbom and Skott (2006) researched patients' existential situation prior to major surgery for colorectal surgery (Moene, Bergbom, & Skott, 2006). Emotions of anxiety and fear of the unknown were consistent with findings by Taylor, where the onset of trauma can trigger thoughts of imminent death.

The postoperative experience of patients' recovery, after undergoing surgery for colorectal cancer was the focus of a study by Worster and Holmes (2008). Their account provided a realistic description of how patients suffered recurring episodes of anxiety associated with fear, loss of dignity and control of normal daily living activities. A similar study by Jonsson, Stenberg and Frisman (2011), which also focused on the lived experience of the early post-operative period after colorectal cancer surgery, found that patients experienced insecurity due to lack

of control, fear of wound and anastomosis⁷⁸ rupture (Jonsson, Stenberg, & Frisman, 2011).

One of the inevitable outcomes of colorectal cancer is the ongoing effects of long term treatment regimes. Hewitt, Greenfield and Stovall (2005) studied this aspect and how health care had altered over time for survivors of colorectal cancer. The prime objective of the study was to examine effective follow up and appropriate treatment options for bowel cancer sufferers after transition from surgery to postoperative care. The study showed how experiences of anxiety and emotion for bowel cancer patients can result in significant changes in lifestyle including altered relationships and how patients interact with others in the community (Hewitt, Greenfield, & Stovall, 2005). Patient behaviour in this study was consistent with findings in a study by McCaughan et al. (2011) who investigated how people with colorectal cancer were coping at diagnosis and during surgery.

The experiences of people with advanced colorectal cancer and the effect that had on their partners was the subject of a study conducted by Sjövall, Gunnars, Olsson, and Thomé (2011). Living with the illness was compared to surviving inside or outside the healthcare system. Significant among the findings of this study were how altered relationships can develop once patients were discharged from hospital care. Partner relationships were likened to living in the shadow of the disease itself as partners felt very much on their own and deserted (Sjövall, Gunnars, Olsson, & Thomé, 2011). The impact of colorectal cancer on patient and family, and implications of care (Cotrim & Pereira, 2008), showed distinct similarities with the study by Sjövall et al. This study however focused on the added dimension of patients' difficulty of the lived experience of having to survive with a stoma⁷⁹.

Shahid and Thompson (2009) explored issues related to cancer among indigenous populations in Australia, Canada, New Zealand, and the United States of America. They examined variations in the epidemiology and indigenous

⁷⁸ The procedure of joining portions of the intestinal tract

⁷⁹ An artificial stoma is a surgically created opening in the large intestine that allows the removal of faeces from the body to drain into a pouch or alternative collection device

peoples' perceptions about cancer and the potential effects on care seeking behaviour. Of interest in this study were the qualitative findings of indigenous beliefs about cancer. Although similarities to non-indigenous beliefs were noted such as fear of death and fatalism, there were distinct differences from a cultural perspective including shame, payback for indiscretions committed in the past, and the belief that cancer is a white man's disease (Shahid & Thompson, 2009). Cultural beliefs can create significant barriers in terms of Western treatment options. Going to the doctor is an option that many indigenous people would rather circumvent as Western medicines are perceived as poisons that destroy rather than heal. These are some of the underlying factors that influence indigenous peoples' decision-making when asked to participate in treatment programmes. The authors concluded that there was a definite case to be made for a holistic approach to healing for indigenous people and that the concepts of individual, family, and wider community are inseparable. Their recommendation that further research is needed on indigenous people with cancer is a timely suggestion. Indigenous knowledge and beliefs needs to be incorporated into policy and practice guidelines when developing health treatment programmes for indigenous peoples. This aspect has, and continues to be a topic of vigorous discussion for Māori, the indigenous people of Aotearoa/New Zealand. Māori attribute the loss of health to the loss of land resulting in diminished tapu and impaired mana. For Māori, the land and the environment has significant economic and spiritual meaning.

3.5 Bowel Cancer in Aotearoa/New Zealand - A National Dilemma

Bowel cancer is the second most common cancer in New Zealand and the second highest cause of cancer death in 2008. That year, 2,801 people were diagnosed with bowel cancer, and 1,280 people died from the disease. New Zealand's death rate from bowel cancer is one of the highest in the developed world, with the third highest mortality rate in the OECD⁸⁰ for women and the sixth highest for men. By 2016, the number of new cases of bowel cancer diagnosed each year is projected to increase by 15% for men and 19% for women. By 2016 a projected increase

⁸⁰ Organization for Economic Cooperation and Development

of a further 500 diagnosed cases per year will raise the number of cases to over 3000 for all ages (Bowel Cancer Aotearoa., 2015).

By international standards, New Zealand has a low rate of early stage diagnosis of colorectal cancer and the lowest percentage of surgically curable localised disease (28%) when compared with Australia (34%), United Kingdom (42%), United States (40%) and Hong Kong (35%). Twenty percent of disease at diagnosis in New Zealand is metastatic. In 2001, New Zealand had the highest age-specific incidence of colorectal cancer in the 50 to 70-year age group, when compared with Australia, United States, United Kingdom and Japan (Samson, O'Grady, & Keating, 2009). Although research shows that the prevalence of bowel cancer among Māori is not as high as non-Māori, there has been an increase in mortality rates for Māori, especially Māori males (Ministry of Health., 2015b). Māori/non-Māori registration and mortality comparison rates for bowel cancer are shown in Appendix H.

Māori, Cancer and the Quest for Meaning

There is a perception that many Māori are guilty of indifferent behaviour when it comes to maintaining good health. This trend is apparent in younger urbanised Māori who find themselves in a predicament of being locked between cultures where the damaging effects of drug and alcohol abuse and attitudes to chronic illness are evident. A disturbing issue and a significant part of this study is that the same ambivalent attitudes prevail well into their mid-life years (40–50 years) which can then have a major impact on their wellbeing in later years. Addressing health literacy has been the subject of numerous studies (Jones et al., 2010; Kickbusch, 2001; Mogford, Gould, & Devoght, 2011; Ness, 2012; Nutbeam, 2000, 2009b). According to Nutbeam (2009b) there is a need to empower patients by implementing knowledge gained from research:

The reason why we care so much about literacy is that even the most basic functional literacy skills enable people to better develop their knowledge and improve the potential to achieve personal goals, and through this to participate more fully in society, both economically and socially. (p. 303)

In building health literacy in Australia, Nutbeam (2009a) postulated the need for three specific strategies if Australians are to make informed and productive choices when it comes to utilisation of health services:

(1) Health care providers and those responsible for patient management and administration need to demonstrate greater sensitivity to the needs of patients with poor health literacy by creating a less alienating health care environment that is more responsive to patient needs; (2) greater care needs to be taken to improve the quality of patient communication and the materials that support it; (3) outside the health care system as well as investing in school education, Australia would do well to follow the lead of the United Kingdom in adopting adult education programs such as the 'Skilled for Health' program, which brings health content into an adult basic skills programme. (pp. 525-526)

I assert that issues pertaining to health literacy in Aotearoa/New Zealand are no different to the dynamics that exist in the Australian context. Much of the research carried out by Nutbeam and others is, in fact, highly relevant to Māori whānau. Evidence tells us that Māori in the 50-65, 19-24 and 16-18 year, age groups have the poorest health literacy compared to the rest of the New Zealand's population. This is particularly concerning because over half of the Māori population (53%) was less than 25 years of age at the 2006 census. Also, older age groups have high levels of health need and are generally high users of health services (Ministry of Health, 2010).

Enhancing health literacy within Māori whānau and the need to transfer knowledge productively within whānau is an important issue in terms of whānau dynamics. Finding out how these issues impact on whānau would set the foundation for effective intervention and health promotion strategies when engaging with whānau who have a perpetual history of chronic health conditions. There would need to be a significant drive to promote leadership within Māori communities to improve health literacy through coaching, collaboration, and empowerment (Connolly et al., 2010). I am aware that Māori whānau can be dismissive of the professional help required to monitor and sustain good health. It is well known that Māori often seek professional help when they have no other choice, that is, when the acute stage of chronic disease has occurred.

My assertion that loss of land, loss of mana and consequent loss of health may have some credibility in relation to a study conducted by Ferguson et al. (1995). Despite factors that contribute to obesity and associated ill health Māori were found to have significantly lower incidence of colorectal cancer than Pākehā (Ferguson et al., 1995). The authors attributed the findings to possible differences

in consumption of specific food types which may explain differences in the incidence of colorectal cancer between Polynesians and European New Zealanders. Although Ferguson's study was conducted over 20 years ago, health professionals and researchers suspect diet is still one of the major factors that contributes to colorectal cancer. Similar findings by Sutton (1993) were recorded on the incidence of bowel cancer and factors concerning diet. The inclusion of green vegetable plants such as pūha⁸¹, poroporo,⁸² weno weno,⁸³ and kamokamo⁸⁴ was a big part of staple diets for most Māori whānau pre-urbanisation. Although the registration rates for bowel cancer for Māori remain much the same there has been a rise in the mortality rate for Māori men (Ministry of Health., 2015b). Access to traditional foods in the urban environment is rare and when available, Māori will often refuse consumption because of the possibility that food may have been taken from areas that are wāhi tapu.⁸⁵ Urbanisation has also meant easy access to cheap processed foods including an endless supply of red meat. Such diets have replaced many of the traditional food gathering practices in the rural environment. This has the potential to exacerbate the already burgeoning state of multiple chronic diseases that affect Māori (Dickson et al., 2010; Sutton et al., 1993; T. Walker et al., 2008).

3.6 Government Policy and Māori Health - Changing the Landscape for Māori

The New Zealand Public Health and Disability Act (2016b) sets the foundation for health strategy in Aotearoa/New Zealand. The new refreshed strategy, (Ministry of Health, 2016a) updates the previous version launched in 2000. The Strategy has two sections: New Zealand Health Strategy Future direction; and New Zealand Health Strategy Roadmap of actions 2016 (Ministry of Health, 2016a). He Korowai Oranga, the Māori Health Strategy provides the foundation for Māori health policy (Ministry of Health, 2015).

⁸¹ A weed more commonly identified as sow thistle

⁸² A wild plant used for medicinal as well as a food source

⁸³ Pre-flowering kamo kamo shoots

⁸⁴ Māori traditional pumpkin style squash

⁸⁵ Sacred ground in most cases associated with historical battlegrounds where death has occurred

He Korowai Oranga

Because Māori experience poorer health outcomes than non-Māori, He Korowai Oranga was developed as a strategy to reduce inequalities in health for Māori. Consequently, He Korowai Oranga, which was updated in 2014, sets the overarching framework to guide the health and disability sector to achieve the best health outcomes for Māori. Key threads, directions and pathways provide the foundation in which the synergy of Wai Ora⁸⁶ Mauri Ora⁸⁷ and Pae Ora⁸⁸ culminate in the overall aim – Whānau Ora.⁸⁹ He Korowai Oranga is the window through which the health system recognises and addresses the principles of the Treaty of Waitangi.

Although the current approach to health recognises there is a need to reduce inequalities, the realities for Māori often fall short of the desired outcome. A study by Connolly et al. (Connolly et al., 2010) found that there was very little conceptual understanding by senior managers, including funders, of the realities of reducing inequalities in health for Māori.

Despite significant changes that came with the establishment of 21 District Health Boards (DHB's) and the restoration of a less commercially oriented system, addressing issues concerning Māori health has been slow. Significant within the new look system was the devolution of funds and decision making to DHB's and developments in primary health care. Numerous Government documents and policies have been developed over the years to address the burden of poor health for Māori (Ministry of Health, 2010, 2015, 2016a, 2016b). The current Māori health strategic document, He Korowai Oranga (Ministry of Health, 2015), acknowledges the importance that whānau priorities need to be identified by whānau, hapū, iwi, and Māori communities. The strategy is based on the concept that whānau operate within the wider context of community and that community development models offer cultural engagement processes that are of benefit to Māori (Te Momo, 2002). For tauiwi⁹⁰ a healthy family is a nurturing family, a safe family, a happy family and a family that is financially secure. For Māori, there are

⁸⁶ Healthy environments

⁸⁷ Healthy individuals

⁸⁸ Healthy futures

⁸⁹ Healthy families

⁹⁰ A European New Zealander

additional needs associated with rediscovering whakapapa⁹¹ and rebuilding cultural capacity which are crucial aspects to improved whānau cohesion. Access to housing and shelter and a culturally safe environment create the best possible means for Māori to participate in and contribute to Te Ao Māori⁹² and to wider New Zealand society. Māori participation at all levels of the health and disability sector is fundamental to achieving whānau ora (Ministry of Health, 2015). Active participation by Māori in planning, development, and delivery of services ensures services are appropriate and effective for Māori. The irony here, of course, is that Māori are never quite afforded the resources to do the job despite a plethora of statistical evidence that shows Māori have the poorest health in New Zealand (Ministry of Health., 2015a).

3.7 Whānau Ora - Focusing on Outcomes That Make a Difference

Whānau Ora is a significant cross-government work programme jointly implemented by the Ministry of Health, Te Puni Kōkiri, and the Ministry of Social Development. In the recent budget (26 May 2016) the National Government allocated a \$40 million boost of operating funding over the next four years, allowing Whānau Ora to substantially increase the number of whānau it can support (Ministry of Health, 2014). While the New Zealand Health and Disability Act (Ministry of Health, 2016b) sets the foundation for health strategy and policy in Aotearoa/New Zealand (Ministry of Health, 2016a), He Korowai Oranga (Ministry of Health, 2015), the Māori Health Strategy provides a clear mandate to reduce inequalities between the health of Māori and non-Māori in New Zealand. The latest initiatives have come out of the fruitful and proactive initiatives to drive Whānau Ora by the former Associate Minister of Health, Dame Tariana Turia.

In June 2009 Dame Tariana Turia, who at the time was co-leader of the Māori Party, commissioned a six-member taskforce to find better ways for government to work with Māori. Members were selected based on individual skills, knowledge and experience. The taskforce, led by Professor Sir Mason Durie was given the task to develop policies to promote a new way forward for Māori based on the concept of 'Whānau Ora'. In launching the initiative the incumbent Minister Turia,

⁹¹ Genealogy

⁹² The Māori World

stated that Whānau Ora is the way forward to achieving a future where whānau determine what is in their best interest (Durie, Cooper, Grennell, Snively, & Tuaine, 2010). Whānau Ora is about establishing a clear focus on developing strengths within whānau to facilitate change from within. It stresses the need to develop a new approach for the design and delivery of Government funded services and initiatives to whānau, one that places whānau at the centre and builds on the strengths and capabilities already present within whānau. The taskforce identified five key elements of a whānau-centred approach to service delivery: whānau action and engagement; whānau-centred design and delivery of services; iwi leadership; active responsive government; and funding. Underlining the whānau-centred approach are seven principles: ngā kaupapa tuku iho;⁹³ whānau opportunity; best whānau outcomes; coherent service delivery; whānau integrity; effective resourcing; and competent and innovative provision. The elements and principles identified by the taskforce have significant relevance to this study. While the wellbeing of individuals is not discounted, most importantly the principles refer to the ways whānau are able to function as a group, the ways they care for each other, transmit knowledge and values, model healthy lifestyles, provide access to society and to Te Ao Māori and transfer of language, culture and ethics (Durie et al., 2010).

3.8 Relevance of Other Studies

A qualitative project in West Surrey in the United Kingdom by Broughton et al. (2004) investigated the care of bowel cancer patients' and carers' perspectives, using semi-structured interviews. Interviews were recorded, transcribed and analysed to identify recurrent themes. Forty-nine patients treated surgically for bowel cancer from three hospital trusts in West Surrey were visited at home and eight of their carers attended a focus group from a choice of three geographical locations. Five main themes were identified: experience of symptoms; general practitioner (GP) management; impact of diagnosis; perceptions of clinical care and treatment; and information needs. Results showed that patients and carers were ignorant of the symptoms and signs of large bowel cancer and wanted more information. They were satisfied when the GP took symptoms seriously and referred promptly. Three groups of patients were particularly vulnerable: those

requiring stomas (25); those diagnosed with polyps initially (11); and patients admitted as an emergency (7). Specialist nurses were regarded as the main source of written information and support which was most needed at the time of diagnosis and discharge. Findings from the study showed that the public needed more accessible information about the symptoms and signs of bowel cancer. Referral to multi-professional bowel cancer teams was essential to provide appropriate support and clear information from the time of diagnosis throughout the care pathway (Broughton, Bailey, & Linney, 2004).

A study by Huriwai (2000), *Whanaungatanga: A process in the treatment of Māori with alcohol- and drug-use related problems* noted that Māori have advocated that culturally based care requires goals and processes specifically defined within their ethno-cultural context. Positive cultural identity and pride were posited as integral to achieving wellbeing for Māori. Data relating to tribal affiliation, cultural self-identity and upbringing of that sample was presented. The key concepts of whānau and whanaungatanga (relationships) in the treatment process for Māori were explored and the implications of their utility discussed. Although the context of the study was diversely different to this study the meaning of whanaungatanga engenders similar outcomes – feelings of improved wellbeing. The findings highlighted the complexity of providing treatment that is cognisant of ethno-cultural factors.

Research conducted by Slater et al. (2013), supports the notion that whanaungatanga is critical when attempting to engage with Māori in healthcare settings. Aspects of Slater's study emphasises the importance of whanaungatanga posited by Huriwai (2000). A recent study conducted by Slater et al. (2015), which explored Māori cancer patients', their families, community and hospice views of hospice care, showed that Māori cancer patients felt uncomfortable when they used mainstream healthcare services because Māori tikanga or culture was ignored.

Māori and Cultural Safety

The issue of cultural safety in health among indigenous peoples throughout the world is slowly gaining momentum. Irihapeti Ramsden (2002) was a leading figure in the context of cultural safety in nursing and midwifery in Aotearoa/New Zealand. She is remembered for her contribution to the health system in

Aotearoa/New Zealand regarding cultural safety in the health worker/patient relationship when engaging with Māori. Her doctoral thesis, *Cultural Safety and Nursing Education in Aotearoa and Te Waipounāmu*, injected much needed intervention processes for Māori seeking healthcare within the New Zealand health system. She instigated a three-part process around cultural safety for Māori that has become the blueprint across all disciplines in healthcare: *Ko Wai Matou? He Huarahi Hou* and *Whakawhanuitanga*. *Ko Wai Matou?* – the private narrative explored the historical, social, educational, physical, emotional, political and moral influences which introduced cultural safety ideas into nursing and midwifery. *He Huarahi Hou, A New Pathway*, examined the theory and its relationships to education pedagogy and to nursing practice. *Whakawhanuitanga* addressed the public narrative by introducing cultural safety into the nursing education system and its implementation. Although her thesis is set in neo-colonial New Zealand her work has been acknowledged as highly applicable across all indigenous peoples throughout the globe. Ramsden (2002) proposes that the process toward cultural safety as a step-wide progression from cultural awareness through to cultural sensitivity culminating in cultural safety, each as separate entities:

Cultural awareness is a beginning step towards understanding that there is difference. Many people undergo courses designed to sensitise them to formal ritual rather than the emotional, social, economic and political context in which people exist;

Cultural sensitivity alerts students to the legitimacy of difference and begins a process of self-exploration as the powerful bearers of their own life experience and realities and the impact this may have on others;

Cultural safety is an outcome of nursing and midwifery education that enables safe service to be defined by those that receive the service (p 117).

3.9 Cross Cultural Perspectives

Nursing educator and academic Rose McEldowney has taught cultural safety for many years. She has always questioned the status quo, challenged prevailing orthodoxies and realised the pivotal nature of negotiated partnerships to good nursing practice. She has further recognised the fact that things needed to be

different in terms of Māori health. She knew something had to change. McEldowney adopted the position that nursing in New Zealand healthcare institutions had to take Treaty of Waitangi responsibilities seriously. As head of the nursing school at Waikato Polytech in the 1990s she became involved in developing a parallel nursing programme for Māori. This programme was run alongside the cultural safety programme. Her role was to get the resources and deal with the resistance and she says there was plenty of it. McEldowney espoused the responsibility of privilege and says, Pākehā as the dominant group, must take that responsibility seriously. Pioneering the parallel programme for Māori was conducted in a hostile environment. The responsibility of privilege meant dealing with the racism that emerged. She stated that there has been some slippage in the influence of cultural safety in nursing. It is not as embedded as it was in the 1990s. It is now a registered nurse competency among many competencies. That approach of course takes the onus of the nursing fraternity away from responsibilities inherent in true partnership that acknowledges the Treaty of Waitangi (McEldowney, R & O'Connor, 2012).

According, to Richardson (2011) the focus of cultural safety is the nurse and the person for whom he or she cares for within the complex fields of healthcare. She argued that culturally safe care is open to multiple interpretations and depends on the lens through which cultural safety is perceived and how care is applied. Richardson asserted that cultural safety and nursing need to acknowledge the world view of the person receiving care, while at the same time subscribing to a moral idea of protection and enhancing human dignity through acts of caring. She stated that cultural safety adds another dimension to those shared characteristics of power, difference, and identity by placing them in the foreground of healthcare interactions. Richardson noted that to build cultural safety in healthcare settings there needs to be a fuller appreciation of the meaning that health professionals attach to the concept, as well as more informed understanding of the concepts within which culturally safe care happens (Richardson, 2011). Spence (2001) argued that hermeneutic notions can illuminate cross-cultural nursing experiences is based on philosophical hermeneutics. The emphasis of the paper, rather than being methodological, is on showing how specific hermeneutic notions contribute to deeper understanding of the nature of cross-cultural practice (Spence, 2001).

3.10 Summary

Most Māori receive treatment in mainstream services where there is an overwhelming approach to biomedical intervention. Whānau Ora epitomises the attainment of optimal health for Māori and supports the notion that services with input from Māori communities, designed by Māori for Māori, have a far greater chance of succeeding. Government responsibility and funding are fundamental to appropriate resourcing of Whānau Ora and DHB's can play a significant role in this respect. Management and treatment of bowel cancer for Māori will therefore, depend on political leverage for greater resourcing within the primary health care sector and the establishment of specialist lead oncology clinicians who can engage with Māori in a culturally safe way. Ramsden's (2002) initiative on cultural safety has set the benchmark in terms of cultural competency when working with Māori. She advocated a three-part engagement process: cultural awareness; cultural sensitivity and cultural safety. Cross cultural perspectives embraced by McELdowney and Richardson discuss notions and strategies to improving Māori health. Unless these issues are addressed Māori will not be positioned to take control and make rational decisions about their overall health, and especially the need to test for bowel cancer. The literature reviewed is silent on the experiences itself for Māori who are found to have bowel cancer. This thesis seeks to address that gap, anticipating that revealing experiences, both positive and negative, will provide guidance for future diagnosis and care initiatives that will specifically meet the needs of Māori.

CHAPTER FOUR: METHODOLOGY

4.1 Introduction

In chapter two the foundations of Te Ao Māori were presented as an interwoven collection of Māori concepts and systems that constitute Māori knowledge and Māori practices. Methodology is the articulation of underpinning assumptions and values that guide the design and method of the study. In keeping with a Kaupapa Māori approach, research methods for this work have been adapted from current research approaches collectively known as Kaupapa Māori. These methods draw on philosophical aspirations expressed by other Kaupapa Māori researchers and academics which recognises the epistemological and ontological realities that are embedded in Kaupapa Māori. The principles of Kaupapa Māori research and their associated ethical commitments are thus discussed in this chapter.

A Kaupapa Māori approach does not prescribe a way of working with the data. This study is, therefore, also informed by Gadamerian hermeneutic interpretive methodology which unpacks the nature of how we understand and interpret. However, the lens through which understanding will be drawn is from a Māori worldview. One may ask the question why a hermeneutic interpretive approach to the lived experience of having bowel cancer is appropriate for Māori and what significance does such an approach have in terms of improving health care practice? It is anticipated that a hermeneutic approach which unpacks the nature of how we understand and interpret Māori experiences of bowel cancer will reveal both initiatives and approaches that supported participant wellbeing, and those that act as impediments.

4.2 Gadamer's Hermeneutics and Te Ao Māori

Gadamer's emphasis on application in understanding already implies that all understanding has a practical orientation in the sense of being determined by our contemporary situation, the now, as well as all that has been before and all that looms ahead (Gadamer, 1960). Gadamer's approach is characterised, not by the attempt to apply any pre-existing theory to the domain in question, but rather by the attempt to think from within that domain and in a way, that is attentive to what may be revealed. Gadamer's practical philosophy as applied to this study, opens the doors to Te Ao Māori where interpretation of participant stories and hence

text, comes from within the domains of whakapapa, mauri and tapu. According to Malpass, (2009):

the application of Gadamerian Hermeneutics is neither a subsequent nor merely an occasional part of the phenomenon of understanding, but co-determines it as-a-whole from the beginning. Theory and application do not occur in separation from one another, but are part of a single hermeneutical 'practice'. (p. 10)

Gadamerian Hermeneutics

Gadamer's hermeneutics is about the methodology of interpreting texts. All understanding that is directed at the grasp of some particular subject matter is thus based in a prior 'ontological' understanding—a prior hermeneutical situatedness (Gadamer, 1960).

Hans-Georg Gadamer [1900–2002] was the decisive figure in the development of 20th century hermeneutics. He was one of the few philosophers for whom the 'interview' has become a significant category of philosophical output. Gadamer's thinking began, and always remained connected with Greek thought, especially that of Plato and Aristotle. In this respect, Gadamer's early engagement with Plato, which lay at the core of his doctoral dissertations, was determinative of much of the character and philosophical direction of his thinking. Under the influence of Heidegger, Gadamer also took up as a central element in his thinking, the idea of *phronesis* (practical wisdom) that appears in Book VI of Aristotle's *Nicomachean Ethics*⁹⁴. For Heidegger the concept of *phronesis* is important, not only as a means of giving emphasis to our practical 'being-in-the world' over and against theoretical apprehension, but it can additionally be seen as constituting a mode of insight into our own concrete situation (both our practical situation and, more fundamentally, our existential situation), hence *phronesis* constitutes a mode of self-knowledge (Malpas, 2009). To put the point more generally, and in more basic ontological terms, if we are to understand anything at all, we must already find ourselves in the world along with that which is to be understood. It follows that to understand anything concerning Te Ao Māori it is to our advantage to be of the Māori world along with that which is to be understood. For example,

⁹⁴ The *Nicomachean Ethics* (is the name normally given to Aristotle's best-known work on ethics. The work, which plays a pre-eminent role in defining Aristotelian ethics, consists of 10 books, originally separate scrolls, and is understood to be based on notes from his lectures at the Lyceum).

if we wish to understand a piece of carved art based on Māori tradition, we already need to have some prior understanding of that work even if only as a set of indents and grooves set in wood. Understanding always occurs against the background of our prior involvement in life. Understanding, for Gadamer, is thus always an effect of history, a 'historically-effected consciousness'. Awareness of the historically affected character is, according to Gadamer, identical with an awareness of the hermeneutical situation. Thus, it was important to begin this thesis with the prologue that describes my situatedness in terms of historicity and my knowing in relation to the historical background in relation to the place I was raised.

According to Malpas (2009), meaning emerges not as an object that lies in the text or in the interpreter, but rather an event that results from the interaction of the two. For Gadamer (1960), interpreting a text involves a fusion of horizons. Both the text and the interpreter are interlocked within a specific historical tradition, or horizon. Each horizon is expressed through the medium of language and both text and interpreter belong to, and participate in, history and language. This belongingness within culture is the common ground between interpreter and text that makes understanding possible. As an interpreter seeks to understand text, a common horizon emerges. This fusion of horizons does not mean the interpreter now fully understands a subject, but is an event in which a world opens itself to him. The result is a deeper understanding of the subject matter.

Hans-Georg Gadamer was born on February 11, 1900, in Marburg, in Southern Germany. He grew up in Breslau (now Wroclaw in Poland), where his father was Professor of Pharmacy at the University of Breslau. Showing an early interest in humanistic studies, he began university studies in Breslau in 1918, moving to Marburg with his family in 1919, and completing his doctoral studies in 1922. During the 1930s and 1940s, Gadamer accommodated himself, albeit reluctantly, first to National Socialism and then briefly, to Communism. Nevertheless, his scholarship is considered untainted by such associations (Palmer, 2002). His main philosophical impact was not felt until the publication of *Truth and method* in 1960. He engaged in numerous important public debates in the following decades, most notably with Emilio Betti, Jürgen Habermas, and Jacques Derrida. Gadamer was twice married, in 1923 to Frida Kratz (later divorced) and in 1950, to Käte Lekebusch. Gadamer received numerous awards and prizes including

Knight of the Order of Merit, the highest academic honour awarded in Germany. Gadamer died in Heidelberg on March 13, 2002, at the age of 102.

Hermeneutics - Assumptions

Gadamer's hermeneutic philosophy places emphasis on language and extends Heidegger's existential ontological exploration of being and understanding. Gadamer's key philosophical underpinnings are encapsulated in metaphors including the hermeneutic circle, dialogue, and the fusion of horizons (Gadamer, 1960). The essence of Gadamerian Hermeneutics can be expressed through the following expressions:

- Hermeneutic phenomenology is concerned with the life world or human experience as it is lived;
- Language is the universal medium in which understanding occurs. Hermeneutics must start from the position that a person seeking to understand something has a bond to the subject matter that comes into language through traditional text and has, or acquires, a connection with the tradition from which it speaks;
- Language and understanding are inseparable structural aspects of human 'being-in-the world';
- Understanding occurs in interpreting;
- Interpretation is viewed as a fusion of horizons, a dialectical interaction between the expectation of the interpreter and the meaning of the text;
- Prejudice is a condition of knowledge and determines what we find intelligible in any situation. These understandings are based on our 'historicality of being' and all understanding will involve some prejudice (p 295).

In developing a Gadamerian based research method on hermeneutic research in nursing, Fleming (2002) stipulated a five step programme on how the research should be carried out: (1) deciding upon a research question; (2) identification of pre-understandings; (3) gaining understanding through dialogue with participants; (4) gaining understanding through dialogue with text; and (5) establishing trustworthiness (Fleming, Gaidys, & Robb, 2003). The five steps espoused by Fleming et al. thus sets the framework for ongoing description of the approach adopted for this study.

Combining hermeneutics with Kaupapa Māori for this study means the textual interpretation of meaning recognises that participants capture their experience in the language of who they are against the socio-cultural background of their place of origin, in this case Māori participants who whakapapa to Taranaki. As the researcher for this study I also bring my own interpretive lens corroborated by my own life journey as outlined in the prologue and chapter one. Furthermore, the cultural values, notions and ways of understanding the world as espoused within Kaupapa Māori will inform all interpretation.

4.3 Kaupapa Māori Research Methodology

The organisation of Māori knowledge and the holistic manner by which the Māori world is viewed is important to Māori when research is done on Māori. It is my experience that Māori will not part with knowledge too readily as the notion of indiscriminately imparting knowledge which has been passed down through many generations is extremely tapu and if used inappropriately, serves only to reduce the tapu and the mana of the whānau. If we are to conduct research on/with Māori, it is essential that we understand Kaupapa Māori and the application of research principles and assumptions from a Māori world view.

Kaupapa Māori Research Principles and Assumptions

According to Durie, Kaupapa Māori research methodologies are underpinned by three main assumptions: (1) Māori have a distinctive world view and manner by which to organise knowledge in accordance with the distinctive nature of Māori knowledge⁹⁵; (2) Its relationship with other bodies and forms of knowledge; and (3) Māori experiences are at the centre of the research activity (Durie, 1998a). These assumptions are vividly illustrated in the methodological basis for Māori research because they are underpinned by traditional folklore and history. Passed down verbally from generation to generation, this in the Māori world provides the best form of evidence. The organisation of Māori knowledge and the holistic manner by which Māori view their world is important and in this respect, whakapapa is paramount as it epitomises all the major components of Māori knowledge. Kaupapa Māori principles guide researchers when they conduct research that is by Māori for Māori. In this mode of research, the

⁹⁵ Maturanga

researcher's position is established through the process of whanaungatanga. Whanaungatanga consists literally of kin relationships between ourselves and others. Kaupapa Māori research, therefore, articulates a reciprocal relationship between the researcher and research participants. The relationship between researcher and participants in this study was an important aspect. My whakapapa is firmly entrenched in Taranaki and the appropriate area to conduct interviews for this study was in Taranaki, the place where I was born, the place where I was raised, and the place where our family is known. In discussing the life story interview Atkinson (2001) argued that stories have the power to connect us with the deepest part of ourselves:

The reason we tell our stories today can be traced to the original functions of the earliest known stories. Myths and folktales have traditionally served four classic functions: bringing us into accord with ourselves; with others; with the mystery of life and with the universe around us. A living mythology contains symbols, motifs, and archetypes that speak to us on a fundamentally human level; they reverberate beyond the personal and into the collective realm. They carry a power that connects with the deepest part of ourselves. Sacred, or traditional, stories touch a centre of life that we all have within us. (p. 122)

Atkinson argued that both research context and research process are fundamental to understanding lifestyle stories and what comes out of research are interconnected aspects of the research journey. The analogy that Atkinson proposed is consistent with prevailing principles and assumptions of Kaupapa Māori research. Smith (1990) outlined some working principles specifically for the purposes of research involving Māori. Whakapapa, which is defined generally as being 'genealogy', also describes the way in which Māori view the world. It is a way of thinking, learning, and storing and debating knowledge. In terms of Kaupapa Māori research whakapapa is integral as it allows for the positioning and contextualising relationships between people, communities, participants, landscape, and the universe. Principles advocated by Smith applicable to this study include the principle of te reo, the principle of rangatiratanga, the principle of extended family structure and the principle of collective philosophy.

The Principles of Te Reo and Tikanga Māori

Te Reo Māori is integral to Kaupapa Māori. The way in which we communicate with each other as Māori provides an insight into the way we interact with the

world and the way in which we build and maintain relationships. Tīkanga⁹⁶ Māori refers to customary practices, ethics, cultural behaviours, considerations, and obligations that Māori have with each other. Tīkanga is important as it enables Māori to navigate and operate within a Māori context and make judgements and decisions within that space (G. Smith, 1990).

The Principle of Rangatiratanga

The notion of Rangatiratanga, or autonomy, is also relevant in the research process in terms of allowing Māori to shape their own research processes. Smith, on Kaupapa Māori research asserted that research on Māori is related to being Māori, is connected to Māori philosophy and principles, takes for granted the validity and legitimacy of Māori, the importance of Māori language and culture and is concerned with the struggle for autonomy over our own cultural wellbeing (G. Smith, 1990). The above recommendations ensure the issues related to power and control before, during, and after the research relationship is addressed and then aligned with Māori aspirations for knowledge development and transformation where qualitative assumptions such as trustworthiness and credibility are important aspects.

The Principle of Extended Family Structure

The principle of whānau sits at the core of Kaupapa Māori. It acknowledges the relationships that Māori have with one another and to the world around them. Whānau, and the process of whanaungatanga is a key element of Māori society and culture. This principle acknowledges the responsibility and obligations of the researcher to nurture and care for these relationships and the inherent connection between the researcher, the researched, and the research (G. Smith, 1990). In keeping with these obligations, I have maintained contact with the participants in this study for the past three years.

The Principle of Collective Philosophy

The principle of collective philosophy refers to collective vision, aspiration and purpose of Māori communities. Larger than the topic of the research alone, the kaupapa refers to the aspirations of the community. The research topic or intervention systems, therefore, are considered to be an incremental and vital

⁹⁶ A correct set of protocols in a Maori context

contribution to the overall 'kaupapa' (G. H. Smith, 1990). In the context of this study, research on bowel cancer is being done in order that health providers and institutions can take the learnings gained from participant experiences and apply new knowledge to practice. Over the last 12 months there has been an increased awareness about bowel cancer in Taranaki among Māori due in part to the coverage that this study has received in the media⁹⁷. In 2015, the passing of one of the participants of this study drew widespread comment in the Taranaki Daily News. There was a clear message that there is a need for Māori to become more aware of what bowel cancer is and how to overcome the asymptomatic nature of how bowel cancer develops.

The Principle of Pono

The Williams Māori Dictionary (1971) provided a translation of pono as true. Ryan (1995) gave similar meanings as truth, valid. Tate (2010) used the word pono to depict truth and used the following illustrations to make his point: *kia pono te mahi* (to work honestly or with integrity); *pono marika*, in context to mean (true indeed); *pono marika, koia rawa tēnā*, in context to mean (true indeed, that is the reality). The usage of pono in this sense can indicate that people have become truly enlightened through some occurrence or what has been said by someone. They can now perceive the reality or the truth of a situation that they had not previously been fully aware of, or were not aware of at all. According to Tate, (2010) pono used in this sense enlightens people in their perception of reality and truth. Tate posited the following definition of pono:

Pono is a principle of perception of truth by which we address tapu and mana. It is an ethical principle of action in that it qualifies how we manifest, address, enhance, sustain and restore tapu and how we exercise mana. It consists in truly and fully acknowledging tapu, in all its relationships with Atua, tangata and whenua and in responding with integrity to tapu by the full exercise of mana. It is the basis of another principle, tika. (p. 88)

The Principle of Tika

The Williams Māori Dictionary (1971) defined tika as meaning direct, keeping a direct course, just, fair, right and correct. Tika is usually used as an adjective and describes something or someone as being right, proper, in order, in right

relationship. A derivative of tika, tikanga is the noun form of tika. Marsden and Henare (1992) described tikanga as a method, plan, reason, custom, a course of action, while adding another important aspect, that is – the right way of doing things. We can also say the right way of doing things in a moral as well as social sense. For the purposes of this study, I now focus on the definition of tika according to Tate (2010):

Tika is the second of the three principles by which we manifest, address, enhance, sustain and restore tapu. It consists in right acknowledgement of tapu and mana, and right ordering of relationships among Atua, tangata and whenua, and appropriate response to tapu by the right exercise of mana. It presupposes pono and is, in its turn, the presupposition of aroha. (p. 96)

The Principle of Aroha

The Williams Māori Dictionary (1971) defined aroha as love, yearning for an absent friend, pity, compassion and affectionate regard. The concept of aroha describes the quality of a relationship between or among persons. There are several derivatives of aroha; however, in the context of this study aroha will be used in the analysis when describing relationships between Atua and tangata⁹⁸ and between tangata and tangata⁹⁹. Tate (2010) defined aroha as:

Aroha is one of the three principles governing the relationships among Atua, tangata and whenua, by which we manifest, address, enhance, sustain and restore tapu and exercise mana. Aroha is love, namely, a principle of communion and of action by which the fullness of tapu of some (and implicitly, all beings) is manifested, addressed, enhanced, sustained and restored in affection, compassion, sacrifice and generosity, by the right and gratuitous exercise of mana. (p. 105)

Tate's definition tells us that a true and rightful Kaupapa Māori process adheres to a systematic engagement protocol when we engage with other beings – be it Atua, other tangata, or whenua. The process in strict order of engagement is: pono; tika; and aroha. Altering the order can significantly change an outcome. If, for example, a care plan for a patient was structured by health professionals without the input by that patient and his/her whānau, the plan would be structured in accordance with the health professional's viewpoint only, thereby negating the principle of pono. When care plans

⁹⁸ The aroha that exists between people and God

⁹⁹ The aroha that exists between people and other people

proceed, in the first instance, without due consideration of the principle of pono then the correct and rightful pathway, based on tika, may be compromised from the outset. Such practice has the potential to create dependency on services where patients can remain in the service for extended periods of time, in some cases for years. Possible outcomes might include multiple admissions to healthcare services, inappropriate assessments from a cultural perspective, ongoing missed appointments (DNAs) and so on.

4.4 Māori Consciousness and the Concepts of Tapu and Noa

The concepts of tapu and noa, as a healing intervention in today's health environment is often sought by Māori who have been diagnosed with a serious chronic illness. This is especially so when the illness has been difficult to diagnose despite the seriousness of symptoms. This type of illness is often seen as 'mate Māori' or Māori sickness. The usual and often only successful intervention is carried out by a tohunga or Māori healer. Much of the work of traditional healers depends on drawing distinctions between tapu and noa and re-establishing balance between the two. The diagnostic process was therefore directed at uncovering any breach of tapu so that the somatic reaction might be better understood. A detailed case history thus involved the patient and his/her whānau where the focus was on any violation of tapu, be it Atua, other tangata, or whenua.

Whakanoa as a Derivative of Noa

The Williams Māori Dictionary (1971) defines whakanoa as:

1. Make or consider free from tapu;
2. Remove or abrogate¹⁰⁰ tapu. (p. 222)

Whakanoa is the derivative verb form of the word noa. It is the act of rectifying a violation thereby inducing a state of noa. The Williams Māori Dictionary defines noa as:

free from tapu or any other restriction, ordinary. (p. 223)

The common meaning for 'noa' is used to signify a positive meaning, free from tapu or restriction. An example where whakanoa is enacted is the process for powhiri where visitors who upon entering a marae for the first time and subject to

¹⁰⁰ To nullify

tapu restrictions, go through a process where the tapu restriction is lifted. The concept of whakanoa can also have negative connotations. This occurs when a person or people 'puts down' another person or people. This act is referred to as - *te takahi*, or to trample a person or peoples tapu and/or mana.

Māori believe that there are reasons as to why people exhibit certain behaviours associated with illness. Questions arise as to the possible causes of the illness, has there been a violation of a sacred site? Where have you been and what have you done in your life for something like this to happen? Māori have certain beliefs around the concept of tapu and such transgression can lead to some form of punishment. Any violation of wāhi tapu, such as ancient burial sites, places of sacredness, and locations that are strictly out of bounds, are in this category. Wāhi tapu sites exist whether you know about them or not and a person may not be aware that such violation has been committed. A person may then be subjected to ongoing episodes of ill health that cannot be diagnosed or remedied by Western medicine. In desperation, Māori will often turn to traditional sources of healing by consulting a tohunga in the hope that the source of the violation can be revealed. Tate (2010) asserted that Māori who find themselves in this situation exist in diminished tapu as the result of some form of violation toward Atua, tangata, or whenua. The corresponding behavioural patterns of the unwell person, the tell-tale signs that lead to suspicion that a violation has occurred are exposed. Tate's definition of negative noa therefore can be understood as:

The act of violation by which the tapu of Atua, tangata and whenua is diminished, and the exercise of their mana is obstructed or impaired. (p. 131)

Tate thus separates the above definition into three components: whakanoa is the act of violation; the tapu of Atua, tangata and whenua is diminished; the exercise of their mana is obstructed or impaired. Whakanoa thus, can be understood, depending on the context, as violation in general, or as a very specific act of violation. The following section examines some of these elements in the context of negative noa.

Whakanoa i te Hauora o te Tangata¹⁰¹

According to Tate (2010), whakanoa i te hauora o te tangata are acts that diminish the physical health and wellbeing of the person through which a violation of the human body has occurred. Specific acts that diminish the physical wellbeing of people and that cause injury or inflict unnecessary suffering fall into the category of negative noa. Thus, *patu tamariki*, physical violence on children, *patu wahine, tāne*, physical violence on women and men, *mahi pūremu*, illicit sexual acts, sexual abuse and *ngau whiore*, incest, are all acts of whakanoa i te hauora o te tangata. Whakanoa i te hauora o te tangata also includes self-inflicted injuries such as *haurangi* (drunkenness), *momi hikareti me te kai taru* (smoking and taking of illicit drugs) and *puku kai* (excessive consumption of food). All these acts of whakanoa can inflict physical and mental injury on the body thereby diminishing one's intrinsic tapu where the body is open to the harmful effects of substance abuse, disease or injury. Whakanoa can be either deliberate or accidental. The above scenarios of whakanoa, which involve acts that diminish the physical health and wellbeing of the person, are perceived as deliberate.

4.5 Mauri - A Method to Determine Behavioural Patterns of Māori Experiences of Bowel Cancer

In envisioning this thesis I came to see the importance of incorporating the concept of mauri as espoused by Pohatu (2011). Pohatu's reasoning enables a process for recognising the various states of mauri, namely, mauri moe, mauri oho and mauri ora, for Māori whānau who have experienced bowel cancer. Mauri enables us to determine behavioural patterns of where participants are in their journey at any given point in time, their immediate feelings, thoughts and anguish associated with being diagnosed with bowel cancer. Such feelings may include anxiety associated with the unknown, the experience of colonoscopy, the experience of invasive surgery, the experience of after surgery care and experiences between themselves, health professionals, and the health system.

Tapu as Antecedent to Mauri

Mauri as an interpretive approach for this study is contextualised as an approach that offers unique angles from which the potential of mauri may be considered in

¹⁰¹ Acts that diminish health and wellbeing of a person

relation to tapu. It allows for greater understanding of wellbeing of Māori when we examine tapu in all its possibilities as the source and antecedent to states of being of mauri. Tapu as antecedent to mauri adopted for this study has thus been categorised in accordance with three states of being of mauri namely:

- diminished tapu – to exist in mauri moe;
- enhanced tapu - to exist in mauri oho;
- restored tapu - to exist in mauri ora.

Diminished Tapu as a State of Being of Mauri Moe.

The state of being of mauri moe expresses thoughtfulness in terms of inactivity, including the manifestation of isolation withdrawal and non-participation (T. Pohatu, 2011). The behaviours mirror inhibitors to progress and are grounded in responses framed within the notion of mamae and its negative elements of neglect, hurt, pain, anguish, and sorrow. Reflecting on these perspectives offers researchers a platform on which to conduct analysis. Māori experiencing mauri moe are continually in a state of flux where instability can lead to fragility, deep anxiety, and ultimately depression. These expressions increase our awareness of certain behaviours by examining the core issues and seeking answers as to why certain behaviours are being exhibited, through the concept of tapu where the intrinsic tapu of a person has been diminished.

Enhanced Tapu as a State of Being of Mauri Oho

Mauri oho is considered a proactive state. There has been a definite shift in a person's wellbeing to spur interest and a willingness to participate and become involved in their recovery. According to Pohatu (2011):

The mauri ora blueprint of being willing to move outwards and engage with others is also affirmed as integral to the normal pattern of engagement for the state of mauri oho. Significantly, it indicates a point of personal courage, the manawanui, kia kaha (be strong) notion. As people strive to face and manage their fear so do they locate inner strength and understand more about their personal courage and therefore the potential to proactively engage and advance. (p. 3)

The following expressions signal markers to identifying states of being of mauri oho that can increase our awareness of and understanding as to how and why the various 'states of being of mauri oho' occur. Mauri oho denote actions and

expressions of activity, an awakening, a new beginning, a rebirth. Participants signal their willingness to participate in activities and or discussions about their wellbeing and begin to share their inner views with others. That can prompt thoughts about past lifestyle options as they look back retrospectively on life and plan for a new and better future. Again, the expressions increase our awareness of certain behaviours by examining the core issues through the concept of tapu where the intrinsic tapu of a person has been enhanced.

Restored Tapu as a State of Being of Mauri Ora

Mauri ora signals increased energy and awareness that comes from a high level of energy. There is an obvious purpose for being and a willingness to actively engage in enjoying a future with loved ones and all other relationships of which we are part. The following expressions signal markers to identifying states of mauri ora that can increase our awareness of and understanding as to how and why the various 'states of being of mauri ora' occur. States of being of Mauri Ora find expression in actions and knowledge that signify successful outcomes and where participants become highly motivated by what is happening to them in terms of their wellbeing. It is the stage in their journey where they are feeling good about their health, where they remain alert and actively engaged in and committed to keeping good health. These behaviours are further heightened by stronger family relationships and social engagement in the community. Again, the expressions increase our awareness of certain behaviours by examining the core issues through the concept of tapu where the intrinsic tapu of a person has been restored.

4.6 Summary

In keeping with a Kaupapa Māori approach, research methods for this work were discussed by applying current research approaches collectively known as Kaupapa Māori. Gadamer's hermeneutic philosophy was also considered an important component of this study. Gadamer's hermeneutical methodology is part of the fundamental process of interpreting texts. Gadamer's philosophy thus complements Te Ao Māori where interpretation of participant stories and hence text, comes from within a worldview that is Maori and within the domains of whakapapa, mauri and tapu. The principles of Kaupapa Māori research and their associated ethical commitments were also discussed in this chapter. These

methods draw on philosophical aspirations expressed by other Kaupapa Māori researchers and academics that acknowledges the epistemological and ontological realities that are embedded in a Kaupapa Māori approach.

CHAPTER FIVE: METHOD

5.1 Introduction

Chapter five focuses on the story of doing the research. Ethical considerations also included consultation with iwi for approval to do the research. Measures to protect participants, including privacy and confidentiality issues, were also put in place. Gathering information for the study involved engaging participants to conduct interviews which were then transcribed and the transcripts verified by the participants themselves. The verified transcripts were furnished as stories in the first person. Finally, a framework is presented on how the analysis was conducted for this study. The research design of the study is depicted in Figure 6 below.

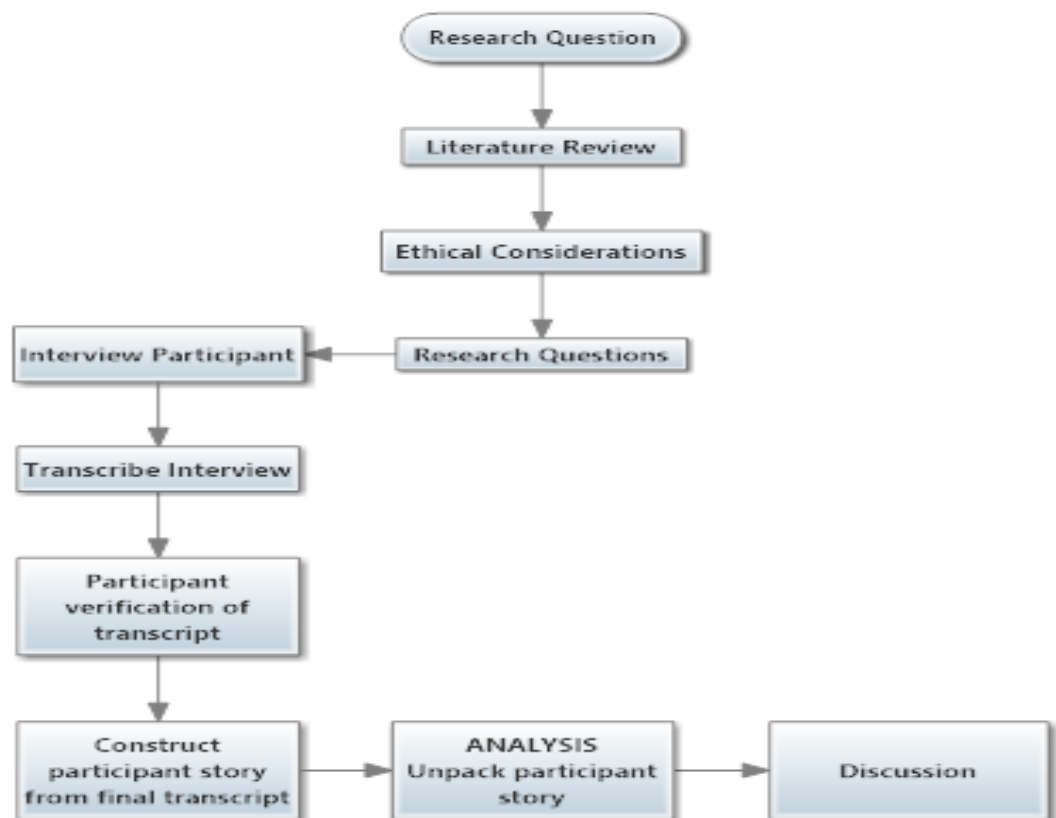


Figure 6: Research design

5.2 A Kaupapa Māori Approach

It is perceptible that the values of the researcher (and indeed those being researched) played a central role as to why this study was conducted. The

mythologies surrounding Tāne-mahuta's¹⁰² journey into the heavens and his search for a female principal provide the best introduction to Māori theoretical approaches to research. His journey into the 12th heaven saw him gain access to nga kete wānanga¹⁰³. His quest for knowledge sought to provide hauora¹⁰⁴ for all humankind. Tāne Mahuta's pursuit, carried out on behalf of his brothers, for the uha¹⁰⁵, arose from a desire to benefit the group (Buck, 1949). Collective requirements and benefits were, therefore, the recurring motives for Tāne Mahuta's quest. The notions of collective need, the requirement for a consultation process, collective accountability, and collective benefits are grounded in Māori attitudes to knowledge embedded within the mythologies surrounding Tāne Mahuta's¹⁰⁶ journey into the heavens. The approach to inquiry throughout this study takes cognisance of the above elements which form the basis of interpretation from a Kaupapa Māori world view. The task of inquiry involved matching research questions to a set of appropriate research strategies to provide in depth understanding of Māori whānau who have experienced bowel cancer in their lives. The title for this study is thus: *The experience of living with bowel cancer for Māori in Taranaki*.

5.3 Engaging Participants

All 10 participants recruited for this study whakapapa to iwi of Taranaki. Participants were interviewed kanohi ki kanohi¹⁰⁷ in an environment where they felt comfortable and in most instances, this was done in their homes. The observation of tikanga was integral to the engagement process which included mihimihi¹⁰⁸, whānaungatanga¹⁰⁹, karakia¹¹⁰, and kai hākari¹¹¹. Consent to be involved in the study was sought prior to conducting the interview.

¹⁰² God of the Forest

¹⁰³ The three baskets of knowledge

¹⁰⁴ wellbeing

¹⁰⁵ The female principal necessary for the creation of humankind

¹⁰⁶ God of the Forest

¹⁰⁷ Face to face

¹⁰⁸ Speeches

¹⁰⁹ Linking of relationships

¹¹⁰ Prayer

¹¹¹ Kai/kapu ti

5.4 Ethical Considerations

Consultation with Iwi

This study received ethical approval from the Auckland University of Technology Ethics Committee (AUTEC) on 17th May 2013 for three years. Application 13/86 (Appendix D).

As the primary researcher in this study I have a direct whakapapa to whānau, hapū, and iwi of Taranaki. Such belonging has led to constant consultation concerning other projects concerning Māori health in Taranaki over several years. The study was presented to Te Kaunihera O Te Atiawa Nui Tonu¹¹² on April 23, 2013 where it received unconditional support, including support from health professionals from the Taranaki District Health Board and Tui Ora Primary Health Organisation.

Accessing Participants

The quest to find participants for the study began by placing advertisements in the regional and community newspapers (Appendix E). A single page research flyer was also distributed at whānau hui inviting people who have experienced bowel cancer to participate in the study. Information, including contact details of the primary researcher, was noted on the flyer (Appendix E). The initial advertisement in the Taranaki Daily News sought potential participants who were willing to share their stories of what it means for Māori to experience bowel cancer in their lives. A second advertisement was published in the Taranaki Daily News and the regional midweek news. This was followed up by an article I wrote which was published in the community newspapers in Taranaki. The article, which drew widespread interest, was circulated to every household in North and South Taranaki.¹¹³

Informing Participants

As calls to participate in the study were received from whānau, appointments were organised to meet to go over the research documents. Participants were

¹¹² Kaumatua group

¹¹³ North Taranaki Midweek, July 16, 2014; South Taranaki Star, July 17, 2014

sent information sheets including a consent form (Appendix D) via post so that they could go over the documents for up to two weeks before the meeting. This allowed potential participants and their whānau time to consider whether they wanted to participate. Prospective participants were then visited to verify their participation in the study. Care was taken to explain the research in a language they could understand. Those who consented to participate were then interviewed for the study. Audio-taping of interviews was part of the consenting process.

Protecting Participants

A comprehensive information sheet (Appendix D) was presented with full explanations regarding the following issues pertaining to the research:

- The purpose of the research;
- That their involvement would be voluntary and that they could withdraw at any stage of the study if they so wished;
- What will happen with the research;
- Any discomforts and risks, and measures to alleviate any such event;
- How the research will benefit Māori and;
- Protection of privacy and confidentiality of information.

Privacy and Confidentiality

Participant privacy issues and confidentiality of information remain in confidence with me, the primary researcher. In terms of interview transcripts, I provided pseudonyms for all participants involved in the study. Participants, therefore, could not be identified at any stage of the research process other than by myself. Information provided by participants, as included in a report or published will be done in a way that does not identify them as its source. The consent forms have been given to my primary supervisor for safe storage. Table 2 (p. 73) provides a summary of the participants who took part in the study.

Table 2: Overview of participants

Age	Gender	Time since interview	Story included with thesis	Story included in appendix B	Domain
39	Male	2 years	Yes		Mauri Moe
73	Female	2 years	Yes		Mauri Moe
29	Male	2 years	Yes		Mauri Oho
52	Male	2 years	Yes		Mauri Oho
42	Female	2 years	Yes		Mauri Ora
79	Male	2 years	Yes		Mauri Ora
65	female	2 years	Yes		Mauri Ora
37	Female	2 years		Yes	Mauri Ora
42	Male	2 years		Yes	Mauri Ora
67	Female	2 years		Yes	Mauri Ora

Koha

The impact on participants was minimised as there was no requirement for them to travel. All interviews were conducted either in the homes of participants or in an environment of their choosing. At the completion of interviews each participant was given a \$50.00 PAK N SAVE grocery voucher.

Provision for Counselling

For instances where impairment to health occurred, due to unforeseen psychological events, participants were given an option for counselling with the New Zealand Cancer Society, CancerChatNZ, toll free number (0800 226237). Participants were also provided a second option to contact Ngaropi Cameron, the Chief Executive for Tu Tama Wahine o Taranaki Incorporated who confirmed that they would cover counselling needs that may arise for participants should they request it. This information was included on the Participant Information Sheet. There were no requests for counselling by participants in this study.

5.5 Research Questions

The questions for this study were aligned to a need to facilitate greater awareness and knowledge of the experience of bowel cancer for Māori. The purpose was to elucidate deeply engrained social and cultural aspects pertaining to bowel cancer. Stories of the lived experience of surviving with bowel cancer can provide graphic accounts of surviving with bowel cancer, the experience of not wanting to know, the experience of knowing, the experience of colonoscopy, and the experience of post-surgery care. There is a dearth of literature on Māori lived experience of bowel cancer. The interview questions (Appendix D), thus formed the thinking I took to each interview and in most cases, acted as prompts only. Thus, the list of my questions became more of a checklist to review at the end of the conversation to see if there was any ground I had not covered.

5.6 Semi-structured Interviews

The semi-structured interview format for this study was conducted in a way that left participants feeling at ease. Most of the interviews were conducted from a Kaupapa Māori positioning which included elements of karakia, mihihihi, whānaungatanga, and kai hākari. Interviews were structured to allow participants to freely express their views and experiences without being limited in any way about what they wanted to say. It was about their story as told. Four of the participants were interviewed for a second time. Repeat interviews were conducted only when participant responses were unclear and required further clarification. All interviews were transcribed ad lib and posted to participants for verification. Any alterations that needed to be made to the text were then made by participants. Once the interview transcripts were returned by participants the stories were then crafted to hold the key forms to ensure easy readability (Crowther, Ironside, Spence, & Smythe, 2016).

The Fit Between Research Questions and Methodology

This study searches to uncover hidden elements in our quest to understand Māori more fully, both as patient and whānau who share in the emotional journey of a loved one who has been diagnosed with bowel cancer. Participant stories of substance or origin relates to the realm of whakapapa, the stories construct which relates to the realm of mauri and the stories meaning which relates to the realm

of tapu. The concepts of whakapapa, mauri and tapu, in the context of this study, were the principle concepts in the process of analysis.

5.7 Unpacking the Stories – Working with the Data

Interpretive lens

I now posit the following example to illustrate how Gadamer's hermeneutic interpretive methodology can be utilised to furnish deeper meaning through the dialectical relationship between the researcher and the text of participant stories. A participant in this study made the following comment, "Did you know my husband had a PhD?" I remained momentarily stunned. I had not seen the person in question for the past 12 years and I knew the whānau well. My immediate thought was - how was this possible? She then explained that her comment in relation to PhD referred to 'putting hāngī down'. I am aware that Māori can sometimes use humour as a way of conveying a message. I pondered with that comment for some time, what was the real message? My intrusion into a deeper mode of thinking was influenced by Gadamer's method of unpacking data. The realisation of what she meant emerged through continued reference to the text. It was a meaning furnished out of the hermeneutic practice of enacting the hermeneutic circle, the back and forth motion of a dialectical relationship between myself as the researcher and the text. What she was referring to was the fact that her husband had been the principle manaaki person for the marae for many years, putting hāngī down. He taught the youth of the marae all the skills necessary to cater for special occasions, large or small. It did not matter whether he was preparing a hāngī for five people, a hui gathering of 50 people or a festive occasion involving up to 5,000 people. He was the head chef for the marae – the main hāngī person. As far as his wife, his tamariki, and the people were concerned that was his PhD. He had earned it over many years and possessed great tapu.¹¹⁴ The fusion of horizons shows itself in the following way: the comment at-the-moment of telling was perceived more as a joke and I as the receiver treated it as such. The back and forth motion between myself and the text existed for months. That continual back and forth motion was in fact the process of enacting Gadamer's theory of unpacking stories because the

¹¹⁴ Tapu whakahirahira

dialectical relationship over time between researcher and the text revealed that behind the joke was the deeper meaning.

The new meaning then imbued the original superficial interpretation. The real and deeper meaning showed itself and the perception of 'joke' was superseded. I now had a different perception through a fusion of horizons – a perception that was now pono, to be true. When Māori cater for others on the marae the concept of manaaki takes centre stage. Manaaki is the exercise of mana when we welcome and entertain others who arrive as visitors to our home or marae. The exercise of manaaki in this scenario is a pragmatic way of addressing and enhancing the tapu of visitors while at the same time preserving the tapu and the mana of the hosts. The texts of all participants in this study were thus unpacked using the same method. Once I started re-reading the stories through these dynamic notions the meaning of the experience shone through. I thus moved beyond the physical experience to consider a much more holistic perspective, moving between the parts and the whole (Van Manen, 1997). The key notions that underpin my analysis are thus whakapapa, mauri and tapu.

Tapu is Dynamic

Tate (2010) defined tapu as being-in-itself, to be or to exist. The realm of tapu challenges us to seek answers as to why people are feeling the way they are at any given point in time. According to Tate, tapu is dynamic (Figure 7) and can be diminished, enhanced, and/or restored.

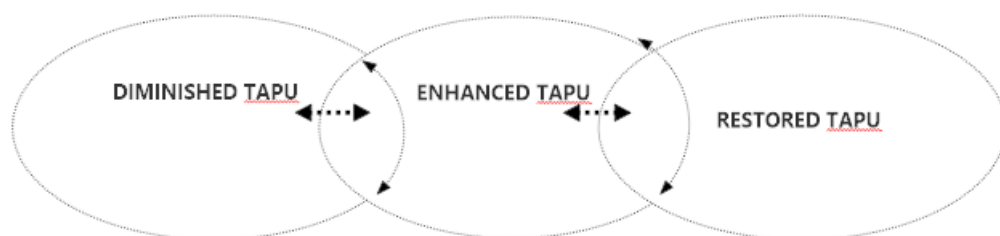


Figure 7: Tapu is dynamic

Mauri is Dynamic

Pohatu (2011) has a specific focus on mauri in relation to human wellbeing. Pohatu asserted that mauri is dynamic (Figure 8) and subject to changes associated with behavioural patterns linked to mauri moe, mauri oho, and mauri ora.

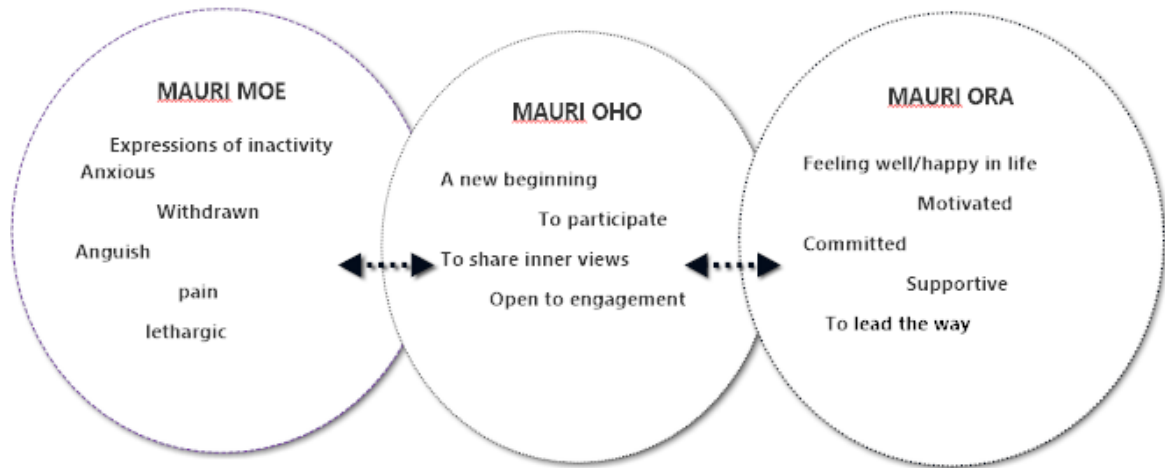


Figure 8: The behavioural patterns linked to mauri

In the following section I allude to the intersecting circles and arrows (Figure 9) which represent the dynamic movement of mauri. The double arrows connecting circles represent the potential of mauri to shift in either direction. Such movement can happen in a positive way – for example from mauri moe to mauri ora. Mauri can also gravitate in a negative direction – from mauri ora to mauri moe.

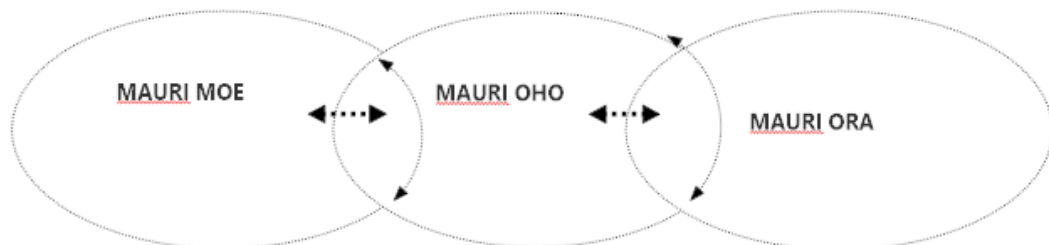


Figure 9: The dynamic movement of mauri

Tapu as Antecedent to States of Mauri

I now posit a correlation between the concepts of tapu and mauri. Tapu is expressed as antecedent (that which come before or underpins) to states of mauri. Mauri has thus been expressed as a way of recognising behavioural patterns for participants and their whānau when they speak of their experiences of living with bowel cancer. According to Tate (2010), tapu is dynamic and can be diminished, enhanced, and/or restored. Pohatu (2011) asserted that mauri can change in the same dynamic way. Tapu has thus been postulated in this study as antecedent to the three states of mauri, diminished tapu as a state of mauri moe, enhanced tapu as a state of mauri oho, restored tapu as a state of mauri ora. The framework (Figure 10) combines the two theoretical perspectives. Mauri, Rethinking Human Wellbeing, as espoused by Pohatu, and tapu as being-in-itself, to be or to exist, as advocated by Tate.



Figure 10: Tapu as antecedent to states of mauri

5.8 Analysis

Marsden and Henare (1992) have postulated that the retelling of Māori history, by describing events that occurred and the heroes and villains associated with those pieces of history is only one aspect of the Māori cultural set. They were deeply concerned with the lack of exploration of the inner consciousness of the Māori mind undertaken by scholars. In their view, only an approach that describes the main features of the consciousness of Māori is acceptable. It offers a way of looking at what is regarded as real in the world for Māori (M. Marsden & Henare, 1992).

The inner consciousness of the Māori mind is something worthy of further comment; for even Māori themselves, in contemporary times must understand intimately more about themselves instead of taking for granted their Māoriness¹¹⁵. People must therefore, possess a sense of consciousness about what being is about. A response to Marsden and Henare's assertions on the concept of being and Māori consciousness has in recent times been the focus of two Māori academics and scholars, Dr. Pa Henare Tate and Taina Pohatu. Tate's PhD thesis, *Towards, some foundations of a systematic Māori theology*, examines in some depth the inner being of Māori consciousness and thought through the concepts of tapu in relation to the principles of pono, tika, and aroha.

The realm of whakapapa in the context of this study assumes the genealogical position of participants' existence in the world as Māori. The realm of whakapapa also relates to the stories' substance of origin and constitutes the first consideration in analysis. Pohatu proposed that the concept of mauri be expressed as a window to rethinking human wellbeing, a viewpoint that examines mauri at any given point in time in a person's journey in life. He asserted that mauri holds a central place in informing us how our lives take the form they do. In terms of this study, mauri is about the behavioural patterns or the indicators that Māori exhibit when changes in their wellbeing occur. Mauri in the context of this study, therefore, becomes the second consideration when we are interpreting participant stories because it enables us to put some interpretation on how they perceive their personal wellbeing at a given point in time.

Both Tate (2010) and Pohatu (2011) proposed approaches 'to the state of being' that are closely interconnected. In terms of this study the dynamic movement of tapu is about the ontological meaning of being and allows us to understand why people exhibit the various behavioural patterns that equate to changes in mauri, be it mauri moe, mauri oho, or mauri ora. The unpacking of participant stories from a hermeneutical perspective is viewed as a fusion of horizons between the expectation of the interpreter and the meaning of the text. The Gadamerian tradition compels the reader to continually explore a given text to source the deeper interpretation connected to an experience. Participant stories were

¹¹⁵ Outwardly, our Māoriness can be very evident but we can still know very little about the inner self of being Māori

analysed by incorporating the concepts of whakapapa, mauri, and tapu (Figure 11).

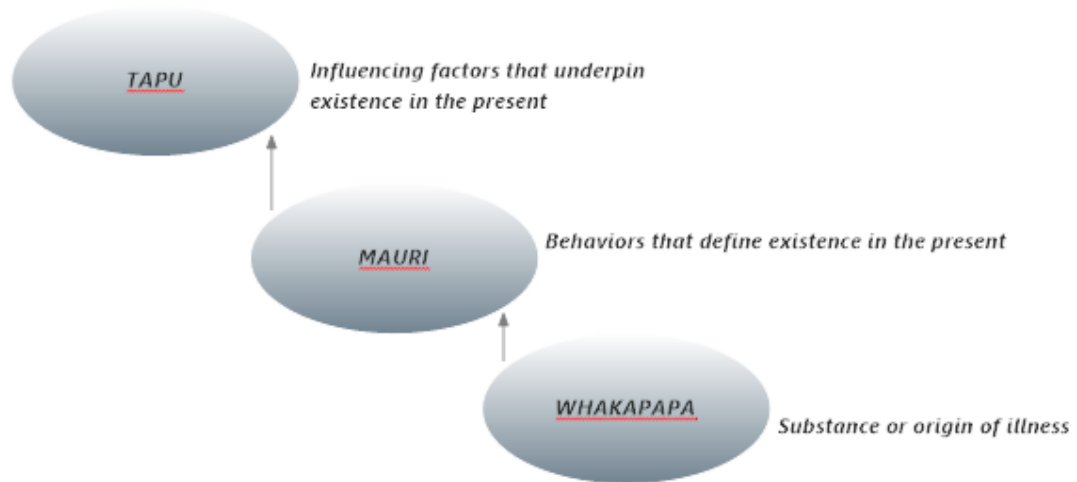


Figure 11: Analysis framework

1. The first consideration in analysis of participant stories is linked to whakapapa which is the critical step that relates to the stories substance or origin – the onset of the disease. It sets the foundation for the second consideration, mauri;
2. The second consideration mauri, addresses the construct or body of participants' stories and examines where participants are in relation to the various states of mauri: mauri moe; mauri oho; and mauri ora. Mauri sets the foundation to analysis in relation to the third consideration, tapu;
3. The third consideration addresses the concept of tapu in the search for meaning when we examine the influencing factors that underpin participant existence in the present.

5.9 Presentation of Data in the Thesis

The more I dwelt with the data from all 10 participants the more I realised that to cut each story up into pieces and to present the findings as themes would diminish the Kaupapa Māori insights. What became important was to examine the journey from first insights of a problem, through to how they are now, and that needed to be in the context of the participant and his/her whānau. Thus, I made the decision to privilege some stories over others. When I recognised how the notions of mauri, that is, mauri moe, mauri oho, and mauri ora wove through these stories I chose to include those stories within the body of the thesis that most clearly revealed a

given state. That decision was made after having worked with each participant's story. In honouring the contribution of each participant, and as evidence of my process of analysis, I have included the additional three stories in Appendix B, with my interpretations. They are integral to shaping my insights. In honouring the person in the context of whanaungatanga I present whole stories of seven participants within my findings chapters. As I step back to offer my interpretation it comes out of this sense of openness. I repeat short sections of data to help reorient the reader, but do not unpack them to the degree that may be expected in a study based ascetically on a hermeneutic study. My interpretive lens is zoomed out to the bigger picture within Te Ao Māori, to draw in the notions of whakapapa, mauri, and tapu. My sense is that if I had become immersed in detail I would have lost the bigger picture of being that pervaded the stories.

5.10 Trustworthiness

Guba and Lincoln (1981) postulated four major traditional criteria on establishing trustworthiness: truth value of findings; applicability to other contexts or other respondents; consistency of findings in other studies; and neutrality of findings based on respondent feedback which has not been contaminated by biases, motivations, and interests of the inquirer.

The source of trustworthiness for this study, however, finds relevance in the works of Smith (1999). At a pragmatic level the principle of rangatiratanga would govern the way in which critical questions are answered:

- What research do we want to carry out?
- Who is the research for?
- What difference will the research make?
- Who will carry out the research?
- How do we want the research to be done?
- How will we know it is a worthwhile piece of research?
- Who will own the research?
- Who will benefit? (p. 120)

The notion of rangatiratanga, or autonomy, is also relevant in the research process in terms of allowing Māori to shape their own research processes. Smith, on Kaupapa Māori research asserted that research on Māori: is related to being Māori; is connected to Māori philosophy and principles; takes for granted the

validity and legitimacy of Māori; the importance of Māori language and culture; and is concerned with the struggle for autonomy over our own cultural wellbeing (G. Smith, 1990). The above recommendations by Smith ensure that the issues related to power and control before, during, and after the research relationship, are addressed, and then aligned with Māori aspirations for knowledge development and transformation where qualitative assumptions such as credibility, transferability, dependability, and confirmability are important aspects. Awekotuku (1991) discusses several key considerations when conducting research on Māori:

- There must be a genuine love and affection for the people you are working with (aroha ki te tangata);
- It is essential to meet people face to face if we are to engage in the right way (kanohi ki kanohi);
- We need to look and listen before we speak (titiro, whakarongo);
- Sharing with others (manaaki ki te tangata);
- Tread softly, be careful (kia tupato);
- Do not trample the mana of the people (kaua te takahi te mana o te tangata);
- Do not flaunt your knowledge (kaua e mahaki) (pp 27/28)

Aroha ki te tangata (a respect for people) is about allowing people to define their own space and to meet on their own terms. All the participants in this study were accorded respect through te reo me ona tikanga Māori¹¹⁶. Participants were given the option of where interviews for this study were done, which was usually in their own homes.

He kanohi ki kanohi is about the importance of meeting with people face to face. All interviews for this study were conducted face to face. Titiro, whakarongo is about the importance of looking and listening so that you have a clear understanding of what is being said. This allowed both myself and the participants to verify and if necessary, alter the transcripts of the original interview. Manaaki ki te tangata is about taking a collaborative approach to research and reciprocity. The philosophy behind this study was always connected to giving back to the people. All the participants in this study will be

¹¹⁶ Māori language and customs

given a bound copy of the thesis at the time of dissemination. Dissemination will be done with each whānau in the first instance followed by presentations to iwi and healthcare providers. Kia tupato is about being politically astute, culturally safe, and reflexive about our insider/outsider status. Throughout this study, I have been mindful of participants' expectations. I have been careful to observe any protocols that needed to be done, as well as being mindful of the confidentiality issues and anonymity of participants. Kaua e takahi te mana o te tangata means, do not trample the mana of the people. This study was presented to Te Kaumatua Kaunihera o Te Atiawa Nui Tonu before it was commenced. There have been regular updates and feedback on the study to the Kaunihera at weekly hui by a kaumātua of my advisory group. Kia ngākau māhaki means be humble in your approach, do not flaunt your knowledge. This study has been conducted always with humility in mind. I am fully aware of the consequences that can befall researchers who flaunt their knowledge. Māori have a way of dealing with someone who is whakahihi¹¹⁷ - you risk being chastened in the public arena, at whanau, hapū or iwi hui.

The above ethical requirements were fundamental to the process of engagement in this study.

5.11 Summary

This chapter focused on the process of doing the research. In keeping with a Kaupapa Māori approach, research methods for this work were adapted from current research approaches collectively known as Kaupapa Māori. These methods drew on philosophical aspirations expressed by other Kaupapa Māori researchers and academics which acknowledges the epistemological and ontological realities that are embedded in a Kaupapa Māori approach. The other important aspect of this study was Gadamerian hermeneutics. As Kaupapa Māori itself does not prescribe a way of working with the data, this study was also informed by Gadamerian hermeneutic interpretive methodology which unpacks the nature of how we understand and interpret. Alongside this, the lens through which understanding was sought was Kaupapa Māori. The research method included literature and document reviews and semi-structured interviews. Ethical considerations were highlighted through safe practice including privacy and

¹¹⁷ Lacking humility – to show off

confidentiality issues; and how participants were recruited including consents to be part of the study. Establishing trustworthiness through consistency of findings in other studies was also mentioned. Finally, a framework on how the analysis was conducted was provided through the concepts of whakapapa, mauri, and tapu.

CHAPTER SIX: DIMINISHED TAPU AS STATE OF BEING - OF MAURI MOE

6.1 Introduction

In this chapter I examine and interpret the stories of participants who displayed the archetypal behaviours of mauri moe framed within the notion of mamae¹¹⁸ and its negative elements of hurt, pain, anguish, and sorrow. According, to Pohatu (2011) the state of being of mauri moe expresses thoughtfulness in terms of inactivity including the manifestation of isolation and withdrawal. Reflecting from these perspectives offers researchers a platform on which to conduct analysis. Māori experiencing mauri moe are continually in a state of flux where instability can lead to fragility and deep anxiety. These expressions increase our awareness of how and why the various states of being of mauri moe occur. Pohatu's theoretical postulation of Mauri – Rethinking Human Wellbeing provides further avenues for contemplation when we look at the concepts of tapu and mauri in relation to human wellbeing.

Tate (2010) defined tapu as being-in-itself, to be or to exist. According, to Tate tapu is dynamic and can be diminished, enhanced, and/or restored. Pohatu asserted that mauri can change in the same dynamic way. Consequently, I do not assume that the participants illustrated in this chapter remain encamped in the state of being of mauri moe. I now turn to stories of participants who displayed archetypal signs of mauri moe framed within the notion of mamae and its negative elements of hurt, pain, anguish, and sorrow.

Mihi's Story

Whakapapa of Mihi's Story

The realm of whakapapa in the context of this study relates to the stories' substance or origin. This is Mihi's story and her experiences and initial signs that not all was as it should be in terms of her husband's health. Mihi's husband was ill, lacked energy, and in pain. They struggled to come to terms with the pain he was experiencing. The signs that it was bowel cancer were present but Mihi, her husband and their children were totally oblivious of what was happening. When

¹¹⁸ Hurt/pain

she received news that I was conducting a study on bowel cancer in Taranaki she approached me to find out more because of the experiences they, as a whānau, had endured during her husband's illness. She had recently lost her husband to bowel cancer and wanted to tell their story of her husband's journey so that others can learn from the trauma they experienced of a loved one diagnosed with bowel cancer.

This is Mihi's story:

I'll go back to the time when my husband really, got ill. It was 2010 we had him at home and he was very ill. He was full of pain and we couldn't understand what was happening to him and he refused to go to the doctor and then one morning we had to carry him and help him to the toilet, wash and bathe him in bed and all that stuff. One morning after I had finished giving him his shower, I gave him his breakfast and we settled him comfortably in his bed. I came up here to get a glass of water and when I went back he was shaking all over. I said, "what's the matter?" He said, "I don't know I'm all shook up" and I said, "are you sore anywhere?" And he said, "no". He was just shaking all over. I said, "OK" so I rang the 0800, emergency services number at the hospital and explained what had happened to my husband. She said, "can I talk to him?" So, I said I'll take the phone to him. It was like – his speech was slurred and incoherent and she must have said to him, give the phone back to your wife. I took the phone and she said, "what I'm going to do is ring for an ambulance and they'll take him through to A & E in New Plymouth." He arrived there and about half an hour later they came to see him. They kept him in hospital for about four months. I'm one of those who don't ask questions. I just sat with him all the time in hospital during the day and at night I would go and stay with my son and then come back every day. They released him and brought him home – now that was alright. He was OK when he came home and he just carried on with his work and then I noticed that he hadn't hardly any energy. This was in 2013. Around about September/October I said gosh, he's usually full of energy. Normally he goes down to the local for an ale but he wasn't interested in that. I said, "what's the matter with you?" He said, "I don't know."

All throughout that time he carried on working. He was OK. It seems my husband had bowel cancer then and that's why he said to me – he said back when he was in hospital, he said, "they should have picked it up then." On his death certificate, he was diagnosed with colon cancer. He was officially diagnosed with bowel cancer in November last year (2013) – he had a cat-scan. Well, it had been 2 years. That sort of bugged me a bit because out of the blue one day he said, "they should have picked this up when I was in hospital" back then. I said, "well they didn't." But anyway, one morning he woke up and went to the toilet and he called out to me. He said to me, come and have a look at this. So, I went in to the toilet – he didn't use the toilet. He got a newspaper and did his motion on the paper so I could have a look at it – it was black, black, black. I said, wow, so I got a jar and put some in and I said, "I'm taking you to the doctor and I'm taking this." So, we went through and straight away they said you had better go to hospital. The doctor suggested I take him to hospital and so we did.

I think what caught my eye one morning was when he was walking to have a shower. I was just sitting in there, I said, gosh, he's skinny. I noticed how skinny he was. I said, "I'm coming in to have a look at you." He said, "what's the matter?" I said, "look at you – you're skinny as." He just went down like that. He lost weight and all that. That was in November 2013. Well that was my observation of him from that time up to the time he was diagnosed with bowel cancer. Some mornings he didn't feel too good - he didn't feel like getting up. He had a pain in the back and that type of thing. Sometimes he had no energy at all. But he just went and did his job because he missed mowing the rugby grounds and the marae. He did the cemetery there and he used to do the schools as well.

Well, my husband, he refused treatment when they told him he's got bowel cancer. They offered to do chemo and radiotherapy straight away and he said, "no, I don't want any of that." He said he was going to sit it out from November (2013) right through to 14th February (2014) when he was gone. He said no to treatment. That's why I go back - he said, this should have been picked up right from then in (2010). So, that's it. Me and the kids – we had him home, we brought him home. He said, "no, take me home to

die at home, not in hospital.” And that’s him. He said it didn’t worry him and I said, “what about me, think about me please?” We used to talk about this. I said, “no, no, no I’m going before you” and he said, “sorry I’m going to go before you.” We used to talk and he’d say, “oh when you die where do you want to be buried?” I said, “where do you want me to be buried?” He said, “I want you to come up to Parihaka.” I said, “we got our own cemetery.” He said, “well alright I’ll leave it up to you.” I think he wanted me to be with him and when they dug the grave they dug it for another. I said, “when I die and they bury me turn me over because I don’t want my backside on him” (laughs). We used to have laughs and we would talk about burying one another. He joked about his sister who has passed on. He would say, “when we bury you we can leave your hands sticking up and you can wave out to us when we go past” (laughs). That’s the kind of korero we would have.

Anyway – I would say he suffered in silence. He just didn’t show it. He wasn’t afraid of dying. He just didn’t want to annoy anyone. That’s him, that’s him. I knew there was pain because I could see it on his face. There was pain there but he wouldn’t let on he was in pain. I didn’t question the doctors and I don’t know why. I wasn’t one of those to question but it was my daughters – they’re the ones – why aren’t you doing this, why aren’t you doing that? But they live in Australia and can’t be here all the time. They will be coming back in October. We’re taking (my husband’s) kawemate¹¹⁹ back up north. That’s where his mother is from. They were the nosy ones. They wanted to know what exactly was happening to their father. It was important for them to know why. So, they wanted to find out why. How can we look at it? Look at a person and know that they’ve got that cancer. They were great they asked the questions. Sometimes they asked the questions when I wasn’t there.

On one occasion my husband had already showered himself, he said to me, the mangumangu¹²⁰ nurse was going to shower him and I said no, I’ll shower myself. I’ll shower myself. If it was someone else then maybe, but

¹¹⁹ The grieving ceremony at another *marae* subsequent, to the tangihanga and burial of a loved one

¹²⁰ A derogatory term

not her. He wasn't comfortable having her as his nurse. It was just the way my husband described it. He didn't like the mangumangu nurse who looked after him. He didn't like her – he said she was too rough. They had to turn him over carefully but not them. It was an everyday happening. Here's another thing (quotes from a notebook) 'tumour located around the bowel area'.....the size of a tennis ball. Bleeding coming from the bowel and the faeces black. The use of the bagoh it's talking about the bag. He refused that. He didn't want it. He didn't want anything to do with that bag. They suggested he should have it but he didn't want it. You have explained what bowel cancer is to us but they didn't do that. They didn't explain that to us. And that's it – he just didn't want that bag. I understand it now. I can see now what could have been done for my husband.

Another thing that comes to mind is when they were telling us after the scan. The explanatory language of the doctor's documents was beyond our understanding - what is that to me? He's talking in another language and of course we as Māori say, yes, we understand - all the time, we don't. You know during this time his urine became orange and then he broke out in some ugly spots on his hand and that type of thing. We had some nurses that travelled all the way from Stratford (approximately 60 kilometres away). It didn't matter what time of the day or night we needed them – they came. Those two nurses were Pākehā – they were great.

We never ever discussed bowel cancer as a family but the thought came to mind – I wonder if anybody is doing anything about you know, bowel cancer to see why? It was a few months after those thoughts that I saw that notice in the paper. Someone was doing something about it. I thought, choice, someone is doing something about it. I was talking to someone and he said that you had come down one weekend and he mentioned something about bowel cancer and I said oh I saw something in the paper a while ago. I told him about my husband having bowel cancer. He said that is what you're doing.

6.2 Mihi's Story – The Search for Meaning

Manifestation of Anxiety - We Were Worried

Some mornings he didn't feel too good. He didn't feel like getting up. He had a pain in the back and that type of thing. Sometimes he had no energy at all. But he just went and did his job. (NM. 2014)

Mihi shared her concerns about her husband's health when he became ill. She witnessed his pain yet he refused to go to the doctor – she worried alone. He continued to work despite the pain he was experiencing. Pohatu (2011) asserts that at the primary level mauri moe alerts us to the effects of inactivity, with its manifestations of isolation and anxiety. From personal experience, I know that Māori whānau, especially Māori men, tend to keep information about their health hidden. Maybe Mihi's husband thinks that if he keeps on going he will beat this thing. Maybe pretending to ignore it was his way of coping with his underlying anxiety. Nevertheless, his body was announcing its struggle with pain in his back and decreased energy.

I'm one of those who don't ask questions. I just sat with him all the time in hospital during the day and at night I would go and stay with my son and then come back every day... I didn't question the doctors and I don't know why. I wasn't one of those to question. (NM. 2014)

Mihi regards the doctor as the expert, a person whose knowledge and expertise is beyond reproach. In her eyes, he had mana. However, Mihi displays the classic signs of not knowing which way to turn or what she could do to help. She simply had to trust what the health system had to offer. Even once they are in the system where there are doctors and other health professionals that they could ask, whakama¹²¹ seems to keep them from asking questions that perhaps they did not want to hear the answers to. They seemed to prefer the anxiety of not knowing or maybe they never felt safe enough to share this sacred conversation with strangers.

... he said to me, the mangumangu nurse was going to shower him and I said no, I'll shower myself. I'll shower myself". If it was someone else then maybe, but not her. He wasn't comfortable having her as his nurse. (NM. 2014)

¹²¹ Whakama is about shame sometimes can be interpreted as a reluctance to query one's integrity, in this case, health professionals

Tate, (2010) postulated that the meaning of tapu, '*te tapu i*', can be understood as being-in-itself. Thus, the primary meaning of tapu is 'being'. According to Tate, tapu encompasses the being of the whole spectrum of all realities, and their relationships to all other realities. He also proposed that because tapu is dynamic, it encompasses relationships, encounters which take place between one reality and another, between tapu and tapu, in this case between the patient and health professional. It is foundational to the initial encounter of one reality towards another and is captured in the phrase *te tapu o*, the tapu of being in relationship. The phrase *te tapu o* raises issues regarding tapu as being in relationships with other primary beings. This reality was borne out by an encounter Mihi's husband had with one of the nurses in his ward. From the very beginning the appropriate approach should have been one where the focus was on enhancing, sustaining, restoring, and empowering those in relationship. From an interpretive perspective, a critical issue arises from this statement - did the hospital have a valid cultural assessment procedure and if so was such an assessment done for Mihi's husband? The reason why cultural assessments are important is because health professionals require guidance on how to engage appropriately with Māori who present to the wards after admission. The practice approach should have been one where the focus was on enhancing, sustaining, restoring, and empowering. It appears that was not the case and where tapu (*te tapu i te tangata*)¹²² and mana (*te mana i te tangata*)¹²³ is not acknowledged then the relationship is distant at best. The consequences then become evident and any attempt to engage with patients such as the transfer of critical information between patient and health professional is impeded. It appears that the critical step of whanaungatanga, where health professionals have an opportunity to learn about the person, about the whānau, was ignored. Health professionals thus, remain kūare.¹²⁴ This may have been the case when Mihi's husband was admitted to hospital.

The absence of valid cultural assessments can be ignored in a process where clinical assessment takes priority. This may have been the cause of Mihi's husband's annoyance when he refused the nurse's help to shower him. Mihi's

¹²² A person's tapu

¹²³ A person's mana

¹²⁴ Ignorant, unaware of

husband described the nurse as mangumangu¹²⁵ because he did not want that nurse to shower him. There is a possibility she may have had very little understanding about his cultural background because the information may not have been available. Mihi's husband was a respected kaumātua among his people. In such instances kaumātua prefer the presence of a spouse or a favoured son who have a much more personal understanding of their cultural needs, especially around issues of tikanga. Mihi's husband reacted to his nurses in much the same way that many Māori Kaumātua do in that situation. They do not like to be attended to by someone in that situation other than their own and then only by selected members of the whānau.

Manifestation of Withdrawal – Being Alienated

The explanatory language of the doctor's documents was beyond our understanding - what is that to me? He's talking in another language and of course we as Māori say, "yes we understand", all the time, we don't. (NM. 2014)

Mihi shared her views as to why her husband refused treatment for bowel cancer in November 2013. They had no understanding of Western biomedical treatments offered to him for bowel cancer and preferred instead to sit it out in the hope that this whole thing would disappear and that his life would return to normal. Experiences of isolation and withdrawal can potentially impede progress. These are founded on responses framed within the urges of mamae and its negative elements of neglect, hurt, pain, anguish, and sorrow. A holistic approach in the initial engagement phase between Mihi's husband and the hospital would have made a world of difference, getting it right sets in motion a correct and rightful process¹²⁶ for them throughout the remainder of the treatment journey. The consequences for failure to enact such process become evident and any attempt to engage with patients and/or their whānau such as the transfer of critical information between patient and health professional is impeded. Tate (2010) contended that when beings come into relationship, this comes about by an encounter of one being with another. Māori give special attention to the encounter itself and to the way the encounter comes about, and thus to the quality of the encounter and to its consequences. In encounter, the relationship imparts some

¹²⁵ A derogatory term; ugly

¹²⁶ To be pono, to be tika

aspect of quality of being that is creative or productive, enhancing or empowering from one to another. All that one imparts and gives, and all that the other receives and participates in is captured in the phrase *te tapu o*. *Te tapu o* means that tapu is seen here as an aspect or quality of someone or something. The relationship is mutually enhancing, restorative and empowering.

Addressing health literacy among indigenous peoples has been the subject of numerous studies (Jones et al., 2010; Kickbusch, 2001; Koay, Schofield, & Jefford, 2011; Mogford et al., 2011; Ness, 2012; Nutbeam, 2000, 2009a). According, to Nutbeam (2009) there is a need to empower patients by implementing knowledge gained from research:

The reason why we care so much about literacy is that even the most basic functional literacy skills enable people to better develop their knowledge and improve the potential to achieve personal goals, and through this to participate more fully in society, both economically and socially. (p.303)

In building health literacy in Australia Nutbeam postulated the need for specific strategies if we are to make informed and productive choices when it comes to utilisation of health services:

- (1) Health care providers and those responsible for patient management and administration need to demonstrate greater sensitivity to the needs of patients with poor health literacy by creating a less alienating health care environment that is more responsive to patient needs;
- (2) greater care needs to be taken to improve the quality of patient communication and the materials that support it. (pp. 525-526)

I concur with both recommendations that Nutbeam speaks of; but would like to add another in respect to what Tate (2010) is suggesting. The Māori concept of tapu is about understanding the nature of one's own intrinsic being and the unspoken restrictions that tapu brings to protect the tinana - the physical and hinengaro, the mental dimensions of wellbeing. Understanding one's body in terms of one's own intrinsic tapu and associated restrictions is, in my opinion, the best approach if we are to teach Māori about health. Adopting this stance from an early age for Māori could make a real difference because it focusses on awareness about the negative influences that we all experience throughout our lives. Such negative influences include drug, alcohol, and sexual abuse, physical and emotional abuse, and overindulgence in food. We begin to understand ourselves better and learn to overcome and manage negative issues whenever

they present. Understanding from the inner being negates the necessity to know and learn about biomedical approaches to health promotion based on statistical data. That area is the realm of clinicians. It is my contention that Māori at grass roots level will never be able to grasp biomedical interpretations and discourses that come with mainstream health literacy material because of its superficiality. It speaks to the surface only, in other words, cannot be absorbed in a way that is meaningful for Māori.

Mihi clearly stated that the explanatory language of the doctor's documents was beyond their understanding – it was another language. Creating awareness within whānau of the seriousness of bowel cancer needs an alternative to purely bio-medical approaches. The efficacy of a Kaupapa Māori approach to healthcare is, in this case, appropriate because Māori epistemology and the ontological realities of what is real in the world elucidate important social and cultural content that is important to Māori.

Being Pono – We Didn't Know

...he just didn't want that bag... I understand it now. I can see now what could have been done for my husband. (NM. 2014)

The Williams Māori Dictionary (1971) gives us a basic meaning for pono as true¹²⁷. Tate goes further, suggesting that pono literally means 'the truth'. He used cultural analogies such as '*Kia pono te mahi*' (work honestly or with integrity) and '*kia tika te mahi*' (to do things in a right or proper manner). According to Tate, (2010) pono is a principle of perception of truth by which we address tapu and mana. It is an ethical principle of action in that it qualifies how we manifest, address, enhance, sustain, and restore tapu, and how we exercise mana. The failure of health professionals to work with integrity¹²⁸ with Mihi and her whānau left them bereft with little understanding of bowel cancer and the reasons why certain actions needed attention. It may have been the trigger that lead to Mihi's husband refusal to further treatment because of the stoma bag. In hindsight Mihi realised that a real opportunity to do something for her husband had been lost – if only they had known.

¹²⁷ Williams Dictionary, p291

¹²⁸ The failure of health professionals to act with integrity is in this case – is the absence of pono

The prudent point here is that the treatment possibilities for bowel cancer were never adequately explained to him or his whānau by the doctors. One of the major issues for Mihi and her whānau was the language doctors used when explaining her husband's illness. The language used was beyond their understanding. Māori often tell their doctor they understand when, in fact, they do not. They agree with the doctor by merely covering up their lack of knowledge. Mihi did not question the doctor and she most certainly did not understand him. The signs were there that the stoma bag would be problematic. Maybe Mihi's husband felt uncomfortable about the stoma bag. For many Māori, this is wrong - it doesn't feel right. It is a process that is analogous to tampering with *te tinana*¹²⁹. Whakamā sets in, resulting in diminished tapu and impaired mana.

A study by Shahid and Thompson (2009) explored issues related to cancer among indigenous populations in Australia, Canada, New Zealand, and the United States. They examined variations in the epidemiology and indigenous peoples' perceptions about cancer and the potential effects on care seeking behaviour. Of special interest in this study were the qualitative findings of indigenous beliefs about cancer, for although similarities to non-indigenous beliefs were noted such as fear of death and fatalism, there were distinct differences from a cultural perspective including shame, payback for indiscretions committed in the past, and the belief that cancer is a white mans' disease. The authors concluded that there was a definite case to be made for a holistic approach to healing for indigenous people and that the concepts of individual, family, and wider community are inseparable. Cultural beliefs can create significant barriers in terms of Western treatment options. These are some of the underlying factors that influence indigenous peoples' decision-making when asked to participate in treatment programmes.

Manifestation of Distress - He Suffered in Silence

There was pain there but he wouldn't let on he was in pain. (NM. 2014)

The pain that Mihi's husband was experiencing was also her pain, and the pain experienced by their children. Mihi's husband knew that what affected him would

¹²⁹ The human body

affect his wife and children. He was meant to be their protector and provider. He was in pain but refused to show it.

I would say he suffered in silence. He just didn't show it. He wasn't afraid of dying. He just didn't want to annoy anyone. That's him, that's him. I knew there was pain because I could see it on his face. (NM. 2014)

Mihi's husband suffered in silence. He felt let down by the health system and simply accepted the inevitable and he was prepared to just sit and wait. The pain he was experiencing was both physical and emotional. The physical pain he could accept but the emotional pain and suffering of his wife and children is what troubled him most, for they too were now in the same space – in diminished tapu and impaired mana:

It seems my husband had bowel cancer back then in 2010. On his death certificate, he was diagnosed with colon cancer. He was officially diagnosed with bowel cancer in November last year (2013). Well, it had been 2 years. That sort of bugged me a bit because out of the blue one day he said, they should have picked this up when he was in hospital back then. I said, well they didn't. (NM. 2014)

Mihi expressed her concern at the delayed diagnosis of her husband's cancer – how could that happen? It had been two years since his initial admission to hospital. She said they should have picked it up when he was in hospital back then, but that did not happen. As whānau they remained isolated and withdrawn, the classic signs associated with the archetypal behaviours of mauri moe.

Research tells us that the approach to healthcare for Māori needs a significant change in culture. Connolly (2010) emphasised that from diagnosis, health providers should include patients and families as part of the team and that key functions relating to self-management should include health literacy, health coaching, health navigation, patient-centred service, and empowerment. One of the key findings of the study was the existence of inhibitors to quality health care for Māori throughout New Zealand's secondary healthcare system. There appeared to be very little conceptual understanding by senior managers, including funders, of the realities of reducing inequalities in health for Māori. Findings also revealed that some DHB's had substantially undeveloped chronic conditions management strategies that focus on patient centred care. One of the principle recommendations of the study was that secondary care services require

a significant shift in culture and changes in roles and relationships if they are to address these issues (Connolly et al., 2010).

Other studies looked at the possibilities around survival outcomes for Māori who have been diagnosed with bowel cancer. A study by Hill et al. (2010) examined ethnic disparities in colon cancer survival between Māori and non-Māori. The study, based on demographics, disease characteristics, patient co-morbidity, treatment options, and healthcare factors, found that Māori had significantly poorer bowel cancer survival rate than non-Māori. The most important factors contributing to poorer survival in Māori were patient co-morbidity and access to healthcare services. The study concluded that higher patient co-morbidity and poorer access and quality of cancer care are both important explanations for worse survival in Māori compared with non-Māori (S. Hill et al., 2010).

A further study by Hill et al. (2010) examined ethnicity management of colon cancer in New Zealand and posed the question: do indigenous patients get a worse deal? Findings showed that Māori patients had similar rates of surgical resection but were less likely to undergo extensive lymph node clearance and were more likely to die in the postoperative phase. In addition, Māori were less likely to receive chemotherapy at the appropriate stage of diagnosis and when they did, the evidence supported delays in treatment. The study showed that there is evidence of disparities in treatment between Māori and non-Māori who have been diagnosed with colon cancer.

6.3 Summary

Mihi's story showed they had very little or even no knowledge of bowel cancer. Mihi and her whānau were unaware of what was happening because they did not know any better - they had no understanding of Western biomedical treatments for bowel cancer. Mihi's story reminds us of the reality that can transpire for Māori who present to healthcare institutions for treatment. The inability of the healthcare provider to engage in an appropriate manner and to furnish adequate information pertaining to her husband's dilemma was the first major inhibitor to an intervention where Māori should feel respected and welcome. The lack of a valid cultural assessment for her husband may have contributed to a situation where inappropriate treatment options were adopted. The ability of health professionals to engage in ways that promote positive relationships was not evident which then

manifested in a situation that left Mihi, her husband, and their children, oblivious to the nature and reality that bowel cancer can cause.

Whanaungatanga is such an important aspect of healthcare for Māori, no matter what illness they present with, when they enter primary or secondary healthcare institutions. Whanaungatanga is important because it sets in motion the correct and rightful process where knowing the person, knowing the whānau is vital and of the greatest significance in determining where participants are at any given point in time in their journey. It is the pre-requisite to correct and rightful process (tika) where a correct treatment plan, based on both clinical and cultural knowledge, is implemented. Mihi and her whānau continued to exist in a state of mauri moe two years after the interview was conducted as they reminisced on the possibilities that could have been. They exist as extensions of the primary tapu, of a father, of a husband in a state of diminished tapu and impaired mana. Her focus now is on spreading the message to others by sharing the story she lived through with her husband, with those to whom she is closest. Perhaps in this way she and her children can move on in the knowledge that their story has contributed in some way to bring about greater awareness of this terrible disease among Māori families.

In the following section I introduce Manu. Manu has been a survivor having bowel cancer for 10 years. He continues to manage his many challenges associated with the trauma of being trapped, for much of his time, confined in the state of being of mauri moe.

Manu's Story

Whakapapa of Manu's Story

The realm of whakapapa in the context of this study relates to the substance and origin of Manu's story. The experiences and initial signs that not all was right with his health was evident two years prior to his diagnosis. He was experiencing bowel problems but chose to ignore them. Manu was diagnosed with bowel cancer in 2004 when he was just 39 years old. After his initial treatment programme he returned to live with his people in Taranaki. He wants his story to be heard so that others can learn about this terrible disease and hopefully avoid the horrendous experiences he is currently going through. Manu contacted me

after reading the advertisement I had posted in the Taranaki Daily and Midweek Newspapers.

This is Manu's story:

Something was going wrong, and I knew something was wrong – something out of the ordinary. I think first and foremost when we know something like that is a bit bigger than a prickle we go into denial and that's is exactly what I did – I put it off until it eventually tackled me which meant it sent me to the doctor. It was growing. Mine was stage three. I had a tumour in my bowel – it was rectal cancer and was six inches from the spincter. I had cancer in the rectum – of all places!! It's uncool, it's so uncool however it was for real. I just lost my dad and all that type of thing and I thought it was my turn.

They had a bus that goes around, a sort of health bus like a mobile hospital where they did tests. They brought it into town sort of thing and I went in. I was in Wellington at the time. They didn't tell me after they did the tests – they knew, they knew. I was looking at the TV and I could see something and next minute I'm waking up in recovery because they don't want you to see it. I had radiation and chemo - I'm sure you'd know what that is. I had six weeks of that – I've still got the pump on me now for the chemo and I didn't know about its after effects – the cancer is gone, it's the after effects of the treatment. I look big and strong but I am not. It's all a bluff. I still got to live in this world and there's a lot of things out there. I had six operations – open surgery at the public hospital. I had a tumour in there the size of a golf ball. I guess that's what they were comparing it to. They cut it out and basically joined me back up again.

I ended up with a colostomy bag and I had that for nine months and then they reversed everything again. Things haven't been running right ever since. I am seriously thinking of having my large intestine removed. In all reality, it's been nothing but a detriment to my life. I had six operations, one to remove the tumour, and then I woke up with hoses sticking out everywhere and of course, the bag. After that nine months was completed I had that reversal and then I was having blood clots. I don't know what that is. They reckon it was travelling up my leg and going toward my lungs.

Hence, I had so many operations – I was in hospital for seven months and I was off and on there for a long time afterwards. As I look now I can't believe I've come 10 years - but I have. It's never pleasant and I'm forever getting threats from my bowel. It tells me I'm going to evacuate so I had better disappear – things like that and it's costing me – underpants, clothes, sheets and things like that. I have about 10 showers a day. I don't mean full showers. I've still got to keep myself clean and hygienic. I've still got to mix in this world and I'm very fussy now about hygiene standards and things like that. If someone is going to catch something I hope, it's not from me. This morning I've had six showers. Right now, my doctor has got me on a new medication. It causes acidic bowel evacuation which means it's burning on the way out. Not only is it burning on the way out there is gripping and staggered evacuations, like a bus stop theory, stop, let you off, carry on to the next bus stop, every 20 minutes or so. It does my head in, it really, does. The doctor seems to think I'm in a better place than I was. I am, don't get me wrong but they haven't had it – how could they know?

I've got rags. I go through two towels a day because I'm in and out of the shower so often. The normal person will have a shower once a day and go to the toilet once a day – not me. Everything happens in multiplications and I'm using times tables before I even go to a doctor's appointment. I come out looking like everyone else but behind closed doors no one really knows the preparation that is taking place. And there's the clean-ups – there's lots of clean-ups going on and sometimes I'm just too sore and I just want to lay there. And my bowel says no you're not, get up, get up now or I will come out prematurely and it doesn't matter what time of the night either. There are times when my bowel feels great and I think to myself I'm go to bed now and I can get me some rest – it (the bowel) could say, I'm not finished yet so I'm up. I never have any real night's sleep, not really. I sleep during the day. I look like a lazy fellow that's just on the sickness benefit that just wants to lay around all day but I'm both the nurse and the patient and they get sick of one another – they really do. The nurse never gets a break and the patient never gets better. Yes, I am that same person. I could be creating a split personality within me. I need

assistance but I don't want anybody doing that for me and I'd hate to think what's going to happen when I get older. I can barely get by now. I'll never be an old Māori - I can't really see that. It's a lot of work – it's too much work. I was a caregiver myself, taking care of cancer patients. I already know what I am in for. And really, at the end of the day it's a horrible, horrible thing.

I never got to know my grand-dad – it killed him, the same thing. His was in the bowel. I never got to know him and I guess it does rob people and steal from them - no doubt about it. I had a promising career. I've been studying psychology at university but now that's all over, what's the point. Like I say I spend so much time, 20 odd hours devoted just to me and that kind of sounds like idolatry but the fact of the matter is, I've got to. I've got to be sorted otherwise things are going to go wrong, very quickly. I've got a friend who tutors me now for some lessons that I'm taking and he's got one leg and I tell him if your leg falls off someone is going to come and help you up and grab your leg for you. But it's only a wooden leg. That's not minimising how he feels about it but for me, if I s... my pants they're not going to come and scoop that up for me – not at all, you've got to take care of that yourself.

I attend the medical centre here and I had to give them a reminder and I said look we're dealing with cancer here. I understand what a doctor is but a specialist is just that – they're supposed to know. The specialist said he will see me every three months but I haven't had a CEA¹³⁰ tumour check for almost a year and I get kind of anxious. I don't want to deal with this again, I don't want to go back there. It's an old man's disease they told me. I can vouch that it is not – jingers I was in my late 30s. My life was not too bad but it cost me my relationship. However, I only have myself now. My kids don't want to know but they have got to know - I don't want this to happen to them. That's exactly what my boy said – he said, "I don't want to hear that dad". I was just trying to warn him. He needs to know what I'm talking about but he says, "why are you talking like that for?" However, that could be his journey if he wants to look at it that way. I can

¹³⁰ Crypto Embryonic Antigen – a test that determines the level of cancer cells in the blood

voice my concern because I've been there and I'm still there and I can't see myself ever breaking free from it unless they come up with a miracle medication type of thing within the health system.

They told me all about chemotherapy and I said yes. I didn't know enough about it. I didn't know – all I wanted to do was live so I just said yep go ahead and then I heard that there was some people that were opting to go without chemo, have operations and they were juggling it around. It was then I started taking an interest – what are they doing? It makes sense – that'll teach me. No matter what I wished for and desired for back then I have what I have and it is true, a lot of this is the after effects of the treatment. Half of me looks like a great big giant but my legs, I got none. They've withered away type of thing and I feel like an old man. I don't know what an old man feels like but I think I feel like one. Like I say, the cancer is gone, the operation is done. What's going on now? How come I'm not well? I should be 95% but I would be lucky to be 65% restored. At night, things just change – my bowel starts going crazy you know. I don't know why it's like that during the night – it just becomes active. As far as my diet is concerned I've tried everything. Juices, fresh squeezed fruit and vegetables, the fibre diets and all the cereals, yogurts to try and get over it. Biblical menus, goat and rice, the whole thing but no different. In fact, if I keep toying around with it like that it makes things worse. There's nothing wrong with our traditional kai. They are a great help and I don't mean just the taste but I mean when passing through me and they seem to work alright but for some reason too much red meat – well my body doesn't like it anymore and yet my head loves it and I don't know what's going on there and how it can have that effect but it kind of has. Everything is chicken - I eat a lot of chicken now. It's lovely and all that but my head, the way I was brought up, all I can see is those boil ups and that type of thing.

I would like to see testing for Māori at an early age, even 35 years. I'd even go back to teenagers, start monitoring from there. I wish I had that opportunity, especially now. What gave me a clue on this was kids getting cancer. They may not have bowel cancer but they've got cancer. That's what Starship Hospital is all about. Then there's this, bowel cancer where

early detection is not taking place. What the heck's going on? Okay, there seems to be a safe area somewhere but it wasn't safe for these kids type of thing even though it's not bowel cancer. My point is still relevant - it still hits somebody and for a lot of those kids, it's over for them even though it's a different type of cancer. I mean cancer as you know is a lot more than bowel cancer. But as for this bowel cancer stuff I wish I could run away from this life, I really do. I find myself thinking of when I was a young boy, I start reminiscing back when things were good, but that's all it is now - a memory because there's no way, even after we do this. I had a good breakfast this morning and things like that and today's not such a bad day. I know that if I get through today and have a quality meal and a bit of a quality day and a quality rest, that's really all I'm after. I'll settle for that and quite often like I say with a diary thing that I keep for my doctor, it's not so, life for me is not good at all.

I don't know how you feel about things biblical, but biblically, the word plague is mentioned in the Bible. I will give you a disease in your bowel God says where you will die from it type of thing. Now this is because we're not playing Christian but I've been reading that book since I was a young fella. I don't know why because I'm not a practicing Christian and all that but I have a huge interest in it and ever since you got in contact with me I really read the details as to those plagues that the Bible mentions and curses and things like that and he (God) was pointing out that he was going to send in a wasting disease of your bowel. I don't know what you think about that but he's not far wrong at all and there's a reason for it and I think I must have been a bad boy.

See in Chronicles 21, 14 – 15, it mentions terminal bowel cancer. So, there's two scriptures there and it's only about bowel cancer. God wanted people to behave themselves, to observe his 10 commandments. I was thinking just to try and grab these 10 commandments and run with it, then all this good stuff is going to happen to me because I didn't know. How would I know because my parents were only trying to do their best to raise me and things like that? I was more interested in drink, drugs and sex outside of marriage. I was not only breaking God's laws but man's laws. I'll get away from that but I look at it because I'm always looking for ways

out. I'm always looking for ways out. I'm looking for a way out of this. I've got a rough idea that I'll never find it but I think my way out might be my eternal rest which I hope is not too close. I do want to have a life, I don't like it like this, this is not a life, this is half a life; however, I can't blame anyone, I can't complain too much, they (my parents) did the best they could.

I don't have any fixed abode which is surprising to people. It's not because I'm a paru¹³¹ guy but looking after me is a lot of work and all I'm going to do is clean myself knowing that it's going to be all messed up again in a few hours. That's me only trying to take care of myself. It's not because I'm lazy, or a dirty guy, it's just that I'm going to use this facility or that facility to take care of me if you can understand that. Our iwi just got ... amount of dollars and that's fine. I'm not going to jump on them, it's my job to sort things out for me. I've been on that Ministry of Social Development high needs list since April 2014 when it came out. All I've ever got is get plonked on the wait list. They haven't got a home available for me and they know I've got no fixed abode and things like that. Geez I want a home and things like that. I'd be crazy not to want a home, I didn't choose to be homeless. The people I know, well, they're all trying to protect their benefits and things like that and having people there without being declared could compromise their benefits.

But I do use their gears (washing machine, dryer, etc) and get my clothes washed and stuff like that. I don't want to burden them. I should have a home myself. I have an iwi here that has got ...amount of money and I can't even get into a little flat. I get money, don't get me wrong, I'm on ACC which is worse because they don't give out the big money like they do on the dole to get a house. That's crazy and in fact, there are times that if I could have had a quick look at where I am now I might have just said no to chemotherapy treatment. This is too much work, everything in life is now twice as hard but that's life. I didn't realise this but I've been digging graves for 40 years with my old man and my uncles. We all dug holes and things like that around here. That's why I say and I go back to

¹³¹ Dirty

when I was a young boy when life was great. Kicking around with those men and things like fishing off the coast here. Those were the days when I didn't even know what a bowel was let alone bowel cancer.

I can understand others when they don't want to talk about bowel cancer. They don't know what I mean and they say, "well what happened to you type of thing?" So, what does that mean for me? I'm here to take care of it myself and I do. I do the best I can. I can't help but think about what it must be like to have the proper healthcare products and the proper food. We have roughly three meals a day type of thing, certain times within seven days. You could have something like 18 of those meals absolutely dedicated to the health and wellbeing of your digestive system and then you have your boil ups. I like KFC, I like all that stuff too so when it comes to the diet, when it comes to all those yoghurts etc and all that, they want big money for all those healthcare products. I can't afford it. Some of the breads that are supposedly good for us are too expensive. They're almost five bucks a loaf. I buy bread for a dollar, the cheap option. That means with that other four dollars I can get me something else. I know that sounds pathetic but even though I'm on ACC and getting a little bit more than someone on a benefit it isn't that much more. I feel sorry for my family and other friends on benefits and other things like that. Even though I was going to the toilet and it was hard to push, nothing was coming out. It was blocked and I knew my bowel was sore because the tumour was pushing on things inside so I had to go, but I don't want my friend to go through that.

I didn't realise this hurdle in life could be in the way and what a beauty, what a beauty. It's cost me in clothes, I go through clothes, I go through a lot of underpants because I might as well throw them out after just a few times. I mean there's only so long you can use them. I mean it's not a full evacuation but if I get to the toilet too late and things like that. It is just that everything's a cost now, everything's a cost. I don't use toilet paper anymore - I can't. I experience a lot of exfoliation and I experience a lot of chafing. I resort to baby wipes and things like that, I carry them around with me. I have my emergency breakdown kit just like when you take a baby, you're taking bits and pieces for that baby - well I'm the baby. I'm

not so much a baby but I need those things to come with me because the unexpected can happen. I've had a lot of time to think about what's going to happen. The problem is I don't know what's going to happen, what's going to happen in my life or where I'm going to go.

My friends think this whole thing is a joke. My best friends when it comes to this type of stuff believe it or not is the Pākehā because they treat it properly and seriously. They look at it for what it is, they don't laugh at you and things like that. And I'm referring to my Māori friends that I grew up with. They'll laugh at me if I s... myself in front of them; whereas these other ones know what I'm going through and they'll try and help me even it's just to help me get off the main street or something like that. I mean I've done it before, before I came back home here to Taranaki. I was kicking around with a lot of Christians and I just used to say I'd better get off the street because my stomach starts rumbling and I know something's up and it's just best to get off the street. And they'll take me there straight away. I've got to learn to position myself correctly. I've got to take care of myself, it's only me, I haven't got a missus or anything like that, it's only me and I stick pretty much to myself. This stuff does keep me withdrawn because of what it is. I mean if I had a toupee and it fell off in front of everyone we'd all have a great laugh but at least I haven't gone and risked my life and this stuff here is a health risk and hugely embarrassing because it's dealing with the lowest of our human side possible. That's something that we're supposed to keep to ourselves, sort out ourselves and keep ourselves hygienically clean.

I have a friend who has just turned 50 this year who is experiencing the same problems I had. I pulled him aside - I knew straight away. I mean this has been going on for a little while and he's interacting with us and has a rough idea of how I take care of myself. We were at a tangi, a local one, and he's interacting with everyone but the way I take care of my situation and the way he's taking care of his are vastly different. He soils the seats then he gets up and walks off and next minute little babies come along and dabs their rusks or whatever they've got in their mouth on the seat and that could cause something highly toxic, highly horrible type of thing and I don't want that to happen. He's already told me to shut up, who are you he

says? I tell him that's fine, you can dismiss me and go away from here but you're creating a health hazard for us all. I have my problems when it comes to taking care of myself but I make sure that when I'm moving around in the public it's all done properly.

6.4 Manu's Story – The Search for Meaning

Being in Denial

Something was going wrong, and I knew something was wrong – something out of the ordinary. I think first and foremost when we know something like that is a bit bigger than a prickle we go into denial and that's is exactly what I did. I put it off and it eventually tackled me and sent me to the doctor. (JN. 2014)

Manu's decision to ignore his predicament was more about the space he occupied at that time in his life. He was young and active within the social environment where the important things in life were overshadowed by the events in the present. He was enjoying life in the present. Nevertheless, he was experiencing something out of the ordinary and his body was sending him the same message. Despite the warnings, he proceeded down the pathway of denial. Such acts of denial can be interpreted as a violation of one's own intrinsic tapu (*whakanoa te tapu i a ia*), resulting in the diminishment of tapu and impairment of mana. Being pono constitutes an undertaking that speaks to the self. It is about being pono with the self. Tate (2010), says pono is a perception of truth by which we address tapu and mana. It is an ethical principle of action in that it qualifies how we manifest, address, enhance, sustain, and restore tapu and how we exercise mana.

Being in Withdrawal

I've got to take care of myself, it's only me, I haven't got a missus or anything like that, it's only me and I stick pretty much to myself. This stuff does keep me withdrawn because of what it is. (JN. 2014)

The state of being of mauri moe surfaces in Manu's mind. Thoughts manifest as isolation and withdrawal, behaviours that mirror inhibitors to progress and framed within the notion of mamae and its negative elements of neglect, hurt, pain, anguish, and sorrow. Manu is continually in a state of flux where instability brought on by a diagnosis of bowel cancer can lead to fragility and deep anxiety. An outcome of significance from a study by McCaughan et al. (2011) showed that

while most people could not avoid the inevitable exposure to others suffering with bowel cancer, there were cases where individuals deliberately avoided contact through fear of exacerbating depression associated with the disease.

Being in Distress

... I'm always looking for ways out. I'm always looking for ways out of this. I've got a rough idea that I'll never find it but I think my way out might be my eternal rest which I hope is not too close. (JN. 2014)

Manu's diagnosis with bowel cancer sends him to a place that offers a rudimentary form of solace. He prefers to keep to himself where he finds a safe-haven in isolation hidden away from the scrutiny of others. The state of being of mauri moe has manifested itself through withdrawal and isolation. He struggles to come to terms with an ailment that he describes as the lowest of our human side possible. Manu struggles with the position he now occupies - he is suspended in a continuous state of being of mauri moe, the antecedent to which I assert, is diminished tapu, possibly brought about by past lifestyle choices.

...I do want to have a life, I don't like it like this, this is not a life - this is half a life... I can't blame anyone, I can't complain too much, they (my parents) did the best they could. (JN. 2014)

Manu is constantly looking for ways out of his predicament. He has life, but one which he perceives is not worth living. He reflects on the life he had as a youngster and comes to the realisation that the life he had as a young person is what he now seeks. After leaving home, he had become a person of the wider and unsafe world where the advice of his elders, taught and practiced in his formative years, may have been compromised. There is a plethora of international evidence that support the experiences that Manu is currently going through. The postoperative experience of patients' recovery after surgery for colorectal cancer was the focus of a study by Worster and Holmes (2008). Their account provided an explicit description of how patients suffered recurring episodes of anxiety associated with fear, loss of dignity and control of normal daily living activities. One of the inevitable outcomes of colorectal cancer is the ongoing effects of long term treatment regimes. Hewitt et al. (2005) studied this aspect and how health care had altered over time for survivors of colorectal cancer. The prime objective of the study was to examine effective follow up and appropriate treatment options for bowel cancer sufferers after transition from

surgery to postoperative care. The study showed how experiences of anxiety and emotion for bowel cancer patients can result in significant changes in lifestyle including altered relationships and how patients interact with others in the community. (Hewitt et al., 2005)

Being Rejected

My friends think this whole thing is a joke. My best friends when it comes to this type of stuff believe it or not is the Pākehā because they treat it properly and seriously. They look at it for what it is, they don't laugh at you and things like that. And I'm referring to my Māori friends that I grew up with. They'll laugh at me if I... myself in front of them whereas these other ones know what I'm going through and they'll try and help me even if it's just to help me get off the main street or something like that. (JN. 2014)

Perhaps one of the greatest disappointments for Manu was the lack of empathy he received from his own. Those closest to him did not want to know him at a time when he needed them most. Whakanoa is the act of violation by which tapu of tangata is diminished. Manu's treatment by the friends he grew up with exemplifies the concept of negative whakanoa between tangata and tangata, between tapu and tapu. Such acts of whakanoa are considered specific acts of violation toward others. Tate (2010) stated that where there is whakanoa of this nature, there are perpetrators and there are victims. There are those who violate, thereby diminishing their own tapu and crippling their own mana and there are the violated, whose tapu is diminished and whose mana is impaired.

Being Both Nurse and Patient

...I spend so much time, 20 odd hours devoted just to me and that kind of sounds like idolatry¹³² but the fact of the matter is 'I've got to'. I've got to be sorted otherwise things are going to go wrong, very quickly. I never have any real night's sleep, not really. I sleep during the day. I look like a lazy fellow that's just on the sickness benefit that just wants to lay around all day but I'm both the nurse and the patient and they get sick of one another – they really, do. The nurse never gets a break and the patient never gets better. (NJ. 2014)

Manu continues to dwell in mauri moe where he expresses his frustrations in terms of his own self-care. His thoughts mirror inhibitors to progress and are grounded in responses framed within the notion of mamae and its negative

¹³² Self-worship

elements of neglect, hurt, pain, anguish, and sorrow; archetypal of the state of being in mauri moe. He is locked in a state of flux where instability can lead to fragility and deep anxiety. His feelings of entrapment are mirrored in a paradoxical perception of being both nurse and patient. The weariness of the experience shines through. Manu is both the person experiencing this demeaning illness and the nurse who needs to address those demands. The constant unpredictability gives no rest. There is no break from caring and no healing from the care.

Being in Ignorance

They told me all about chemotherapy and I said yes. I didn't know enough about it. I didn't know – all I wanted to do was live so I just said yep go ahead and then I heard that there was some people that were opting to go without chemotherapy. It was then I started taking an interest – what are they doing? It makes sense – that'll teach me. No matter what I wished for and desired for back then I have what I have and it is true, a lot of this is the after effects of the treatment... there are times that if I could have had a quick look at where I am now I might have just said no to chemotherapy. (JN. 2014):

Manu agonises over his decision to accept chemotherapy as a treatment option. He trusted the advice he was given by health professionals and just went along with their decision. He is convinced that much of the downside of his present situation is the after effects of the treatment. He reminisces over lost opportunities that come with knowing. If he had known more about the downside effects of chemotherapy he might have just said no to that option.

The Road to Nowhere

I didn't realise this hurdle in life could be in this way and what a beauty, what a beauty. I don't use toilet paper anymore - I can't. I experience a lot of exfoliation and I experience a lot of chafing. I resort to baby wipes and things like that, I carry them around with me. I have my emergency breakdown kit just like when you take a baby, you're taking bits and pieces for that baby - well I'm the baby. I've had a lot of time to think about what's going to happen... ..the problem is I don't know what's going to happen, what's going to happen in my life or where I'm going to go. (JN. 2014)

Manu's daily living is about dealing with one emergency breakdown after the next. There is a call for constant vigilance reminding of the relentless needs of a baby. He recounts the events of a typical day of surviving with bowel cancer. He is

living life a day at a time, hostage to an illness that knows no bounds. He is living a life where destiny may have the final word and expresses his fear of leaving this earth before his time. In desperation, he changes his focus to survival to a reconnection to the faith he was part of in his early days – to be in communion with Atua.

The Road to Redemption - Turning to God

“I will give you a disease in your bowel God says, where you will die from it” (Chronicles 21, 14-15).

I don't know what you think about that but He (God) is not far wrong at all and there's a reason for it and I think I must have been a bad boy. God wanted people to behave themselves, to observe his 10 commandments. I was thinking just to try and grab these 10 commandments and run with it, then all this good stuff is going to happen to me because I didn't know. (JN. 2014)

After 10 years of searching Manu sought refuge in the biblical teachings of the Bible in his quest to sever the shackles of his life he considered not worth living. He is consumed by God's word in the hope he will find redemption and ponders over the times he has not only transgressed God's law, but man's law. We are born into this world in mauri ora. We are born into this world with the fullness of tapu (Tate, 2010). The question posed here is, what has happened in Manu's life to change all that? Manu makes a frank admission about his past which may have contributed to his current dilemma. One of the most common acts of whakanoa among Māori men, especially, is *whakanoa i te hauora o te tangata*. These acts of whakanoa diminish the physical health and wellness of the person. Another saying among some Māori communities, *whakanoa i te tinana o te tangata*, has the same meaning; where the term *tinana* refers to the body. According to Tate (2010), *whakanoa i te tinana o te tangata* refers specifically to the violation of some part or parts of the physical body. Furthermore, he stated that *whakanoa i te hauora o te tangata* also includes self-inflicted injuries such as *haurangi* (drunkenness) and *momi hikareti me te kai taru* (smoking and taking of illicit drugs). All these acts of whakanoa can inflict physical and mental injury on the body, thereby diminishing tapu and mana by exposing the tinana¹³³ to the harmful effects of disease and/or injury.

¹³³ Physical body

Manu's change in focus is one of reconnection to be in communion with God. His belief in the intrinsic tapu of God (*te tapu i te Atua*) confirms his belief in the existence of Atua and his wish to be in relationship with Atua (*te tapu o te Atua*). He realises, in hindsight, that despite his parent's best efforts he may have gone off the rails in the early years of his life. This realisation is about being pono. Manu is beginning to face up to his past by acknowledging the fact that he cannot blame anyone else for the life in which he is now entrapped.

Reflecting the Past

I didn't realise this but I've been digging graves for 40 years with my old man and my uncles. We all dug holes and things like that around here. That's why I say and I go back to when I was a young boy when life was great. Kicking around with those men and things like fishing off the coast here. Those were the days when I didn't even know what a bowel was let alone bowel cancer. (JN. 2014)

Manu reflects on the past when life was great. Those were the days when he was kept safe within the wider whānau network, to be in the company of whānau - whanui¹³⁴. It was a time when he was always within the safety network of whānau within the safe precincts of relationships that constitutes whanaungatanga. Tate (2010) says *te tapu o te tangata* is about being in relationship with other primary beings such that the relationships enhance, sustain, restore, and empower those in relationship.

...I must have been a bad boy. I was more interested in drink, drugs and sex outside of marriage. I was not only breaking God's laws but man's laws. (JN. 2014)

Manu recalls a time in his life when he became distracted by a false belief of being bullet proof. It is quite possibly a time when he was most vulnerable and open to the temptation of consuming alcohol, partaking of drugs and sex outside of marriage.

You know, there's this, bowel cancer where early detection is not taking place. What the heck's going on? I would like to see testing of bowel cancer for Māori at an early age, even as early as 35 years. I'd even go back to teenagers, start monitoring from there. I wish I had that opportunity, especially now. (JN. 2014)

¹³⁴ Whānau and extended whānau

Manu laments the missed opportunities to learn about bowel cancer from an earlier age, especially now. He makes his own plea of what he would like to happen in the future and uses his own situation to make his point.

6.5 Summary

Manu's experiences of bowel cancer tell a story of isolation and disconnection, where he is constantly living a life of stress. His decision to ignore his predicament when early signs of bowel cancer presented was more about the space he occupied at that point in his life. He was young and active within the social environment where the important things in life were overshadowed by the events in the present. He was enjoying life in the present. Despite the warnings, he proceeded down the pathway of denial. It appears that Manu's failure, on both moral and social grounds, to make changes to his lifestyle resulted in devastating consequences where he was forced to see his doctor. A diagnosis with bowel cancer sends him to a place that offers a rudimentary form of solace where he prefers to keep to himself and where he finds a safe-haven in isolation hidden away from the scrutiny of others. He struggles to come to terms with an ailment that he describes as the lowest of our human side possible and now exists suspended in a continuous state of being of *mauri moe*, the antecedent to which I assert is diminished *tapu*. He is constantly looking for ways out of his predicament. He has life, but one which he perceives is not worth living. In desperation, he changes his focus on survival to a reconnection to the faith he was part of in his early days, to be in communion with Atua. He seeks refuge in the teachings of the Bible in his quest to sever the shackles of a disease that has had a huge impact on his life, bowel cancer. He is consumed by God's word in the hope he will find redemption and ponders over the times he has not only transgressed God's law but man's law.

Manu currently lives with his brother and remains with the classic signs associated with an existence typical of the state of being of *mauri moe*. Since being interviewed for this study Manu has experienced a life in isolation and withdrawal where the notion of wellbeing seems more distant than ever. He continues to live his life in which the behaviours that mirror inhibitors to progress are grounded in responses framed within the notion of *mamae* and its negative elements of neglect, hurt, pain, anguish, and sorrow.

6.6 Conclusion

The state of being of mauri moe expresses thoughtfulness in terms of inactivity including the manifestation of isolation, withdrawal, non-participation and attitudes of indifference. The behaviours mirror inhibitors to progress and are grounded in responses framed within the notion of mamae and its negative elements of neglect, hurt, pain, anguish, and sorrow. Both Manu and Mihi's experiences of bowel cancer tell a story of isolation and anguish. Mihi had lost her husband and both she and their children continue to live life in diminished tapu and impaired mana. Manu too, has experienced a life in isolation and withdrawal where the notion of wellbeing seems more distant than ever. He struggles to come to terms with an ailment that he describes as the lowest of our human side possible and now exists suspended in a continuous state of being of mauri moe, the antecedent to which I assert is diminished tapu. In the following chapter I interpret the stories of participants who have moved beyond the notion of mamae and its negative elements of neglect, hurt, pain, anguish, and sorrow. Their stories exemplify the experiences of survivors who live their lives in enhanced tapu as the state of being of mauri oho.

CHAPTER SEVEN: ENHANCED TAPU AS STATE OF BEING - OF MAURI OHO

7.1 Introduction

In chapter six I searched for meaning in the stories of participants who displayed the archetypal signs of mauri moe framed within the notion of mamae and its negative elements of hurt, pain, anguish, and sorrow. Mauri oho is considered a proactive state which alerts us to a definite shift in a person's behavioural patterns and hence wellbeing. Expressions signifying states of being of mauri oho can increase our awareness and understanding of how the various states of being of mauri oho occur. Mauri oho denotes actions and expressions of activity, an awakening, a new beginning, a rebirth. Participants signal their willingness to participate in activities and or discussions about their wellbeing and begin to share their inner views with others. The following stories exemplify the experiences of participants who were enabled to navigate their way through a journey which from the outset portrayed elements of mauri moe but advanced distinctively to a proactive state that is characteristic of enhanced tapu as state of being - of mauri oho.

Matanuku's Story

The Whakapapa of Matanuku's Story

Matanuku was diagnosed with bowel cancer at the age of 52 years. He was diagnosed early in 2011 and lived with his whānau in Taranaki. Matanuku spoke of the first signs of bowel cancer when he noticed blood on his undies. It was interpreted as being piles. He began losing weight, was not eating and his health took a downward turn. He realised then that something needed to be done. An initial appointment with his doctor resulted in an appointment at the hospital where he was examined by a specialist and a diagnosis of bowel cancer was confirmed. He remained upbeat and hopeful that he had caught the cancer in time. Matanuku phoned me after reading the bowel cancer advertisement placed in the Taranaki Daily and Midweek newspapers. He wanted to tell his story so that he could do his part in helping others who may find themselves surviving as he was, with bowel cancer.

This is Matanuku's story:

When I was going to the toilet at first there was a bit of blood on my undies. I didn't take much notice of it. I didn't know what it was – someone told me it might be piles. The first week was alright. A week later it started getting worse and something came out so I rang my doctor to make an appointment and the nurse asked me what it was for and I told her. She said you'd better come in and she made an appointment for me the next day. I went in to see my doctor and he did things to me with the fingers and he said, "well you'll have to go up to the hospital to get checked". I said, "Oh well", but when the doctor said it might be something else, well we knew about the other cancers but we did not know what this one was. I couldn't wait – I started going down. I didn't know what was happening to me, I was losing weight fast and I wasn't eating. I realised I needed to get it done. I was quite sick for a while before it was done because I lost a lot of weight. We got hold of them again and they made an appointment for a couple of weeks later at the hospital. I went up there and had all that done and I waited for a while and then they said, "Yes you will need to come back as the doctor will be wanting to see you again." So, I went up there a couple of weeks later and they did the colonoscopy. That's when they told me I would need to come back. They said they would send me a letter for another appointment to see the specialist. That was about four days later I think. I went up there and they said I would have to go up to the hospital for a night to do another test in the morning. It was a bit scary, them looking at me, doing this and that. I just closed my eyes – they've got to go in somewhere and look for it. They did all that and they found out what it was. I didn't have a choice – well I could have just said no I didn't want it done – I wouldn't be here today I think. I wasn't whakama - I had to get it done. If I was whakama I would have walked out and just carried on you know. I know what that means. After I found out I went right down. I came right after a while but it took me a while.

They couldn't get me up there for the operation for four or five months. I had to wait a while to get in there but I did get there. I felt like I only had a 50/50 chance especially with all my other health problems – my kidneys, my liver but no - they went through and did it the only way they could do it.

I was feeling OK – I knew I had to get it done. If I didn't get it done well - I'll be down in the ground somewhere. The day I was going in for the operation was a bit scary. I was feeling a bit scared – I will say that. I knew I only had a 50/50 chance. In the morning, I went in for the operation. They came to see me before I went in – the doctors, the nurses – they assured me I'll be alright and everything. They said we'll keep an eye on you because it is a major operation.

I pulled myself through. I thought, I'm going to go through with the operation and I went through with it. But it was the pulling through, to come through with it. That was the major one because they told me I only had a 50/50 chance. I woke in ICU¹³⁵ and it was all over - done. When they came in to see me about it the next morning they said it is going to take a while. Getting used to the bag was a bit hard – but once I learnt everything about that I coped alright. It took a couple of months – I wouldn't go anywhere but after a while I just took my bags with me and I would just change it in the toilet - I'm used to it now. Once I got used to it I didn't feel so closed in to stay home – I had go out too. It took me a while to get around, to get all healed and all that. It was difficult for a while, showering and all that. I had to have a nurse come in every second day. That's embarrassing isn't it but I just had to get it done. I couldn't go out anyway for a few months but when I did get going and driving again I was happy. I just couldn't do other things like I used to.

I had other health problems and they put me on dialysis. They thought I was anaemic and all that and I wasn't putting on weight. I wasn't eating properly until they started putting some blood back into me - some red cells. I started feeling good when they started giving me injections, that's when I started coming right – I was getting fitter every day after that. I mow all our lawns now whereas before I couldn't. It took a year for my tissues to heal. In between that time, I had another operation because they found another tumour – that was this year. It took 18 months for me to pull all through and get my health back up to what it is now. The doctor said that when I came in they didn't think I was going to make it - but to look at me

¹³⁵ Intensive Care Unit

now. I'm bringing up my mokos - they know I'm on the bag. They felt sorry for me for a start and then they got used to it. The bag makes a noise – it's embarrassing but it's all good and even when I've had friends here well, they know I've got bowel cancer and they just take me as I am. In my day, I used to be a gang member but my brothers still come up here and see me.

During my recovery, they didn't give me chemotherapy because of my heart and kidneys. I had lost a lot of weight during the surgery and I was that skinny. I wouldn't have been-able to handle it anyway because when I went into ICU I was on life support. They said they lost me, I don't know for how long but I was on life support for two days. Usually you don't go up to ICU but in my case, my heart and all that, well I ended up on life support for two days but I pulled through. I'm glad I have got my health back again. I have started walking a little further each day. I was surviving – I took each day as it came. My wife said, "don't sit on the couch and feel sorry for yourself, get out there and potter around in the shed"; she said get out and around. I was still sore but then I thought why should I just sit around here and watch the TV. In time, I began to feel good and I was getting further and further with my mokos on their paper run. When I first started, I couldn't get very far. Now I do the whole run with them because I was feeling good. I wasn't sitting around thinking I can't do this and I can't do that. I just thought get out and do something - like walk. I'm lucky I've got these boys. I can walk around the streets on their paper run with them and I can still drive and I can mow the lawns. When I first started, I used to push a pram. A lot of people toot their horn at me and they stop and say - gees you're looking well - walking and all that.

If there is a single message I would give to other Māori about bowel cancer it is this, get yourself checked out – you're going to feel shy and scared. Don't be whakama, don't be that. If you're going to be that it will only hold you back. Get someone to take you to the doctor if you think you've got it. If you don't get it done you're going to go right down. I wish I got it earlier. I could have had a colonoscopy earlier but I didn't. Once you get over all your hurts and everything, get up and do something to take your mind off it and after that you'll come right – start walking and potter around and if

you've got a garden you can still do it. If you feel sorry for yourself and I sort of did that because in the early stages I just laid back and watched TV. I wasn't feeling well but after my wife told me to get up and go outside in the sun and move around even though I was hurting I realised it was the best way to heal.

7.2 Interpreting Matanuku's Story – The Search for Meaning

Being Pono – Facing Reality

I knew I had to get it done. If I didn't get it done well - I'll be down in the ground somewhere. (TM 2014)

Matanuku realised soon after he was diagnosed with bowel cancer he had to have the operation, there was no other alternative. This was a time where he had to face up to the truth about what was happening to him. A course of action involving invasive surgery was a major decision that he had to make.

They couldn't get me up there for the operation for four or five months. I had to wait a while to get in there but I did get there. I felt like I only had a 50/50 chance especially with all my other health problems – my kidneys, my liver but no - they went through and did it the only way they could do it. I was feeling OK. The day I was going in for the operation was a bit scary. I was feeling a bit scared – I will say that. I knew I only had a 50/50 chance. (TM. 2014)

Pohatu (2011) asserted that the state of being of mauri oho indicates a point of personal courage, the manawanui, kia kaha (be strong) notion. As people strive to face and manage their fear so do they locate inner strength and understand more about their personal courage and, therefore, the potential to proactively engage and advance. The fact that Matanuku had to wait five months before he could access surgery provided reason for concern – the tumour could develop further and possibly spread to other parts of the body. Matanuku was frightened but optimistic, he was told that he had a 50/50 chance of survival. Despite the odds he was determined to go through with the operation. Hill et al. (2010) showed that higher patient comorbidity and poorer access and quality of cancer care were both important explanations for worse survival in Māori compared with non-Māori New Zealanders with colon cancer. Understanding the cancer patient's search for meaning, O'Connor et al.'s study (1990) focused on patients' experiences immediately following a diagnosis of cancer. The study portrays patients' struggle to find meaning in their lives after being diagnosed with an

illness that signifies likely and impending death. Two factors of note to emerge from the study were a strong commitment and belief in faith and the importance of ongoing social support. Taylor (2001) too described an account of the experience of being diagnosed with colorectal cancer. The objective was to understand an experience and uncover the meaning and the trauma of being diagnosed with bowel cancer and one of the most poignant themes, feeling on your own provides us all with the reality of what it is like to be diagnosed with bowel cancer. A similar study by Moene et al. (2006) researched patients' existential situation prior to major surgery for colorectal surgery. Matanuku expressed emotions of anxiety and fear of the unknown which were consistent with findings by Taylor where the onset of trauma can trigger thoughts of imminent death.

A New Awakening – A Rebirth

I started feeling good when they started giving me injections, that's when I started coming right – I was getting fitter every day after that. I mow all our lawns now whereas before I couldn't. I just couldn't do other things like I used to. I am glad I have got my health back again. I have started walking a little each day. I am surviving – I take each day as it comes. (TM. 2014)

Matanuku's words tells us something of the new space he finds himself in. The state of being of mauri moe mirrors inhibitors to progress and are grounded in responses framed within the notion of mamae and its negative elements of neglect, hurt, pain, anguish, and sorrow. Matanuku's health had improved, he had transitioned to a state that mirrors behaviours archetypal of mauri oho which denotes actions and expressions of activity, an awakening, a new beginning, a rebirth. Matanuku signalled his willingness to participate in activities and discussions and share his inner views with others about his new-found health. He was making progress and felt rejuvenated. He had overcome the anxiety associated with the operation and he could see light at the end of the tunnel. He was feeling happy with his progress but he just could not do the things he used to.

Tate (2010) stated that *te tapu i* encompasses existence. Matanuku's experience of coming through his operation was significant in terms of his wellbeing. A new awakening, a rebirth intimated an enhancement in the state of his own intrinsic

tapu, a repositioning from diminished tapu to enhanced tapu, the reason why he was feeling well again. He had come through his ordeal and survived despite being told he had only a 50/50 chance of survival. It was the beginning of a new chapter in his life. He was experiencing a new existence, an existence that had moved dynamically from a state of being of mauri moe to that of mauri oho.

Being with a Stoma

The bag makes a noise – it's embarrassing... when I've had friends here well, they know I've got bowel cancer and they just take me as I am. In my day, I used to be a gang member but my brothers still come up here and see me. (TM. 2014)

Matanuku struggled with the colostomy bag in the early stages of post-operative care. Having a colostomy bag was a barrier for Matanuku. The fact that his friends still visited him knowing he was a survivor with bowel cancer was healing for him. In doing so, his friends were expressing their aroha for him and it was their way of providing support through the act of whanaungatanga. Being in whanaungatanga enabled Matanuku to overcome a problem that may have persisted had he not had that support. Once he learnt everything about it, he could manage it and he did not feel so closed in to stay at home.

The prospect of having to live one's life with a stoma surfaced with other participants in the study. I have mentioned this aspect here because it was problematic with other participants. Four of the other participants experienced problems with having to survive with a stoma. One of the participants seriously considered refusing surgery if having to live one's life with a stoma bag was the outcome. All the participants affected with the prospect of having to live with a stoma suffered a form of embarrassment associated with whakamā. That, from a Māori perspective, says this is not normal, it is not right, and thoughts of past misdemeanours engenders thoughts of the past. What have I done in the past for this to happen? The outcome of whakamā leads one to become distant from others and a tendency to remain in isolation.

A study by Cotrim and Pereira (2008) provides us with insights of people who have no option but to live the rest of their lives with a stoma. Study findings showed that the quality of life of a colorectal cancer patient and his family is deeply modified when faced with a diagnosis that can cause physical and psychological changes induced by it. The aim of the study was to identify and

assess the impact of colorectal cancer on patients and their families. In terms of quality of life, those patients who had a stoma reported a lower overall quality of life, lower body image, poorer health related quality of life, and poor social activity when compared with colorectal cancer patients who had no stoma. The stoma patients also had significantly higher depression and anxiety than non-stoma patients (Cotrim & Pereira, 2008).

7.3 Being with Whānau

My wife said, “don’t sit on the couch and feel sorry for yourself, get out there and potter around in the shed” - she said get out and around. I was still sore but then I thought why should I just sit around here and watch the TV. I’m lucky I’ve got my boys. I can walk around the streets on their paper run with them and I can still drive and I can mow the lawns. When I first started, I used to push a pram. A lot of people toot their horn at me and they stop and say – “gees you’re looking well” - walking and all that. (TM. 2014)

Matanuku had entered a new phase in his life, a life that grounded him in the reality of what his whānau meant to him and, conversely, the new person he has become in the eyes of his whānau. His past life as a gang member was far removed from the reality he was now experiencing. He speaks of his wife as a driving force in his quest to become well again. I now consider that relationship between Matanuku and his whānau, between tangata and tangata. *Te tapu o* means that tapu is seen here as an aspect or quality of someone or something. It is not about an existing reality, considered absolutely, but rather it is something of, or about, an existing reality. The relationship between Matanuku and his whānau had moved dynamically to the point where their relationship was mutually enhancing, restorative, and empowering. His whānau had witnessed his struggle as a survivor with bowel cancer and had come to appreciate his courage and commitment. The same can be said of the relationship between Matanuku and others in the community where he lived. Matanuku remained optimistic about the future. He was existing, a day at a time. We can say he was existing in a state of being that is consistent with the behaviours that Pohatu (2011) defined when a person moves dynamically from mauri moe to mauri oho. He was motivated to participate in chores around the home and he was walking the paper run with his

mokopuna.¹³⁶ Being in whanaungatanga was the glue that cemented his new-found wellbeing – enhanced tapu as the state of being, in mauri oho.

7.4 Reflecting the Past

...If there is a single message I would give to other Māori about bowel cancer it is this, get yourself checked out – you're going to feel shy and scared. Don't be whakamā, don't be that. If you're going to be that it will only hold you back. Get someone to take you to the doctor if you think you've got it. If you don't get it done you're going to go right down. I wish I got it earlier. (TM. 2014)

Matanuku shares his thoughts on what he thinks Māori should know about the dangers of bowel cancer and what needs to be done to prevent it. He laments his own missed opportunities to recognise the symptoms of bowel cancer to make his point. He is aware of what whakamā is, perhaps it was that which prevented him from going to the doctor earlier in life. He just wishes his diagnosis of bowel cancer happened earlier.

7.5 Summary

Matanuku, like many others in Taranaki, possessed very little in terms of health literacy, a feature that has surfaced among all participants in this study. He had become a person acculturated into a brotherhood he refers to as his friends.¹³⁷ His story tells us of the subtle transformations that have taken place from a past life of being a gang member to that of going back to the simple things in life. He had reached a time in his life where adversity brings out the best in people. He had come through an operation that was tantamount to a rebirth, a new beginning in life, a new existence.

One of the contentious issues that surfaced for him was the reality of having to survive with a stoma. This was not just a case for Matanuku but for others as well. All the evidence points to a stoma as being repulsive and something that is difficult for Māori to accept. Despite that experience Matanuku, and other participants in the study who shared his dilemma, managed to overcome a seemingly impossible burden once they realised what a stoma was and why it was necessary for survival.

¹³⁶ Grandchildren

¹³⁷ Gang associates

Matanuku began to feel better than he had been feeling in a long time by going back to the simple things in life. The doors had opened to a new-found wellness. He had entered a new phase in his life that brought him back to the reality of the true meaning of whānau and conversely, the new person he had become in the eyes of his whānau. Matanuku had entered the true spirit of what it means to be in whanaungatanga with his whānau. He was making wonderful progress - he was shooting for the stars. He had everything to live for and he was looking to the future with great expectations.

In July 2014, I visited Matanuku and his wife to see how they were coping. I was greeted with the news that Matanuku had been diagnosed with another tumour which had spread from the bowel to other parts of the body. While Matanuku had expressed hope for a better life with his whānau the reality was the new diagnosis was terminal and it became evident that his health had regressed. It was with sadness that I received the news of Matanuku's passing in August 2014.

In the following section I introduce Rihari. Rihari was diagnosed with stage 4 bowel cancer in July 2014, two weeks prior to being interviewed for this study.

Rihari's Story

The Whakapapa of Rihari's Story

Rihari was always acknowledged as the white Māori in his whānau, even up to and including his early 20s. It was something that he and all his whānau treated as being normal. In the months leading up to his 29th birthday Rihari was to experience complications with his health, and several visits to his doctor failed to pinpoint anything out of the ordinary. He remained optimistic about the future. Rihari was diagnosed with stage four bowel cancer in July 2014. Despite being diagnosed with stage four bowel cancer he was hopeful that his age would be a significant factor in his recovery. He expressed a wish that his story would raise awareness of bowel cancer among other Māori, especially younger Māori.

This is Rihari's story:

You know there wasn't much on bowel cancer in this community. We didn't know much about it but after I got diagnosed we looked back at our family history and that explained everything. I was pale and restless at that time – I was the pale Māori. I was like the whitest in my whole family. I think I

must have been only 25 years old at the time, I might have been younger. We didn't know any better. We just thought oh well – we're just working hard and that's just how it goes. It's just this year it's got a bit worse and my family know and I don't mind if anybody finds out about my condition. It was about October/November (2013) when we had a family reunion and they were just saying that I looked a bit washed out and stuff. I started going downhill about October. I went into hospital with a little bit of chest pain. They did chest x-rays but they found nothing. They also chucked the heart monitor on and no, nothing happening there. They sent me home with a chest infection, gave me antibiotics and then a couple of weeks after that my neck started to swell up. Big as, I couldn't move and we could see all the veins and everything popping out. They just told me it's just a throat infection, a viral infection or it might be swollen lymph nodes so they just gave me more antibiotics and pain killers. So, I took those and it went down a little bit and then the pain started going through my shoulder, under my arm. So, I just went to my GP. He did an examination and he told me that he thought I had a blood clot in the neck. That was my GP speaking, just an ordinary examination. He's a good doctor and he said that I really need to go to the hospital and get some tests done like an ultrasound on my neck because he was just a bit worried that it might have been bowel cancer because of my mum and my uncles and all of them. It's just the big family history. So yeah, we went over to the hospital. They said it was highly unlikely that I've got a blood clot in my neck because I'm too young so they just sent me home with more antibiotics.

That was about February of this year (2014), it's all been happening this year so the process for me was OK - sweet as, we'll just go home take some more antibiotics. So, I took them but no, the pain just wasn't going away and one morning I woke up and my wife grabbed my arm and we just sat there for like half an hour just watching my arm swell up. So, we went to A & E at hospital and told them our story. We had been coming in and out of A & E and they were just saying infection, infection, infection. My GP ordered an ultrasound and the doctor that was on that morning said OK and grabbed the machine had a look, did the ultrasound and said yes, you've got a blood clot in your arm and your neck so you need to go to

hospital. So yes, I was admitted for about a week, they did a colonoscopy and an endoscopy. There was nothing down my throat but the colonoscopy, well there was about three quarters of my large bowel right up the top - they found the tumour. We googled it just to get some idea what and where it was in relation to the stomach and other organs. So, we went up to the hospital and I kind of had to rub it in the doctor's faces for sending me home saying it's highly unlikely that I'm that likely person in that 1% who could have bowel cancer at such a young age. It was big. About three quarters along the bowel but he could still get the scope past it but only just. I could feel everything. They said that I will feel nothing but I could feel everything. Despite all the drugs they were pumping in I could still feel it. I don't know if many people seen what's inside but I was looking at their TV screen and I saw it and wow – they look so ugly. At first, they didn't tell us how bad it was. They didn't tell us at which stage it was. They just said yes, you've got a tumour in your bowel and because of the lump in my neck they had to take a biopsy. They got the surgeon to poke a needle in and take a sample and then they said it's the same as my bowel so it had spread from my bowel through my chest and to my neck. It was not until a couple of weeks ago that we found out that the cancer was stage four. So, it has gone through the bowel wall and invaded other parts of the body. We just googled it and found out it had spread through the lymph nodes through to my neck - something like that.

I'm still young and I've still got a lot to live for. When we first found out (me and my wife) – we didn't have enough time to be sad or anything like that. We found out just before my birthday – about the 1st March (2014). That's when we found out. I spent my birthday in hospital. Everyone else was there for us so it was kind of positive. Our attitude was OK just give me the treatment and deal with it and that's it. They didn't want to operate because they said it's too risky. If they risk taking it out, then the rest of my chest and neck will probably turn into something else. They expressed that it's too risky and if it's already spread, I'm wondering why can't they just take it out? I'm on intravenous chemotherapy right now. I have chemo, every three weeks. I'm not having radiotherapy just chemo, 14 days of

tablets. The coming Tuesday will be my sixth treatment – so I've been having treatment for the last four months.

I've noticed in the last week that my neck starting to swell up again. I think I'm a bit more in touch with my body now. I know what's going on, I can feel everything. I'm tuned in to my body now and I know what's there. It's scary but I can deal with it. It does knock you for six but I'm OK. You feel worse than what you would normally and you get a bit constipated and bloody. It just feels like you're bloated. It's just from the tablets. I haven't altered my diet in any way and if anything, I think I'm eating a bit more. When I first started, I was only 95 kilograms – now I'm 110 kilograms. 95 kilograms is the lightest I've been my whole life. I used to be 120 kilograms and then I suddenly lost weight. I went down 25 kilograms. I had blood tests and everything – it came back that I had a form of anaemia but we didn't find that out until the doctor did the ultrasound for the blood clots and it's like I've been living with anaemia for years – looks like it. But nobody has told us and that would explain why I was so white you know, and no energy.

I don't know why it took so long because we have a history. There is my mum. She had her operation and got it all taken out and her brother, he had his operation. He had a bit of radiation because it had spread but he's doing alright. And then there is uncles' brother, uncle (M). He would have been alright but I think they just put it down to bad practice or something. I don't know what happened there [uncle M died after having an operation for bowel cancer]. My mum's brother has also got bowel cancer but he's doing OK. I think there's a few more uncles up in Auckland but I'm not too sure about those ones up there but I know there is about 13 of us in our family, just on our side.

You know, when we found out I had bowel cancer I said OK I'm going to do the tuākana (older brotherly) thing on all the cousins out there. You know, go to the doctor book yourself in and all that stuff. I don't care if it's going to hurt or whatever I just wanted them all to get checked out. I think five of my cousins up in Auckland and Taranaki have already done it and they have all come back clear. They've been told by their doctors to come

back every two years because it can move fast. I should know, I'm only 29 but I think I might have had it when I was 25 or even earlier.

I think our people joke about it sometimes and they don't take it seriously. They talk about the smelly farts, it's a bit like that, a bit of humour. A couple of our friends and family are like that. They feel a bit awkward and don't know what to say and all that. It's alright, I don't care. It needs to be talked about. I never ever thought I would get bowel cancer. I was just living my life, making my family, looking after my family like a normal young person. I thought I was invincible – I'm not going to get sick. I'm not going to get those diseases.

I've got an appointment with my doctor just to see what he wants to do. They don't go past six treatments with chemo so I'll probably just go on to the pills forever just to keep it where it's at, to stop it from spreading even more. We'll see what the doctor says first and we should know a little bit more. The last time I had a CT scan there was a little bit of shrinkage but not significant. It just stopped – it didn't grow - it was just the same. That was after four treatments. I have another scan after this treatment. It doesn't matter if other people know about me. I want to be the face for bowel cancer for young Māori in Taranaki. I'll be that example you know, to do something. There's not much information out there on bowel cancer. We were looking for information but there was nothing then out of the blue some doctor, she organised a meeting about bowel cancer. She was just telling her story and I think she is part of 'Bowel Cancer Aotearoa.' She had something to do with the health system. She also said that she wanted to see a national screening programme in New Zealand. I'm 29 and I think younger people should be tested. I think young people aged 19 and upwards should be getting tested. I think that's a great age to be tested because of what it is - there's no risk. They don't want to do it like colonoscopies and stuff you know. It should not be for children and not for old people. I think that 20 – 40 years is a good age to be tested. That would be perfect.

You know, I was a healthy person, I went through a vegetarian stage in my life and they just seem to think it could be genetics. I still eat MacDonald's and stuff like that but I hardly ever played sport. My wife wants to start up

a programme to teach people to live off the land and how we used to live - you know like our old traditional ways and diets. I've heard that one in four of our children could possibly get this because of the genes and stuff. If we can give more information to prevent it then we will try. My wife is a strong woman but deep down I think it's having an effect. It's getting to the point where we just want to sit there and have our cry. We haven't (not once) have sat there together and had a cry about it. We don't seem to have the time. We are young and have a lot to live for and we are just going to tackle it head on.

7.6 Interpreting Rihari's Story – The Search for Meaning

Trust in the System

...I went into hospital with a little bit of chest pain. They did chest x-rays but they found nothing. They also chucked the heart monitor on and no, nothing happening there. They sent me home with a chest infection, gave me antibiotics and then a couple of weeks after that my neck started to swell up. Big as, I couldn't move and we could see all the veins and everything popping out. They just told me it's just a throat infection, a viral infection or it might be swollen lymph nodes so they just gave me more antibiotics and pain killers. So, I took those and it went down a little bit and then the pain started going through my shoulder, under my arm. So, I just went to my GP. He did an examination and he told me that he thought I had a blood clot in the neck. (TR. 2014)

Rihari's encounter with health professionals in the lead up to his diagnosis leaves him dependent on an outcome that has been clinically defined. He simply accepted what was prescribed, the doctor knows best, an assumption that many Māori have. Tate (2010) stated pono is a principle of perception of truth by which we address tapu and mana. It is an ethical principle of action in that it qualifies how we manifest, address, enhance, sustain, and restore tapu, and how we exercise mana. In the absence of whanaungatanga, the engagement process adopted by the doctors in consultation with Rihari had very little resemblance to what Tate proposed when he speaks of encounter that imparts some aspect of quality of being that is creative, productive, enhancing, or empowering from one to another. I reiterate the point I made earlier that Rihari was left dependent on an outcome that had been clinically defined as the basis for his intervention and treatment plan. He had no knowledge of bowel cancer. As far as he was concerned there was a problem but the problem was perceived as nothing major.

He trusted the system and remained optimistic despite being misdiagnosed on several occasions.

A willingness to be involved in, and an eagerness to discuss issues about personal health with others is a fundamental stance that is one of the characteristics of the state of being of mauri oho. As noted earlier, the necessity of a valid cultural assessment for Māori upon admission to healthcare institutions is imperative. It is the equivalent of any pre-entry/entry facets of the pathway that all healthcare institutions should have in place. The significance of a culturally appropriate assessment for Māori who present for assessment is more than just knowing a person's name and their religion – it is also about understanding the person, understanding the whānau. When we acknowledge the tapu and mana of a person in a healthcare setting we explore possible links as to why they present to healthcare services in the first place. The fact that Rihari's whānau had a history of bowel cancer may not have been mentioned. Past family history can be overlooked to the detriment of the person seeking help.

A study by Blair et al. (2013), *Cancer in Māori: Lessons from prostate, colorectal and gastric cancer and progress in hereditary stomach cancer in New Zealand* examined persisting ethnic disparities in cancer incidence and outcomes between Māori and non-Māori in Aotearoa/New Zealand. In Māori, the sites of highest cancer incidence were the prostate in men, breast in women and lung in both. The next most common cancers in Māori were colorectal and stomach cancer. Colorectal cancer was discussed to illustrate the importance of accurate cancer statistics to focus on management strategies that would explain how cultural factors impacted on delivery of care. The point I make here is that many Māori are not given the opportunity to address cultural factors when they are admitted to healthcare institutions. In my experience, valid cultural assessments are rarely conducted at the pre-entry and entry stages of care. The research by Blair et al. showed how successful clinical partnerships in collaboration with Māori providers can improve patient outcomes. One example is the Kimi Hauora Clinic¹³⁸ which provides support to cancer patients and their families, helping them navigate the interface with the many health-care professionals involved in the multidisciplinary care of cancer patients.

¹³⁸ Healthcare clinic in Tauranga

...my doctor said that I need to go to the hospital and get some tests done like an ultrasound on my neck because he was just a bit worried that it might have been bowel cancer because of my mum and my uncles and all of them. It's just the big family history (TR. 2014)

After successive consultations Rihari's doctor had suspicions that bowel cancer might be the real issue because of the family history. This was not picked up by doctors at the hospital who simply went ahead and prescribed more antibiotics. The point to be noted here is, Rihari's doctor was aware of the family's history of bowel cancer and it appears his advice was not mentioned when he was examined at the hospital in subsequent consultations. A review of literature on bowel cancer, conducted by Almuammar (2010), examined how delayed presentation or late diagnosis of bowel cancer is associated with low survival. The aim of the review was to identify factors associated with delayed presentation. Twenty-four studies met the inclusion criteria which identified factors associated with patients' delay, including patients' knowledge, stress and fear, and nature of the disease. Other factors were attributed to health providers such as doctors' experience, referral delay, and younger age people presenting for consultation being considered as low risk. Consultations were less investigative, so symptoms were missed.

We Didn't Know Any Better

They did a colonoscopy and an endoscopy. There was nothing down my throat but the colonoscopy, well there was about three quarters of my large bowel right up the top - they found the tumour. You know there wasn't much on bowel cancer in this community. We didn't know much about it but after I got diagnosed we looked back at our family history and that explained everything. We didn't know any better. (TR. 2014)

Despite evidence that the family had a significant history of the disease Rihari said he and his family did not know any better. Very little was known about bowel cancer in the community.

We just thought oh well – we're just working hard and that's just how it goes. We found out just before my birthday – about the 1st March 2014. Our attitude was OK just give me the treatment and deal with it and that's it. I'm wondering why can't they just take it out? (TR. 2014)

Rihari remained enthusiastic and buoyant about the future and it was only a matter of time before he considered he would be back to normal health. For many a diagnosis of stage four bowel cancer can be demoralising but Rihari does not

perceive his diagnosis as that. His demeanour is more about a person who is optimistic about being well again. He was certainly not exhibiting the characteristic signs of mauri moe where behaviours mirror inhibitors to progress grounded in responses framed within the notion of mamae and its negative elements of neglect, hurt, pain, anguish, and sorrow. Pohatu (2011) stated: mauri oho is considered a proactive state where a person becomes enthusiastic about life and becomes eager to find out more about their condition. It is the point at which personal behaviours signify a transition from mauri moe to that of mauri oho. Something has happened to spark interest, a willingness to participate and share with others. Rihari was firmly focused on the future, a future that involved his wife and young family.

Being with Others

I'm still young and I've still got a lot to live for. When we first found out we didn't have enough time to be sad or anything like that. I want to be the face for bowel cancer for young Māori in Taranaki. I'll be that example you know, do something. There's not much information out there on bowel cancer. (TR. 2014)

Rihari believed they had a lot to live for; after all he was still young and able. He felt that there was a need to be involved, to spread the word, to do something about bowel cancer. This despite being diagnosed with stage four bowel cancer himself. As far as he was concerned there was no time to be sad. He was exuberant and motivated to do something about bowel cancer among Māori in Taranaki. He appeared to be more concerned about others by taking away the focus from himself and in doing so, he personifies in right order the principles of pono, tika, and aroha. He wanted to spread the word about bowel cancer for the right reason, to be pono to the task ahead. He was committed to saving others by advocating on their behalf. Such was the aroha he had for others, especially younger Māori.

At first, they didn't tell us how bad it was. They didn't tell us at which stage it was. They just said yes, you've got a tumour in your bowel. They got the surgeon to poke a needle in and take a sample and then they said it's the same as my bowel so it had spread from my bowel through my chest and to my neck. It was not until a couple of weeks ago that we found out that the cancer was stage four. I don't know why it took so long because we have a history. (TR. 2014)

There appeared to have been some reticence by the doctors to let Rihari and his family know the true extent of his condition after a series of misdiagnosed decisions led to a consultation that finally established that he had stage four bowel cancer. The principle of pono is the perception of truth by which we address tapu and mana. As an ethical principle of action, it qualifies how we manifest, address, enhance, sustain, and restore tapu through the proper exercise of mana. It appears that Rihari's doctors may have realised he had been misdiagnosed due to a lack of information. That is something they should have picked up much earlier given the family history. This analysis is congruent with the scenario presented earlier on the need to conduct meaningful assessments for Māori who are seeing their doctor in both primary and secondary healthcare institutions for the first time. The appropriate admission process sets in motion a correct and rightful process for ongoing planning for healthcare interventions. That process encapsulates the principle of tika, the right way of doing, which presupposes pono the truth that sets in motion - the right way of doing.

You know, when we found out I had bowel cancer I said OK I'm going to do the tuakanā, the brotherly thing on all the cousins out there. You know, go to the doctor book yourself in and all that stuff. I should know, I'm only 29 but I think I might have had it when I was 25 or even earlier. (TR. 2014)

Rihari's exuberance to be with others is captured within the concept of whanaungatanga. All he wanted to do was to do the best he could for the rest of his whānau by creating greater awareness of bowel cancer.

7.7 We Have a Lot to Live for

...It's getting to the point where we just want to sit there and have our cry. We haven't, not once have we sat there together and had a cry about it. We don't seem to have the time. We have a lot to live for and we are just going to tackle it head on. (TR. 2014)

Despite a forecast of stage four bowel cancer, Rihari and his wife remained optimistic. They were determined to do whatever it takes to beat it.

my wife is a strong woman but deep down I think it's having an effect. It's getting to the point where we just want to sit there and have our cry. (TR. 2014)

The irony for Rihari was the reality that a prognosis of stage four bowel cancer meant that his health was slowly deteriorating. The dynamic movement of mauri

had regressed to an existence archetypal of diminished tapu as a state of being - in mauri moe. It was with sadness that I received the news of Rihari's passing aged 30 years.

7.8 Summary

Rihari was diagnosed with bowel cancer in March 2014 - he had just celebrated his 29th birthday. Despite his diagnosis, he was hopeful that his age would be a significant factor in his recovery. Throughout the months prior to his diagnosis Rihari was subject to several consultations with doctors who failed to detect the primary source of his condition, bowel cancer, despite his family having a significant history of the disease. Sadly, that history had not been discussed by his whānau either, who remained oblivious to the fact that there was a significant problem. The concept of whanaungatanga surfaces yet again. In the first instance Rihari is subjected to engagement where he does not go through a cultural engagement process which can reveal crucial information about the person, about the whānau. The outcome can be interpreted as the wrongful exercise of mana by health professionals because they failed to access critical information that may have made a difference. Rihari's naivety is concealed by the belief that it would be only a matter of time before he would be back to normal health. To him, bowel cancer was just another episode in life to be dealt with, and he had no time to be sad. His willingness and commitment to connect with others, to do something about bowel cancer for other Māori, especially younger Māori, became his focus. Rihari and his wife remained positive toward a better life - there was no other alternative. They had a lot to live for and as far as they were concerned they were going to tackle it head on. For Rihari and his wife living in hope was the better option than having no hope at all. Sadly, he passed away leaving a wife and young children.

7.9 Conclusion

Mauri holds a central place in informing Māori, how and why our lives take the form they do. It imbues Māori thinking, knowledge, culture, and language. Both Matanuku and Rihari were positive in their outlook on life, a core element of the state of being of mauri oho. Mauri oho denotes actions and expressions of activity, an awakening, a new beginning, a rebirth. Both participants signalled their willingness to participate in activities and/or discussions about their

wellbeing and share their inner views with others. We grow up in a world where the dynamic interchange of mauri dictates how we are feeling. At times, we face critical moments in our growing up in the world. A judicious moment can lead to gratitude in life, a vulnerable moment to despair. We become a product of those moments created by the choices we make in life. We exist in tapu and the choices we make in life can determine the way we exist in, and how we interact with, the rest of the world. Both Matanuku and Rihari had great expectations for life after bowel cancer. Sadly, it was a life that eluded them both in passing. In the following chapter I interpret and search for meaning in the stories of participants who find themselves as survivors having bowel cancer in restored tapu as the state of being of mauri ora.

CHAPTER EIGHT: RESTORED TAPU AS THE STATE OF BEING - OF MAURI ORA

8.1 Introduction

In chapter seven participants were chosen because their stories conveyed prevalent behaviours that illustrate the state of being of mauri ora. Mauri ora signals increased energy and awareness that comes from a high level of energy. There is an obvious purpose for being and a willingness to actively engage in and enjoy a future with loved ones and all other relationships of which we are part. The following expressions signal markers to identifying states of mauri ora that can increase our awareness and understanding. States of being of Mauri Ora find expression in actions and knowledge that signify successful outcomes where participants become highly motivated by what is happening to them in terms of their wellbeing. It is the stage in their journey where they are feeling good about their health, where they remain alert and actively engaged in, and committed to keeping good health. These behaviours are further heightened by stronger family relationships and social engagement in the community. Participants' experience of life has changed for the better – they now have a new purpose in life brought about through a new sense of wellbeing. Six of the participants in this study navigated through a journey that transitioned across all three domains of mauri culminating in mauri ora. All six stories exemplify the experiences of participants who experienced a sense of wellbeing that resonates as restored tapu as the state of being – of mauri ora. I have chosen three of the stories for this chapter that show this most clearly. The remaining three stories appear with my interpretations in Appendix B.

Moana's Story

Whakapapa of Moana's Story

Moana is 80 years old and was diagnosed with bowel cancer at the age of 79. He knew very little about bowel cancer and what knowledge he possessed was from the experience of a work colleague who had died from the disease some years previously. When Moana travelled to Australia to his grandson's 21st birthday his behaviour of constantly going to the toilet on the plane was noticed by his eldest daughter. When she asked him why he was going to the toilet so

often he said he did not know why and told his daughter that he had been doing so for the past six months. At the time, he had absolutely no idea that he had bowel cancer. The fact that his condition was noticed early on by his children is testimony of the affection and love that his children had for him. That affection was the catalyst that enabled Moana to be where he is today.

This is Moana's story:

Back in 2012 I went to Perth for my grandson's 21st birthday and coming back on the plane I kept on watching the toilet because I knew that when I wanted to go to the toilet I had to go. I had to use the toilet straight away so I kept on getting my daughters to move away so that I can sit beside the aisle so I can go to the toilet. Anyway, when we got home my oldest daughter asked me why I was doing that, looking at the toilet all the time. I told her that I was watching the people going in and coming out and when they were coming out I was ready to go in because I had to use the toilet. She said, "Why is that?" "Well," I said, "When I wanted to go to the toilet I had to go". She said, "How long has it been like that?" I said, "About six months". She said, "We'll go and see the doctor." So, she made an appointment for me to see the doctor. My daughter and my youngest son took me in to see the specialist and he said we'd like to see your dad go through and have this sorted out so we can see why he's doing what he's doing. The specialist said I'll have him examined and we'll see what it's all about. Anyway, I had to go in and see him and he examined me and found that I had a growth inside of me and that's when they told me it was cancer. My best mate worked with me and he had that cancer. We used to talk about that cancer - bowel cancer. He died of bowel cancer. It went from there up into his pelvis to his lungs - it went through him. When I found out I had bowel cancer it hit me very bad because I knew my best mate died of that cancer and it brought back the memories of those people that passed away.

Well I couldn't do a thing. I accepted that I had to go and get this operation and the specialist said that I could go to the general hospital and get that done. The kids agreed and that's how I got in there to have this operation. After I had the operation everything was good. My surgeon said everything is all good - that was on the Friday. I came out of the operating theatre on

Friday and on Sunday they said, “you can go home - you’re looking good”. I came home and that night I couldn’t sleep. There was something wrong inside and I said to my youngest son to ring the ambulance or would he take me to hospital. I thought to myself it’s not going to beat me and I’m going to try and get cured. They rang the ambulance and the ambulance came out. They found that they never joined the bowel up properly, it was leaking. I had to go through another operation. The first operation was disastrous. Anyway, they had this bag on the left side of my tummy. When I came back after the second operation I had the bag and I said I wasn’t going to touch that bag. I wasn’t going to do anything and my daughter said, “Oh well, we’ll do it”. The district nurse said, “No, you have got to do it”. You’ve got to learn to do it”. I said, “No” and I would just lay on the bed there and they would come in and take it off and dispose of it. They had another one there where you can just sit on the toilet, and open the bag. I said, “No, no I won’t do that either”.

Anyway, after about a month or so I had to do it myself because the girls couldn’t come in every day. I knew what to do but I just didn’t want to touch it, but I had to do it I got into a routine - in the mornings I would get up have a shower and then I’d change the bag. My stoma was sticking out and I used to clean around it. After drying myself I put the bag back on. The way I think of that is that it is dirty and I was conscious of being clean all the time. A couple of times I got caught out. I didn’t have the bag on and it just went everywhere. It was just as well I was in the shower.

You know, it was my kids that made me go and see the specialist. When we came back from Aussie they said now there’s something wrong we should go to see the specialist. That’s how I found out that I had it. Otherwise I would have been just doing the same thing, just carry on – go to the toilet...

Knowing what I now know has been very beneficial for my whānau. Since I had this sickness and what I’ve been through, they’re very supportive and they know what it’s all about and they know that. I’m not sure whether my oldest son has been tested yet but the younger one goes and gets the test himself. He lives by himself and I listen to him talk about hygiene and the welfare of his body – he’s very strong. He’s 50 now and he’s still working

down at the works and he tells them. I listen to him talk – he comes back and he says, so and so has asked how you are. They know what I've had and what I've gone through and they say, is he still alive? He tells them – very much so and he's walking every day, so all his mates down at the works know about this bowel cancer. He's got the right attitude,

The worst time for me was the worry I had about that second operation. They never joined the bowel back together properly and everything started to leak outside into my tummy. They used a camera and you could see where the two holes were. At that point, they had closed-up everything and I thought it must be all good. I didn't have chemotherapy or any of those things. I had the district nurse come around to see me every day to change the bandage and they were good. The bandage they put on is good because they wrap it around and it holds the tummy together. The nurse visits are great and a couple of the nurses are very good.

The one thing about my kids is their commitment to their father. They wanted to do everything. In the beginning when I was having trouble with changing the stoma bag my daughter said, "we will do it". You know once I got used to what I was doing I said, "No, no I will do it". So, that's what I do and if during the day I feel it's getting full, I change it. After a while I got stronger and more confident about my own self-care. I lost a lot of weight at first. I was nearly 70 kilograms and I went right down to 60 kilograms. As you can see I'm right back to where I was. As a matter of fact, I'm watching my tummy now. As for the future, well it's been three to six months since my operation, I have a few acres up here. I've got 60 acres and for the last five years I've taken in grazing. I have about a dozen sheep up there and about four pigs. I go up there every day. I see the future for me as being active, to keep myself busy.

It may be just three to six months since I had this operation but I had been up there lifting buckets of pig scraps. Well they're 20 litres you know and some of them they're quite heavy, and I used to lift them up onto the truck. I developed a hernia and it was huge. So, every time I went for a shower I took the bag off, cleaned the hernia and then pushed it back in. And it used to go back in, it just popped back in. The doctors said, "You've been

lifting - you keep away from that farm of yours". So, I have my other son and he's not working anywhere, so he goes up to look after the farm.

I would like to see Māori push the message that we need to go and get tested for this disease and live a clean life. You know when I was working down at the works here I was smoking and drinking. Well I never stopped drinking until my wife got sick. They thought she had cancer so she went to Palmerston North for treatment. They were treating her for cancer. At the time, she was down and out. So, I threw away the smokes, the drinking and I just stayed home and looked after her. It was only about a month later when she went into town for a doctor's appointment that found out that she had osteoporosis. Well she's never looked back since.

I like to go out in the community still. I'm doing the same what I used to do as best I can. When I had the stoma, I didn't venture out much. When I came home I had pyjamas that hid it and I couldn't go out very much because I had to change my bag all the time. Once the bag began to fill I was aware that it might burst so I just stayed at home. If I did go out – well, I went on the car and I stayed in the car. I no longer have the stoma and I like to look at the bright side of life now. When I found out that I had a growth I was hoping they got everything out of me. Thinking about it now - I am positive all the time - everything is good. I never look back on the bad side. Despite the fact we have had big challenges in the past, my wife and I are both happy at where we are in our lives.

8.2 Interpreting Moana's Story – The Search for Meaning

Accepting the Challenge

When I found out I had bowel cancer it hit me very bad because I knew my best mate died of that cancer and it brought back the memories of those people that passed away. I accepted that I had to go and get this operation and the specialist said that I could go to the general hospital and get that done. (NN. 2014)

What little knowledge Moana had of bowel cancer surfaced when his best mate died of bowel cancer. Although the diagnosis came as a shock he did not dwell on it as he knew only too well what a diagnosis with bowel cancer meant. He had no time to feel sorry for himself. His determination to survive is reflected in his decision to have surgery. An existence in the state of mauri moe for Moana was

brief. All he could think of was survival and the best way forward, was to move on and do something about it.

After I had the operation everything was good. My surgeon said everything is all good - that was on the Friday. I came out of the operating theatre on Friday and on Sunday they said, "you can go home - you're looking good". I came home and that night I couldn't sleep. There was something wrong inside and I said to my youngest son to ring the ambulance or would he take me to hospital. I had to go through another operation. I thought to myself it's not going to beat me and I'm going to try and get cured. (NN. 2014)

Moana's first operation did not proceed as planned - the wound was leaking and he had to be readmitted to hospital for a second time. Although Moana's response to a failed operation showed signs of anxiety he remained determined and prepared himself mentally to overcome obstacles and challenges in his quest to become well again. He did not become bogged down in self-pity. He remained determined and focused. He refused to let it beat him.

A study by Jonsson et al. (2011) focused on the lived experience of the early post-operative period after colorectal cancer surgery. The study found that patients experienced insecurity due to lack of control and fear of wound and anastomosis¹³⁹ rupture. Social support was described as important during the postoperative period. The purpose of their paper was to describe patients' experience of the early postoperative period after colorectal cancer surgery. Interviews were recorded with adult participants, within one week after discharge from hospital. The essence of the phenomenon was to regain control over one's body in the early postoperative period after colorectal cancer surgery. Lack of control, fear of wound, and anastomosis rupture, insecurity and complications, were prominent among the findings. Moana was to experience the same anxieties associated with anastomosis rupture however, the support he received from his children was an important aspect of care that helped him to overcome the anxiety associated with a failed operation.

8.3 Being with a Stoma – Overcoming Whakamā

...they had this bag on the left side of my tummy. When I came back after the second operation I had the stoma – the bag and I said I wasn't going to touch that bag. I wasn't going to do anything and my daughter said, "Oh well, well do it". The district nurse said, "No, you have got to do it. You've got to learn to do it". I said, "No" and I would just lay on the

¹³⁹ The procedure of joining portions of the intestinal tract

bed there and they would come in and take it off and dispose of it. (NN. 2014)

Moana was to experience the first signs of whakamā¹⁴⁰ after the second operation a stoma had been attached on the left side of his body and he was adamant that he would not touch that bag. His whānau understood why he was reluctant to touch the bag but the visiting nurses did not understand the reasons why he was so reluctant. Their view was that he simply had to deal with it – he had to do it. The issue concerning the stoma for Māori is a cultural one. A stoma is perceived as being dirty where the normal procedures of excreting waste from the body has been altered. For Māori that can be a source of embarrassment. The nurses' view was merely a routine aspect of their duty - they had seen it many times before. Moana's view was tantamount to a crisis – his body would not be the same. He dwelled on the thought of remaining in a state of dirtiness for the rest of his life, which was the source of his whakamā.

In the beginning when I was having trouble with changing the stoma bag my daughter said, "we will do it". You know once I got used to what I was doing I said, "No, no I will do it" – so that's what I do and if during the day I feel it's getting full, I change it. The way I think of that is that it is dirty and I was conscious of being clean all the time. After a while I got stronger and more confident about my own self-care. (NN. 2014)

His resistance to the stoma moderated as he became more informed and educated about the necessity of having it. Daily visits from the nurses had ceased and his daughter could not always be there on demand. He had a choice to make – he chose to step over the cultural threshold and do what he was so vehemently opposed to – to remove, clean and change the stoma himself. He became stronger in his ability to care for his own needs and more confident when changing his stoma bag.

8.4 Whanaungatanga – The Essence of Collective Wellbeing

It was my kids that made me go and see the specialist. When we came back from Aussie they said there's something wrong - we should go to see the specialist. That's how I found out that I had it. Otherwise I would have been just doing the same thing, just carry on – go to the toilet... knowing what I now know has been very beneficial for my whānau, since I had this sickness and what I've been through. They're very supportive and they know what it's all about and they know that. The one thing about

¹⁴⁰ Shame, embarrassment

my kids is their commitment to their father. They wanted to do everything.
(NN. 2014)

Moana speaks of the impact his children had on him. The love and affection that Moana's whānau had for him was not just a matter of making appointments with the doctor but reflected more on how the whānau had come together as a collective in whanaungatanga. The reciprocal nature of how whanaungatanga works provided the stimulus for Moana to accept, move on, and adopt a positive stance on how he and his whānau would counter the challenges he was facing. He had experienced an upsurge in motivation and energy because of the commitment his children had shown for him.

Tate (2010) proposed four models of relationship including their relationship terms. He sets out the dynamics of whanaungatanga, which manifest, address, enhance, sustain, and restore *te tapu o te tangata* (tapu as being in relationship with other beings). The four relationship models he purported to are:

- Heke Tika relationship – the direct line of descent including tupuna (ancestors), matua (parents), tamariki (children), and mokopuna (grandchildren);
- Tuakanā – Teina relationship (sibling line, brothers and sisters);
- Karanga – Uncle, aunt, cousin, niece, nephew;
- Hunaonga – Hungawai (in law) relationship. (pp. 40-41)

I now focus on the *Heke Tika* model of relationship in terms of whanaungatanga being the direct line of descent. The important relationships in this scenario include Moana (as mātua) and his children (tamariki). All individuals who are part of the whanaungatanga process impart something to others, or share in something of others. The dynamics of whanaungatanga in this relationship is possible and effective only when all members play their rightful roles in taking initiatives, supporting initiatives, or providing options for manifesting, addressing, enhancing, sustaining, and restoring the tapu and mana of its members. The goal must be to rekindle, establish, and maintain as many whanaungatanga links as possible. In this way whānau are enhanced, restored, and empowered.

Let us now examine how the *Heke Tika* model has sustained and empowered Moana throughout his journey as a survivor with bowel cancer. Tate's (2010)

definition of '*te tapu o*' tells us something about the relationship between him (as *mātua*) and his children (as his *tamariki*):

Te tapu o is the tapu of being in relationship with other beings. As a consequence of this relationship between existing realities, those beings in relationship are manifested, addressed, enhanced, sustained and restored. (p. 36)

The intimacy of the relationship between Moana and his children is encapsulated through their actions of enhancing, sustaining, empowering, and restoring their father's wellbeing – to restore his tapu, to regain his mana. It was through their actions he had become highly motivated where he was now experiencing a new surge of energy and fulfilment. Slater (2013) conducted a study on the experiences of Māori cancer patients and services regarding access to, and provision of care. Slater's study described the cancer journey of Māori patients and whanau and identified factors that may facilitate or inhibit access to and through cancer care services. Three key areas were identified that impacted upon the cancer care journey: the experience of whanau support; continuity of care; and the impact of financial and geographic determinants.

Although there are numerous studies that focus on health care practice for Māori, there is a dearth of literature on Māori lived experiences of cancer. Walker (2008) explored Māori experiences of cancer in a general context and aimed to shed light on the causes of cancer inequalities for Māori. Significant among the findings was the involvement of whānau in the cancer journey as this facilitated a holistic approach to their wellbeing. Among the recommendations was the need to improve cancer services for Māori through better resourcing of Māori providers, more effective utilisation of systems navigators and inclusion of whānau in the cancer control continuum.

The Proper Exercise of Mana

Moana speaks with passion and pride on past decisions that have helped to sustain his family through the enactment of the principles of pono, tika and aroha. Being pono sets a foundation that paves the way for the right and correct manner by which issues affecting whānau can be addressed – tika. Aroha is about compassion, sacrifice, and generosity. It fulfils a process where outcomes are achieved through the right and gratuitous exercise of mana.

Tate (2010) defined aroha as:

Aroha is love, namely, a principle of communion and of action by which the fullness of tapu of some (and implicitly, all beings) is manifested, addressed, enhanced, sustained and restored in affection, compassion, sacrifice and generosity, by the right and gratuitous exercise of mana. (p. 105)

Tate asserts that aroha is communion in relationship between tangata and tangata that can only be achieved by applying the principles of pono (perceptive) and tika, (right action). In the process, it governs actions that enhance and restore relationships between tangata and tangata.

You know when I was working down at the works here I was smoking and drinking. Well I never stopped drinking until my wife got sick. They thought she had cancer so she went to Palmerston North, came back and they were treating her for cancer. At the time, she was down and out. So, I threw away the smokes, the drinking and I just stayed home and looked after her. (NN. 2014)

By focusing on the wellbeing of his wife, Moana expressed the aroha he had for her through the right and gratuitous exercise of his mana. He threw away the smokes and drinking to care for her. He is reciprocated in kind by his whānau who acknowledge the correct exercise of his mana through the principles of pono, tika, and aroha. He adopted a stance that his wife's wellbeing must come first. That acknowledgement manifests as his wife's wellbeing became the driving force behind not only his recovery but their recovery as a whānau.

8.5 Being in Mauri Ora

We are Happy in Our lives

I like to look at the bright side of life now. When I found out that I had a growth I was hoping they got everything out of me. Thinking about it now - I am positive always - everything is good. I never look back on the bad side. Even though we have had big challenges in the past, my wife and I are both happy at where we are now in our lives. (NN. 2014)

Moana gives the clearest indication that he and his whānau have achieved an outcome where his tapu and mana has been restored. He and his wife are happy in their lives. They look to all that is positive and good and are thankful for what they have together.

8.6 Summary

Moana was diagnosed with bowel cancer at the age of 79 years. Some prior knowledge of bowel cancer enabled him to accept the reality that medical intervention was the only possibility as he had witnessed first-hand what the outcome could be. His best mate died of the disease. Despite the trauma of a failed first operation he was determined to take on the challenges he faced. Throughout the early stages of his journey Moana was confronted with other challenges, one of which was the possibility of having to live the rest of his life with a stoma. Having a stoma was a barrier; however, the problem was not insurmountable and once he learnt everything about it, he could manage it.

A stoic attitude and a caring whānau became the platform upon which the whānau based his recovery. The concept of whanaungatanga has been a dominant feature throughout this study and, in Moana's case, it has been no different. The reason why whanaungatanga is so important is because it sets in motion the correct and rightful process where knowing the person is vital and of the greatest significance in determining where participants are at any given point in time in their journey. This was most certainly the case for Moana. Moana's children took it upon themselves to guide him through his ordeal of having to cope with challenges in the early part of his journey because his recovery was a critical part of recovery for them as well. He was their papa and in their eyes, he had *tapu whakahirahira*¹⁴¹. As the source of all mana is tapu, he, in their eyes, also possessed great mana. It has been two years since I interviewed Moana and I am happy to say that he is well and living at home with his wife. Despite all the challenges he has faced throughout his illness he and his wife are happy at where they are in their lives. The dynamic movement of mauri from mauri moe to mauri ora was symbolic of Moana's progress. Moana's children did what they knew best and that was to care for their father in a way that enhanced, sustained, empowered, and restored his tapu and his mana. Both he and his wife continue to exist in restored tapu as the state of being - in mauri ora.

In the following section I introduce Roimata. Roimata has navigated her way through the challenges associated with the trauma of being diagnosed with bowel

¹⁴¹ Extremely important

cancer and continues to live her life managing her daily challenges as a survivor with bowel cancer.

Roimata's Story

Whakapapa of Roimata's Story

Roimata was diagnosed with bowel cancer when she was 42 years old. She was experiencing a persistent pain in her side which would not go away. After having a CT scan a diagnosis of bowel cancer was confirmed. Roimata's story is significant as it was an example of what can happen when people report to health services at the first signs of discomfort. The early signs for Roimata highlights the asymptomatic development of bowel cancer over time where even the slightest pain can result in a diagnosis of bowel cancer.

This is Roimata's story:

I was diagnosed at age 42 after experiencing a pain in my side. I'd been experiencing those pains for quite a while but just one day I got the pain and it just wouldn't go away. I ended up going to the doctor and they sent me to hospital. I had a CT scan which revealed there was a tumour in my bowel. They wouldn't tell me at first what they had found but I insisted that they tell me. They eventually gave me the news and I stayed the night in hospital. I saw the surgeon the next day and from there everything was rushed pretty much. I was in there on the Tuesday night and saw the doctor on Wednesday. I was sent home while they did all their bits and pieces and was back there a week later for the operation.

They said I was lucky because I was diagnosed at stage two when they operated and got in there. The tumour it-self was encased in a ball of pus and that was my saving grace. It didn't go any further and it was on the verge of rupturing through the bowel wall. I was in hospital for a week. They didn't muck around. They just went straight in and did the operation, did the resection and joined it back up again. Yes, that was it and then two months later I started chemotherapy. They suggested I have chemotherapy and I was under really-good care through the hospitals. They suggested that I have chemo because I saw the oncologist after the operation and she suggested that I have chemo just as a precaution

because I was so young and because I was the first one in my family to get it. My first treatment was a bit rough because I was on a higher dosage. It was a bit rough mainly when they were taking all those plasters off on my arm – it hurt, but my next lots were very good. I was very well cared for. The treatment wasn't a problem and I haven't suffered any side effects. It's been six years since I had the treatment.

I had no reactions or anything like that. There were the odd times when I was sick but not to the stage where it was like I had to go to hospital. I think it was my faith that helped me through, my church family as well as my own whānau. They were all there for me. They supported me to my appointments and stuff like that. My faith really-helped me through a lot of it to the point where I wasn't going to let it take control of my life. I wasn't going to let it rule how I lived my life. So, I refused to give in to it. I just continued to live my life the way I have done in the past – as per usual.

I had never heard of bowel cancer before I was diagnosed. You hear of everything else but I had never heard of bowel cancer. Dad's family never talked about it. Mum's family - they never talked about it because we didn't think it was part of us. You know there are other forms of cancer but we had never heard of bowel cancer. Our family had never spoken about it. I didn't know what it was therefore I didn't talk to my kids about it. I did afterwards. I talked to my kids and encouraged them to get tested. I also talked with my brothers and sisters. I encouraged them to get tested. You can only say something but it's up to them whether they do it. They've all stepped up. I know that it was hard on my husband and my kids to see me go through that but you know I had a mountain of support. I couldn't have asked for a better way of getting through this. My whānau was a huge factor.

My sister here has been for her test and got the all clear and my other sister is booked in for hers as well. We have a very good doctor. He understands our family so he pushes for these things for us as a family because of the history of our family. My uncle died of bowel cancer. I think part of my saving grace too was because I chose to go to our local hospital. I wouldn't allow myself to dwell on it and cause me to think 'why me'... having bowel cancer wasn't the end of everything for me. Losing my son

two years ago was the end of stuff for me at the time. He was a spina bifida boy. He taught me a lot about life you know. He didn't let anything get him down. He was there for me as well, he looked after me. He brought meaning to my life as a bowel cancer sufferer. You know, any form of cancer is bad but if you choose to allow it to take over your life, it will.

I believe my Christian background is a big part of my recovery, a big part. The people at my church all pray for me and my son who has also got bowel cancer. There is always someone else worse off than you... you know we had a cousin and an uncle diagnosed with bowel cancer a couple of years ago. Our cousin is much younger than me and she was a lot worse than me because she had the bag. And again, none of us would have known to go and get tested. It's just one of those things that you go to the doctor and next minute you are being told you've got bowel cancer.

I had a really-good team of doctors and nurses. When I was diagnosed, my doctor came to see me in hospital and apologised for not picking it up earlier. So, when you have a team of doctors like that... well, I was able, to get back on my feet again. I hadn't worked for a long time so I got back into the workforce. I'm loving my work and loving my life.

8.7 Roimata's Story – The Search for Meaning

I Had Never Heard of Bowel Cancer

I had never heard of bowel cancer before I was diagnosed. You hear of everything else but I had never heard of bowel cancer. (SG. 2014)

Roimata had never heard of bowel cancer before she was diagnosed. Her lack of knowledge about bowel cancer is a factor among all the participants in this study. Current evidence on health literacy tells us that Māori have the lowest health literacy for all groups in Aotearoa/New Zealand (Ministry of Health, 2010).

Dad's family never talked about it. Mum's family - they never talked about it because we didn't think it was part of us. You know there are other forms of cancer but we had never heard of bowel cancer. Our family had never spoken about it, I didn't know what it was, and therefore I didn't talk to my kids about it. (SG. 2014)

There is some contention as to whether Roimata's parents knew anything about bowel cancer. She says her parents never talked about it because they did not think it was part of their whānau. We know that Māori are reluctant to talk about bowel cancer, about that part of the body. For Roimata the intergenerational transference of knowledge within whānau did not happen because it appears that her parents had no knowledge of bowel cancer. Bowel cancer was never mentioned to her as a young person and, by implication, she did not discuss it with her children. Enhancing health literacy within Māori whānau and the need to transfer knowledge productively within whānau is an important issue in terms of whānau dynamics. Finding out how these issues impact on whānau would set the foundation for effective intervention and health promotion strategies when engaging with whānau who have a perpetual history of chronic health conditions.

Being in Fellowship - The Grace of Atua

I believe my Christian background is a big part of my recovery, a big part. It was my faith really, that helped me through, my church family as well as my own whānau. They were all there for me. They supported me to my appointments and stuff like that. (SG. 2014)

Roimata speaks affectionately of her Christian fellowship. She possessed a genuine love for both her church family and her own whānau. In addressing the close fellowship, she had with her church and whānau I now turn to the phrase *te tapu o* – the tapu as being in relationship espoused by Tate (2010). There is a certain aspect of quality in the relationship Roimata has with her church. The encounter between Roimata and her church imparts some aspect of quality of being that is creative, productive, enhancing, and empowering. It is not about an existing reality, considered absolutely, rather it is something of or about an existing reality. Roimata's relationship with her church whānau was enhancing, restorative, and empowering.

There is another aspect, however, when we speak of *te tapu o te Atua* that is, to be in relationship with Atua. Tate (2010) discussed some of the Māori attributes of Atua that reflect life and sacredness. *Atua Mātua*, the attribute of *mātua*¹⁴² reveals that Atua is the source of life and parenthood. In sharing in *te tapu o te*

¹⁴² Parent

Atua, human parenthood shares in the parenthood of *Atua*. To share in *te tapu o te Atua* is to have a share in the source and fulfilment of all life.

...my faith really, helped me through a lot of it... I wasn't going to let the cancer take control of my life. (SG. 2014)

Roimata acknowledged that her faith was a crucial factor in her journey to wellbeing. Her belief in *te tapu i te Atua* was her acknowledgement of the very existence of *Atua*. Her belief in *Atua* thus cements her relationship with *Atua*. Roimata says the relationship was a crucial factor in her journey to wellbeing. She refused to let the cancer take control of her life.

I wasn't going to let it rule how I lived my life. So, I refused to give in to it. I just continued to live my life the way I have done in the past. I know that it was hard on my husband and my kids to see me go through that but you know I had a mountain of support. I couldn't have asked for a better way of getting through this. My whānau was also a huge factor. (SG. 2014)

The relationship that Roimata had with her whānau gave her the strength to remain resolute and determined, to live her life as she had done in the past. A phenomenological study by Albaugh (2003) researched spirituality and life-threatening illnesses on the lived experience of individuals when confronted with a life-threatening disease. Participants in the study included patients who had been afflicted with colorectal cancer. Participants described how their spirituality provided comfort throughout their journey, strength in facing the life-threatening illness, many blessings despite the hardship of the illness and trust in a higher power to see them through their journey. Participants described a sense of meaning in their lives throughout their experience.

8.8 The Proper Exercise of Mana

I had a really, good team of doctors and nurses. My doctor came to see me in hospital and apologized for not picking it up earlier. So, when you have a team of doctors like that... well. I was able, to get back on my feet again. They said I was lucky because I was diagnosed at stage two when they operated and got in there. The tumour it-self was encased in a ball of pus - that was my saving grace. It didn't go any further and it was on the verge of rupturing through the bowel wall... ..they didn't muck around. They just went straight in and did the operation, did the resection and joined it back up again. (SG. 2014)

Roimata is thankful that she had an understanding team of health professionals. They were there for her. Their thoughtfulness is an example of how power in operation through the proper exercise of mana by health professionals can result in the best possible outcomes when engaging with Māori. Most clinicians are perceived by Māori as having mana. They have studied hard to get to where they are. According to Tate (2010), they have mana in potentiality (*te mana i te tangata*). Problems arise for Māori when that potentiality cannot be delivered in a way that Māori are comfortable with, in other words, to practice in a culturally safe way. Their perceived mana thus remains in potentiality only, because their ability to convert that potential in an operational sense (*te mana o te tangata*) cannot be put to good effect. That is about cultural awareness, cultural sensitivity and cultural safety that Ramsden (2002) speaks about. Roimata's doctors have been interpreted here as having both mana in potentiality and mana in operationality. They could use their skill to the best possible effect. Roimata could not have wished for a better outcome.

Losing my son two years ago was the end of stuff for me at the time. He was a Spina Bifida boy. He taught me a lot about life you know. He didn't let anything get him down. He was there for me as well, he looked after me. He brought meaning to my life as a bowel cancer sufferer. (SG. 2014)

Roimata spoke affectionately of the relationship she had with a son who had passed away two years previously. Although he was no longer with her and their whānau, his spirit remains – in the now. He too was a rock on which she nurtured her own determination to survive as a bowel cancer sufferer. Although he is no longer with her, his contribution is an example of how the proper exercise of mana can manifest, sustain, empower and restore tapu and mana.

8.9 Being in Mauri Ora - I'm loving my Work and loving my life

I hadn't worked for a long time so I got back into the workforce. I'm loving my work and loving my life. (SG. 2014)

Roimata has reached a point in her life where her own intrinsic tapu and mana has been restored. Roimata's exuberance for life shines through. She has re-joined the workforce and is loving her life. Mauri ora signals increased activity and awareness that comes from a high level of energy. There is purpose for being and a willingness to actively engage with others. The state of being of

mauri ora finds expression through successful outcomes where participants become highly motivated by what is happening to them in terms of their wellbeing. It is the stage in their journey where they are feeling good about their health, where they remain alert and actively engaged in and committed to keeping good health. Roimata is currently living her life in restored tapu as the state of being – in mauri ora.

8.10 Summary

Health literacy has been a dominant theme across all participants in this study, and Roimata's story is no exception. Her lack of knowledge of bowel cancer concurs with all the other participants in the study. She knew about the other cancers but not bowel cancer as it was a topic that was never discussed by her family. One of the greatest blessings throughout her journey was the relationship she had with her church whānau. She attributes her survival to her belief in Atua and, by association, her church whānau. That was a big part of her recovery. It was a relationship she exercised through her belief in Atua (*te tapu i te Atua*) and, consequently, the tapu of being in relationship with Atua (*te tapu o te Atua*). The relationship for Roimata was mutually enhancing, restorative, and empowering. I have mentioned this aspect throughout this thesis on several occasions but I raise the concept of whanaungatanga yet again. The reason why whanaungatanga is so important is because it sets in motion the correct and rightful process where knowing the person and knowing the whānau is vital and of the greatest significance in determining where participants are at any given point in time in their journey. It is the pre-requisite to all ongoing forms of engagement. Roimata's story tells us that she had a wonderful team of doctors and nurses who through their concern and commitment engaged through the proper exercise of mana. They were there for her and were a crucial factor in her success to be well again. Her story is testament to the early detection of a tumour which left unattended would have meant a very different outcome.

Ripeka's Story

Whakapapa of Ripeka's Story

Ripeka's whānau whakapapa to Taranaki iwi. In February 2010 prior to visiting her family in Australia, she had a suspicion that something was wrong after

experiencing a constant pain in her side. She assumed that all she had was haemorrhoids and decided to visit her doctor thinking that is all it was. Up until that point in time she had always been very healthy. Ripeka's story presents us all with a timely reminder of the asymptomatic nature of how bowel cancer can develop. The following passages are about Ripeka's experiences as a survivor living with bowel cancer.

This is Ripeka's story:

In February 2010, I was going to Australia for a holiday and in the week before I went I thought I got haemorrhoids so I went to see my doctor thinking that's all it was because I've always been very healthy. Anyway, when I got there I told him what I wanted and he had this little thing he uses and he had a look and then walked over to his phone wanting an appointment with the specialist the same day. Anyway, it all sort of developed from there and I heard him say CA (cancer) and I knew straight away what that meant. Anyway, he rang about three different people and he couldn't get in with them and luckily the specialist could take me so I went from one surgery straight to another and he confirmed it. It was a change of life really. I never went back to work from that day to now.

They said I'd had it for five years at that time because they could tell by the size of the tumour which was 20cm so I hadn't had anything to say that something was wrong with me because all I had was a little bit of tiredness. I didn't have pain or discomfort, nothing. So, if I hadn't been going away I may have ignored that and ended up worse off. So anyway, the specialist let me go on holiday but he sent letters with me in case something went wrong while I was away. Within a day of arriving back I went to Palmerston North for treatment where I had chemotherapy and radiation. Once I finished my treatments I had to recoup as I got very sick with the treatments and once I'd recouped enough I had surgery in June. That took about five months and I needed that time because I had to get my strength up for the surgery, it took that long. They just kept seeing me every week to see if I was ready for the surgery.

Anyway, even two years later I still wouldn't have been ready because I had a lot of trouble with other surgery. The radiation treatment had

destroyed the tissues inside me so whenever I had surgery they couldn't put me together properly, I just ripped apart. That's caused a lot of problems. In June, I went in for my surgery and was told before the surgery that I would end up with a colostomy bag. If I woke up and it was on my right side that was temporary but if it was going to be on the left side, that's where it would stay forever. So anyway, when I woke up it was on the right side but it didn't stay there long because there were so many complications. So, I've now ended up with a colostomy bag. That was the biggest issue actually - the colostomy. That was one thing I couldn't handle. I could handle the fact that I had cancer and if they could have made me better and I didn't have to have a bag there wouldn't have been a problem - but the bag was my biggest issue. I had worked in a rest home in the past and dealt with someone with a colostomy bag and it was a younger person and he wasn't very clean with himself or anything. I couldn't bear having to attend to him so all I could remember when I knew I was going to have a colostomy bag was that guy. I just didn't think I could live with a colostomy bag. I didn't think how I could be normal with one. So anyway, I was in hospital for 13 weeks all told and at that stage my specialist had told me that he could not do any more for me. At that stage I had about nine surgeries.

I had colon cancer. I don't know what they did inside but I know that the specialist told me that there's a stump where the rectum would have been, where the anus would be so they took that out. The thought of bowel cancer is a horrible thing to have really. It probably wasn't the worst cancer to get but probably anywhere else would be better than there.

We suspected that dad may have had bowel cancer and I can remember that dad had problems where he had to rush off to the loo and stuff like that. That had gone on for a while, a couple of years that I can remember but he chose to ignore it. He would be at the RSA and he would mow their lawns and he was sick as and I knew that but he kept saying it was nothing. He just wanted to live, he just wanted to keep going, so if he didn't talk about it, then as far as he was concerned he had nothing wrong. Anyway, one night he ended up in terrible pain and they took him in and did surgery and found it was a bowel problem. He never ever recovered. That was

the end of it so that's the scary bit too, it can run in the family. My children are really, aware of it now. They even ask me what age would you need to start asking the doctor to check you for that but they live in Australia. If they lived here and we had the same doctor all the time, he would probably be talking to them all the time. I know my daughter she waits until she comes home here and goes back to this doctor.

The thing that was horrible with this cancer was that I couldn't tend to myself. The nurses didn't even like doing it. It would leak and they had all that to put up with and you could tell that they didn't like to do that all the time. This happened when I was still in hospital and this could happen 10 times a day and they were all sick of it really. I hated what was happening to me but they seemed to hate what was happening because it was extra work for them – work that they didn't like doing. I wanted to die rather than be like that. Not all the nurses were like that.

Whenever I mentioned it to the specialist he would deal to those nurses but the best person ever was the specialist colostomy nurse. I used to tell her what was happening so she made sure she was there more than what she needed to be really, to keep an eye on things and see how they were connecting the bags. She gave them lessons in how to do it properly. It was always leaking and I was always asking them for towels so I could put them there because when it starts leaking, you can feel it going around your back and everywhere and they just didn't like that part of the job really. They made me feel like it was my fault. I always felt that it was my fault, that this had happened and I was lazy and that I should be up sorting myself out which I would have done if I could. And sometimes when you've been asleep and you wake up and it's a big mess you can just about see them saying you dirty bitch. But because I'd been in there so long, I pulled a bit of my professional training on to them and that's how I got around it in the end. I just didn't let them make me feel any worse than what I felt. I made several attempts to come home and the first time the specialist let me out for a weekend I had two heart attacks while I was home because it brought other things on.

The specialist told me he couldn't do anything more for me and that I was going to die. He had tried really - hard. He had done everything really,

and said to me to find a tohunga because that was the only way he thought I was going to survive - we were desperate. My specialist was conferring the whole time through my surgery with someone down in Christchurch. When he was stuck, and couldn't move in any other direction with me he would confer with the doctor down there and that must have been what they came up with. That was 2010, this is now mid 2014 so something has worked. We made an appointment to see the tohunga. He's a very old gentleman and I reckon he would have been in his 80s. I believe in tohunga and when I went to him he didn't really - talk to me personally but still went about his work. We used to go to a tohunga and he was awesome. All the staff were very surprised about being told that I was going to go to a tohunga to be healed. They said they'd never ever heard it before.

I remember that trip well because when just before we got to our destination my bag had burst because of the seat belt and that was horrible. So, I had to send my son to go and find a shop that was selling women's clothes to buy me some clothes to put on to carry on. It wasn't a good experience actually - it's bad enough having it. I do believe that if I'd known about bowel cancer three years earlier than what I did, I wouldn't have gone through as much as I did. I believe the earlier you can detect it the better so it wouldn't be so horrific. The specialist said by the size of the tumour, it could have been there for five years. I was skin and bone and couldn't eat anything really.

As soon as my children arrived back from Aussie the first thing they did was buy some mussels and they cooked some but I wanted some raw ones. That was probably the most substantial thing I had eaten for ages and I'm sure that's why I got better, because of those mussels. I'm not a mussel eater but I wanted that taste and every day they'd get me more and that was my main meal. Another thing - I love watercress. I don't like pūhā and poroporo. I talked to someone about poroporo¹⁴³ and they said, "What's that?" I found out later that some people refer to it as deadly nightshade - that's true, I never thought about it that way, but I did want

¹⁴³ A green leaf plant similar in texture to spinach

that food, our traditional food. When my stoma nurse used to come, she would ask what have you eaten and at that time that was all I was eating in the first week or so of being home. It's now been four years.

When I first started seeing my specialist after I came home, he would say things like "can't believe you're here, you shouldn't have been but you are." But I've just got better and better, as you can see, I'm not skinny anymore and I saw him only two weeks ago and he's really - pleased. He just goes "looking good". I look after myself, I don't drink, I have smoked and I still do. I'm on Champax and I do want to stop. When I was in hospital I had the best chance then, because I came out and never smoked for seven months after I'd come home but I wasn't sleeping that well and I'd wake up about three in the morning and I'm all by myself and I would make a cup of tea and look at my husband's cigarettes. I did that for a week and next thing I wanted to have one and that was the end of that but it was a good opportunity and I do want to stop so I have cut down heaps.

I couldn't have coped with all this without my husband and the way he handled everything - we probably wouldn't be together now. When we went to see the tohunga I was just too sick and weak, I just couldn't do anything. I had all drains and tubes everywhere and he had to tend to all those things. He did it without flinching whereas if I had to do it for him, I don't know whether I could, it's not pleasant. My husband and the kids have been a tower of strength for me. The ones in Aussie were coming back frequently. My son in Aussie has now come back, he wants to be here to keep an eye on things. I think my family and my friends would do anything to help. When I was in hospital I almost blamed myself for being a nuisance to the nurses.

When I first learnt that I had cancer there were four of us and they were people that I knew well and one of them was a relation of mine and we were both receiving treatment at the same time but because we were staying at different places, I didn't know he was there and he didn't know I was there. I'm the only one left out of the four of us now. All the others have passed away, one had bowel cancer and the others had cancer somewhere else and that's sort of horrible too when you're watching them pass away and you're thankful that you're still here. Some people say to

have cancer and survive makes a better person of you. I don't know if it does probably because I got so close to dying.

I'm only just starting to go out. For a long time, I couldn't go out because I'm still on medication for pain, that's probably the only thing we haven't got right is the pain. So, I'm on that and I'm on steroids because I was putting on weight, they were bloating me up and I've been off them for about a month. My friends would come and take me out but because it was that area I didn't like to sit down. Two years ago, to sit down on my butt for a couple of hours was so uncomfortable, you either got to stand up or lay down and at first, I didn't want to go anywhere in case I had an accident with my bag. There was always that and I always loved trendy clothes and I find now I can't wear what I want to wear because of my bag and those bags can blow up very quick. I mean you can leave home and have a fresh bag on and half an hour later change it again. It's not like that anymore so whenever we went anywhere like work functions or out for meals with friends, everyone knew that I wasn't going to stay long and they all accepted that. I've only just started getting in the car and going somewhere in the last six months.

I've had the colostomy bag for four years now but I must tell you something about that. Before I had my surgery, the specialist arranged for the colostomy nurse to come and see me and talk to me about the bag. She rang up and I was rude to her and told her that I didn't want a bag. You know, in a way I think, because of the bag I was so close to saying no to surgery. Because of that bag, I was going to say no to surgery. The colostomy nurse rang and said I need to speak to you, surgery is next week and the specialist is on my back. I've got to come and see you. I said, "No, I don't want to talk about it." Anyway, when I went into hospital she came in to see me. From the moment, she came in she wasn't mucking around with me. She didn't pussyfoot around and I liked her. She was the one among all the staff that got me through having the colostomy.

She said to me - "Okay so you don't want a bag." I said, "No I don't." She replied, "Oh well I'll get hold of the specialist and tell him you don't want surgery and you're just going to die anyway". I tell you she's so awesome and there are two other nurses that work with her who are training in that

area. I saw her about a month ago when she came here and she told me she was getting ready to retire. Another year I think because I asked her. I said to her, "I think you've got to be a special person to do that job." I said to the colostomy nurse one day, "Have you got a colostomy bag?" She said, "No, why", and I said, "I just wondered why you went into this type of nursing rather than pick something else?" She said, going back years when she went into this she realised that people were having surgery, going home and there was no one to look in on them, to see how they were going or anything else and that's why she dedicated all those years to it. She was my saviour really.

The bag hasn't worried me for the last three years because no-one knows it's there - my friends know. I think it's the stigma, you think it is a stigma but it's not really, and it doesn't worry me. It has its advantages because you're never going to get caught short. I don't have burst bags anymore. It all comes back to educating yourself in how to manage them and make sure they're on properly. They're very good. The bags just feel like a soft fabric. They're waterproof and they don't make that scratchy noise - you just learn ways of surviving. As soon as I take mine off I've already rolled a little bit of toilet paper so I just take it off and plug it so you haven't got the smell or anything that goes with it. You just find ways to make life easier for yourself. You can't get caught short looking for a loo in a hurry.

Before I knew anything was wrong with me I did the same thing day after day. I got out of bed, made the coffee, had several cigarettes and coffee, went to the loo for my bowels, had a shower got dressed and went to work. In the last week, that's all I've done really - a week with little difference from how things were before. You just get into these things - you've done it for years. Before I was diagnosed with bowel cancer I'd find that I needed to have sweeter coffee or stronger coffee to make me get up and go, and that's what made me think. I sort of felt like there was something there. I just thought, oh it must be piles. I had haemorrhoids after I had one of my children and that's exactly what it felt like so it was a very big surprise to find out that it wasn't that at all. The chemo and radiotherapy has caused side effects. I've still got numb feet. I went to Palmerston and had chemo and radiotherapy at the same time. I didn't know which one was making

me feel as bad as I did. This would have been 2011 or 2012 when I had a massive dose of chemo - it went on for six months. In the end, I had to pull out. I pulled out I think in the last month because I had no feeling. My feet or my toes were numbed and I couldn't touch a fridge as my fingers were all numb but now it's nearly all back in my fingers but my feet are still numbed. The radiation did shrink the tumour a bit and really, I think at that time my head was thinking if I have this, I might not have to have surgery. I said after my last chemo I'd never have it again because it was so awful. But a year and a bit later, I'm thinking now if I should, I would if it's going to keep me here a bit longer. It's a hard decision, not a nice thing. It's hard to explain really. If I hadn't read your article in the paper, that you were doing this research on bowel cancer, then nothing would have come of it. Sitting here talking to you about how it's been – well I just hope it helps someone else.

8.11 Interpreting Ripeka's Story – The Search for Meaning

I Thought It Was Haemorrhoids

In February 2010, I was going to Australia for a holiday and in the week before I went I thought I got haemorrhoids so I went to see my doctor thinking that's all it was because I've always been very healthy. ...when I got there, I told him what I wanted and he had this little thing he uses and he had a look and then walked over to his phone wanting an appointment with the specialist the same day. It all sort of developed from there... I heard him say CA and I knew straight away what that meant. I sort of felt like there was something there. I just thought, oh it must be piles. (NS. 2014)

Ripeka had an idea that something was wrong with her health. She decided to check with her doctor for treatment which she presumed was hemorrhoids. Ripeka recalls the moment she was diagnosed with bowel cancer. A diagnosis of cancer is serious but what puzzled her so much was the fact that she had not experienced any real pain or discomfort prior to her diagnosis.

8.12 Being with a stoma

In June, I went in for my surgery and was told before the surgery that I would end up with a colostomy bag. If I woke up and it was on my right side that was temporary but if it was going to be on the left side, that's where it would stay forever... when I woke up it was on the right side but it didn't stay there long because there were so many complications. So,

I've now ended up with a colostomy bag. That was the biggest issue actually - the colostomy. That was one thing I couldn't handle. I could handle the fact that I had cancer and if they could have made me better and I didn't have to have a bag there wouldn't have been a problem - but the bag was my biggest issue... I just didn't think I could live with a colostomy bag. I didn't think how I could be normal with one (NS. 2014).

Having to live one's life with a stoma was one of Ripeka's greatest fears. Her perception of surviving with a stoma was worse than the diagnosis of bowel cancer itself. To her it was dirty and repulsive. The issue concerning the stoma for Ripeka is a cultural one. She perceives the stoma as being dirty where the normal process of excreting waste from the body has been altered in a significant way. Ripeka's resistance to the stoma is understandable. Māori are reluctant to talk about a stoma as this was a topic that came up with other participants in the study. Others said they felt it was dirty and repulsive, an outcome that comes from the deeper cultural aspects connected to whakamā.¹⁴⁴ It appears Ripeka may have had those same thoughts as she referred to a colostomy bag as not normal. The prospect of remaining in a state of dirtiness for the rest of her life was the source of her embarrassment – to be in whakamā.

8.13 The Intervention of Tohunga

I was in hospital for 13 weeks. My specialist told me that he could not do any more for me. At that stage I had about nine surgeries. He said that I was going to die. He had tried really, hard. He had done everything he could and said to me to find a tohunga because that was the only way he thought I was going to survive - we were desperate. (NS. 2014)

Ripeka was to receive news of her condition from the specialist that was tantamount to a death sentence. He said there was nothing more they could do. The specialist told her that he could not do any more for her and that her only hope was to see a tohunga. He told her that it was the only way she was going to survive. By turning to tradition Ripeka sought intervention by a tohunga. She was desperate – she had nothing to lose.

We made an appointment to see the tohunga. I believe in tohunga and when I went to him he didn't really talk to me personally, but still went about his work. We used to go to a tohunga and he was awesome. My specialist was conferring the whole time through my surgery with someone down in Christchurch. When he was stuck, and couldn't move in any other direction with me he would confer with the doctor down there

¹⁴⁴ A feeling of shame

and that must have been what they came up with. That was 2010, this is now mid 2014 so something has worked. (NS. 2014)

The fact that Ripeka wanted to see a tohunga indicates that there was something in the past that needed to be put right. Had there been a violation in the past? Such violation may have been committed without her knowledge. She speaks of past visits to the tohunga and her belief in tohunga. Perhaps it was that powerful belief that carried her through. Her belief in tohunga professes a belief in spirituality and the possibilities that come with healing through Atua.¹⁴⁵ The traditional aspects of healing for Ripeka may have been a factor in her quest to become well. She is, after all, a survivor, after being told that the medical profession could not do any more for her.

In ancient Māori society tohunga acted as the mediums of the gods. Tohunga were experts in matauranga Māori¹⁴⁶. Qualifying terms were ascribed to them to distinguish specific areas of expertise. Buck (1949) described tapu as a factor in the aetiology of mate aitua¹⁴⁷, an illness for which there is no obvious physical cause. In the absence of regulations and law enforcement processes as we know them today, tapu enabled social systems to function because tapu was the platform on which law and order was maintained. Marsden (1992) spoke of the untouchable sacredness of tapu of persons or things and any disrespectful or irreverent abuse is tantamount to sacrilege, violating the law of tapu. In another sense, a tapu object may be classified as an accursed or unclean thing. The unclean element that constitutes the tapu can then be transmitted by contact or association and a person can be contaminated and polluted by it. According to Tate (2010) tapu restrictions arise from the intrinsic nature of being, whether considered in-itself, or in relationship with other intrinsic beings. Consequently, the existence of tapu restrictions does not depend on people's awareness of such restrictions, they exist whether people know about them or not. It appears this scenario may have been the situation for Ripeka and intervention by tohunga may have taken that approach to healing. It has been four years since Ripeka's diagnosis. Something has worked for Ripeka and going to the tohunga was the

¹⁴⁵ God

¹⁴⁶ Maori knowledge

¹⁴⁷ Unexplained Maori sickness

right thing for her. She described her past whānau experiences of healing by tohunga as awesome.

8.14 I Hated What was Happening to me

...the thing that was horrible with this cancer was that I couldn't tend to myself. The nurses didn't even like doing it. It would leak and they had all that to put up with and you could tell that they didn't like to do that all the time. This happened when I was still in hospital and this could happen ten times a day and they were all sick of it really. I hated what was happening to me. I wanted to die rather than be like that. They made me feel like it was my fault. I always felt that it was my fault, that this had happened and I was lazy and that I should be up sorting myself out which I would have done if I could. (NS. 2014)

During her time in hospital the attitude of some of the nursing staff caused anxiety for Ripeka as they appeared to have very little interest in assisting her to manage an issue she was already having difficulty with – the colostomy bag. Pono is a principle of perception of truth by which we address tapu and mana. It is an ethical principle of action in that it qualifies how we manifest, address, enhance, sustain, and restore tapu, and how we exercise mana. In the absence of whanaungatanga the engagement process adopted by the nurses in caring for Ripeka had very little resemblance to what Tate (2010) proposed when he spoke of encounter that imparts some aspect of quality of being that is creative, productive, enhancing, or empowering from one to another. She was made to feel that what was happening to her was her fault. She was left feeling helpless and isolated.

8.15 I was Close to Saying no to Surgery

...the colostomy nurse rang and said I need to speak to you, surgery is next week and the specialist is on my back. I've got to come and see you. I said "No, I don't want to talk about it." Anyway, when I went into hospital she came in to see me. When she came in she wasn't mucking around with me. She didn't pussyfoot around and I liked her. She was the one among all the staff that got me through having the colostomy. She said to me - "Okay so you don't want a bag." I said, "No I don't." She replied, "Oh well I'll get hold of the specialist and tell him you don't want surgery and you're just going to die anyway." I tell you she's so awesome and there are two other nurses that work with her who are training in that area. She was my saviour really. You know, in a way I think, because of the bag I was so close to saying no to surgery. Because of that bag, I was going to say no to surgery. (NS. 2014)

Ripeka's anxiety and discomfort was to receive an unexpected boost from a senior staff member. The Clinical Nurse Specialist (CNS) for oncology took a restorative approach to Ripeka's care. Health professionals of other cultural backgrounds are quite capable of working in ways that restore a person's wellbeing as was the case with Roimata. The relationship between the CNS and Ripeka was achieved through the principle of pono. It is an ethical principle of action in that it qualifies how we exercise mana. The CNS was upfront and honest in her approach to informing Ripeka about the upcoming surgery and it was an approach that Ripeka respected. Ripeka's story tells us that she had developed a great relationship with the CNS. The CNS was assertive but remained committed to doing the best she could for Ripeka (to be pono). The correct process had been followed (tika) with affection and trust (aroha). That approach proved to be a crucial factor that enabled Ripeka to trust fully her CNS and, in doing so, to accept surgery in the first instant and the stoma as a normal part of her life.

8.16 Whanaungatanga – Being with Whānau

As soon as my children arrived back from Aussie the first thing they did was buy some mussels and they cooked some but I wanted some raw ones. That was probably the most substantial thing I had eaten for ages and I'm sure that's why I got better, because of those mussels. I'm not really, a mussel eater but I wanted that taste and every day they'd get me more and that was my main meal. I did want that food, our traditional food. When my stoma nurse used to come, she would ask what I had eaten and at that time that was all I was eating in the first week or so of being home. It's now been four years. (NS. 2014)

Ripeka's children were aware of her diagnosis and what that could mean for them as a family. She was their mother and an important part of their lives. Their relationship with their mother was such that they were focussed on her wellbeing and in doing so worked as a whānau to restore their mother's wellbeing. She was obviously a person who enjoyed her Māori kai, especially kai moana.¹⁴⁸ Ripeka loved her traditional food and her children knew that. They did all they could to make their mother well again and traditional diet was one of those options. Māori often crave for their traditional kai when they become unwell and are admitted to hospital.

¹⁴⁸ Seafood

8.17 The Irony of Invasive Therapy

...the chemo and radiotherapy has caused side effects. I've still got numb feet. This would have been 2011 or 2012 when I had a massive dose of chemo - it went on for six months. In the end, I had to pull out. I pulled out I think in the last month because I had no feeling. My feet and my toes, were totally numb and I couldn't touch a fridge because my fingers were all numb. Now it's nearly all back in my fingers, but my feet are still numbed. The radiation shrunk the tumour a bit and I think at that time I was thinking if I have this, I might not have to have surgery. I said after my last chemo I'd never have it again because it was so awful. But a year and a bit later, I'm probably thinking now if I should have radiation treatment I would if it's going to keep me here a bit longer. It's a hard decision, not a nice thing. It's hard to explain really. (NS. 2014)

Ripeka reflects on the past of having radiation and chemotherapy treatment. She describes the treatment as awful and ponders whether it was the right treatment for her. Despite the downside she said that the awful effects of chemotherapy treatment may have been the very thing that has kept her alive. She is surviving well.

8.18 Being in Mauri Ora

When I first started seeing my specialist after I came home, he would say things like "can't believe you're here, you shouldn't have been but you are." But I've just got better and better, as you can see, I'm not skinny anymore and I saw him only two weeks ago and he's pleased. He just goes "looking good". My husband and the kids have been a tower of strength for me. The ones in Aussie were coming back frequently. My son in Aussie has now come back, he wants to be here to keep an eye on things. I think my family and my friends would do anything to help. (NS. 2014)

I have recently taken the time to speak to Ripeka. She has experienced a journey in which the process of whanaungatanga has been fundamental to her recovery. Her recovery has been interpreted here as an outcome where the proper exercise of mana within her whānau, intervention through traditional healing, and a wonderful nurse specialist has enabled her to navigate through a challenging journey. Although Ripeka has not returned to the workforce she said that she is experiencing a quality of life where she considers herself to be well considering her diagnosis. She said that given the fact that the health system could do no more for her, other possibilities including cultural intervention, a supportive whānau, and nursing staff have enabled her to survive in restored tapu as the state of being – in mauri ora.

8.19 Summary

Health literacy has been a dominant theme across all participants in this study and Ripeka's story is no exception. Her lack of knowledge of bowel cancer concurs with all the other participants in the study. She assumed the pain she was experiencing was haemorrhoids, nothing to worry about. She attributes her survival in part to her belief in *tohunga* and by association, a relationship with *Atua*. That was a big part of her recovery. Ripeka's story alludes to the wrong exercise of *mana* by some of the nursing staff in her early postoperative care. Ripeka's story also tells us that she had a wonderful and supportive relationship with some of the other nursing staff including her clinical nurse specialist. They were there for her and they were a crucial factor in her acceptance of the stoma and to undergo surgery. Ripeka's children were aware of her diagnosis and what that could mean for them as a family. She was their mother and an important part of their lives. They too were an essential part of her recovery. Their relationship with their mother was such that they were focussed on her wellbeing and in doing so worked as a *whānau* to restore her *tapu* and her *mana*. Ripeka reflects in the past of having radiation and chemotherapy treatment. She describes the treatment as awful but, despite the downside, said it may be the very thing that has kept her alive.

8.20 Conclusion

Throughout this chapter it was shown that all three participants experienced an upsurge in energy and awareness of bowel cancer and the need to do something about it. There was an obvious purpose for being and a willingness to actively engage in enjoying a future with their loved ones. The state of being of *mauri ora* was expressed as successful outcomes where participants became highly motivated by what is happening to them in terms of their wellbeing. They had reached the stage in their journey where they were feeling good about their health, where they remained alert and actively engaged in and committed to keeping good health. Moana, Roimata, and Ripeka continue to enjoy life as survivors in restored *tapu* as the state of being - in *mauri ora*.

CHAPTER NINE: DISCUSSION

9.1 Introduction

The debate and discussion in the literature in this research has been about journeys of emotion, despair and inequalities in healthcare for people who have experienced the trauma of being diagnosed with bowel cancer. There is a need to facilitate greater awareness and knowledge of the symptoms and causes of bowel cancer for Māori. Stories of procrastination through fear of knowing, the anxiety of knowing, explicit accounts of colonoscopy, surgery, and current care strategies post-surgery, can result in significant insights on the lived experience of Māori whānau who have experienced bowel cancer in their lives. Creating awareness within whānau of the seriousness of chronic conditions needs an alternative to purely bio-medical approaches. The efficacy of a Kaupapa Māori approach to health care is, in this case, appropriate because Māori epistemology and the ontological realities of what is real in the world for Māori elucidate critical social and cultural content that is important to Māori.

Involving whānau from the very beginning is a pre-requisite to ongoing engagement with Māori. Improving collaborative interaction between Māori and health professionals is a strategy that could lead to improved health outcomes for Māori. I believe that the entry pathway to care for Māori cannot ignore the cultural context in which Māori have experienced life. The entry pathway, therefore, must begin by addressing the cultural aspects. Once in place, health professionals are then in a better position to explain the biomedical aspects of chronic diseases that Māori present with. Cultural and biomedical aspects of care are necessary for Māori when they enter the healthcare system. It establishes a genuine pathway for Māori to make informed decisions about the healthcare they receive. The way forward could mean crucial lifestyle changes concerning exercise and diet are more likely to gain acceptance. Adherence to prescribed medications by medical practitioners may well be another outcome. There appears to be a disturbing acceptance by many Māori that they cannot do anything about life threatening conditions and that they are destined to die at a younger age than other New Zealanders. The perception here is that serious chronic illnesses are part and parcel of the lived experience for Māori. Gouty arthritis for instance is perceived as being part of life and you just put up with the pain (Winnard et al.,

2008). That perception has far greater implications than just putting up with pain. The ongoing impact can lead to major chronic illnesses including diabetes and an outcome that nobody wants to experience – the need to undergo dialysis two or three times a week. In my experience, this scenario is endemic within whānau, hapū, and iwi.

What we do know is that acculturation into Western society has exacerbated the plight of Māori through alienation from traditional values and customs (Riseborough, 2002). There are numerous possibilities on how lives can change if the emphasis on resources was channelled into targeted health promotion programmes designed to educate Māori about bowel cancer. What is required are innovative programmes in communities that educate Māori about bowel cancer in a Māori environment by implementing approaches that Māori can identify with.

9.2 Whakapapa

The realm of whakapapa in the context of this study, relates to the stories' substance or origin and has been contextualised to participants experiences of the initial signs that something was wrong. Seven participants in this study experienced the same symptoms - blood in the faeces, the necessity to go to the toilet on multiple occasions and difficulty to empty the bowel. Despite this, some of the participants refused to either to go to the doctor or had to be coaxed into accepting professional help. One participant went into denial and ignored the signs altogether. Two of the participants showed minimal signs and reported to their doctors because they were experiencing some pain in the side of the body. One participant reported to his doctor because of swelling to his neck and lower arm. The outcome in all cases was a diagnosis of bowel cancer at varying stages of development.

9.3 Mauri

Mauri holds a central place in informing Maori, how and why our lives take the form they do (T. Pohatu, 2011). It imbues Maori thinking, knowledge, culture and language. We are born into this world in mauri ora. We grow up in a world where the dynamic interchange of mauri dictates how we are feeling. Being pono constitutes an undertaking that speaks to the self in honesty. It is about being

honest with the self. At times, we face critical moments in our growing up in the world, a judicious moment can lead to gratitude in life, a vulnerable moment to despair. We become a product of those moments created by the choices we make in life. We exist in tapu and the choices we make in life can determine the way we exist in, and how we interact with the rest of the world.

Manu chose to ignore the symptoms of bowel cancer. Nevertheless, he was experiencing something out of the ordinary and his body was sending him the same message. Despite the warnings, he proceeded down the pathway of denial. Such acts of denial can be interpreted as a violation of one's own intrinsic tapu, (*whakanoa te tapu i a ia*), resulting in diminished tapu and impaired mana. After being diagnosed he preferred to keep to himself in isolation hidden away from the scrutiny of others. The state of being of mauri moe had manifested through withdrawal and isolation. He struggled to come to terms with an ailment that he described as the lowest of our human side possible. He labours and continues to exist for much of his time in the state of mauri moe, the antecedent to which I assert, is diminished tapu.

Mauri oho denotes actions and expressions of activity, an awakening, a new beginning, a rebirth - dynamics which were experienced by all the participants in this study throughout the course of their journey. Both Matanuku and Rihari displayed the archetypal characteristics of mauri oho where they remained vibrant and enthusiastic about the future and that reclaiming their health and wellbeing would be just a matter of time. They said, "*why can't they just cut the cancer out*", and, "*I was hoping that they would get rid of it and I would be all good.*" For them, it was just a matter of dealing with the problem and they would be fine. They remained oblivious of their situation, expressing a degree of naivety as to the enormity of the problem – a diagnosis of stage four bowel cancer. Rihari said he did not know any better. Both participants were aware of their diagnosis but chose instead to suppress the reality of end stage bowel cancer. They preferred instead to live in hope, for where there is life there is hope. It is perceivable that both participants shared moments where they had experienced times when they existed in mauri moe, however, their vitality and enthusiasm for life remained more frequently – in mauri oho.

The state of being of mauri ora finds expression through successful outcomes where participants become highly motivated by what is happening to them in terms of their wellbeing. Moana, Roimata, and Ripeka spoke of the impact their children had on them. The love and affection that their children had was not just a matter of making appointments with the doctor but reflected more on how the whānau had come together as a collective in whanaungatanga. The reciprocal nature of how whanaungatanga works provided the stimulus for them to accept, move on and adopt a positive stance on how they and their whānau would counter the challenges they were all facing. All three participants had experienced an upsurge in motivation and energy because of the commitment their children had shown for them. It was through that bonding and commitment that Moana, Roimata and Ripeka were empowered to experience a journey that manifested as restored tapu as the state of being – in mauri ora.

9.4 Whanaungatanga – Maintaining the Boundaries of Tapu

The Proper Exercise of Mana

The intervention of whānau members in the restoration of tapu and mana was exemplified in six participant stories. The dynamics of whanaungatanga in all six stories were possible and effective only when all members played their rightful roles in taking initiatives, supporting initiatives, or providing options to address, enhance, sustain, and restore the tapu of whānau who had been afflicted with bowel cancer. Although both Moana and Ripeka suffered anastomosis rupture¹⁴⁹ of the bowel, the extra stress and fear of possible death was countered by the correct exercise of mana through the actions of whānau members who provided both spiritual¹⁵⁰ and physical support to alleviate the pain and anxiety that they were all experiencing as whānau. Ripeka sought traditional intervention by tohunga and by implication the spiritual healing of Atua. She said her whānau have always believed in tohunga. She attributes traditional healing as one of the reasons she is still here, this after being told by her specialist that he could not do any more for her. It has now been five years since she had the operation.

Roimata spoke of the experience of the relationship she had through being in communion with Atua. She attributed her survival to her belief in Atua where she

¹⁴⁹ Anastomosis rupture – life threatening rupture of the bowel after surgery

¹⁵⁰ Karakia

exercised the tapu of being in relationship with Atua. She also spoke of the unifying devotion of her whānau and how they too contributed to her wellbeing. She continues to live her life in restored tapu as the state of being - in mauri ora. Moana, Ripeka, and Roimata, whose stories appeared as exemplars in chapter eight, continue to live their lives in restored tapu as the state of being - in mauri ora. Mere, Tama, and Kataraina whose stories appear in Appendix B, experienced similar outcomes, and they too continue to live their lives in restored tapu as the state of being - in mauri ora.

9.5 Violating the Boundaries of Tapu

The Wrongful Exercise of Mana

According to Tate (2010), whakanoa is the act of violation by which the tapu of Atua, tangata, and whenua is diminished, and the exercise of mana is obstructed or impaired. The concept of whanaungatanga surfaced as a major issue regarding engagement with participants in this study because it appeared that health professionals failed to engage with Māori through whanaungatanga when they were admitted to healthcare services. Consequently, some participants were left struggling to cope, to exist in what Tate described as diminished tapu and impaired mana. The clinical engagement process for Māori proceeded without cultural input. Some participants felt isolated because they did not have a clear picture of the proposed treatment they would receive or why certain aspects of the treatment were necessary. The absence of whanaungatanga for some of the participants was tantamount to talking past rather than talking to. The participants involved had no sense of connection and the boundaries of tapu in the absence of whanaungatanga had been violated. This can happen when health professionals attend to part of the person's wellbeing without reference to the person's total wellbeing. Health professionals may readily and conscientiously care for bodily (*tinana*) wellbeing in a clinical sense, but neglect *te taha wairua*¹⁵¹ and/or *te taha hinengaro*¹⁵² aspects of wellbeing. Maori interpret this as *whakanoa i te tapu o te tangata* which is tantamount to the suppression and prevention of the dynamic movement of tangata toward achieving total wellbeing.

¹⁵¹ Spiritual wellbeing

¹⁵² Mental wellbeing

My experience of working in the health system has shown that many health professionals regard the introductory time to engage with Māori in whanaungatanga as a waste of time. According to Dallmayr (2009) inter-cultural dialogue is frequently treated as unnecessary or impossible. It is said to be unnecessary because we are all the same or share the same human nature. The reality of the situation however, from a Māori perspective is quite the opposite. Māori regard the process of whanaungatanga as essential as it provides an opportunity for them to say who they are, how they are, and why they are. Whanaungatanga is so important because it sets in motion the correct and rightful process where knowing the person, knowing the whānau, is vital, and of the greatest significance in determining where participants are at any given point in time in their journey. This action is about being pono. Pono is a principle of perception of truth by which we address tapu and mana. It is an ethical principle of action in that it qualifies how we address, enhance, sustain and restore tapu through the proper exercise of mana.

The expectation from participants was for health professionals to step up to the roles and positions they occupied and to implement them fully. When health professionals failed to respond with integrity, by the full exercise of mana, they not only violated the tapu and mana of the participant, they also created a situation whereby they were perceived by participants as being in diminished tapu and impaired mana¹⁵³. Māori thus lose faith in the health professional and either seek help from someone else or simply continue to accept the status quo, that is, treatment from a clinical perspective only. Mihi's husband chose not to proceed with clinical intervention at all after receiving the news that he had end stage bowel cancer. It had been two years since his initial admission to hospital, after experiencing symptoms of bowel cancer. He chose instead to remain at home with his whānau until he passed away. His treatment pathway had been prescribed clinically by health professionals without cultural input which resulted in delayed diagnosis. Two other participants were to experience this scenario where treatment had been prescribed for ailments other than bowel cancer. When the diagnosis of bowel cancer was finally confirmed participants were angry to the point where the members of two whānau shed their anger by verbally abusing health professionals and the health system. Kataraina's cancer was

¹⁵³ To lose one's status – loss of mana

finally diagnosed after a considerable delay at stage three. Rihari's diagnosis may have already metastasised to other organs throughout the body when he first met with his doctor. Matanuku's diagnosis was confirmed after a colonoscopy was performed five months after he experienced first symptoms. Mere's diagnosis was confirmed seven months after experiencing symptoms when the colonoscopy was finally done.

9.6 Alienation Through Ignorance

O'Connor (2012) stated:

...there has been some slippage in the influence of cultural safety in nursing. It is not as embedded as it was in the 90's. It is now a registered nurse (RN) competency, among many (RN) competencies. (p. 17)

Some of the participants in the study remained alienated because they did not understand the language health professionals adopted when they explained what was happening to them. When the approach to engagement by health professionals is not pono, that is to engage in ways where Māori cannot understand the medical terminology, Māori tend to disengage. They may intimate that they understand, but they do not. This was the case with some of the participants. Lower educational and health standards in Taranaki has been widely acknowledged by academics and many Māori as the root cause for disparate standards of education and health in which Māori currently find themselves (Leung-Wai & Sanderson, 2010). The fact that literacy has shown itself as a major issue in this study emphasises a point that Māori at grass roots level struggle to understand health literacy from a purely biomedical viewpoint. Current evidence tells us that Māori in the 50-65, 19-24 and 16-18 year age bracket have the poorest health literacy compared to the rest of the New Zealand's population (Ministry of Health, 2010).

The English Thesaurus Dictionary quotes several meanings for the word ignorance: unawareness; inexperience; illiteracy; unfamiliarity; and obliviousness. In short, it could refer to a lack of knowledge or education. All the stories in this study revealed the reality that participants had very little or no knowledge of bowel cancer before they were diagnosed. Conversely, health professionals ignored the necessary cultural input to reach a balanced assessment when participants sought professional help. This position did not

improve given the approach adopted by some of the health professionals in the engagement process. That approach may have contributed to delayed diagnosis and/or incorrect treatment options that some of the participants experienced.

The concepts of whakapapa, mauri and tapu creates a genuine cultural pathway in addressing issues concerning cultural awareness, cultural sensitivity and an outcome that culminates in cultural safety. It holds clinicians accountable to delivery of healthcare that makes sense to Māori. For Ramsden (2002) cultural safety is an ongoing journey that allows Māori to define their own care:

Cultural safety is an outcome of nursing and midwifery education that enables safe service to be defined by those that receive the service and is achieved when the recipients of care deem the care to be meeting their cultural needs (p 117).

Most health professionals are perceived by Māori as having mana. They have taken time and effort to study and achieve their goals. According to Tate (2010), they have mana in potentiality, *te mana i te tangata*. Problems arise for Māori when that potentiality cannot be delivered in a way that Māori are comfortable with, in other words, to practice in a culturally safe way. Their perceived mana remains in potentiality only because they do not have the ability to convert that potential to good effect. For Māori, that is about cultural awareness, cultural sensitivity and cultural safety that Ramsden speaks about. Clinical intervention thus take precedence and cultural input remains superficial only. Māori will often reject that approach, as was the case with Mere and Kataraina. Others will simply accept what the health system had to offer, as was the case with Rihari, Matanuku and Mihi. In Mihi's case, Mihi, her children and extended whānau have become victims of the health system and continue to exist in diminished tapu as a state of being – in mauri moe.

9.7 Alienation Through Unconscious Bias

The English Thesaurus Dictionary quotes several meanings for the word bias: prejudice; preconception; unfairness; preconceived notion; favouritism; partiality; and foregone conclusion. According to Byrne and Tanesini (2015) there appears to be a fundamental inconsistency between research which shows that some minority groups consistently receive lower quality healthcare and the literature indicating that healthcare professionals appear to hold equality as a core personal value. The evidence suggests that these disparities in outcome may in part be

due to social biases that are primarily unconscious. For some health professionals, the activation of these biases may be facilitated by excessive workload associated within clinical practice. A range of measures, such as counter-stereotypical inducements and targeted experience with minority groups, have been identified as possible solutions in healthcare settings. The authors suggested that social bias should not be seen exclusively as a problem of conscious attitudes which need to be addressed through increased group seminar awareness. Such an approach lacks pragmatism. Instead, the delivery of bias free healthcare should become a habit, developed through a continuous process of practice, feedback, and reflection. My experience in working with health professionals in healthcare institutions affirms the suggestion that Byrne and Tanesini intimate. Group seminar awareness lacks pragmatism because in most mainstream institutions that I have been engaged with, educational group seminars have proven to be unproductive. Health professionals thus continue to attend group seminars as a ritual that ticks the box rather than as a dedicated learning goal. I agree with what Byrne and Tanesini suggest - a process that incorporates feedback and reflection on one's practice should be part of everyday practice. Spence (2015) in *Exploring prejudice, understanding paradox and working towards new possibilities* builds on the suggestion by Byrne and Tanesini by showing how prejudices as enabling through 'being with' and 'being present' where the delivery of bias free healthcare should become a habit, developed through a continuous process of practice, feedback, and reflection. When I interviewed one of the participants in this study for a second time, a whānau member vented her anger toward health professionals because the whānau were not advised of a routine operation prior to resection of the bowel. The operation from the health professional's perspective was routine. The operation from the whānau member's perspective at that moment was – it might kill him:

He had the colostomy bag for nearly a year and when he went to hospital to have his bowel re-joined he came out with an 'ileostomy' instead. It was a smaller bag on a different part of the bowel. The doctor said to me that I have done this so when we go to re-join the bowel it would only be a minor operation. I said, "he hates the bag and now you've given him another one." I want to tell you something what he said when I was sitting there. He came in and I saw him and he saw me and he walked over to the nurses. I said, "I want to know why he has got this bag – what happened, what happened. Why has he got this bag?" He sort-of just flagged me off. All the nurses came in and to me it seemed that no one knew anything. His comment to me was: "Well, what do you expect –

he's diabetic and he's Maori." I stood up and I said, "you (b.....)". He wasn't even talking to me. He just ignored me and he was just talking to the nurses and then he left – he just walked out. I said, "hey I want to talk to you." I wanted to know why he said that. Why was this comment necessary? I felt like punching him on the nose. (MH. 2014)

This is an example of the wrongful exercise of mana in which a violation of tapu had been committed. The above scenario may have been avoided if the operation had been explained in detail beforehand and in a way that the whānau could understand, hence the need for a valid cultural assessment procedure. For Māori, that is about a process that draws clinicians attention to issues concerning cultural awareness, cultural sensitivity and an outcome that culminates in cultural safety (Ramsden, 2002). The outcome was a very angry whānau member because the comment was derisive and disdainful. The comment from a cultural perspective left the whānau member feeling belittled, berated, and of no consequence. The outcome was violation of the tapu and mana of the person and, by implication, violation of the tapu and mana of the whānau.

9.8 Being with a Stoma

The prospect of having to live one's life with a stoma was an area that was perceived as a negative outcome for some of the participants. I have mentioned this aspect here because it was a dominant factor when we consider all the stories. It impacted six of the 10 participants in the study. Mihi stated that although the specialist explained to them what the stoma was, they retained very little of the information that they were given. She said the language was beyond their comprehension, well beyond their understanding. She said she agreed with the doctor as it seemed to be the simple solution to a problem they were later to regret. It may have been the trigger that lead to her husband's refusal to further treatment. He simply did not trust the doctors and, by implication, Western medicine. In hindsight, she realised that a real opportunity to do something for her husband had been lost – if only they had known. The brief mention that her husband gave when referring to the stoma bag may have had far reaching effects in terms of accepting surgery from the outset. Having to live with a stoma for example may have been the real reason why he refused surgery. Mihi said:

"...he just didn't want that bag. I understand it now. I can see now what could have been done for my husband."

Ripeka seriously considered refusing surgery if having to live one's life with a stoma bag was the outcome. For Kataraina it was the biggest issue. Moana refused to touch it for weeks, and Mere and Matanuku suffered embarrassing moments as well. Whanaungatanga sets in place a process to explain medical procedures in a language that is acceptable to Māori. This did not happen and the outcome was one where the stoma was perceived as repulsive, even unbearable. What became evident from this study was the fact that there was significant misunderstanding by participants of the clinical explanation of what a stoma is and its purpose. Their resistance to the stoma is understandable as an affliction of bowel cancer could be perceived as some form of punishment for past misdemeanours. The issue of whakamā also surfaced. Having a stoma was not only a source of embarrassment but considered to be wrong and not normal. The significant aspect of the majority participants however, is that they were enabled to navigate their way through what was conceivably an impossible situation – to finally accept life with a stoma.

Refusal to have a stoma is tantamount to a refusal to undergo clinical intervention to remove a tumour. That can lead to a devastating outcome – people die because of it. A study by Cotrim and Pereira (2008) provides us with insights of people who have no option but to live the rest of their lives with a stoma. Study findings showed that the quality of life of a colorectal cancer patient and his family is deeply modified when faced with a diagnosis that inculcates physical and psychological changes induced by it. The aim of the study was to identify and assess the impact of colorectal cancer on patients and their families. In terms of quality of life, those patients who had a stoma reported a lower overall quality of life, lower body image, poorer health related quality of life, and poor social activity when compared with colorectal cancer patients who had no stoma. The stoma patients also had significantly higher depression and anxiety than non-stoma patients.

9.9 Whanaungatanga – A Health-Giving Relationship

The concept of whanaungatanga portrays the notion of a health-giving relationship and is applicable across all domains in healthcare. A study by Huriwai (2000), *Whanaungatanga: A process in the treatment of Maori with alcohol- and drug-use related problems*, notes that Māori have advocated that

culturally based care requires goals and processes specifically defined within their ethno-cultural context. Positive cultural identity and pride were posited as integral to achieving wellbeing for Māori. Data relating to tribal affiliation, cultural self-identity, and upbringing of that sample was presented. The key concepts of whānau (family) and whanaungatanga (relationships) in the treatment process for Māori were explored and the implications of their utility discussed. The findings highlighted the complexity of providing treatment that is cognisant of ethno-cultural factors. Research conducted by Slater et al (2013) supports the notion that whanaungatanga is critical when we attempt to engage with Māori in healthcare settings. Aspects of Slater's study emphasises the importance of whanaungatanga posited by Huriwai. A more recent study by Slater et al., (2015), *Exploring Maori cancer patients', their families', community and hospice views of hospice care*, showed that Māori cancer patients felt uncomfortable when they used mainstream healthcare services because Māori tikanga or culture is ignored. Walker et al. (2008) in, *The road we travel: Maori experiences of cancer*, identified that the involvement of whānau in the cancer journey was viewed as highly significant, as was a holistic approach to care. Participants had many suggestions for improvements to cancer services such as better resourcing of Māori providers, cultural competence training for all health workers, the use of systems navigators and the inclusion of whānau in the cancer control continuum. The superficial perception of whanaungatanga by many health professionals is about developing a relationship only. In the context of healthcare, the health-giving properties of whanaungatanga goes much deeper.

9.10 Surviving with Bowel Cancer

It has been two years since the interviews for this study were conducted. Mihi's husband had passed away prior to the interview which was done with Mihi and her whānau. Sadly, Matanuku and Rihari also passed away during this study. Despite the adversity of having a diagnosis of bowel cancer, Moana and Roimata were living their lives in mauri ora at the time they were interviewed. Today, they continue to live their lives in restored tapu as the state of being – in mauri ora. Ripeka and Mere experienced challenging effects of alternative therapy - chemo and radiotherapy. Mere described the treatment as having a synergistic effect on her eventual recovery. Ripeka's experience of the treatment was awful. She

questioned whether it was the right intervention for her. Despite the down-side she said the treatment may have been the very thing that has kept her alive.

As I near the end of writing this thesis I have taken the time to speak to all the surviving participants. Moana, Roimata, Kataraina, Ripeka, Tama, and Mere, are currently experiencing a quality of life where they consider they are surviving well. They have experienced a journey in which the process of whanaungatanga has been fundamental to their recovery and hence, wellbeing. Their experiences of recovery have been interpreted here as an outcome where the proper exercise of mana within whānau has enabled them to navigate through a challenging journey that has culminated in restored tapu as the state of being – in mauri ora. Manu contacted me recently and I asked him where he perceived he was in terms of mauri moe, mauri oho, and mauri ora. This is what Manu had to say:

This is what mauri ora means for me. It's my life and I'll pick up what's left of my life and move it forward. This means researching answers, solutions, and possibilities for myself and by myself. Where there's life there's hope. I still possess life and as hectic, fragile and demeaning as it can be for me at times I still have life. My life may be still now, but I'm doing my best with the little I have."

He said he remains for much of his time in a state of mauri moe, but there have been times when he has experienced brief moments of mauri oho and even mauri ora but those moments have always been interrupted by a state where the dominant indicators are characteristic of the state of being of mauri moe, the antecedent of which I contend, is diminished tapu.

9.11 Implications for Ongoing Research

Proposed Study 1

One of the most compelling outcomes from this study was the fact that Māori had very little knowledge of bowel cancer before they were diagnosed. There is great need to address this question. I believe it is no longer possible to promote disease awareness and healthier lifestyles via dictatorial approaches that are structured on the 'one size fits all' approach that most mainstream health institutions have adopted. Additionally, endless streams of literature have a place, however, cannot be used to simply tick the raising awareness box. Therefore, unique impactful fun stand-alone tools are required to achieve the

desired effect. A possible study would incorporate the inflatable colon¹⁵⁴ (Appendix F) as an apparatus to conduct an evaluation on the effectiveness of improving awareness of bowel cancer among Māori in Taranaki. A good place to begin would be a proposal to conduct a Kaupapa Māori action research study in conjunction with introducing the inflatable colon to the community working with a group of stakeholders to plan, enact, and evaluate an intervention throughout Taranaki iwi.

Implications for Health Education in the Community

The above study could be structured in accordance with the following key aims:

- Increase knowledge of the disease and its symptoms through educational presentations throughout Taranaki iwi to break down the barriers to early diagnosis;
- Identify and recruit local ambassadors or community champions to assist in pushing home the prevention and awareness message;
- Educate local service providers/stakeholders where appropriate;
- Utilise the bowel cancer campaigning platform to integrate other health and lifestyle messages where obesity, smoking, active lifestyle, and diet which are also inked to bowel cancer;
- Empower communities and individuals to take ownership of their health;
- Reduce inequalities, incidence, and bowel cancer mortality rates among Taranaki Māori and;
- Create a campaign template that can be integrated in other geographical areas of New Zealand.

Proposed Study 2

I believe that the entry pathway to healthcare for Māori cannot ignore the cultural context in which Māori have experienced life. I propose an action research study to develop an engagement pathway that integrates clinical and cultural aspects of wellbeing for Māori. The study would explore prejudice, understanding paradox

¹⁵⁴ The inflatable colon has been constructed as a walkthrough educational replica of the colon. The internal imagery consists of translatable signage boards for nine common diseases of the colon: pre-Cancerous Polyps; Colorectal Cancer (Malignant Tumour); Mild Colitis; Healthy Tissue; Advanced Polyps; Severe Colitis; Diverticulitis and Crohns Disease.

and working towards new possibilities in addressing cultural differences that focuses on the meaning of enabling for Māori patients who present to healthcare providers with a suspected prognosis of bowel cancer.

An Integrated Approach to Healthcare Practice

Whānau centred care requires a commitment by health professionals to work together with families in ways that enhance taha whānau ideals that are essential as we seek to restore the tapu and mana of the whānau. The attainment of family centred care can be captured by a dual clinical/cultural pathway which, although based on competing paradigms, has the capacity to enable health professionals and others to work together, learn together, and establish agreed protocols and processes where best practice initiatives are shared. This sharing and learning process enables clinicians, therapists, and managers to employ a process together, rather than in conflict with existing systems. Some ideas for a proposed action research study involving stakeholders are presented in Appendix G. The notion of an integrated model draws upon existing models of healthcare including the generic clinical model, sanctioned by the World Health Organization, the International Classification of Impairment, Disability and Handicap (ICIDH2).

Implications for Education in Healthcare

The concepts of whakapapa, mauri and tapu consolidate issues around cultural safety espoused by Irihapeti Ramsden (2002). This approach can be utilised across all disciplines in healthcare. Understanding an engagement pathway that incorporates the concepts of whakapapa, mauri and tapu would be invaluable for undergraduate students seeking a career within the healthcare system. It enables students to practice in the right order of relationship when engaging with Māori through the action principles of pono, tika and aroha.

Implications for Indigenous Peoples

I have utilised the concepts of whakapapa, mauri and tapu to interpret Māori experiences of bowel cancer. Interpretation of those experiences was informed by Gadamerian Hermeneutic Interpretive Methodology, which unpacks the nature of how we understand and interpret. I have been involved in the helping profession for the past 26 years and at times, I have experienced ongoing innuendo regarding discourses associated with Kaupapa Māori as being controversial, preposterous and even ludicrous. The works of the Greek philosophers Plato and Aristotle influenced Gadamer's (1922) dissertation for his

PhD. Gadamer's emphasis on *phronesis*, a common topic of discussion in ancient Greek philosophy suggests ways in which we can minimise negative perceptions of indigenous ways of knowing and doing. Because of its practical character, the term *phronesis* was often interpreted by the ancient Greeks as practical wisdom, something that comes through experience. In contemporary times *phronesis* can describe a person who acts with prudence, meaning to be far-sighted, careful and judicious, where one makes decisions after considerable forethought. I regard practical wisdom as fundamental to the concept of *kaumātuatanga*, something that comes through experience gained as the fruit of years. I have posited Gadamer's interpretation of *phronesis* as another voice to endorse Kaupapa Māori ways of knowing and doing. Gadamer (1960) infers that language is the universal medium through understanding occurs. If we are to understand anything, one must have a bond to the subject matter that comes into language through text and have or acquire a connection with the tradition from which it speaks. This is the basis by which hermeneutics has been applied to this thesis. I thus make the assertion that interpretation of text using Gadamerian Hermeneutics can be applied across other indigenous ways of knowing and doing.

9.12 Limitations of the Study

The proper exercise of *mana* through *whanaungatanga* has been a highpoint of this study. Six of the participants in this study currently survive in restored *tapu* as the state of being of *mauri ora*. The proper exercise of *mana* from within *whānau* was a significant factor in their recovery. What we do not know however, is how Māori have fared in the past when support structures have not been present. Five of the 10 participants experienced problems to varying degrees with having to survive with a stoma. The data provides some evidence that Māori may refuse surgery because they do not turn up (DNA¹⁵⁵) to a First Specialist Assessment (FSA).¹⁵⁶ I make the point that this study does describe the experiences of one participant whose *whānau* told his story. Mihi's husband chose not to proceed with clinical intervention after receiving the news that he had end stage bowel cancer. It had been two years since his initial admission to

¹⁵⁵ Did not attend

¹⁵⁶ FSA – an assessment by the multi-disciplinary team of health professionals to plan a course of clinical intervention, usually, surgery

hospital, after experiencing symptoms of bowel cancer. He chose instead to remain at home with his whānau until he passed away. This may be an isolated case. The question remains, however, whether Mihi's husband's case is archetypal of Māori who choose to simply forego any further treatment and instead just return home to be with their whānau until they pass away. There is a case for further research if we are to have a more definitive answer to this issue.

Finally, as the researcher I acknowledge and accept instances where this study may not be taken on board by other iwi who would prefer research to be done by their own for their own. I anticipate such a possibility as Māori become more innovative in a changing Māori economy where tino rangatiratanga¹⁵⁷ is of the utmost importance. The findings of this study may be limited in terms of applicability to iwi throughout the motu¹⁵⁸.

9.13 Conclusion

Throughout this thesis, I have called upon theories and aspirations of numerous Kaupapa Māori theorists and academics including Te Rangi Hiroa, Māori Marsden, Michael Shirres, Pa Henare Tate, Elsdon Best, Ranginui Walker, Huirangi Waikerepuru, Taina Pohatu, and Sir Mason Durie. I have also utilised the substantial knowledge resources that I have within my own whānau and the strong links I have within Taranaki iwi. I have canvassed the assistance of other health professionals, academics, iwi leaders, the Taranaki Cancer Foundation, and health professionals in the Oncology Department at Auckland District Health Board. Despite the constraints of financial resources, I have striven to produce a thesis that will help Māori in Taranaki to understand the terrible disease that is bowel cancer. As I conclude the writing of this thesis I am convinced more than ever that there is a need to inculcate greater awareness and knowledge of the symptoms and causes of bowel cancer for Māori in Taranaki. There is also a need for health professionals to develop a deeper understanding of cultural aspects that are unique to Māori as most Māori attend mainstream health services.

My approach to this study has focused specifically on bowel cancer. All the participants of this study have sent a clear message that Māori need to know

¹⁵⁷ Self-determination

¹⁵⁸ The country

more about this disease. They have all said this in hindsight knowing full well what their perception was before they were diagnosed. Although there are numerous studies on cancer and Māori, there appears to be very little information on Māori experiences of bowel cancer. In the prologue, I spoke about my story. This thesis has given others the opportunity to know me as a person and to know the environment in which I was raised. Conceivably, my story is also about the participants in this study. More importantly however, it has given us all the opportunity to know the experiences of Māori who have experienced bowel cancer in their lives. We have learned that the concept of mana is an important factor when we engage with Māori. We have learned how the proper exercise of mana can empower Māori who have been diagnosed with bowel cancer to be well again. We have learned how the wrongful exercise of mana can exacerbate unnecessary and painful experiences for Māori who present with a prognosis of bowel cancer. We have learned that the proper exercise of mana, in which the process of whanaungatanga has been acknowledged, provides the foundation on which all proceeding elements of engagement depend. We have also verified the perception that Māori have very little conceptual understanding of bowel cancer.

When we engage in a kaupapa where the specific aim is to benefit Māori, we do so in accordance with the principles of pono, tika, and aroha. Pono is to believe in the inviolability of life on which we base our actions on honesty. Tika is to be upright and correct, doing things the right way. Aroha is love, a principle of communion between ourselves and Atua, between ourselves and other tangata, and between ourselves and the whenua. Dr. Te Huirangi Waikerepuru, a distinguished Kaumātua from Taranaki reminds us of the sanctity of tapu:

*Tihei mauri ora
he tapu, he tapu, he tapu
kia tika, kia pono, kia marama
Tapu is the fundamental principle of life and natural law guided by
boundaries of respect and safely protected by tikanga Māori and Māori
law.*

From tapu comes tikanga and from tikanga expresses the idea of kia tika, kia pono, kia marama. Tika means to be upright, honest and correct. Pono is to believe in the sanctity of life, and marama is the importance of knowledge, understanding and enlightenment.

And it is through the application of these principles integrated into the practice and protection of tapu that we are able to make headway through difficult periods and enjoy and uphold the principles of life. Therefore, whānau have a responsibility of maintaining the boundaries of tapu that protect life.

Tui i runga That it be woven above

Tuia i raro As it is below

Tuiai i waho Woven without

Tuia i roto As it is within

Tuia i te here tangata Interwoven within the threads of humanity

Dr. Te Huirangi Waikerepuru

In keeping with the principles espoused by Dr. Te Huirangi Waikerepuru I make the assertion that his words are fundamental to the approach adopted for this study when he says: *whānau have a responsibility of maintaining the boundaries of tapu that protect life.* The stories in this thesis are not only about the participants - the stories are also about their whānau, their hapū, their iwi. The stories, as told, constitute the most important components of this thesis because they send a powerful message to Māori at grassroots level by creating awareness of the dangers that bowel cancer presents. It is my hope that this study will engender rigorous discussion among Māori and healthcare institutions in Taranaki on ways forward to counter the threat from a disease that is the second highest cause of cancer deaths in Aotearoa/New Zealand.

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APPENDICES

Appendix A: Glossary

Ngā Kupu (words)

arohā

Atua

awa

hapū

hara

hauora

haurangi

heke tika

hinengaro

hui

hunaonga

hunga

hunga kainga

ia tangata

Io

iwi

iwi ke

kai

kai moana

kāinga

karakia

kaumātua

kaupapa

koha

kōrero

Kupu Whakamārama (Meanings)

affection, love, compassion

God, Supreme Being

river

extended family grouping

violation, offence, transgression

health, physical wellbeing

drunkenness

direct descent

seat of thoughts and emotions

meeting

in law relationships

person, people

home people

each person, the individual

supreme being, Atua

tribe

people of other tribes

food

seafood

home

prayer

elder (male)

principle, ground rules, purpose

gift of food or money

speech

<i>kuia</i>	<i>elder (female)</i>
<i>mana</i>	<i>spiritual power and authority, influence</i>
<i>mana manaaki</i>	<i>power and honour of providing hospitality</i>
<i>mana tuku iho</i>	<i>power and authority handed down from one generation to another</i>
<i>manaaki</i>	<i>caring attitude and action</i>
<i>manuhiri</i>	<i>guests, visitors</i>
<i>Māori</i>	<i>person of the native race of Aotearoa, New Zealand</i>
<i>marae</i>	<i>land on which whare hui and other buildings are located</i>
<i>mātauranga</i>	<i>Māori knowledge and wisdom</i>
<i>matuā</i>	<i>parent</i>
<i>maunga</i>	<i>mountain</i>
<i>mauri</i>	<i>life principle</i>
<i>mihi</i>	<i>greet, address, acknowledge</i>
<i>moana</i>	<i>sea</i>
<i>momi hikareti me te kai taru</i>	<i>smoke cigarettes, take illicit drugs</i>
<i>noa</i>	<i>state of violation, lack of freedom (negative state); state of freedom from restrictions (positive state)</i>
<i>ora</i>	<i>life, wellbeing</i>
<i>Pākehā</i>	<i>fair skinned people, “white people”</i>
<i>patu tamariki</i>	<i>physical beating of children</i>
<i>patu wāhine, patu tāne</i>	<i>physical beating of women, men</i>
<i>pono</i>	<i>true, genuine, honesty</i>
<i>pouri</i>	<i>sorrow, regret</i>
<i>powhiri</i>	<i>ritual of welcome</i>
<i>puku kai</i>	<i>over-indulgence in food</i>
<i>pūremu</i>	<i>illicit sexual acts, sexual abuse</i>

<i>pūake</i>	<i>root of, source, cause</i>
<i>rangatira</i>	<i>chief, leader</i>
<i>rangatiratanga</i>	<i>quality and dimensions of chieftainship, leadership and nobility</i>
<i>rātou</i>	<i>them</i>
<i>reo</i>	<i>language</i>
<i>reo Māori</i>	<i>Māori language</i>
<i>rohe whenua</i>	<i>specific geographical territory</i>
<i>rongoa Māori</i>	<i>Māori herbal medicines</i>
<i>runga</i>	<i>above, on</i>
<i>taha wairua</i>	<i>spiritual dimension</i>
<i>takahi</i>	<i>trample on, violate</i>
<i>takahi i te mana</i>	<i>trample the mana of</i>
<i>takahi i te tapu</i>	<i>trample the tapu of</i>
<i>take</i>	<i>reason, purpose</i>
<i>tamāhine</i>	<i>daughter</i>
<i>tamariki</i>	<i>children</i>
<i>tāne</i>	<i>adult male. Husband</i>
<i>Tāne – Mahuta</i>	<i>spiritual guardian with responsibility for forests, birds and human beings</i>
<i>tangata</i>	<i>person, people</i>
<i>Tangata Whenua</i>	<i>people of the land; indigenous people of Aotearoa New Zealand</i>
<i>taonga</i>	<i>special objects and possessions, treasures, artefacts</i>
<i>tapu</i>	<i>being, restriction, sacredness</i>
<i>tapu i a ia</i>	<i>a person's own intrinsic tapu</i>
<i>tapu i a rātou</i>	<i>their own intrinsic tapu</i>
<i>tapu i te Atua</i>	<i>intrinsic tapu of God</i>
<i>tapu o te whenua</i>	<i>intrinsic tapu of the whenua</i>

<i>tapu o rātou</i>	<i>their tapu</i>
<i>tapu o te Atua</i>	<i>tapu of Atua</i>
<i>tapu whakahirahira</i>	<i>highly important tapu</i>
<i>tautoko</i>	<i>support</i>
<i>tawhito</i>	<i>old, ancient</i>
<i>teina</i>	<i>younger brother of a male</i>
<i>tika</i>	<i>right, correct</i>
<i>tikanga</i>	<i>custom, right way of doing things</i>
<i>tikanga Māori</i>	<i>Māori customs and protocols</i>
<i>tinana</i>	<i>body</i>
<i>tohunga</i>	<i>expert in Māori custom</i>
<i>tuāhine</i>	<i>sister of male sibling</i>
<i>tuākana</i>	<i>older of sisters, older of brothers</i>
<i>tuākana-teina</i>	<i>older and younger siblings of same gender</i>
<i>tungāne</i>	<i>brother of female</i>
<i>tūrangawaewae</i>	<i>home-land</i>
<i>wāhi tapu</i>	<i>forbidden or sacred place, burial ground</i>
<i>wāhine</i>	<i>women, wife</i>
<i>wai</i>	<i>water</i>
<i>waiata</i>	<i>song</i>
<i>wairua</i>	<i>spirit</i>
<i>whakamā</i>	<i>shame</i>
<i>whakanoa</i>	<i>violate, defile, render worthless, lifeless (negative); set free from restrictions (positive)</i>
<i>whakapapa</i>	<i>genealogy</i>
<i>whakapapa heke tika</i>	<i>genealogical descent in direct line</i>
<i>whakawātea</i>	<i>set free</i>
<i>whānau</i>	<i>family</i>
<i>whānau hui</i>	<i>family gatherings</i>

whanaungatanga

family relationships, relationship structures

whenua

land, placenta

Appendix B: Three Stories

Kataraina's Story

Whakapapa of Kataraina's Story

Kataraina first noticed that something was wrong when she was experiencing continual episodes of constipation. She visited her doctor and explained her difficulty to empty her bowel whenever she went to the toilet. She wasn't eating properly and the episodes of constipation continued for weeks despite being given medications to make her go to the toilet. Her anxiety increased as she was aware that she comes from a family who have a history of bowel cancer. This study came to her notice through other members of her whānau who encouraged her to volunteer for this study.

This is Kataraina's story:

In the beginning, I was getting constipated and that was going on for a while. I went to the doctor and told her I was getting constipated and that I couldn't go to the toilet. She said it was constipation. I wasn't eating properly so she gave me some medicine to make me go to the toilet. All that did was make me go to the toilet and then it just happened like that week after week. I went back to her about six or seven times over the next year. I told her that the family has a history of bowel cancer but it never prompted her to move any faster. In the early stages I thought about it more because my uncle was diagnosed with it and I think that's what made me look more into it than what I had done before. I had just kind of left it at what the doctor was saying and never thought it was cancer.

I did the test for blood in your stool and I still had to wait for a colonoscopy. I think it was about a year before I got to have a colonoscopy from the time I started showing symptoms. I was pissed off because it took her so long to get me in for a colonoscopy. I was pissed off with her. She didn't care about me. To me she was more worried about the cost. I went to the doctor on numerous occasions and I had to pay to go to the doctor every time. I went in there and still came out with, 'oh, I'll give you this for three months' and then she would try something else for another three months. I felt she didn't try and get me in for a colonoscopy. I've changed doctors now because I was not happy with the whole attitude she had. She did all those

other things before going to the colonoscopy even though she knew that it was in the family. And then when I finally did get to go for the colonoscopy they never let me out of hospital.

I was 46 when I was diagnosed, that's two years ago and I had stage three bowel cancer. If I had known any different at those earlier visits to the doctor, then I would have stood at the bloody doctor's door and pushed for it. But because it wasn't until my uncle was diagnosed with it that I looked at the symptoms more and then went back to the doctor saying that my uncle had it and another uncle had died from it and I was pushing for the colonoscopy even more. I felt like going and punching her in the face when I found out. You know I'd been there so many times and I said you put me off all those times when I could have found out a year earlier. She put me on laxatives instead to make me go to the toilet.

I found out that I had cancer after I had the colonoscopy and they wouldn't let me out of the hospital. I was in there for two weeks and I didn't want to be there. Everything was just pushed onto me at once and then it took them ages to tell me what they needed to tell me. They took me through what they wanted me to do and said that I might have to have a bag and that there was a three percent chance that I would have to have a bag. When I woke up I had the bag and I was not happy - I was really upset. I didn't want to live with the bag because I didn't want to go through having to live with it. And then they have the cheek to tell you, 'oh lots of famous people have it' but for me it didn't make any difference. It was me they were talking about and it's a personal thing, having to live with it.

It takes a while to get used to putting it on. You can get used to it but you still don't like it. It's a personal thing to accept especially with Māori because having a bag, well it doesn't matter where you are or what occasion you are at, it makes noises and it just happens. They told me I can only have one bag a day because of the cost. They tell you that you are only allowed to use one a day because of the cost but to you, you're not going to sit there with just that one bag all day. Even if you have been and cleaned yourself up. It still doesn't feel like you're clean.

You know when your bowels start to move and you're sitting at the table it's not right so you just want to get off the table. You don't want to sit there when people are eating and your bowels are moving even though they don't know. But you know yourself that you just don't want to sit there with other people eating. Socially wise, I wouldn't go out and I haven't got over it. I would go out sometimes but half an hour later I'd be on my way home. Or if we went somewhere to a restaurant I would go in and eat and then go and sit in the car or I wouldn't eat until I went home. And even your clothes, you need to take extra clothes wherever you go and you also need an extra bag as well. Even if you just go into the shop and if it bursts, well you have a problem. The stoma nurses aren't very helpful either. They can say whatever they like but they don't know how you feel because they're not the ones who have to walk around with the bag all day.

I had to live like that for about 18 months until I had the reversal done. I was relieved not having the bag to cope with but then your bowel doesn't go back to what it was before you had the operation. So, you've still got to watch out what you eat and you've got to get used to trying to get your bowel back to what it was before but you never get back to that. Sometimes I need to go to the toilet all the time. Like I will go to the toilet and then I will need to go back again like five times in a row or something like that. There are tablets that can stop you from going or laxatives to make you go. You've just got to figure out a way that suits you and that is about what you eat and the times you eat. If you know you can't have something that's not good for you then you just can't have it.

Although I've been living in Auckland for 35 years I still have our traditional foods like pūhā but it just goes straight through me now. And seafood, I love seafood but I can only eat a little bit whereas before I could eat heaps of kina, like punnets of it, but now I can only eat a couple. But that's not because I don't want to eat it, it just doesn't agree with me anymore. One thing though, after the reversal to join my bowel up again I just kept on farting and that's probably worse than what was going on before and it isn't just the normal smell, it's the worst smell you could ever get and there is not a lot you can do about it. Metamucil helps a bit but they don't tell you

a lot about what you could try or do and you should try things yourself to find ways to cope.

The nurses have no respect for different cultures. They just think everybody's the same. You can't go into a Māori home without understanding their culture and thinking it's alright. They just expect you to live with it. I had issues with the bag leaking. All the nurse did was stick it on and went. When I rung her to say it was still leaking she said, 'oh, it's nearly 5 o'clock' and never came back until the next day and I ended up going back to the hospital and that was just a waste of time. On another occasion, I went to an appointment at the hospital and as I walked in it just burst and it all ran down my legs. I just went straight to the toilet and I just waited for somebody to come. When someone eventually came in I asked her to tell the nurse. She got a nurse to come out. I was so embarrassed but there was nothing I could do. I had nothing, no clothes or anything so they ended up giving me some pyjamas and told me to sit on the bed and wait while I got my daughter to come up and bring me some clothes. The same thing happened to me at work once where it burst but I knew it had just started so I just went straight to my car. It's so embarrassing when it does happen. There is no warning or anything that it is going to happen and that worries me.

There was one time when I had a very nice district nurse. She came and she sat here for five hours when I came out of hospital to try and get something to work. You don't know whether to go out – is it safe or should I use this bag or that bag. There are lots of different types of bags as well. They just give you the cheapest kind of thing. They don't give you the ones that suit you. You must figure it out with what you've got. I ended up getting different ones but that option wasn't given to me at the beginning. I think they just wanted me to use the cheapest ones because of the cost, the ones that cost them the least. There are also different creams and powders that you can get but they don't tell you that those things are available. They don't tell you everything that they should tell you. They don't mention all the different things that are available or whether you would you like to try them. What you have is it. Even when you are in hospital like after you have had the operation, the nurses don't want to

touch you because you've got a stoma. They don't even want to empty the bag. You have got to get out of bed to empty it out but they just don't want to do it. They don't want to know you and they expect you to learn it straight away. After you have the operation they give you three days. They don't sort of want to do it. They want you to do it but you're still busy trying to get over the operation, get up and out of bed and they still expect you to do it. They use the excuse that you have got to learn how to do it.

Something happened to my stoma. I think I got an infection or it may have been the stitches but had they been looking at it themselves and not just making me do it they would have picked it up sooner. One of the stitches came out and it went all black. Had they been looking at it instead of worrying about making me do it, it might not have happened. Even when you go for a bath or a shower you've got to take the bag off to wash it. You don't know whether something is going to come out or not when you're having a shower. That's the sort of thing that can happen to our people.

When we suspect something is not quite right we need to make the effort to go to the doctor. They select an age when they think you should have it done. If you're under 35 they say it's too young. We ended up writing down our family history. We wrote it all out and took it to our doctors and now we are being taken notice of. We've been pushing since it's all happened. It's not something you want anybody to go through regardless of who it is. Having a bag and having to live with a bag is not something you want anybody to go through. Since I've had the reversal things are far better, but there are still some issues but surviving without the bag is a whole lot better. I can understand how older Māori who have no choice but to live with a bag don't like it. It's not something you just get used to over time. You put up with it because you must, but you never really get used to it.

I had chemotherapy for six months. One thing I have noticed after I had the treatment is that I have a constant runny nose and that didn't happen before I had chemotherapy. Another thing I have noticed is that I had tingling and numb sensations in my fingers and toes. I couldn't touch anything cold and I couldn't drink or eat for a while. The tingling and numbness is not there anymore. I'm lucky because of the way my kids

treated me during the time I had the bag because. They made it not so much of an issue and they were able to laugh about it. We were all able to laugh because we needed to really. I changed my doctor about six months ago. I shared all those issues with the district nurses who were coming around to see me. I was telling them all the issues I was having about the doctors and they said for me to change my doctor. I still haven't found one that I can trust.

It's been helpful with family involvement right from the beginning. We had a meeting up here in Auckland with the Cancer Society and there was probably about five people besides us here that turned up from mum's family. There's probably about 20 of us up here but they didn't want to come and that's what pisses me off because I know that it's hereditary and that it's in the family because so many of our family have had it. Our family were given the opportunity to fill out a special form so that they can have a colonoscopy free of charge but they didn't want to fill it out. They think they're invincible. I don't want my kids to have to go through what I went through when it can be prevented through having a colonoscopy. Any parent should make that choice to sign the necessary forms to get tested and get on the registry so that their kids can get on it as well. Others of my family have been given the opportunity to do this but they don't want to accept that help. The fact that my nephew has been diagnosed with stage four bowel cancer at such a young age, he's only 29, should be enough but it's not.

It doesn't worry if people know who I am and that I have bowel cancer. I would rather people know and do something about it than just go to the doctor one day and then find out you already have stage four bowel cancer. I would rather people learned from my story and do something about it rather than wait until it's too late because they were too embarrassed or shy to go to the doctor. We need to get through to the parents first. I think that by having people at health promotion hui who have experienced bowel cancer, people like us, rather than just having people there just talking about would be a good thing.

Interpreting Kataraina's Story – The Search for Meaning

Being Constipated

In the beginning, I was getting constipated and that was going on for a while. I went to the doctor and told her I was getting constipated and that I couldn't go to the toilet. She said it was constipation. I wasn't eating properly so she gave me some medicine to make me go to the toilet. All that did was make me go to the toilet and then it just happened like that week after week. (NK. 2014)

Kataraina had a suspicion that something was wrong because she wasn't eating properly and suffered from continual episodes of constipation. Despite her doctor's diagnosis of constipation, she continued to show the same symptoms week after week. The doctor continued to prescribe laxatives regardless of the recurring episodes of constipation.

In the early stages I thought about it more because my uncle was diagnosed with it and I think that's what made me look more into it than what I had done before. I had just kind of left it at what the doctor was saying and never thought it was cancer. (NK. 2014)

Despite several visits to the doctor throughout the ensuing year her visits made no difference. The question of bowel cancer had not entered her mind and she just went along with what the doctor was saying. She trusted in what the health system had to offer.

I think it was about a year before I got to have a colonoscopy from the time I started showing symptoms. I was pissed off because it took her so long to get me in for a colonoscopy. I was pissed off with her. She didn't care about me. To me she was more worried about the cost. I went to the doctor on numerous occasions and I had to pay to go to the doctor every time. I went in there and still came out with... oh, I'll give you this for three months and then she would try something else for another three months. I was 46 when I was diagnosed, that's two years ago and I had stage three bowel cancer. If I had known any different at those earlier visits to the doctor, then I would have stood at the bloody doctor's door and pushed for it... I felt like going and punching her in the face when I found out. You know I'd been there so many times and I said you put me off all those times when I could have found out a year earlier. She put me on laxatives instead to make me go to the toilet. (NK. 2014)

Knowing the Person – Knowing the Whānau

There appeared to be no meaningful relationship between Kataraina and her doctor. Kataraina felt her doctor did not care about her and therefore had no real interest in her. Kataraina felt her doctor was more concerned about the cost of

treatment rather than her wellbeing. It took a year for Kataraina to get a colonoscopy from the time she first noticed symptoms. The wrongful exercise of mana through the absence of whanaungatanga between the doctor and Kataraina appeared to exacerbate a failing relationship. The necessity to know a person through appropriate assessment procedures for Māori upon admission to healthcare providers is imperative. It is the equivalent of any entry pathway that all healthcare providers should and need to have in place. The significance of a culturally appropriate assessment for Māori who present for assessment is more than just knowing the person by name and their living arrangements, it is also about understanding the person and their whānau. When we acknowledge a person's mana we achieve a crucial step in reducing distance between patient and health professional. The purpose of cultural assessments is to guide health professionals to know in greater detail Māori who present for the first time. Most Māori are enrolled in mainstream healthcare institutions where clinical intervention takes precedence. The correct and rightful approach by health professionals should be to focus on empowering Māori through appropriate engagement practices. Crucial information from a cultural aspect is often overlooked to the detriment of the person seeking help. The family history of bowel cancer in Kataraina's case was missed and therefore had no bearing on the treatment options that were prescribed for her. Kataraina's encounter with her doctor in the lead up to her diagnosis left her dependent on an intervention programme that had been clinically defined.

I changed my doctor about six months ago. I shared all those issues with the District Nurses who were coming around to see me. I was telling them all the issues I was having about the doctors and they said for me to change my doctor. I still haven't found one that I can trust. (NK. 2014)

Kataraina was diagnosed with stage three bowel cancer. She laments the opportunity that was lost to learn of her diagnosis 12 months earlier. Her delay in diagnosis served only to exacerbate the cancer that had been present from the very beginning. A diagnosis of bowel cancer at stage two would have been a far better outcome. A treatment regime on laxatives over the past year did not compensate for the fact that when she was finally diagnosed with bowel cancer. She vented her anger at her doctor once she found out. Although she has enrolled with another doctor she has not yet found a doctor that she can trust.

Being with a Stoma

I found out that I had cancer after I had the colonoscopy. I was in there for two weeks and I didn't want to be there. Everything was just pushed onto me at once and then it took them ages to tell me what they needed to tell me. They said that I might have to have a bag and that there was a three percent chance that I would have to have a bag. When I woke up I had the bag and I was not happy - I was really upset. I didn't want to live with the bag because I didn't want to go through having to live with it. (NK. 2014)

Kataraina struggled with the colostomy bag in the early stages of post-operative care. She remained hidden from the public eye in the initial months after surgery. Even after she got used to it the bag remained a constant source of embarrassment, bursting on several occasions when she was visiting others or attending hospital appointments. A study by Cotrim and Pereira (2008) provides us with insights of people who have no option but to live the rest of their lives with a stoma. Study findings showed that the quality of life of a colorectal cancer patient and his family is deeply modified when faced with a stoma and the physical and psychological changes induced by it. The aim of the study was to identify and assess the impact of colorectal cancer on patients and their families. In terms of quality of life, those patients who had a stoma reported a lower overall quality of life, lower body image, poorer health related quality of life, and poor social activity when compared with colorectal cancer patients who had no stoma. The stoma patients also had significantly higher depression and anxiety than non-stoma patients (Cotrim & Pereira, 2008).

Kataraina's resistance to the stoma is understandable. Māori are reluctant to talk about bowel cancer as this was a topic that came up with other participants in the study. Others said they felt it was dirty and repulsive, an outcome that comes from the deeper cultural aspects connected to whakama.¹⁵⁹ It appears Kataraina may have had those same thoughts. Although the problem associated with the colostomy bag was a barrier, having the bag was not insurmountable and once she learnt everything about it she could manage it. Another study by Shahid and Thompson (2009) explored issues related to cancer among indigenous populations in Australia, Canada, New Zealand, and the United States. The authors examined variations in the epidemiology and indigenous peoples' perceptions about cancer and the potential effects on care seeking behaviour

¹⁵⁹ A feeling of shame

(Shahid & Thompson, 2009). Of interest in that study were the qualitative findings of indigenous beliefs about cancer for although similarities to non-indigenous beliefs were noted such as fear of death and fatalism, there were distinct differences from a cultural perspective including shame, payback for indiscretions committed in the past, and the belief that cancer is a white mans' disease. The study is applicable to the behaviours that Kataraina was demonstrating concerning whakamā, even though her resistance to the stoma moderated, the whakama of being with a stoma remained.

Overcoming Whakamā

It takes a while to get used to putting it on. You can get used to it but you still don't like it. It's a personal thing to accept especially with Māori because having a bag, well it doesn't matter where you are or what occasion you are at, it makes noises and it just happens... even if you have been and cleaned yourself up it still doesn't feel like you're clean. (NK. 2014)

The prospect of having to live one's life with a stoma surfaced with other participants in the study. I have mentioned this aspect here because it is a definite theme when we consider all the stories that are part of this study. Four of the other participants experienced problems in the initial stages of having to survive with a stoma.

Since I've had the reversal things are far better, surviving without the bag is a whole lot better. I can understand how older Maori don't like it. (NK. 2014)

The reversal operation to re-join the bowel was not only a relief for her but enabled her to regather her confidence. As a young person, she could handle the trauma of having the bag but she also understands the feelings of older Māori who struggle to cope because of whakamā. For them whakamā is a far greater issue from a cultural perspective because it raises issues of neglect and personal misdemeanours that may have occurred in the past.

Being with Whānau

I'm lucky that the way my kids treated me during the time I had the bag because they made it not so much of an issue. They could laugh about it. We were all able to laugh because we needed to really...it's been helpful with family involvement right from the beginning. (NK 2014)

Kataraina was thankful that she has a family who understood what she was going through. She was thankful for her whānau who were there for her. Aroha is about compassion, sacrifice, and generosity. Tate (2010) stated aroha is communion in relationship between tangata and tangata that can only be achieved through love and affection. Kataraina's whānau focussed on her and her future wellbeing. It was their way of expressing their aroha for her through the right and gratuitous exercise of mana.

Being in Mauri Ora

As I near the end of writing this thesis I have taken the time to speak to Kataraina. She has returned to the workforce and is experiencing a quality of life where she considers she is surviving in restored tapu as the state of being – in mauri ora. She has experienced a journey in which the process of whanaungatanga has been fundamental to her recovery despite all the challenges she had faced in the past. Her recovery has been interpreted here as an outcome where the proper exercise of mana within her own whānau has enabled her to navigate through a challenging journey that has culminated in mauri ora. Tate (2010) postulated that the tapu of being in relationship with primary beings finds success through relationships that enhance, sustain, restore, and empower those in relationship. He stated that the source of all mana is tapu. By implication we can say that Kataraina and her whānau exist in restored tapu as the state of being – in mauri ora.

Mere's Story

Whakapapa of Mere's Story

Mere lives with her whānau in Taranaki and was diagnosed with bowel cancer early in 2011. Mere had experienced bleeding from the bowel for some time and interpreted it as a simple case of hemorrhoids. When the bleeding worsened Mere decided to visit her doctor for a checkup. Seven months after her initial appointment Mere was diagnosed with bowel cancer. Mere phoned me after she read the advertisement placed in the Taranaki Daily and Midweek newspapers. She wanted to tell her story so that she could help others to recognise, understand, and prevent bowel cancer from becoming part of their lives.

This is Mere's Story:

I had a notion that something was wrong - the evidence was there for a long time but it wasn't interpreted as cancer. When I worked at ... we used to have a two-yearly medical check but the main emphasis was on prostate cancer. There was a little lump there but everyone thought they were hemorrhoids and then it started bleeding and it got worse and I ended up getting quite a fright – it was liquid blood and it was in July 2011 that I went to A & E. Unfortunately, I had a two hour wait and by the time the doctor got around to examine me the bleeding had stopped. Never the less she wrote a letter to my doctor and she seemed to think that it didn't seem to be malignant but just in case, I should be booked in for a colonoscopy. It took seven months on the waiting list to have a colonoscopy examination at the hospital – that was February 2012. I was concerned that during that time it got worse and I twice told my GP that I didn't think it was just bleeding haemorrhoids but something else. I did however, have a tendency, to cover up my true feelings and concerns at times when seeing my doctor.

My doctor said two things which upset me: Firstly, he said “we can't advance people up on the waiting list, you'll have to wait your turn. There's a limited health budget and we've got insufficient resources to have everyone done at short notice.” That is paraphrasing but that is virtually what he said. Secondly, he said that he didn't think I had cancer because I would have lost weight and would be feeling very ill. Well I hadn't and didn't - so those two criteria cannot be relied on. I wasn't very happy about it and it was getting worse throughout that time. I felt I wasn't being listened to. I could have presented evidence but I was a bit shy of doing that – I could have shown evidence of bleeding and in retrospect, I should have and that would have woken them up. I am no longer with that doctor, as you can understand. Anyway, I had the colonoscopy examination, they did a biopsy and the biopsy result proved to be malignant. When I found out I had bowel cancer I had that cathartic experience of crying it out. Once I had done that and got over that stage I set my house in order and arranged a funeral plot. I've got a pre-paid funeral plan so the people left behind won't have to struggle - to go through funeral arrangements and all that. Consequently, I went to my lawyer and made my 'will'. I have a

funeral plot arranged at ... which is next to my partner's mother's grave. It kind of keeps everything together.

They then booked me in for a CT and MRI scan and based on that planned for chemo and radiation therapy down at Palmerston North. That treatment lasted for five and a half weeks. At the same time, I was getting worse and I already knew when I went to Palmerston North that they were going to have to operate afterwards and that was just preparation to shrink the tumour and to sterilize the area around it because they require two centimetres of clear cells. Those tests and preparation took me through to July 2012 and then I had to have the operation at the hospital. I was convinced that I had a 90 – 95% chance of survival if I went through those stages. The operation was for rectal cancer and they had to remove the anus and two centimetres around it so they could put in place a stoma bag. That was on the 23rd of August 2012.

My understanding from my interviews with the doctors is that if they had waited for another two weeks the tumour would have invaded other parts of my body to the point where it would have taken even more radical surgery and much more radiation. That was pretty-scary but I quickly adjusted to the colostomy bag. The stoma nurse was very good, very helpful. I also had my partner with me who's a nurse. She was with me for the whole time. We occupied our time doing normal things because radiation only takes about 20 minutes per day and the chemo wasn't by intravenous infusion— it was by tablet. I stayed at ... which is a very friendly environment. There were people there worse off than me – they were terminal – they had had multi stage treatments. I had friends phoning and texting me, I just got on with it. I already knew that it was going to happen and that's why when we came back to Taranaki I set my house in order. If I hadn't survived things were in place. I was scared but I realised that I just had to get over it and get on with it.

I have a mixed whānau, both Maori and Pākehā and they looked after me before, during and after my surgery. I had my sister-in-law, I had my partner, I had a very good friend here also. They stayed here and cleaned up the house and got things ready for me to come home. I came straight home into a family environment. I'm fairly-good at looking after myself and

I do have others who can help me but it was so great to have my partner with me, a family person with me, she was there every day. She understood what was happening to me.

As I look back and reflect on everything leading up to my operation I don't think I was personally in denial but I think the medical establishment in my case was as they didn't progress it as fast as they should have. I mean, a seven-month waiting list - when I told that to the people down in Palmerston North where I was having radiation they were surprised at the time it took to get into the system. Every stage took quite a long time. That is ambulance at the bottom of the cliff stuff and it was just in time as it turned out. Just as there is with the breast cancer campaign there needs to be far more emphasis on early detection. People, particularly men need to get over the embarrassment of going to a doctor for examinations and that includes for prostate cancer. They're very embarrassed at going for that but if for any reason you get bleeding from the bowel it needs to be investigated – it might be benign, it might be just a node, but you need to know. They need to do an investigation and take a biopsy and find out what it is. I don't know of any other way, beliefs and so on that it could have been detected in any other way apart from the symptoms and the biopsy. I don't know whether by good diet or by keeping yourself healthy that it could have been prevented – it just happens. It just seems to happen in my age group.

While I was waiting for chemo and radiation treatment I had a couple of bad bleeds and one of them was half an hour before I was to lead a process safety review meeting in my job. I had to clean myself up at work and get myself together and go and lead the meeting hoping that it wasn't going to happen again. After I had the operation I had to get used to having a colostomy bag and there was a couple of times when the carbon filter vent got blocked. You just need to take yourself away to a quiet corner and fix that. I also carry spare disposable bags with me in my purse so I'm not caught short. I wear clothing to disguise the lump and I tend to wear tops like a maternity top. There's also the embarrassment of the bag – it can burp and if someone hears that, I explain and say I'm sorry I've got a colostomy bag. I've got no control over the bowel peristalsis and venting

of the bag, it's totally involuntary. It won't affect you, it's all filtered and vented – it's just a noise. It hasn't inhibited me in any way and in fact two and a half months after I had the bowel cancer operation and I got the bag I travelled internationally.

The surgery for bowel cancer was very successful. I have now had another CT scan which showed there was no metastasis – that's where pieces break away and spread to other bodily organs. What you need to worry about is lymphoma. If they lodge in the lymph glands they start up another site. I've also had the CEA blood test (Crypto Embrionic Antigen). These are antigens produced in the presence of cancer cells that will be floating around in the blood. That was clear so I'm very pleased. I knew that that was going to be the case because I put on weight. I went back to what I call my 'birth weight', my pre-cancerous weight. The operation could have been terminal - I might not have survived it. I was down to 60 kilograms when I had that operation because during chemo and radiation you don't feel like eating much because of nausea from the chemo and radiation. There is a sort of synergistic effect between the two treatments.

I have now regained my 'birth weight'. The operation for me was a rebirth. My body was recovering and I pretty-well knew when I got that CEA blood test result that it would be clear but I wasn't certain. All the medical profession could guarantee me from their statistics was five years. That's as far as their statistics go but I met cancer survivors at the 'Walk for Life' cancer walk who have been survivors for 18 to 20 years out and they survived because they were detected early and the treatment was done in time. A lot of those were breast cancer victims. They had radical double mastectomies and one of the woman is now an executive in the Cancer Society here in ... So, the message is, find out what it is and get it done as fast as possible within the medical system and you can survive to your natural lifetime. I've got my weight back, I'm in heavy demand by the people I work for and everyone who sees me comments on how well I look because they saw me when I was very sick and I had to stop working. My perspective has gone out to longer range and so I now have at least a five-year viewpoint instead of a 'one day at a time' viewpoint. I am now making my arrangements to visit relations and do a bit of sightseeing and do a bit

of travelling. My family are very well looked after with the arrangements I've made but any spare discretionary income I've got I will travel with my partner overseas.

My advice to others about bowel cancer is that if something is going wrong do something about it – go to the doctor. You won't all have my experience of a slowness in diagnosis because I have a friend whose wife has breast cancer and she is deliberately having the treatment in Australia because they get on the job very much quicker – within weeks, they're onto it. They don't have the same waiting lists that we have here. I know it's a cliché but I know that every day is another one that I wouldn't have had if I hadn't taken the action to get something done about it. I was reluctant myself in the beginning to think that the bleeding could be something other than haemorrhoids – in fact I went along with my GP in the first place, thinking oh yes not a problem – if it gets really-bad they can burn it out or something. But no, it was worse and they took a biopsy sample which when analysed under the microscope proved to be malignant. You need to overcome your embarrassment, overcome whatever racial overtones there are. Overcome the attitude of being bullet proof it's not going to happen to me. Get regular tests and pretty much follow the plan, the pathway they set up for you, the treatment pathway – don't get in denial.

If you know your symptoms are bad and in need of further investigation and you're not happy with the diagnosis you've been given, particularly from your doctor, then you don't have to stick with your doctor for life. Be prepared to change and get a second opinion. I didn't change my GP until after the treatment and I'd had the surgery. That was when my doctor changed address and went to another medical practice. I took the opportunity to change to a more local one in ... I didn't feel that I was letting him down. I had that sort of thought that you have the same doctor for life as that's the way I was brought up. The reality is, you know your own body better than any doctor could possibly know - you know how you're feeling. I was getting so weak that I could barely get up the stairs and so my symptoms were rapidly getting worse. Every time I went to the doctor I must have put on an act or something. I wasn't trying to but you seem to try and put on your best. I just went along with the programme that the

health system has for cancer. It wasn't confirmed at that stage that I had cancer but once you're in the system and the biopsy results come out things do start to move faster.

I am now part of a much bigger whānau. I'm starting to realise how the beliefs and the reticence of people particularly Māori men can be counter-productive to their health. We need a similar programme to the breast cancer programme for Māori women encouraging their whānau to go and get tested. We need a similar system to encourage Māori men to overcome their reticence and go and get tested because this can sneak up on you very fast. There doesn't seem to be any rhyme or reason that you will suddenly get bowel cancer and for a long time there may not be growth symptoms – it's very easy to misinterpret it as a node or a bleeding haemorrhoid. You do need the colonoscopy and the biopsy and you need to overcome the embarrassment, it's done under anaesthetic – just do it for your family. The message is don't give up - because you leave a big hole behind if you've got a loving family who love you. Don't abandon this world too soon because they want you and you want them.

Interpreting Mere's Story – The Search for Meaning

Something was Wrong

I had a notion that something was wrong - the evidence was there for a long time but it wasn't interpreted as cancer... there was a little lump there but everyone thought they were hemorrhoids and then it started bleeding and it got worse. The doctor said that he didn't think I had cancer because I would have lost weight and would be feeling very ill. Well I hadn't and didn't - so those two criteria cannot be relied on. I wasn't very happy about it and it was getting worse throughout that time. (KP. 2014)

Mere had a notion that something was wrong – the evidence was there for a long time. She was worried but it was interpreted as hemorrhoids. The fact that her condition was becoming worse did not concur with her doctor's prognosis - he didn't think it was cancer because she had not lost weight and did not appear to be ill. Despite her doctor's prognosis her condition was getting worse.

Being with anxiety

It took seven months on the waiting list to have a colonoscopy examination at the hospital – that was February 2012. I was concerned that during that time it got worse and I twice told my GP that I didn't think

it was just bleeding haemorrhoids but something else. ...the reality is you know your own body better than any doctor could possibly know - you know how you're feeling. I was getting so weak that I could barely get up the stairs and so my symptoms were rapidly getting worse. I just went along with the programme that the health system has for cancer. (KP. 2014)

Mere went through a period of several months living in constant anxiety. Inaction by the health system only served to exacerbate the current problems Mere was experiencing – constant bleeding. Mere had no knowledge of bowel cancer but she had a notion that all was not well. Her symptoms throughout that period rapidly grew worse but still, she tolerated what the health system had to offer.

As I look back and reflect on everything leading up to my operation I don't think I was personally in denial but I think the medical establishment in my case was as they didn't progress it as fast as they should have. I mean, a seven-month waiting list...

Mere reflects on the time she had to wait for an operation. She interpreted the delay to have a colonoscopy as a form of denial by the medical establishment.

Being in Ignorance

My GP said two things which upset me: Firstly, he said "we can't advance people up on the waiting list, you'll have to wait your turn. There's a limited health budget and we've got insufficient resources to have everyone done at short notice." That is paraphrasing but that is virtually what he said. Secondly, he said that he didn't think I had cancer because I would have lost weight and would be feeling very ill... I wasn't very happy about it and it was getting worse throughout that time. I felt I wasn't being listened to. I am no longer with that doctor, as you can understand. (KP. 2014)

Pono is a principle of perception of truth by which we address tapu and mana. It is an ethical principle of action in that it qualifies how we manifest, address, enhance, sustain, and restore tapu; and how we exercise mana (Tate, 2010). The engagement process adopted by Mere's doctor had very little resemblance to what Tate proposed when he spoke of encounter that imparts some aspect of quality of being that is creative, productive, enhancing or empowering from one to another. Her doctor's focus was more about the capability of the health system to accommodate her and she simply had to wait until they were ready. She felt she wasn't being listened to and, consequently, lost all trust in her doctor and the health system. Tate says the source of all mana is tapu. When tapu is violated,

mana is impaired. Mere's was existing in diminished tapu and impaired mana. She no longer consults with that doctor.

Accepting the Challenge

When I found out I had bowel cancer I had that cathartic experience of crying it out. Once I had done that and got over that stage I started planning. I set my house in order. I already knew that it was going to happen and that's why when we came back to Taranaki I set my house in order. If I hadn't survived things were in place. I was scared but I realized that I just had to get over it and get on with it. (KP. 2014)

Mere did not dwell on being diagnosed with bowel cancer as she knew only too well what a diagnosis with bowel cancer meant. Existing in mauri moe and mauri oho were but brief episodes in her journey. Mere's optimism is reflected in her decision to accept the need to go with the decisions made by the medical staff – she set her house in order. She overcame behaviours which mirrored inhibitors to progress framed within the notion of mamae¹⁶⁰ and its negative elements of neglect, hurt, pain, anguish, and sorrow. Her focus was on moving forward and being well again. For her, this was a new beginning, a rebirth.

Being with Whānau

I have a mixed whānau, both Māori and Pākehā and they looked after me before, during and after my surgery. I had my sister-in-law, I had my partner, I had a very good friend here also. They stayed here and cleaned up the house and got things ready for me to come home. I came straight home into a family environment. It was so great to have my partner with me, a family person with me, she was there every day. She understood what was happening to me. (KP. 2014)

Mere was thankful that she has a family who understood what she had gone through. She speaks affectionately about the effect her whānau had in assisting her to recover and was thankful that she has a family who understood what she was going through. Her family expressed their love and affection in the only way they knew how. Aroha is about compassion, sacrifice and generosity. Tate (2010) stated aroha is communion in relationship between tangata and tangata that can only be achieved through love and affection. Mere's whānau focussed on her and her future wellbeing. It was their way of expressing their concern for her through the right and gratuitous exercise of mana. Tate asserts that aroha is communion in relationship between tangata and tangata that can only be

¹⁶⁰ Hurtfulness

achieved through the principles of pono (perceptive) and tika, (right action). The process maintains actions that enhance and restore relationships between tangata and tangata.

Being with a Stoma

After I had the operation I had to get used to having a colostomy bag and there was a couple of times when the carbon filter vent got blocked. You must take yourself away to a quiet corner and fix that. I wear clothing to disguise the lump and I tend to wear tops like a maternity top. There's also the embarrassment of the bag – it can burp and if someone hears that I must explain and say, I'm sorry I've got a colostomy bag. (KP. 2014)

Mere had similar experiences of having to cope with a stoma as some of the other participants who raised the issue of whakamā. Mere was always faced with the fear of involuntary noises that comes from the stoma. She uses the word noises but the real embarrassment is about involuntary passing of wind. There was nothing she could do about that except perhaps stay cooped up in the house or away from others as much as possible and for her, that was not an option either. A study by Cotrim and Pereira (2008) provides us with insights of people who have no option but to live the rest of their lives with a stoma. Study findings showed that the quality of life of a colorectal cancer patient and his/her family is deeply modified when faced with having to survive with a stoma because of physical and psychological changes induced by it. The aim of the study was to identify and assess the impact of colorectal cancer on patients and their families. In terms of quality of life, those patients who had a stoma reported a lower overall quality of life, lower body image, poorer health related quality of life, and poor social activity when compared with colorectal cancer patients who had no stoma. The stoma patients also had significantly higher depression and anxiety than non-stoma patients (Cotrim & Pereira, 2008).

The Irony of Invasive Therapies

They booked me in for a CT and MRI scan and based on that planned for chemo and radiation therapy. That treatment lasted for five and a half weeks. At the same time, I was getting worse and I already knew they were going to have to operate afterwards and that was just preparation to shrink the tumour. The operation could have been terminal - I might not have survived it. I was down to 60 kilograms when I had that operation because during chemo and radiation you don't feel like eating much because of nausea from the chemo and radiation. There is a sort of synergistic effect between the two treatments. (KP. 2014)

Mere reflects on having radiation and chemotherapy treatment over a five-week period. She describes the treatments as nauseas. She lost weight through loss of appetite - she was feeling worse. Despite the downside she describes the two treatments as having a synergistic effect on her eventual recovery. In a second interview, Mere intimated that if it was not necessary she would have refused it because of the ongoing after effects. She said she felt nauseous for days at a time and some days were worse than others. Despite the challenges she experienced with the invasive therapies, she is surviving well.

Being in Mauri Ora

The surgery for bowel cancer was very successful. I have now had another CT scan which showed there was no metastasis. I went back to what I call my 'birth weight', my pre-cancerous weight. I have now regained my 'birth weight'. The operation for me was a rebirth. I've got my weight back, I'm in heavy demand by the people I work for and everyone who sees me comments on how well I look because they saw me when I was very sick and I had to stop working. My perspective has gone out to longer range and so I now have at least a five-year viewpoint instead of a 'one day at a time' viewpoint. I am now planning to visit relations and do a bit of sightseeing and do a bit of travelling. (KP. 2014)

Mere has experienced a journey in which the process of whanaungatanga has been fundamental to her recovery despite all the challenges she had faced in the past. Her recovery has been interpreted here as an outcome where the proper exercise of mana within her whānau has enabled her to navigate through a challenging journey that has culminated in mauri ora. Tate (2010) postulated that the tapu of being in relationship with primary beings find success through relationships that enhance, sustain, restore, and empower those in relationship. As I near the end of writing this thesis I have taken the time to speak with Mere. She is currently running her own business and is experiencing a quality of life where she considers she is surviving in restored tapu as the state of being – in mauri ora.

Tama's Story

Whakapapa of Tama's Story

The first signs for Tama that something was wrong with his health were episodes of unusual pain. A series of visits to his doctor in 2013 yielded nothing. The doctor eventually said he had a viral infection but despite the doctor's prognosis,

the pain remained. Tama would not to share his predicament with his family and chose instead to lock himself away in his room where he remained isolated. In 2014, he decided to change his doctor. He was then diagnosed with bowel cancer.

This is Tama's story:

I became unwell around about October last year 2013 and I would go to the doctor practically every two weeks to see what was going on and I got nothing. It was just a virus according to those people in the health profession. I ended up having a CT scan and they told me it was due to something... which they said was the main problem. I changed my GP in January 2014 and everything went from there – that's when I was diagnosed. I told one of my cousins when I saw her in early December 2013 and she said what do you think is your problem and I said I think it may be bowel cancer and it was confirmed when I had the colonoscopy done in the middle of January this year 2014. It took about a month before I was told I had bowel cancer. Fortunately for me they caught it early and could remove it.

I went into surgery and had it removed in February 2014. The doctor said that he was 99% sure that he got it all. He wouldn't give it 100% guarantee though. Since then I have been back for another colonoscopy and it is all clear. When I had my first colonoscopy they only went to where they found the cancer which was at the lower end of the colon. They didn't go any further than that. That was followed up with six weeks of radiation. I saw the medical oncologist about chemotherapy and he told me that I didn't require chemotherapy but he wanted to know why I agreed to have radiation. They said I had radiation because it was a centimetre away from the abdomen wall and they wanted to radiate it there so it wouldn't turn into a bigger thing. So, I had six weeks of radiation. I was quite happy when the medical oncologist said that I didn't need to have chemotherapy because I didn't want to have both. I'm surprised I'm back at work but they caught it early. They said that they're happy they got it all. One thing that I did forget was to ask the surgeon if I automatically go on the waiting list for a colonoscopy, every two years or so. I haven't yet been able to ask

him that question so that is one question that I want answered because I think there should be an automatic recall through the health system.

I was a bit hesitant when I had my last colonoscopy because I didn't want them to come back to me and say there's some more there. I find also with our Māori people that they are a bit whakama about doing it because it's something that they think is not right, to have something go up your bottom. I don't know why but my view is that 90% of our male population don't want to do it because of the fact they must go up your behind. I have a cousin that won't do it because of it. He just says it's wrong. As a whānau we are trying to twist his arm and a lot of us have told him what it's like. They stay away from the procedure because they will be able to feel it. Take me for example, I didn't, I was zonked. With the anaesthetic that they gave me, I woke up in recovery. It had been and done and I didn't feel a thing. Everybody reacts differently to those sorts of procedures. I wasn't really whakama, I just wanted something done. I didn't care what my dignity was like, I just wanted to know but I know there are a lot of Maori out there that are Whakama. It is very big.

You see, until I was diagnosed I carried the burden myself. I didn't let the family in until I was diagnosed. And then, suddenly, I was flooded with support. I probably went into more of a depression state before I was diagnosed than after. You know because I didn't know what was going on with me I went into depression. I would go to work, come home and I would just lock myself in my room. I wouldn't talk to anybody about anything. I'd just shut down because I didn't know what was happening with my body. It happened to me couple of times. I brought it to the doctor's attention and he wanted to prescribe anti-depressants but I refused them because I was on them before for other reasons and they just made me worse. I said to him I didn't need them because I wasn't suicidal at the time and now that I have the family involved I know that I don't need to have drugs. I guess just the start of it was not knowing how to deal with it at the beginning.

My whānau was a huge factor in bringing me out of depression. If I didn't have the support of my whānau I probably would have thought about suicide. I went to my aunty first because she had been through it. I talked

to her and she spoke to the rest of the whānau for me. She had it, she had gone through it and once I handed it over to her I felt more at ease. When I was told that I was going into surgery and that was a week after I had spoken to the surgeon, I gave him a good 10 minutes to sell the surgery he was going to perform on me knowing what had happened to my uncle¹⁶¹. We lost him in December through the same thing and he had just come out of surgery. He (the doctor) had to sell what he was going to do, what his success rate was and all that before I even agreed to even look at having the surgery. After he explained how he was going to do it and what was involved I agreed and asked again when it was going to happen. He told me it would happen the following Tuesday so I had a week to prepare myself. After that appointment, I told my family that I agreed to have surgery and I wanted them all there. They were all there but one. I knew that one of my sisters wouldn't be there and that was OK. I felt sorry for my whānau because when I was told I was going in for surgery they said it would take three hours but it ended up taking five. They had to put up with a certain amount of anxiety because of the time it took. They thought it was taking too long. I went in at 8.30 am and I didn't get out until 1.30 pm in the afternoon. I was off work for seven months throughout the whole period.

I've been back at work since June this year 2014 and everything is going fine. Some of the people I support in my work have had surgery as well and I think how I need to go about that. They don't necessarily have bowel cancer but surgery because their bowel has been blocked. I've probably been four times for check-ups since the operation. When I finished the radiation treatment I came home sick so I was a little bit concerned about my immune system at that stage. I was picking up every little thing and I was at work and I didn't want to spread it.

I've been back to the hospital four times to have a check-up since the operation. I have been back twice to see the surgeon. After the second visit, he told me I didn't need to go back and see him again for another three months. Now, I just go to work, come home and basically blob out.

¹⁶¹ Tama's uncle never recovered and died after surgery for bowel cancer

Before I had surgery, I stayed at home, I didn't really go out that much. But after surgery, not a problem. I'm a socialite. Whenever there is something on I like to be in the middle of it.

I feel I have been lucky. The medical oncologist told me that when you are diagnosed too late then there is a possibility it will spread to other parts of your body. That's why I feel people need to be tested at a young age like in their mid-20s. I think our people need to test early for bowel cancer. I would say as early as 18 years of age. I don't see the point with older Māori being tested because to put it bluntly, it's too late. As far as I am concerned it's far too late and there is usually nothing they can do.

Interpreting Tama's Story – The Search for Meaning

Being in Anxiety

I became unwell around about October last year 2013 and I would go to the doctor practically every two weeks to see what was going on and I got nothing. It was just a virus according, to those people in the health profession. (TP. 2014)

Tama became unwell and had a feeling that not all was well with his health. Several visits to his doctor did not change that. His doctor said he was suffering from a virus.

Manifestation of Withdrawal – Carrying the Burden

You know, until I was diagnosed I carried the burden myself. I didn't let the family in until I was diagnosed. I probably went into more of a depression state before I was diagnosed than after. Because I didn't know what was going on with me I went into depression. I would go to work. I would come home and I would just lock myself in my room. I wouldn't talk to anybody about anything. I'd just shut down because I didn't know what was happening with my body. I changed my GP in January 2014 and everything went from there – that's when I was diagnosed. (TP. 2014)

Tama struggled to come to terms with what was happening to him and chose to remain silent. He carried the burden alone. His visits to his doctor were not helpful. Not knowing what was happening to him sent him to a dark place. He was in effect in a state of depression and simply locked himself away in his room. He refused to speak with anyone, including his family. Tama knew there was

something wrong and decided to change his doctor. Soon after the change, he was diagnosed with bowel cancer.

Being with Whānau

My whānau was a huge factor in bringing me out of depression. If I didn't have the support of my whānau. I probably would have thought about suicide. I went to my aunty first because she had been through it. I talked to her and she spoke to the rest of the whānau for me. She had it, she had gone through it and once I handed it over to her I felt more at ease. Suddenly, I was flooded with support. Before I had surgery, I stayed at home, I didn't really go out that much. But after surgery, not a problem. (TP. 2014)

Tama speaks affectionately about the effect his whānau had on his recovery. When his whānau became aware of his predicament they came to his assistance together to express their aroha for him. Tate (2010) asserts that aroha is communion in relationship between tangata and tangata that can only be achieved through the principles of pono (perceptive) and tika, (right action). The process governs actions that enhance relationships between tangata and tangata. Tama's whānau focussed on him and his wellbeing. It was their way of expressing their aroha for him through the right and gratuitous exercise of mana.

Being in Mauri Ora

I was off work for seven months throughout the whole period. I'm surprised I'm back at work but they caught it early. They said that they're happy they got it all. I've been back at work since June this year and everything is going fine. (TP. 2014)

Tama has returned to the workforce. He has experienced a journey in which the process of whanaungatanga has been fundamental to his recovery despite contemplating the possibility of suicide when he was suffering from episodes of depression. His recovery has been interpreted here as an outcome where the proper exercise of mana within his whānau has enabled him to navigate through a challenging journey that has culminated in mauri ora.

You know I have changed. I was a bit hesitant when I first heard about bowel cancer but now I've been through it I just want more people to go out and do the test, get it done. I would encourage our people not to be whakama and just do something about it. Life is short as it is - just get out and get it done. I feel I have been lucky. The medical oncologist told me that when you are diagnosed too late then there is a possibility it will spread to other parts of your body. That's why I feel people need to be tested at a young age like in their mid-20s. I think our people need to test

early for bowel cancer. I would say as early as 18 years of age. I don't see the point with older Māori being tested because to put it bluntly, it's too late. As far as I am concerned it's far too late and there is usually nothing they can do. (TP. 2014)

Tama has experienced the trauma of being diagnosed with bowel cancer and he now finds himself in a space where he is feeling well and optimistic about his future. His enthusiasm is evident as he now encourages others to do the right thing by visiting their doctor and taking the test. He has progressed through a continuum where his patterns of wellness have blended gradually and seamlessly to the point where his own intrinsic tapu has been restored. He posits his thoughts on what should be done in the future for Māori and the need to test for bowel cancer from an early age. Tama continues to live his life in restored tapu as the state of being – in mauri ora.

Appendix C: Signs and symptoms of bowel cancer

Bowel cancer may not show any symptoms in the early stages. The following signs are cause for suspicion:

- Change in bowel habits: diarrhea or constipation or change in the consistency of stool;
- Narrow pencil-thin stools;
- Rectal bleed or blood in stool;
- Persistent abdominal discomfort such as gas, pain, or cramps;
- Feeling bowel does not empty completely;
- Unexplained weight loss;
- Constant fatigue.

Screening tests for bowel cancer

The following screening tests are the most common ways of testing for bowel cancer:

- Fecal Occult Blood Test [FOBT] establishes if blood which cannot be detected by ordinary sight is present in the stool.
- Sigmoidoscopy – a sigmoidoscopy is a long flexible tube with a tiny video camera at the top that is inserted into the rectum to allow the doctor to view the lower part of the colon, the rectum, the descending colon, and the sigmoid colon.
- Colonoscopy – a colonoscope is a long flexible tube with a tiny video camera at the tip that is inserted into the rectum to allow the doctor to view the inside of the entire colon.

Staging bowel cancer

When a diagnosis of bowel cancer has been established the stages of the development of the cancer are identified as follows:

- Stage 1 or Duke's A – the cancer has grown into the inner wall of the colon or rectum;
- Stage 2 or Duke's B – the tumour extends more deeply into or through the wall of the colon or rectum. It may have invaded nearby tissue but cancer cells have not yet spread to the lymph nodes;

- Stage 3 or Duke's C – the cancer has spread to nearby lymph nodes but not to other parts of the body;
- Stage 4 or Duke's D – the cancer has spread to other parts of the body such as the liver or lungs.

Treating bowel cancer

- Surgery – Is the most common treatment. It is used to remove polyps and tumours and to check for the spread of the disease;
- Chemotherapy – drug therapy that prevents the spread of cancer cells;
- Radiation therapy – high energy rays to kill cancer cells.

The lymph nodes and cancer

What is the lymph system?

Our bodies have a network of lymph vessels and lymph nodes. This network is a part of the body's immune system. It collects fluid, waste material, and other things (like viruses and bacteria) that are in the body tissues, outside the bloodstream. Lymph vessels are a lot like the veins that collect and carry blood through the body. But instead of carrying blood, these vessels carry the clear watery fluid called lymph (American Cancer Society, 2015).

How does cancer spread to lymph nodes?

Cancer can spread from where it started (the primary site) to other parts of the body. When cancer cells break away from a tumour, they can travel to other areas of the body through either the bloodstream or the lymph system. Cancer cells can travel through the bloodstream to reach distant organs. If they travel through the lymph system, the cancer cells may end up in lymph nodes. Either way, most of the escaped cancer cells die or are killed before they can start growing somewhere else. But one or two might settle in a new area, begin to grow, and form new tumours. This spread of cancer to a new part of the body is called metastasis. For cancer cells to spread to new parts of the body, they must go through several changes. They first break away from the original tumour and then attach to the outside wall of a lymph vessel or blood vessel. Then they must move through the vessel wall to flow with the blood or lymph to a new organ or lymph node (American Cancer Society, 2015).

Appendix D: Research Documents

Ethics Approval



17 May 2013e

«Applicant_First_Name» «Applicant_Surname»

Faculty of «Faculty»

Dear «Applicant_First_Name»

Re: «**Application_No**» «**Project_Title**»

Thank you for submitting your application for ethical review. I am pleased to confirm that the Auckland University of Technology Ethics Committee (AUTECS) has approved your ethics application for three years until «Expiry_Date».

«Additional_Comment»

As part of the ethics approval process, you are required to submit the following to AUTECS:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on «Expiry_Date»;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on «Expiry_Date» or on completion of the project;

It is a condition of approval that AUTECH is notified of any adverse events or if the research does not commence. AUTECH approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTECH grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply within their country.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,



Madeline Banda

Acting Executive Secretary

Auckland University of Technology Ethics Committee

Cc: «Student_Name» «Student_Email_Address»

Participant Information Sheet



PROJECT TITLE

The Meaning of Living with Bowel Cancer: A Study Informed by
Kaupapa Māori Interpretation of the Experiences of Māori

INTRODUCTION

Ko Kurahaupo te waka

ko Taranaki te maunga,

Ko Taranaki te iwi

ko Matanehunehu te awa

Ko Puniho te marae

Ko Nga Mahanga a Tairi te hapū

Ko Tom Ruakere taku ingoa

Tena koe,

My name is Tom Ruakere and I am currently doing research on bowel cancer at AUT University. The aim of the study is to understand the experiences of Māori whanau who experience bowel cancer. Bowel cancer is something that most Māori have very little or even no knowledge of. By doing such a study I hope to gain a deeper understanding of Māori experiences of surviving with bowel cancer so that any new insights gained can be used to develop strategies to minimize the incidence of bowel cancer among Māori. I assert that sub-optimal services by health providers and limited knowledge about bowel cancer by Māori creates major barriers to improving health outcomes pertaining to bowel cancer for Māori.

WHAT IS THE PURPOSE OF THIS RESEARCH?

The reason I have chosen to do this study is to understand the experiences of Māori who are living their lives as survivors having bowel cancer. Up to 13 Māori

will be recruited to take part in this study. Although there is a plethora of international research on the experiences of bowel cancer, there is no known study on Māori who are living their lives as survivors having bowel cancer. It is hoped this study will help in the early detection and prevention of bowel cancer for Māori by improving awareness of and the need to take the test early for bowel cancer.

YOUR PARTICIPATION IN THIS RESEARCH?

Your invitation to participate in this study will come as the result of whanau and marae hui, health promotion events, by word of mouth and through advertisements placed in the local newspapers.

Your participation is entirely voluntary. You are free to withdraw from the study at any time if you so wish and you can request the removal of your interview data up until three weeks after receiving the transcribed stories from your interview. The primary language of communication for this study will be English.

WHAT WILL HAPPEN IN THIS RESEARCH?

Tom Ruakere, the primary researcher will go over the study prior to your scheduled interview. This will give you time to consider whether you wish to proceed as a participant in the study. You will be asked for written consent to conduct the interview which will take place at a time and location of your choosing. Your consent to audio-tape your interview will also be sought at that time so that your feedback can be accurately recorded and transcribed. The researcher may contact you to conduct a second interview. This will only happen in cases where data in the initial interview needs further clarification. Your interview will take approximately 60 minutes.

WHAT ARE THE DISCOMFORTS AND RISKS?

It is anticipated that talking of your experiences as a survivor having bowel cancer may be distressing for you as the interview may remind you of the threat that bowel cancer presents. You can stop the interview at any time if you feel the need to. The researcher is aware of these discomforts and risks and will ensure that the study will be conducted in a way that respects the wishes of participants.

If you experience significant discomfort, embarrassment or incapacity, you can contact CancerChatNZ (0800 226 237) and receive free counsel from the Duty Nurse. Cancer ChatNZ is a free service available to all New Zealanders. You also have the option to

contact 'Tu Tama Wahine O Taranaki' Counselling Services if you need to talk to someone. This is also a free counselling service and the contact number is: (06) 758 5795.

HOW WILL THIS RESEARCH BENEFIT MĀORI?

This study will benefit Māori by creating awareness of the need to test early for bowel cancer. Bowel cancer is a disease that can develop over time without symptoms. Tom Ruakere the primary researcher will also benefit from this study as it is part of a Professional Doctorate in Health Science at AUT University.

HOW WILL YOUR PRIVACY BE PROTECTED?

Privacy issues relating to confidentiality will remain with the primary researcher, Tom Ruakere. In terms of interview transcripts, the primary researcher will provide pseudonyms for all participants involved in the study. Your feedback therefore cannot be identified at any stage of the research process. If the information you provide is included in a report or published, this will be done in a way that does not identify you as its source.

WHAT ARE THE COSTS OF PARTICIPATING IN THIS RESEARCH?

The impact on you financially will be minimal as there will be no requirement for you to travel. However, to alleviate any financial burden you may experience and to acknowledge your time and contribution, you will receive a \$50.00 PAK-N-SAVE voucher.

WILL I RECEIVE FEEDBACK ON THE RESULTS OF THIS RESEARCH?

An important part of the study will be the acknowledgment of participants who agree to take part in the study. Each participant will receive a summary of the research outcomes the study. Participants will also be personally invited to presentations where the research findings will be presented to all stakeholders including whānau, hapū and iwi.

WHAT DO I DO IF I HAVE CONCERNS ABOUT THIS RESEARCH?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor: Associate Professor Denise Wilson Primary Supervisor.

Phone: +64 9 921 9999 ext. 7392

Email address: dlwilson@aut.ac.nz

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

**WHOM DO I CONTACT FOR FURTHER INFORMATION ABOUT THIS
RESEARCH?**

Researcher Contact Details:

Tom Ruakere: Primary Researcher

Phone: 027 4877136

Email: tomruakere@hotmail.com

Project Supervisor Contact Details:

Associate Professor Denise Wilson: Primary Supervisor

Phone: +64 9 921 9999 ext. 7392

Email: dlwilson@aut.ac.nz

Approved by the Auckland University of Technology Ethics Committee on 17
May 2013 AUTECH Reference number 18/36.

Consent Form



Project title: The Meaning of Living with Bowel Cancer for Māori in Taranaki.

Project Supervisor: Associate Professor Denise Wilson

Researcher: Tom Ruakere

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated dd mm yy;
- ☐ I have had an opportunity to ask questions and to have them answered;
- ☐ I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed;
- ☐ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way;
- ☐ If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed;
- ☐ I agree to take part in this research;
- ☐ I wish to receive a copy of the report from the research (please tick one):
Yes ☐ No ☐

Signature

Name (printed)

Participants' contact details (if appropriate)

.....

Date.....

Approved by the Auckland University of Technology Ethics Committee on 17 May 2013 AUTEK Reference number 18/36



Confidentiality Agreement

Project title: The Meaning of Living with Bowel Cancer for Māori in Taranaki.

Project Supervisor: Associate Professor Denise Wilson

Researcher: Tom Ruakere

- ☐ I understand that all the material I will be asked to transcribe is confidential;
- ☐ I understand that the contents of the tapes or recordings can only be discussed with the researchers;
- ☐ I will not keep any copies of the transcripts nor allow third parties access to them.

Signature

.....

Name (print)

.....

Transcriber's Contact Details (if appropriate):

.....

Date:

Project Supervisor's Contact Details (if appropriate):

.....

Approved by the Auckland University of Technology Ethics Committee on 17 May 2013 AUTEK Reference number 13/86

Research Questions/Prompts

<p>Question 1 - Did you think you would ever get bowel cancer?</p> <ul style="list-style-type: none"> • He/she may talk about life as a younger person and how their knowledge has changed/never changed about health over the years • He/she may talk about cancer in general or more specifically, bowel cancer
<p>Question 2 - Tell me about the time when you first thought something might be wrong with your bowel?</p> <ul style="list-style-type: none"> • He/she may talk about life as a younger person and how their knowledge has changed/never changed about health over the years • He/she may talk about cancer in general or more specifically, bowel cancer • Physical wellbeing; • Emotional wellbeing • Describe an incident or occasion
<p>Question 3 – Did you talk to someone in your whanau about it?</p> <ul style="list-style-type: none"> • If answer is yes – then ask him/her to talk about that • If no - then get him/her to say why they didn't want to talk about it
<p>Question 4 – What about the doctor – did you talk to a doctor or other health professionals about what you were experiencing?</p> <ul style="list-style-type: none"> • If yes – describe the visit e.g. did the doctor explain fully what was happening to him/her? • If no – why they didn't want to see a doctor • Did he/she understand what the doctor was saying? • Did he/she take support
<p>Question 5 – Tell me about the time when you were diagnosed with bowel cancer?</p> <ul style="list-style-type: none"> • Feelings; mood; emotions • What stood out most of all • Describe an incident/occasion
<p>Question 6 - What happened after you were diagnosed?</p> <ul style="list-style-type: none"> • How he/she was feeling physically • How he/she was feeling emotionally • What did he/she do? • What did the Health Provider do? • Preparing for a major operation
<p>Question 7 – What can you tell me about colonoscopy?</p> <ul style="list-style-type: none"> • Did it happen immediately? • Did it happen later e.g. weeks, months later? • Did it happen at all?
<p>Question 8 – You had major surgery – tell me about that</p> <ul style="list-style-type: none"> • Did it happen immediately/later; • How he/she was feeling physically • How he/she was feeling emotionally

Describe an incident/occasion
<p>Question 9 – Was any other form of therapy offered to you? For example, chemotherapy and/or radiotherapy treatment?</p> <ul style="list-style-type: none"> • How important was that extra therapy for you? • Did he/she seek any other form of treatment? • Tell me about alternative treatments if any?
<p>Question 10 – Tell me about going home after surgery?</p> <ul style="list-style-type: none"> • How was he/she was feeling emotionally? • Were things the same as before - different? • If different - describe how things were different • Describe whanau dynamics • What about managing at home?
<p>Question 11 – Tell me about how you see the future as a survivor with bowel cancer?</p> <ul style="list-style-type: none"> • Lived life • Being prepared • Acceptance • Coping
<p>Question 12 - Based on your overall experiences of having bowel cancer, what would be your message to other Māori men and women?</p>

Appendix E: Bowel Cancer Advertisement

Are you a survivor of bowel cancer?

**Sharing your experiences can make a
difference for our people**

**You are invited to participate in a study on
what it means for Māori to be a survivor
of bowel cancer.**

*If you would like to tell your story about what
living with bowel cancer means for you,
please contact me by text, phone or email,
Tom Ruakere (principal investigator):*

Phone: 027 487 7136

Email: tomruakere@hotmail.com

**RESEARCHING BOWEL
CANCER**

AUT
UNIVERSITY
THE AUTOMATIC RECORD OF THE AUTOMATIC RECORD

Recruitment Flyer



**Are you a
survivor of
bowel cancer?**

**Sharing your experiences can make a
difference for our people**

You are invited to participate in a study on what it means for Māori to be a survivor of bowel cancer.

If you would like to tell your story about what bowel cancer means for you, please contact me by text, phone or email, Tom Ruakere (principal investigator):

Phone: 027 487 7136

Email: tomruakere@hotmail.com

Appendix F: The Inflatable Colon – To See is to Believe

The inflatable colon is 2.4 metres high, 7 x 7metres area to exhibit (approx.) and has been constructed as a walkthrough educational replica of the Colon. The internal imagery consists of translatable signage boards for 9 common diseases of the Colon: pre-Cancerous Polyps; Colorectal Cancer (Malignant Tumour); Mild Colitis; Healthy Tissue; Advanced Polyps; Severe Colitis; Diverticulitis and Crohns Disease.



Figure 1F: The Inflate-able Colon – A young family being educated early about bowel cancer

Source: <https://www.growingbolder.com/step-inside-the-inflatable-colon-0-131888/>



Figure 2F: The Inflate-able Colon – Professional staff on hand to guide and educate people about bowel cancer

Source: <https://www.growingbolder.com/step-inside-the-inflatable-colon-0-131888/>



Figure 3F– All ethnicities benefit from the Inflate-able Colon

Source: <https://www.growingbolder.com/step-inside-the-inflatable-colon-0-131888/>

Appendix G: Mapping the Boundaries of Tapu that Protect Life

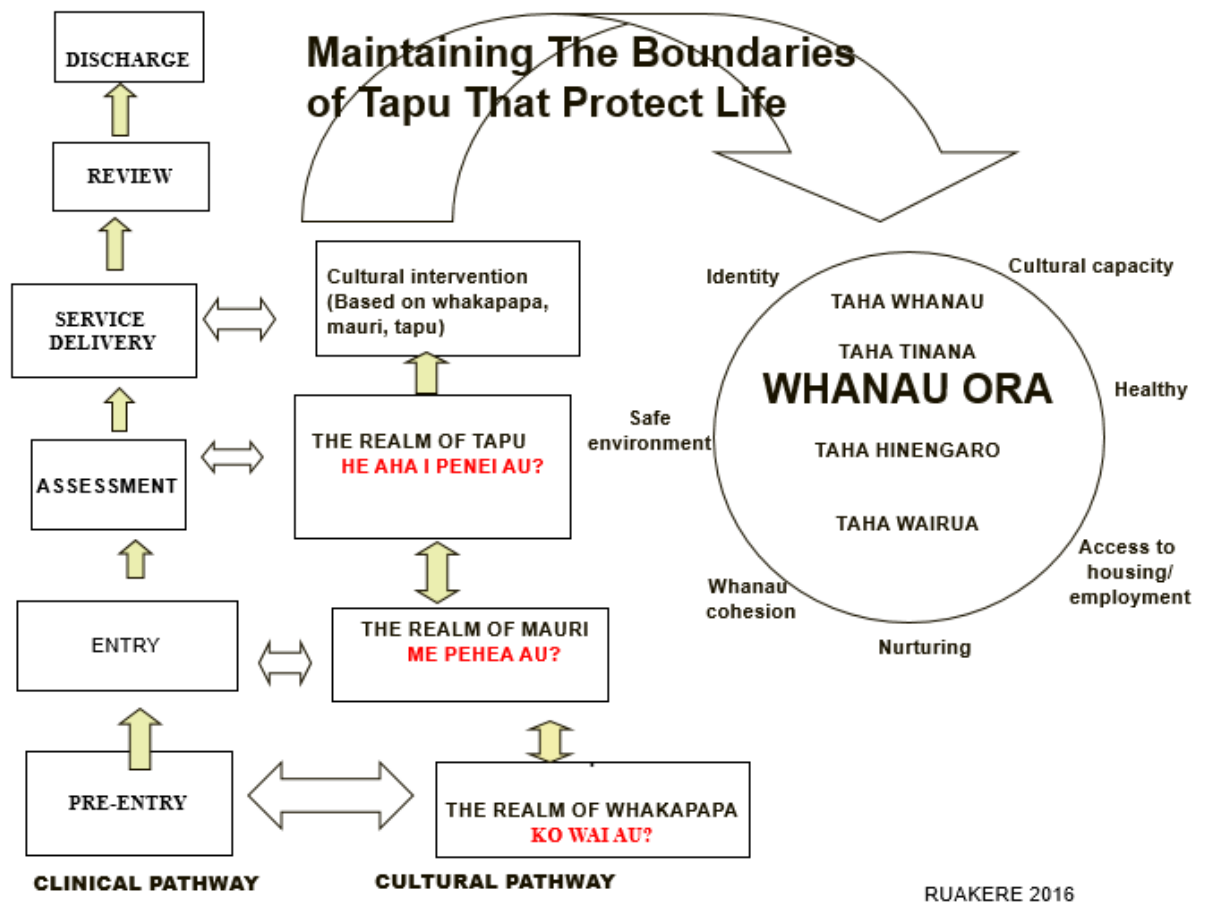
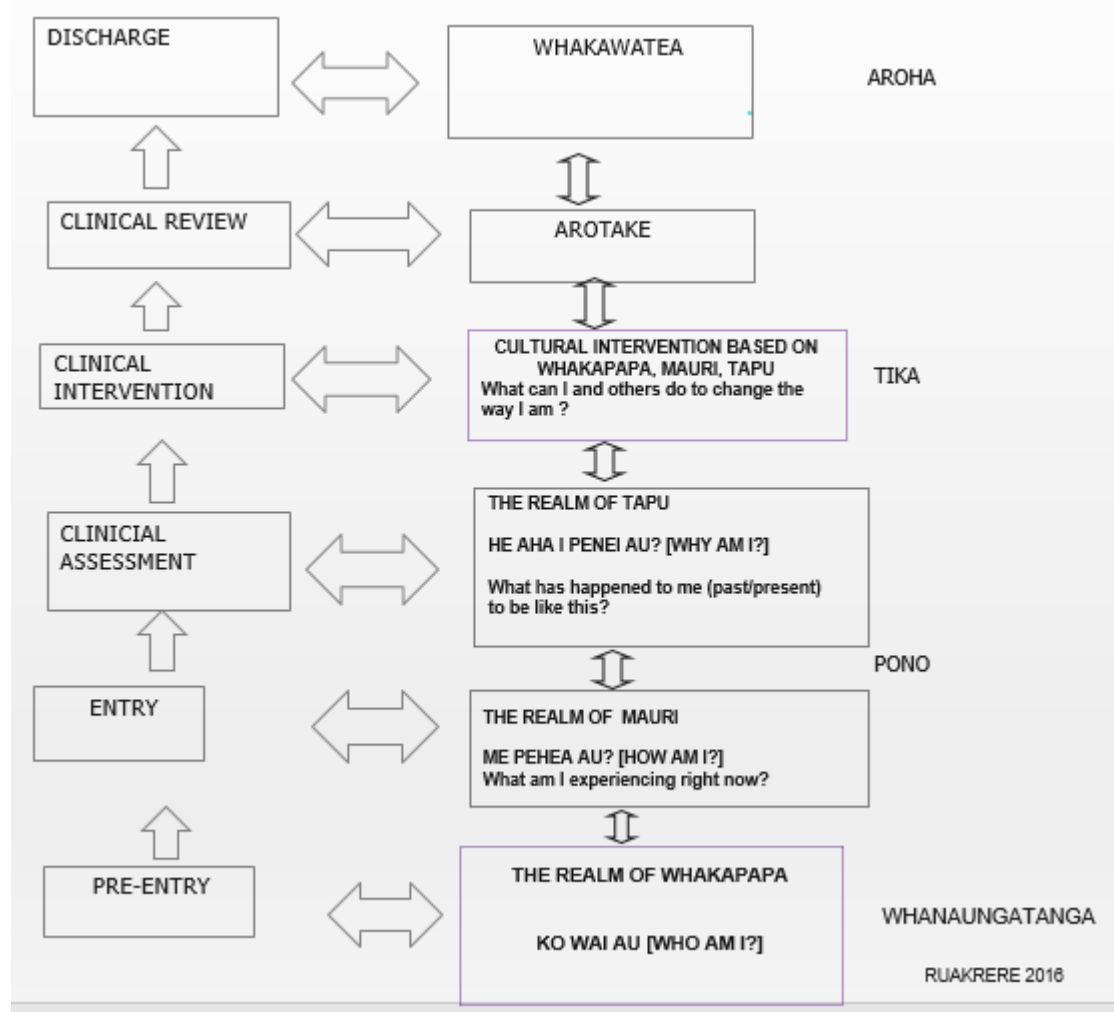


Figure G1

Ideas for Kaupapa Māori Action Research (G1 & G2) to devise an integrated cultural/clinical pathway in healthcare for Māori who present to oncology with a prognosis of bowel cancer

Figure G2



Appendix H: Registration and Mortality Bowel Cancer Rates – Māori/Non-Māori

Female cancer registration rates, 25+ years, Māori and non-Māori, 2010–12

Māori	Non-Māori	Rate ratios (Māori compared to non-Māori)
35.8	44.7	0.8

Female cancer mortality rates, 25+ years, Māori and non-Māori, 2010–12

Māori	Non-Māori	Rate ratios (Māori compared to non-Māori)
12.5	14.8	0.84

Colorectal registration rates were significantly lower for Māori females than for non-Māori females.

However, the ratios for both registration and mortality were constant at 0.8

Male cancer registration rates, 25+ years, Māori and non-Māori, 2010–12

Māori	Non-Māori	Rate ratios (Māori compared to non-Māori)
44.5	55.7	0.8

Male cancer mortality rates, 25+ years, Māori and non-Māori, 2010–12

Māori	Non-Māori	Rate ratios (Māori compared to non-Māori)
19.8	18.7	1.06

Age standardised rate per 100,000

Colorectal registration rates were significantly lower for Māori males than for non-Māori males.

However, there was an increase in the rate of colorectal cancer mortality between Māori and non-Māori males

Source: Tatau Kahukura Māori Health Chart Book 2015