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**He kupenga mate pukupuku uu mo ngā wāhine Māori.**  
**Te Whare Tapa Whā: A multidimensional exploration of  
the impacts of breast cancer among wāhine Māori  
survivors.**

A thesis  
presented in partial fulfilment of the requirements for a  
Master of Philosophy  
in  
Māori Studies

At Massey University, Palmerston North,  
New Zealand.

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# ABSTRACT

Verse 1:

*Breast Cancer  
The illness that threatens the lives  
of mothers, daughters, sisters and wives  
Why me, we ask, oh why me?  
Perhaps the answer lies deep within the family*

A breast cancer diagnosis for wāhine Māori (Māori women) impacts on the whole whānau (extended family), hapū (sub-tribe) and iwi (tribe). This thesis captures the experiences of seven wāhine Māori who went through the diagnosis of, and treatment for, breast cancer. A personal experience of breast cancer provided the impetus for choosing this topic, enriched by the opportunity to speak with other women and reflect on their own experiences. The qualitative method of interviewing and sharing experiences between the researcher and the participants was exceptionally enlightening for all concerned. This reciprocity and exchanging of experiences produced similar as well as unique, individual stories.

Surrounding the design, data gathering and analysis were kaupapa Māori (customs, traditions and philosophies of being Māori) concepts and research methods to help ensure the cultural safety of all participants, as well as garner a deeper understanding of the information gathered from a Māori perspective. Whakapapa (genealogy) played a significant role in all the interviews. For various reasons, tūpuna (ancestors) remained a source of strength as well as a source of vulnerability when it came to acknowledging their contribution to the wellness of the participants. The women felt reminded to search for strength from their tūpuna to help with their healing, yet were also mindful of the reasons

they were diagnosed with breast cancer in the first instance, through whānau history and genetic makeup.

This multidimensional exploration of how breast cancer impacts on the well-being of Māori women uses Te Whare Tapa Whā (Durie, 1994) to capture the aspects of well-being in a Māori context. The objective of this research therefore is to investigate the experiences of Māori women who have travelled the journey of breast cancer. Their stories will provide an increased understanding of the impacts on their physical, spiritual and mental and emotional wellness, including the impacts on whānau structures and relationships.

## ACKNOWLEDGEMENTS

Verse 2:

*Family histories are full of hidden treasures  
Health, education and wellbeing measures  
Things that help us to understand  
Help us to know where to get a hand.*

This work has been a great motivation for me and with the support of whānau, friends, Māori health provider colleagues, academic advisors and even strangers, I was able to bring a little bit of everyone to this thesis.

The greatest inspiration came from the breast cancer survivors themselves. Their stories have made the utmost contribution and I want to thank Whaea Jackie, Brigette, Olive, Ihaia, Ramari and Moana for their backing. Ngā mihi nunui ki a koutou me tō whānau hoki.

To my whānau, especially my mother Gemma Leef, who so courageously had to relive the experiences as a daughter and sister of those who have suffered from breast cancer. To all my eight brothers and sisters and their whānau, who shared and experienced the shock of my breast cancer diagnosis as much, if not more than, myself. Taku aroha ki a koutou.

To my hoa rangatira (husband) Donald and our sons for having the patience and allowing breast cancer to be a conversation and not a curse. You have all let this be something we should not hide but share with many. Thank you for the strength. Ngā manaakitia mātou.

Having been blessed with a mokopuna during this thesis journey has added a new dimension to our whakapapa. I will forever be vigilant with her health and the health of all our mokopuna, who through whakapapa are at risk of being diagnosed with breast cancer in their adult years,.

This work would not be possible without the guidance of Massey University academics and friends that have travelled the Masters and Doctoral journey. Special thanks go to Professor Sir Mason Durie for the initial encouragement and having greater trust in my abilities than I did. Extra special acknowledgements go to Dr Margaret Forster and Dr Lily George, who have walked beside me throughout this thesis journey. Ngā mihi ki a kōutou.

Finally, I extend a huge expression of gratitude to Te Rau Puawai staff for investing in my academic journey which has provided me with academic and cultural insights and understandings. Mauri ora.

## GLOSSARY

### A

aroha – to love, to care

awhi – to embrace, to cherish

### H

hinengaro – mind, intellect

hōhā – a nuisance

himene – hymn

### I

iwi – tribe

### K

karakia – prayer, incantation

Kohanga reo – learning nest

kōrero – to talk, converse

kaitiaki – guardian

koha – gift/gifting

kupenga - net

### M

mana – self-determination

manaaki – caring for others

manaakitanga – respect for others

manuhiri – visitors, guests

mokopuna – grandchild

marae – meeting house

Māori – indigenous peoples of Aotearoa New Zealand. Of Māori descent/blood/whakapapa

### P

Pākehā – non-Māori, European, Caucasian

## **R**

rongoa – traditional Māori medicine

Rātana – a Māori religious faith

## **T**

tikanga – customs, protocol

tinana – physical being

tokotoko – walking/talking stick

tōhunga - skilled person, chosen expert, priest

## **W**

wahine – woman

wahine toa – female warrior; woman of strength

wāhine – women

wairua – spiritual

whā – four

whaea – mother, aunt

whānau – extended family, social

whakawhanaungatanga – relationship building

whakapapa – genealogy, continuity

whakamā – embarrassment, shame, shyness

whare – house

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# CHAPTER ONE – INTRODUCTION

## 1.1 Woven Reflection:

### *Breast Cancer*

*The illness that threatens the lives  
of mothers, daughters, sisters and wives  
Why me, we ask, oh why me?  
Perhaps the answer lies deep within the family*

*Family histories are full of hidden treasures  
health, education and wellbeing measures  
Things that help us to understand  
Help us to know where to get a hand*

*A hand up is all that's needed  
to keep the faith that this cancer won't be seeded  
The spirit, body, emotions and family have been tested  
Support is essential for the patient to be rested*

*Rested to ensure all wellbeing is regained  
from the treatment and anguish that has been sustained  
Love and support for all involved  
No-one wants the cancer to evolve*

*Evolve into something that heightens the risks  
That turns our world into drama and twists  
Staying positive, keeping active and praying together  
Alleviates the turmoil in all kinds of weather*

*Whether to tell, to share or to keep  
all we want is a good night's sleep  
The worry, the stress, the concern is depressing  
Nurses are careful when checking the dressing.*

*Dressing up to consider partying  
Create thoughts of doubt that turn disheartening  
A wig, a hat, a scarf is to be worn  
A new sense of life is about to be born*

*Born from the illness that threatens the lives  
of mothers, daughters, sisters and wives  
Stay strong for all that amounts  
Stay strong everyone for that is what counts!!!*

Lucy Ripia – Author & Breast Cancer Survivor

By utilising words spoken from the wāhine Māori interviewed for this research, I have condensed this thesis to an eight verse poem that tells of their stories with breast cancer. Each verse is dedicated to a section or chapter of the thesis.

Verse one introduces the abstract section. The purpose of the abstract summarises the research thesis. In short, the verse identifies that breast cancer threatens the lives of many women and when confronted with the diagnosis there are more questions than answers.

Verse two supports the acknowledgements' section. For the people acknowledged in this section it is important that the gratitude is extended to the past, present and future. When an illness such as breast cancer has been identified, it can be interpreted as a source of strength or a source of weakness. Either way, support in all facets is encouraged and received.

The complete poem is placed in this introduction chapter to establish the entire thesis. Each verse is used to show the reader a picture of how the thesis will flow. Verse three has the specific role of showing that this whole thesis is about supporting all previous research and this project adds to the material to support any further work to be done. The more researchers can show with evidence that breast cancer is preventable, the better.

Verse four sets the platform for the literature review chapter. The literature needed to support this thesis has been identified as work that can show their importance in helping prevent the stresses of breast cancer through early diagnosis, as well as support the best possible care for Māori women and their whānau when a diagnosis is made. This will contribute to ameliorating the pressures of breast cancer diagnosis, and save many whānau the grief of losing their mother, daughter, sister or wife, especially if there is a history.

Verse five used in the methodology chapter brings a sense of calmness. With the support of the appropriate methods and methodologies keeping things in perspective this chapter eliminates any confusion of their purpose and direction.

Verse six facilitates the data analysis in chapter four. The retelling of the breast cancer stories needed sensitivity and consideration particularly around who will want to know, who really cares, is this the right thing to do? The greatest question for this project was, how does breast cancer impact on the wellbeing of Māori women?

Verse seven supports the discussion chapter, chapter five. There were many factors to consider whilst working through the discussion chapter including what direction needs to be taken on the journey of breast cancer.

Verse eight, the final verse, helps complete the thesis by supporting the conclusion chapter, chapter six. Although the diagnosis of breast cancer is a huge shock, the rule is to stay strong and positive and that it can be beaten. In ways, this does change the direction of life and there is a sense of being reborn and a new sense of strength is tested. This verse also ties back to verse one which reminds us about the threat breast cancer makes to all women and their families.

## 1.2 The Research:

Breast cancer is one of the most prevalent diseases affecting New Zealand women today - 2458 cases, 27.4% of all female registrations for cancer in 2005, and also the leading cause of cancer death among New Zealand women (647 deaths, 17.1% of female deaths), with an age-standardised mortality rate of 21.7 per 100,000 females (New Zealand Guidelines Group, 2009, p. v). A 2011 Otago University study revealed that there has been a significant increase in breast cancer rates for Māori women. The rate per 100,000 women increased 24% in the period 2001-2004, from 123 to 210 (University of Otago Press Release, 15/2/2011). Project leader Dr Ruth Cunningham noted however, that it is still uncertain as to the reasons for this increase. Dr Cunningham speculates this could be attributable to factors such as post-menopausal obesity and a high rate of smoking, but there is no conclusive evidence of this. While biological factors can play a part, little research has been done in this area (University of Otago Press Release, 15/2/2011). However, while these statistics paint a particular kind of picture, they can obscure the realities of a breast cancer diagnosis for wāhine Māori, their whānau, and their whakapapa.

The title of this thesis, *He kupenga mate pukupuku uu mo ngā wāhine Māori. Te Whare Tapa Whā; A multidimensional exploration of the impacts of breast cancer among wāhine Māori survivors*, encapsulates the ambitions of a researcher seeking and capturing stories from other Māori breast cancer survivors. The research is based around the question: 'How does breast cancer impact on the well-being of Māori women? Te Whare Tapa Whā (Durie, 1994) is used to capture aspects of well-being in a Māori context. The objective of this research therefore is to investigate the experiences of Māori women who have travelled the journey of breast cancer. Their stories will provide an increased

understanding of the impacts on all dimensions of wellness, including those on whānau structures and relationships. Exploring the experiences of and with other wāhine gave this work real and exciting personal meaning. Identifying other keen and reliable participants made for an interesting exploration on its own. The participants and their closest whānau members were especially intent on sharing their experiences and committed to the interview process.

This project arose from my own known history and personal experience of breast cancer, and this topic provided an opportunity to expand the knowledge and evidence that is lacking in this research field. The literature search for personal breast cancer stories from a Māori perspective was to no avail, therefore leaving me with the question about how other Māori women felt about their breast cancer experiences. The academic literature accessed to support this thesis in terms of Māori experiences of breast cancer itself was very limited. Although there was medical evidence that supported the high risks of breast cancer for Māori, documented personal evidence was limited. For this reason, this research will provide some new evidence surrounding the effects breast cancer has on the wellbeing of Māori women.

Have you ever wondered how Māori women and their whānau feel about being diagnosed with breast cancer? This thesis will discuss how breast cancer impacted on the holistic wellbeing of Māori women survivors. The news of someone close to you being diagnosed with breast cancer has an immediate impact on your state of mind. Imagine the feelings and emotions going through the person's mind that has been directly affected by the diagnosis. As already mentioned, this topic emerged from a personal experience of breast cancer diagnosis and the realisation that there was potential opportunity to research, share, and reflect on what the breast cancer encounter was like for other wāhine like me.

This research will set the stage for further discussions to support Māori to talk openly and freely about breast cancer and the effects on whānau. This thesis shares stories from breast cancer survivors using culturally-sensitive and appropriate research methodologies and methods.

### **1.3 The Thesis Structure:**

Following this chapter, the thesis continues with a literature review in Chapter two which looks at the history of Māori health, the inequities that have existed and continue to exist, and the initiatives, strategies and policies that have arisen to lessen those inequities. This includes the development of Māori models of health such as Te Whare Tapa Whā. An exploration of breast cancer is also included in this Chapter, covering what breast cancer is, the cause of breast cancer, and risk factors associated with breast cancer. It establishes the importance of early detection in order to prolong life and therefore alleviate the hurt and pain of losing our wāhine Māori to breast cancer unnecessarily. Using a holistic view captures perspectives around how Māori view the world and includes; spiritual, mental and emotional, and physical aspects, and whānau and social connections. These aspects provide measures of balance toward improved health and wellbeing. The literature review chapter is dedicated to the characteristics of breast cancer, signs and symptoms, treatment and preventative measures.

The contribution of Māori women in relation to Māori health and the health of the whānau is explored in this chapter. Māori women are essential to the nucleus of whānau and therefore their presence remains important to the strength and bond of whānau. Wilson (2004) refers to Māori women as the 'weavers of health and wellbeing' of their whānau and

communities. This research therefore considers the impact of a breast cancer diagnosis on the wellbeing of the entire whānau.

Whānau wellbeing is an issue that is currently receiving considerable attention. The Government's Whānau Ora initiative, introduced in 2010, recognises the importance of whānau for Māori wellbeing. Whānau Ora advocates a whānau-centred approach to provide whānau with the tools to develop and sustain sound health, and improve social and education outcomes. This approach ensures whānau get equal opportunity to participate in their own development and understanding of their aspirations.

The methodology chapter provides an overview of a kaupapa Māori approach which acknowledges the importance of a Māori worldview for guiding the research process and determining culturally appropriate methods and ethics. Storytelling as a technique is employed to gather the life stories from Māori breast cancer survivors. My own experiences as a breast cancer survivor also provide a lens through which to interpret the stories. This qualitative methodology was the only consideration for such a sensitive topic and is the most appropriate for this study. The method of interviewing and sharing experiences between the researcher and the participants was exceptionally enlightening for all parties. This reciprocity and exchanging of experiences identified similar as well as individual and unique stories.

This research was approved by the Massey University Human Ethics Committee; MUHECN 11/140. All participants consented to be involved in the research and were fully aware of their role and the role of the researcher.

The data analysis chapter draws together the stories shared by the women. This section describes the main themes using a Te Whare Tapa Whā theoretical framework to show

the holistic interaction between the hinengaro (mental), wairua (spiritual), tinana (physical) and whānau (family) dimensions of the data.

The discussion and conclusion chapters meld the data together to give this thesis consolidated closure. These chapters weave together the experiences of the women to provide some insight to how breast cancer really does impact on the wellbeing of Māori women. The conclusion chapter provides some recommendations from the women that could make significant difference to the way the whānau view the importance of mammograms and how early detection is the best prevention for breast cancer.

The experience of being an organic researcher has expanded my thinking to consider further ideas and understandings around how our private world can be consumed by this deep and meaningful subject. This journey has in many ways provided me with the insight to reassess the importance of my life and of those around me.

## CHAPTER TWO – LITERATURE REVIEW

Verse Four:

*Rested to ensure all wellbeing is regained  
From the treatment and anguish that has been sustained  
Love and support for all involved  
No-one wants the cancer to evolve.*

### **2.1 Introduction:**

Considering breast cancer from a holistic perspective brings a new dimension to an unfortunate experience; hence the reason for this research. The literature review contextualises the epidemiology of breast cancer among wāhine Māori within the broader perspective of Māori health. It assists in providing indications of where the effects of breast cancer are most manifested within multidimensional aspects of holistic health.

The literature review focuses on three main topics – Māori health, including a look at developments over time; breast cancer generally and in relation to Māori women; and the important roles women have in Māori society, detailing also the contributions some of our leaders have made. Literature relating specifically to Māori women's experiences of breast cancer was limited, highlighting the value of this project.

Recognition of disparities in relation to Māori health inequities has been acknowledged for decades, and although many gains have been made, wide disparity between Pākehā and Māori still exist (Bryder & Low, 2001; Cormack, Ratima, Robson, Brown, & Purdie, 2005; Durie, 2011b). The burgeoning of Māori research in recent decades has provided a body

of literature pertaining to the above topics and Māori-specific perspectives to build the thesis and provide background for the collected data.

Inequity of health between Māori and Pākehā has relevance to Māori experiences of breast cancer. Health inequities have been created by a variety of factors including colonisation and loss of tangible and intangible resources. Reid and Robson (1999) note that:

It is impossible to understand Māori health status or intervene to improve it without understanding our colonial history. Central to colonisation is creating a 'new history'...[where] indigenous knowledge and beliefs are relabelled as myths, legends and superstition....Unless we recognise colonisation as a deliberate and continuous process it is easy to assume that colonising events are accidental, inevitable and over. (p.10)

Strategies for decolonising Māori women's space include a focus on Māori development and the introduction of Māori models of health in the health sector. Māori development advocates a focus on health gains and the use of models which are culturally sound, improve the effectiveness of a health service (Durie, 2011b). Ellison-Loschmann and Pearce (2006) concur that "Māori-led programmes designed to improve health care access are taking a two-fold approach that supports both the development of Māori provider services and the enhancement of mainstream services through provision of culturally safe care" (p. 616). These types of strategies require mainstream health providers to understand the cultural needs of Māori in their care. One of these models – Te Whare Tapa Whā (Durie, 2001) – is used in this thesis as a tool of analysis for the collected data.

Another important strategy for supporting Māori health gains is the Whānau Ora Initiative (Taskforce for Whānau-Centred Initiatives (TWCI), 2010). A discussion of Whānau Ora as it relates to health development is provided here in the literature review. In order to alleviate health inequities, the New Zealand Government has endorsed the implementation of Whānau Ora as a strategy that can relevant ideas for a more collective support system to ensure better health outcomes for wāhine and their whānau.

Following the diagnosis of cancer there is the realisation that death could be near or certainly inevitable. This stress causes major issues for the healing process following treatment (Cormack & Robson, 2005). Early diagnosis is crucial to early treatment for many forms of cancer (Simmonds & Robson, 2008), which increases chances of survival. An awareness of the different types of cancer and ways they can be detected early is critical to receiving the most optimal treatment available which helps alleviate some of the stress relating to diagnosis. Access to appropriate services and early detection supports the chances of greater recovery and increased life expectancy. The *Access to Cancer Services for Māori Report* (Cormack & Robson, 2005) was clearly aimed at enabling a better understanding of issues relating to access to cancer services for Māori. The importance of accessing the appropriate services provides a clearer and less stressed experience.

The literature shows that through awareness and understanding, breast cancer and the stress of finding out can certainly be minimised as soon as it is discovered. This includes literature that supports the epidemiology of breast cancer among Māori women. Curtis, Wright and Wall (2005) add that, "Indeed, the successful screening of Māori women has the potential to produce even greater benefit for Māori women than non-Māori women" (p. 1). Māori women are "the weavers of health and wellbeing" (Wilson, 2004) for their

whānau, and are usually those most likely to care for the health of the whānau. There is a long history of Māori women contributing to better health outcomes for Māori and the literature explored in this chapter acknowledges some of the pioneers. Through sheer determination to address major challenges, these wāhine toa sometimes used protest and activism as a vehicle through which to force the Government to take notice of what changes needed to take place. These challenges were not always welcomed by people in authority however these women were persistent and determined to be heard. Their legacy continues today.

## **2.2 Māori health:**

### **2.2.1 History of Māori health development:**

Aotearoa New Zealand does not have a good reputation for providing equal opportunities of healthcare for Māori (Caccioppoli & Cullen, 2005; Durie, 1994b; Robson & Harris, 2007). Māori health research therefore, has an important role to advocate for and develop medical and scientific practices to improve results for Māori, in ways that are relevant to Māori. Reid and Robson's study – *Dying to be counted* (1999) – shows that there are wide health disparities between Māori and Pākehā. Reid and Robson (1999) also note that disparities in health status for indigenous people within their national populations are found worldwide.

Māori participation in health was previously based on a Eurocentric and medical model of health delivery and adapted to fit in with changing governmental priorities (Durie, 1994). An example of the Eurocentric nature of health delivery for Māori is shown with events that took place in the Waikato in the early 1900s. King (2003) writes that the Auckland District

Health Officer was concerned about the state of affairs, but only because of its implications for Pākehā communities. The Health Officer wrote in 1911:

A recent outbreak of typhoid among European in the Waikato district is attributed to Māori polluting a stream...there is no Māori Council for this district...As matters stand, the Native race is a menace to the wellbeing of the European. (cited in King, 2003, p. 29)

This statement indicates the manifestation of some tension between the health goals of the state, and Māori health. Durie (1994) details three periods of Māori health development (see Table 1) through features such as Māori leadership and Māori participation in Māori national organisations such as the Māori Women’s Welfare League as well as constraints on Māori health development such as the Tohunga Suppression Act of 1907 and inadequate funding.

**Table 1: Māori participation in health** (Source: Durie, 1994 p. 41)

| Years                       | Features   | Major participation   | Constraints   |
|-----------------------------|--|---|---|
| 1900-1930<br>Mana Rangatira | Māori leadership.<br>Māori professional guidance.<br>Māori recovery. | Māori councils.<br>Division of Māori hygiene.<br>Pōmare, Rātana<br>Te Rangihiroa,<br>Te Puea. | Tohunga suppression.<br>Māori nursing service.<br>Abolition of Division of Māori Hygiene. |
| 1931-1975<br>Mana Wāhine    | Māori support.<br>Māori women’s organisations.<br>Marae and          | Women’s Health League.<br>Māori Women’s Welfare League.                                       | Professional and institutional domination.<br>Monocultural                                |

|                         |   |   |   |
|-------------------------|---|---|---|
|                         | community action.   |   | policies.   |
| 1976-1992<br>Mana Māori | Māori initiatives.<br>Māori perspectives.<br>Iwi/Māori health programmes.<br>Māori development. | Iwi &<br>Māori health professionals.<br>Māori community health workers. | Short-term and inadequate funding.<br>Uncertain and changing health policies. |

In a survey of the history of our nation, Reid and Robson (1999) conclude that Māori health was a “casualty of the collision of two cultures at the time of contact between Māori and Pākehā” (p. 265). This statement highlights the definite ways in which Māori have been victims of an ever-changing climate of events. Continual comparisons between Māori and Pākehā have implications for enduring disparities, as comparison does not acknowledge the unique experience and needs of Māori as a colonised people, nor does it acknowledge the strengths of Māori to develop their own health strategies, including the diagnosis and treatment of Māori women with breast cancer.

Durie (2003) considers that 1999 was “an important milestone in public health...particularly for the advancement of Māori health” (p. 35). One hundred years earlier the first Māori to gain a medical degree, Maui Pōmare, graduated in 1899. By 1999 there were about 200 Māori medical specialists and around 100 medical students (Durie, 2003). This increase in the Māori workforce over a century has significant implications for the delivery of Māori health services and addressing health inequalities, and is reason to celebrate.

Indeed the Māori medical pioneer, Maui Pōmare, was arguably the country’s first health promoter with his commitment in the late 1800s to fostering community leadership and

addressing socio-economic adversity (Durie, 1999). Today, these concerns are particularly relevant given lower Māori life expectancy and higher rates of poverty when compared with the general population (Ministry of Social Development, 2010). New Zealand health promoters undertake initiatives such as working with teachers and students to develop health promoting schools' programmes, carrying out education and support for cervical and breast screening, and working with local leaders to achieve healthier communities' goals. The qualifications of health promoters undertaking this work vary enormously but practical experience is more common than formal qualifications. In part, this is because New Zealand tertiary providers have been slow to embrace health promotion and to design programmes to include it. Wise and Signal (2006) share their finding that, "While government has been the major investor in health promotion, investment has remained relatively small, in part because decision-makers have failed to be convinced of its value" (p. 237).

In Aotearoa New Zealand, there are significant health inequalities between Māori and Pākehā (Robson & Harris, 2007). Health inequalities, or more correctly health inequities, are defined as "differences which are unnecessary and avoidable, but in addition are considered unfair and unjust" (Whitehead, 1992; cited in Robson & Harris, 2007, p. 4). The disparities between Māori and Pākehā have led to wider gaps in many health issues between the two groups. Therefore, the challenge is to close the gaps and right the imbalance of health between Māori and Pākehā. Attitudinal and behavioural changes are required from mainstream health professionals at all levels to ensure Māori cultural needs are considered and therefore dispel the prejudice Māori often feel when accessing health services.

Durie (2001) states that:

Māori health cannot be separated from Māori lives. Nor for that matter can Māori lives be separated from the diversity of experience that constitutes modern living and which has the potential to reinforce good health or under adverse circumstances, to threaten health and wellbeing. (p. 279)

This statement is a considerable reminder of challenges faced by Māori in order to access adequate and appropriate health care. The cost of ill health, whether it is emotional, financial or cultural, weighs heavily on whānau. Low participation rates of Māori presenting for medical appointments are one of the constant challenges faced by Māori. These issues affect not just the individual that needs treatment, but the whole whānau.

However there are some signs that despite the continuing serious disparities between Māori and Pākehā standards' of health, early intervention is being practiced more frequently and access to health services has improved (Durie, 2001). For example, the life expectancy for Māori men in 1955-57 was 10.8 years less than that of non-Māori, and 14.3 years less for Māori women. From 2005-2007, the gap improved by 2.2 years for Māori men and 6.4 years for Māori women (Te Puni Kōkiri, 2009). This has been encouraged by factors such as health sector restructuring in the 1990s which facilitated a dramatic growth in Māori health providers and a philosophy of 'By Māori for Māori' that encouraged culturally appropriate care (Wise & Signal, 2000). For example, the Mana Wahine Taumatatanga Trust is contracted by Te Puna Whānau Ora Network Alliance (TWONA) to provide empowerment programmes that aim to "offer wāhine Māori and their whānau ways to be confident to operate in two worlds" (Ripia, 2013, p. 134).

It must be remembered however that because the lifestyles of Māori are diverse (Durie, 1994a; 1995), flexibility is required in responding to health needs. The development of Māori models of health (such as Te Whare Tapa Whā) which are appropriate and beneficial for many Māori individuals and whānau, are only one step in addressing these diverse needs. Assumptions of cultural connection, where there is little or none, can also contribute to increasing health inequities. While many Māori feel uncomfortable in mainstream health services, many others easily access these, and may also alternate easily between mainstream and Māori services.

### **2.2.2 Māori models of health**

The development of Māori models of health has been one of the strategies put forward by Māori to improve health outcomes for Māori. Māori models of health advocate the development of health initiatives, policies and strategies that reflect Māori culture and aspirations. Te Whare Tapa Whā is a Māori health model that was developed by Mason Durie and presented at the Hui Whakaoranga in 1984. The model drew also on the work of the Māori Women's Welfare League in their initiatives for Māori health which included acknowledgement of the importance of whānau and wairua (Durie, 2001), as shown in the *Rapuora* project (Murchie, 1984) and which Durie considers was the first instance of kaupapa Māori research.



**Figure 1. Te Whare Tapa Whā: A model of Māori health (Source: Ministry of Health, 2012b)**

Te Whare Tapa Whā emphasises the importance of all dimensions of health – spiritual, physical, emotional and intellectual, as well as social/whānau – for optimal wellbeing. The precise translation of Te Whare Tapa Whā is the four sides (cornerstones) of the house. These aspects of health and wellbeing contribute and intertwine with each other. The figure above identifies the aspects of wellbeing that are significant to Māori. The depiction of the whare (house) maintains the importance of having balance in each dimension of wellbeing in order to live healthily and happily<sup>1</sup>.

Dr Rose Pere also provides a Māori model of health that is consistent with the values and principles held dearly by Māori. According to Pere (1997), Te Wheke depicts the octopus and celebrates infinite wisdom in terms of the ancient teachings from Hawaiiiki. The symbol of the octopus is described in the following manner:

The head represents the child and whānau, each tentacle represents a dimension that requires and needs certain things to help give sustenance to the whole, the tentacles move outwards in an infinite direction for sustenance when the octopus

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<sup>1</sup> See Chapter 3 for further explanation of Te Whare Tapa Whā.



McNeill (2009) explains that Te Whare Tapa Whā is representative of most cross-tribal models because it depicts the basic components of a Māori concept of health. She also adds that the problem with the Te Wheke model however is that it is difficult to apply due to the multiple factors it incorporates, which may account for the preference toward the simplicity of Te Whare Tapa Whā. Adaptability, practicality, the wide use in health and social services, and my prior knowledge of the latter model are reasons Te Whare Tapa Whā has been chosen as the framework to analyse the research data.

These models and others are used by the health and education sectors to help deal with disparities by providing an understanding for the necessity of a holistic approach to health. Models such as Te Whare Tapa Whā have been introduced as strategies that acknowledge dimensions important to Māori such as whānau and wairua, in order to bring Te Ao Māori (a Māori worldview) and Te Ao Pākehā (a European worldview) together in ways that ensure more health benefits accrue for Māori, rather than having mainstream initiatives imposed on Māori (Durie, 2003).

### **2.2.3 Whānau Ora**

The introduction of the Whānau Ora Initiative (2010) has added to the positive direction of health services and providers for Māori throughout the country. Whānau Ora has sparked some excitement as the suggestion is to “encourage whānau to be part of the solution” and is explicit in its role to support whānau and families (Taskforce on Whānau-Centred Initiatives (TWCI), 2010, p. 18). According to TWCI (2010), the key outcomes are for whānau to be self-managing, able to live healthy lifestyles, participate fully in society,

confidently participate in Te Ao Māori, economically secure and successfully involved in wealth creation, and be cohesive, resilient, and nurturing.

Previously Wilson (2004) had noted that having trust in services enables the access and use of relevant services. Positive interpersonal relationships, information, and feelings of comfort are key features that influence access and use of services. This is essential when considering the treatment of breast screening and breast care of Māori women, as it contextualises Māori women within whānau and culture. According to the TWCI, the main objective is to construct an evidence-based framework that will lead to:

- Strengthened whānau capabilities;
- An integrated approach to whānau wellbeing;
- Collaborative relationships between state agencies in relation to Whānau services;
- Relationships between government & community agencies that are broader than contractual;
- Improved cost-effectiveness and value for money (TWCI, 2010).

The framework below shows, amongst other factors, the importance of initiatives being well-resourced to achieve optimum whānau ora outcomes. Design and delivery of services must be centred on whānau needs to ensure full engagement with whānau. The Whānau Ora navigator has the responsibility of developing collaboration between service agencies so that coherent service delivery is enabled.



**Figure 3: Whānau Ora framework (Source: TWCI, 2010, p. 21)**

In relation to how these points align to supporting wāhine with breast cancer, an example will be to educate whānau about the potential effects of breast cancer among their whānau, should their mothers, sisters, daughters, aunts and/or grandmothers be diagnosed with the disease. For those whānau who have a member with a diagnosis of breast cancer, a Whānau Ora practitioner could help facilitate relationships between that individual and their whānau, with the service agencies necessary to ensure timely and effective treatment. This would be an integrated approach to whānau wellbeing.

The Whānau Ora Initiative is one of the most important health initiatives to be released in relation to Māori social and physical health in recent years by government. Whānau are essential to the recovery and healing of breast cancer patients. It is just as important for whānau to have access to resources and information as much as the wāhine. The wellness of their wāhine while she is experiencing breast cancer has strong implications

for the whānau. The confidence of whānau to understand and be educated in health shows a true commitment to the wellbeing of their loved one. Whānau confidence and capability manifests itself in wāhine wellbeing (Pere, 1997).

#### **2.2.4 Strategy for health gains**

The *New Zealand Cancer Control Strategy* (Ministry of Health) was released in 2003; the overall aim of the strategy is to improve cancer-related services for all New Zealanders. My particular interest in the *Strategy* was to see how improvements would be made for Māori. As with many other health issues, Māori suffer disproportionately from the effects of cancer. The responsibility of reducing inequalities falls on both Māori and mainstream health providers. As highlighted in the *Strategy*:

Although Māori have an important role in implementing a cancer control strategy for Māori, responsibility for improving the quality of service delivery to Māori does not just lie with Māori service providers. Mainstream service providers must also make serious efforts to improve the acceptability and accessibility of health services and their responsiveness to the needs of Māori....in addition, support for the continuing development of Māori providers is necessary. (Ministry of Health, 2003, p.7)

The *Strategy* also supports the centrality of Māori-centred approaches to applying good practice for Māori cancer patients. This observation maintains an important aspect of accountability to all service providers throughout New Zealand.

Further to the *Strategy* is the *Access to Cancer Services for Māori Report* (Cormack, Robson, Purdie, Ratima & Brown, 2005). Cormack et al. reveal that the Report was

prepared for the Ministry of Health to establish how effective the *New Zealand Cancer Control Strategy* has been toward better health outcomes for Māori. According to the Report, cancer is a leading cause of disability and death in Aotearoa New Zealand, with a significant impact on Māori. “Māori experience a disproportionate impact of cancer, and inequalities in terms of cancer risk, incidence and outcome are well documented. Further work, particularly that incorporating Māori patients, whānau and community voices, is vital” (p. i).

In practice, the Report discusses the accessibility of health services and reflects that access is conceptualised in multidimensional and multileveled ways. That is, access is about obtaining entry into and through health services and encompasses the timelines and quality of both the process and the outcome (Cormack et al., 2005). Over the years the Ministry of Health has been concerned about the level and time taken to care for people with primary healthcare needs. The quality of care for patients in a broader sense has had serious implications for Māori, and the Ministry is determined to improve care provided. As recounted by Cormack and Robson (2005):

The Ministry of Health Intervention Framework for Reducing Inequalities posits that policies that impact differentially on the Māori and non-Māori populations at the structural level, such as labour market, policy, tax policy and welfare policy, produce inequalities. (p. 33)

As a result, continued research and policy development that give a more positive outlook to the health of Māori is fundamental to positive outcomes. Cormack and Robson (2005) found that access to cancer services for Māori needed further investigation in order to

enhance Māori-specific services or service components (such as integrated Māori expertise and advice, locating services in Māori settings and incorporating te reo Māori), and to address the institutional racism that was identified. These findings show the presence of barriers for Māori and their whānau within and across the healthcare sector.

## **2.3 Breast cancer:**

### **2.3.1 Epidemiology of breast cancer in Māori women:**

Cancer is a generic term used to describe a group of diseases that occur when malignant forms of abnormal cell growth develop in one or more body organs. These cancer cells continue to divide and grow to produce tumours (Ministry of Health, 2003). Breast cancer is the most common cancer among Māori women. According to the New Zealand Guidelines Group (2009):

While the incidence of breast cancer is increasing in New Zealand, the female mortality rate has reduced by 19% over the last decade, mirroring international trends. This reduction is generally attributed to earlier detection and the greater use and effectiveness of adjuvant treatment. (p. v)

Data collected on breast cancer over decades continue to produce high figures for Māori and unfortunately the figures tell us that younger wāhine are now suffering from breast cancer in high rates. McCredie, Paul, Skegg and Williams (1999) have found that since the mid-1960s, statistics identify higher rates of breast cancer in Māori women under-40 years of age than their non-Māori counterparts (p.189). This is a major concern for whānau; McCredie et al. add that “the excess of breast cancer in young Māori may reflect unknown

genetic factors that increase susceptibility” (p. 189). These genetic factors that contribute to breast cancer among Māori will only be revealed if Māori and their whānau allow studies to take place. Port (2009) suggests that, “Debate relating to scientific advances becomes increasingly urgent when human life is at stake. In addition, while there is a natural desire to improve health some Māori feel that DNA testing would interfere with their whakapapa” (p. 3). However, genetic testing is becoming more acceptable for some Māori; for example, an enviromomics collaboration between the Institute of Environmental Science and Research and an iwi seeks to “identify combinations of genetic and environmental factors that may contribute to current health status” (Hudson, Ahuriri-Driscoll, Lea, & Lea, 2007, p. 2). Continuing debate in this vital area is important for Māori health, especially in relation to diseases such as cancer.

The Ministry of Health has acknowledged the need for Māori-focused strategies that take into account the requirements of Māori. One aim of the *New Zealand Cancer Control Strategy* (Ministry of Health, 2003) is to “reduce the incidence and impact of cancer” (p. iii). Cancer has a major impact on the whole whānau, not just the individual. The *Strategy* document discusses, among other topics, the importance of early detection and cancer screening of breast cancer. This *Strategy* document also provides treatment options and a cancer control continuum. The purpose of the continuum is to provide support and direction throughout the care related to breast cancer. Nevertheless, Māori women have a particular need that involves an extended amount of support. As noted by the Ministry of Health (2003), “The Māori concept of hauora is central to the lives of many Māori, and this strategy acknowledges that cancer control activities in New Zealand need to be consistent with this broad, holistic view of health” (p. 7). The journey along this road can be less

stressful with the right supports and enthusiasm for Māori values practiced within the activities.

### **2.3.2 What is breast cancer?**

A simple description by Robbins (2004) allows the reader to gauge an understanding of breast cancer. She suggests that women's breasts are complex factories for milk production. While cancer can occur in any part of them, 90% of cases start in the milk sacs (also known as lobules) where milk is manufactured, or milk ducts that connect the sacs to the nipple (Robbins, 2004). The New Zealand Breast Cancer Foundation (2012) considers that cancer is initially a cell that keeps on growing and dividing. This mutated cell keeps on producing more abnormal cells in large numbers, which in turn reproduce. For breast cancer, this abnormal growth starts in the breast tissue. It is not clear why abnormal growth starts. According to the *Breast Cancer: Te matepukupuku o ngā ū* booklet (Cancer Society of New Zealand, 2007):

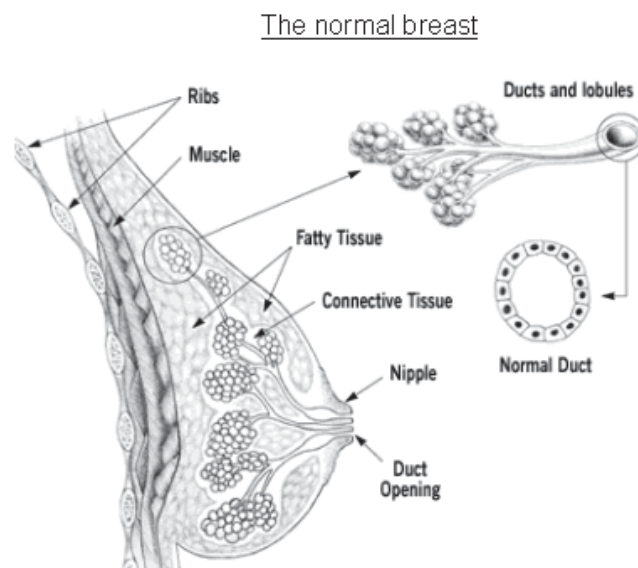
The cause of breast cancer is unclear so there are no certain ways of preventing it.

There are some clues, or risk factors about who is more likely to develop the disease. These factors include;

- Age – a woman's chances of developing breast cancer increase as she gets older
- Previous breast cancer
- Atypical hyperplasia can be seen in a breast biopsy
- A whānau/family history of breast cancer. (p. 12)

Although these factors are not always relevant to someone developing breast cancer, these aspects can encourage some vigilance regarding the appropriate steps to take if there is concern.

Up to 5% of breast cancer may be caused by an inherited genetic abnormality ([www.thebreastcentre.co.nz](http://www.thebreastcentre.co.nz)) which makes it much more likely for breast cancer to develop as the genetic message is already contained in the cells. Two genes that have been identified as connected to breast and ovarian cancer are BRCA1 and BRCA2 cell mutations which interfere with the normal process of cell DNA repair ([www.thebreastcentre.co.nz](http://www.thebreastcentre.co.nz)). Awareness of this genetic abnormality can increase vigilance in regular mammograms, and therefore increase chances of survival.



**Figure 4: Breast anatomy (Source: American Cancer Society)**

The diagram above shows where the start of breast cancer can occur, in the lobules. Regular checks by professionals are critical as the early stages of breast cancer by self-checking can be missed.

### **2.3.3 Signs & Symptoms:**

Information gathered from the Southern Cross Healthcare Group's website ([www.southerncross.co.nz](http://www.southerncross.co.nz)) signals that most commonly, the first sign of breast cancer is a new lump in the breast, which is usually painless. Other signs of breast cancer include:

- A new area of thickened tissue in the breast;
- Nipple discharge or a change in the nipple;
- Dimpling or puckering of the skin of the breast;
- A change in breast size or shape.

While these symptoms may not indicate breast cancer, it is important to see a doctor promptly for assessment and accurate diagnosis if they are present. Early detection is vital in the successful treatment of breast cancer (Southern Cross Healthcare Group, 2012). This stresses the importance of being vigilant about watching out for these signs and symptoms in order to alleviate unnecessary stress and concern:

My heart breaks whenever I am told of a woman that ignored her lump out of fear, failed to see her GP about it and consequently has a slim chance of survival when cancer is finally diagnosed. It also grieves me when I hear about a GP who didn't take a woman's concern about a lump seriously, failed to check her, and the cancer went untreated. Both are no-win situations. (McLeod, 1998, p. 10)

Breast checks, especially if any of the signs and symptoms is present, should not be delayed. Torrie (2012) interviewed Professor Tony Blakely on the success of improved health services for cancer patients. Professor Blakely reveals that “The good news is that, averaged across all cancers, people diagnosed with cancer in 2004 had a 32% lower death rate than people diagnosed in 1991” (p.?). In the same article however, Associate Health Minister Tariana Turia is still very concerned about the increase of inequality between Māori and Pākehā. Turia concludes that “Cancer has always been an illness of high incidence among Māori...inequalities occur when Māori don’t get screened or referred to treatment early enough” (in Torrie, 2012, p. A1). Therefore, although research suggests there are improvements in treatment and early detection, Māori are still missing out on accessing services and receiving timely and effective treatment.

#### **2.3.4 Treatment:**

There is a process that determines the type of treatment required for the particular type of cancer detected; this includes the severity of the cancer. During this stage it is important to not be alone with the doctor or specialist as they advise what is best suited to your situation. As discovered by Owen (1990):

I can't believe my ears. I pray that I am dreaming. I want to cry but I cannot, and I cannot stop the doctor's words telling me, I am sorry Mrs Owen, the lump is malignant. It is cancer. Others have experienced this moment, yet I am alone. No one can help me. I am isolated, trapped. I have cancer. (p. 1)

Having to assimilate such difficult news and then be advised of what treatment is required can be too much to fathom. Having support is therefore essential in this situation.

We are reminded that breast cancer occurs with equal frequency in Māori and non-Māori women. However, Māori women are nearly twice as likely to die from the disease as Pākehā; one contributing factor is they are presenting with breast cancer at a later stage of disease. The reasons for their presenting late are complex, but a contributing factor is the low rate of attendance by Māori women for screening mammograms (Cancer Control Council of NZ, 2008).

Treatment is therefore very limited and invasive if Māori women are presenting late. As advised by the Southern Cross Healthcare Group (2012), treatment of breast cancer depends on the type of breast cancer, its size and position, whether it has spread, the woman's age and general health, and the woman's preference. In general, some type of surgery is recommended followed by additional treatments (adjuvant therapies). Surgery and radiotherapy are classed as local treatments (as they affect a localised, specific area), while chemotherapy and hormone therapy are classed as systemic treatments (as they have the potential to affect the whole body). With any and all treatments that involve care and support for the patient, the attention for care needs specialist and whānau support.

### **2.3.5 Prevention:**

The importance of early detection of breast cancer cannot be reiterated often enough. According to Robbins (2004), the effectiveness of the breast cancer screening programme in New Zealand in recent years has meant that more women are being successfully treated. However there is still a great misunderstanding that breast cancer only develops after the age of 45 years and therefore free mammograms are not prescribed until after 45 years of age. While peace of mind can arise from a negative mammogram result, for many

Māori women the cost of \$250 is prohibitive, and waiting for free mammograms when they are 45 years or over may be too late. Such a policy needs to be modified in order to identify women who are younger and at high risk for being diagnosed too late. The reality is that many women under 45 years **do** develop breast cancer. In a recent newspaper article, Johnston (2012) reports that “Early mammogram averts cancer misery”, and that “the Ministry of Health figures show that in 2009, 149 women aged 20 to 39 were diagnosed with breast cancer – 5% of the 2759 women of all ages diagnosed” (p. A7). Johnston notes that the New Zealand Breast Cancer Foundation conducted this survey to gauge the awareness of the importance of mammograms. The findings reveal that:

*Women aged 20-39:*

- 35% do not know breast cancer is the commonest cancer for women in their age group;
- 12% never check their breasts for change;
- 33% have never asked about family history of breast cancer

*Women aged 40-44:*

- 30% have had a mammogram;
- 60% of those who have had a mammogram said the main reason was they were worried about a lump or other breast change;
- 45% of those who have not had a mammogram said the main reason was they were too young (Johnston, 2012).

These findings are a concern for whānau who have a history of breast cancer, and therefore support and education is of utmost importance. There is limited information on

access from the point of view of Māori with cancer and their whānau, which is vital to developing policies and interventions to address access (Cormack, et. al, 2005, p. iii).

From my own experience of accessing information and finally hospitalisation, I was very aware of the need for whānau support. Unlike the experience of Sue McLeod (1998) who returned to her room after surgery and recovery to find her husband not there and phones him to leave the message, “Where the hell are you?” (p.39), I had my nearest and dearest waiting for me in the room which is some of the best ‘medicine’ you can receive after the horrific ordeal of surgery.

The study and research of breast cancer has made an impact on the ways in which the health sector delivers care to women across the world. The Pink Ribbon campaign is widely recognised as an international crusade, with the aim of raising breast cancer awareness. To bring this awareness closer to home, studies on Māori and non-Māori women have also been documented. One such article by Curtis, Wright and Wall (2005) tells of the implications for Māori. The authors declare that the deaths of Māori diagnosed with breast cancer are higher compared to non-Māori, “Ethnic disparities in breast cancer mortality have been consistently documented with Māori women having a higher mortality rate than non-Māori” (Curtis, Wright & Wall, 2005, p. 1).

McCredie, Paul, Skegg and Williams (1999) support these conclusions, stating that:

Breast cancer has been as common for Māori as in non-Māori for as long as ethnic origins were tabulated separately in 1962-1966. Furthermore, for the past 25 years Māori rates have been higher than those of non-Māori for women under the age of 40 years (p. 189).

Moreover, the history of breast cancer can be traced through whakapapa; a factor that increases the risk of breast cancer is a strong family history of breast and/or ovarian cancer (National Breast Screening, 2012). Therefore, although accessibility to and provision within the healthcare systems need to be improved for wāhine, evidence shows that for a range of reasons today, many Māori women are still diagnosed too late. Curtis, Wright and Wall (2005) note that “One proposed explanation for this finding is that people identified as Māori are at risk of institutional racism and differential health care access, and therefore differential health outcomes” (p. 13).

### **2.3.6 The importance of screening:**

The education around the importance of screening for breast cancer has somehow failed to capture the attention of many Māori as there remains disparity in relation to Māori women and the prevalence of breast cancer. Even with more creative ways to inform this population group, it still misses the mark in terms of uptake for early detection. Reminnick (2006) notes that even when breast screening services are accessible and women-friendly, they fail to attract many women because of psychological and sociocultural factors such as fear of a cancer diagnosis and treatment.

*BreastScreen Aotearoa*, a national breast screening programme, was launched in December 1998 (National Health Committee, 2003). *BreastScreen Aotearoa* continues to foster strong messages to all women regarding the importance of accessing services. A key message from their pamphlet is, “Having a mammogram every two years improves a woman’s chance of surviving breast cancer” (Ministry of Health, 2011). I would argue that in my experience it was only one year between checks when I was diagnosed with early

stages of breast cancer. This sends a contradictory message to women that are vigilant about their health in that two years may be too late. However, as it stands now, women over 45 are eligible for free checks every two years, which is the norm, unless something untoward is found.

Breast cancer can however be curable when detected early. Nevertheless, we are prompted by McLeod (1998) that, “The truth is that breast cancer shows no mercy, so as soon as a suspicious lump is found, you have to act. Remember that nine out of ten lumps are not cancerous, they are benign” (1998, p. 10). Stacey (1997) reminds us that if a person with cancer has lived to tell the tale, the story is often of a heroic struggle against adversity. She continues to reaffirm that pitting life against death and drawing on all possible resources, the patient moves from victim to survivor and “triumphs over the tragedy” (p. 1) that has unexpectedly threatened their lives.

In the Ministry of Health’s *Management of Early Breast cancer: Evidence-based Best Practice Guideline*, cultural awareness and consideration are important within the New Zealand health care context. There are specific issues relevant to Māori (New Zealand Guidelines Group, 2009). Cultural practices that support care and processes in the wider context of managing breast cancer is pertinent to recovery.

## **2.4 Māori women as weavers of health and wellbeing:**

Health and wellbeing is essential for the survival of Māori. The concept of ‘ngā whare tangata’ refers to Māori women as the guardians of life and as the birthplace of our future leaders: “Ko te wahine he whare tangata, he waka tangata (Within the woman is the nurturing home of humankind and the channel from the spiritual to the physical)” (Herangi-

Panapa, 1998). Māori women are respected for their place in Te Ao Māori for how we birth life, and nurture life. This acknowledgement places many responsibilities on wāhine, including being the uniting force of their whānau. Māori women have also often been in the forefront of initiatives for health gains.

Throughout history Māori have had to rely on leaders with the confidence and strong conviction to voice the needs of whānau, hapū and iwi. One such group of Māori women leaders developed the Women's Health League in the 1940s and Māori Women's Welfare League (MWWL) in 1951, and thereby maintained a strong voice for Māori (Bryder & Dow, 2001). This was a time that saw "the flourishing and nurturing of Māori women as leaders of their people" (Rogers & Simpson, p. xiv). Sissons (2005) describes the MWWL as the "first truly national lobby group to address the social problems confronted by indigenous city dwellers" (p. 67). Leaders such as Whina Cooper and Mira Szaszy led these organisations which were innovative in their approach to Māori health, especially in relation to that of Māori women and children.

Irwin (1995), of Ngāti Kahungunu and Ngāti Porou descent, reflects on the integrity of wāhine Māori. She contributes her work to the celebration of Māori women who are healers, artists, policy analysts, writers, and so on, who have been able to share their lives as leaders of their communities (Irwin & Ramsden, 1995). The stories told in *Toi Wahine – The worlds of Māori women*, are rich and tell of many aspects including struggles, pain, confusion, whānau and tūpuna. They are creative in the way that Māori women are. Irwin adds:

Just as herstory of every woman is different, so too will the telling of those stories be. As time and life have been experienced, so will the women's lives be shaped.

There are, not surprisingly, many stories to be told by many Māori women. Given what we know about Māori women's lives, the diversity of the stories is understandable...another possibility for weaving. (p. 10)

Wilson's (2004) thesis *Ngā Kairaranga Oranga – The weavers of health and wellbeing*, tells of the strengths Māori women have and use on a daily basis to maintain the health and wellbeing of themselves and their whānau. Her thesis is an important articulation of the roles and importance of Māori women. Of Tainui descent, Wilson, (2004), alludes to one of the factors of Whānau Ora in relation to wāhine Māori being the holders of knowledge on health and wellbeing within their cultural context and life expectations. They are the kaitiaki of whānau ora, as shown in the following whakatauki:

Ko te mana o wāhine Māori, ko rātou te whare tangata, te kairaranga oranga, ko te kaitiaki o whānau ora. Tihei mauri ora.

The integrity of Māori women, who are the bearers of life, the weavers of health and wellbeing, the guardians of whānau health and wellbeing. (p. iii)

In order for whānau health and wellbeing to be successful, there is much dependency on the wāhine to fulfil that responsibility. As the guardians of life, the strength of Māori women makes for robust and connected whānau, hapū and iwi. The awahi required to ensure these women get the best possible support will need to be maintained by a collective of whānau around her.

The drive for the Whānau Ora Initiative was led by Minister for the Community and Voluntary Sector, and Co-Leader of the Māori Party, Tariana Turia. The Taskforce gathered together scholars of the highest level, such as Professor Sir Mason Durie. Turia, the driver of Whānau Ora, helped to ensure that Whānau Ora will benefit all New Zealanders, and also ensured that the government would take notice of the collaborations between agencies working with whānau and families.

In time and with support, the care for Māori has improved with the introduction of Māori health services such as hauora providers in Primary Health Organisations (PHOs), and Māori services within hospital settings. These services provide culturally-appropriate care for Māori that was previously lacking in the mainstream system. At times Māori health and the State have been moving in opposite directions so that conflict has been inevitable, as Māori participation was being constrained by narrow definitions of health and moulded to fit in with changing government priorities (Durie, 1994). This thesis tells the stories of wāhine who have experienced ill health and whose lives have certainly been shaped or reshaped by the experience of breast cancer. Yet also integral to these stories are their strength and courage, and their fundamental roles as ngā whare tangata, and as weavers of whānau health and wellbeing.

## **2.5 Conclusion:**

Breast cancer is a disease that impacts greatly on Māori women and their whānau. Accessing the correct services reduces the stress related to this issue, and enables timely and effective treatment. Awareness of knowing where to go for the appropriate services in order to get through the experience of being diagnosed with breast cancer with as little

stress as possible is important. With the introduction of Whānau Ora and the responsibility of Māori health providers to ensure the messages of health and wellbeing are provided, this should produce better health outcomes for Māori women. The introduction of Māori health providers has highlighted that more informed decisions and the awareness of Māori health issues are beneficial for communities. It is with the confidence and understanding of the roles of health services that Māori women can be comfortable to follow through on the care needed to ensure the best possible breast care. Capacity building among whānau has improved due to the increase of services developed and adapted to suit Māori.

The merging of Te Ao Māori and Te Ao Pākehā has improved health outcomes for all, especially Māori. Although there is still more work, more whānau are willing to attend to health issues than in the past particularly if the specialist or health promoter is Māori. The need for whānau to share their stories and be counted in positive health statistics is essential to the application of services. A major contributor to being diagnosed early for breast cancer is that with the correct follow up services more Māori women will live longer and have a better quality of life.

This literature review found that there is little research that encompasses the full dimensions of wellbeing for Māori women. Unfortunately, much of the literature is from a non-Māori perspective. It was difficult to find information relating to the wider impacts of breast cancer on Māori, discussions of, and especially successes of breast cancer treatment among Māori. Most of the research on wāhine Māori has similar findings relating to disparities and inequalities between Māori and Pākehā. Māori continue to be portrayed as 'missing out' or not accessing services as well as other groups. This issue needs to be addressed immediately to reduce the suffering of whānau from an illness that can be preventable.

## CHAPTER THREE – METHODOLOGY

Verse Five:

*Evolve into something that heightens the risks  
That turns our world into drama and twists  
Staying positive, keeping active and praying together  
Alleviates the turmoil in all kinds of weather.*

### **3.1 Introduction:**

The aim of this project was to gather stories from breast cancer survivors and analyse the data shared in order to contribute to a deeper understanding of these experiences. My own breast cancer journey provided an additional lens through which to interpret the data gathered. Qualitative research was the primary approach driving this project. In this study, the methodologies include life story interviews woven together with kaupapa Māori research theories and methods, along with a personal lens. Storytelling is a non-threatening process that enables people to feel they are making a valuable contribution. A Kaupapa Māori research approach is an important component to this study due to the ethnicity of the participants and to ensure that the project was Māori-participation focused. The methods used to gather the stories allowed participants to have the opportunity to freely discuss their experiences.

## 3.2 Methodology:

### 3.2.1 Kaupapa Māori Research:

Kaupapa Māori is a research paradigm underpinned by Māori traditions and values. Utilising kaupapa Māori research methodology was non-negotiable in this study. Linda Smith (2006) argues that “Indigenous methodologies tend to approach cultural protocols, values and behaviours as an integral part of methodology” (p. 15). It is my belief that integrity as a Māori researcher is potentially the main driver of our work in research. The trust between researcher and participant is pertinent to the expressive nature of the discussions. As a new researcher there is much to understand and Smith provides some enlightening points that support kaupapa Māori research. She argues three explicit concerns related to Māori research; decolonisation, Treaty of Waitangi, and kaupapa. According to George (2010):

The first is *decolonisation* which refers to convincing Māori that research can be a positive endeavour that is useful for our own. Secondly the *Treaty* argument states clearly that partnership includes rights in policy decision making that is often related to Māori research. The *kaupapa* argument is the ‘how’ of research. (p. 35)

Smith (1999) explains the ‘how’ as:

How to proceed, how to develop approaches and ways in carrying out research that takes into account, without being limited, by the legacies of previous research and the parameters of both previous and current approaches to research. (p. 2)

Such politics fuel resentment and as Harris (2004) observes, “Māori were expected to fit into Pākehā society in the interests of race relations, but nothing encouraged Pākehā to develop even a small level of understanding of the Māori world” (p. 23). Kaupapa Māori research provides opportunity for Māori to deliver their own understandings of Māori issues.

Kaupapa Māori research incorporates Māori philosophy and culture, and is important for a better understanding of things Māori. Pihama (2001) claims that:

Kaupapa Māori theory is conceived of as being a Māori framework that has its foundations in mātauranga Māori. It is argued that kaupapa Māori is of ancient origins, which derive from within the many realms of the Māori world. Kaupapa Māori theory is a framework that both draws upon, and affirms mātauranga Māori as fundamental to Māori understandings. Kaupapa Māori theory is also multiple in its articulation. (p. ix)

The articulation of Māori research is expressive and emotionally charged, and asserts the rights of Māori to represent themselves. Creative and innovative techniques have enabled Māori to develop research methods, methodologies and theories that benefit and reflect our own epistemology and concepts. Also, just as “culture is not static but instead dynamic and ever-changing, the same could be said for research processes” (George, 2010, p. 34).

Other Māori researchers, including Jahnke and Taiapa (1999), note their concern is that “Much of Māori research done on Māori in the past has proven to be of little benefit to Māori themselves” (p. 39), and was more likely to reinforce negative stereotypes than contribute to increasing Māori health and wellbeing. The use of kaupapa Māori research

also prevents a non-Māori perspective being imposed on things Māori. It helps prevent the abuse of research and lack of understanding of Māori culture and people when researching from another culture and worldview. It was important for me as the researcher to concentrate primarily on Māori participants, and therefore to be aware of the importance to the participants of their cultural worldviews.

The opportunity to interview the wāhine for this research is truly appreciated. The sharing of whakapapa was pivotal to building a strong foundation in the relationship of trust and acceptance for who I was as the researcher. Being Māori provided great benefits for the process of how the interviews were navigated. The ability to be flexible and patient was maintained throughout the meetings; this included knowing when to say something and when to pause for reflection. The significant contribution of the wāhine to this topic makes it the treasure that it is. This emphasises the reality that in order to continue in research with Māori communities and Māori issues, foundations of cultural practice and theory need to be incorporated and acknowledged to support the multiple layers of research benefits.

According to the Health Research Council of New Zealand (HRCNZ) (n.d.):

Equity and justice are ethical principles underpinning the importance of benefit sharing. Research will also have a range of outcomes and part of the ethical deliberation is to consider the nature of the outcomes (risk versus benefit, short versus long term) and their relative distribution (researchers, participants, communities, society). Researchers will legitimately benefit from being involved in research but consideration should be given to how participants and their communities might also benefit from participation. (p. 17)

There are real benefits in sharing the knowledge gathered for this project which reflect the principles outlined above regarding the multiple layers of how wāhine Māori are impacted upon by breast cancer. In order to understand the difference between method and methodology, I likened the whole process to a childhood memory of mine when my father and his mates would go fishing for mullet with a net. The trip required preparation: this included the knowledge accrued over generations of how to catch the fish (e.g. where they were most likely to be plentiful, and the best times to ensure a plentiful catch), as well as ideas around kaitiakitanga and fish stock preservation, and other tikanga (ritual practices) associated with fishing. The methods included having the net ready, karakia (prayer) on entering the water, walking the net out into the waves, and how the fish would be cleaned, and then be shared among our community, according to tradition.

Therefore, my current understanding is that the 'net' is the method on how I gathered the information - who to talk to and how the process took place to ensure that all participants were familiar with what needed to happen. The methodology is in knowing the most appropriate 'net' to use and why that was so in gathering participants' narratives and sharing their experiences with communities to expand understanding about breast cancer among Māori women. With both net fishing and researching, respect and knowledge is in knowing when the 'tide/time' is right.

The main title of this thesis is *He kupenga mate pukupuku uu mo ngā wāhine Māori*. He kupenga is the net which gathers together Māori women who have had breast cancer. Kupe is the Māori ancestor credited with the discovery of Aotearoa in the 10th century (Tate, 2012); it was a crew member of Kupe's Matahaorua waka (canoe) who gave this land its name. Kupe's first landing place was in the Far North, later named Hokianga-nui-a-Kupe, as the place to which Kupe returned several times. Hokianga is the land of my birth,

and where my father fished with his net. Therefore, the title has multiple layers of narrative that gives it meaning within this study.

In addition to utilising a kaupapa Māori approach, the research also employs an interpretative approach to enable the researcher to focus solely on an interpretative paradigm. This approach, is described by Davidson and Tolich (1999) as “the systematic analysis of socially meaningful action through the direct detailed observation of people in natural settings in order to arrive at understandings and interpretations of how people create and maintain their social worlds” (p. 26). Māori are very diverse (Durie, 1995) and individual experiences can vary widely; however for the purpose of the project the advantage was that these diverse Māori women were willing to share their stories about their experiences of breast cancer. While the stories share similarities, each one is a unique interpretation of those experiences.

Māori can perform unique and traditional practices every day which can affect how we engage in western practices and approaches. Somekh and Lewin (2005) explain that “Human experience is characterised by complexity, and social science researchers need to resist the temptation to impose unwarranted order through the application of ‘one size fits all’ theories” (p. 3). Thus, this highlights the importance that researching this topic is best supported with an indigenous focus and practice from the researcher’s and participants’ perspectives. However, this does not preclude utilisation of non-indigenous research methods where appropriate.

Jahnke and Taiapa (1999) maintain that appropriate methodologies for Māori research are essential. They uphold that “the construction of methodologies appropriate and relevant to Māori is based on several underlying assumptions. The first is a Māori viewpoint and a

distinctively Māori way of organising knowledge” (p. 41). For example, using Durie’s Te Whare Tapa Whā model ensures the knowledge from the participants is placed in culturally meaningful themes of spiritual, emotional, physical and social dimensions of health and wellbeing. Jahnke and Taiapa’s second assumption is the validity of mātauranga Māori (Māori knowledge). My own assumption of the stories gathered from the participants was that the levels of mātauranga Māori for each individual would vary, although it was an important factor in all their lives. For example, I was aware that each participant would have her own understanding of Te Whare Tapa Whā, and to ask each for what it means to them, rather than imposing a general conception of Māori knowledge. With my limited knowledge of mātauranga Māori, it was nevertheless necessary to ensure the cultural safety of all participants, including seeking further cultural advice from elders when it was required.

The third assumption was that “the process of enquiry is one that locates Māori people as the focus of the research activity” (Jahnke & Taiapa, 1999, p. 43). Smith (1999) writes that the “word itself, ‘research’, is probably one of the dirtiest words in the indigenous world’s vocabulary” (p. 1), and that:

Under colonialism indigenous peoples have struggled against a Western view of history and yet been complicit with that view. We have often allowed our ‘histories’ to be told and have then become outsiders as we heard them being retold. (Smith, 1999, p. 33)

There are many examples of how research has been used to the detriment of Māori and other indigenous people. By locating Māori at the centre of research, the needs of Māori

are taken as integral to the research, and benefits are thereby returned to the researched and their communities in ways that make positive differences for those communities (Durie, 1998).

Knowledge is power, and “choosing a particular methodology is a political act” (Kovach, 2009, p. 53). In the beginning stages of undertaking this research topic, my initial motive was to lobby for the age of free breast screening to be lowered from 45 to 40 years or less, particularly for Māori with a history of whānau breast cancer. Therefore, choosing to use a kaupapa Māori methodology is in my view a political act. By doing so, it is more likely to gain a deeper understanding of the impact of breast cancer for Māori women and their whānau. Additionally, relating this topic to the Whānau Ora Initiative places it as a significant issue within current health policy for Māori. Therefore, transformative change which makes a positive difference is enabled, along with raising awareness of the issues resulting in improved outcomes for Māori women who develop breast cancer.

According to Bishop (1999), “Maori and other indigenous peoples are concerned about the power and control that non-indigenous people hold over research” (p. 1). All research is value-laden, and kaupapa Māori methodology allows for the researcher and the participants to practice Māori values throughout the study. The use of important concepts within Māori culture and tradition such as whakapapa and tikanga is one way in which to affirm the vitality and validity of Māori worldviews contributing to research. It is therefore of significant value that the stories and histories of these women are captured so that we may contribute to the expanding body of Māori knowledge. This project had significant processes in place to allow a kaupapa Māori approach.

### 3.2.2 Life Story Interviews:

Silverman (2005) suggests that “qualitative researchers are often interested in the narratives or stories that people tell one another (and researchers)” (p. 303). Life story interviews bring a certain appeal to the project. Although many research projects have a dimension of storytelling to them, something about sharing your own experience of breast cancer with someone who has a similar story can add value to the process. Māori by nature are a storytelling people. According to Orbell (1995) “All societies possess collections of narratives which explain the past, and therefore the present” (p. 10). It is therefore no surprise that our traditional narratives have great influence on our culture.

Within traditional Māori society stories were a method of passing on knowledge in narrative form within oral traditions. Smith (1999) explains that today “Storytelling, oral histories; the perspectives of elders and of women have become an integral part of all indigenous research. Each individual story is powerful” (p.144). Smith also points out however, that the telling of the stories is not the main purpose. What is more important is the contribution individual stories have to collective stories “in which every indigenous person has a place” (p. 144). Therefore the stories are about the relationships we have *with* each other (*whakapapa*) and consequently the collective responsibility that we have *to* each other (*whanaungatanga*).

Thus, a critical technique in gathering the data was using a life story approach. Atkinson (2001) discusses his idea of life story interviews with this claim:

In traditional communities of the past, stories played a central role in the lives of the people. It was through story that the timeless elements of life were transmitted.

Stories told from generation to generation carried enduring values as well as lessons about life lived deeply. (p. 121)

Binney (2004) argues that “Oral histories of the Māori as a people handed down primarily through song, proverbs and genealogies are intimately bound with the histories of particular families” (p. 203). It seems that breast cancer has not been a subject talked about through conversation over the generations, whether in waiata, haka, or whakatauki. However it does now have an important place in our oral histories for whānau. The untold stories, and consequently unknown stories of cancer history, have restricted the ability to maintain good health as breast cancer seems to have been confined to only the most recent generations. We now know that early detection measures such as regular breast screening are valuable and this type of knowledge is power, including the power to take care of oneself and our whānau to the best of our ability.

### **3.2.3 Self as lens:**

From a personal view, the experience was a whirlwind of emotions. From anger, to despair, to depression and confusion, the feelings were horrendous. There are questions that plague your thoughts such as - How did this happen? Why me? - I’m fit and active! Sleep is minimal as these thoughts take over your world. One of the most important strategies to get through a dramatic experience such as cancer is the support from whānau, and this was certainly my experience. Importantly, my whānau were aware that I am the third generation in my maternal whakapapa to have been diagnosed with breast cancer. Unfortunately for my grandmother and aunty, the late diagnoses of their breast

cancer consequently meant their lives were cut short and they both passed away in their early 50s. The difference in outcomes for them and myself, show the absolute necessity of early diagnosis. For reasons that can only be speculated about, my Nan and aunty would not have had the support and encouragement that we are now provided with.

These and other experiences enabled me to have a shared understanding of the emotions and challenges of being diagnosed with breast cancer, with the participants of the study. This could be termed 'insider research', which has become quite common in qualitative research. As noted by Taylor (2011), insider research is "[f]avoured by ethnographers with some degree of closeness to the culture they wish to examine" (p. 3). Edwards (2002) writes of 'deep insider research', defining it as "research that is undertaken by a person who has been a member of the organisation or group under research" (p. 71). I share Māori culture with the participants as well as the experiences of being a wahine with breast cancer.

Taylor (2002) also notes that "While being intimately inside one's field does offer significant advantages, it also reshapes the researcher's role in and experiences of her own culture and those within it" (p. 3). De Lyser (2010) writes that "An important aspect of my work became understanding how I was a part of my own research and negotiating the challenges that being an "insider" presented" (p. 441). Certainly there were several challenges I faced during the interviews with the participants.

One of these challenges was that when the participants spoke of their experiences and the associated emotions, there were times when my own emotions were brought up in remembrance of my own experiences. I was able to identify with their stories, and in some sense lived their stories too, feeling empathy and connectedness, even in instances where

the experiences were not the same and I could not relate directly. For example, as my cancer was detected earlier than that of the participants, I did not have to go through chemotherapy, radiotherapy or drug therapies. Nevertheless I could easily imagine the associated emotions. There were times when the participants cried, and I cried too. I found it almost impossible to be detached and unemotional.

However, I feel that this also allowed me to show the wāhine that I was empathetic and understood what they were talking about. With regard to her Treaty of Waitangi claims' research, George (2003) states that for her, working with the participants was about "Culture meeting culture, subjectivity meeting subjectivity, wairua meeting wairua" (p. 74). For many Māori, research is about relationships – whakapapa and whanaungatanga – and what we were sharing was the whakapapa of our disease. Within this sharing and relationship building though, I approached each interview as unique, and each participant as unique. There were times when the participants would ask me about my own experiences but I didn't always tell them, because I felt that at certain points in the interview, the focus had to be on their experiences, not mine.

Utilising 'self as lens' the understandings and relationships between researcher and participants were able to be established and advanced without difficulty. Many of the women's experiences resonated with my own, and while I didn't impose my experiences over theirs, I nevertheless was able to know them in a deeper way than someone who had not experienced breast cancer. Another benefit was that it helped with my own emotional and spiritual healing process as a consequence of "Wairua meeting wairua, Māori meeting Māori" (George, 2010, p. 74) and not just about meeting another wahine who had had breast cancer. For Māori, spiritual healing is something often understood as necessary to overall wellbeing.

### **3.3 Methods:**

The aims of this project were 1) to investigate the experiences of Māori women who have been diagnosed and treated for breast cancer; 2) to provide an increased understanding of the multidimensional journey and the physical, spiritual and mental effects; and 3) to explore the effects on whānau of a breast cancer diagnosis within the family. The research question posed is “How does breast cancer impact on the wellbeing of Māori women?” Goals sought to include influencing health policy in relation to breast cancer, particularly in lowering the age for free breast screening.

#### **3.3.1 Participant Recruitment<sup>3</sup>:**

The sample criteria for this project were that participants had completed their stages of surgery and other treatments for breast cancer. I was not looking to interview wāhine who were about to have surgery or who were in treatment or nearing the end of their treatment process. I did not have the skills to manage the vulnerabilities of women in the process of treatment, such as the effects of pain associated with surgery and/or treatment or the emotions they were likely to exhibit. Therefore I was mitigating risks that may have been painful for the participants. I have personal friends that have been through the breast cancer journey and they were aware of my experience, so it was no surprise to them that I was looking for participants to interview for this research topic, and two were willing to participate. After gaining ethics approval, I immediately started making contact with other wāhine in my networks that were potential candidates to participate in the study. The group of wāhine involved was a purposive sample as opposed to a random sample; i.e. I

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<sup>3</sup> See Appendices for copies of the ethics approval letter, Information Sheet, Consent Form, and Interview Schedule.

consciously selected participants who fulfilled the criteria outlined above especially that of having experienced breast cancer.

The participants were then identified in a variety of ways: Olive and Ihaia are friends; Ramari is the aunty of a friend; Brigitte is a colleague who then suggested I interview her mother (Jackie) as well; and I met Moana at a breast cancer event. An invitation to participate was conducted *kanohi-ki-te-kanohi* (face-to-face). This approach is most appropriate from a cultural dimension and is considered to reflect Māori cultural norms. It was not difficult to find participants to share their stories of breast cancer. I had to turn women away because I just did not have the resources to interview more than six *wāhine*. All the interviews were *kanohi-ki-te-kanohi* and were not negotiable as it is the preferred manner for Māori, unless circumstances are such that they cannot take place. All the interviews were held in Auckland, except for Brigitte's and Jackie's who live further south.

All but one of the women gave permission to use their real names in the research study. One woman chose a *nom de plume* for herself. Use of real names however, means that anonymity of the participants cannot be guaranteed. Confidentiality relates to the ethical use of the information given in the stories, to ensure that while details of the women's lives are used in the thesis, this is done so in a sensitive manner that maintains the dignity of the *wāhine*. For similar reasons, care was taken with the storage of the data.

### **3.3.2 Participant Interviews:**

Interviews were organised and scheduled to suit the participants. There were times when the place of meeting was not appropriate for reasons of confidentiality and/or being too noisy. These issues were realised after the participants understood the true nature of the

study. After an overview on what the study required we then moved to an appropriate setting. In one case the original setting was chosen by the participant for childcare reasons and we needed to be close to where the children were. There was definitely a need to be flexible, and on a couple of occasions interview arrangements were changed. This kind of flexibility is a necessity for qualitative research of this nature, as the participant needs must be made a priority with them at the centre of the process. I was prepared with the voice recorder, Information Sheet, Consent Form, koha (petrol vouchers and *Wahine ki te wahine: Ngā piki ngā heke. Woman to woman: Our ups and downs* DVD), and kai to go with a cup of tea/coffee. The purpose of koha is a recognition and acknowledgement for the participant's knowledge and sharing of stories.

Bishop (1999) suggests that stories allow the diversities of truth and meaning, rather than one dominant version. He extends his comments to include the purpose of koha during the process of storytelling as an offering from the researcher to the participant to assist with the meeting process. The participant has the opportunity to accept or refuse the offer which is given as recognition of their input to the research. Sporle and Koea (2004) agree that it may be appropriate to provide koha in recognition of the contribution that participants make to the research process. For this reason, providing koha to all the wāhine was practiced although all were reluctant to accept.

I was greeted with respect and curiosity. Our whakawhanaungatanga (relationship building) happened easily; however I soon realised I needed to get on with the interview. The women knew that time was limited and would ask for another catch-up, but in a much less formal way. For me, this meant we had more than a researcher–participant relationship; we were whānau in the sense of sharing a common kaupapa.

All the interviews commenced and were completed with karakia, but these were not recorded because of their sacred nature. On one occasion a participant offered to close the interview with karakia. I was honoured, and again this was not recorded. The trust from this participant towards me ensured that ours was more than just a researcher/participant relationship. Although we were from different iwi, we were whānau in the sense that we shared not only our ethnic and cultural backgrounds, but also our experience of breast cancer.

Interviews lasted for between 40 and 90 minutes in which the richness of the data was collected on voice recorder. There was no reluctance from participants to share freely, and some women could have gone on to share much more. While ensuring that the topic got the time and focus it deserved, I nevertheless managed to keep within the realms of Te Whare Tapa Whā. In this way we could be more structured with our time and dialogue. While this could be criticised as restricting the flow of storytelling, I felt that there had been sufficient time to gather the necessary information, and we had moved on to more general discussions that weren't necessarily relevant to the research project.

With the data collection complete, the next step was to transcribe the information. The transcribing process of the data required many hours of quiet and full concentration. I did not prepare myself well for the time required and it took a lot longer than I had imagined. The purpose of me transcribing the information was to further absorb the discussions. As a result of transcribing the data, I was able to relive the emotions that took place throughout the interviews. I could recall the moments of laughter and sadness, and the tears shed, the pauses and general quietness as interviewees shared their journey with breast cancer. These emotions were as important as the dialogue shared.

### **3.3.3 Māori worldview approach:**

#### ***Karakia:***

As part of kaupapa Māori methods, karakia was done at the start and end of the interview. As mentioned above, I did not record the karakia as I did not think it was appropriate to do so due to its sacred nature. According to Royal (1992), traditionally, Māori information and knowledge resided in the memories and minds of the people. It was not recorded in books or in any other such medium. Knowledge was passed down from parents and elders to children in informal and formal learning situations by oral expression. Karakia was one such learning that has continued to be an important practice for many Māori. These practices are significant to the spiritual wellbeing of Māori. Royal (1992) maintains that “Karakia was extremely important to them as a tool for maintaining good spirituality as a taproot of all things, and all activities, including intellectual pursuits, were attended by appropriate karakia” (p. 12). Since the arrival of Pākehā however, much information and knowledge has been recorded. Using media such as books and films and sound tape, Māori information has been recorded both formally and informally (Royal, 1992). Karakia remains fundamental to everyday engagement and activities for many Māori.

For this project karakia was as important as sharing my whakapapa. Karakia opened the way to the process of being able to share each other’s whakapapa, build the relationships and trust to continue with the project. Throughout the discussions interviewees would recount their knowledge of whakapapa and the history of cancers within their whānau.

**Whakapapa:**

The most common and best understood use of whakapapa is to identify one's whānau, hapū and iwi. This is important to build relationships, although whakapapa is just one aspect of this. In the figure below, Hudson et al., (2010) lays out a model that explains whakapapa:

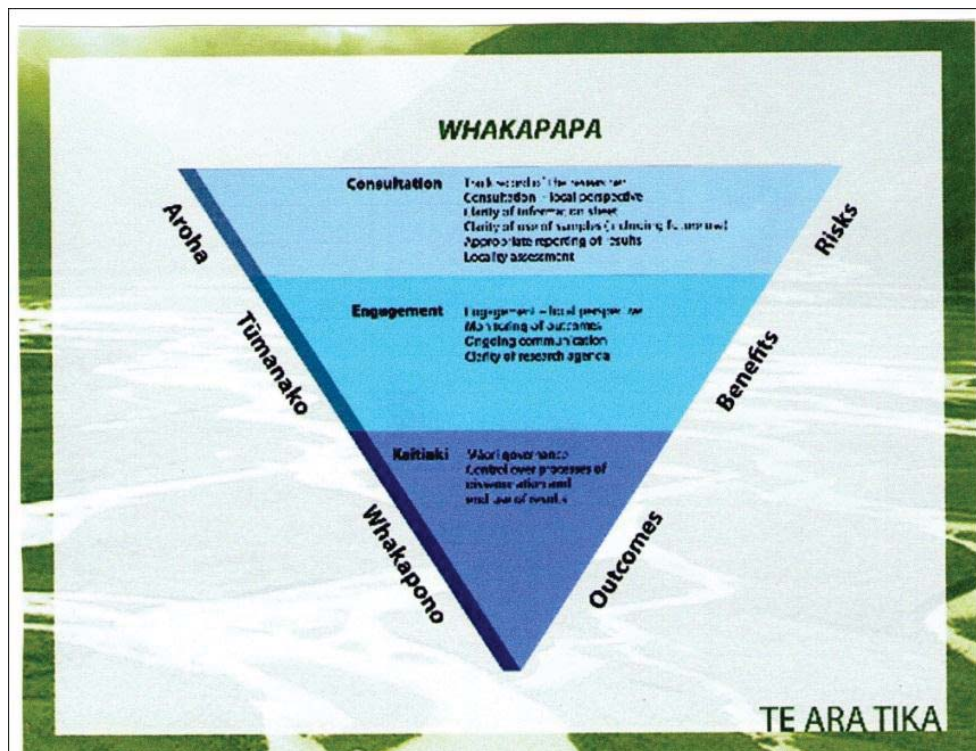


Figure 5: Whakapapa (Source: Hudson et al., 2010, p. 6)

Within the context of decision-making about ethics, whakapapa refers to the quality of relationships and the structures or processes that have been established to support these relationships. In research, the development and maintenance of trustworthy relationships between researcher and research participants forms a powerful partnership. This

partnership has the potential to extend to other areas of research and more specifically, can build interest for other research projects.

**Whānau:**

In 2011, I developed the W.H.Ā.N.A.U engagement model below, which provides an approach for ensuring that working with whānau is done in a concise and simple way:

| WHĀNAU ENGAGEMENT MODEL |                              |
|-------------------------|------------------------------|
| W                       | Why, what, when, where, who? |
| H                       | How?                         |
| Ā                       | Assist parents               |
| N                       | Networks                     |
| A                       | Acknowledge                  |
| U                       | Unite                        |

**Figure 6: WHĀNAU Engagement Model (Source: Te Momo & Ripia, 2011, p. 138)**

In aligning the Whānau Engagement Model to the health issue of breast cancer among Māori women, the model is modified as follows:

**W: Why** is this research important? Provide the women with clear explanations about why the research is being conducted. **What** will the research be used for? What is it that we are hoping to gain from interviewing the women? **When** is a good time to meet with each participant diagnosed and treated for breast cancer? As the interviewer, **where** will I meet with these women? **Who** will be present when the interview takes place?

**H: How** will the interviews be conducted? Are the participants clear that they will be recorded with a voice recorder and the conversations transcribed and used in the final thesis?

**Ā:** How do whānau **assist** the participant during and after the interviews? Do they assist with resources, finance, driving, karakia, and/or himene?

**N:** What **networks** are available to the participants? Are they aware of the resources in their communities? Do participants know that 'Look Good, Feel Good' social gatherings take place and where these are held?

**A:** It is of major importance that the participants and their whānau are **acknowledged** for their assistance and support in this research project. **Also how** do they **acknowledge** the services available to them and how do they access the resources?

**U:** Participants have clear descriptions around how their information will be disseminated. As the researcher it is my responsibility to ensure I work with the material to ensure their recommendations are actioned appropriately. Also by knowing what is available and where to access services they can **unite** with available carers and organisations to ensure they get the services they are entitled to, such as with insurance companies and breast care services.

This framework places whānau at the forefront of discussions. For this reason the support from me as the researcher was to ensure that care and management during the interviews valued and practised manaakitanga.

### ***Manaakitanga***

The practice of manaakitanga is the process of caring for self and others with high regard. It also ensures safety for both parties. Manaakitanga was demonstrated prior to and during the research processes. For example, during the recruiting phase, it was important that permission to conduct this research was fully understood by potential participants and they

were clear that there was no obligation for them to participate. During the interviews, respect was shown to the wāhine by ensuring that if they felt uncomfortable at any stage, they would be fully supported to withdraw from the study. Finally, the mana of each wāhine was respected through their stories becoming available to be read, discussed, shared, and referenced by iwi Māori as we seek to improve our health outcomes. My intention is that the wāhine and their whānau are respected for the significant contribution they have made to understanding Māori women's experience of breast cancer

Manaakitanga also has the ability to accelerate the healing of cancer patients as this care and support helps alleviate stress. Manaakitanga is usually demonstrated by everyone involved in the lives of patients. Dr Pita Sharples announced at the Higher Education Research and Development Society of Australasia Conference in 2008 that in Te Ao Māori, a very high value is placed on manaakitanga (Sharples, 2008). The principle of manaakitanga is represented in all rituals of encounter. Manaakitanga begins before the encounter takes place, while there are also obligations on the visitors to show respect and manaaki to the hosts. The reciprocal nature of manaaki potentially speeds up recovery and decreases the stress and uncertainty within any environment. Whether at home, at work, or in the hospital, it is the care that makes the difference to the experience of breast cancer.

As stated in Hudson et al., (2010), the concept of manaakitanga encompasses a range of meanings in a traditional sense with a central focus on ensuring the mana of both parties is upheld. In this context it is associated with notions of cultural and social responsibility and respect for persons (Health Research Council of New Zealand, n.d.). Manaakitanga very much extends to healthcare providers' care. Cram, Smith and Johnstone (2003) investigated how Māori talk about health; Māori health; and Māori experiences of

interacting with both mainstream and Māori providers of healthcare. Breast care providers and specialists have a great responsibility to ensure good practice of manaaki is demonstrated to women going through breast cancer.

### **3.4 Analysis:**

Te Whare Tapa Whā will be used as the method of analysis to gather the information from the women interviewed, due to its connection to the concepts and values within Te Ao Maori. It is with these four cornerstones that I will relate the impacts of breast cancer among Māori women. The inner strength of these women was significantly tested after being diagnosed with breast cancer, but with the support of those around them and professionals they were able to identify their own limits relating to restoring their wellbeing back into balance.

Accordingly, the Ministry of Health provides useful models to explain each aspect and how the whole promotes a balance of wellbeing<sup>4</sup>.

#### ***Te taha tinana (physical wellbeing)***



To facilitate strength in physical growth and development - Our physical existence supports our ability to manage other areas of our environment. The physical

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<sup>4</sup> The four figures below (Figures 7-10) come from the Ministry of Health website - <http://www.health.govt.nz/our-work/populations/Māori-health/Māori-health-models/Māori-health-models-te-whare-tapa-wha>

dimension is just one aspect of health and well-being and cannot be separated from the aspect of mind, spirit, and family.

***Te taha hinengaro (mental and emotional wellbeing)***



The ability to communicate, to think and to feel mind and body are inseparable - Thoughts, feelings and emotions are integral components of the body and soul. The mental and emotional wellbeing is how we see ourselves within the universe and how we manage these feelings.

***Te taha whānau (extended family and social wellbeing)***



The sense of belonging and staying connected to whānau is the absolute to extended family and social wellbeing - Whānau provides us with the strength to be who we are and know our place in this world. This is the link to our ancestors, our ties with the past, the present and the future.

***Te taha wairua (spiritual wellbeing)***



The strength of faith and wider communication is relevant to spiritual wellbeing - Optimal health is related to unseen and unspoken energies. The spiritual essence of a person is their life force. A traditional Māori analysis of physical

manifestations of illness focuses on the wairua (inner spirit) to determine whether harm is a contributing factor.

Based on these four aspects I developed a framework for data collection to demonstrate a method for utilising a kaupapa Māori methodology to illustrate the findings from the interview transcripts off the wāhine.

**Table 2: Te Whare Tapa Whā framework**

|   |  |
|---|--|
| <p><b>Te taha tinana – the physical dimension</b></p> <p>What types of trauma did the body experience?<br/>         How did it affect your body image?<br/>         Were there artificial dressings required and what kind?</p> | <p><b>Te taha wairua – the spiritual dimension</b></p> <p>Was an awareness of wairua significant for you?<br/>         Did karakia become more important?<br/>         Was there an intensity of things spiritual?</p> |
| <p><b>Te taha whānau – the extended family and social dimension</b></p> <p>Were cancer histories suddenly told?<br/>         What kind of support and/or challenges were there?<br/>         Was there appropriate manaaki?</p> | <p><b>Te taha hinengaro – the mental and emotional dimension</b></p> <p>How did you manage grief?<br/>         Was depression an issue?<br/>         Who/what helped with coping mechanisms?</p>                       |

Analysis of the data needed to be carefully thought through and processed. To ensure the integrity of the data I was entrusted with, all dimensions of Te Whare Tapa Whā were captured and recorded within each particular aspect which was sometimes difficult as each dimension influences the others. For example, to separate emotions from the physical pain

caused by breast cancer was difficult to comprehend. Therefore, although the table above shows that particular data has been placed under certain headings, for the exercise of this thesis it is to capture the points of difference relating to the impacts of breast cancer on the wellbeing of wāhine Māori survivors.

A brief explanation follows of how the analysis was finally decided: *Te taha tinana – the physical dimension* was aimed at what types of trauma did the body experience and how did it affect body image? Were there artificial dressings required and what kind? *Te taha wairua – the spiritual dimension* raised questions such as - Was an awareness of wairua significant for you? Did karakia become more important? Was there an intensity of things spiritual? *Te taha whānau – the extended family and social dimension* warranted questions such as - Were cancer histories suddenly told? What kind of support and/or challenges were there? Was there appropriate manaaki? *Te taha hinengaro – the mental and emotional dimension* was explored through - How did you manage grief? Was depression an issue? Who/what helped with coping? I wondered if there could be a better way to streamline the dimensions, however the analysis and writing co-constructed the meaningful threads and themes in to a whole. This can be likened to a piece of art that has had many people contribute to it, and the goal would be a masterpiece that deeply honours the contribution of all. What is presented here can still be considered a beautifully woven kūpenga that validates a particular perspective within our world.

According to the ethical guidelines within a kaupapa Māori framework, the ownership of the data belongs to the women who participated, and therefore there is a responsibility to keep all the data including unused data safe. A copy of each transcript was returned to the participants to ensure they were satisfied with the information they had provided, or to add anything further. Spiller, Pio and Erakovic (2011) claim that by drawing on Māori values,

we present a wisdom position through the ethics of kaitiakitanga (guardianship) to emphasise and illustrate the interconnectedness of life in a woven universe. The guardians of the data are the researchers who weave the richness of the stories and histories of the participants and their whānau for the benefit of future generations.

### **3.5 Ethics:**

During my interview with the University Ethics Committee, I was advised to remove a sentence regarding my claim that the interviews with participants would or could be emotionally and/or spiritually healing because they can talk about their experience with someone who has also experienced the journey of breast cancer. I was bemused by this instruction, but did as advised. It was very interesting however, that although I did not specifically ask during the interviews, many participants actually acknowledged that they felt the interview was healing for them in the sense that they can share with someone Māori who has had a similar experience. This is perhaps an example of the importance of including a wairua dimension in our work, which in this case allowed for the acknowledgement of the healing that occurred during the research process.

Nevertheless, the ethics application process provided me with the opportunity to develop clear guidelines and practices for carrying out the research. *Te Ara Tika: Guidelines for Māori Research Ethics* (Hudson et al., 2010) is a useful tool that ensures a cultural approach to researching in a kaupapa Māori way. For example, the Māori ethical framework points out that to ensure best practice, whakapapa, tika, manaakitanga and mana are upheld in proceeding with research. The importance of these practices being applied to the process of research maintains the integrity for all involved. The example

outlined below incorporates the relevant Māori concepts such as manaakitanga, whakapapa, mana and tika. The use of kaupapa Māori methodologies helps ensure the ethical and actual safety of all participants. As noted by Hudson, et al. (2010), “Ethics is about values, and ethical behaviour reflects values held by people at large. For Māori, ethics is about ‘tikanga’ – for tikanga reflects our values, our beliefs and the way we view the world” (p. 2).

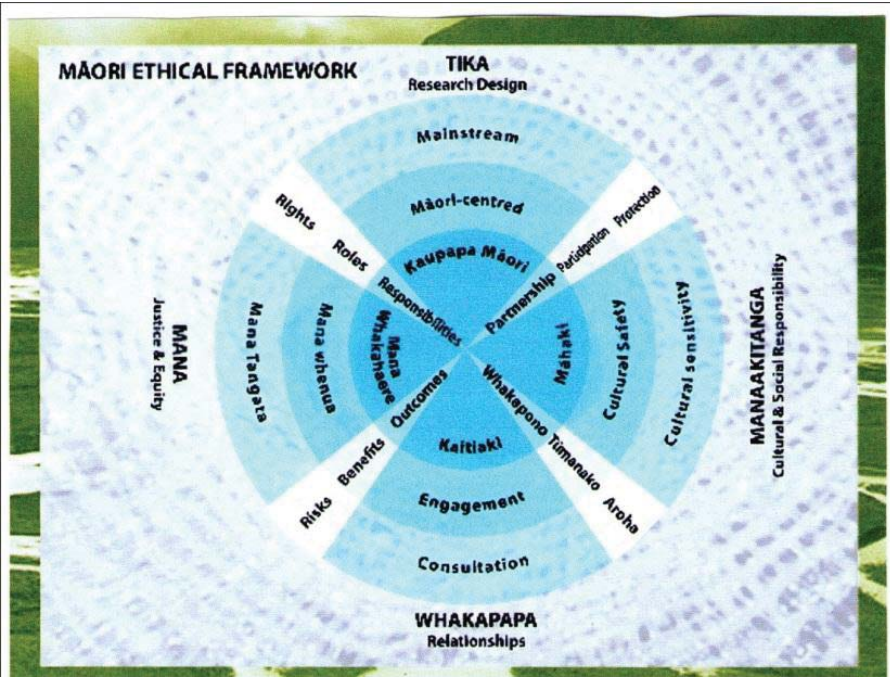


Figure 11: Māori ethical framework (Source – Hudson, et al., 2010, p. 4)

Spiller et al. (2011) demonstrate the values which comprise our woven universe and emerging from within a Māori wisdom tradition. These values offer an elegant simplicity designed to communicate with both researchers and practitioners (Spiller et al., 2011). This allows for the integrity of the project and the trust between parties.

Tupara (2011) expands further:

Whether indigenous standards are required for ethical review does not appear to be the most pressing issue. Over the past two decades, there has been growing recognition among ethicists internationally that morals are human inventions that are culturally constructed, including indigenous culture. Culture plays a significant role in guiding moral judgment and behaviour, and therefore attitudes, ideas, and decisions about health and well-being (p. 367).

Tupara is correct in recognising how culture plays an important role in the decisions pertaining to research involving Māori and their whānau. Potential ethical issues for this study included respecting the cultural needs of each individual participant, and not assuming because they were Māori, they would be fully comfortable with a Māori approach. Another was the sensitivity of the subject, for example the ethical process to take should a wahine feel that an aspect of her story was something she did not wish to discuss. Managing any emotional distress could have required me to contact a close whānau member to return to support the participant. Being aware of the possible scenarios involved with this research topic was at the forefront of my processes.

### **3.6 Conclusion:**

Gathering the stories in the 'net' was in many ways, simple. Perhaps the conditions were suitable and the tools used to support the work were the most appropriate. The women

were very willing to share, and believed that their sharing would enable them to help other Māori women who mattered to them.

Binney (2004) claims that stories Māori tell about their own families “differ sharply from traditional white historiography, the perspective of the 'Pākehā’” (p. 203). This experience of research has definitely widened my perspectives around the usefulness of research as a development tool, and has motivated me to explore other topics of interest. Kaupapa Māori and life-story interviews are pertinent methodologies to use and validate our work within a Te Ao Māori paradigm. Bringing the stories to ‘life’ has been an honour and privilege. The honour of being told these stories and then the privilege to recall them in transcripts was truly a great experience. My own story seemed both less and more significant after hearing what was told and felt by all the participants.

I am incredibly humbled by the stories told by the women. Their acceptance and enthusiasm of participating in this research was definitely an experience I will not forget. I could not be more proud of the work, their work, which has gone into weaving their stories and capturing them in a net that brings it all together. The metaphor of the net encapsulates everything involved in bringing this rich catch together, and as a novice ‘fisher’ I am truly grateful for the experience.

## CHAPTER FOUR – DATA ANALYSIS

Verse Six:

*Whether to tell, to share or to keep  
All we want is a good night's sleep  
The worry, the stress, the concern is depressing  
Nurses are careful when checking the dressing.*

### 4.1 Introduction:

“I’m sorry to tell you this but you have been diagnosed with breast cancer”

As the recipient of that news you sit there analysing what was just told to you and questions flood the mind. Did I just hear correctly? Did the doctor just tell me I have breast cancer? Are they sure they have the right person? Who do I tell? Do I tell? When do I tell? After doing your best to break down the information, the fact remains that you have just been told you have breast cancer. Upon receiving my positive diagnosis, I just wanted to leave the GP’s office and cry.

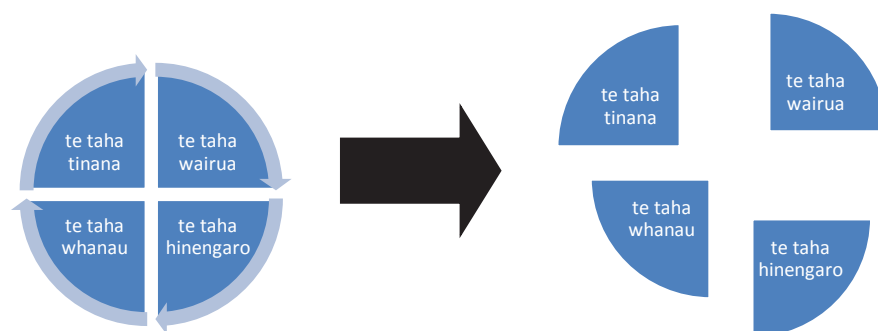
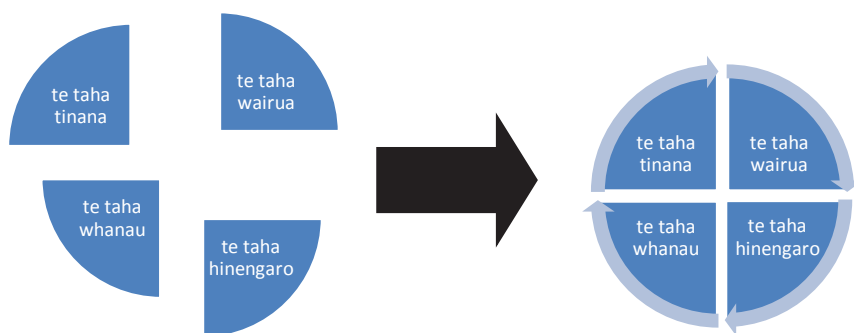


Figure 12: Post-trauma imbalance of Te Whare Tapa Whā (see Ripia, 2013, p. 135)

The strength you thought you once had has just shattered. Your world feels like it is collapsing. The balance of Te Whare Tapa Whā has suddenly fallen apart around you (see Figures 12 and 13).

This chapter will draw the narratives together to help others understand what someone diagnosed with breast cancer goes through. We all experienced our breast cancer journeys quite differently, but in some ways quite the same. It is also about the journeys of bringing our worlds back into alignment (see Figure 9 below).



**Figure 13: Rebalancing Te Whare Tapa Whā (Ripia, 2013, p. 135)**

The following sections demonstrate how the women's narratives fit into the dimensions of Te Whare Tapa Whā. As noted in Chapter Three, while the narratives are separated into the different dimensions of Te Whare Tapa Whā, they are nevertheless interlinked and some overlap into another dimension. For the purposes of this data analysis however it was necessary to separate them in this way.

## **4.2 Te Taha Tinana – Physical Wellbeing:**

Breast cancer and its treatment have a range of effects on the physical body and these physical changes can affect how others interact with the sufferer. There are several treatments for breast cancer, including surgery, radiotherapy and chemotherapy. Surgery can entail an initial biopsy, followed by the removal of cancerous lumps (lumpectomy – includes about 1cm of healthy tissue), through to the severity of losing the entire breast (mastectomy). Modified radical mastectomy includes removal of the lymph glands. There is opportunity for reconstructive breast surgery at the same time as the mastectomy operation or at a later date. The aim is to recreate a breast that looks and feels as natural as possible for the purpose of a physical and emotional connection (Southern Cross Healthcare Group, 2012).

Non-surgical treatments are also used; radiotherapy is used to destroy any residual cancer cells following lumpectomy and/or mastectomy. Chemotherapy uses medications if the cancer has spread or is suspected of spreading. Although chemotherapy affects people in different ways, these effects include the feeling of being tired all the time, not wanting to eat, having no energy, and nausea and vomiting after the procedure. Another side effect, hair loss, can make it more obvious to an observer that a serious illness is present. Observers can often avoid engaging with the sufferer for fear of asking the wrong questions or saying the wrong thing. Making an assumption of the health of someone can be an awkward situation for both parties, especially if the observer has no knowledge of the diagnosis or illness and/or has not seen the patient in a while.

The physical appearance of someone with an illness such as breast cancer can affect the patient in the sense that she feels she has to explain that although her health may not be good, things are improving for the better. What is less obvious is the strength needed to

maintain a positive attitude despite the physical trauma. The line between the physical and emotional impacts can be very fine and can readily merge, such that 'I'm feeling like this because I look like this'.

When Ihaia was initially diagnosed she went into a minor panic and felt she needed further attention sooner than the specialist had advised. This anxiety built-up further concerns and Ihaia felt that the cancer may be spreading. She was convinced that other parts of her body were being affected by the cancer diagnosis and therefore sat in her GP's Waiting Room wanting more medical advice:

*My arm and my shoulder were sore because I was stressed out! And so it had tensed the whole side of my body, the side I had been diagnosed on. I actually thought the cancer was eating away at me! But it was just stress; I stressed myself out so much that I tensed up!*

Moana spoke of her shock on being told about the diagnosis:

*The doctor said something along the lines of, "We need to remove the whole of your left breast for you to live". That was his sentence and at the time I was like, 'Oh that must be pretty bad for them to want to take the whole left side off'. I immediately said and I said it a little flippantly, "Oh, lop it off" [chuckle]. When I think about it now [laughing], that's not very elegant [laughing]. Well I wasn't feeling elegant so I said, instead of chop it off - lop it off [laughing]! He was nodding and happy with my response. For me I was just thinking, at that moment, I just want to live! Do whatever it takes for me to live, I don't care just make it so for my kids!*

Further to Moana's experience was a moment of realisation that this was for real:

*You know the, 'out of body' kind of feel about it, like I was observing myself [laughter]. I remember blinking a lot because I was blinking back tears. So I cried a couple of tears, no sobbing [chuckle]. No sobbing allowed [laughter]! It was shock, the whole shock of it!*

Moana felt somewhat prepared for the experience given her childhood heart surgery, "But it was still a huge adjustment in the mind".

Brigitte was devastated to hear her doctor tell her that she had breast cancer:

*Unbelievable, I didn't believe it. Took me a bit of a while to actually believe that I actually had cancer, yeah, because I don't get those things! That's how you feel, that's how I felt.*

Jackie also had strong emotions associated with hearing the news of a positive diagnosis:

*For me I knew I had it, I knew I had the lump. And I thought 'Oh gosh, here I go just like my sisters' [Un]like my mum, who was 99; she never had a day's illness in her life. I was really, really angry.*

The news received by Olive was far from what she had expected:

*I suppose my first reaction was that I was going to die tomorrow, something like that. It's just the initial shock and why did it happen to me because I'm not a smoker and I'm not a drinker, so I was thinking why did it happen to me!? It was just the initial shock but luckily for me I took whānau along with me. I just thought, it [doctor's letter] just said to bring family along just in case so I just thought, I'll get*

*somebody and get it all over and done with, but I didn't think I'd get the result that I got. So yeah, it was the initial shock I suppose!*

Olive's reaction to her diagnosis was compounded by recent whānau loss:

*Probably about four weeks, yeah about a month [until receiving the diagnosis]. At that same time we had just buried my mum on the Monday and my appointment was on the Tuesday. So I mean a lot of the emotion was fresh from losing our mum. I was going for tests while she was really, really ill. And then it wasn't long after that that they said I needed surgery to remove it and it was sort of 'bang, bang, bang', after that.*

Olive's breast cancer was nearly undetected however. Although she suffered from physical pain the cause of which was difficult to pinpoint, breast cancer was the last cause she would have considered as she had only recently reached the age of free mammograms. Her kōrero (dialogue) highlights the need for more education on breast care and breast screening for younger women and a shift in perception:

*Well I don't need to go until I'm 45, I won't get cancer until I'm 45, it won't happen to me until I'm 45...I would not have gone if I had to pay for it, I wouldn't have gone! I would have said to my doctor, "No I'll just leave it thanks. I'll survive my sore chest [chuckle]". I wouldn't have gone! And that's probably true with a lot of women. With these young mums with five kids, they need to get checked out themselves because at such a young age it does something to your body, it changes. I was a rugby player from way back and so I would get booted and kicked and everything so I would think that may not have helped it as well. I don't know. All the bumps*

*and bruises. I don't think there's a lot of education out there for breast cancer because it hits so many people.*

Ramari, unfortunately, had to deal with two types of cancer:

*Yeah, but that was the only time I really cried [when diagnosed with breast cancer], yeah pretty much. Because I had my bowel cancer you see, but it's not an aggressive one. But I've always known about this and with both I said to them (doctors) that I received a phone call about this one the same day and that's when the breast doctor said, "We'll have to talk to the bowel doctor to see what to do." Even though I wasn't worried about the bowel part because I'd had it for over a year and they hadn't followed through so obviously it wasn't major, and then when this [breast cancer] came they said, "Yeah, it is" [major].*

Ramari spoke further about how her breast cancer was detected:

*Yes, [a lump] in my breast which was very noticeable but I hadn't picked it up. And it was funny, because I waited for about three days and when I did it felt like a peanut. So everything started moving, they said be in here in two weeks blah, blah and then I had my surgery at the end of August. It went so quickly, but good. They operated on both [cancers - breast and bowel] at the same time.*

The external and sometimes obvious elements of someone going through treatment for breast cancer can cause a person to withdraw from attending functions that would normally be a priority. The impacts that are most concerning for the women because of their obvious nature include hair loss, looking frail and ill, and wearing full winter attire during the hottest time of the year due to the effects of chemotherapy. Another physical aspect that most of the women endured was the fact that they ate more and were probably

less conscious of the types of foods they consumed, and therefore gained weight. Weight gain added to the women's self-consciousness of the negative changes to their physical appearance.

Energy levels were diminished after treatment sessions and therefore their motivation and confidence were tested when asked to attend events. Ihaia had moments when she knew attending functions would be difficult while she continued to work through radiation treatment. She would prepare for events and suddenly realise she actually couldn't attend because of the way she felt about her physical appearance. Ihaia shared this experience:

*Well I was meant to go to a Māori Mental Health Awards' dinner. I got dressed up and looked in the mirror and thought, "Nah I don't want to go!" I wasn't happy about my body image and what I looked like [clears throat].*

Ihaia was very uncomfortable about her physical appearance and her hair loss in particular - "No hair!" She was not the only one severely impacted by her loss of hair. Her younger son was shocked to see his mum without hair:

*The visual thing impacted on him really bad. He couldn't stop staring at me actually, because my hair was actually quite long and thick and then, of course nothing!*

This was not the only reason she would cancel out of functions. Ihaia would be physically drained from the effects of chemotherapy:

*I got really tired. I fell asleep in the chair. I got really, really, tired. That was the last one, thank goodness! I had no taste for food; [chemo] impacted on my taste buds. It just felt like I wanted to be sick, you know, just wanting to puke.*

Ramari was aware that her hair would fall out after chemotherapy and had mentally prepared herself as much as possible for this experience:

*Well, you know it's going to happen. You could just go like this [demonstrates pulling hair] and your hair just falls out. I thought this is ridiculous, so I went to the hairdresser and they made a mess of it, so I got my girls to shave it all off because it was falling out in clumps. It was yuck!*

With the determination to not feel sorry for herself Ramari felt ready for the impact of losing her hair: *"I always kept warm. I wore beanies to bed, and you kind of just got used to it really!"* This attitude was common among all the women interviewed. They knew they had to build their emotional and spiritual as well as physical strength in order to regain their health.

At the time of hearing the news, Moana was more concerned about how to rid herself of the cancer than the physical effects. However, her story regarding the impacts of chemotherapy on her body is similar to that of Ramari and Ihaia:

*My experience, especially from chemo, my appetite was gone and more than that I couldn't stand the smell of food cooking, which was odd because I love food! [laughter]. Some days I could feel it right up my nostrils; it was a heightened sense of smell for me, and I could smell it a mile away.*

Moana knew that that was unusual behaviour for someone who enjoyed her food a lot. She did however muster the strength to get back to normal behaviour; *"I enjoy my food more [laughter] now that everything is over".*

The physical impacts also included requirements regarding clean and sterile spaces for the women. This is significant to the recovery of breast cancer survivors in that if their space is not clean and germ-free they could spend more time in hospital. Moana was very careful about her physical surroundings. If she felt she might come into contact with others who had communicable diseases, she would not attend events or even visit friends and whānau. In this way she could keep her energy up as best she could:

*Sometimes I was a bit more careful. When I was a bit low on my reserves like needing a sterile environment after the bouts of chemo and not needing to be beside someone that's been coughing all day, I would say, "Sorry I heard that someone's coughing over there. I don't need to be there but I'll send my husband over [laughing]"*

Rest is essential for the healing of the physical body. As much as time allowed, all these wāhine needed to balance their already stretched lives, in order to gain sufficient rest for their recovery. The physical impacts of weight-gain, hair-loss, and tiredness were a strain on the wāhine as they continued to cope with all the other duties of being a mother, sister, daughter and wife.

Olive's treatment included trips to Australia:

*It was at the time that the machines, the radiology machines were breaking down in Auckland and so they shipped us over to Australia. I mean I got rung up on a Friday and they had booked me tickets for the next day, Saturday for treatment in Australia. I'm not a traveller; I'd rather see New Zealand than go to Australia, let alone go for five weeks, so yeah it was bang, bang, bang! I wasn't actually going to go to Aussie only because I'd just started my job, a new job, and then I'm being told*

*I'm going to Aussie so I phoned my boss up and told her that they've [hospital] told me I'm booked for Aussie, and I don't want to go! She just told me to go! And I'd only been in the job for a few weeks so the job was very supportive too.*

Olive's stay in Australia was complicated by contracting influenza:

*I just couldn't move for three days and if you missed your treatment you had to stay extra long, extra time. At the time it was just before Christmas and there was no way I was going to stay there for Christmas! The hospital we were going to was only three minutes' walk, but I couldn't even walk. I had to catch a taxi to the hospital because I didn't want to miss my treatment. That really knocked me.*

Jackie's treatment experiences were somewhat more positive:

*I went to her [doctor] in January and I was done [operated on] in February and I had no problems. I went for bone density. You name it I went there, everything...she was wonderful. Because of her, and now she's nearly dead because she has cancer too. She knew what it was really like, knew what the future would be like. She opened doors for me. When we went to hospital we got the best of treatment....I never wanted for anything, truly, through my doctor; she was great, and she paved the way for me and today I'm as well as can be. All because of her.*

Brigitte was in the same hospital, although the month before:

*So they truly looked after us. Mum was in the Surgical Ward and it was like a four star motel. Beautiful, only has 8 beds.*

Jackie noted however, that “*Yeah, Brigitte was more difficult because she was really, really sick*”. Brigitte added:

*It was just that I think they made a mistake in the first operation. I never went into depth with it because of the care; I think there was a blood clot that wasn't picked up previous. The night before, my cousin came round with her husband and we drank a bottle of wine. Next minute I was in hospital and my husband said it was the wine. I said, "It was not!! [laughing]"*

The importance of regaining weight after chemotherapy is another issue that required strength and the ability to maintain a somewhat healthy eating plan. Ramari explains that eating was sometimes a chore after chemo, but this changed as she proceeded through the treatments:

*I ate like a horse. I think I only just slowed before Christmas [2010]. Just when everyone was eating lots, I couldn't which wasn't such a bad thing. Everyone would say, "Gee, you look good". I would laugh and say, "Yeah, probably a bit too good!" I knew I had put on weight but that was okay. I wasn't worried about it too much.*

For Ihaia, when all the necessary surgery was over, the less-invasive implant and reconstructive surgery was vital in helping her get back to some sort of normality. She was still relatively young and for this reason was happy to have the implant. Ihaia's approach was positive:

*When they took the breast away, they put an expander in during the same operation; after that I needed a saline solution pumped into it. The whole rationale behind that was to stretch my chest so they could eventually take the expander out and replace it with an implant. I opted for the implant and that was a process and a*

*half. Each week I had to go back to the Super Clinic and get the nurse to inject saline into the expander. So yeah I had that done and then the reconstruction was to take the expander out and put in the implant.*

This implant had a significant impact on Ihaia's attitude about herself and her physical appearance. However on closer examination the specialist found that the implant was not the same size as her untreated breast. This piece of conversation was full of laughter and Ihaia freely shared:

*So I decided to have my other side reduced so they would match. Because [chuckle] my boobs were large anyway and they didn't have a big enough implant to match my other side [laughter] so they had to reduce the other side otherwise I'd be walking around lopsided [laughing]. I always say my boobs are customised [laughing] because they didn't have implants big enough. So that was the funny side of the journey. It was a good positive thing as well. They've also offered to tattoo a nipple as well, should I wish....Whānau have said, "Oh gosh you may as well have the cherry on the top [laughing], you've come this far".*

One of the best things about her reconstructive surgery was that she could afford to purchase more than one brassiere at a time. She had not experienced this in a very long while:

*Yeah so got that done and it was funny because I went shopping about three weeks ago for a new bra and there were some special deals [on lingerie], and I rocked in there and got the lady to measure me. I had gone down a few cups and I went WOW! [laughing]. In the past I could only afford one bra because it had to be*

*a larger cup size because it was more expensive. I could buy two bras that day because I had smaller boobies [laughing].*

The major shift in thinking around eating and exercise enabled Moana to reassess and review her capability to make the changes required to become healthier. With a renewed appreciation for food, Moana understood the importance of keeping physically active as well:

*I have exercise machines [cross trainer] in my house. I do enjoy swimming which was recommended to me because I had lymph nodes removed, to keep supple and even. I am careful about what I eat now. I used to eat too much; actually just watching what I eat is good for me too. I have definitely changed in regards to my eating habits and exercise.*

*I think that the fuel you put into your body is very important to your overall health and wellbeing. I've actually lost a bit of weight in the past few months which is actually really good. But it's a slow process and it's a lifestyle change.*

This shift also gave Moana the motivation to do activities she would not normally consider:

*I did a triathlon. Came last in the country but I passed that damn finish line [laughing]!! I've climbed a volcano in Hawaii, doing things that I wouldn't normally do like kayaking, rowing, things like that. That's what I mean when I say it [breast cancer] motivates you.*

This final comment illustrates an important point. While there are many negative physical impacts to diagnosis and treatment for breast cancer, positive consequences can also be gained. Looking back on their journeys, the women were able to find laughter and joys, as

well as losses and tears. While experiencing a range of treatment options and physical impacts, all were able to articulate how that journey changed their attitude to their health. What the experiences showed them was that physical health and physical appearance could no longer be taken for granted.

### **4.3 Te Taha Hinengaro – Mental and Emotional Wellbeing:**

While there are definite changes and restructuring of the physical body for each wahine, the interpretation of the experience occurs in te taha hinengaro. According to the project and research team from Te Whare Wānanga o Wairaka (Unitec Institute of Technology, 2010), coherent thinking processes that acknowledge and express thoughts and feelings occur within the realm of te taha hinengaro. It is here that we attempt to make intellectual and emotional sense of our physical experiences.

The emotional and mental impact of breast cancer among the women varied in its degree of anger and eventually for some, depression. Although this roller-coaster of emotions can be considered a normal part of the process of dealing with cancer, nevertheless the range of their emotions and mental sensitivity was real, resulting in the realisation that help was needed for this imbalance. For example, the feelings of grief required a modicum of support and care from professionals, as well as whānau and friends. Stephens (1972) suggested that grief only becomes a tolerable and creative experience when love enables it to be shared with someone who really understands.

The five stages of grief are defined by Kubler-Ross and Kessler (2005) as denial, anger, bargaining, depression and acceptance, although not everyone goes through all of the stages or in a prescribed order. There is an assumption from a western perspective that

this is what all people go through. Craps (2010) however, considers that western writers tend to ignore traumatic experiences and histories of currently subordinate groups both inside and outside western society, and/or to take for granted the universal validity of definitions of trauma and recovery that have developed out of the history of western modernity. As noted by Mallon (2008), "Grief has its own rhythm, pace and refrains, which differ from person to person" (p. 103). The experience of professional and whānau support was optimised through cultural values and understandings.

For Jackie, her whakapapa had already determined her future to a certain extent with a close family history of breast cancer. Unsurprisingly she was eventually diagnosed with breast cancer. Initially she was "*Really, really, angry*", and endured considerable emotional stress during her breast cancer journey:

*I got very depressed so I had to go for help and this helped me intensely. My husband and I both went and the counselling was very good for both of us. The Cancer Society has been fantastic for us too.*

As Māori we often deal with a situation of grief and grieving through conversations and whānau hui where particular fears can be confronted or discussed, memories reviewed and a clear direction be ascertained and acted upon (Nikora, Masters-Awatere, & Awekotuku, 2012). The actions of Jackie in seeking professional support was a decision made through whānau hui, supported by whānau, and therefore a relatively simple decision.

The continuum of support changed as the needs of the wāhine changed. For this reason the value of life stories about emotional and mental wellness from these wāhine Māori give a deeper and richer understanding of this dimension. Within these narratives there is

evidence of strong whānau relationships and discussions of mental shifts in attitudes to life and ways of living.

Coping with this situation for Jackie meant ensuring the right supports; “*One day at a time*” was a quote used often by Jackie. She noted that there is a reason for everything, finding comfort in such thoughts:

*I always think if it's for the right purpose it will happen. And we're not to agonise over anything. If it's meant to be, it will happen. It's like life in general, well, I shouldn't have said that, because we don't ask for problems they just come on us so we deal with them best we can, don't we? It's mind over matter really. If you consciously make a point of it you'll get over it. I guess it's getting over the inhibitions, isn't it really? Accepting the fact that life goes on and we are making the best of it.*

Jackie talked about how she is shy and finds it difficult to relate to people at times, and prefers the company of her husband only. She also acknowledged that this puts pressure on her husband to be with her all the time; “*It's about sharing everything!*” Nevertheless he is a great support and strength for Jackie:

*I'm a bit shy. Actually I just don't want to go out and mix with other people. We're [husband and I] off to a conference next week and we've booked into a motel because we want to be by ourselves, you know? I feel sorry for my husband sometimes. Whatever you feel shy about or uncomfortable with, you've got to talk to your partner. You have to, otherwise what's the point?*

For Jackie, te taha hinengaro was linked to having faith and keeping true to the fact that with all the right supports and asking for professional help there is a shift in your mental and emotional wellbeing:

*We need to lift our spirits up! And there is hope always and its mind over matter. As I said before if you've got a lot of faith it carries you through and it really does.*

The physical changes impacted on mental and emotional wellbeing and Ihaia, like Jackie, emphasised the importance of the strength of the mind to get you through those times. Ihaia indicated that she suffered from mental and emotional stress during her journey and described her experience as:

*You actually become quite withdrawn and don't want to go out. I got all dressed up to attend a function and looked in the mirror and thought, 'Nah I don't want to go!' I didn't feel good about myself. Yep, so that sort of stuff. So yeah definitely become withdrawn.*

She said further:

*Yes so it's a mind over matter approach to things. Your mind is definitely powerful in deciding your fate. So if you're gonna get through you'll get through, but if you think you're not going to get through, you may not get through. Your mind can either go against or for you. And that can really cause and play havoc on your physical being, so that's how it played havoc with me. Through my depression I actually gained quite a bit of weight, because it was kind of, 'Oh well I'm going to die tomorrow so who cares?' So I ate everything and anything and I actually gained quite a bit of weight.*

Fortunately, Ihaia had the comfort of knowing that she was going to have further surgical treatment, “*So the whole reconstruction that was about to take place had added value to my own mental health*”. Ihaia understood that she would feel better about herself eventually. She had particular coping strategies to help deal with the fear and anxiety and when asked what the strategies were she said:

*Karakia and going for walks, that sort of stuff. Talking to others who had gone through that breast cancer journey. Whānau members ... drawing on that support when I wanted it. So yeah, that's how I coped.*

Moana often felt anxious about how breast cancer would impact on her two young children:

*So it was a very life-changing moment; I thought immediately of my children. The reason I thought about my kids is because my Mum grew up without a Mum. And I didn't want my kids to be without a Mum. It was more about their welfare. I didn't really think about my husband because you know, I think he would be okay but I wasn't sure about my children, so my tears were more for them than for myself and you hear a lot of things about cancer and cancer equates to death!*

She wanted to scream at the doctor:

*Do whatever it takes for me to live. I don't care just make it so for my kids! I started to cry a bit, I was saying 'My kids, my kids'. That was the only time I was really, really emotional was actually when I was told. My impressions were when I was growing up that this only happened to older women, like much older women, not a 32-year-old so my son was 10 and my daughter was 5 so they're 15 and 10 now and all I could see was these lost kids looking for their mummy. That was the main*

*image in my head and I just said 'Whatever it takes, help me to be here longer for my kids'.*

It is the association of breast cancer and death that makes it more difficult to deal with and emotions are certainly tested. Much like Jackie and Ihaia, Moana also had to reassess her life and think about other ways to deal with her situation. The stress impacted on general wellbeing and left them very tired by day's end. Moana grappled with finding a balance:

*When the stress happens that can drain your reserves so I had to pull back a bit and I found that I'm working a bit smarter now but yeah it does fast track everything, the whole experience of cancer, all the things you wouldn't normally do [laughing]*

It took time for each wahine to realise that things do get better and that the stress does subside. Moana finally got to a point where she felt she could move forward and plan for a brighter future for her and her whānau:

*It wasn't actually until two years ago that my head space was such that I felt comfortable to move forward. It certainly honed me in on what I wanted to do and that focused me positively, but I truly felt that my journey and battle with cancer was over two years ago and because of that, not even waiting for my five years! It was two years ago that I thought I might actually survive. I'm coming out of the dark! I'm gonna live! I'm gonna live, live!! To come fully out of that head space, it was only then that I actually realised and it felt like I had my head right and I was focusing on survival.*

Making a positive difference to other women was a recurring comment, as they were able to find a positive purpose for their trauma by making a useful contribution to breast cancer

education, and came up with creative ways to deliver messages to other Māori women. This kind of attitude was very different from feeling depressed, which helped to increase their mental strength.

Ihaia gave a presentation to a community group about her journey with breast cancer:

*One picture I had on my power-point presentation was of a person on a rollercoaster. This picture portrayed my emotional mental health and feelings to the audience that my journey was like a rollercoaster. I would really like to get an opportunity to share my journey again.*

Moana also had an epiphany about supporting others that had experienced breast cancer. “Then I had a moment where I looked up and thought I can do something to help other ladies”. She started a cancer support group in her local region:

*I feel for the ladies of migrant communities especially if they've just come over and they get it (cancer). All they've got is the migrant services. There are very few support people that can assist them and they do it all alone and especially if they've come from pretty traumatic circumstances and the countries they're originally from. So, as much as we talk about whānau and friends I'm very mindful of the ladies that don't have any. Must be really hard and I've heard it's really hard, I'm just talking to some in my journeys. But boy, they really have strong spirits too, and they've had to. Again just from their past experiences have made them stronger and more equipped - still aroha (sympathy) for them though!*

The whole experience has provided Jackie and Brigitte with the motivation to support other women and their whānau with dealing with this dreaded illness. Although it took them a while to tell others, they now do feel that if they can make a difference to others about the

importance of sharing their story, they will, “*But it’s communication. You’ve got to talk about it, everything, and anything*”. Together they have featured in their local newspaper and had their story told publicly:

*We’ll do what we can to help people with this illness. Yes I call it an illness and we do what we can, as we can, as we’re asked. We know that they’re [support groups] there. We’ll help the best way that we can. It’s about our attitude, it’s about being positive [Jackie].*

The range of deep emotions experienced throughout the breast cancer journey for the women was a roller-coaster of feelings and thoughts that sometimes turned into deep and dark thoughts and emotions around depression. Some women sought professional support and others felt that whānau and friends’ support was enough to keep them strong. The main points regarding the aspect of mental health for the women during their illness was; seek professional help, talk to whānau and friends about how you’re feeling and karakia to keep connected with your feelings. The realisation that they could provide comfort and support to others diagnosed with breast cancer was a common theme among the wāhine interviewed. They also realised that through their breast cancer experience they could certainly warn others of the risks involved if they didn’t seek to have breast screening early and regularly. For all participants, early detection and therefore timely treatment was the key to minimising stress and anxiety, and to their survival.

#### **4.4 Te Taha Whānau – Family/Social Wellbeing:**

The introduction of culturally-appropriate initiatives into hospitals meant that I was asked how many whānau members would be needing seating in my room after my surgery. I took

advantage of this and had seven whānau members in attendance - my mother, my husband and our sons, two nieces and a family friend were in the room when I came out of recovery. The relief on their faces said it all. I was awake and, from what we could all gather, free of breast cancer. Having friends and whānau there when I woke was important for me because I really didn't want to be alone. Although there was a sense of not knowing what to say and trying to make small talk, I was happy and comforted by the fact that I had whānau there with me.

Defining whānau can be complex and difficult given the diversity of Māori individuals and groups. Durie (1994) describes whānau as two main categories; whakapapa whānau – members that share a common ancestor, and kaupapa whānau – members that share a common activity or event, such as breast cancer. However we describe whānau, we must not forget that some contemporary whānau have lost connections to their ancestral ties. Moeke-Pickering (1996) considers that contemporary whānau arrangements such as single parent-whānau, predominantly headed by women, are often disconnected from whānau, hapū and iwi ties.

When it comes to the significance of wellbeing within whānau, some illnesses can be manifested down through generations and some are left unexplained. For example, finding out that you have been diagnosed with breast cancer can conjure up questions about where this cancer came from. In the life stories told by wāhine Māori survivors of breast cancer these questions were certainly raised when they received their news of diagnosis. For some however, they knew who the previous and present whānau members were that had suffered the same illness and/or didn't live long enough to tell their story.

Ihaia has strong whānau connections and although raised away from her biological whānau, she has always known her turangawaewae (place of belonging). She has a good understanding of how the history of cancer has links to her own personal experience:

*Because of the history through my birth whānau, that's how I found out about my grandmother being diagnosed with breast cancer, my aunty which is my birth mother's sister being diagnosed with breast cancer, and then my birth mother being diagnosed with ovarian cancer, and then my first cousin being diagnosed with breast cancer, so I thought to myself, I've definitely got something.*

With this knowledge Ihaia drew on the strength of her ancestors to build her confidence to know that she could survive this dreaded illness:

*All the people in these photos have in some way or another played a role in my breast cancer journey. My great grandmother, I took that photo with me during hospital stays, surgery, and everything else. They keep me going.*

Although Ihaia felt much comfort in getting strength from her ancestors, she also needed support from whānau in the present. She had whānau members that had first-hand experience with breast cancer and this was a comfort to her also:

*I took a whānau member with me to each appointment and she was able to take notes and that for me. Because she'd gone through breast cancer five years ago she was also able to ask some questions that I would not know to ask; she was like my secretary.*

Whānau support came in many forms and Ihaia was surrounded by lots of aroha. This was important to her recovery and general wellbeing:

*I had my sister who was there supporting in caring for my sons while I was in hospital. And I had John who was supporting me in karakia and general care. So they all had their different support strengths. It was really important to have my children and moko[puna] close at this time. So yeah, that's how I coped.*

Ihaia would worry about how her sons were coping with the news of their mother having breast cancer. Her teenage boys would not say much during the process of hospital visits so she felt the best way was to involve them in some way. At one stage she needed help to cut her hair because it was just making a mess everywhere:

*When my hair started falling out [long pause] I got my eldest boy to shave my hair off because it was falling out all over the place. My niece came over and she decided she was coming over to get her hair shaved off to support me, but I forgot to include my youngest boy in the whole process. He actually got quite a shock from seeing me bald.*

Ihaia began her story by reflecting on her whānau history regarding cancers, “*Because of the history through my birth whānau*”. The presence of her children and mokopuna was essential to her healing: “*It was really important to have my children and moko[puna] close*”. The role her colleagues played in her healing was greatly appreciated also: “*My colleagues were really supportive; there were lemons all over my desk, a heater under my desk, plugged in*”. In this example of how whanaungatanga played a role in Ihaia's experience, these key points can be concluded; family history and family support [whakapapa whānau] played a major role in her diagnosis, treatment and recovery; and work colleagues [kaupapa whānau] also supported her and made her feel valued.

Olive, like Ihaia, was well aware of the cancer history in her own whānau:

*Breast cancer is not in my family [history] but lung cancer, liver cancer, throat cancer, stomach cancer and cervical cancer are. So it was really important for my whānau to be my support because I didn't really know anyone with breast cancer. That's where my main support came from. I've got 12 of my whānau and they were there for me. That's just the way we are as whānau.*

One of Olive's sisters had gone through her own challenges with cancer at a young age and therefore Olive would depend on her sister to support her, especially when she was sent to Australia for her treatment:

*I took my sister to Australia, while I was receiving treatment and she had never been out of the country. While she was over there she cooked for me and it was nice to have her with me.*

Another time Olive needed her sister was when she decided that the best way to support other women in her community was to talk freely about the experience of breast cancer and the importance of having mammograms:

*I brought my sister down from Whāngarei to deliver in one workshop and she's not a speaker but getting her to share was special. There's a healing process for any woman and sharing stories helps. It then dawned on me that maybe I need to share my story and maybe I'm the right person to be sharing that information with whānau and to help others.*

Olive has and will continue to support whānau through her work and advocacy in the momentum of expressing the importance of mammography and self-checks for all wāhine.

She is very aware of the risks associated with a whānau history of cancers. In this instance Olive and her sister are a strong support for each other.

As noted previously, mother and daughter – Jackie and Brigitte - were interviewed together, and their situation was unique in that they were diagnosed within weeks of each other. The fact that this whānau was not dealing with just one member suffering with breast cancer but two at the same time and were willing to share their story together, was a privilege for me as the researcher. Their support for each other was strong and present.

In contrast to Ihaia and Olive, Jackie was particularly forthright in her view of where this cancer came from and especially because her sisters had suffered the same fate and died from breast cancer:

*I was cursing my father because this is where our illness comes from, our dad. I'm going down that same track that my sisters went down. I saw the pain and agony my sisters went through because I was with one sister right to the end. Gee I thought I was so sure it was going to happen to me. But Brigitte picked me up because I thought; I'm old so I've got to help our daughter Brigitte.*

Brigitte supports what her mother says about her aunties and remembers how they would support and manaaki them when they were younger. Brigitte was very fond of her aunties and would mention them regularly throughout the interview:

*Really good role model my Aunty Ruby, all my aunties actually. She eventually died of breast cancer because it spread from one side to the other. Sad but she's gone to a better world, joined her sisters Nancy and Josie so they're together now.*

It was wonderful to witness the support Jackie and Brigitte had for each other. While they were both shocked about their situation, they initially wanted to keep it to themselves to process before telling anyone else, including whānau:

*Mum, Dad, we [all] went to the RSA. My husband was playing in the band so we danced the night away. The joy, the fun, the mixing together, the whanaungatanga, it was exciting. But felt sorry for Mum because we didn't tell anyone eh Mum? You know it was right on Christmas, so just thought, just won't tell anyone and even at New Year's, still hadn't told anyone. We went out and we had a great big party, [laughter] on New Year's. You know in the back of my mind I knew it's getting close and I know that I'm not gonna be like this after the operation. This life's gonna be different.*

After Brigitte's operation and starting back at work, she was well-supported in ensuring her wellbeing was accommodated as best as possible. Her organisation was preparing to attend an event on a marae and her boss asked, "What would you like to do Brigitte, stay on the marae or stay in a motel?" This was essential to enabling Brigitte to feel she was valued by her employers.

Moana also acknowledged the support she received from whānau and how whanaungatanga contributed to her situation. Moana recognises her Māori and Samoan heritages and is proud of what they bring to her life, but also acknowledges the losses of grandmothers on both sides of her whakapapa:

*My mum's mum passing away with cancer, I didn't find out about what type of cancer and then with my Samoan dad's mum, she died of cancer as well...it's more about the missing mums and the effect that had on whānau and aiga.*

Nevertheless, Moana has strong bonds with her whakapapa whānau; for example, her mother moved home from Melbourne to look after her. Her employers were also very supportive. Moana also notes that:

*I actually learnt about how reliant I am on my husband and my twin. I don't think I would have been able to handle things without their strength and support.*

In fact, it was her twin that Moana told of her diagnosis after her husband. This closeness was not just about the bonds of twins' whanaungatanga, but also gave Moana the opportunity to share tears of grief and fear with someone to whom she was "Glued at the hip". With all her friends and family around her from throughout the country, Moana felt she had sufficient support to nurture her through the experience:

*Doing the whole connections and whakapapa, you know doing it the organic way of building relationships and identifying and being. That shared purpose of being together in a Māori way was important to me.*

For Moana and her loved ones, connecting with whānau and strengthening those relationships made "A positive from the cancer!" As with the others, Moana noted that although there were negatives to a breast cancer diagnosis, there were also moments of positivity and joy.

Ramari too was familiar with her whānau cancer history:

*My mum's sister had cancer. She was in her 50s. My dad's brother and his daughter both had bowel cancer so now I've got cancer.*

While a diagnosis of cancer was almost to be expected given the obvious symptoms, there were nevertheless many ups and downs to cope with. As with the other participants,

Ramari was fortunate to have strong whānau support. Her sister and father were with her at the initial doctor's appointment, and other whānau came from Australia to support her. Ramari spoke fondly of the support her children gave her:

*My kids were great; they took me [to appointments]. If they were working they would work around me, or tell their job they had to take me to appointments. My daughter's been wonderful...Yeah, it was good to have whānau around me.*

Following chemotherapy and the loss of her hair, Ramari's sister in Australia sent scarves over so she could wear a different one each day, finding them easier to manage than a wig. Ramari was also grateful for the constant support of the District Health Nurses who "Helped out heaps!"

As with the stories told by others, Ramari felt that whakapapa contributed to her being diagnosed with breast cancer. All the wāhine would in some way or another make reference to the importance of having regular checks if there is a whānau history of breast cancer. Unfortunately for reasons unknown, a couple of the participants did not get the opportunity to be told relevant whānau histories. As a result, there was some resentment and anger from these participants toward certain whānau members for not sharing the whānau history of breast cancer. Although these feelings are now resolved, there are still questions about why stories of whānau illnesses are not passed down through generations. We can only wonder why previous generations limit the information handed down through whānau.

We are all thankful that we are alive to tell our stories today knowing other relatives and close friends have been much less fortunate in that it was too late for them and their doctors to do anything about their situation. It was Brigitte that said, "We can all be vigilant

eh? And get our whānau to all be vigilant as well". She was referring to ensuring that we keep the health and wellbeing of our whānau a priority. As noted by Moana:

*The bottom line is that they're not getting there; they're not getting to the doctor in time! The doctors can't work miracles if you're stage three, stage four, and it's about caring about yourself enough to do what you have to do. If that makes me vain, sweet! At least I'm vain and alive!*

Moana makes a strong point about whānau being aware of the need to maintain good health and especially if there is whānau history of breast cancer. Close whānau members are trusted to care and manaaki the survivors. This trust is important when a diagnosis of breast cancer is placed on a wahine who is a mother, daughter, sister and wife to a whānau that needs her support as much as she needs theirs. This experience also changes the dynamics in the whānau and it can require extra effort to build stronger and more supportive whānau relationships.

The kaupapa whānau of friends and work colleagues made a particular fuss over each of the wahine and provided ongoing manaaki too. As with whakapapa whānau, these people felt drawn together by the suffering of their work colleague which brought another perspective in to the workplace life. The encounter of experiencing a close friend and colleague recovering from breast cancer had an impact on everyone around her.

Te taha whānau – Whānau wellbeing has many layers and levels of whānau wellness. Although it is never an easy discussion to start or participate in, the questions about health and wellbeing need exploring if we are to sustain a strong healthy whakapapa. Whanaungatanga throughout all the experiences was pertinent to the wellbeing of all the participants. The importance of these relationships played a role that cannot be replaced

by any other aspect in the healing process, therefore these key points can be concluded; family history (whakapapa) played a major role in the diagnosis. The realisation for some of the wāhine that this illness was passed down from a previous generation directs a clear pathway to ensure that future generations get the opportunity to be monitored effectively and efficiently. “Early detection is your best protection” Ministry of Health (2011). There is strength and care shown in all aspects of whānau, including from the wāhine. Just as much as these experiences contain suffering and pain, they can also strengthen relationships. Whānau – whakapapa and kaupapa – can be a pillar of strength in times of challenge.

#### **4.5 Te Taha Wairua – Spiritual Wellbeing:**

The spiritual aspects aligned with wellbeing during the breast cancer experience, is a topic that for some wāhine is not readily discussed. However, as a culture, Māori spiritual wellbeing can be the most important dimension to any component of health. Patterson (1992) suggests that, in the case of Māori, a central element is the importance accorded to spiritual matters. The belief that the strength and ability of te taha wairua can break down barriers and diminish further hurt and stress is important for healing to progress.

Olive was raised by her grandparents (now deceased) and spiritual guidance including receiving tohu (signs) from spiritual guides was a common practice throughout her life. She maintains the reason why certain things happen is that there is some sort of spiritual activity taking place. Olive tells her story:

*Spiritually, because I was brought up by my grandparents, I called upon them if I was confused or half-minded about something, about myself. If I'm not well, why is that? If I'm not thinking right, why I am not doing something right?*

Olive's initial medical concerns produced no results, but she had a strong sense spiritually that there was something going on that needed some medical assistance, so she sought another opinion to provide the answers she required:

*I was having tests in Rotorua and they couldn't find anything and I kept on saying to them that there's something wrong. In my whānau we're very spiritual and when your body is mamae [sore, unwell], there's something happening.*

Olive's mother also felt that the pain Olive was suffering warranted another opinion and consequently booked Olive into a medical centre:

*I spoke to my mum and she told me to come back to Auckland. I came to see the doctor up here. The doctor said, "Look we've done all these tests and we can't find anything, do you mind if we send you for a mammogram?" He says, because the pain is in the chest area and we've done all the tests we can for the chest so let's have a look at a mammogram - it won't hurt you.*

The advice to have a mammogram was not something Olive was expecting and she was slightly shocked by the suggestion. As mentioned previously, Olive was aware of the cancers that had affected her whānau and now to think that breast cancer could be added to the list was surprising:

*"Well is it free?" At the time I was 45. The doctor said, "Yes, you just scrape in". I said, "Yeah, well I'll do it". If I had to pay for it I wouldn't have done it. I had had all*

*these other tests and I'd had it! So I thought, 'Oh well it's free, what the heck let's go!' I thought, this is another test, another result and they're not going to find anything and then they rang up and said, "Come in, we've got your results". Not expecting anything, I went along. Man, how wrong was !!*

Spiritually, in some small way Olive knew that this had happened for a reason and was adamant that without the support and guidance of her mother and the doctor things could have turned out very differently - *"If my doctor hadn't recommended that I go in for a mammogram and if I wasn't 45, I wouldn't have gone for it"*. Behind this however, it was the persistence of Olive's spiritual insight which ensured that she pushed further to find what was wrong with her.

Others also felt a connection and received *tohu* from their spiritual guides. It was also important to all to keep their faith alive through *karakia*, attending church and generally praying for guidance and support. Spirituality has different meanings to different people. For some it can be deep and the feelings come from many sources and vibrations. Brigitte shares her story about how her brother maintained close spiritual contact:

*My faith has always been really strong. One thing though about spirituality, I felt my brother (who passed away as a child) really close to me. I couldn't stop thinking about him around that time. He was really close to me all through that time, through surgery, treatment and recovery.*

During Brigitte's hospital stays she would request the support from hospital personnel to uplift her *wairua*. Chaplain services enable the patient to focus on their health and saving energy to preserve the determination essential to survive. Brigitte felt the lack of Māori chaplains keenly though:

*I asked if there were Māori chaplains in the hospital. There were none so I made comments on the evaluation. People (in our communities) don't find out that you're up there because there are no Māori chaplains around.*

Brigitte, like her mum, is a regular church attendee and would catch up with her community when she regained her energies and could muster the effort to go along. This was also an opportunity to thank fellow parishioners for their prayers and best wishes while she was being treated:

*I went to church, not long after the operation, the third one, I went to church to thank everyone. I looked at everyone at church, they've all got one foot in the grave. Poor ole Ben over there, Doug [laughter], and here they're all feeling sorry for me. I thought 'There's nothing's wrong with me!' I could identify something wrong with the whole lot of them [laughter].*

Jackie added to the conversation with regard to the relationship that Brigitte and her brother had as children, and which continued in another form in Brigitte's adulthood. Jackie too, had spiritual connections with her deceased sisters:

*Yes, they've passed on, and I thought 'Oh my gosh, there's something about the supernatural; they do come back to you, especially when you're in your deepest, darkest pit'. We're very spiritual and it's natural for us to think of them.*

Both Jackie and Brigitte agreed that spiritual wellbeing comes from all dimensions, but more importantly they agree that there will come a time when they will be together with their tūpuna and whānau who have passed on. In Jackie's words, "We're all going to the same place – up there (pointing upwards)". They were very sure of that!

Ramari, although not a regular churchgoer, nevertheless felt that she is supported spiritually. She describes her experience with spiritual wellbeing:

*Yes, I have friends from church, not that I'm a big church goer. They knew I wasn't well and would call in to see me but I'm happy with my spiritual life. The church got a bit annoyed with me because they didn't think I took things seriously, but I was happy and didn't think I needed it. I was busy and never really got to go to church but I always know I can pop across the road and see them. They've been wonderful. Otherwise I'm pretty happy spiritually.*

This confirms for Ramari that she does not have to physically attend a religious establishment to get spiritual fulfilment and enrichment.

In contrast Ihaia has a strong conviction in her beliefs and uses a combination of traditional Māori forms of seeking spiritual support to uplift and guide her through her daily activities:

*My Ratana faith, my religion I feel, has supported me through my journey as well and so I'm a great believer in karakia and in the fact that I was baptised Ratana. So I draw on that. Prior to surgery we had karakia, and we had a himene [hymn]. This all helped me to not be so scared while I was being operated on and it gave me faith to leave the physical side of what needs to be done up to the surgeons because the wairua, spiritual side, has been taken care of as well. The karakia aspect of the whole journey, drawing on my tūpuna and those who have passed on, supported me to mentally and spiritually stay alive and to get through, and so the physical part I left up to the surgeons to sort of deal with.*

The spiritual aspect of this research has been described by the women in various forms and all are as important as the other. They all expressed their acknowledgment for seeking

assistance from the spiritual world and by doing so they felt confident that their physical needs would be met and provided for by the specialists and professionals. Key points from these women were that karakia helps alleviate the mental, emotional and physical pain brought about by breast cancer; church as a place of worship was not as important to some as it was to others; and no matter how you chose to ask for guidance and support, it was the asking that was most important.

#### **4.6 Conclusion:**

We find that we discover and express our deepest thoughts and emotions through our creative endeavours. This thesis has been a significant piece of creativity for me, bringing together the breast cancer stories of other Māori women. I began this chapter with Ihaia's journey through her breast cancer experience using her own words and reflections on how various whānau members supported her through her journey. Her story – as with the others - aligns with storytelling methodology. It is the stories themselves that provide the richness with which this thesis expresses the qualitative nature of experience.

Te Whare Tapa Whā has proven to be a very useful framework through which to organise the data from the narratives, asserting the fundamental importance of these four dimensions to the wellbeing of the women. Breast cancer diagnosis imbalances the dimensions and how they interrelate. Part of the journey for each woman has been centred on re-balancing the dimensions. Importantly for these Māori women, the spiritual dimension was of equal consideration to that of the physical impacts of the disease, its treatment and recovery, while experiencing what felt like an emotional and intellectual roller-coaster, and with the unconditional support of both kaupapa and whakapapa

whānau. These four dimensions have given voice to the women, and their calls for acknowledgement, education and healing have been responded to.

Although there are some strong messages clearly expressed by the women, one of the most important was the critical importance of timely breast screening. Early detection cannot be underestimated and this was a strong message voiced by the women. This also reiterates the importance of breast screening for women with a known whānau history of breast cancer, as most of the participants had this awareness.

## CHAPTER FIVE – DISCUSSION

Verse Seven:

*Dressing up to consider partying  
Creates thoughts of doubt that turn disheartening  
A wig, a hat, a scarf to be worn  
A new sense of life is about to be born.*

### 5.1 Introduction:

The careful consideration of the literature throughout this thesis has been as a result of the narratives provided by the participants who have kindly shared their personal life stories on breast cancer. The main themes captured from the women are a mix of discussions regarding further education on the importance of breast screening and how being in a position to make an informed decision about one's health and wellbeing can ultimately lessen the risk of being diagnosed with breast cancer.

Having the space and being in an environment to be and feel Māori was important to the women and their whānau. Another strong theme discussed was the importance of whakapapa and how these relationships hold connections to who we are and how we manage life-changing situations. The dimensions of Te Whare Tapa Whā provided a clear framework to discuss the impacts of breast cancer on the whānau, tinana, wairua and hinengaro of each wahine. The timing of this research project has I believe also provided the participants with a valuable opportunity to better understand their own experience of breast cancer through kōrero and reflection.

## **5.2 Education:**

Education remains an important factor in caring for our own health. However the confidence to access appropriate and relevant information requires some skill and sometimes, persistence. Olive's experience to insist on a second opinion for her 'chest pains' eventually established a diagnosis of breast cancer and not the 'heart condition' as first determined. Most of the participants found that contributing to breast cancer awareness with other wāhine and whānau has been a positive outcome of their illness.

It takes personal experience to really get a full understanding of how breast cancer impacts on aspects of life. Research study experiences allow women an opportunity to open up and talk freely, or close down and feel uncomfortable about that experience. Fortunately, I was able to access participants who wanted to talk about their experience of breast cancer. It takes inner strength to discuss an experience that is difficult and awkward to share, especially as Māori can be whakamā about discussing such a topic. Nonetheless, the strength demonstrated by all participants was amazing and was evident throughout the study.

Lovell, Kearns and Rosenberg (2011) suggest that health education and health promotion seeks to arm individuals with the knowledge to make the best decisions for their own health and that is a personal responsibility. Health promotion on the importance of breast screening has proven valuable over the years. However, the messages are still missing target groups such as Māori. The advantages of early detection have been mentioned throughout this thesis, and therefore its importance cannot be underestimated. Early detection has the potential for less stress in a multitude of health and wellbeing-related factors, such as less invasive surgery, nil or minimal drugs, and less suffering overall. Most importantly, early detection increases the chances of survival. Given the dismal statistics

on the survival rates of Māori women from breast cancer, education regarding breast screening and early detection is incredibly vital to increasing survival rates of those mothers, daughters, sisters and wives who are vital to the wellbeing of their whānau.

### **5.3 Trauma:**

Trauma is typically seen as an experience which exceeds people's mental frameworks, and which, as a result, continues to haunt them, collapsing the distinction between past and present. One of the standard therapies for this condition, known as the 'talking cure', consists in having the sufferer confront their painful memory, relive the moment, and integrate it into their life stories (Craps, 2010). This allows the traumatised person to understand that the event is over and there is a process of healing that takes time and effort. Trauma can impact on the wellbeing of breast cancer survivors and their whānau requiring the whole group to deal with it.

For the wahine affected by breast cancer the trauma was felt on varying levels and was dealt with through a variety of methods. The trauma felt by the women was personal and quite different to the trauma felt by the whānau and friends around her. No-one wants to see their loved one suffer and this suffering is felt by all.

The ability to maintain and stay focused on increasing the chances of overcoming the disease requires amongst other things including timely and appropriate treatment, a strong resolve, and of course the correct supports around to help with recovery. The rich and diverse conversations involved in this study have shown each woman's level of confidence and belief as a breast cancer survivor has increased to now allow them to continue to contribute to society, and more importantly, to Māori society.

## 5.4 Being Māori and Māori wellbeing:

From the outset it was important for this research study to be confined to wāhine Māori participants only. For this reason it was vital that the subject was approached and respected from within a Māori worldview context. Culturally as Māori we tend to understand the dimensions of physical, emotional and mental, spiritual, and whānau aspects of wellbeing because in so many ways it is inherent in our way of life. We have a belief about the realm of holistic wellbeing that does not need an explanation and is a subconscious understanding.

The combination of physical strength and spiritual power within each participant was evident as we shared stories of breast cancer. One aspect of strength comes from a physical force however. Tate (2012) suggests that kaha is physical power and strength. Tate also suggests that “Mana is spiritual power” (p. 78). An expression used by Mere Tana (cited in Tate, 2012) provides an understanding of the difference between the two:

Ko te kaha kei te tinana, ko te mana kei te wairua” – Kaha is the strength of the body while mana is the strength of the spirit” (p. 79).

The Mana Wāhine Taumatatanga Trust (MWTT) (to which I am affiliated) also draws from the work of Mere Tana, who was the mother of the Trust’s founder, Rangī Davis. Rangī has translated her mother’s words to mean – “Your physical strength is in the body, but your power is in the will of the spirit” (MWTT, 2012). Consequently, from a cultural perspective it has taken both kaha and mana to share our stories of breast cancer with wider society. These strengths are not ours alone and as Māori neither do our stories belong only to us. There is history and whakapapa in everything we practice and participate in. Mere Tana’s insight above makes a connection with the participants in

relation to the strength of the spirit – mana, is perhaps stronger than the strength of the body – kaha. The women know their mana and kaha were greatly tested through the breast cancer journey.

## **5.5 Whakapapa:**

Whakapapa is fundamental to all things Māori; everything has a whakapapa, a starting point, a genealogy, a story about its existence. We as Māori women sharing our stories of breast cancer each have a whakapapa that includes other whakapapa. We came to a point in the research where we established another whakapapa through sharing our stories. Kōrero whakapapa has been a theme throughout all the interviews regarding the origins of breast cancer for each participant. Jahnke and Taiapa (1999) suggest that a “Worldview of the Māori is encapsulated in whakapapa” (p. 41). This statement supports the importance of a cultural approach to researching kaupapa Māori discussions, as everything Māori participate in has whakapapa.

Revisiting the whakapapa of how the individual journey of breast cancer started has been an emotional encounter for these survivors. In some cases it was not until the diagnosis was made that some participants actually came to know about their whakapapa. The anger and despair when realising the outcome from a regular doctor’s visit or a suspicion that turned out to be a major concern generated questions of where, when, and how.

## **5.6 Whānau:**

The realities and complexities of whānau are important to the development of the strength, capacities and capabilities relating to how support and resources will be accessed and understood regarding their loved one's experience of breast cancer. Whānau, kaupapa and whakapapa, are the greatest support during each step of the diagnosis, treatment, and healing stages. When a wahine is too whakamā to discuss the whole experience with anyone, this is the opportunity for whānau to step in with support and engage with others on her behalf.

Engagement within the whānau is of great benefit to the process but in some cases can be a burden on the patient. The ordeal of having a loved one treated for breast cancer can be as scary for the whānau as much as the patient and this can cause some difficult moments. For example, a participant had to ask a friend that flew in from another country to leave her home because the friend's emotional state was uncontrolled. It was not helping the participant with her own resolve to be strong and actually required her to comfort the friend, adding to her own stress and perhaps compromising the healing process.

## **5.7 Physical impacts:**

There are numerous ways that breast cancer impact on the lives of the wāhine as well as the lives of the whānau around her. Nevertheless the physical impacts sustained from the treatments were for most of the wāhine, the greatest impact. There was a concern from one participant that others will notice that her hair had fallen out and she would be asked about her health. She was not ready to be questioned about her cancer and all the ills

associated with it. In many ways it was the physical impact that kept the women in their homes where they felt they were safe and did not have to deal with the sometimes ridiculous questions or statements from others. These experiences were felt by all the participants.

Some of the physical impacts were obvious and less able to hide. One participant spoke of how she wore winter clothing during our summer season. The effects of chemotherapy made her feel cold and she was vulnerable to contracting viruses. People looked at her as if she was strange.

Losing a breast was a relatively easy decision to make for most of the women. They understood that losing a breast was about gaining more years to live and with breast reconstruction an option, they felt all was not lost. Although the physical impacts took a heavy toll on the lives of these women it was the emotional and mental effects that had the greatest impact.

## **5.8 Emotional and mental impacts:**

The effects of breast cancer on the minds of the wāhine affected them in a variety of ways, with some needing professional advice from a counsellor. Others became reclusive and were not confident to attend social events and gatherings. The impact on their social lives increased as their emotional states worsened. For them it became obvious who in their whānau and friend networks had the time and understanding to care about their situation, and were able to cope in a supportive way. On the other hand, some whānau and friends were just not able to express their sorrow and sadness for their wāhine during this time. All

the wāhine agreed that the demands on whānau and friends were significant, and they appreciated all they received.

The risk with the mental impacts on the women was the disease had the potential to bring on depression and cloud seeing a way clear of the illness. Periods of depression were a factor for many of the women and some sought professional advice while others shared their feelings with close friends and whānau. In both situations, accessing support for this aspect of the process enabled them to become much stronger emotionally and mentally, and helped them deal the possibility that they could survive this dreaded illness.

## **5.9 Spiritual impacts:**

An important characteristic of Te Ao Māori is spiritual beliefs. These beliefs are present in everything in and around us. For me, this aspect of wellbeing is the most powerful and distinctive of all aspects. The ability to keep our spirit strong, intact and healthy has the capability to destroy the disease that threatens your life, or at the least, enable you to deal with it from a calmer and more peaceful frame of mind. The threat of breast cancer shortening your life and impacting on the lives around you can diminish the spirit of everyone affected, whereas the collective spiritual strength can provide a greater opportunity for extended life.

Spirituality is an area that is, if any, the most important aspect of being Māori. All the participants expressed their experiences of spirituality and how they knew through being connected spiritually, that they had breast cancer even before the general practitioner told them. One participant was definite in her submission that her experience was a predetermined reality and that there was no getting away from her being diagnosed with

breast cancer. The impact on her spirit when it was confirmed was not shock in finding out, but shock in the confirmation. The sense of 'knowing' comes from the spiritual dimension within the holistic approach to wellbeing (Te Whare Tapa Wha).

### **5.10 Whānau impacts:**

The risk of losing a wahine to breast cancer is major. Following diagnosis, whānau have many questions, assumptions, and sometimes, misinformation about the illness. No one really knows what lies ahead for the patient which is difficult for the whānau as much as it is for the patient. Throughout the whole ordeal the whānau are concerned for the potential loss of a dear and significant wahine. I recall the reaction I got from whānau members who thought I was dying and in all fairness we knew that when people got cancer they died! So there was great sadness for these whānau members convinced that I was going to die.

An extreme reaction can be that whānau and friends disappear from your world; this was sometimes due to the fear of 'catching' something from you. Friends and whānau do their best to understand the situation a cancer patient is in, but can make some superficial and uncalled-for statements that can make everyone uncomfortable. This can lead to further anger, confusion and breakdown in relationships.

These kinds of reactions are manifested by doubt and uncertainty. No one really knows what is going on, including the patient, and this can create anxiety for all involved. On the other hand, other whānau members can be supportive and rally around to create a positive and emotionally strong environment to ensure their wahine is in the best possible space to heal and recover from the ordeals of breast cancer. After being educated about the risk, possible causes and the process a wahine goes through, it becomes less scary and

whānau are better informed to approach their loved one with less anxiety. Education therefore is important not only about breast screening and early diagnosis, but also about the actual process a wahine and her whānau will undergo in the treatment and recovery from breast cancer.

### **5.11 Te Wā:**

The timing of my diagnosis and the development for further studies was a signal for me to grow in my ability to research this topic. In many ways I have felt this research project has produced a sense of strength for a subject that has not been researched widely. In a spiritual way this research has been a topic 'waiting to happen' and the time (te wā) was now.

Tregear (cited in Tate, 2012) translates wā as "The time, season or space in time. Thus 'te wā' can refer specially to a moment in time, to a season or to a space in time" (p. 213). Tate suggests that "Kua tae ki te wā' means 'te wā' (the time) has arrived. The English phrase does not capture the sense of fulfilment or achievement that this phrase has for Māori. It means one series of actions is completed. A goal has been achieved" (p. 212).

For this reason, I feel the timing of my completing my post-graduate studies, my breast cancer diagnosis, 'searching' for my next step in academia, and the process of 'te wa' was fitting. This research topic has kept me focused on producing a piece of work that will provide Aotearoa New Zealand society with some useful and meaningful information to apply to others, and may contribute to easing the burdens of whānau whose mothers, daughters, sisters and wives have been diagnosed with breast cancer.

The timing of ethics also contributed to *te wā* of the when and what my topic would finally be. The ethical discussions that took place prior, during and post confirmation of topic were around the drama that was unfolding due to my own breast cancer journey. In many ways this ethics' process kept me focused on the job at hand – to have the application discussed and approved.

### **5.12 Ngā wahine:**

There can never be enough acknowledgments and recognition for the wāhine who shared their stories here. To muster the strength and confidence to open their lives to an audience, unknown in many ways, is a feat that deserves great commendation. Again the ability to share their feelings on the impacts that breast cancer has had on their holistic worlds has been a journey on its own.

Although they were all Māori, these women had very different stories to share. Some were raised outside of their birth whānau, as were the case for Olive and Ihaia. Ramari, Olive and Jackie had already lost siblings through cancer. Ramari already had a cancer and was then diagnosed with breast cancer. Moana was 32 years old when she was diagnosed and had two young children. Brigitte was fit and active and getting on with life. All these factors and more made up the rich tapestry of these women's lives, and breast cancer had a major impact on these women and the people around them. Their stories can go on being a part of discussion regarding Māori women and their experiences of breast cancer.

### **5.13 Conclusion:**

There were a plethora of experiences that took place throughout this research. As the researcher and writer of this thesis I have constantly visited and revisited not just the wāhine experiences, but my own. I shared the same anguish as these women, my whānau shared the same agony as their whānau, we felt the same pain of the unknown and tried to guess the outcomes. We all let our minds wander into the depths of despair. We got angry with tūpuna and looked for answers wherever we could find them. We turned to others apart from whānau to bring another view of understanding, but after all of that, it was always whakapapa we felt the most comforted with.

The concept of holistic wellbeing has varying levels of depth and is steeped in culture, a culture that comes from our integral ways of being Māori. As the indigenous people of Aotearoa, it is not difficult for us to feel the strength of holistic wellbeing but it is sometimes difficult to explain. As Māori we can reach into the whakapapa, and search for an answer. If this search is successful and the answer comes, this provides some relief; on the other hand if the answer is not so apparent and further investigation is required, this provides some research and discussion.

## CHAPTER SIX – CONCLUSION

Verse Eight:

*Born from the illness that threatens the lives  
Of mothers, daughters, sisters and wives  
Stay strong for all that amounts  
Stay strong everyone for that is what counts!!!*

### 6.1 Introduction:

The final verse in the poem is aimed to reflect the strength required by everyone near and dear to someone with breast cancer. Once diagnosed with breast cancer there is still a slim but possible chance that the cancer will return and therefore the ability to remain strong is required by everyone. The poem has used the words from the women interviewed for this research, and this makes it an appropriate and meaningful piece of work.

Reflecting on the intricacies of how breast cancer impacts on the wellbeing of Maori women has been thought-provoking as well as providing conversation starters outside of this piece of writing. The challenge has been to continue the conversation with people that have had little or no experience with breast cancer but feel they have a contribution to make. Breast cancer is one of the most harrowing experiences someone can go through, much less talk about it openly and share it with more than just friends and whānau.

## **6.2 Purpose of this thesis:**

As the title infers, this thesis was to capture the stories of Māori women challenged by breast cancer within the dimensions of Te Whare Tapa Whā, “*A multidimensional exploration of the impacts of breast cancer among wāhine Māori survivors*”. This purposeful thesis helped to capture some valuable contributions to the future direction of breast-care advocacy for all women, but more particularly Māori women. For example, early detection has been noted as vital to increasing survival rates. A breast cancer diagnosis for wāhine Māori impacts on the whole whānau. Early detection is the best way in which to alleviate the stress of being diagnosed with breast cancer. I chose this research topic for personal reasons due to the fact that I have a whānau and individual history of breast cancer. The initial intent of this project was to lobby for the age to be reduced for free breast screening, however during the research it became evident that access to services for Māori women and their whānau are more of a priority.

Understanding and mastering a new language used mainly by professional medical and clinical people is another skill attained through the breast cancer journey. As a result it is important that you and everyone around you are able to confidently access resources available to women. This is the dilemma for many Māori because the financial cost (e.g. of mammograms) to accessing the resources to ensure the best possible outcomes to treatments is a barrier. Which then in lies further stress and concern about what can and cannot be done to provide assistance? The ability to access information needed to assure a safe and understanding pathway to minimise or eliminate the confusion of what is taking place with your health. Māori are forever reminded of the risks with the high numbers of Māori women who die too soon from breast cancer. As noted by Moana:

*there is one thing I need to highlight...I think there should be a real public message out there; that if it's determined that it's in your whānau that the fee should be waived for a mammogram.*

There is much concern about affordable accessibility for breast screening services which is a barrier for many women, especially, Māori. This thesis argues strongly therefore, that if there is a whānau history of breast cancer there should be free or reduced cost for these members. A number of other priorities in their whānau outweigh the ideas of giving them a second thought on having a breast screen or even a general health check.

### **6.3 Whānau support:**

Staying strong is difficult when you are directly impacted by breast cancer. It takes as much strength to talk about breast cancer as it takes to believe you beat it and survive. One of the most difficult aspects of going through a journey of breast cancer is the strength to remain confident that everything will be fine and that you are not going to die. The skills required to test your capacity of self-assurance that life will improve following a traumatic ordeal such as breast cancer, increases the strength of character of the individual and reassures the ones around her.

Whānau and friends do their best to provide the support for their loved one. Moments of awkwardness are an often occurring situation. Whānau not knowing what to say and when to say something allows for silence and mind shifts. Just being able to communicate lessens the moments of silence and awkwardness. But for most Māori women diagnosed with breast cancer, it is the presence and support of whānau that is the factor most likely to bring comfort at a time that is invariably stressful, and unfortunately for some, fatal. A

variety of resources – including emotional and spiritual as well as financial – is required from whānau to provide that most needed support for the loved one. Education is therefore vital in this part of the process to enable whānau to provide the best possible support; this includes knowing which external resources are there for them to access.

Seeking advice and support is important not just for the patient but the whakapapa whānau and kaupapa whānau. Understanding a new language is a major feat by any means and the language spoken in the clinical field is and will be something new to any whānau going through the trauma of having a member diagnosed with breast cancer.

#### **6.4 Visions of Health:**

A variety of recommendations were aired during the interviews from participants and the conclusion was always the same. They all felt that if it was evident that women diagnosed with breast and had a whānau history of it, they should be exempt or subsidised from paying horrendous fees to have a mammogram. Although she wasn't asking for a total exemption from breast screening, Ramari remarked that *"I wish they could change the rules or make it easier for our kids, my daughters to be able to have a breast screening, maybe cheaper"*.

Some women that have gone through breast cancer have been supportive of others that are new to the experience. One participant acknowledged some amazing work done by a particular Māori woman that was diagnosed and survived a few years but later could not continue her fight any longer. Olive spoke highly of this wahine:

*even though she's gone she did a really good job and sticking to it [helping others] and all the wonderful things that she did. She'll always be remembered for that". There are other women out there that are still going, that are doing some great work, information sharing, promotion about breast cancer.*

This was one example of many stories of women encouraging others to be vigilant about caring for your own health and as a result the health of those around you.

## **6.5 Recommendations:**

After much discussion and consideration the following recommendations are drawn from the kōrero of the women who participated in this project:

- There was strong feeling that the age for free breast screening be lowered from 45 to 40 years of age. This decision was agreed to by all the women that participated in this project as all but two were diagnosed under the age of 45.
- Further to this kōrero, if there is evidence of a family history of breast cancer then breast screening should be free.
- Another significant discussion was that access to breast screening services could be more culturally sensitive. By 'culturally sensitive' the women were expressing their need for a space that can be made available to our older women who are more modest and find the whole experience of breast screening intrusive. The conversations overheard in the breast-screening waiting rooms can be rather disconcerting and disturbing.

## **6.6 Conclusion:**

Breast cancer is such a personal and serious condition but it does not have to be. Affordability and accessibility is a huge barrier for whānau. All the women who participated in this study were concerned for the future generations, especially because the risk is so much higher if you are a Māori woman and there is a history of breast cancer in the whānau.

One of the main findings of this research was the importance of whakapapa and how this linked with the cause of why these wāhine Māori were diagnosed with breast cancer. For all the women whakapapa held the key to their situation. Whether the link was made to a tūpuna two or three generations previously or if it was an immediate sister, whakapapa helped bridge the gap. Another specific finding flowing on from that was how the women would therefore be more supportive and vigilant toward their daughters and mokopuna. The importance of being Māori and respected for being Māori was the most definite conclusion for all.

This research has been helpful in realising the power of sharing and healing with such a sensitive topic. This topic has taken many hours of self-reflection and determination to get through the hours of researching, reading, talking to others and writing. Determination to realise that the work we do in this research will serve for others to express their shared experiences. We need to feel comfortable and safe to talk to others about breast cancer and the impacts it has on, but not exclusively, the patient. The holistic framework applied supports a certain angle to make certain the participants are aware of what the research is about and how it will contribute to a wider society is crucial. This realisation may eventuate in forms not familiar or even recognisable until further down the track. It is not known how this research will make a difference to societies but it is comfort to know that new

information is available for researchers or anyone interested in the effects of breast cancer from a Māori perspective.

There were many rewards from this whole experience but the greatest reward from the experience of breast cancer has been the opportunity to share with others in a deep and rich way. Olive sums up the whole experience of this thesis with, "*There's a healing process for any woman and sharing stories helps. Talking about it is a healing process on its own*". If there is a positive in having breast cancer and surviving it, it is the opportunity to be able to share the experience with others.

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# Appendices

## Appendix 1: MUHECN Approval Letter



6 July 2011

Lucy Ripia  
c/- Ms M Forster  
College of Humanities and Social Sciences  
Massey University  
Manawatu

Dear Lucy

**HUMAN ETHICS APPROVAL APPLICATION – MUHECN 11/041**

**He kupenga mate pukupuku uu mo nga wahine Māori. Te Whare Tapa Whā: A Multidimensional Exploration of the Impacts of Breast Cancer among Wāhine Māori**

Thank you for your application. It has been fully considered, and approved by the Massey University Human Ethics Committee: Northern.

Approval is for three years. If this project has not been completed within three years from the date of this letter, a reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

A handwritten signature in blue ink, appearing to read "R Bathurst".

Dr Ralph Bathurst  
Chair  
Human Ethics Committee: Northern

cc: Ms M Forster  
College of Humanities & Social Sciences

cc: Dr L George  
Office of AVC (Māori & Pasifika)

Te Kōwhiri  
Ki Pūrehuroa

Research Ethics Office  
Private Bag 102 904, Auckland, 0745, New Zealand Telephone +64 9 414 0600 ex 9539 [humanethicsnorth@massey.ac.nz](mailto:humanethicsnorth@massey.ac.nz)

## Appendix 2: Information Sheet



### INFORMATION SHEET

**Topic:** He kupenga mate pukupuku uu mo nga wāhine Māori. Te Whare Tapa Whā: A multidimensional exploration of the impacts of breast cancer among wāhine Māori survivors.

#### Researcher introduction

Kia ora, my name is Lucy Ripia. I am undertaking a thesis as a partial requirement toward a MPhil Maori Studies at Massey University during 2011 and 2012. You have been identified as a potential participant. I would like to learn about and understand your experiences as a wāhine Māori after you were diagnosed and treated with breast cancer.

#### Project Description and Invitation

My project is looking at how the impacts of being diagnosed and treated for breast cancer affected your wairua; your tinana; your hinegnaro; and your whanau.

As a breast cancer survivor myself, that is, at diagnosis, after surgery, at the end of treatment, when you pass your 5-year checkup, or whenever you say you are a survivor?<sup>1</sup> The outcome I would like to see come from this research is that treatment for Māori women diagnosed and treated with breast cancer will improve in the future.

#### Participant Identification and Recruitment

My selection criteria for participation in this study is that you are a Māori woman and a breast cancer survivor.

I will not be interviewing you however if you are unwell or cannot manage the interviews. I will interview 5 women who fit this criteria. This number of participants allows me a useful sample number in order to gain a range of stories and experiences. I would like you to participate.

#### Project Procedures

If you agree to participate, you may be involved in one 1.5-2 hour interview with myself. The interview will be voice-recorded. I will travel to your choice of meeting place. A koha of a voucher will be provided following the individual interviews as an appreciation for your time and for sharing your stories.

Should you wish to contact me at any time, my contact details are provided below. In all, the commitment by yourself may be up to 3 hours total.

During these interviews, it is likely that emotional issues connected to your experiences may arise, although every effort will be made to minimize negative effects. If you wish, you may bring whānau support with you to the interviews.

#### Data Management

<sup>1</sup> Breast Cancer (2011) Retrieved July 1 from <http://breastcancer.about.com/ua/whatisbreastcancer/bc-survivor-defn-1-A.htm>



**MASSEY UNIVERSITY**  
COLLEGE OF HUMANITIES  
AND SOCIAL SCIENCES  
TE KURA PŪKĒNGA TANGATA

The sound recording of the interview will be transcribed by myself. The recordings and all research notes are held in a locked cabinet in my supervisor's office, and no one other than us will have access to this data.

Participants will have the opportunity to remain anonymous. You will be given an alias of your choosing so that you cannot be identified by anyone other than myself or my supervisors. Therefore, in formal publications such as journal articles and conference presentations you will remain anonymous. A copy of the research findings will be given to you as a taonga for your whānau. After a period of 10 years, all data relating to your involvement in the research will be returned to you and your whānau, if you so choose.

#### Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the project within a week of conducting the interview;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;
- ask for the recorder to be turned off at any time during the interview.

#### Project Contacts

Researcher

**Lucy Ripia**

Ph: 09 520 4796 ext 205

[ludon@vodafone.co.nz](mailto:ludon@vodafone.co.nz)

Supervisor

**Dr Lily George**

Ph: 09 414 0800 ext 9848

[l.george@massey.ac.nz](mailto:l.george@massey.ac.nz)

Supervisor

**Margaret Forster**

Ph: 06 356 9099 ext 7091

[M.E.Forster@massey.ac.nz](mailto:M.E.Forster@massey.ac.nz)

- If you have any questions, concerns or comments to make please feel free to contact either the researcher or supervisor

#### Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application 11/041 (*insert application number*). If you have any concerns about the conduct of this research, please contact Dr Ralph Bathurst, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 x 9570, email [humanethicnorth@massey.ac.nz](mailto:humanethicnorth@massey.ac.nz).

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 3: Participant Consent Form



### PARTICIPANT CONSENT FORM

Topic: He kupenga mate pukupuku uu mo nga wāhine Māori. Te Whare Tapa Whā; A multidimensional exploration of the impacts of breast cancer among wāhine Māori survivors.

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Full Name - Printed \_\_\_\_\_

## Appendix 4: Interview Schedule

[Print on Massey University departmental letterhead]

School of Māori Studies  
Massey University

### INTERVIEW QUESTIONS/SCHEDULE

Topic Title: He kupenga mate pukupuku uu mo nga wāhine Māori. Te Whare Tapa Whā; A multidimensional exploration of the impacts of breast cancer among wāhine Māori survivors.

#### Questions for participants

##### **Question 1**

How has breast cancer impacted on your wairua – spiritual aspects of your health and wellbeing?

##### **Question 2**

How has breast cancer impacted on your hinengaro – emotional aspects of your health and wellbeing?

##### **Question 3**

How has breast cancer impacted on your tinana – physical aspects of your health and wellbeing?

##### **Question 4**

How has breast cancer impacted on your whānau – immediate and extended whānau aspects of your health and wellbeing?

##### **Question 5**

Do you have any further comments?