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The role and potential of community based cancer care for Māori in Aotearoa/New Zealand

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Abstract

There are unacceptable ethnic differences in cancer survival in Aotearoa/New Zealand and quality of life differs between Māori and non-Māori at all stages of the cancer journey. Overseas studies have recognised that all the priorities for cancer services are affected by actions in primary care – reducing the risk of cancer, early detection and faster access to specialist treatment, improved support for patients living with cancer, and reducing inequalities. Additionally, the importance of strategic policy to direct practical and effective community-based cancer care has also been identified. Māori health provider organisations have been using a ‘Whānau Ora’ approach to provide primary health care services for over twenty years; however their contributions to cancer care have been largely invisible. This qualitative study explores the role and potential of community based cancer care for Māori as a means to addressing three study questions:

- What helps patients and whānau to access and receive cancer services?
- What is the role of primary care, which includes Māori health providers and mainstream providers, in facilitating access into and through cancer care services?
- Does current cancer control policy adequately address Māori needs?

Using a case study approach, participants from four areas of cancer care were recruited within a Māori-centred, ethic of care framework, to explore the experiences of those who plan, manage and administer, deliver, and receive cancer care. The main source of data was in-depth semi-structured interviews.

The key themes identified from this research are that: whānau hold critical and multiple roles across cancer care; there are gaps in supportive cancer care and information that is appropriate for Māori; ongoing relationships with a primary

health care provider assist whānau to navigate their cancer journeys, with Māori health providers in particular, delivering wide ranging cancer care services, and linking patients with mainstream services; engaging successfully with the cancer care system currently requires an individual rather than collective approach; cultural safety education should extend across all cancer care services; communication between cancer care providers is improving and; cancer control policy in Aotearoa has a universal focus which does not adequately address Māori needs.

The role of primary care is pivotal in Māori cancer care access, from prevention through to survival, and must be at the forefront of cancer policy.

Acknowledgement of the different support and quality of life needs of Māori, including recognition of the interdependence of whānau as a strength, is required. Māori health providers have the potential to play a much greater role in cancer care and support, but sustainable funding models are required if Māori health providers are to continue, and expand on, the wide range of work that they undertake within their communities. The newly implemented Whānau Ora Initiatives may provide a vehicle for provision of sustainable community cancer care services.

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Glossary

Aotearoa	Land of the long white cloud. New Zealand
awhi	embrace, support
hapū	sub tribe
hīmene	hymn
hinengaro	mental state
hui	meeting

iwi	tribe
kai	food
kaimahi	worker
kanohi	face
kanohi ki te kanohi	face to face
karakia	prayer
kaumātua	elder
kaupapa	topic, idea, foundation
Kaupapa Māori	Māori foundation
Kite	basket
Kohanga reo	Māori language nests
Ko wai au	What do I bring to this?
korero	talk, to speak
Māori	normal (also the name of the Indigenous people of Aotearoa)
Māoridom	the Māori world
marae	meeting ground
manuhiri	visitors, or proper behaviour with new people
matua	father
mihi	greet
mirimiri	massage
mokopuna (or moko)	grandchildren
noho whakaiti	appropriately quiet and watchful
ora	wellness
Pākehā	descendants of colonial settlers from England, Ireland, Scotland and Wales
Pounamu	greenstone
rongoā	medicine
tane/tāne	man/men

tamariki/tāmariki	child/children
tangata whenua	people of the land
tapu	sacred, forbidden
Te Ao Māori	the Māori world
Te Reo Māori	the Māori language
Te wanatanga katoa	complete governance
tikanga Māori	Māori values and beliefs
tinana	physical body
tūpuna	ancestor
wahine/wāhine	woman/women
waiata	song
wairua	spirit
whakairo	carving
whakamā	shy
whakapapa	genealogical table, cultural identity
whānau	people connected by whakapapa or kaupapa
whānau ora	healthy families
whenua	land
whakapapa	lineage, genealogical table, cultural identity
whanaungatanga	relationship, kinship
whare	house
wairua	spirit, attitude

Abbreviations

CEO	Chief Executive Officer
CCDHB	Capital and Coast District Health Board
CCNZ	Cancer Control New Zealand
DHB	District Health Board
DNA	Did Not Attend
GP	General Practitioner
HRC	Health Research Council
IPA	Independent Practitioner Association
ISP	Independent Service Provider
KOETI	Kia Ora e Te Iwi
MWWL	Māori Women's Welfare League
NSU	National Screening Unit
NZ	New Zealand
PHO	Primary Health Organisation
UN	United Nations
WHO	World Health Organisation
WINZ	Work and Income New Zealand

Chapter 1

Introduction

1. Thesis Introduction

There are unacceptable ethnic differences in cancer survival in Aotearoa/New Zealand (hereafter referred to as Aotearoa). It has been documented that the Māori mortality rate for cancer overall is 79% higher than the non-Māori rate (Ministry of Health, 2015e). As well as significantly higher cancer mortality rates, quality of life differs between Māori and non-Māori at all stages of the cancer journey (Ministry of Health, 2004a).

Campbell and colleagues (2002) note that nearly all the priorities for cancer services are affected by actions in primary care “reducing the risk of cancer, early detection and faster access to specialist treatment, improved support for patients living with cancer, and reducing inequalities” (p. 578). Māori health provider organisations have been providing primary health care services throughout Aotearoa for over twenty years. Their contributions to cancer care include prevention through health promotion activities, information dissemination, and advocacy across the cancer journey (Slater et al, 2016) (Appendix 1). It is therefore timely to explore the role of primary health care in facilitating access of Māori into and throughout the whole cancer care continuum.

For people with cancer, quality of life and survival are shaped by access to care (Mandelblatt, Yabroff & Kerner, 1999), but there is limited research regarding Māori access into and through cancer care (Cormack et al, 2005; Slater et al, 2013 (Appendix 2); Walker et al, 2008). A number of studies have highlighted difficulties in access to health care for Māori at all levels of service provision (Baxter, 2002; Cormack et al, 2005; Crengle et al, 2005; Shoen et al, 2011; Westbrooke, Baxter & Hogan, 2001). Access has been conceptualised in terms of levels of access – primary, secondary, and tertiary – which incorporates the idea of access through, as well as access to, health care services (Bierman et al,

1998; Walker et al, 2008; Cormack et al, 2005; Ellison-Loschmann & Pearce, 2006).

Using a case study approach, participants from four areas of cancer care were recruited within a Māori-centred (Cunningham, 2000), ethic of care framework (Tronto, 1993,1998) to explore the experiences of those who plan, manage and administer, deliver, and receive cancer care. Together, the four cases provide a lens on the system of care for Māori with cancer which includes the structural causes of inequality in cancer outcomes (Cormack et al, 2005).

1.1 Research objectives

The overall aim of the study is to identify factors that may facilitate or inhibit greater access into and through cancer care for Māori. The study approaches identification of these factors by exploring the system of cancer care, with a particular focus on the role and potential of primary care for Māori with cancer, as primary care is the first contact and entry point into the health system (Campbell, MacLeod & Weller, 2002). Māori health providers are also at the forefront of the primary care focus, although their contribution to cancer care has been, until recently, largely invisible (Slater et al, 2016).

The research questions are:

1. What helps patients and whānau to access and receive cancer services?
2. What is the role of primary care, which includes Māori health providers and mainstream providers, in facilitating access into and through cancer care services?
3. Does current cancer control policy adequately address Māori needs?

By exploring the views of Māori patients and whānau who have received cancer care, alongside the views of those who work in cancer policy, management and community care, this research aims to inform decisions that will make a positive contribution to improving survival and quality of life for Māori with cancer.

1.2 Scope of the research

A range of disciplines overlap to inform this research including public health, social science, cancer care, and palliative care. It is important to note that the technical competence of cancer care providers, and patient and clinician choices about cancer treatment, as well as the efficacy of different treatments, fall outside the scope of the study.

The focus of this work is on how the journey to receive cancer treatment has been experienced by patients and whānau, how this journey is perceived by those who plan, manage, administer and deliver cancer care, and what, if anything, they would like to do differently. Cancer care services in this study include health promotion, screening, diagnosis, treatment, palliative care and rehabilitation. At each point along the cancer journey, supportive care is also integral to the experience of cancer care services.

Central to this research is Māori health and development. This thesis explores the role and potential of primary care for Māori with cancer, with particular attention paid to the role of Māori health providers. For the purpose of this study, a Māori health provider is a Māori organisation which can be iwi (tribe) or kaupapa (topic or philosophy) based, that holds a contract or contracts to deliver health services. Some Māori health providers also provide social services. Māori health providers deliver health services primarily but not exclusively to Māori whānau, and have a critical role in facilitating access to mainstream health

services (Crengle, 2000). When the term 'Māori health provider' is used in this thesis, it refers to the organisation itself and/or those who work for the organisation, including, but not limited to; community health workers, nurses, doctors, managers and social workers.

The terms 'follow-up' and 'survivorship' as they are used in this thesis, are defined as follows. This thesis takes the position that follow-up means the days, weeks and months after cancer treatment has ended, and survivorship begins at the time of diagnosis and runs until the end of the person's life. For various reasons, some patients and whānau do not identify with the word 'survivor' (O'Callaghan et al, 2015). Reasons include the implication that cancer is a battle and that those who do not 'win' the battle have somehow failed, or the way people choose to identify with having cancer (Mukherjee, 2010). However this thesis is concerned with the services available to people preceding, throughout and after their cancer treatment, which requires discussion around defined periods, including the follow-up time after treatment and overall survivorship from cancer up until the end of life.

Regarding use of Te Reo Māori (the Māori language), Māori words are translated in brackets in the first instance and also listed in the glossary.

A final clarification regarding the research is that all participants in this study were adults. The experiences of children with cancer fall outside the scope of this study. However some participants described services linked to child cancer care in the context of whānau ora (healthy families), for example discussion regarding the excellent facilities available to whānau (families) at Starship children's hospital.

1.3 Thesis organisation

Chapter 1 introduces the study. Objectives are described, and the scope of the study is made explicit. Each thesis chapter is outlined, and a background to the study is provided.

Chapter 2 sets the scene for the study. The background begins by briefly describing the parameters of the literature review that informs the study, and goes on to outline the historical and contemporary contexts for Māori engaging with cancer services in Aotearoa. It then examines Māori health outcomes as they relate to social determinants of health, Māori access to health services and the importance of culturally safe care (Ramsden, 2002). The role of primary care for Māori with cancer is described, alongside the development and role of Māori health providers. Whānau is defined and whānau ora, both as a kaupapa and as a framework for delivering health services, is described. An outline of the policies related to cancer control in Aotearoa is also presented.

Chapter 3 describes the methodology, study design and methods of the study. First, the research is positioned as Māori-centred (Cunningham, 2000). Then, critical theories that inform and guide the study are articulated including: a feminist ethic of care (Tronto, 1993 & 1998), cultural safety education (Ramsden, 2002), and racial discrimination (Jones, 2000). Multiple bounded cases (Creswell, 2007) are defined according to Tronto's Ethic of Care framework (Tronto, 1993,1998). The multiple case study analysis is then set out, with the Circles of personalist care ethics model (Denier & Gastmans, 2013) used to assist in structuring the comparative analysis. The study methods are described, including development and piloting of the interview schedule, recruitment of participants, interviews, transcribing and data management. Finally, the process

of the thematic analysis is outlined, including data immersion, comparison and discussion of emergent themes.

Chapter 4 presents the findings from the interviews with Case 1 - the perspectives of patients and whānau. These participants shared their experiences of cancer detection, diagnosis and treatment, as well as supportive care services throughout the different stages of their cancer journeys.

Chapter 5 presents the findings from the interviews with Case 2 – the community participants. This case was made up of perspectives from people who work in primary care and hospice settings. Participants were asked about their work with whānau experiencing cancer. They shared their experiences of advocating and supporting whānau throughout cancer prevention, detection, diagnosis, treatment, palliative care and rehabilitation.

Chapter 6 presents the findings from the interviews with Case 3 participants. These participants worked in management positions within primary health care settings, a hospice and a hospital. Management participants reflected on supporting whānau in their communities and also their administrative work in managing teams and funding contracts.

Chapter 7 presents the findings from the interviews with Case 4 participants, each of whom worked in cancer policy. Participants describe their previous work with whānau as well as their policy work in wider contexts as well as the administration of funding contracts for cancer screening and other activities.

Chapter 8 discusses the combined findings assisted by the adapted Circles of personalist care ethics model (Denier & Gastmans, 2013). The major findings from the study, their implications on the research questions, and how these relate

to the local and international literature are presented. Study strengths and limitations are described.

Chapter 9 presents the main conclusions of this thesis. The implications of the research are discussed in relation to improving Māori cancer outcomes.

Recommendations, including identification of future research, which could build on and extend the findings from this study, are made.

Chapter 2

Background

2. Literature review

The background section begins by outlining the context in which cancer care and support are delivered to and by Māori (and non-Māori) in Aotearoa. This includes defining who Māori are, our history, Te Tiriti o Waitangi and on-going colonising practices. This section then provides an overview of the public service reforms of the 1980s and the emergence of nationwide Māori health provision in the 1990s. Māori access into and through mainstream health services is then explored, alongside the role of primary care in improving access to cancer care, with particular attention paid to the health service delivery context. As most Māori access mainstream primary health care, and almost all cancer care services are located in the mainstream, the approach of health care workers to those they 'serve' is critical (Ramsden, 1993). Therefore, cultural safety education is defined and its application to care described. Whānau ora, both as a kaupapa and as a framework for delivering health and social services, is outlined in relation to cancer care, alongside specific cancer control policies and their implications for Māori health service provision.

Search strategy

The following primary search terms were used: Māori, Māori health providers, Māori cancer, cancer navigators, supportive care, palliative care, primary care and cultural safety. Additionally, general cancer information and international Indigenous cancer control initiatives were explored. This was not a systematic review of the literature in that the search parameters were fluid, and this left room to include publications that fell outside the original search terms. For example whānau ora, an approach to health and service delivery which supports whānau instead of treating individuals and illness, appeared strongly in the Māori and Māori health provider literature, so became a search term. Inclusion of whānau

ora then led to literature on the Whānau Ora Initiatives (Te Puni Kōkiri, 2015) - funded health and social services which focus on whānau aspirations and encourage collaboration across sectors to wrap around (address all the needs of) whānau. The Whānau Ora Initiatives began to be implemented at the same time that this research was being undertaken. Similarly, racism is named in some of the literature regarding both Māori people and Māori health, so this too was included in the searches as it was relevant to this research.

The review used a cross disciplinary approach, combining public health, social science, cancer care and palliative care from both qualitative and quantitative studies. It involved searching electronic journals on the following electronic databases: Scopus, Medline, Pubmed, CINAHL, Google Scholar and Te Puna. It also included books located via the Massey University Library electronic catalogue and grey literature from government websites, as well as mainstream news articles in newspapers, magazines and radio broadcasts. A snowball approach to citations was also applied, in that relevant references, cited in the searched papers, were identified and retrieved.

2.1 Māori in Aotearoa

Aotearoa is a country in the South Pacific that has two main islands: Te Ika-a-Maui (the North Island) and Te Waipounamu (the South Island) as well as over 30 smaller islands. Māori are the Indigenous people of Aotearoa and comprise almost 16% of the 4.5 million population. The other major ethnic groups are: Pacific peoples, with the main groups being: Samoan, Cook Island Māori and Tongan (8%); Asian, made up primarily of Chinese, Indian and Korean peoples (12%); Middle Eastern, Latin American and African (1%), and New Zealand European, the majority of whom are descendants of colonial settlers from

England, Ireland, Scotland and Wales (also known as Pākehā) (75%) (Statistics New Zealand, 2015).

As Indigenous people, Māori are the first peoples of Aotearoa and have a special connection to the land that reaches back over a thousand years. There are over 65 iwi and each is different, with variations in language and tikanga (values and beliefs) (Durie, 2001). Within iwi are smaller hapū (sub tribes) and within hapū there are groups of whānau (familial groups or groups connected by activities) (Durie, 2003).

There are many ways of experiencing the world that are different for Māori compared to non-Māori, for example, Māori collectivism and models of health are different, as will be described in further sections of this chapter. However it is important to understand at the outset that there is no single Māori identity (Durie, 1995) and no single way to be Māori, just as there is no one way to be Pākehā (Ramsden, 2002).

Māori have always been a diverse and dynamic population and this is no more apparent than in the present day. Durie (1995) has identified four main groups of Māori in Aotearoa. In his *Ngā Matatini Māori* paper, Durie (1995) initially described three groups of people who identify as Māori. The first group was described as those who are comfortable in the Māori world, for example, attending tangihanga (mourning/funeral, also called tangi), and also connected to conservative Māori networks such as kohanga reo, marae, cultural groups or committees. Durie described the second group as integrated into mainstream New Zealand society, with lifestyles no different from Pākehā. The third group are alienated from both Māori and mainstream society, accessing neither marae activities, nor publically available amenities and services such as early childhood education, swimming pools or libraries. Rata (2015), Borell (2005) and Webber

(2008) have shown how Māori can move between these groups, with identity being fluid, particularly among young people.

Cunningham (2008) recently added a fourth group; those who are secure in their Māori identity and equally at ease in both Māori and mainstream situations. He refers to this group as the 'pluralistic elite', but points out this was a relative term, in that even well-resourced Māori do not fare as well in health outcomes as their Pākehā counterparts.

Income, education, housing and employment are well recognised as key determinants of health (Braveman, 2006; Crampton, Dowell & Woodward, 2001; Easton, 2008; Hill, 2008; Howden-Chapman & Bierre, 2008; Marmot et al, 2008; Marmot & Allen, 2014; Reid & Cram, 1999; Reid, Robson & Jones, 2000; Smedley, Stith & Nelson, 2003; Salmond & Crampton, 2002; Walton, Signal & Thomson, 2009; The Marmot Review, 2010; World Health Assembly, 2009). The differential distribution of deprivation, living standards, and employment status by ethnicity in Aotearoa have consequences in terms of access to care and health outcomes with Māori, Pacific and low income groups experiencing the greatest levels of unmet health need compared to other population groups (Borell et al, 2009; Brewer et al, 2012; Cram, 2014c; Durie, 1994; Ellison-Loschmann et al, 2015; Foliaki & Matheson, 2015; Gott et al, 2015; Hill et al, 2010a; 2010b; Jansen, Bacall & Crengle, 2008; Lee & North, 2013; Lovell, Kearns & Friesen, 2007; Matheson & Loring, 2011; McKenzie, Ellison- Loschmann & Jeffries, 2011; Pomare et al, 1991; Robson, 2008; Robson & Harris, 2007; Robson, Purdie & Cormack, 2006; Robson, Purdie & Cormack, 2010; Robson & Ellison-Loschmann, 2016; Seneviratne et al, 2015a-c). Moreover, Māori face racism at individual, system and institutional levels which has been shown to impact negatively on health (Cormack, Harris & Stanley, 2013; Harris et al, 2012a, 2012b; Harris, Cormack & Stanley, 2013; Houkamanu & Sibley, 2015; Huria et al,

2014; Kearns, Moewaka-Barnes & McCreanor, 2009; King, Smith & Gracey, 2009; McCreanor, 2008; Mutu, 2014; Paine et al, 2016; Pack, Tuffin & Lyons, 2015; Tobias & Harris, 2010).

In order to provide the historical and contemporary contexts in which Māori experience poor cancer outcomes (Cormack et al, 2005; Kendall Roundtree et al, 2011; McGrath & Holewa, 2012; Ministry of Health, 2015a-e; Robson & Ellison-Loschmann, 2016; Robson & Harris, 2007; Robson, Purdie & Cormack, 2006), as well as poor outcomes in health overall (Carr, 2013; Chong & Dai, 2013; Crampton & Robson, 2014; Durie, 1995; Janssen & Nelson, 2014; Kiro, Von Randow & Sporle, 2011; Milne et al, 2012; Ministry of Health, 2013b, 2015e; Ramsden, 2002; Robson, 2008; Robson & Harris, 2007), education (Caccioppoli & Cullen, 2006; Curtis et al, 2015; Nga Kairangahau Manatu Māori, 1991; Tomlins-Jahnke, 2012), housing (Houkamau & Sibley, 2015; Kiro et al, 2011; Millar, 2014; New Zealand Child and Youth Epidemiology Service, 2012; Te Puni Kōkiri, 2006), and justice (Gulliver & Dixon, 2015; Green, 2015; Ministry of Justice, 2009; New Zealand Law Commission, 1999; Shepherd & Illalio, 2016; Williams, 2001). A short account of colonisation in Aotearoa will be presented in the following section.

2.2 The colonisation of Aotearoa

The colonial history of this country is referred to in a skewed and often very romanticised way in the general education system. (Ramsden, 1997, p. 117)

Smith (2012) has described colonialism as an expression of imperialism with the latter a worldwide campaign launched hundreds of years ago as European *explorers discovered and developed* (my own emphasis) the land of other nations, subjugating Indigenous inhabitants (ibid).

Colonisation is not relegated to history, it is expressed in on-going practices that undermine the worlds of Indigenous peoples, for example, in health services that are not culturally safe (Ramsden, 2002), unrelenting, negative media portrayals of Māori (McCreanor, 2008), or confiscation of land by the State such as occurred with the Foreshore and Seabed Act 2004. This legislation removed Māori title to the foreshore and seabed and vested it in the Crown (Jackson, 2003). The Act also removed existing court jurisdictions over the foreshore and seabed and created new jurisdictions to hear Māori claims of customary rights (Bess, 2011). The Act was repealed in 2011 (Dorsett, 2006; Rivers-McCombs, 2010).

Another on-going colonising practice is in the ownership, definition and transmission of knowledge, for example, the power to control what children are taught at school about who they are and what happened in the past to create the world they live in today (Smith, 2012). The quotation from Ramsden at the beginning of this section resonates with this writer's experience of the mainstream education system regarding the history of this country. Primary school students in the 1970s were taught that Māori came to Aotearoa by accident. They were shown the painting by Steele and Goldie: *The arrival of the Māoris in New Zealand* (Steele & Goldie, 1898). The painting by these well-known English portrait artists of the 19th century (Blackley, 2001) depicts emaciated and forlorn Māori aimlessly floating in a damaged waka (canoe).

Students were taught nothing of the navigation skills of their Māori ancestors, nor the planning that was involved in their journeys here (Reed & Calman, 2006). Instead, they learned about New Zealand being *discovered* by Captain Cook, and the *brave and hardy settlers* from the British Empire who, through their *hard work and ingenuity, built New Zealand into the great country it is today* (my own emphasis). According to Taylor and Sheehan (2011) this approach to teaching history was typical of the era, with many teachers resisting the new Social

Studies syllabus, which was beginning to engage with world views beyond the European, and exploring culture as more than decoration.

A trickle of traders and missionaries in the early 1800s grew to larger numbers of whalers and sealers, alongside increasing numbers of settlers from Britain. By 1830, Māori sought assurance that the British would govern their own people and that Māori would continue to trade and prosper with the new migrants. Thus, most hapū agreed to sign a Treaty with the British Crown in 1840 (Orange, 2011).

There were discrepancies between the Māori (Te Tiriti o Waitangi) and English (Treaty of Waitangi) versions of the Treaty. Importantly, Te Tiriti o Waitangi described 'te wanatanga katoa' (complete governance) over land in exchange for protection. However, the Treaty of Waitangi described the queen of England as having "all the rights and powers of sovereignty" over Māori (Orange, 2011, p. 40).

Subsequently, the Treaty, followed by the New Zealand Constitution Act in 1852, and further legislative processes such as the Native Lands Act 1865 and the Native Land Act 1873, were the first steps in the process of mass settlement and land confiscation by the British (Durie, 1994). At the heart of this colonising process was the belief by those governing the British Empire that Indigenous people (in the language of the day –*natives* or *savages*) (Lange, 1999; Smith, 2012) (my own emphasis) were *inferior beings*, unable to reason and much too concerned with the *supernatural* world (Tomlins-Jahnke, 2011).

A pivotal British character in facilitating the signing of the Treaty was Captain William Hobson, who was the first Governor of New Zealand, appointed by the British Empire. Hobson is said to have declared to those signing at Waitangi: "We are now one people" (Orange, 2011, p. 60). Despite this inclusive statement, the British were unable to acknowledge that the Treaty was a contract

between two very different peoples, with different world views and ways of living (Tomlins-Jahnke, 2011). The Treaty was effectively used as a tool of dispossession (Jackson, cited in Ramsden, 2002), opening the way to large scale immigration by British settlers which was facilitated by legislation and by force. The resultant land seizures which began during this period have been recently described as a holocaust (Radio New Zealand National, 2000, 2012) and genocide (Pihama, 2012).

This disconnection from land and way of life occurred at a time when Māori lives were being lost through death from firearms and no immunity to colonialists introduced diseases (Pool, 1991). These key determinants of population decline, alongside policies which facilitated colonial settlement in overwhelming numbers, meant that the late 1800s were a bleak time for Māori, and the population dwindled dramatically. Although census data were far from accurate, it is estimated that there were between 90,000 and 114,000 Māori in 1840 but by 1896 this had diminished to approximately 40,000 (Lange, 1999).

Those responsible for the accelerating population decline appeared apathetic. Newspaper articles, public addresses and journal articles from the mid to late 1800s show a belief that Māori would inevitably die out and be replaced by a “superior race” (Lange, 1999). An often-quoted example from Dr Isaac Featherston, Superintendent of Wellington in the 1800s, sums up the view of the British colonisers towards Indigenous people in general, but in this case specifically Māori: “A barbarous and coloured race must inevitably die out by mere contact with the civilised white; our business therefore, and all we can do is to smooth the pillow of the dying Māori race” (Miller, 1958 quoted in Durie, 1994, p. 30).

Subsequent assimilation policies by successive governments had a number of serious consequences for Māori which began during the time following the signing of the Treaty of Waitangi and, can be argued, continue in various forms to this day (Durie, 1994; Smith, 2012).

2.3 Māori activism and development

It is outside the scope of this thesis to describe the myriad of actions undertaken by Māori to retain and reclaim self-determination from the time of signing Te Tiriti o Waitangi to the present. Consequently, important events such as the land wars, the Kingitanga, Ratana and Parihaka movements (Durie, 1994), are not elaborated on. However in terms of health outcomes, it is vital to mention the work of Māori leaders including Maui Pomare; Te Rangihiroa (Peter Buck); Sir Apirana Ngata; and Te Puia Herangi. They, alongside many others, contributed to improving the health of an increasingly dispossessed people over the course of the late 19th and early 20th centuries. Their efforts included public health education in Native Schools, community outreach services in the form of Native Officers, Māori hospitals, Māori Councils, and attempts to promote more Māori in the health workforce (Durie, 1994; Lange, 1999).

Participation in the Great War (1914-1918) and World War II (1939-1945), where the numbers of Māori killed were disproportionately large compared to non-Māori (Fletcher, 2014; Ministry for Culture and Heritage, 2014), was followed by rapid social change in Aotearoa, with Māori moving from ancestral lands in rural areas, to cities in search of employment (Durie, 1994; King, 2003). Just as land confiscation in the 1800s impacted negatively on the ability of Māori to retain ownership of tribal lands, the migration into cities facilitated a second wave of Māori disconnection from whānau, hapū, iwi and whenua (land) (Durie, 1994). Some authors have reframed this view by questioning whether this disconnection

was as prevalent as widely believed, or that it resulted in Māori assimilating into Pākehā society to a great extent (Hill, 2012; Mahuika, 2009; Morrow, 2014). In fact, Morrow (2014) describes Māori urbanisation after World War II as the “seedbed of the Māori Renaissance” (p. 98.).

Concerns about the health of Māori led to the creation of the Māori Women’s Welfare League (MWWL or the League) which was formed in 1951. The MWWL engaged with communities, actively supporting women through a range of activities such as education about provision of clean water and fresh food, growing vegetables, and the care and feeding of infants. It could be argued that the approach of the MWWL in health promotion and building relationships with whānau within their communities, was a valuable precursor to the later development of Māori health provider organisations in the 1990s. The League also became a strong political force, with its members lobbying government for action on Māori health and, as will be described in a later section, undertaking health research (Durie, 1994). In this way, the MWWL also played an important role in advocating and promoting Māori development (Durie, 1994).

Māori determination, activism and resilience, alongside strong leadership, ensured that Māori did not succumb to the pressures of poverty and alienation caused by colonisation. The people of Aotearoa began to undergo a shift in consciousness during the 1960s, 70s and 80s, as more and more Māori began to publicly challenge the status quo and question taken-for-granted assumptions, such as the mono-cultural focus of the education (Smith, 2012), health (Durie, 1994; Ramsden, 2002), and justice (King, 2003) systems. One example was the Ngā Tamatoa movement (the Young Warriors), a group of young Māori activists primarily based at Auckland University who worked to include the teaching of Te Reo Māori in schools (Smith, 2012), promote Māori control of Māori land, and provide legal assistance for Māori defendants appearing in court (King, 2003). In

1975, The Māori Land March, from Te Hapūa to Wellington, presented a Memorial of Rights supported by a petition of more than 60,000 signatures, regarding unacceptable and on-going loss of Māori land (Keane, 2014). A 17-month occupation of Bastion Point in 1977 protested against land losses by Ngāti Whatua in Auckland, and the following year, the Raglan golf course was occupied as it too was built on land taken by the Crown and never returned (Orange, 2011).

These actions held the government to account for loss of land, language and culture, and were supported by some non-Māori who were beginning to realise that theirs was a culture of privilege that did not include all people. This privilege has been defined by McIntosh (1988) who developed a checklist of entitlements in what she called the “invisible knapsack” that is carried by people who dominate mainstream culture. These privileges centre around the world view that to be Pākehā is to be normal, and in being normal, feeling accepted by the world around you on a daily basis. McIntosh’s invisible knapsack of privileges includes acceptance and tolerance by others when shopping, attending school, hiring a car, or renting a house. Those who are not Pākehā face daily challenges. Without the invisible knapsack of privileges *they are not normal* (my own emphasis), and experience racism in structural, institutional and interpersonal forms.

Events such as the 1981 Springbok Tour brought racism to the dinner table conversations of most of the country. By reflecting on the apartheid regime in South Africa, many people here questioned for the first time the idea that Aotearoa had what King (2003) has described as “the best race relations in the world” (p. 413).

A new era began for Māori development in the 1980s. Sometimes referred to as the “Māori Renaissance” (Derby, 2014, p. 98; Hill, 2012, p. 257), Māori were recognised as important partners with the Crown in education, justice and health, as well as art. An example was the Te Māori exhibition, a tour of taonga Māori (Māori treasures), which involved meaningful engagement between the guardians of the taonga and the museums exhibiting them. Thus, as described by Mead (1997), the taonga were presented as works of art instead of ethnographic specimens and proved hugely popular both in Aotearoa and the United States.

In education, the Kōhanga Reo movement, education language nests in Te Reo Māori, offered alternative early childhood education (Smith, 2012). In 1987, Te Reo Māori was recognised as an official language when the Māori Language Act was passed. The Act also established Te Kōmihana Mō Te Reo Māori, the Māori Language Commission (Ministry for Culture and Heritage, 2015). In politics, the Mana Motuhake political party emerged. Mana Motuhake was the first Māori political party to be established since the Young Māori Party of 1897 (Durie, 1994; King, 2003). The Hui Taumata (Māori economic summit) took place in 1984 which called for a decade of Māori development based on Māori involvement in public services for Māori (Durie, 1994). This can be distilled into describing activities and services promoting positive Māori development when they are undertaken *by Māori for Māori* (my own emphasis). Durie (1994) has described the goals of Māori development: “Reduced reliance on the State, the conversion of negative spending into positive funding, and confidence in tribal delivery systems were emphasised in order to enhance Māori social and economic advancement” (p. 146).

In this way, the decade of Māori development sought to advance Māori economic, health and education outcomes within a framework of Māori sovereignty.

Te Tiriti o Waitangi, previously an instrument of colonisation, became a tool for de-colonisation (Campbell, 2011). The Waitangi Tribunal was established under the Treaty of Waitangi Act in 1975. For the first time, breaches of the Treaty could be presented and examined. The role of the Tribunal is to examine examples of Treaty breaches, and provide recommendations to the government. Hearing and settling Iwi claims by the Tribunal is an on-going process.

Recognition of the importance of Māori input into policy and practice continued to gather momentum in the 1990s. One example was environmental legislation which began to take Māori views into account, as shown in the Te Ture Whenua Māori Act 1993, which made it easier for Māori land owners to make decisions about the use of their land (Taonui, 2012). Law in Aotearoa began to incorporate Treaty principles, known as the three Ps – partnership, participation and protection (Orange, 2011; Royal Commission on Social Policy, 1998).

In terms of health, the Māori Women's Welfare League undertook a health survey of Māori women by Māori women in 1981-83 and produced the Rapuora report (Murchie, 1984), which showed that Māori were able to carry out robust research with their own research methodology (Durie, 1994). In 1984, the Hui Whakaoranga, the first national hui (meeting) on Māori health, facilitated calls by Māori health professionals for the government to recognise that Māori health and disease issues were different from those of the general population (ibid).

Ministerial responses to Māori health issues were undertaken, such as the Māori Asthma Review (Pomare, 1991). This review was initiated because of the unacceptably high number of Māori dying from asthma. Conducted in 1990, the review found a need for reducing health care costs, more education for people with asthma, use of asthma management plans and greater participation by Māori in the planning and delivery of asthma services and education (Ellison-

Loschmann & Pearce, 2000). This was one of the first documents to identify access to care as an important determinant of health outcomes for Māori.

Both the Māori Asthma Review and the Hui Whakaoranga promoted the necessity for Māori involvement in Māori health service design and delivery and importantly, the recognition of culture as a positive resource for health and education institutions (Ramsden, 2002). What followed was the implementation of cultural safety education, which will be described in the following section.

2.4 Cultural Safety

Cultural safety is primarily about difference, respect for difference, power relationships between people, and the fundamental basic human rights of respect, dignity, safety, autonomy and empowerment (Papps, 2015, p. 46).

Cultural safety's beginnings were in education for nursing and midwifery students in Aotearoa. Cultural safety was developed by Irihapeti Ramsden, a nurse, in response to growing evidence showing poor Māori health outcomes (Ramsden, 2002). Ramsden recognised that nurses and midwives, as the largest health workforce in Aotearoa, could make a substantial difference to the way in which health care was delivered. This was in contrast to transcultural nursing, which followed the ethnocentric approach of providing care shown in the Florence Nightingale oath, directing that people should be nursed *regardless of colour or creed* (Ramsden, 1997, p. 116). Cultural safety stated that people should be nursed *regardful* of their culture (ibid). Culturally safe care encompasses: age, gender, sexual orientation, socioeconomic status and class, ethnicity, religion, and disability (Jungerson, 2002).

The term 'cultural safety' originated from the Hui Waimanawa, a national education meeting organised in 1988 by Ramsden (2002). The hui was attended by educators and nursing students, including one student who coined the term 'cultural safety' when she said: "...legal safety, ethical safety, safe practice/clinical base and a safe knowledge base were all very well to expect from graduate nurses – but what about Cultural Safety?" (Ramsden, 2002, p. 93).

Cultural safety recognised that understanding and confronting power imbalances and racism, both within health services and among the individuals who worked in them, shifted responsibility rightly back onto those institutions and health workers to address the poor performance of services in meeting the health realities of Māori, including ensuring access to care (Ellison-Loschmann & Pearce, 2006).

The development of cultural safety education coincided with the establishment of Māori health provider services in the 1990s. While Māori health provider organisations were able to reach their communities using kaupapa and tikanga Māori, cultural safety was essentially a resource for mainstream health providers to improve service delivery. Cultural safety education aimed to produce a workforce of mainstream nurses and midwives who were "...well-educated, self-aware and culturally safe to practise defined by the people they serve" (Ramsden, 2002, p. 87). Although initiated by nurses, cultural safety education has been extended to other health practitioners. Canadian examples show its benefits for better equipping medical students (Klopp & Nakanishi, 2012) and other health workers (Shah & Reeves, 2012) to be regardful of their own power and the ways in which that power could impact on their engagement with patients.

Cultural safety has now been a core component of nursing and midwifery studies in Aotearoa since 1992, although initially this was met with resistance from media

commentators. Ramsden (1997) has described a “minor media explosion” (p. 113), as newspapers, radio talkback and cartoonists tried to understand issues of race relations. Cultural safety developed from the experience of colonisation and recognises that the social, historical, political and economic diversity of a culture impacts on contemporary health experiences. For patients to be considered in terms of their political status and historical circumstances required an understanding and knowledge of history, a fact that the media commentators appeared unable to process (Ramsden, 1997, 2002). Also, given this information is not necessarily part of the general education system, including teaching about the Treaty of Waitangi, it was consequently very difficult to move the issues of cultural safety in relation to Māori health, forward. The vast majority of nursing and midwifery students were exposed to this information for the very first time in their lives as part of their training programmes (Ramsden, 1997). Issues of deprivation, loss of economic resources, land, people and identity, that is, of colonisation, have major health and disease outcomes which had remained largely unrecognised and unanalysed in nursing and midwifery education until challenged by the ideas of cultural safety (Ramsden, 2002).

As outlined by Ramsden (1997), the key objectives of cultural safety education were to teach student nurses and midwives the following:

Not to blame the victims of historical processes for their current plights; to examine their own realities and attitudes brought to each new person encountered in their practice; to be open minded and flexible in attitudes toward people who are different from themselves.
(p. 122)

A foundation document for cultural safety is the ‘Model for Negotiated and Equal Partnership’ (Ramsden, 2002). The model required an understanding of the

Treaty and its implications for power and resource sharing at a policy and governance level, as well as outlining processes for the translation of nursing and midwifery education into positive action. Thus, cultural safety was an educational model that could provide mainstream health services with the tools to approach care in a way that was culturally safe for all patients. This will be further expanded on in Chapter 3 where cultural safety education theory is discussed as one of the critical theories informing the methodology of this thesis.

2.5 The need for equitable health care

Colonialism has left a legacy of health inequalities affecting indigenous peoples in many countries, including New Zealand (Crompton & Robson, 2014, p. 6).

More than 175 years have passed since two peoples signed Tiriti o Waitangi. Durie (1994) has pointed out that over this period, Māori society, rather than blending into mainstream social structures, has remained distinctive. However without links to health services and structures, equitable health care has never been achieved. One contributor to this inequity is that health care in Aotearoa has historically followed a 'one size fits all' approach. Cormack and colleagues (2005) have highlighted for example, how the cultural focus of mainstream health providers is based on European norms and that this focus, together with issues of funding, resourcing and location of services, means that mainstream health services do not always meet Māori needs.

European norms include concepts such as the nuclear family, and individual autonomy by patients rather than a collective whānau focus for health (Wilson & Barton, 2012). Indeed, the very definition of health held by mainstream health providers runs counter to Māori norms. For Māori, health does not mean the absence of physical or mental illness in an individual (Durie, 2001). Māori

models of health include the wellbeing of the whole family, including spiritual, mental and physical health. These are defined in Durie's Te Whare Tapa Whā (the four cornerstones of Māori health) model (Durie, 1994) and Pere's Te Wheke (the octopus) model (Pere, 1994). Other work also includes the environmental factors that impact on wellbeing such as historical and current processes inhibiting access to tribal land (Cram, Smith & Johnston, 2003; Warbrick et al, 2015), through sale or confiscation.

Māori have been health care providers in Aotearoa for over a thousand years (Ratima, 2001). Early interactions between Māori and visitors from the other side of the world provided accounts of robust public health systems, medicines and treatments (Lange, 1999), but these were eroded by events following the arrival of British traders and settlers in the 1800s.

Provision of health services by Māori for Māori were not funded on a nationwide scale until the 1990s (Durie, 1994). The time when Māori were finally afforded the opportunity to participate in health service delivery followed massive economic and social changes as a result of public sector reforms in the decade prior (Kelsey, 1993; Robson, 2008). In this way, Māori health providers were born in an era of uncertainty and adversity which will be discussed later in the chapter.

Health reform and Māori health providers

The 1980s were a time of significant economic and social change in Aotearoa as the state stepped back from taking a central role in the provision of public services. The national health care system had been established in the 1930s with secondary care under state control and funding. Primary care was largely state funded but controlled by general practitioners (GPs) (Ellison-Loschmann & Pearce, 2006). This remained unchanged until the late 1980s when a radical

restructuring of the public sector was initiated which included a series of major health service reforms (Scott, 1996).

Alongside other deteriorating Western economies such as the United Kingdom and United States of America, the New Zealand government embraced the belief that owning and running public services was expensive and inefficient, and that creating competition between service providers in a marketplace would improve efficiency and provide choice (Barnett & Barnett, 2005; Kiro, 2001). This move was partly in response to economic pressures but also reflected a philosophical shift to promoting individual responsibility, with the people of Aotearoa considered to be autonomous individuals who were able to make informed choices about the services they wished to purchase (Kelsey, 1993). Extensive public sector reforms were undertaken, transforming the way the labour market, education, housing and health were managed (Kelsey, 1994). The reforms have been described as the most sweeping and wide ranging of any in the Western world (Kiro, 2001).

As described earlier, two significant hui (meetings), the Hui Taumata and the Hui Whakaoranga (Durie, 1994), which were pivotal in shaping the beginnings of Māori health service provision, were held in 1984, during this period of extensive public service restructuring. At that time primary care delivery had remained unchanged since the 1930s and was not reaching all parts of the population. Indeed, primary care was mainly provided by GPs who operated on a self-employed, for-profit, small business model with fees subsidised but not controlled by government (Crampton, Dowell & Woodward, 2001). Barnett and Barnett (2005) have described primary care at that time as: “essentially a private service, historically resistant to change and lacking the organisational structures necessary for contracting”(p.187). This model of primary health care delivery encouraged higher numbers of GPs in wealthy areas, and fewer in poor areas.

Cost was a barrier to care for many, and not surprisingly, the provision of health care was inversely related to its need (Hart, 1971), with people on low incomes unable to access primary health care as readily as wealthier people, despite more health service need by those living in poverty (Matheson, 1992).

The opportunity for Māori to fully participate in health service delivery occurred when the overall reforms agenda extended to health in the early 1990s and a 'market' was created for health services. Two particularly important changes concerned the way in which public hospital and population health services were organised and delivered, and a new funding scheme for the provision of primary health care that enabled health practitioners to bid for and provide contracted primary care services (Borren & Maynard, 1994). This opened the way to the establishment of Māori health providers, and the first focussed opportunity for Māori organisations to deliver culturally safe health services to their communities within a framework of mainstream health service delivery rather than outside of it as they had previously done (Crengle, 2000; Durie, 1994).

The health reforms of the 1990s separated health service purchasers from providers through the establishment of four Regional Health Authorities (RHAs). The RHAs were tasked with purchasing all health and disability services for their populations (Barnett & Barnett, 2005). Māori provider groups were able to compete with other providers from the public, private and voluntary sectors, for RHA health contracts. These ranged from GP services to child immunisation programmes and health promotion (Crengle, 2000). The number of Māori health providers grew rapidly, and included both iwi and community-based health provider groups (Kiro, 2001).

Primary health care providers responded to the new funding model in two ways. First, most GPs joined Independent Practitioner Associations (IPAs). These

groups are professional collectives, owned and controlled independently by member GPs (Barnett & Barnett, 2004). Some have argued that the formation of IPAs in the early 1990s was motivated by the need of GPs for effective negotiation with RHAs rather than a concern for access to care for patients and whānau (Malcolm, Wright & Barnett 1999; Neuwelt, Kearns & Brown, 2005).

But there was a second response to the new funding by primary health care providers with the establishment of primary care trusts. Also called the 'third sector' (Crampton, Dowell & Woodward, 2001), these were not-for-profit organisations that focussed on community governance and access to care (Barnett & Barnett, 2004; Barnett & Barnett, 2005). One such trust was the Newtown Union Community Health service which took a community development approach and had a strong focus on relationships with unions and local communities (Matheson, 1992). Matheson (1992) has illustrated many instances of community initiation and governance of health services from the Newtown Union Health Service, with the community achieving wider health objectives by distributing health resources in innovative ways. People from the Newtown Park Flats, a large, council-owned housing apartment block, instigated, for example, an outreach clinic on site that would be accessible to older people. The community went on to extend this forum to include establishing networks for checking up on isolated tenants (ibid).

On one hand, the health reforms provided an opportunity for Māori aspirations for autonomous health service delivery, consistent with a Māori development approach, to be realised. On the other hand, short-term, restricted and inadequately funded contracts left Māori health providers investing time in building relationships with ever-changing funders and working to health contracts that focussed on individuals and illness (Durie, 1994; Russell [Pere], Smiler & Stace, 2013). This clashed with a Māori world view that health and wellbeing are

holistic (Barcham, 2007), and came at a time when wider economic reforms were having an adverse impact on Māori (Robson, 2008).

Privatisation of state assets resulted in the most vulnerable communities being stripped of employment, and families being further stressed by massive cuts to the welfare system (Brown, 1999). The far-reaching effects of the reforms compromised the health of many of Aotearoa's working class and unemployed; however, Māori were impacted more severely in terms of unemployment (Robson, 2008), benefit cuts (Kelsey, 1993,1994; Kiro, 2001), and costs of housing and living (Robson, 2008, Smith, 1992). These are listed in the universal social determinants of health defined in the 1986 Ottawa Charter for Health (World Health Organisation, 1986). The Charter describes the absence of income, education, employment, good living conditions, social support, and access to health services causing poor health, but according to King and colleagues (2009), the impact is greater for Indigenous populations, due to additional layers of racism, loss of language and land, environmental deprivation, and spiritual, emotional and mental disconnectedness (King, Smith & Gracey, 2009).

Working with communities who were the 'shock absorbers' of the reforms (Robson, 2008), and navigating through funding and contractual challenges, Māori health providers changed the face of primary health care service delivery in Aotearoa. The values and ways of working embodied by Māori health providers were different to those of mainstream health providers. Māori health providers used a Māori model of wellbeing, positive Māori development and Māori philosophical and practical approaches (Crengle, 2000). Mainstream models of wellbeing tended to centre on the absence of illness in individuals whereas, for Māori, models of wellbeing are holistic (Durie, 1994). Māori had long recognised that health and development are linked and thus Māori health providers had a

focus on self-sufficiency, social wellbeing and cultural affirmation, within a framework of Māori control (Durie, 2001).

That Māori health provider services operated from kaupapa (philosophical) and tikanga (practical) Māori approaches meant that their appropriateness and acceptability among those they served was increased (Crengle, 2000). Māori health providers took practical steps, for example, to remove care barriers and thereby increase access to health services. Clinics could be conducted at locations where Māori felt comfortable such as marae (meeting grounds), other community facilities or in homes. Māori values and beliefs were considered normal and included in health services, with, for example, karakia (prayer) and access to rongoā (traditional Māori medicines) and mirimiri (massage).

Where whānau were missing out on seeing a doctor due to lack of transport, Māori health providers picked them up from their homes. When childcare was a barrier to accessing health care, Māori health providers made the children welcome. When financial barriers inhibited ability to access the doctor or nurse, low or no cost care was available through Māori health providers. When advocacy with other agencies on behalf of families, and addressing issues associated with health determinants such as housing, education and financial support, was necessary, Māori health providers were there to provide this wrap-around care (Janssen & Nelson, 2014).

Māori health providers' aim of positive Māori development was often hindered by the competitive health contracting environment. As well as the issue of Māori health providers being forced to compete with each other for funding, the yearly budgeting cycle of contracts did not guarantee resources for the long-term. Despite Māori health providers operating in a holistic way that supported whānau and communities, they were only paid for what was in their contract and thus

much of the work undertaken was not funded (Barcham, 2007; Kiro, 2001; Lavoie, 2003).

At the beginning of 2000, the health system was restructured again. A change of government marked the end of the market-driven health funding environment. It was replaced with a greater focus on population health and community participation. The Primary Health Care Strategy (Minister of Health, 2001), guided by the New Zealand Health Strategy (Minister of Health, 2000), set out to achieve the vision that:

People will be part of local primary health care services that improve their health, keep them well, are easy to get to and co-ordinate their on-going care. Primary health care services will focus on better health for a population and actively work to reduce health inequalities between different groups. (Minister of Health, 2001, p. 11)

This shift in focus was congruent with the models of care that Māori health providers and other third sector providers already had in place (Abel et al, 2005; Matheson, 1992). Their work in health promotion and emphasis on wellness rather than only responding to illness in individuals (Crengle, 2000) aligned with the vision of the Primary Health Care Strategy (Minister of Health, 2001).

Twenty-one locally governed district health boards (DHBs) were established under the New Zealand Public Health and Disability Act which specifically refers to their Treaty of Waitangi obligations and requires that they try to have Māori representation (Panoho, 2012). DHBs own and manage hospitals, and also manage primary care through primary health organisations (PHOs). PHOs are groups of individual practices, commonly comprising GPs and nurses. PHOs are responsible for delivering primary health care to an enrolled population and are

funded by DHBs on a per capita basis, replacing the fee for service model (Barnett & Barnett, 2005).

PHOs are required to:

- Undertake population health initiatives as well as patient-centred primary care
- Expand the range of providers for integrated primary care delivery
- Facilitate community participation in governance and decision-making for health care services, and
- Improve access to services for disadvantaged populations (Abel et al, 2005).

Most health service providers, including Māori health providers, are members of a primary health organisation and it is intended that all PHO member providers, such as GP and allied health services, have better links between each other (Minister of Health, 2001). However some have argued that there is great variation in size, structure and philosophy between PHOs, and little has changed with funding at a GP practice level remaining dependent on the number of patients seen by a GP. Additionally, less funding is now available for those identified as 'high needs patients', resulting in PHOs with greater numbers of high needs patients being disproportionately affected (Ellison-Loschmann et al, 2015; Finlayson et al, 2012; Raymont & Cumming, 2009).

The New Zealand Health Strategy was reviewed in 2015 and the refreshed Strategy is expressed in two documents, the first focussing on future direction (Minister of Health, 2016a) and the other providing a roadmap of actions (Minister of Health, 2016b). A new principle has been added in the refreshed Strategy, which is: "Thinking beyond narrow definitions of health and collaborating with others to achieve wellbeing" (Minister of Health, 2016a, p.

14). The Roadmap of Actions (Minister of Health, 2016b) describes sustainability and reviewing of contracting mechanisms in primary healthcare, but it is not clear how these will affect Māori health providers.

Māori health provider organisations continue to serve their communities, delivering services primarily, but not solely, to Māori clients. Māori health providers are portioned an exceptionally small amount of the health budget (Robson, 2008). Between 2006 and 2012, for example, Capital and Coast Health DHB allocated less than 1% of its primary health care funding to both Māori and Pacific health providers combined (Matheson, 2013). The contracting environment means that few providers have established long-term funding and many survive on short-term contracts. There have been repeated calls for more certainty and flexibility in provider funding arrangements (Barcham, 2007; Boulton, 2005; International Research Institute for Māori and Indigenous Education, 2002; Lavoie, 2003).

Māori health provider services range from the provision of Māori-specific services such as mirimiri and rongoā, through to playing an advocacy role in engagement with mainstream service providers (Cormack et al, 2005; Slater et al, 2016, Walker et al, 2008). Facilitation of access to mainstream health services is critical as it is well established that there are difficulties in access to health care for Māori at all levels of service provision (Hill et al 2010, 2013a, 2013b; Ministry of Health, 2008; Sadler, McCowan & Stone, 2002; Shoen et al, 2001; Tukuitonga, 2002; Westbrooke et al, 2001). At the secondary care level, in the context of high hospitalisation rates for heart failure, a study found relatively low intervention rates for Māori (Westbrooke et al, 2001). Further, a study investigating health care for Māori with coronary artery disease demonstrated that despite Māori age-standardised mortality rates being at least twice that of non-Māori/non-Pacific people, Māori men and women had

the lowest rates of both coronary artery bypass grafts and percutaneous transluminal coronary angioplasty at the time of the study (Tukuitonga & Bindman, 2002). More recently, Whalley and colleagues (2015) found that despite heart abnormalities being more prevalent in Māori, particularly rural Māori, life expectancy and quality of life were poor, with improvements needed in early identification. Another study found lower rates of some obstetrics interventions among Māori women compared to other women (Sadler et al, 2002).

The 2001 Commonwealth Fund International Health Policy Survey identified that Māori were more likely than New Zealand Europeans to report problems with health care access (Shoen et al, 2001). The 2006/07 New Zealand Health Survey found that Māori were significantly more likely to report an unmet need for GP services in the previous 12 months compared to European/others (Ministry of Health, 2008). In maternity care, studies have shown that young Māori women seek health services early in their pregnancies but face system barriers that lead to delays in accessing streamlined maternity care (Lee & North, 2013; Makowharemahihi et al, 2014). The importance of primary care as the first point of engagement with the health system is described in detail in the following section.

2.6 The importance of relationships in primary care

There are numerous studies from different parts of the world showing the important role of primary care in providing holistic, patient-centred care and information throughout the cancer care journey (Bindman et al, 1996; Burge et al, 2003; Dahlhaus et al, 2014; Earle & Neville, 2004; Kendall et al, 2006; Halkett, Jiwa & Lobb, 2015; Walton et al, 2013). An American study recently reported that Indigenous people had higher levels of trust with their primary healthcare

provider than with larger health institutions such as the hospital (Simonds et al, 2014). In this way, primary care is an important facilitator of access to further health services, including screening, diagnostics, specialist treatment, and rehabilitation services, both at the secondary care level, but also within the primary care environment.

Interpersonal rapport between GPs and patients has been identified as an enabler for Māori to access healthcare (Cram, Smith & Johnston, 2003; Walton et al, 2013). However studies with both patients and practitioners have found that many Māori do not have a positive rapport with a primary health care provider (Crengle et al, 2005; McCreanor & Nairn, 2002; Penney, Moewaka Barnes & McCreanor, 2011).

Furthermore, research has highlighted a lack of good rapport with frontline practice staff such as receptionists (Cook, Clark & Brunton, 2014; Jansen, Bacal & Buetow, 2011; Pitama et al, 2011; Walker et al, 2008). A lack of good rapport has been attributed to the length of waiting and consultation times (Crengle et al, 2005; Jansen, Bacal & Buetow, 2011), not having a regular doctor (Reid, Cormack & Crowe, 2016) poor pronunciation of names and lack of Māori language competency by practitioners (Pitama et al, 2011).

Another barrier to good rapport has been raised by McCreanor and Nairn (2002) who investigated ethnicity-based assumptions by practitioners about their patients. The authors found, for example, that GPs considered Māori patients to have a *laissez-faire world view* (McCreanor & Nairn, 2002, p. 3) implying that Māori patients were less compliant with taking their medication (ibid).

International studies have also found other contributors to poor rapport between Indigenous people and their doctors. A study of the interactions between First Nations people and their doctors in Canada found misleading non-verbal

communication to inhibit understanding and rapport (Kelly & Brown, 2002). Other studies in Canada (Towle, Godolphin & Alexander, 2006) and the United States (Simonds et al, 2011) have shown that different concepts of time between Indigenous people and their doctors can impact negatively on building good rapport. Recent Australian research shows that barriers to building rapport can result from decades of discrimination, with Aboriginal people experiencing socio-economic insecurity and mistrust of health systems arising from experiences of discrimination stretching back many generations (Treloar et al, 2014).

In addition to good rapport, long-standing relationships between patients and primary health care providers, also known as having a 'medical home' (Arend et al, 2012), have been shown to positively influence access to primary care.

Established relationships between patients and primary health care providers assist the quality of communication during consultations (Reid et al, 2016), and importantly, facilitate access to further services along the cancer treatment journey (Slater et al, 2013). Indeed, international studies show that patients with a 'medical home' are more satisfied with their care and report fewer problems with co-ordination between services (Shoen et al, 2011; Steiner et al, 2008).

These long-term relationships with primary care providers are particularly relevant to cancer care with on-going, personal contact recognised as the foundation of community cancer care (Dahlhaus et al, 2014; Kendall et al, 2006).

A key element of the long-term relationship is trust. The importance of trust between patients and their primary health care providers is particularly relevant to access into and through cancer care (Slater et al, 2013, 2016).

2.7 Cancer overview

It has been estimated that in 2012, 15% of deaths worldwide were due to cancer (May, 2014). The increasing global cancer burden has been attributed to the aging and growth of the world population and an increase in behaviours associated with high cancer risk including smoking (Torre, Siegel & Jemal, 2016) and poor diet (Jemal et al, 2010,2011).

There is considerable variation in cancer mortality between high and low income countries (Farmer et al, 2010; Jemal et al, 2010, 2011; Moore et al, 2015; Thun et al, 2010). In particular, incidence and mortality for most cancers are steadily decreasing in Western countries; however, the opposite pattern is being observed in developing countries (Jemal et al, 2010). Influencing the decline in cancer incidence and mortality rates in high income countries and the rise of rates in developing countries are the presence of public health measures (May, 2014) and the availability and ability of people to access cancer screening and treatment (Farmer et al, 2010; Wilson, Tobin & Young, 2004; Zhou et al, 2016;).

Public health measures include improved cancer awareness and prevention such as tobacco control (Thun et al, 2010), reduced exposure to environmental and occupational carcinogens (Stewart et al, 2016), and vaccination programmes such as those preventing Hepatitis B and human papilloma virus (Thun et al, 2010). Additionally, cancer screening programmes assist in detecting cancers at early, treatable stages (Wilson, Tobin & Young, 2004).

Within countries, there are further inequalities in cancer incidence and mortality, with Indigenous peoples from both high and low income countries across the globe experiencing greater cancer mortality than their non-Indigenous counterparts (Condon et al, 2004, Cottrell et al, 2007; Nishri et al, 2015; Robson

& Ellison-Loschmann, 2016; Wampler et al, 2005; White et al, 2014; Wiggins et al, 2008; United Nations, 2009). It must be noted when describing statistics about Indigenous people, however, that the collection of ethnicity data is not standardised across countries. Indeed, research has shown that due to inconsistent and unreliable ethnicity data collection, cancer mortality rates are likely to be higher rather than lower than what is recorded for Indigenous compared to non-Indigenous people (Blakely et al, 2004; Plescia et al, 2014).

Aotearoa is now a recognised world leader in ethnicity data collection (Moore et al, 2015; Robson & Ellison-Loschmann, 2016). However, this has not always been the case. In the context of national statistics, the ethnicity question of the New Zealand Census has changed a number of times (Blakely et al, 2004), making assessment of trends over time difficult. Additionally, inconsistencies in the way in which ethnicity was defined has hampered comparability between datasets. In the health records context, ethnicity was guessed by clinicians rather than self identified by patients (Curtis, Wright & Wall, 2005; Te Rōpū Rangahau Hauora a Eru Pōmare, 2000).

Despite being a high-income country, cancer registration rates in Aotearoa have consistently been significantly higher for Māori compared to non-Māori, having risen from 19% higher during the 2002-2006 period (Robson, Purdie & Cormack, 2010), to 25% higher in 2010-2012 (Ministry of Health, 2015b). Similarly, ethnic disparities in cancer mortality have widened since 1980 (Jeffreys et al, 2005) and remain unacceptably high for Māori compared to non-Māori (Campbell et al, 2015). For the period 2010-12, for example, Māori cancer mortality rates were 79% higher than those for non-Māori (Ministry of Health, 2015a). Cancer is the major cause of death among Māori females and the second leading cause for Māori males (ibid). Māori have a higher incidence of cancers that could be potentially prevented, such as lung cancers, than non-Māori (Ministry of Health,

2015e, Moore et al, 2015). Māori also experience poorer outcomes from cancers that are treatable with early detection such as cervical, breast, and prostate cancers compared to non-Māori (Robson & Ellison-Loschmann, 2016).

The leading cancers among Māori females during 2010-12 were breast, lung, colorectal, uterine and cervical cancers. Incidence rates were significantly higher for Māori than for non-Māori women for each of these cancers except colorectal cancer, which had a lower incidence rate for Māori. Leading cancers for Māori males include: prostate, lung, colorectal, liver and stomach cancers, with lung, liver, and stomach cancer rates higher for Māori than for non-Māori males.

Although Māori prostate and colorectal cancer registration rates were lower than non-Māori, mortality rates were higher for prostate cancer and appear to be rising for colorectal cancer (Ministry of Health, 2015e; Robson & Ellison-Loschmann, 2016).

It has been well documented that Māori are more likely than non-Māori to live in disadvantaged areas (Robson & Ellison Loschmann, 2016) and that cancer incidence and mortality overall are associated with increasing socioeconomic deprivation (Robson, Purdie & Cormack, 2010). This association is stronger for mortality than for incidence, and there is a steeper deprivation gradient in mortality for Māori than for non-Māori (Robson & Ellison-Loschmann, 2016).

From 2002-2006, for example, increased socioeconomic deprivation accounted for 27% of the cancer incidence disparity and 15% of the mortality disparity between Māori and non-Māori (Robson & Ellison-Loschmann, 2016). Robson and colleagues (2010) examined data for overall cancer incidence and mortality by deprivation decile (Salmond & Crampton, 2002; Salmond et al, 2006) for the same 2002-2006 period and found that within each deprivation decile, Māori cancer incidence was higher than that of non-Māori, even in the least deprived deciles, and for each deprivation decile the mortality gap was markedly wider

than the incidence gap. The differences between Māori and non-Māori are greatest in the most deprived decile (Robson, Purdie & Cormack, 2010).

2.8 Māori access to cancer care services

Pathways through cancer care are critically important to cancer outcomes and quality of life (Mandelblatt et al, 1999). There is, however, relatively little information available on access to care specifically for Māori with cancer. Table 1 lists the literature from approximately the last decade, on Māori access to cancer detection and diagnosis, treatment, palliative care, the survivorship period and supportive care services which is followed by a summary overview of each of these key areas.

Table 1: Literature on Māori access to cancer care

Māori face delays in cancer detection and diagnosis	Firestone et al, 2012 Lawton et al, 2014 McKenzie, Ellison-Loschmann & Jeffreys, 2011 Pitama et al, 2012 Priest et al, 2010 Sadler et al, 2004 Sarfati et al, 2010 Seneviratne et al, 2015b
Māori access into and through cancer treatment	Cormack et al, 2005 Cram, 2014a, 2014b Ellison-Loschmann et al, 2015 Dew et al, 2015 Hill et al, 2010a, 2010b, 2013 Obertova et al, 2015 Seneviratne et al, 2015a Slater et al, 2013 Stevens et al, 2008 Swart et al, 2013 Walker et al, 2008
Māori access to palliative care	Bellamy & Gott, 2012 Bray & Goodyear-Smith, 2013 Cottle, Hughes & Gremillion, 2013 Frey et al, 2013 Gott et al, 2015 Palliative Care Council of New Zealand, 2011, 2012 MacLeod et al, 2011 Slater et al, 2015 Swart et al, 2013 Taylor, Ensor & Stanley, 2011 Taylor et al, 2014
Māori experiences of the follow-up and survivorship periods, including supportive care services	Corter et al, 2011 Doherty & Associates, 2006, 2008 Egan et al, 2014 Kendall Roundtree et al, 2011 Kokiri Seaview Marae, 1999 Lawler et al, 2011 Manchester, 2008 McGrath & Holewa, 2012 Ministry of Health, 2011 Murphy, Harre Hindmarsh & Bright, 2010 Nesler & Wharerau, 2011 Pataki Associates, 2002 Sachdeva, 2015 Slater et al, 2013, 2016 Walker et al, 2008

Detection and diagnosis

The Cervical Cancer Audit (Sadler et al, 2004) identified that Māori women with a high-grade smear had an increased likelihood of delays in investigation and diagnosis. The Cervical Cancer Audit then matched cancer registration and New Zealand Health Information service date of death data, and found ethnic differences in cancer survival, recommending that improvements to screening for

Māori women would reduce stage at diagnosis and therefore ethnic inequalities in mortality (Priest et al, 2010).

McKenzie and colleagues (2011) found that ethnic disparities in breast cancer survival were attributable to deprivation and differential access to health care. A recent study showed that this differential access led to lower rates of screen-detected breast cancer for Māori women, contributing to poorer outcomes in terms of breast cancer survival (Seneviratne, 2015b).

A study exploring access to services for women experiencing symptoms of uterine cancer found that Māori women were more likely to experience lengthy delays in seeing a specialist (Lawton et al, 2014). Another study examining the association of ethnicity and socioeconomic status with tumour stage and grade at presentation of uterine cancer found that Māori and Pacific women, and those from lower socioeconomic areas, are more likely to present with advanced uterine cancer (Firestone et al, 2012).

Treatment

Access into and through cancer treatment has been shown to be lacking for Māori compared to non-Māori. Hill and colleagues (2010a, 2010b) found for example, that Māori with stage III colon cancer were 30% less likely to receive adjuvant chemotherapy compared to non-Māori patients, even after adjustment for co-morbidity. The authors also identified poorer quality treatment for Māori in lung and colon cancers, determining that “the health care system as a whole is delivering unequal care” (Hill et al, 2013, p. 39). Similar findings were presented by Stevens and colleagues (2008) whose audit of secondary care management of lung cancer patients in Auckland and Northland found that Māori had lower rates of curative treatment compared to non-Māori and longer wait times from diagnosis to treatment. In regard to prostate cancer, Obvertova and colleagues

(2015) demonstrated that differences in treatment modalities may influence poorer outcomes for Māori men compared to non-Māori men.

Regarding length of waiting time for treatment, a review of 194 rectal cancer patient records found that Māori tended to wait longer between diagnosis and referral to medical or radiation oncology, but once a referral was made, waiting times for further cancer treatment were similar to those of non-Māori (Swart et al, 2013). A study of breast cancer data in the Waikato region, based on data available for 1,449 women, found inequities in timing of treatment, with Māori and Pacific women waiting longer for surgical treatment than non-Māori/non-Pacific women (Seneviratne et al, 2015a). Similar findings were reported in a recent study of barriers to and delays in breast cancer care, with Māori and Pacific women more likely to face delays in seeing a specialist than non-Māori/non-Pacific women (Ellison-Loschmann et al, 2015).

Palliative care

Māori appear to be under-represented in hospice uptake. Although there is little information available on hospice utilisation by ethnicity in New Zealand, work by the Palliative Care Council (2011) has found that for all mortality registrations from 2005 to 2007 “Māori were more likely to die in a private residence or hospital, and less likely to die in residential care or a hospice” (p. 48). This report does not show whether hospice services were accessed in the months or weeks before death, nor does it show if whānau accessed bereavement services. Also absent is information regarding financial and other burdens experienced by whānau who care for their loved ones throughout the final stages of their lives (Gott et al, 2015). A three-year chart review of ethnicities represented within a Wellington hospice provides more context on Māori use of hospice services, finding that just 6% of patients identified as Māori (Taylor, Ensor & Stanley,

2011). This suggests that despite a higher mortality rate for cancer overall, Māori may be missing out on specialist palliative care.

Awareness of palliative care services appears to be universally low throughout the population of Aotearoa. Indeed, a recent survey found that most people were not aware of their local hospice and had little understanding of palliative care (MacLeod et al, 2012). Other studies have found that misconceptions about hospice services exist across many different ethnic groups and a need for more public awareness of the services has been identified (Bray & Goodyear-Smith, 2013; Frey et al, 2013).

Additionally, Māori appear to face further barriers to hospice care. Findings from a review of rectal cancer patient records suggest that there may be ethnic inequalities in access to palliative care services (Swart et al, 2013). The authors proposed that Māori patients and whānau may feel their cultural needs will not be met at a hospice. Findings from Frey and colleagues (2013) suggested that this view may be informed by a lack of ethnic representation on the hospice staff. Māori participants in this study also stressed the importance of including whānau throughout the care journey rather than simply caring for the individual patient (Frey et al, 2013). This focus on whānau as integral to the caring process has also been emphasised in other studies of palliative care in Aotearoa (Bellamy & Gott, 2012; Cottle, Hughes & Gremillion, 2013; Slater et al, 2015; Taylor et al, 2014).

As well as including whānau in palliative care, a recent study focussed specifically on Māori experiences of hospice services recommended that negative perceptions of hospice be addressed, alongside other barriers to accessing hospice (Taylor et al, 2014). The authors highlighted the importance of hospice workers having genuine respect, interest, and compassion toward

Māori and for cultural practices(ibid). Our further qualitative study investigating the perceptions of patients and whānau, hospice workers and non-hospice health care providers, found that negative perceptions of hospice are being changed by hospices' work with other organisations and the positive stories of whānau who have experienced hospice services (Slater et al, 2015). Moreover, the study found that in order for Māori to feel comfortable about accessing hospice services, it is critical that this work continues and gains momentum by incorporating whānau involvement, continuity of care and after-hours care alongside increasing the Māori workforce in this area, and attention to the provision of culturally safe care throughout the final stage of their cancer journey (ibid). Similarly, a study of culturally appropriate palliative care for older people in Aotearoa advocated finding out about individual preferences of patients and whānau instead of making assumptions about end-of-life care preferences (Bellamy & Gott, 2012).

Follow-up and survivorship

While there is some overlap between the periods of follow-up and survivorship, the prevailing understanding of survivorship centres on the long-term future once cancer treatment has ended (Dhillon, 2015), rather than the immediate period after the conclusion of treatment. However, the US National Coalition for Cancer Survivorship has a much broader definition of cancer survival that begins at the time of diagnosis (Hewitt et al, 2006). This is shared by the Ministry of Health in Aotearoa which defines cancer survival as: "The length of time lived after an initial diagnosis of cancer" (Ministry of Health, 2015a, p. 4). Additionally, those who surround the person surviving cancer such as family and friends are also part of the survivorship experience (Koczwara, 2015).

Follow-up after the conclusion of cancer treatment has been shown to be lacking for Māori in Aotearoa (Slater et al, 2013). Follow-up is known to be important in

monitoring health and quality of life as people adjust to life after cancer treatment (Kendall Roundtree et al, 2011). A range of models for follow-up have been put forward in the literature such as GP or nurse-led care, partnership with oncology specialists, and phone or 'e-health' options to provide information and support after treatment (Lawler et al, 2011).

Egan and colleagues (2014) noted the growth in literature focussing on cancer survivorship since the 1970s, but also showed an absence in qualitative cancer survivorship literature, particularly in Aotearoa, with only one major qualitative cancer study completed here which focusses on travel and accommodation throughout cancer treatment (McGrath & Holewa, 2012). The authors of this single study conducted telephone interviews with 46 cancer patients and 16 carers. They found that those who provide cancer supportive care are providing increasing numbers of volunteer drivers to assist with transporting cancer patients and this kind of help is important, as are the health professionals who are "supportive and creative in their efforts to assist people to return home" (p. 1).

Survivorship is included in the supportive care guidelines by the Ministry of Health (Ministry of Health, 2011a); however, Egan and colleagues' Cancer Stories Project (2014) delved deeper into the psychosocial, spiritual matters that were important to a group of cancer survivors in Aotearoa. The authors found a number of factors that helped people get through their cancer experience. These included: attitudes of the patient and those around them; the importance of whānau and friends; the role of the health care practitioners at primary and hospital care; and supportive care, including information; employment; and coping with changes in their lives.

An evaluation of community cancer support services identified a wide range of support needs for people with cancer in Aotearoa. These included: financial

support; practical assistance; transport and accommodation support; advocacy and information support; cultural support; psychosocial and emotional support; continuity of care; support groups; and whānau support (Corter et al, 2011).

Supportive care

The importance of supportive care has been recognised in the Ministry of Health's Supportive Care Implementation Plan (2010a) which defines supportive care as: "The essential services required to meet a person's physical, social, cultural, emotional, nutritional, information, physical, spiritual and practical needs through their experience with cancer" (p. 1).

The Cancer Society of New Zealand (the Cancer Society) is the main provider of supportive care in Aotearoa. Other organisations include those focussed on specific cancer types such as the Breast Cancer Foundation, Melanoma New Zealand, and the Prostate Cancer Foundation of New Zealand. Additionally, the *Look Good Feel Better* charity provides a service for women with cancer. This charity is supported and endorsed by the Cancer Society. The *Look Good Feel Better* workshop is a free service where women learn about self-image, loss of hair, and how makeup can be used to assist with changes in skin tone and texture. Volunteer makeup artists help women learn to apply makeup, and there are professional demonstrations of wigs, hats and turbans.

Like other non-governmental supportive care organisations, the Cancer Society is an independent charity which is funded entirely by donations. The Cancer Society's webpage describes their organisation as "the leading non-government organisation focussed on reducing the incidence and impact of cancer and ensuring cancer care for everyone in New Zealand" (Cancer Society of New Zealand, accessed August 2015a). The Society has a national office based in Wellington, six autonomous regional divisions, and centres within each division.

The Cancer Society has a long history in Aotearoa. It was established in 1929, when the New Zealand branch of the British Empire Cancer Campaign opened in Wellington with the “conquest of cancer” as its mission (Cancer Society of New Zealand website, accessed August 2015b).

Today, the Cancer Society is active in health promotion for cancer prevention, and provides information and support for patients and whānau with cancer. The Cancer Society offers extensive internet and printed information support to cancer patients. They also have a free telephone helpline for contact with an oncology nurse for information, and patients can also email a nurse for information through the website. As well as information, they provide practical support such as driving people to treatments and providing meals.

Importantly, the Cancer Society offer accommodation such as Margaret Stewart House in Wellington, for patients who have to travel from rural areas for treatment. Although availability of face-to-face services varies by division and centre, the Cancer Society also delivers some nursing (Manchester, 2008) and counselling services. They connect patients with each other for support, and they also run the Living Well with Cancer Education Programme (Living Well) which educates patients about living with cancer and provides support. The Living Well programme is modelled on a programme used in Australia (Roberts, Black & Todd, 2002) which was previously adapted from a US programme (McMillan, Tittle & Hill, 1993). The Living Well programme was first run by the Wellington Division of the Cancer Society in 1991 and consists of 6 weekly sessions of 2-3 hours with the overall aim being to support and educate patients about living with cancer. The specific content of the programme varies according to the particular needs of the group (Jasperse, Herst & Kane, 2012).

At a national level, the Cancer Society is an important conduit for raising awareness of the issues faced by cancer patients and their families. The Cancer Society was active, for example, in recent news reports highlighting failings within Work and Income New Zealand (WINZ) where excessive proof of illness and surgery were required by cancer patients in order to receive their benefit entitlements (Edwards, 2015; Sachdeva, 2015).

The Cancer Society acknowledges that there are gaps in its service provision to Māori. Māori are underrepresented in those who access the 0800CANCER information telephone service (Murphy, Harre Hindmarsh & Bright, 2010) and Māori attendance in the Living Well programme is low (Nesler & Wharerau, 2011). A Kokiri Seaview Marae report found an unmet need for culturally safe education and support programmes catering to Māori cancer patients and whānau (Kokiri Seaview Marae, 1999). A fundamental barrier for many Māori is that the Living Well programme focussed on individual cancer patients and their immediate family rather than being a whānau-based programme (ibid). However, within the context of whānau ora service delivery (Minister and Associate Minister of Health, 2002), whānau are recognised as being central to the support and on-going recovery of family members with cancer.

The Wellington Division of the Cancer Society and Kokiri Seaview Marae developed the Kia Ora e Te Iwi (KOETI) programme in 2011. The strength of the programme lay in providing a safe space for Māori that was marae-based and whānau-centred. The programme provided much-needed information and a forum for whānau to support each other in an environment where they were welcomed as integral to the cancer journey. In this way, the programme addressed barriers to accessing supportive care and information which is something that has been identified as a significant gap in previous studies of Māori cancer journeys (Slater et al, 2013; Walker, 2008). Kia Ora e Te Iwi

offers improved access to relevant information including written resources and support requirements, much of which was developed by Kokiri Seaview Marae (Davies, personal communication, 2015). Unlike its mainstream counterpart the Living Well Programme, it is not clear whether KOETI has dedicated on-going funding and its current availability is restricted to the Wellington region only.

A broader range of issues related to Māori access to supportive care were identified in a second report also commissioned by the Wellington Division of the Cancer Society. In a national scoping project aiming to reduce disparities and address difficulties in service delivery to Māori, the report identified: poor access to Cancer Society services; differing treatment pathways for Māori and non-Māori; issues of cultural safety; gaps in service provision; lack of organisational relationships with Māori and information transfer to Māori; and faulty assumptions by the Cancer Society that Māori prefer not to access external specialised and practical support (Pataki Associates, 2002).

As a result of the report, the Wellington Division of the Cancer Society has worked with Māori provider groups and other health services in the Hutt Valley and Wairarapa regions in order to improve their services to Māori (Doherty & Associates, 2006). Most recently, the Cancer Society's Wellington Division, which includes the areas of Kapiti, Wellington, Hutt Valley, Wairarapa, Marlborough and Nelson, have also undertaken an evaluation of the psychosocial support programme, CanSupport services, that they offer to people with cancer and their families (Doherty & Associates, 2008).

Recommendations from the evaluation included considering the provision of support services through contracts with Māori providers so that access to these services will be improved and Māori can fully benefit from them.

2.9 Navigating the cancer treatment system

Equally important to the different aspects of pathways through cancer care is the co-ordination of care between primary, secondary and tertiary cancer care (Blakely et al, 2015; Braun, Kagawa-Singer & Burhansstipanov, 2012; Collinson et al, 2013; Cormack et al, 2005; Corter et al, 2011; Doherty & Associates, 2006; Earle & Neville, 2004; Mandelblatt, et al, 1999; Paskett, Harrop & Wells, 2011; Petereit et al, 2008; Rauawaawa Kaumātua Charitable Trust Research Project Team, 2014; Slater et al, 2013; Walker et al, 2008; Whop et al, 2012; Wilcox & Bruce, 2010). The international literature has highlighted difficulties for cancer patients in navigating through the many appointments, medications, operations and treatments required throughout cancer care (Braun et al, 2012; Earle & Neville, 2004; Mandelblatt et al, 1999; Natale-Pereira et al, 2011; Paskett et al, 2011; Petereit et al, 2008; Whop et al, 2012; Wilcox & Bruce, 2010), with the complexities of cancer care not often explained well to patients by their care providers (Mandleblatt et al, 1999). These barriers to care appear greater for those from the most vulnerable populations. Earle and Neville (2004) described, for example, the need for better co-ordinated care for underserved communities such as African-American, poor and elderly cancer patients, particularly regarding management of their co-morbidities.

A number of qualitative studies have specifically identified the need for improved cancer care service delivery for Māori. A survey of Māori cancer care providers and stakeholders identified a number of relevant issues including: inadequate service co-ordination; a lack of culturally responsive services (including inadequate Māori-specific cancer services and service elements) and culturally competent health professionals (including limited numbers of Māori working in cancer care); poor integration of Māori treatments such as mirimiri (massage)

and rongoā (Māori medicines); difficulties for Māori in negotiating the treatment system; poor support for a whānau-based approach to cancer care; lack of specific funding for providers to facilitate Māori access to cancer care services; poor access to financial support or entitlements for patients; cost-related barriers to access; and limited availability of cancer information relevant to Māori (Cormack et al, 2005).

Walker and colleagues (2008) investigated Māori experiences of cancer through hui and interviews with 44 Māori affected by cancer. They identified the need for more co-ordinated service delivery, flexible mainstream services, better information about entitlements for Māori, increasing the Māori workforce and strengthening cultural competence for all workers, as well as better funding. Doherty and Associates (2006) investigated patient cancer care journeys in the Hutt Valley and Wairarapa District Health Boards. The research involved interviews with 80 cancer care provider representatives and 22 people with cancer and their whānau (including nine Māori). Recommendations for improving Māori cancer journeys particularly related to implementing a pathway care plan to facilitate integration of primary and secondary cancer care, Māori cancer care workforce development, relevant information provision, recognition of the role of whānau/caregiver support, and the investigation of opportunities for kaupapa Māori cancer support services.

Integration between primary and secondary care alongside improved information provision were also key findings in our recent qualitative study (Slater et al, 2013) involving interviews with 12 Māori cancer patients and whānau, finding that primary care plays a key role in support and continuity of care across the cancer journey. Positive, long-standing relationships with primary health care providers including general practitioners, practice nurses and Māori health providers were

crucial in receiving and interpreting information as well as providing practical support as patients and whānau accessed cancer treatment.

Appropriate and timely information for patients and whānau has been shown to be important for navigating cancer care (Cormack et al, 2005; Earle & Neville, 2004; Mandelblatt et al, 1999; Rauawaawa Kaumātua Charitable Trust Research Project Team, 2014; Slater et al, 2013; Walker et al, 2008). Not only must information be delivered in a consistent and timely fashion, it must also be the right information. Cormack and colleagues (2005) recommend high quality Māori-specific resource material about cancer and also cancer services available to individuals, whānau and communities. This was similarly recommended for information content regarding palliative care in a recent analysis that showed some Te Reo Māori was being used, but that Māori world views were largely absent from palliative care information brochures (Rauawaawa Kaumātua Charitable Trust Research Project Team, 2014).

The role of cancer navigators or cancer co-ordinators emerged over two decades ago. This role can be based in primary or secondary care and has been described by Natale-Pereira and colleagues (2011) as: “brokers with the ability to confront health system and environmental barriers that tend to disproportionately burden racial and ethnic minorities” (p. 3548). Cancer navigator roles are said to enhance continuity of care by providing consistency and better access to information (Braun et al, 2012). Cancer navigators have had success in improving cancer care access, information and support overseas, in particular for indigenous populations and those living in poverty (Braun et al, 2012; Eschiti, Burhansstipanov & Watanabe-Galloway, 2012; Freeman & Rodriguez, 2011; Natale-Pereira et al, 2011; Paskett et al, 2011; Petereit et al, 2008; Whop et al, 2012; Wilcox & Bruce, 2010).

Recently, Pasket and colleagues (2011) reviewed cancer navigation studies in North America and argued that despite navigation services being introduced 20 years ago, there is still a lack of consensus about the definition of cancer navigation, the qualifications needed for cancer navigators, and the impact of this work on cancer care. However, Braun and colleagues (2012) have outlined how cancer navigators assist patients and their families to find cancer care understandable, available, accessible, affordable, appropriate and accountable.

Studies of Māori cancer patient and whānau experiences and studies of Māori health provider organisations show that Māori health providers have been informally providing support and navigation to patients with cancer and their whānau for a long time (Slater et al, 2013, 2016; Walker et al, 2008). A cancer navigator pilot programme within Māori health provider organisations in Auckland and Rotorua, and a mainstream, rural organisation in Westport underwent a process and impact evaluation (Corter et al, 2011). Findings showed that each cancer support service programme was received very favourably by cancer patients and whānau and made a great deal of difference to their cancer journeys. The co-ordination of cancer and support services for patients and whānau also had positive impacts for health and social service providers. Despite their successes, the programmes stopped receiving funding at the conclusion of their three-year pilot (Corter et al, 2011).

Recent work by Blakely and colleagues (2015) proposed that hospital-based cancer care co-ordinators could be cost-effective in reducing time and increasing coverage to effective treatments for patients with colon cancer. Additionally, one easily identifiable point of contact could relieve pressure on the cancer care team regarding communication and also reduce patient anxiety in understanding their care (Collinson et al, 2013).

Part of the New Zealand Cancer Plan: Better, faster cancer care 2015-2018 (Ministry of Health, 2014c) is the Cancer Nurse Co-ordinator Initiative which involves rolling out 60 cancer nurse co-ordinators who work as part of each cancer treatment team and provide a link between patients, whānau and health care providers.

The cancer nurse co-ordinator programme is undergoing an evaluation until December 2015 with results due to be reported in mid-2016. An interim evaluation report shows that relationships within DHBs for the nurses are still being established, and patients who access the service are positive about their care (Litmus Limited, 2014).

2.10 The role of Māori health providers in cancer care

Although Māori health providers have delivered primary care services for over 20 years, comprehensive information about the overall services and cancer-specific services they provide is limited. Indeed, there is no central database of Māori health providers and little publicly-available information on the work that is carried out. The first nationwide postal survey canvassing the cancer services of all Māori health providers was undertaken in 2011 (Slater et al, 2016). The study found that Māori health providers deliver a wide range of programmes including cancer prevention services focussed on health promotion, advocacy, information and support. A major finding of the study was the importance of trust and long-term relationships with a focus on families rather than individual-based care. The way that Māori health providers engage with and deliver services to whānau is described in more detail in the whānau ora section of this chapter. Māori health providers' local knowledge and whanaungatanga (importance of relationships

and networks) within their communities meant that they were able to facilitate access for patients into mainstream health care. Māori health providers identified financial hardship, transport difficulties, and lack of information as the greatest barriers to cancer care, and considered that culturally safe care by mainstream providers would improve cancer service provision overall (ibid).

As primary health care providers, Māori health providers have been shown to offer on-going support throughout all parts of the cancer journey including screening, diagnosis and treatment (Cormack et al, 2005; Maniapoto & Gribben, 2003; McLeod et al, 2011; Slater et al, 2016; Thomson, Crengle & Lawrenson, 2009; Walker et al, 2008). The work that Māori health providers do with, and for, whānau in their communities may include the provision of medical care but also encompasses emotional support and appropriate practical and logistical support for the whole whānau (Slater et al, 2013). Such support includes assistance with applying for medical certificates or completion of benefit entitlement forms.

Māori health providers have also shown innovation in their approaches to cancer care. One study for example, reported an increase in Māori breast screening participation rates in their GP population from 45% to 97% (Thomson et al, 2009). The authors documented their community knowledge and practical steps taken to encourage women to attend screening. The providers addressed barriers to participation in screening through improved information, phoning women to confirm appointments, helping with transport, and co-ordinating appointments for women from the same household. The authors suggest that these strategies can also be used by mainstream organisations to improve screening participation by Māori (ibid).

Not all Māori receive their primary care from a Māori health provider organisation. Indeed, most Māori access mainstream services (Cunningham, 2008). The

reasons for this are varied. First, mainstream primary health care providers far outnumber Māori health providers and are therefore more easily accessible throughout all areas of Aotearoa. Second, mainstream health providers have been established for much longer than Māori health providers, and have access to more resources, including a larger proportion of government funding through the PHO system contracting services (Matheson, 2013), even though patients cared for by Māori health providers would meet the definition of 'high needs' (Ellison-Loschmann et al, 2015; Ministry of Health, 2014f).

In addition, as described at the beginning of this chapter, Māori are not a homogenous group. Reflecting the diversity found within all ethnic groups, Māori have different preferences and needs and not all choose to access Māori health providers. Despite this, Durie has noted that during periods of vulnerability such as illness, cultural heritage continues to shape ideas, attitudes and reactions (Durie, 1977).

Studies have shown that access to health services is increased when people have faith in the health system (Cormack et al, 2005; Ellison-Loschmann & Pearce, 2006; Lovell, et al, 2007). Part of that faith rests in the different people who make up the health workforce and just as people universally feel more comfortable with someone of their own ethnicity, Indigenous people too, feel welcomed when there are other Indigenous people represented in health services (Ratima, Brown & Garrett, 2008; Shahid, Finn & Thompson, 2009).

There is agreement in the literature that the current Māori health workforce is stretched very thinly (Huria et al, 2014; Minister & Associate Minister of Health, 2002; Ministry of Health, 2006; Ratima et al, 2008). For example the burnout effect of few Māori staff expected to be the 'go to' Māori for the cultural questions of all staff, and the added workload of caring for every Māori patient on the ward

is described in a recent study exploring the experiences of Māori nurses (Huria et al, 2014).

The Ministry of Health also agrees that the Māori health workforce must increase (Ministry of Health, 2006). The need for greater Māori participation and effective service delivery are evident in He Korowai Oranga (Minister and Associate Minister of Health, 2002). Raranga Tupuake, the Ministry of Health's Māori Health Workforce Development Plan (Ministry of Health, 2006) sets out to grow the Māori health and disability workforce, to expand the expertise of the workforce and to enable equitable access for Māori into training opportunities.

The previous sections have explored the importance of the pathways through cancer care, co-ordination of care between cancer care providers, and the role of Māori health providers in each of these. Equally important in addressing Māori cancer care needs is good cancer control and cancer policy, which will be outlined in the next section.

2.11 Cancer control in Aotearoa

Cancer control has been defined as: “a planned, systematic and organised approach that aims to reduce the number of people diagnosed with and dying from cancer, as well as improving the quality of life for those who develop cancer” (Ministry of Health, 2003, p. 5).

This approach covers a broad continuum from cancer prevention, screening, diagnosis and treatment, to palliative care and survival. Additionally, planning, co-ordination, integration of resources and activities, monitoring and evaluation, and research and surveillance are all key components of cancer control.

Cancer Control New Zealand (CCNZ) was a committee made up of the Cancer Control New Zealand Board, the Palliative Care Council of New Zealand and

Cancer Control New Zealand Secretariat. CCNZ was established in 2005 under section 11 of the New Zealand Public Health and Disability Act 2000. The structure of the CCNZ followed cancer councils already established in the United Kingdom, Canada and Australia. CCNZ provided independent expert advice to the health sector on cancer control developments and successful initiatives. By providing leadership and promoting collaboration within the sector, CCNZ helped improve access to cancer care, as well as the quality of care. (Gavin, Marshall & Cox, 2001).

One of the contributions CCNZ made to cancer control in Aotearoa was to identify the myriad of organisations and individuals involved in cancer control. These include: the Ministry of Health; District Health Board (DHB) staff including funding and planning, operational management and hospital specialists, and other clinical staff; primary care providers; public health specialists; non-government and Māori and Pacific organisations; hospices, private providers; researchers; and consumers and carers (Herbert & Peel, 2010). CCNZ recognised the need for all of these organisations to work together in order to facilitate an integrated approach to cancer control. CCNZ was disestablished in August 2015. A press release from the Minister of Health explained that CCNZ was no longer considered necessary due to the progress made in improving cancer services (Minister of Health, 2015).

The Palliative Care Council of New Zealand was established by CCNZ in 2008. It was an independent body with a multi-disciplinary membership whose role was to report and provide strategic advice to the Minister of Health about palliative and end-of-life care (Palliative Care Council of New Zealand, 2012). The Palliative Care Council, like the CCNZ, was disestablished in 2015. It is to be replaced by an advisory group which, at the time of writing, has not yet been established.

The New Zealand Cancer Control Strategy Action Plan 2005-2010 (Cancer Control Taskforce, 2005) (which has been superseded by the NZ Cancer Plan (Ministry of Health, 2014c)), informed by CCNZ, identified the need to develop formal regional structures that would enhance co-operation and collaboration for cancer control. In 2006, four regional cancer networks were established across Aotearoa. Their role is to work with DHBs to bring together health providers, consumers, NGOs, palliative care providers and Māori, in order to improve service planning and delivery of cancer care. Establishing networks between all the different organisations and individuals involved in cancer care seeks to promote relationship-building, co-operation and integration of services. By working together, it is intended that the different providers of cancer care will plan and co-ordinate services in line with national standards of treatment (Herbert & Peel, 2010).

An evaluation of Regional Cancer Networks identified connecting with primary health care providers as an area where the networks are challenged. The authors focussed on the importance of bringing primary health care providers into the cancer control loop (Herbert & Peel, 2010). Indeed, it appears that there are barriers to primary care services being able to fulfil a central role in cancer control, including a lack of information technology infrastructure to support a robust communication network between primary care services and other specialist care areas.

Primary care is the first level of contact and entry point to the health system with the most obvious primary care involvement in terms of cancer care services being through GP practices and PHOs. Overseas studies have recognised that primary care practitioners should play a greater role in co-ordination across the primary-secondary-tertiary-palliative service interface since cancer patients are required to interact with numerous services and staff but experience fractured

co-ordination of care (Burge et al, 2003; Dahlhaus et al, 2014; Earle & Neville, 2004; Halkett et al, 2015; Kendall et al, 2006; Weller & Harris, 2008).

Additionally, the importance of strategic policy to direct practical and effective community-based cancer care has been identified (National Institute of Clinical Excellence, 2004; Scottish Executive Health Department, 2005).

Management of cancer is complex, requiring specialised skills and knowledge, access to diagnostic and treatment facilities, and often long-term management of symptoms and recurrences (Campbell et al, 2002). Nevertheless, as Weller and Harris (2008) point out, when asked about how their care could be improved, the requests of cancer patients are modest and include: knowing who is in charge of their overall care, obtaining ready access to care, and feeling reassured that specialist services are available if required.

Primary care plays an important role in caring for patients following a cancer diagnosis, including managing side-effects from cancer therapy when patients return home (Campbell et al, 2002; Murchie et al, 2010). Integration of specialist and primary care services can also benefit patients by cutting down on travel and waiting times in hospitals (ibid). Management of co-morbidities while undergoing cancer treatment is often done by primary health care providers. Co-morbid conditions not only impair quality of life for cancer patients, but also impact on their treatment options (Campbell et al, 2002; Sarfati et al, 2014).

2.12 Cancer policy in Aotearoa

Government policies that provide the direction and structure for cancer care provision essentially aim to reduce the number of people who develop cancer, and the number of people who die from cancer, as well as ensuring a better quality of life for those who develop the disease (Ministry of Health, 2003).

Three principles underpin the relationship between Māori and the Crown under the Treaty of Waitangi and these can be applied to health services. The Ministry of Health website (Ministry of Health, accessed August 2015) defines the principles as:

- **Partnership**, which involves working together with iwi, hapū, whānau and Māori communities to develop strategies for Māori health gain and appropriate health and disability services;
- **Participation**, which requires Māori to be involved at all levels of the health and disability sector, including in decision-making, planning, development and delivery of health and disability services; and
- **Protection**, which involves the Government working to ensure Māori have at least the same level of health as non-Māori, and safeguarding Māori cultural concepts, values and practices.

These principles form a background context for the current health policy environment in Aotearoa, with the strategies and frameworks relevant to this research outlined in Table 2.

Table 2: The current health policy environment related to cancer care for Māori

Policy	Relevance to cancer care for Māori
<p>New Zealand Health Strategy (Minister of Health, 2000)</p> <p>Refreshed New Zealand Health Strategy (Minister of Health, 2016a, 2016b)</p>	<p>The reduction of the incidence and impact of cancer is one of the 13 population health priorities.</p> <p>Cancer is provided as one of the examples for visions of services in 2026 that have well-designed and integrated pathways for the treatment journey through cancer starting and finishing at home.</p> <p>Roadmap of actions sets out 27 areas for action under five themes: people powered, closer to home, value and high performance, one team and smart system.</p>
The New Zealand Disability Strategy. (Minister for Disability Issues, 2001)	Ensures that government departments and agencies consider disabled people before making decisions.
New Zealand Palliative Care Strategy (Ministry of Health, 2001)	Sets in place a systematic and informed approach to the provision and funding of palliative care.
The Primary Health Care Strategy (Minister of Health, 2001c)	Provides direction for the development of primary health care in NZ, including the specific contributions that primary health care makes to improving health outcomes.
Guidance for Improving Supportive Care for Adults with Cancer in New Zealand (Ministry of Health, 2010a)	Identifies eight areas within supportive care that require action to improve the quality of life for people affected by cancer.
The New Zealand Cancer Control Strategy (Minister of Health, 2003)	Key platform for action on cancer.
The New Zealand Cancer Plan: Better, faster cancer care 2015–2018 (Ministry of Health, 2014c) Supercedes the NZ Cancer Control Strategy Action Plan 2005-2010 (Cancer Control Taskforce, 2005)	Sets out a strategic framework for the continuing programme of cancer activities for the Ministry of Health, DHBs and cancer networks.
He Korowai Oranga Māori Health Strategy (Minister & Associate Minister of Health, 2002) Guide to He Korowai Oranga (Ministry of Health, 2014e)	Guidance on improving equity in health outcomes.
Equity of Health Care for Māori framework (Ministry of Health, 2014b)	Guidance on improving equity in health outcomes.
New Zealand Cancer Health Information Strategy (Ministry of Health, 2015d)	Sets out a national approach to organising information for the wide spectrum of cancer control stakeholders.

The documents listed in Table 2 are relevant to this research as each plays a role in guiding and setting out approaches to improving cancer care for Māori. Of particular importance to this research is the 'Equity of Health Care for Māori' framework (Ministry of Health, 2014b), as it provides guidance on developing, administering, delivering and receiving health services equitably, and is applicable to Māori experiencing cancer, and Māori access to health services generally.

The 'Equity of Health Care for Māori' framework (Ministry of Health, 2014b) is identified but unreferenced in the NZ Cancer Plan (Ministry of Health, 2014c). The framework is built on substantial work by Cram (2014a-c) which includes specific reviews and research of Māori access to cancer services. The equity framework is based on three areas: leadership, knowledge and commitment; across health system, organisation and practitioner levels.

Leadership

The actions required at health system, organisation and practitioner levels to “champion the provision of high-quality health care that delivers equity of health outcomes for Māori” (Ministry of Health, 2014b) begin with setting an expectation at the health system leadership level that equity of health outcomes will be attained for all New Zealanders. This action is enacted by health policies and strategies, targets, funding formulas for services, and growing a responsive health workforce who recognise the health care needs and aspirations of Māori. Direction is set at the leadership level to remove infrastructural, financial and other barriers that inhibit delivery of high-quality health care for Māori across sectors.

At the health organisational level, the framework defines leadership as “making an explicit organisational commitment to delivering high-quality healthcare that

ensures health equity for Māori” (ibid). This is outlined in policies, strategies and plans that are responsive to Māori health needs and aspirations.

At the health practitioner level, leadership involves health practitioners reviewing their clinical practice through a health equity and quality lens, ensuring high quality ethnicity data is collected, and auditing, monitoring and evaluating health impact and outcome data. At all three levels, leadership of inter-sectoral collaboration is encouraged.

Knowledge

The second column of the framework encourages “developing knowledge about ways to effectively deliver and monitor high quality health care for Māori” (Ministry of Health, 2014b). At the health system level, this involves utilising research informed by Māori methodologies, and collecting high-quality population health data that includes good ethnicity data, cultural competency and health literacy.

At the organisational level, knowledge encompasses “establishing environments that encourage learning and the sharing of high quality health information” (ibid). Actions at this level include developing and building knowledge of evidence-based initiatives that have undergone and been monitored for their effectiveness in achieving health equity for Māori.

At the health practitioner level, routine use of clinical guidelines and tools, as well as building knowledge on the use of quality health equity improvement, is suggested.

Commitment

At the health system level, commitment is defined as “reconfiguring services for high quality health care that meets the needs and aspirations of Māori”(ibid). These are enacted in incentivising and rewarding delivery of equitable health

outcomes for Māori, with a requirement of performance data being analysed by ethnicity, deprivation, age, gender, disability and location. The framework also directs that training for the health workforce must have an emphasis on professional development activities that have a robust health equity, cultural competency and health literacy focus.

At the organisational level, collaborative design, implementation and evaluation of initiatives for Māori must be undertaken in collaboration with Māori. There is an emphasis in the framework of supporting initiatives that work for Māori and letting go of those that are unable to equitably serve everyone.

At the health practitioner level, commitment is expressed by consistent analysis of administrative data to inform practice, using evidence-based innovations that achieve health equity for Māori and tailoring professional development to build capacity/capability in achieving equitable health care. Health practitioners are also guided to support both community and individual/whānau initiatives and take a role in improving health literacy.

By breaking down health equity into leadership, knowledge and commitment at the three levels of health system, organisation and practitioner, this framework shows the complete picture of actions required to progress towards equity of health care for Māori (with the exception that cultural safety should replace the cultural competency component). The focus on robust data to inform policy, for example, consistent collection of ethnicity data alongside other activities to implement policy such as on-going training for the health workforce, provides important directions for improving the overall system of health care for Māori. Of particular note for this thesis is the emphasis on inter-sectoral collaboration and meaningful engagement with Māori individuals, whānau, communities, and health and social service providers.

Whānau ora in policy and practice

Before describing whānau ora as an approach to health service policy and provision, definitions of whānau will be explored. This is important because while it appears that there is often an expectation by the mainstream health system that patients present as autonomous individuals, many Māori engage with the health system as part of a whānau (Jansen, Bacal & Buetow, 2011; Jansen, Bacal & Crengle, 2008; Slater et al, 2015; Slater et al, 2013).

Rather than being a proxy for the word 'family', Tuuta (2011) describes the origins of the word whānau as drawing on understandings related to wha (four) and nau (to seek sustenance). Te Momo (2012) gives the literal meaning of whānau as giving birth, and defines whānau within western, reclaimed and global contexts covering the evolution of whānau throughout colonisation, urbanisation and assimilation.

This research places whānau in the context of whakapapa (genealogy) related descendants of tūpuna (ancestors), and also includes people who are integral to each other through kaupapa such as friendship, sports or work groups (Durie, 2003). Whether whakapapa or kaupapa based, the term 'whānau' has come to be recognised as a basic support structure which embodies Māori health and wellbeing (Cram, Smith & Johnston, 2003).

As noted previously, one of the many outcomes of colonisation was the destruction and displacement of whānau (Durie, 1995, Lange, 1999, Smith, 2012; Te Momo, 2012), so that many Māori no longer have knowledge of their whānau links. For those who do, whānau can be an important source of support and care in times of illness and medical treatment.

For some Māori, collective approaches to decision-making, involving discussion and input from multiple family members, remains as important as individual

choice when considering health care options (Cunningham, 2008). Whānau are therefore often seen as vital in contributing to decisions around treatment options and in the provision of patient care. This collective discussion and decision-making is particularly important during times of illness (Dew et al, 2015; Durie, 1977) and when a whānau member is near the end-of-life (Bray & Goodyear-Smith, 2013; Slater et al, 2013).

Such collective approaches to healthcare are not always congruent with biomedical world views, where a more individualised focus has underpinned policy and practice both overseas (Whop et al, 2012; Treolar et al, 2014; Shahid & Thompson, 2009; Santos et al, 2001), as well as here in Aotearoa (Wilson & Barton, 2012; Cook et al, 2014). Sitting outside an individual care focus is He Korowai Oranga, the Māori Health Strategy (Minister and Associate Minister of Health, 2002; Ministry of Health, 2014e), which will be described in the next section.

Māori have long advocated the value of a whānau ora approach to health care with examples of work undertaken by the Young Māori Party and the MWWL (Durie, 1994; King, 2003), through to current examples including Māori mental health contracting (Boulton, 2005) and Māori health provider approaches to primary care (Crengle, 2000) and cancer care (Cormack et al, 2005; Slater et al, 2016; Slater et al, 2015; Slater et al, 2013; Walker et al, 2008). He Korowai Oranga was first developed in 2002 and provided a key policy platform from which the current 'Whānau Ora' (healthy families) was developed (Minister and Associate Minister of Health, 2002). More recently, the Strategy was revised to incorporate the ultimate goal of pae ora (healthy futures) which is made up of three elements: mauri ora – healthy individuals; whānau ora – healthy families; and wai ora – healthy environments (Ministry of Health, 2014e).

Each of the areas which make up the supporting structure of the framework 'pathways, threads and directions' contribute to He Korowai Oranga's elements and overall aim of healthy futures. Until recently, He Korowai Oranga informed health policy overall but did not have a funded programme to enact the pathways such as 'working across sectors' and 'Māori participation'. In this way, different policies could refer to the pathways, threads, directions and elements of He Korowai Oranga, but not actually commit funding to any of these pathways.

In 2011 the Whānau Ora Initiatives (Te Puni Kōkiri, 2015) introduced a concrete funding model which accepted the immense value from the multi-faceted work that had long been undertaken by Māori health and social service providers. Up until the implementation of the Whānau Ora Initiatives, this work did not fit any government funding structure including working across sectors and with whānau rather than individuals, with an allocated funding provision from the government.

Māori health providers have always held the concept of whānau ora at their base (Crengle, 2000). Paradoxically, by supporting whānau instead of individuals, much of their work is not funded. The fundamental difference between Māori health provider approaches to caring for whānau, and the focus of health service provision contracts on illness and individuals, meant that Māori health providers' work with whānau fell outside of rigid funding contracts (Barcham, 2007; Kiro, 2001; Lavoie, 2003). Thus, whānau ora services have been provided on goodwill by Māori health providers in a reactive way that was described as unsustainable as far back as the 1980s (Durie, 1994).

In 2010, whānau ora was extended beyond a health goal to become a philosophy, model of practice and outcome for social services through the implementation of the Whānau Ora Initiatives (Taskforce on Whānau Centred Initiatives, 2010; Ministry of Health, 2011b). Māori Party leader, the Hon. Tariana

Turia, then the Minister for the Community and Voluntary Sector, established a Taskforce to address her concerns that: "...health and social services often intervene after matters went wrong for an individual, rather than restoring full whānau functioning or extending whānau capabilities" (Controller and Auditor General, 2015, p. 9). Additionally: "...government contracting practices had led to many Māori providers competing for contracts, which fostered a piecemeal approach and inhibited collaboration" (ibid).

The Taskforce was chaired by Professor Sir Mason Durie, a major contributor to Māori health and development through decades of academic and clinical work. The other members of the taskforce were: Rob Cooper, CEO (Chief Executive Officer) of a Māori social services provider, a DHB member and DHB Māori Health Committee Chair with many years of health sector design and implementation experience; Suzanne Snively, an economist specialising in government, financial services and governance advice; Di Grennell, Executive Director of the Amokura Family Violence Prevention Consortium with expertise in family violence prevention, programme development and provider training; and Nancy Tuaine, Manager of a Māori Trust Board and DHB member with expertise in health and social services (Taskforce on Whānau Centred Initiatives, 2010).

The Taskforce identified system changes that were required if whānau were to be placed at the centre of service planning and delivery. The Taskforce also identified features that made whānau ora unique. These included: "...recognising a collective entity (whānau), endorsing a group capacity for self-determination, intergenerational dynamic, Māori cultural foundation, asserting a positive role for whānau within society and application across a range of sectors". (Controller and Auditor General, 2015, p. 10)

A pivotal aim of the Whānau Ora Initiatives is the establishment of a foundation from which whānau can flourish (Kingi et al, 2014). Whānau Ora has been described as a set of three different initiatives: "... largely funded through Vote Māori Affairs, and the government agencies most involved in providing support for those Initiatives are the Ministry of Māori Development, the Ministry of Health, and the Ministry of Social Development". (Controller and Auditor General, 2015, p. 6)

The three initiatives are:

- whānau integration, innovation and engagement,
 - provider capability building, and
 - integrated contracting and government agency support for the initiatives
- (Controller and Auditor General, 2015, p. 14).

A Whānau Ora Initiatives Fund was set up and 34 collectives were established. The collectives are made up of 180 providers who work collaboratively to deliver whānau-centred services (Te Puni Kōkiri, 2015). Through Whānau Ora collectives, whānau are able to access funds and complete plans, with support from Whānau Ora navigators. In this way, Māori health providers with a Whānau Ora contract are now funded to work across sectors, promoting a comprehensive collective approach for multiple agencies to work together (Ratima & Taumata Associates, 2010). As well as agencies working together, the approach that Māori health providers have always had, prioritising Māori development and whānau ora, is now recognised as a kaupapa that should be properly resourced.

At the time of writing this thesis, the Whānau Ora Initiatives are only just being rolled out across Aotearoa. Thus, there is little documentation currently available showing what had been learned by those implementing the Whānau Ora Initiatives, or the effects of its implementation on whānau outcomes. One piece of work completed by Te Puni Kōkiri (2015) documents some initial findings from

their research and monitoring programmes of the Whānau Ora Initiatives. The report was informed by Whānau Ora provider feedback and survey findings from 895 whānau who were recipients of the services (Te Puni Kōkiri, 2015). Five overlapping themes were considered essential to the implementation of a whānau-centred approach: effective relationships, leadership, workforce capability, whānau centred services and programmes, and supportive environments (funding, contracting and policy). The report outlined how collectives addressed these themes and stated:

Their actions were effective in generating high levels of trust among whānau, whānau engagement with providers, motivation, a positive attitude, cultural and whānau connectedness, new skills and tools, greater awareness of resources and access to services, and participation in relevant courses. (Te Puni Kōkiri, 2015, p. 11)

Other reports of the Whānau Ora Initiatives have also been positive. Boulton and colleagues (2013), for example, showed how Whānau Ora as a Māori framework has positively changed ways of working and integration of contracts for a Māori health and social service provider in the North Island. The authors describe how previously unrecognised inter-sectoral and innovative ways of working have been brought to the fore under a Whānau Ora contract.

A Ministry of Health report also favourably reviewed the performance of general practices in Whānau Ora collectives, finding positive changes to service delivery, and improved indicators in cancer prevention initiatives such as smoking cessation, compared to non-Whānau Ora general practices (Ministry of Health, 2013a). A report by the Auditor General on the first four years of Whānau Ora was similarly positive, highlighting Whānau Ora as: “an opportunity for providers of health and social services in the community to operate differently and to

support families in deciding their best way forward” (Controller and Auditor General, 2015, p. 4). The report also pointed out that government spending had been small, but whānau gains significant, with benefits such as whānau re-connecting and sharing expertise, with successes reaching wider than anticipated in original whānau plans. However there were two criticisms in the report. One concerned the amount of funding spent on administration. The second pertained to a lack of consistency from Whānau Ora agencies on articulating the aims of the initiative.

Despite these minor criticisms, it appears that the Whānau Ora Initiatives represent the first opportunity for Māori health providers to be properly recognised and resourced for the whānau ora and Māori development kaupapa that they have always delivered. It is within this context of whānau ora, that improvement in access to care and quality of life for Māori with cancer will be considered.

The need for translational science is increasingly recognised as essential for health systems globally, as called for in the United Nations (UN) and World Health Organisation (WHO) initiatives to address non-communicable disease, social determinants of health, and indigenous health (Di Cesare et al, 2013; Marmot & Allen, 2014). Two critical challenges exist. The first challenge is to identify the determinants of both non-communicable chronic disease and social inequalities in their occurrence and impact. The second challenge is to translate empirical evidence generated by public health, clinical and basic science research into effective health system programmes and policies. One major, unresolved problem concerns how to make health systems responsive to and effective for Indigenous people and also for other societal groups whose health is harmed by economic and social exclusion, both past and present (Blakely, Simmers & Sharpe, 2011).

The new Whānau Ora policy focus on both building and strengthening capability within families, together with addressing health care needs at the family level, offers a unique opportunity for Aotearoa to provide global leadership on how health services can be jointly improved for *everyone* (my own emphasis) and to reduce health inequities. There are a number of other policy statements which are relevant to Māori cancer control, and to which this research is aligned (Table 1). However with the exception of He Korowai Oranga (Minister and Associate Minister of Health, 2002; Ministry of Health, 2014e) and a brief mention of equity focus within the NZ Cancer Plan (Ministry of Health, 2014c), other relevant strategic policy documents, including the Cancer Control Strategy (Minister of Health 2003), are designed around total population needs and do not specifically address Māori cancer control.

Summary

Māori are a diverse and dynamic population, but share poor health outcomes with Indigenous peoples throughout the world, including a disproportionate cancer burden (Anderson et al, 2016; Ministry of Health, 2015e; Moore et al, 2015).

There are important differences in cancer incidence, survival and mortality, and in quality of life, between Māori and non-Māori with cancer and these occur at all stages of the cancer journey (Cormack et al, 2005). As the first entry point into the health system and conduit between community and cancer care, all priorities for cancer services are affected by actions in primary care (Campbell et al, 2002).

Māori activism and resistance to colonising practices have resulted in Māori programmes for Māori people in education, justice and health, and include the emergence of Māori health providers (Crengle, 2000). Māori health providers deliver a range of primary care services and importantly, facilitate access to mainstream health care (Slater et al, 2015). Operating from a kaupapa of Māori development, their focus is on whānau ora rather than individuals and illness.

However Māori health provider contracts are not sustainably or well-funded (Matheson, 2013; Lavoie, 2003). Early reports of the Whānau Ora Initiatives are positive (Boulton, Tamehana & Brannelly, 2013; Controller and Auditor General, 2015; Te Puni Kōkiri, 2015), and the initiatives may provide adequate funding to Māori health providers as they work across sectors to support whānau, including throughout their cancer care journeys.

A lack of culturally safe care (Ramsden, 1993), and co-ordinated care for Māori have been identified as major areas for further work (Cormack et al, 2005; Walker et al, 2008). Taking into account the well-recognised problems that Māori experience with accessing care, including primary care services, as well as the fact that Māori health provider groups have played an important role in increasing access to services generally for Māori, it seems reasonable to assume that similar gains could be made in terms of increasing access to cancer services. The role and potential of primary care for Māori with cancer has not been previously explored across the system of care in Aotearoa.

Chapter 3

Methodology and Methods

This chapter is set out in three parts. The first describes the perspectives, theoretical paradigms and framework of the study. The second part outlines the case study design, and the final part of this chapter describes the research methods.

I will begin by describing the world views and philosophical traditions that inform the study. The goal of this research is to contribute to improvement in cancer survival outcomes and quality of life throughout all stages of the cancer journey for Māori by informing future developments in cancer control. The research does this by critiquing the current structures, systems and roles for cancer prevention, screening, diagnosis, treatment, palliative care and survival. As the title of this thesis suggests, there is a particular focus on the role and potential of community care throughout each of these areas.

This research uses a Māori-centred approach, which has a natural fit with a critical, feminist theoretical lens. To guide the concept development, the research process and analyses, I have drawn on critical theory (Denzin & Lincoln, 2008; Kincheloe, McLaren & Steinberg, 2011; Smith, 2012), feminist theories (Balbo, 1987; Barnes, 2006; Gilligan, 1982, 1995, 2003; Narayan, 1995; Olesen, 2011; Sevenhuijsen, 1998; Tronto, 1993, 1998), cultural safety education theory (Anderson et al, 2003; Bracoupe & Waters, 2009; Denier & Gastmans, 2013; Jungerson, 2002; Nguyen, 2008; Papps, 2015; Polascheck, 1998; Ramsden, 1993, 1997, 2002) and racial discrimination theories (Cormack et al, 2013; Harris et al, 2006, 2012a, 2012b, 2013; Jones, 2000; Krieger, Chen & Waterman, 2011). Each of these approaches and their relevance for this research will be discussed in turn. Firstly however, I will describe how this research is located within a Māori-centred research framework.

Māori-centred research

“From the vantage point of the colonized, a position from which I write, and choose to privilege, the term research is inextricably linked to European imperialism and colonialism. The word itself ‘research’ is probably one of the dirtiest words in the Indigenous world’s vocabulary.” (Smith, 1999, p. 1)

It is important to position this work as Māori-centred at the outset because immediate clarity is required when research involves Māori, regarding who is driving the research, and why, how, and for whom it is being undertaken. This urgency stems from acknowledging a legacy of research, both historical and contemporary, that has exploited and alienated rather than empowered Māori, and research abuses where data were taken from Māori and used to support colonial and *white superiority* (my emphasis) ideologies (Bishop, 1999; Lange, 1999; Smith, 2012). Bishop (1999) describes non-Māori researchers setting out to reinforce European perceptions of Māori as a primitive people, thus justifying the world view that Western culture and people were superior and legitimating the process of colonisation.

This research paradigm cannot be relegated to an awful chapter in research history from the last century. One example within this decade is from 2007 when a pair of non-Māori researchers put Māori data in the *primitive peoples* (my emphasis) category when reporting their “warrior gene” hypothesis (Lea & Chambers, 2007). The authors’ unsubstantiated genetic explanation for negative Māori social statistics was that Māori men are twice as likely to carry the monoamine oxidase gene, which predisposed them to risk taking behaviour including smoking, gambling and violence (ibid). This research was widely

criticised throughout peer reviewed journal publications and the mainstream media, which challenged the scientific validity as well as the ethical conduct of the study (Crampton & Parkin, 2007; Hook, 2009; Merriman & Cameron, 2007; Perbal, 2013).

As noted earlier (Krieger, 2014; Smith, 1999;), ideologies of colonial superiority and power have had harmful effects for Indigenous peoples and resulted in a justified climate of mistrust (Bishop, 1999, 2003; Brant Castellano, 2004; Martin, 2012; Pualani Louis, 2007; Smith, 1999, 2012). That Māori, both as researchers and as participants, approach research with caution, is understandable and has been an area that has facilitated strong and robust debate among academics regarding who should be conducting Māori research and how it should be undertaken (see Bishop, 2008; Pihama, 1993a, 1993b; Smith, 1999 & 2012).

Kiro (2001) distils this into two schools of thought for considering approaches to conducting Māori health research. One recognises that there is a unique way of conducting research which has developed a literature around ontology and epistemology informing the approach (Kaupapa Māori). The other school (Māori-centred) deems any method acceptable if it answers the research question and ultimately leads to a better understanding of the dynamics of Māori health.

Cunningham (2000) has identified four research types, which include: research not involving Māori; research involving Māori, Māori-centred research, and Kaupapa Māori research (Table 3). These four research types were identified and discussed by the author in order to guide directions, competencies and research outcomes for the provision of Māori knowledge required for Māori development (ibid). The research types were developed in response to the Foresight Project (Ministry of Research Science and Technology, 1997) which set out the future and role of research, science and technology in Aotearoa.

Table 3: Characteristics of four identified types of research, science and technology (Cunningham, 2000)

Characteristics	Research not involving Māori	Research involving Māori	Māori-centred research	Kaupapa Māori research
Description	Research where Māori participation or data is neither sought nor considered relevant: Research whose results are thought to have no impact on Māori	Research where Māori are involved as participants or subjects, or possibly as junior members of a research team: Research where Māori data is sought and analysed: Research where Māori may be trained in contemporary research methods and mainstream analysis.	Research where Māori are significant participants, and are typically senior members of research teams: Research where a Māori analysis is undertaken and which produces Māori knowledge, albeit measured against mainstream standards for research.	Research where Māori are significant participants, and where the research team is typically all Māori: Research where a Māori analysis is undertaken and which produces Māori knowledge: Research which primarily meets expectations and quality standards set by Māori.
Examples	Quantum chemistry; clinical trial; volcanology	Analysis of ethnic differentials in disease rates	Longitudinal social science study of Māori households	Traditional study of cosmology: study of cultural determinants of health
Control	Mainstream	Mainstream	Mainstream	Māori
Māori Participation	Nil	Minor	Major	Major, possibly exclusive
Methods/tools	Contemporary- Mainstream	Contemporary- Mainstream	Contemporary – Mainstream and Māori	Contemporary – Māori and Mainstream
Analysis	Mainstream	Mainstream	Māori	Māori

The research undertaken here is by Māori, about Māori and for Māori. It involves Māori participants (although not exclusively, as Māori make up a small number of the cancer policy and care workforce) and will produce Māori knowledge that will be published in mainstream fora such as this thesis and peer reviewed journal articles.

This research is intended to be viewed in the context of Māori health gains and Māori development. This bridging of Te Ao Māori (the Māori world) and mainstream methods and tools in Māori-centred research has similarly been utilized in other Indigenous research endeavours internationally. In particular ‘Two Eyed Seeing’, a framework from American Indian and Alaska Native

researchers for work as Indigenous researchers, within Indigenous communities (Bartlett, Marshall & Marshall 2012; Iwama et al, 2009; Martin, 2012), recognises that there are many ways of understanding the world, some of which are represented by European based sciences and others by various Indigenous knowledge systems and sciences. Two Eyed Seeing takes care not to position one world view over another and instead “honours and accepts diverse ways of knowing” (Martin, 2012, p. 24).

Kaupapa Māori unreservedly holds Māori knowledge, beliefs and processes as normal (Reid & Cram, 1999). In other words, Kaupapa Māori privileges Māori knowledge and measures all other (non-Māori) knowledge against it, rather than the other way around. This is in a context where Non-Māori knowledge has become firmly embedded as *normal* (my own emphasis) within all institutions, as described by Cormack (2007): “It is in and through the various processes of colonisation that white settler ways of being and thinking have become naturalised and universalised, as they have simultaneously become dominant, especially within elite institutions”. (p. 13)

Bishop (2008) describes contemporary Kaupapa Māori as: “a discourse of proactive theory and practice emerging from within the wider revitalisation of Māori communities”, (p. 439) thereby placing Kaupapa Māori research within the context of self-determination that has been voiced by Indigenous peoples worldwide (Smith, 2012).

An important distinction of Kaupapa Māori research is the degree of Māori control (Cunningham, 2000). This research, although undertaken by a Māori researcher under the guidance of a Māori supervisor and in collaboration with Māori health providers, was based within a mainstream organisation (Massey University) and funded by the Health Research Council of New Zealand (HRC), the main

government health research funding agency in the country. Thus, although some control of this project sits with Māori, the locus of control is with non-Māori.

As this research was undertaken from the platform of a university, it was therefore bound by their constraints including ethical approval and funding. That this research was based in a mainstream university setting has strengths and weaknesses. With no political allegiance, universities have the independence and freedom to: “conduct research that is out on the edge of knowledge” (Smith, 1999, p. 224). On the other hand, Webber (2009) argues that there is a risk of academia minimising Māori research by considering it exotic, and therefore enabling “an excuse for later dismissing the validity of the work” (p. 3).

Te Awēkotuku’s seven principles for a Māori-centred methodological approach (cited in Smith, 1999) provided the guidance for this study on how to conduct the research in ways that align with Māori world views and are consistent with Māori values and practices. These principles were important for grounding the research in Te Ao Māori and they provided the foundation for approaching this research.

The principles are:

1. Aroha ki te tangata (respecting people)
2. Kānohi ki te kānohi (communicating face-to-face)
3. Titiro, whakarongo and kōrero (looking, listening and only then, speaking)
4. Manaaki ki te tangata (hosting or taking care of the people)
5. Kia tupato (taking care)
6. Kāua e te takahia te mana o te tangata (maintaining the integrity of the person)
7. Kāua e mahaki (not flaunting your own knowledge). (p.120).

This section has positioned the research as Māori-centred by showing who is undertaking it and for whom, and the ways in which the research is consistent with Māori world views, values and practices. The following section provides the setting for the feminist ethic of care framework (Tronto, 1993,1998), cultural safety (Ramsden, 2002) and racial discrimination theories (Harris et al, 2006; 2012a, 2012b, 2013; Jones, 2000, 2002; Krieger et al, 2011) by describing how the Māori-centred approach fits within the critical theory paradigm that underpins this research.

Critical Theory

“Inquiry that aspires to the name ‘critical’ must be connected to an attempt to confront the injustice of a particular society or public sphere within the society.”
(Kincheloe et al, 2011, p.164)

At the time this research was being conceptualised, I sought a theoretical foundation that would assist in stepping back from assumptions about people’s realities in relation to cancer care. I needed to draw on theories that scrutinised perceptions and power relations within different parts of the cancer care system. Critical, feminist theories fit naturally with Māori-centred research as they recognise different realities within political and cultural contexts and work towards social change (Olesen, 2011). As this research concerns the planning, managing, delivery and receipt of cancer care and support for Māori in Aotearoa, cultural safety theory and racial discrimination theories are also incorporated within the Māori-centred, critical paradigm.

A critical theory approach also enables me, as the researcher to be part of the picture, to have a voice in the research and do this in a careful, documented way that manages unconscious biases (ibid). This is important when considering my

role as a Māori researcher, examining the system of care for Māori experiencing cancer.

To assist in understanding the methodology for this research, I will now position this Māori-centred approach within the critical theory paradigm, as this will aid in further discussion of the feminist ethic of care (Tronto, 1993, 1998), cultural safety theory (Anderson et al, 2003; Brascoupe & Waters, 2009; Denier & Gastmans, 2013; Jungerson, 2002; Nguyen, 2008; Papps, 2015; Polascheck, 1998; Ramsden, 1993,1997,2002) and racial discrimination theories (Harris et al, 2012; Harris et al, 2006; Jones, 2000; Krieger, Chen & Waterman, 2011).

Kincheloe and colleagues (2011) contend that an important part of critical theories is their role in challenging the dominant discourse. In the case of this research, and as articulated clearly in the cultural safety literature from Aotearoa (see Ramsden, 2002), the dominant discourse is that imposed by colonists, which dismissed collectives, reciprocity and relationships, and instead introduced a new construct of the autonomous individual.

According to Kincheloe and colleagues (ibid), the critical theory tradition is constantly evolving, and it is therefore difficult to assign it a single definition. The authors have listed a wide range of theorists who have informed critical theory such as Marx, Kant, Hegel, Weber, and Freire. Work by Indigenous and feminist scholars also fit within the critical theory sphere. Indigenous theorising from Smith (1999), Pihama (1993), Bishop (2008) and Narayan (1995) for example, alongside feminist theorising from Barnes (2006), Gilligan (1995), Tronto (1993,1998) and others, have contributed to the critical theory and ethic of care framework shaping this research.

Kincheloe and colleagues (2011) argue that: “Critical theory should not be treated as a universal grammar of revolutionary thought, objectified and reduced to

discrete formulaic pronouncements or strategies” (p. 164). Having said that, the authors go on to usefully provide the following list of basic assumptions for a ‘criticalist’ researcher:

- All thought is fundamentally mediated by power relations that are social and historically constituted.
- Facts can never be isolated from the domain of values or removed from some form of ideological inscription.
- The relationship between concept and object and between signifier and signified is never stable or fixed and is often mediated by the social relations of capitalist production and consumption.
- Language is central to the formation of subjectivity (conscious and unconscious awareness).
- Certain groups in any society and particular societies are privileged over others and, the oppression that characterises contemporary societies is most forcefully reproduced when subordinates accept their social status as natural, necessary or inevitable.
- Oppression has many faces, and focusing on only one at the expense of others (eg class oppression versus racism) often elides the interconnections among them.
- Mainstream research practices are generally, although most often unwittingly, implicated in the reproduction of systems of class, race and gender oppression. (p. 164)

These assumptions show how the conduct of research is affected by the history, values, beliefs, and cultural contexts of the researcher and the researched. To understand further how critical theory guides this research it is useful to position it alongside other inquiry paradigms such as positivism, postpositivism, constructivism and participatory as identified by Lincoln, Lynham and Guba (2011) in Table 4.

Table 4: Basic beliefs (metaphysics) of alternative inquiry paradigms (Lincoln, Lynham & Guba, 2011).

Item	Positivism	Postpositivism	Critical theory	Constructivism	Participatory
<i>Ontology</i>	Naïve realism - “real” reality but apprehendable	Critical realism –‘real’ reality but only imperfectly and probabilistically apprehendable	Historical realism –virtual reality shaped by social, political, cultural, economic, ethnic and gender values; crystallized over time	Relativism –local and specific constructed and co-constructed realities	Participative reality subjective-objective reality, co-created by mind and given cosmos
<i>Epistemology</i>	Dualist/objectivist; findings true	Modified dualist/objectivist critical tradition/community; findings probably true	Transactional/subjectivist; value-mediated findings	Transactional/subjectivist; created findings	Critical subjectivity in participatory transaction with cosmos; extended epistemology of experiential, propositional and practical knowing; co-created findings
<i>Methodology</i>	Experimental /manipulative; verification of hypotheses; chiefly quantitative measures	Modified experimental/manipulative; critical multiplism; falsification of hypotheses; may include qualitative methods	Dialogic/dialectical Search for participatory research, which empowers the oppressed and supports social transformation and revolution.	Hermeneutical/dialectical	Political participation in collaborative action inquiry; primacy of the practical; use of language grounded in shared experiential context.

Table 4 outlines different beliefs about what knowledge is and views about the best way to obtain it. It must be noted that these are not set in stone, and understandings of different paradigms continue to evolve. Recent discussion on mixed methods, for example, has suggested that elements of inquiry paradigms might be mingled together in a study (Creswell, 2011). The grey shaded column in Table 4 signifies parts of the table that are relevant to this research.

Ontologically, this work is premised on the recognition that not everyone has the same experience of the world, reality is historically, socially, politically and culturally constructed and must be carefully critiqued and challenged to enact change. As outlined in Chapter 2, Māori in Aotearoa have diverse experiences of the world, but share colonised realities. The history Māori children are taught at school, for example, is somebody else's history, and Māori health outcomes are worse than those of non-Māori. This must indeed be challenged to enact change.

I have adopted a subjective epistemological position, acknowledging that the production of knowledge is fluid and motivated by political and cultural values. I therefore acknowledge and reflect on my influence in the knowledge process including my own motivation for social change. In the context of this research, social change, described by Lincoln and colleagues (2011) in Table 4 as social transformation, concerns the structural determinants of health and systems of care that are faced by Māori experiencing cancer.

Having positioned this work within a Māori-centred, critical theory paradigm, the next step in understanding the research methodology is the framework that underpins the way the study was undertaken. The ethic of care theory developed by Tronto (1993, 1998) was chosen as the framework for this research as it

defined 'care' for the study and provided the structure for the multiple bounded systems used in the case study approach. Importantly, the ethic of care theory explores power relations from a feminist perspective and in this way provided a critical lens for the research on the way that care is planned, administered, managed, delivered and received. The power relations inherent within the system of care are further articulated for this research with work by Jones (2000) described which shows different levels of racism in the context of the health system and health outcomes. Importantly, the critical theory of cultural safety (Ramsden 2002), adds a vital cultural identity component to the ethic of care framework for Māori cancer care provision.

3. The Ethic of Care Theory

The ethic of care framework is relevant to the research because it provides both a working definition of care, and a critical lens from a feminist perspective on the power relations inherent within the system of care. The feminist perspective provided by the ethic of care is also aligned with the Māori-centred, critical theory paradigm of the study. At the heart of feminist theory are the study of power and the goal of women's empowerment. Importantly, empowerment has been extended by Indigenous feminists to include whānau, hapū, iwi and ethnic and cultural groups. Feminist theories cover a wide spectrum including liberal, Marxist, socialist, radical, lesbian, psychoanalytic, multiracial, postmodern and post-colonial (Ackerly & True, 2010). Feminist theories continue to evolve, for example decolonized feminist research (theorising by Indigenous women) has grown in importance (Olesen, 2011). Although there is a plethora of diversity among feminisms, for example, some Māori feminists dispute the existence of post-colonial (Pihama, 1993a), they all share a focus of naming and challenging the power and control inherent across societies and systems.

Indigenous women's feminist theorising emphasises the central positioning of women in generating knowledge about ourselves, our communities, and the wider colonising forces that affect these. This can be shown in the example of Māori women having always been situated in colonist discourses as the 'other' (Smith, 1992) and this defining and labelling as the 'other' justifying colonialist ambitions (Said, 1995).

Indigenous feminists have responded to these imposed labels by shifting the ontological and epistemological position of research (Smith, 1992). Instead of being 'othered' by colonising populations, the production of knowledge should come from Indigenous researchers who have positioned the research from our own perspectives. In Aotearoa, these are Kaupapa Māori and Māori-centred research approaches.

The next section will first theorise care, which is important for this research as clarity is required regarding what care 'is', and identifying who has the power to define human needs and relationships (Narayan, 1995). In describing theories of care ethics, the following section will show that although Tronto's (1998, 1993) ethic of care was not developed by Indigenous feminists; it resonates with a Māori view of health and wellbeing. Therefore, alongside other critical theories such as cultural safety, and racial discrimination, it provides a framework for implementing a Māori-centred, critical feminist analysis.

Theorising care

A feminist ethic of care begins with connection, theorized as primary and seen as fundamental in human life.

People live in connection with one another; human lives are interwoven in a myriad of subtle and not so subtle ways. (Gilligan, 1995, p. 157)

The central focus on *care* in this study meant that a comprehensive definition of *care* and the theory informing the definition was required. I discuss here an ethic of care theory, drawing particularly on work by Barnes (2006), Fisher and Tronto (1990), Gilligan (1982, 1995, 2003), Narayan (1995), Tronto (1993;1998, 2010), and Sevenhuijsen (1998). This is followed by a definition of *care* for the study.

Theoretical and normative frameworks that underpin care were first challenged by feminist psychologist Carol Gilligan in the early 1980s. Gilligan's work as a cognitive psychologist focussed on gender differences, with a particular interest in why males scored higher on the Kohlberg scale of moral development (Gilligan, 1982). She found that males solved problems presented in Kohlberg's vignettes by using what were considered universal principles with a focus on individual rights, whereas females tackled the problems differently, focussing on relationships, connection and the welfare of others. This finding enabled Gilligan to critique the normative framework of self and morality which ignored female experience and assumed a single male concept of morals and therefore ethics. Gilligan challenged the assumption that females had a less developed approach to morality and contended that women's morality: "is shaped by sensitivity to the needs of others and an assumption of responsibility for taking care" (Gilligan, 1982, p. 16).

Despite Gilligan's intention to name and change masculine concepts of morality, a torrent of discussion and division has followed the ethic of care theory over the last 30 years. Many feminists applauded an end to what Deveaux called "masculinist myths of standard moral and psychological development" (Deveaux, 1995, p. 116), but the work was also criticised as "ethnocentric, essentialist and the reification of femininity" (ibid). In other words, it was argued that Gilligan's ethic of care was based on interviews with white, middle class privilege, and stereotyped women into feminine nurturers dedicated to self-sacrifice. Gilligan

(2003) counter-posed that a feminist ethic of care “voiced relational realities that were otherwise unspoken or dismissed as inconsequential” (p. 158).

Tronto (1998) added that the normative framework of morality based on universal principles and individual rights could only work if somebody was getting on with maintaining relationships and doing the caring work behind the scenes. In patriarchal societies these tasks were generally undertaken by women. Further, others have shown how the care perspective highlighted difference, norms of justice, impartiality and equality (Bowden, 2003). One aspect of the ethic of care that is particularly relevant to this research is where theory is concerned with who has the power to define human needs and relationships (Narayan, 1995) which will be discussed later in this chapter.

The ethic of care theory made visible the interconnection of people and responsiveness to the needs of others. Gilligan’s trailblazing and often misunderstood beginnings of care ethics were given greater clarity by Tronto (1993) who sought to politicise care. Tronto (ibid) shifted the lens from women’s ideals of care into the public sphere by addressing the need and provision of care as a concern of human life. She illustrated this by saying: “...shifting the terms of the debate about gendered morality requires that we look more closely at the boundaries around contemporary moral life to see how they function to preserve the positions of the powerful” (Tronto, 1993, p. 91).

In describing the powerful, Tronto was referring to those who are privileged by their positions in the dominant culture -traditionally middle and upper class white men. Tronto (1993) was quick to point out that the differences Gilligan found between men and women may not be found as strongly within different classes and ethnicities. Indeed, the rules of moral reasoning by the dominant majority, where individuals’ separate rights were morally stronger than an emphasis on

connection and relationships, did not apply to everyone. For example, research by Cortise (1990) found that non-white students scored lower on Kohlberg's scale of moral development than white students, leading the author to conclude that moral judgement reflects the structure of social relations rather than the structure of human cognition (Cortise, 1990).

Further, examples from non-European cultures including Māori, emphasise the importance of interconnectedness and relationships (see Barnes, 2006; Durie, 1994; Harding, 1987; Houston, 1990). Where European norms celebrated the autonomous, self-sufficient individual and considered mutual dependency among families and communities to be negative (Sevenhuijsen, 1998), interdependence rather than independence is considered the healthier goal for Māori (Durie, 1994).

The ethic of care has been interpreted and applied in a range of studies across different disciplines. Research about a women's movement in Israel used an ethic of care analysis to apply care as a strategic and political tactic (Mansbach, 2012). A study about intensive care nurses applied an ethic of care perspective to analyse the nurses' moral concern experiences (Cronqvist et al, 2004). In Aotearoa, an ethic of care theory was aligned with a 'Five Well Beings' approach to Māori businesses, specifically promoting sustainable behaviour within tourism ventures (Spiller et al, 2011). Further, in Māori mental health nursing, Brannelly and colleagues (2013) connected an ethic of care to Māori worldviews (Moss et al, 2014).

Defining care

Fisher and Tronto's (1990) definition of care positions caring as a 'we' activity rather than an individual one:

On the most general level, we suggest caring be viewed as a species activity that includes everything that we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life sustaining web. (p. 40)

In keeping with Gilligan's ethic of care (1982), Fisher and Tronto's definition implies a fundamental connection of people. Care as a 'species activity' goes against emphasis on the autonomous individual who looks after him or herself and sees the need for care as a weakness, and instead shows that all people are interdependent and vulnerable. Fisher and Tronto (1990) also widen the scope of care recipients beyond concern for specific dependents (i.e. parents caring for their children) into a wider frame of caring for our communities and the world around us. Tronto (1993) has subsequently pointed out that however general the definition of care, thoughts and actions are only considered as care when they are intended towards "maintaining, continuing, or repairing our world" (p. 103).

By including 'repair our world', the definition recognises care as something that encompasses wider needs, in this case, of those with cancer, that are not confined to medical interventions. While some attribute *caring* to nursing and *curing* to medicine (Edwards, 2009), *caring*, for this research, encompasses the work of nurses, specialists, general practitioners, screening providers, policy and administration, and supportive care services such as transport, provision of information and advocacy. Importantly, those who receive care and their

interactions and responses to the care providers are also crucial to a comprehensive picture that is care. *Caring about; taking care of; care giving and care receiving* (Tronto, 1993, 1998) are all categories of care which will be expanded on as a basis for the analysis and interpretation of this research.

The 'complex and life sustaining web' described by Tronto and Fisher (1990) resonates with aspects of Māori models of health, although it is missing some crucial dimensions such as whānau and wairua (spirit) (Brannelly et al, 20113). This thesis expands on Fisher and Tronto's (1990) definition of care by adding that our bodies, ourselves and our environment encompass tinana (the physical element), hinengaro (the mental state), wairua (the spirit), and whānau (the immediate and wider family) as expressed in Te Whare Tapa Whā (Durie, 1994).

As the first Māori health model to be embraced by the mainstream, Te Whare Tapa Whā (ibid) acknowledged these four pillars of wellbeing. However, as pointed out by Warbrick and colleagues (2015), contemporary Māori health discourse extends the concept of wellbeing beyond the four pillars of Te Whare Tapa Whā, to include the land that the whare (house) stands on. This inclusion of environment in the model of health encompasses external influences that impact on health and wellbeing such as socio- economic oppression and racism (Reid & Cram, 1999).

When Fisher and Tronto's (1990) definition of care describes 'repair our world', a further step is taken in extending the definition of care to include foundational improvements to social conditions rather than responding to immediate health needs. This relates to Cram and colleagues' (2003) work on Māori concepts of health which showed that wairua continues to be highly valued by Māori, but has been disrupted due to historical land losses. Therefore the 'repair our world' part

of the care definition for this research includes access to tribal land, language, environment and whanaungatanga.

In a recent reflection on the period when Māori health providers were beginning to participate widely in health service provision, Durie (2011) described the Te Whare Tapa Whā model as: “A reconfiguration of health in terms that made sense to Māori and made it possible for Māori communities to experience a sense of ownership and to balance medical and professional dominance with community involvement and local leadership” (p. 282). The differences in the way that Māori health providers care for whānau in their communities compared to mainstream health care providers can be understood in terms of the feminist ethic of care. Rather than a universal, individualistic health model, Māori health providers tend to focus on supporting whānau, with collective consciousness and interpersonal relationships being strengths to the delivery of services (Barcham, 2007; Bennett et al, 2008; Crengle, Lay-Yee & Davis, 2004; International Research Institute for Māori and Indigenous Education, 2002; Kiro, 2001; Slater et al, 2013, 2015, 2016). These relationships can be expressed in the Māori concept of whanaungatanga.

Whanaungatanga is defined in the Māori dictionary as:

Relationship, kinship, sense of family connection – a relationship through shared experiences and working together which provides people with a sense of belonging. It develops as a result of kinship rights and obligations, which also serve to strengthen each member of the kin group. It also extends to others to whom one develops a close familial, friendship or reciprocal relationship. (<http://Māoridictionary.co.nz/word/10068> - accessed 12 January, 2016)

In the health context, the common understanding of whanaungatanga pertains to relationships -networks and social interaction based on the models of the extended family (Durie, 1994). In terms of cancer care, whanaungatanga includes meaningful relationships between those affected by cancer and the people in charge of their care, but also on-going relationships that have the potential to contribute to cancer prevention (smoking cessation, diet, healthy housing) and screening, as well as those relationships established and maintained in the follow-up period (Slater et al, 2013).

Whanaungatanga encompasses Fisher and Tronto's (1990) 'everything that we do' and is a useful concept for understanding the breadth of caring that is undertaken by Māori health providers and other community organisations who look after those with cancer. Whanaungatanga locates the health providers within their communities and their care extends beyond physical aspects of individual health, to support whānau in spiritual, mental and emotional aspects.

Interconnectedness between providers and their communities is indefinite, rather than being confined to a single appointment, or indeed an isolated 'episode' of care. Whanaungatanga, as expressed by Māori health provider organisations aligns with feminist theorist Noddings' (2002) view that care institutions model themselves upon the realities of how families truly operate, with one of the aspects of this being a willingness to 'hang in there'. The implication of this, and something which underpins the philosophy of Whānau Ora policy is ultimately enabling families to flourish (Kingi et al, 2014).

Studies of general practice and cancer patients who are looked after by Māori health provider organisations report satisfaction with cost, cultural acceptability and convenience of location (Maniapoto & Gribben, 2003), and recognition of the validity of a Māori world view alongside practical support (Slater, 2013; Walker et

al, 2008). This recognition of world views is also a feature of cultural safety theory. Cultural safety theory augments this study's ethic of care framework and its role in 'filling the gaps' will be described in the following section. As a critical feminist framework, the ethic of care begins with challenging and politicising ideas of care. Cultural safety extends this by adding the component of cultural identity, and in doing so provides a body of knowledge for the health workforce to understand their own cultures, and colonial processes that control everyday interactions between the *care givers* and *receivers*. Thus, cultural safety theory adds to the ethic of care framework the opportunity to provide care in a manner that respects the cultural identity of the patient. It also takes into account historical processes that affect the power and control inherent in caring.

Cultural safety education theory

Different theoretical models have varied approaches to understanding culture, the process of cultural identity, and the application of this understanding to provision of health care (Downing et al, 2011). Each model manages the power dynamic inherent in caring differently, with some focussing on the individual carer, others the health system and some both individual and systemic levels (ibid).

Cultural safety was chosen as a contributor to the methodology of this research because it provides a much-needed Indigenous component to the ethic of care by placing power with those who receive care and onus on care providers to recognise how their own systems, processes and interactions can potentially provide culturally unsafe care. Cultural safety is concerned with power relations, and in particular, for a Māori-centred, critical theory based study, cultural safety education theory provides a lens on how colonial processes and structures shape and harm Māori health (Ramsden, 2002). Cultural safety is frequently compared to transcultural nursing. Transcultural nursing is grounded in cultural anthropology, which takes an observational and ethnocentric approach to 'other'

cultures (Downing, Kowal & Paradies, 2011). By focussing care on the 'cultural' activities of the patient, stereotypical views of cultures are fostered over time and inhibit responses by care staff to the individual diversity of patients.

Cultural safety and transcultural nursing are divided by their differing anthropological and sociological definitions of culture and the way they approach the related concept of 'ethnicity'. Cultural safety, for example, employs the term 'culture' in its broadest sense. This definition of culture applies to any person or group of people who may differ from the health care staff because of socio-economic status, age, gender, sexual orientation, ethnic origin, migrant/refugee status, religion or disability.

Transcultural nursing, on the other hand, is based on the premise that the term 'culture' refers to ethnicity. This ethnocentric approach contends that patterns of learned behaviours and values are shared among members of a particular ethnic group and are usually transmitted to others of their group over time (Leininger, 1997).

Transcultural nursing does not, however, recognise power relations between patients and health care staff, or encourage care providers to challenge their 'taken for granted assumptions' about individual patients and groups of people (Downing et al, 2011). Ramsden (1993, 1997, 2002) has outlined how cultural safety is based in attitude change. Health care staff who hold safe attitudes are able to work with the diverse continuum of Māori people, ranging from traditional practitioners of the culture to those who have been isolated from their Māoritanga. Further, a culturally safe approach maintains that cultural knowledge belongs to the culture and should remain with the culture. Thus, teaching nurses to be experts in Māori culture does not empower Māori. Instead, it leads to

further disempowerment of Māori, as many have been deprived of knowledge about their own identity and traditions (ibid).

Ramsden's alternative theory to transcultural nursing and other similar approaches, including cultural competence and cultural awareness (Downing et al, 2011), is articulated in cultural safety which is not concerned with learning about cultural practices (Gerlach, 2012). Instead, cultural safety takes 'culture' to mean anything that is relevant to how the patient sees themselves (Ramsden, 1997). Importantly, in the context of delivering health services in Aotearoa, cultural safety also addresses the way in which colonial processes and structures shape and negatively impact on Māori health (Ramsden, 2002). The cultural competence model is however more prevalent throughout health policy in Aotearoa. For example the Medical Council of New Zealand and most DHBs have a cultural competency requirement (The Royal New Zealand College of General Practitioners, 2007). Cultural competence focusses on managing cultural 'factors' in health service settings (Downing et al, 2011). This ethnographic approach to culture is limited and promotes stereotyping and assumptions (Ramsden, 2002). In Ramsden's words: "The nursing skill does not lie in knowing the interesting and exotic customs of ethno-specific cultures: that is completely unrealistic" (Ramsden, 1997, p. 125).

Cultural safety transfers power from service providers to health care consumers, and in doing so addresses issues of power imbalance (Cooney, 1994). The need to examine dominant power structures and how they impact on health, both within and between groups, has been recognised by a number of commentators (Bruni, 1988; Kearns, 1997; Walker, 1995). Transcultural nursing theory identifies the existence of monoculturalism, but it does not provide health care staff with strategies for challenging it at a political level. Rather, staff learn to work within a monocultural power structure (Cooney, 1994).

Although initiated by nurses, cultural safety has been shown to be equally relevant to many groups of health practitioners and across a range of service delivery environments both nationally and internationally (Brascoupe & Walters, 2009; Cooney, 1996; Downing et al, 2011; Durey, 2010; Jungerson, 2002; Kearns, 1997; Klopp & Nakanishi, 2012; Nguyen, 2008; Papps & Ramsden, 1996; Papps, 2015; Polascheck, 1998; Ramsden, 2000; Richardson & Carryer, 2005; Shah & Reeves, 2012; Sheridan et al, 2011; Wood & Schwass, 1993). However, in Aotearoa, cultural safety education is only mandatory in the teaching of nursing and midwifery, and has been shown to have poor implementation throughout the rest of the health workforce (Sheridan et al, 2011).

In highlighting historical processes and recognising power imbalances between health care providers and patients, cultural safety theory fits within the critical theory paradigm, and is also an appropriate theory for Māori-centred research. The ethic of care framework, to which cultural safety theory adds an important cultural identity component, will be discussed in the following section.

3.1 Applying the theories

I have used Tronto's (1998) four categories of care, applied to Māori access into and through cancer care as a framework to assist in developing the case boundaries for the study, the analysis, and interpretation (Table 5). The definition of care access for this study is taken from work by Cormack and colleagues (2005), who conceptualise access as being: "...about obtaining entry into and through health services and encompasses the timeliness and quality of both the process and the outcomes" (p. 31).

Table 5: Tronto's (1993,1998) four categories of care applied to cancer care

Care type	Principle	Action	Role
<i>Caring about</i>	Attentiveness	Recognition of another's need for care.	Policy/administration of funding contracts
<i>Taking care of</i>	Responsibility	Assuming responsibility and setting up a response to the needs.	Administration/management of services
<i>Care giving</i>	Competence	Practical care work by individuals and groups.	Those working in cancer prevention, screening, primary, hospital and hospice care
<i>Care receiving</i>	Responsiveness	Acknowledging the consent of the care-receiver.	People with cancer and their whānau

Throughout our lives, Tronto (1998) describes ***caring about*** as a necessary first step in the caring process for both men and women. She argues that men are most likely to engage with *caring about* and ***taking care of***, whereas women are generally expected to be the ***care givers***. Rather than focussing solely on those who identify, arrange or provide the care, Tronto also made visible the rights of ***care receivers*** to have access to and an ability to choose high quality care. Throughout the four categories, Tronto has highlighted how care processes can be affected by various factors such as power relations, inconsistencies, competing purposes and different beliefs about good care (Tronto, 2010). Tronto argued further that good care is achievable when these four phases of care fit together in a care process that is integral and holistic (ibid).

Care receiving

For the purpose of this research, *care receivers* are Māori with cancer, but this definition should not be applied only to individuals with a cancer diagnosis. As

discussed earlier, people are generally part of whānau, be that confined to a 'nuclear' unit comprising parents and children (Sear, 2016) or extended to include a much broader group. Whānau can be a group of whakapapa related descendants of tupuna, or in some cases people who are integral to each other through, for example, sports or work groups (Durie, 2003). The effects of a cancer diagnosis may have effects on various types of whānau, with partners, parents, children, grandchildren, aunties, uncles, friends and colleagues, whose lives are interwoven. Locating the cancer care available to *care receivers* within historical colonial structures assists in examining the interaction between those who define, organise and provide care, and those who receive it.

Care giving

In addition to *care giving* provided by whānau, *care giving* is delivered by a range of individuals within organisations, to people with cancer. These include those who work in general practice, oncology, radiology, hospice and community workers. *Care givers* work in time and resource pressured environments and have different levels of communication and cultural safety skills. Research has shown that Māori with cancer value the qualities demonstrated by *care givers* and appreciate the ability of *care givers* to do their best in terms of meeting the cultural needs of patients (Walker et al, 2008).

Taking care of

This thesis takes the position that those who *take care of* are those who administer and manage the *care givers*. These include people who work in managerial and administration roles within health care and support services. Managers of these services do not always have direct caring duties with those who are receiving cancer care. The unconscious biases of those who *take care of* affects the employment and work environment of *care givers*. For example, their

level of commitment to providing culturally safe care impacts on the way that care is delivered.

Caring about

Caring about has been described as commonly the domain of men (Tronto, 1998), but also the territory of another privileged group, government and policymakers. This group is privileged in terms of power and control over a number of factors that influence cancer care. Cormack and colleagues (2005) have described these as health system factors and they include: funding policies; resources; service organisation and configuration; physical accessibility of services; waiting times; and cost.

Those who *care about* in cancer care are individuals, policy teams and ministers within government organisations who design and oversee strategies and action plans (these are listed in Table 2). They may be based within government agencies, DHBs, PHO or health provider organisations.

As well as the *care about* positions of those who write policy, the people at the first layer of implementing policies also fall into this group. This includes administrators and managers who have the power to prioritise what is important in a funding contract and how this is measured. For example, in a breast screening contract, the funding requirements might focus on how many women have had breast screening but not on the work required to encourage and assist women to get to screening, or the support which may be needed for women after screening.

Membership in Tronto's four care groups is fluid. People can and do weave between any of the four groups at different parts of their lives, and indeed, can be part of more than one group at any one time. Barnes (2006) points out that we

are all part of the “universality of human relatedness” (p. 151), and that we each experience being cared for and caring at some point in our lives. For this reason, she warns of making binary distinctions between care-givers and care receivers (ibid).

Relationships between the four categories of care: Who has the power?

In order to discuss how Tronto’s four categories of care interrelate when applied to Māori and cancer care, it is important to first return to the question about who has the power to define human needs and relationships (Narayan, 1995). The previous sections of this chapter have shown how the ethic of care framework (Tronto, 1993,1998) is based on the interconnection and interdependence of people and the importance of relationships.

The ethic of care also rejects the notion of the autonomous individual, and recognises that all of us can move between being *carers* or *cared for*, as well as some of us also being in the *care about* or *take care of* roles. Narayan (1995) argues further that acknowledging interdependence and relationships does not go far enough without recognising whose voice is being heard, in other words, the context of being a *care receiver*: “Notions of differences in vulnerabilities and capabilities should be recognised as contested terrain, requiring critical attention to who defines these differences as well as their practical implication” (p. 136).

The ‘contested terrain’ in this thesis locates Māori with cancer as *care receivers* within a context of more than 170 years of monocultural domination (Pomare & de Boer, 1988). As cancer *care receivers*, Māori face dual definitions of difference from the mainstream, foremost as Indigenous people (Moewaka Barnes, 2008), and also in being positioned as patients in need of care (Narayan, 1995; Tronto, 1993,1998). Thus, Māori are separated from what Barnes (2006) has called the ‘independent majority’ (p. 13). This polarising of groups as either

needy or normal, has been challenged by Barnes (ibid). She illustrates how particular groups are classified as needy and dependent, while others are deemed responsible for delivering care, with both groups considered to be outside the realm of the independent majority –the mythical autonomous individuals who have no need to care about, take care of or care for others in their daily lives (Barnes, 2006).

Moewaka Barnes (2008) has shown that despite our position as Treaty partners with the Crown, Māori are still defined as “different and in need of development” (p. ii). Narayan (1995) has described how the ideology of care has been used in colonial contexts to justify colonial power and oppression. This colonial ideology of care is innately racist. A brief outline of theories of racial discrimination, with a particular focus on levels of racism and how these apply to accessing health services is presented below.

Racial discrimination theories

Racism at institutional, personally mediated and internalised levels has been shown to contribute to poor health outcomes (Harris et al, 2006; Jones, 2000; Krieger et al, 2011). Racism is “a doctrine without scientific support, that claims the superiority of some one race” (Collins, 1981, p. 687). Jones (2000) has provided a theoretical framework to examine levels of racism experienced by non-White Americans, which can also be applied to the structural determinants of health and their potential effects on cancer survival for Māori. Jones has defined institutional racism as “differential access to the goods, services and opportunities of society by race...manifested both in material conditions and in access to power” (p. 1212).

Institutional racism occurs at a systems level, with rules and practices that advantage and include some groups while excluding others. Jones (2000)

names institutional racism as the most powerful in affecting health as it claims to provide the same service to everyone, but ignores the privileges experienced by some groups and barriers faced by others in accessing the service. This 'one size fits all' approach places blame on individuals and groups who "choose" not to use the system, instead of looking at ways the system can meet the needs of all groups. In Jones' (2000) words, institutional racism: "is often evident as inaction in the face of need" (p. 1212). This form of racism is structural in that it is entrenched within institutions and it is therefore difficult to identify the individuals responsible for its continuation.

Personally mediated racism – overt prejudice because of race, is more easily apparent. Harris and colleagues (2006) describe contact between individuals that is direct and observable, including verbal and physical assault, or unfair treatment when applying for a loan or a job. Internalised racism encompasses the despair and futility felt by people when they are subjected to constant institutional and personally mediated racisms, resulting in lower self-worth and expectations (Jones, 2000).

Experience of racism has been shown to affect health outcomes for Māori in Aotearoa, including cancer (Cormack et al, 2005; Harris et al, 2006, 2012a, 2012b, 2013). Jones' Framework (Jones, 2000) is a valuable tool for considering the relationships between all four groups in Tronto's (1998) ethic of care as they apply to cancer care for Māori. Those who *care about* and *take care* have the power to ensure that an equity focus is an important driver in cancer policy and that there are adequate resources for those who provide care.

In a broader sense these two groups are represented across government institutions, working in education, health, justice and all areas to empower and

care for all people, instead of using a universal system that excludes groups who are not from the dominant culture. Under direction and sufficient resourcing from those who *care about* and *take care*, the *care givers* would be enabled to use resources equitably. These are primary care providers, those who work in hospitals and hospices. Equitable use of resources would impact positively on *care receivers*, with improved health outcomes for Māori, including cancer survival rates at the same level as non-Māori.

Study Design

3.2 Outlining the case study design

With the Māori-centred, critical feminist theoretical paradigm and ethic of care framework of this study now articulated, the next part of this chapter outlines the case study design of this research.

Case Studies

There are divergent views in the methodological literature on what case study research 'is'. For example, Stake (2005) defines case study research as a choice of what is to be studied, rather than a methodology, whereas Creswell (2013) contends that case study research is a methodology and: "a type of design in qualitative research that may be an object of study, as well as a product of the inquiry" (p. 97).

Case studies come in many forms. They can be positivist or descriptive, interpretive or theory building (Gerring, 2004). Given the wide breadth of case study designs, it is not surprising that those who write about how to undertake case studies have different approaches to their theoretical paradigms, design and methods. Batten (2008) has considered case study approaches on a continuum,

with positivist psychology research such as that undertaken by Yin (2009) at one end, and case study researchers from education and sociology such as Stake (2006), Creswell (2007, 2011, 2013) and Hamel (1993) at the other.

A case study design was chosen for this research as it was considered the most appropriate strategy for examining the role and potential of community care for Māori with cancer, within a wider system of care. The system of care includes the views of people at different vantage points of care planning, delivery and receipt. Thus, the ethic of care groups (those who *care about*, *care for*, *give* and *receive* care) defined by Tronto (1998) lend themselves to identifying the boundaries of the cases in this research.

The case study approach enables the investigation of four different environments within the system of cancer care, facilitating examination of how individuals within these environments connect with each other, and where their views diverge. This importance of identifying different contexts is described by Goodrick (2011) who defines the case study as: “a research approach that facilitates understanding of complex social phenomena where it is difficult to disentangle the phenomena from the context in which it is embedded” (p. 36). In this way, the case study design is consistent with the ethic of care theoretical framework of the study and is most appropriate to answer the research questions posed in this research.

Other study designs would not have provided the same opportunities to examine cancer care for Māori from different perspectives of the system of care. An alternative research strategy for this study, for example, might have been a phenomenological study. Creswell defines phenomenology research as “describing the common meaning for several individuals of their lived experiences of a concept or a phenomenon” (Creswell, 2013, p. 76).

In this research, 'cancer' is a lived experience, whether as a patient, whānau member or person delivering or planning cancer care. However a phenomenological study combining the views of a plethora of individuals regarding cancer treatment and support services would not assist in examining different parts of the system of care, and how these relate to each other. To return to Goodrick's definition, the environments (or contexts) in which the research participants inhabit, as cancer patients, care providers, managers or planners cannot be easily "disentangled" from their views of cancer care and services (Goodrick, 2011, p. 36). To attempt this research with a phenomenological approach would miss potential differences and similarities between groups at different levels of the system of care.

Thus, in choosing a case study approach, the focus of the inquiry is on the views and interactions of clearly established cases, rather than the phenomenological approach which would endeavour to find common meaning from a universal group. The study of cases for this research not only facilitates identification of similarities and differences between various parts of the system of cancer care, but also the reasons why they might exist. Creswell (2013) said that: "case study research begins with the identification of a specific case" (p. 98).

Multiple bounded systems

In establishing the boundaries of the case studies I will first present the geographical boundaries of the study, second, outline the levels of care, including cancer services available within the bounded context and finally, describe the characteristics of each case.

The study was based in the lower North Island, predominantly in the Wellington, Lower Hutt and Wairarapa regions (for the purpose of this study, called the greater Wellington region). The cancer co-ordinator was based in Palmerston North. All areas can be seen in Figure 1.



From: www.tourism.net.nz

Figure 1: Lower part of Te Ika a Maui (the North Island of Aotearoa)

Primary care

Primary care is usually the first point of contact for people who go on to have a cancer diagnosis (Campbell, Scott & Seneviratne, 2002). Capital and Coast DHB has four PHOs and each of these has up to 53 GP practices, each serving thousands of patients. As described in our earlier work exploring the cancer care services of Māori health providers, it is difficult to estimate the number of Māori health providers in any area as this information is not publically available (Crengle, 2000; Slater et al, 2016). Participants from four GP clinics and four Māori health provider organisations took part in the study. Due to confidentiality, these health service providers will not be named here, but some of them can be described.

One of the Māori health providers is based in a marae setting, with kōhanga reo and other whānau services provided. The services are set in a very welcoming environment, with people coming and going, children playing and a large outdoor space. Another Māori health provider organisation operates its services from a modern building with light flooding in from large glass windows. The waiting area is spacious, with whakairo (carvings) at reception, toys for children, fresh flowers, a large television screen and comfortable chairs. Both examples in this study have large reception areas with wāhine Māori behind the desk, greeting whānau who visit the service and making them comfortable. One of the GP clinics is based near the shops of a small urban village. It is surrounded by trees and a playground for children. The building is modest, but houses a large and welcoming waiting room with comfortable chairs, toys for children and is decorated with posters presenting public health messages such as the importance of vaccination and cancer screening. At the time I visited, the consulting rooms were being painted and had a fresh, modern feel. Cheerful women at reception welcomed and chatted to people as they arrived at the clinic.

Cervical and breast screening services are available at GP clinics, and some Māori health providers also provide cervical screening services in homes. In the greater Wellington area, Breastscreen Central, part of Breastscreen Aotearoa, is the lead provider for mammography, with screening units in Lower Hutt, Wellington and Kenepuru as well as mobile units which are scheduled to serve each area for periods of between one week and two months.

Cancer services

There are three DHBs in the region selected for this study: Capital and Coast, Wairarapa, and Hutt Valley DHBs. Depending on where patients live, the type of cancer, and treatment required for patients, they could be treated at either Masterton, Hutt Valley, Kenepuru or Wellington hospitals. The Wellington Blood

and Cancer Centre at Wellington Hospital provides medical oncology, radiation oncology, haematology and palliative care services. They also provide outreach services at Masterton, Kenepuru and Hutt hospitals.

There are two hospices in the greater Wellington region: Te Omanga hospice in Lower Hutt and Mary Potter hospice in Newtown. Both provide outreach services, with Mary Potter serving the Porirua and Kapiti Coast communities and Te Omanga working in conjunction with Kahukura specialist palliative care nursing service in the Wairarapa.

Much of the palliative care work provided by hospices and the hospital is undertaken in the community rather than in inpatient units (Slater et al, 2015). However both Te Omanga and Mary Potter hospices have comfortable and welcoming premises, where patients can have whānau stay with them. The hospices provide services to support whānau and include them in care, as well as caring for the dying patient. Te Omanga hospice is based in an historic convent building with extensive grounds and beautiful gardens. Mary Potter hospice is located next to Wellington hospital and optimises its space with beds for 18 patients, communal spaces for families and a self-contained apartment for larger families. Both hospices have meeting rooms, libraries and chapels available to staff and families.

Supportive care services

The supportive care services provided by the Cancer Society, who are the main providers of supportive care for people with cancer in Aotearoa have previously been described. Other organisations include those focussed on specific cancer types such as the Breast Cancer Foundation, Melanoma New Zealand and the Prostate Cancer Foundation of New Zealand. Free telephone and online information services are provided by the Cancer Society.

For patient and whānau study participants who were undergoing treatment in Wellington, supportive care services were available at the Cancer Society Wellington Division, which has a large, welcoming building with free parking directly across the road from Wellington hospital. The Wellington Division provides counselling and advocacy services. There are also smaller centres in Masterton and Kapiti.

The Cancer Society runs the 'Living Well with Cancer Education Programme' which supports and educates patients about living with cancer. The Living Well programme was first run by the Wellington Division of the Cancer Society in 1991 and consists of 6 weekly sessions of 2-3 hours with the overall aim being to support and educate patients about living with cancer. The specific content of the programme varies according to the particular needs of the group (Jasperse, Herst & Kane, 2012). The *Look Good Feel Better* charity also offers workshops free of charge to women in the Wellington region who are undergoing cancer treatment.

For Māori in the Hutt Valley, the KOETI programme is also available. This programme was developed by the Wellington Division of the Cancer Society and Kokiri Seaview Marae and provides a safe space for Māori that is marae-based and whānau-centred. Like the Living Well programme, KOETI supports and educates patients about living with cancer. However, KOETI also provides a forum for whānau to support each other in an environment where they are welcomed as integral to the cancer journey.

Parking vouchers are available through hospitals for those undergoing cancer treatment. Some shared driving services are provided by the Lions Club and the Cancer Society. For patients from out of town who must travel to Wellington for treatment, accommodation is available at Margaret Stewart House in Wellington.

This accommodation has bedrooms for families and shared cooking facilities and is based on the hospital grounds.

Characteristics of the cases

I have taken Tronto's (1998) ethic of care framework and constructed case boundaries using Creswell's (2007) multiple bounded systems categories. Creswell (ibid) has outlined three requirements for defining multiple bounded systems. The first is the necessity to study more than one case (or bounded system). For this research, the four perspectives (*care receivers*, *care givers*, those who *care for* and *care about*) from Tronto's (1998) ethic of care framework (Table 5) determined the case boundaries. The way that the cases worked as a system of care are further explored in the comparative analysis using Denier and Gastmans' (2013) Circles of personalist care ethics model, which will be described later in this chapter.

Creswell's (2007) second requirement in studying multiple bounded systems is to collect multiple sources of information from each case. The primary data source for this research was the interview data from participants in each case. Finally, Creswell's multiple bounded systems categories include reporting case based themes. The case boundaries defined by Tronto's (1998) ethic of care framework identify four perspectives from different parts of the system of cancer care, thus allowing examination of the themes through four different lenses.

Case 1 comprises the views of Māori cancer patients and their whānau. As *receivers* of cancer care, they are able to share their experiences of access into and through different parts of cancer care and support including screening, diagnosis, treatment and survival.

Case 2 explores the perceptions of people who work in primary care and hospices within the community. Within the boundaries of the ethic of care, these views come from the *care givers*. Community participants include community health workers, Māori Liaison workers, nurses and doctors. Their experiences of *care giving* provide an important perspective of Māori access into and through cancer care.

Case 3 contains the views of people who manage primary and secondary health care services. They manage hospices, Māori health provider organisations and Whānau Care Services at a hospital. In their *take care of* roles, they provide an organisational perspective, managing services, staff and administration of funding contracts. However, management participants also work with whānau who access their organisations' services, and many of these participants are also able to reflect on their experiences in supporting whānau.

Case 4 consists of the perspectives of people who work in the *care about* realm of cancer care. These participants have an in depth knowledge of research and policy in their areas. They come from the Cancer Control Council, Palliative Care Council, Central Cancer Network, supportive care and DHB organisations. As well as providing a research and policy overview, many of the Case 4 participants have also worked in *care giver* roles and thus, many also have a community perspective.

The key data collection method for the study is semi-structured interviews with participants from each case perspective. With the cases defined, the next step for outlining the case study design is to consider the research methods. The following section will explain why qualitative methods were most appropriate for this study, given my research questions and methodology.

Qualitative research

The case approach was qualitative and the predominant method of data collection was semi-structured interviews. This method was considered appropriate for this study, in order to describe four distinct parts of the cancer care system, and to capture an in-depth understanding of the cancer journey from the perspectives of the participants (Green & Thorogood, 2009). To show how a qualitative approach was the best way of answering the research question, a brief explanation of quantitative methods and their fundamental difference to qualitative methods, is required.

Denzin and Lincoln (2005) have described the focus of quantitative research as: “emphasising the measurement and analysis of causal relationships between variables” (p. 10). Quantitative studies set out to prove or disprove a hypothesis, and emphasise statistical power, reproducibility and generalizability (Patton, 2002). Qualitative research, on the other hand, is concerned with investigating the: “socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry” (Denzin & Lincoln, 2005, p. 10).

Qualitative methods are best suited to this study as the Māori-centred, critical feminist theory paradigm the research is based on has both transactional and subjectivist epistemology, with recognition that findings are value mediated (Lincoln, Lynham & Guba, 2011). To undertake this study using quantitative methods would place the research in a positivist or post-positivist frame, with objectivist epistemology. Given the subject matter of this study, I would have found it very difficult to keep my own values out of this research. It would be somewhat dishonest to place myself outside the research and pretend that I am not ‘in it’. Indeed, critical theory allows me to be part of the research and to acknowledge my own influences throughout the process (Olesen, 2011).

Therefore, a case study approach, using semi-structured interviews with a range of participants from different parts of the cancer control continuum, were the chosen methods for this study. The way in which the data were collected is outlined in the following section.

Methods

The final part of this chapter considers the methods used to undertake the study. The data collection methods, analyses and ethical considerations of the research will be outlined.

3.3 Data collection methods

Patton (2002) lists in-depth, open-ended interviews, direct observation and written documents as sources of evidence for qualitative studies. The primary data collection method for this research was in-depth, semi-structured interviews. I also recorded my thoughts about the research as it developed in a reflective journal. The data collection will be presented in two parts, first the patient and whānau case (Case 1) and second, the policy, management, and community cases. All four cases will be brought back together for outlining the transcription, data management and analysis sections.

The reason for breaking the data collection outline into two parts is that this thesis stems from work undertaken as part of a larger project, the Health Research Council funded study 'Māori with cancer – the role of primary care' (HRC 09/092B). The patient and whānau interviews were conducted by co-investigators from Kokiri Marae during the early stages of the project and as a member of the project team, I was privileged to analyse this data and be the lead author on the two papers published to date, based on this work (Slater et al, 2013, 2015) (attached as Appendices 2 & 3). At the outset of my doctoral work, it was not

anticipated that the patient and whānau data would be included in this thesis.

However, as the ethic of care framework and cultural safety theory were chosen for this research, it became apparent that the voices of patients and whānau were critical in providing a holistic picture of cancer care for Māori.

After some discussion with the Māori health provider collaborators in the overall study, it was decided that with the verbal consent of the surviving patients and whānau, their findings could also be reported in this thesis. As can be seen in Appendix 5, the patient and whānau consent form does not specify the types of publications their data will be used for, however it was important to me as the author of this work that the participants and their interviewers were happy about the different forums their stories would be presented in. Feedback from this showed that there was support for the findings to be shared through further dissemination in addition to the peer reviewed journal papers and conference proceedings. Therefore, the findings from the patient and whānau interviews were included in this piece of work, so that their stories could be shared and a full picture of the cancer care system presented, with the voices of those at the core of cancer care heard.

The patient and whānau recruitment and interview processes differed from Cases 2-4 in that the interviews were undertaken by interviewers from a Māori health provider organisation, and there were differences in the data collection tools such as the information sheet (Appendix 4), consent form (Appendix 5) and interview schedule (Appendix 6). The interview schedule focussed specifically on the patient and whānau experiences based on work conducted by Doherty and Associates (2006), which investigated cancer service availability and experiences of patients and providers. Because of the different process used for Case 1, this is first described separately, followed by the process undertaken for Cases 2-4. For clarity, the data collection process for each case is shown in Table 6.

Table 6: Data collection process for each case

Process	Case 1 Patients and whānau	Case 2-4 Community, Managers and Policy
Recruitment	<p>Participants identified and contacted by Māori health providers.</p> <p>Information provided by Māori health providers, and interview set up at a time and place convenient to the participants.</p> <p>Consent form completed before interview.</p>	<p>Participants identified and contacted by TS *</p> <p>Information provided by TS, and interview set up at a time and place convenient to the participants.</p> <p>Consent form completed before interview.</p>
Interviews	<p>Interviews conducted by CD and HT from Māori health provider.</p> <p>All interviews audio recorded.</p>	<p>Interviews conducted by TS following pilot interview.</p> <p>All interviews audio recorded.</p>
Transcribing	Interviews transcribed by TS	Interviews transcribed by TS
Checking	Transcripts checked by participants.	Transcripts checked by participants.

* TS is myself

Case 1 Patients and whānau

Participant Recruitment and Information

Inclusion criteria were Māori with a cancer diagnosis, from enrolled populations in two Māori provider organisations in the Wellington and Wairarapa regions.

Whānau of the person with cancer were also welcome to take part in the interviews.

Interview Process

Potential participants were identified by the Māori health providers who recruited participants and gained their written, informed consent. Face-to-face interviews took place between May and November 2011 and were conducted by two Māori health workers Cheryl Davies (CD) and Huia Tavite (HT) from one of the Māori health provider organisations, at a time and location chosen by the participant. Almost all interviews were undertaken in the patient's home, although one took place at the Māori health provider clinic. With consent, interviews were digitally recorded.

The transcription process and data management for patients and whānau were the same as for Cases 2-4 and are outlined below. The data analysis was slightly different as it included the input of CD and HT, which will be described in the analysis process part of the following section.

Cases 2-4: Policy, Management and Community

An information sheet, consent form and interview schedule were developed for the study. The information sheet (Appendix 7) listed study collaborators, aims and what participation in the study would involve. The information sheet also stated that while some study findings would be published as part of the larger study, the data would also be used to form part of my doctoral research. An 0800 number and email address were provided for the purpose of being available to answer any questions a potential participant might have.

The consent form (Appendix 8) contained a request for interpreter option (as it turned out, all interviews were conducted in English), and a request for a summary of study results. The consent form sought permission for the interview to be digitally recorded and transcribed. Importantly, the consent form specified that while none of the published results would include any identifiable information such

as names of participants, it would be possible that some people may be able to be identified due to their role or organisation.

The interview schedule (Appendix 9) was developed based on our survey of Māori health providers undertaken in 2011 (Slater et al, 2016). Findings from the study informed the questions and probes, which focussed on what participants thought of the cancer journey generally in terms of their own work, and questions specific to Māori experiences of cancer care services.

Pilot interview

Before contacting participants, the consent form, information sheet and interview schedule were tested in a pilot interview. This was a good test of these study tools and also my interviewing, note taking and transcribing skills. The pilot interview was conducted with a colleague who is also a GP, and she was able to provide feedback as a participant. The pilot transcript was reviewed by one of my supervisors (AM) and myself. We were able to identify areas where I could improve the use of probes. Based on review of the pilot interview, a few interview questions were also added. Data from the pilot interview were not included in the study.

Participant recruitment and information

At the outset of this study, careful planning was undertaken to choose bounded cases that could be compared and contrasted. The cases are described in more detail earlier in this chapter, but for the purpose of this section, potential participants included:

Case 2: Care giving - The Community Case

Case 3: Taking care of - The Management Case

Case 4: Care about - The Policy Case

Potential participants were selected using both purposeful and opportunistic sampling approaches (Patton, 2002). Initial selection was guided by the overall study collaborators who were able to suggest participants able to talk about the issues. Once participants were contacted, a snowballing technique was also harnessed, in that the key informants were asked to recommend others who had experience and expertise in their area (Liamputtong & Ezzy, 2005).

Interview process

Potential participants were provided with an information sheet. After being given time to consider the information sheet, participants were contacted and if they agreed to take part in an interview, a time and location was set up. This generally took place at the workplace of the participant but some interviews were undertaken at my office. Of note, all but two people invited to take part in an interview consented to take part and were subsequently interviewed. Of the two who were not interviewed, both were GPs. One declined for personal reasons and the other agreed to be interviewed but had very limited availability for an interview appointment.

Face-to-face interviews were undertaken. Before the interview, each participant was asked to sign a consent form. Participants were asked for permission to have their interviews audio recorded. Every participant consented to this and interviews were recorded on a small digital recorder. Handwritten notes were also taken. Interviews varied in length from 45 to 240 minutes.

The interviews used a semi-structured format. According to Hancock and Algozzine (2006), semi-structured interviews are particularly well suited for case study research as they invite interviewees to express themselves openly and freely and to define the world from their own perspectives. Participants were asked about the services their organisation currently provides to people with

cancer, including the care and treatment options available and the type of support services offered to people with cancer and their families. Participants from the policy case were asked about their thoughts on the cancer treatment journey in general and for Māori, and what role their work plays in this.

The interview schedule can be viewed in Appendix 9. It must be noted that these were reasonably open ended questions which did not necessarily follow in a linear fashion and each participant was given the opportunity to explore their own views on each question. When points were raised I used probes to find out more about what participants meant and why.

After each interview I ran through my notes and recorded observations in my reflective journal. This included the interview setting, my own impressions of the interview and what was said.

All Cases

Transcription process

For all the cases, the interviews were downloaded from the digital recorder onto my computer and transcribed using Microsoft Media Player. I transcribed all interviews as soon as possible. This was often the day after the interview and certainly within the week following. Raw transcripts were sent to participants for checking and amending. Participants were given the option of withdrawing their transcript within a month of reviewing it. No participant chose to withdraw their transcript.

Data management

The audio and text versions of the interview were stored on a password protected computer. Printed copies of transcripts were given identification numbers instead of names and kept in a locked filing cabinet. Consent forms were stored in a

separate locked filing cabinet so that there could be no cross-referencing by any unauthorised person. Ultimately, the safety of all data storage is the responsibility of the Director of the Centre for Public Health Research. After 10 years, all the paper records will be destroyed.

3.4 Analysis process

Analyses within each case

Interview data were grouped into the four cases, and a thematic analysis was undertaken on data from each case. According to Boyatzis (1998) a theme is: “A pattern found in the information that at the minimum describes and organises possible observations or at the maximum, interprets aspects of the phenomenon” (pvii).

Themes were generated inductively from the data, meaning that they emerged from the data rather than being pre-determined (deductive) (Dew, 2007). The thematic analyses of the interview transcripts were undertaken in three parts. First, two researchers, Anna Matheson (AM) and I (TS) repeatedly read the transcripts and independently carried out preliminary coding of the transcripts by hand. This process is called ‘data immersion’ where the researcher becomes intimately acquainted with the data (Ulin, Robinson & Tolley, 2005). Having more than one researcher undertake this step provided analytic triangulation which safeguards against bias in data analysis (Padgett, 2012).

Secondly, we compared and discussed the emergent themes with each other and for Case 1, the patients and whānau, we also discussed the emergent themes with the participating Māori health providers. Thirdly, qualitative analysis software *NVivo* (QSR International Pty Ltd, Doncaster, Australia) was used to

help organise thematic codes. A paper trail documented methodological and analytic decisions to ensure procedural rigour (Padgett, 2012).

Comparing and contrasting the four cases

The established themes from each case were compared with the other cases from the entire data set (Braun & Clarke, 2006; Green & Thorogood, 2009).

This multiple case study analysis (Stake, 2006) emphasises better understanding of each of the cases as well as providing a basis for the cross case comparisons. To compare the cases Denier and Gastmans (2013) Circles of personalist care ethics model was used (attached as Appendix 10). The model provided a structure for comparing the study findings across all four cases and in this way, examining the system of care for Māori experiencing cancer. The model was used to structure the themes that were shared across the cases, and to compare and contrast how each perspective approached the theme.

The *Patient as person* circle of care ethics, depicts each patient as unique, with different caring activities that they find important (Denier & Gastmans, 2013). This pertained to the experiences of patients and whānau, as captured by the themes that were generated from their interview data. *Clinical ethics* is described as the relational circle, encompassing relationships and encounters between patients and the people who provide their care (ibid). *Clinical ethics* was applied to the environment of Case 2, and the themes generated by the interviews with community participants who provide care and advocacy to Māori cancer patients and whānau. The third realm, *organisational ethics*, refers to the ethical responsibilities of healthcare organisations, determined by management and governance structures such as boards of directors (ibid). *Organisational ethics* was most relevant to the Case 3 participants, whose management and administration perspectives related to relationships and

information sharing between organisations, as well as their perspectives of the work undertaken by the people they employ to provide whānau services, and indeed, their perceptions of whānau cancer experiences. The final level, *social ethics*, is determined by policy making, public perceptions, social climate and the impact of media on society (ibid). The Case 4 participants were able to provide a policy perspective on research, policy and funding related to Māori cancer priorities, while at the same time recognising that all cases influenced, and were influenced by, other *social ethics* factors such as public perceptions and social climate.

Thus, the ethic of care framework (Denier & Gastmans, 2013; Tronto, 1993,1998) provided a lens on the system of care faced by Māori with cancer, and the Circles of personalist care ethics (Denier & Gastmans, 2013), alongside cultural safety (Ramsden, 1993, 1997, 2002), and theories of racial discrimination (Jones, 2000) served as the basis for this stage of the analysis that considered all of the data together.

3.5 Ethics

This project received ethical approval of the Multi-region Ethics Committee which covers all of New Zealand (Ref: MEC/ 09/11/131). The ethical review process validated our research team's consideration of a number of ethical issues, which split into two parts. Firstly, we were mindful of the safety of individuals (such as the participants and researchers) and organisations (cancer care/support providers and the university). This includes personal safety, but also privacy, informed consent, and handling all information carefully. In particular, it was important to clarify the issue of anonymity with the policy participants, as a description of their organisation and role meant that although their names were not used, there was potential for some to be identified.

Participants and their information were treated with respect and care. In order to ensure that participants gave informed consent, they were provided with information about the study and time to consider whether they wanted to participate. Those who chose to take part in an interview signed a consent form which stated the responsibilities of the researchers and the university. The consent form also made clear the rights of the participant to withdraw from the study and the right to decline to answer any questions. Participants were also given the opportunity to review and amend their transcripts.

The second and much wider ethical issue pertains to implications of this research for Māori. Indeed, Ratima (2001) and Cunningham (2000) point out the ethical obligation to work in a way that is consistent with Māori expectations. I kept a reflective journal which assisted in trying to address potential consequences, whether intended or not, of this research. By reflecting carefully on the research throughout each step of the process, I am able to stand behind the findings and confidently share them.

Importantly, Māori researchers and Māori health providers walked alongside me throughout the research. This project attempts to meet Māori expectations through collaboration with two Māori health provider organisations, who have contributed to the study since the inception of the overall project.

Summary

This chapter has provided the methodology and methods for this research examining the role and potential of community based care for Māori with cancer in Aotearoa/New Zealand.

Indigenous people worldwide have been subjected to research without receiving its benefits (Martin, 2012). A Māori-centred, critical feminist research approach, including critical theories such as cultural safety and theories of racial

discrimination, ensures significant governance by Māori researchers, with Māori (and non-Māori) participants, producing Māori knowledge by incorporating both mainstream and Māori methodologies. The locus of control is with a mainstream academic entity, which provides scope to publish findings without political interference, but also risks mainstream academia treating the work as “quaint folk theory held by the members of a primitive culture” (Denzin & Lincoln, 2008, p. 6). Like Two Eyed Seeing (Martin, 2012), a Māori-centred approach bridges mainstream and Māori worlds, and will guide the application of an ethic of care theory (Tronto, 1993, 1998).

This research seeks to examine how community care might have a role in improving Māori cancer outcomes, in particular what can be learned from the ethic of care demonstrated by Māori health providers. The ethic of care framework (Tronto, 1993, 1998), with its foundations in critical feminist theory, guides this research by providing a definition of care. While showing that everyone needs care at some time in their lives, Tronto’s ethic of care framework (ibid) delineates four groups within the care definition including those who *care about*, *take care of*, *give* and *receive care*. Narayan (1995) and Jones (2000) work contributes to the ethic of care by showing how levels of racism can affect who defines care and whose voices are heard in the care debate. Cultural safety (Ramsden, 2002) provides a much-needed Indigenous context to the use of the ethic of care framework in this research, by explicitly rejecting the ethnographic definition of culture and focussing instead on the process of cultural identity. Cultural safety also guides this research in highlighting historical processes and contributing to the recognition of power imbalances between *care givers* and *receivers*.

The power to define vulnerabilities and relationships, described by Narayan as contested terrain in care ethics (Narayan, 1995) has been explored in the

Aotearoa context. This was provided with clarity by theories of racial discrimination and cultural safety. This exploration of power and control includes the on-going effects of colonisation, with particular attention to Māori as cancer *care receivers* but also introduced the whanaungatanga expressed by *care givers* working from Māori health provider organisations.

A multiple bounded case study design has been articulated, with four cases bounded by Tronto's (1998) ethic of care framework and applied to Māori cancer experiences. Denier and Gastman's (2013) Circles of care ethics has been introduced as the model for assisting with the comparative analyses. Ethical considerations and data collection methods have been considered, alongside an explanation of the analysis process.

Chapter 4

Case 1: **Patients and Whānau**

4. Patient and whānau backgrounds

Twelve patients and four whānau members took part in the interviews. All patients were Māori, and ranged in age from mid-30s to mid-70s. The patient and whānau case consisted of two men and 10 women. All had experienced cancer in the last five years, with the exception of one who was a cancer survivor for more than 20 years.

Participants had been diagnosed with a range of cancer types, including breast, cervical, prostate, uterine, lung and laryngeal cancers. There was variation in support available from whānau with some patients having strong support and others estranged from their whānau. All whānau members who took part in the interviews were women.

Patient 1

...if I have got enemies out there I wouldn't wish it on them.

Because you know it is bloody hard financially, emotionally, physically.

Patient 1 had recovered from breast cancer and then been diagnosed with uterine cancer. At the time of her interview she had completed treatment for the second cancer. Stresses from the treatment had led to her marriage breaking down and she was raising her children alone. Patient 1 had a regular GP but based on negative experiences did not have a good relationship with the GP and mistrusted her. Patient 1 had not received information about supportive care throughout her cancer treatment. She had travelled long distances and lived for long periods away from her hometown to receive treatment.

Patient 2

Everybody was so good, you know? There was nobody grumpy or you know can't be bothered and they didn't mind how many people went in.

Patient 2 was being treated for laryngeal and lung cancers and was under the care of her local hospice. She had very strong whānau support, and one of her sons was her key spokesperson throughout her cancer journey. Patient 2 had a good relationship with a regular GP, and had instructions from the GP to call directly if there were no appointments available. Patient 2 had also been offered transport and other support from her local Cancer Society.

Whānau 3

...he said you don't know what it is like to go through and I said well you know I can only imagine, you know, put myself in your shoes but hey listen, I am the one looking after you so you have got to look after me too. And at the end of the day I am the only one here every day with you.

Whānau 3 is the wife of **Patient 3**. Patient 3 had laryngeal cancer and had difficulty communicating so the interview was conducted with Whānau 3. At the time of the interview, Patient 3 had completed his cancer treatment but was having on-going surgery on his voice box and speech therapy. Patient 3 had strong whānau support. Although his family had had a regular GP for a number of decades, Patient 3 had enjoyed very good health and only visited the family GP twice in twenty years, first for a slipped disc and the second time when he had thyroid problems which then led to his cancer diagnosis. Patient 3's kidneys

were affected by his chemotherapy and he now requires regular dialysis. The Cancer Society had provided transport during Patient 3's chemotherapy, and he was also able to access DHB taxi funding for his dialysis appointments.

Patient 4

I didn't want to. But you know they were just saying Aunty you have got to go. Blah blah blah so, so I did and I went to Wellington for the radiation.

Patient 4 had just completed treatment for breast cancer. She lives with her daughter, **Whānau 4**. Patient 4 had a regular GP and a good relationship with a Māori health provider. A community worker from the Māori health provider organisation had accompanied and supported Patient 4 to every appointment for her treatment which was a great comfort to Whānau 4 as she was not always able to do this. Patient 4 had also stayed at Margaret Stewart House when she was undergoing radiotherapy. Margaret Stewart House and other services available to patients are described in the background section of this thesis.

Patient 5

And like they give you a lot of stuff eh. They give you a big booklet of stuff but you just don't process anything at all. So you just sit there and think wow, how did that happen, you know.

Patient 5 was undergoing treatment for breast cancer at the time of her interview. Patient 5 did not have a regular GP and her cancer was diagnosed due to her insistence on a mammogram, after being told by a GP at her local clinic that she did not need one. Patient 5 had received support from a community worker at a Māori health provider organisation throughout her diagnosis and treatment. She had also received support from her local Lions Club with transport to the hospital.

Patient 6

And I went like that, because I still had stitches (laughing) and you should have seen their faces. I said but, and I made all my mokos (grandchildren) have look at it, and they go eeeeww and I says no this is what you have to go through. So you know just be careful what you do and treat women properly. They all thought I was cracked.

Patient 6 had completed her treatment for breast cancer. Patient 6 had a regular GP. Her husband had died from cancer the year before and she lived with her adult children who provided her main support. Patient 6 had been contacted by volunteers from her local Cancer Society and offered transport and other support. She had returned to her hospital bed after surgery to find a gift from the Cancer Society and had participated in the *Look Good Feel Better* workshop.

Patient 7

Well they told me but it doesn't sink in this head you know? I forget a lot of things. When my son used to stay with me he used to be my thinker. He used to come with me all the time now he is gone now so... I am on my own again.

Patient 7 had completed his treatment for prostate cancer and was under the care of his local hospice. He was estranged from his family and appeared to have most of his support from the Māori Liaison at the hospice. Patient 7 was socially-isolated and did not have a regular GP. He was unclear on the process of his cancer diagnosis and treatment. Patient 7 did not have support from the Cancer Society throughout his treatment; however, he eventually had access to patient transfers arranged by the DHB to assist with transport for his treatment.

Prior to this, Patient 7 had to take three buses to get to the hospital at a cost of around \$20 each way.

Patient 8

I wish they had lowered the age before I ...you know. You had to be 50 first before they did breast cancer free - otherwise you pay. So one thing I would have liked if they had lowered the age earlier, it might have been picked up earlier.

Patient 8 had completed her breast cancer treatment. She had the support of **Whānau 8** throughout her treatment and her interview. Patient 8 used to have a regular GP but now sees whichever doctor is available at her GP clinic. During her treatment, Patient 8 received support with transport from her local Lions Club. She also attended the *Look Good Feel Better* programme.

Patient 9

But in those days there was just no communication. There was just nothing eh. But I had a good specialist... so he used to fill me in on what was happening but in terms of where I could get that support from, no I didn't know.

Patient 9 was diagnosed with breast cancer 20 years ago. It had recurred after two years but at the time of her interview, Patient 9 had been clear of cancer for a long time. Patient 9 had to travel from the Wairarapa to Wellington for her treatment in the early 1990s. She was reluctant to stay away from home but had no choice. Throughout her treatment Patient 9 had support from her Māori health provider organisation and she frequently talked about the companionship from them and assistance with understanding information. Patient 9 had adult children who helped look after her and also received petrol vouchers from the

Cancer Society. In addition, she received support with wigs and took part in the *Look Good Feel Better* programme.

Patient 10

So every family member was dealing with it differently. I didn't want to... she gave me all these books and I didn't read them because I just didn't want to scare myself into, you know. All I wanted from the doctors and nurses was what I had, this is what has to happen and this is how.

Patient 10 had completed treatment for cervical cancer. She did not have a regular GP and was diagnosed with cancer when she was in the United Kingdom. Patient 10 received her treatment in Aotearoa and had strong whānau support throughout her cancer journey. She visited her local Cancer Society but was not offered any support or information. Patient 10 travelled from a rural area to Wellington to receive her treatment and found the travel and parking very stressful. Towards the end of her treatment the hospital provided her with a free parking voucher.

Patient 11

A lot of awhi, a lot of support. I was doing it on my own with strangers. No-one to put their arm around and say kia kaha (stay strong), we are with you sis. You know just that awhi.

Patient 11 had completed treatment for laryngeal cancer. She had a regular GP. Patient 11 lived alone and had some whānau support but throughout her cancer treatment had most of her support and transport from the Cancer Society.

Patient 12

...my attitude was hey, too late to moan about it now. I have got it. You know and I will deal with it the best I can. But you know we walked out of there after I had had the mammogram, and the amount of women that walked out crying and I thought oh hell.

Patient 12 had completed treatment for breast cancer. She had a positive and long-standing relationship with a regular GP and had strong whānau support.

Whānau 12 and **Whānau 12A** were also present at the interview but contributed very little. Patient 12 lived in a rural area and had to travel to Wellington for her treatment. She stayed at Margaret Stewart House during her treatment and was very positive about the companionship and support between different patients and whānau who stayed there. Patient 12 had also attended the *Look Good Feel Better* programme and received assistance with prosthetics and bra fittings.

4.1 Three phases of care

Three phases experienced by patients and whānau were apparent through the interviews: the situation that led to a participant being diagnosed with cancer and offered treatment options; the participant's experience of treatment; and the experience of follow-up after treatment ended.

Cancer diagnosis

Participants described the events that led to their cancer diagnosis in two main ways. First, some patients went to their GP when they were symptomatic. Second, several women had their cancer detected as a result of participation in breast or cervical cancer screening programmes. Three participants had different

experiences. Patient 7 was unclear about when his cancer was diagnosed, and the process that led to his diagnosis. Patient 2's son had driven her straight to the hospital when she felt a lump on her neck and she had then been referred for a CT scan. Patient 3's cancer had been detected during a thyroidectomy.

Patients who detected the symptoms of their cancer themselves differed in their approach to seeing the GP. For those who had a good relationship with their family doctor, it was a matter of making an appointment and seeing the doctor promptly. For others, financial barriers to seeing the GP, or a poor relationship with their GP, delayed their diagnosis:

I had it apparently 18 months prior to diagnosis. Because I was stubborn, I didn't go to the doctor. I couldn't afford it and this went on for months. (Patient 1)

How I actually found out, I went to my doctor and said that I couldn't swallow. So he gives me a panadol. I was not happy and I went back about three or four times, in (name of place) and I said oh I think you need to refer me to a specialist. And he says why and I said because it is like I have got a razor blade cutting my throat every time I swallow. (Patient 8)

The women who had participated in breast or cervical screening programmes, whether through a scheduled programme appointment or as part of a consultation with their GP, also had varied experiences. For some, participation in a mobile breast screening programme led to their cancer being detected quickly. For others, a routine trip to the GP had resulted in a cervical smear, for example:

Oh I was going to the doctor for something and they banged on, they just said you haven't had a smear since you were registered here. And I was like ok. (Patient 10)

Aotearoa's national breast screening programme provides free mammograms every two years to women aged between 45 and 69. One patient had asked her GP about the free mammography service and been told that she didn't need it. Due to her own perseverance with obtaining a form from the receptionist at her GP clinic, she obtained a mammogram appointment, which led to her cancer diagnosis:

He goes did your mother have cancer? I said no. And then he goes well then you don't need it. So I wasn't really happy with that answer so I went out and I was moaning to the receptionists... So she threw me a form. She says fill that out and I will post it off. (Patient 5)

Another patient reflected on how the age of eligibility had prevented her receiving a free mammogram and her cancer may well have been detected earlier if she had had access to the free service:

I think I was, how old was I? I think I turned 50. And they um...I think at that time I don't know if it was before then like when they changed it to 45. I wish they had lowered the age before I ...you know. You had to be 50 first before they did breast cancer free otherwise you pay. So one thing I would have liked if they had lowered the age earlier, it might have been picked up earlier. (Patient 8)

The age of eligibility was changed from 50 to 45 in 2004 (Baker, Wall & Bloomfield, 2005).

Timing and delivery of cancer treatment

In general, participants reported being happy with the timing and delivery of their treatment, although many described having difficulty in communicating with the many hospital staff involved in their care, side-effects of treatment, and juggling travel, children, financial and other aspects of their lives. This will be described in more detail in a later section of this chapter. Some participants talked about treatment delays; for example, one had her surgery rescheduled seven times. Another participant was treated within days of his cancer being discovered:

Everything happened all within, oh I think it was a Thursday, Saturday he had the operation. On Saturday he was meant to have it, then they put it off because there was a you know, an emergency. (Whānau 3)

One participant was unclear on details about when he was diagnosed, and what his treatment entailed. Another participant described her surprise at the short time it took for her to have her radiation therapy treatments:

And then I just sat there for about three minutes and they said it is ok now, you can go now. It is all over. (Patient 4)

Follow-up

Of the three phases, follow-up appeared to be the most inconsistent for participants, with many gaps in support apparent. Some participants had contact from their GP during this time while two participants were under hospice care but for many, there was little engagement or follow-up at the end of their treatment

and whānau were often relied on to provide support at this time. One patient who had undergone surgery described receiving follow-up care at home from the district nurse, but relying on whānau to look after her other needs:

Oh the district nurse come to you. Because you come home with your bits and pieces. Drainage. And my kids had to take me to housie because you are not allowed to drive. (Patient 6)

When patients had follow-up appointments at the hospital, these were often not adequate to provide reassurance or answer all questions. One participant outlined, for example, how her follow-up appointments with the specialist were restricted by tight time constraints, leading her to feel pressured and rushed:

I don't feel the length of time I spend with him is enough to discuss...what I need... like the last time I met just a few weeks ago, I had a list...and I couldn't even get through that. I think I felt rushed so I didn't want to continue with the list of stuff that I had. (Patient 1)

Three interrelated themes that ran across these three phases of care emerged through the analysis of the interviews. These were: the experience of supportive care; the continuity of care; and the wider determinants of health, in particular the impacts of geographic distance and financial constraints.

4.2 Supportive care

I was quite lucky because my son is a chef and he would come. And he would say 'here is this kai (food)' and 'Dad this kai had fish in it, and this one, and this one'. Yeah and he would put it in the freezer and then we didn't have to cook. You know. Other than that I got a lot of support from the Māori providers and from Māori in general.
(Patient 9)

The experiences of supportive care varied for participants but they all shared similar needs throughout their cancer detection, diagnosis and treatment. Patients required emotional support, both at appointments and in day to day home life. Patients and whānau also required practical support with, for example, provision of meals, travelling to and from appointments, childcare, and housework. Support was also an important factor in the ability of patients to obtain and understand information. This included information about their cancer, and also information regarding availability of financial support such as benefit entitlements or petrol vouchers.

Participants obtained their supportive care from a number of sources. For most participants, at the forefront of support was the solid, long-term support provided by whānau, but there were also a number of organisations offering support. These included Māori health providers, GPs, hospitals/DHBs, PHOs, local divisions of the Cancer Society, Lions Clubs and hospices.

Some participants had large, supportive whānau and others had less whānau contact. Whānau were required to provide personal and emotional support through the cancer journey at all stages, including at home for some participants.

Whānau support came predominantly from one family member who was subject to great stress from being in that position. In a number of circumstances time off work was required, which negatively affected household income:

My husband and I argued. The stress, you know he had to take time off his job to do it. You know when I had breast cancer he actually gave up his job to take me to my treatments. (Patient 1)

So sometimes I would just storm out. Just like because it was hard for me to get there too. Because I was working. I did take a couple of weeks off in the first, when he first got this but I was like, you know, still need to go to work. (Whānau 3)

For whānau who were supporting a cancer patient, these stresses built up. However none of the whānau reported having time out or seeking support for themselves. Some participants described the 'burnout' of whānau in a support role:

...at the end of the day, even if I had asked for other support, he would have just wanted me there.... [other whānau] were good, they filled in here and there...because I was just hospitalized out. (Whānau 3)

Another significant support role undertaken by whānau was helping patients to understand the information they were given by health workers, related to diagnosis, treatment and other available support. This support role was crucial

as participants reported difficulty in processing information given to them at the time of their consultations:

...they use a lot of big words and so you are with them for the first five minutes and then you just drift off. You only hear the beginning, and the end. You don't hear the in-between...

(Patient 5)

They offered me a tablet. What was that for? Well I couldn't get at, grasp what he was on about, you know? (Patient 8)

In another example, a whānau member outlined the importance of having a support person at consultations to debrief later on what had happened:

And like a second pair of ears too, you know going to the appointments, and we would come out. What did he say?

(Whānau 8)

Not all participants had whānau or personal support (because of estrangement, social isolation or other stresses on whānau) which seemed to disadvantage them in the degree to which they were able to gain information or indeed understand information they were given. Māori organisations often stepped into this gap in support:

Sometimes it is not good to have your own whānau but if you have got someone like (name) there from the [Māori health provider], you are fine. So no it is good. There are things that you miss. I mean you don't know the language.

(Patient 9)

Every appointment, every single appointment that Mum has, they [Māori health provider] are there... Because I can't always be there. (Whānau 4)

Māori health providers also acted as conduits for information on other available support, such as the Cancer Society or WINZ. They provided companionship and offered help through the day-to-day necessities of the journey through care. These included accompanying participants to appointments and helping them to find out where to park cars at the hospital. The way that personal support was given by Māori health providers was discussed in a similar way by participants to the support they received from their whānau support. There was trust and warmth expressed as well as knowledge that Māori health providers were available at any time to provide support:

It is the companionship eh. I mean yeah, you know... come on, let's go in there and I will shout you a cup of tea or I go, I say to [Māori Provider] let's go to Petone and look at some fish heads, you know because there is a fish factory there. (Patient 9)

I mean I was quite comfortable with everybody from [Māori Provider]. I was like oh my gosh is there anybody there that I don't know? ... So um, no all those kind of things that you expect from a Māori service you know and it's whanaungatanga and all that kind of stuff...and you know they empathise and sympathise, you know? (Patient 5)

DHBs and hospitals provided a number of services to cancer patients including access to specialists and outpatient care. They also helped with transport needs such as parking, petrol vouchers, and ambulance or shuttle services. Two

participants reported provision of heating and other assistance within their homes by the DHB and another had their home modified by hospice with handles and appropriate modifications to the bathroom.

For the most part, patients and whānau described their interactions with cancer specialists very positively. These exchanges were in the context of someone finally providing answers or options at a time of great uncertainty for participants. Nonetheless, it was often expressed that appointment times were not long enough and there were few opportunities to ask questions that participants might have wanted to ask – this was often where personal support was described as invaluable.

The interviews showed that the availability and understanding of information appeared to be greatly influenced by the degree of support patients had at key moments throughout their cancer care. One patient outlined how her son intervened during a consultation with a specialist so that she could better understand the information that was being delivered:

.. the doctor was going on and on... He told the doctor hold on, hold on and he said what is wrong Mum? And I sat down in front of him and said oh he is going too fast, I can't understand him. So he pulled the doctor up and said can you sort of go slower with your explanations. Because mum is 70 now and she can't sort of, you know, and he said I am very sorry I should have realised. (Patient 2)

The sharing of information was a two-way street, with support people helping patients to digest information, but also patients communicating their treatment and needs with their support people. For example Patient 11 described the

benefits of being able to share an information DVD about her cancer with her family:

I actually had to go down and watch a video about the throat cancer...and I bought the DVD home and I showed it to my family, what I will be going through and a lot of it the effects it would take on my body.

(Patient 11)

Participants were positive about the provision of Margaret Stewart House, accommodation provided by the Cancer Society for out-of-town cancer patients who are undergoing treatment at the Wellington Blood and Cancer Centre. This service is described in the background section of this thesis. Patients who stayed at Margaret Stewart House spoke very favourably of this facility. They appreciated the practical aspect of having somewhere close to the hospital to stay, but also the opportunity to give and receive support from others staying at the house.

...but we were all there for the same thing. It might be different type of cancers but you know it was good ...Oh and I adopted the young fulla over there. He had leukaemia, young Māori boy. Looked just like one of my mokos... it was good because we would all sit down at the table and have a meal together yeah. (Patient 12)

Yeah so I stayed there yeah it was sort of bittersweet because it was sort of like everyone was suffering from cancer and it was horrible to see but at the same time everyone was there together. (Patient 10)

The Cancer Society offered a number of services to support those affected by cancer, ranging from telephone support, support groups, counselling, massage, transport, accommodation and other services. Participants were divided on their feelings about the services offered by the Cancer Society. Some participants did not always feel able to access Cancer Society services. In one example, a young patient had walked in off the street to her local Cancer Society division but had not been given any information:

I went in there and they didn't help me. It might have been a volunteer that was new but... I went there on my own. I just you know, have you got any groups to go talk to but it wasn't a good day so I walked out with nothing that day.

(Patient 10)

There were also feelings expressed of discomfort with making contact with the Cancer Society, especially regarding support groups where there was concern that participants would not relate to the other support group members:

Well I am not a very good talker. I am alright here amongst you fullas, but as soon as I get there [Cancer Society support group] I am...duh. (Patient 9)

Patients who did obtain Cancer Society support were grateful for the help they received. One participant described volunteer drivers from the Cancer Society going above and beyond their transportation requirements and visiting her after her treatment:

I take my hat off to the Cancer Society. I must tell you that...(the transport) and the support. They wanted to help me...They really did look after me. They were the only ones that would ring me. Some of the drivers would even come back and see me after I finished my treatment. (Patient 11)

The Cancer Society provides free transport to and from the hospital for patients requiring cancer treatment. Volunteer Cancer Society drivers transport patients in a shared van. A number of participants expressed apprehension about sharing transport to appointments with unfamiliar people. Some reported the inconvenience of taking this transport option as it meant being away from home or work for an entire day when they were only required to be at the hospital for a short appointment. One participant said she preferred to be accompanied by a community worker from her Māori health provider organisation to being transported with other patients in a Cancer Society van, due to missing the companionship of other Māori when she felt unwell.

Another participant described initial reluctance by her husband to accept Cancer Society transport as he was not ready to engage with them, due to being in denial about his cancer. However, he eventually used their services and this was much appreciated in a time of financial strain:

I went to the Cancer Society and (husband) used to just say no. He was kind of like in denial, I don't know... He didn't want to. Come on I said. You are very lucky, we are very lucky to have this. Talk to him like that, you know? Very lucky. I says it costs us nothing, because we aint got much you know? (Whānau 3)

Discussed frequently and in detail throughout the interviews was a programme run by the *Look Good Feel Better* charity, who are supported and endorsed by the Cancer Society. Participation in the programme was received favourably and with good humour from many of the female participants who enjoyed the pampering and opportunity to engage with other women affected by cancer, as well as the free gift pack.

Ah that was funny. That was funny because you have still got all your eyelashes and your eyebrows so you don't just you know. And I don't wear makeup anyway...So I was like oh my gosh they made me look like a drag queen! (laughing). (Patient 5)

When I lost all my hair they um give you makeup classes eh. Real hard case. And I would sit there you know, because you have got no hair on your eyebrows eh and I only used to get one eyebrow right, and next one used to be... (laughing). (Patient 9)

Travel support was offered by other organisations such as the Lions Club and also the hospice was mentioned in two interviews as providing practical assistance within participants' homes. One participant's main source of support was his regular visits from the hospice Māori Liaison.

4.3 Continuity of care

I haven't seen a doctor in over 20 years and all of a sudden I see 40. (Whānau 3)

Yeah I saw heaps. Can't remember. Ten gynaecologists in my time. (Patient 10)

Continuity of care refers to the existence or absence of a consistent person or team to establish and maintain a relationship with patients and whānau throughout treatment. As can already be seen through the discussion of 'support', 'relationships' were a central feature of the interviews. A common thread was the myriad of different individuals involved in care throughout the cancer journey.

Exchanges between participants and those providing their cancer care were mostly described positively, but the overall picture shown through the interviews was one of countless doctors, nurses, specialists, and administrative people from different organisations involved in the process of care. This plethora of relationships appeared to lead to gaps in information and support for participants. For example one participant described feeling overwhelmed by the number of staff approaching her for different aspects of her care in the hospital, and as shown in the quotation below, another did not understand why there were so many nurses looking after her:

I have had about six or seven nurses...you know they rotate. I don't know what they mean by that, if they haven't got enough people for all the people around. (Patient 7)

GP and patient/whānau relationship

There was considerable discussion of the relationship between patients and their GPs. There were two main ways that participants described their GP relationship. Some participants had long-standing relationships with a family GP; others never had or had lost a long-term relationship with their GP.

Seven of the 12 participants saw the same GP regularly and most of these participants described having a positive relationship with their GP. One participant however, had many negative experiences with her GP and another

had only ever seen his GP twice in 20 years, due to his good health. The remaining five participants did not have a regular GP available to them. One of these participants had a long-term GP who had recently moved to another practice. Others either saw whoever was available at their local clinic, presented at after-hours medical centres, or did not seek medical care at all. For the latter participants, this resulted in engagement with a clinician when they were at crisis point.

Those with a positive, long-term GP relationship placed emphasis on the significance of this history. One patient for example, described an extensive medical history and swift referral from her GP when she had cancer symptoms:

Same GP, yeah. She has got two files that thick. And she was the one that um, when I first was diagnosed she sent me to a specialist. So there was no shilly shallying.

(Patient 9)

Access to the GP varied for participants. Most telephoned in advance to make an appointment but one patient who had a long-standing relationship with her GP had been told to call directly with any problems if there were no convenient appointments available:

Yep, yes she (GP) is the one that's been putting me on to different people... she (GP) is another one that said if she rings up (clinic) and they say oh I can't see you, just tell them oh yes I can and just tell them to come and buzz me. (Patient 2)

A reported issue with GPs which impacted negatively on participants was the short 15 minute timeslot for appointments:

And he goes I don't have enough time to do this, you have only got a 15 minute slot. And I go no, I asked for a medical certificate and he goes well you will have to rebook. (Patient 5)

Highlighted throughout the interviews was the benefit of having a positive and long-standing relationship with a GP. When this relationship continued throughout the cancer care journey, participants experienced more positive experiences of support and follow-up.

4.4 Impact of wider social determinants of health

The financial burdens it puts on you. Because I had to travel from (town) to (town) every day, for five days, for five weeks for um radiotherapy. And the stress just in that alone. (Patient 1)

The wider determinants of health were touched upon in a number of ways through the interviews – particularly the impacts of geographic distance and income. Travel to appointments, even when distances were close – were not straightforward for participants. But for those who lived a greater distance from the cancer services they needed, there were significant difficulties in attending appointments. Those living in the Wairarapa (compared to those living in the Wellington/Porirua region), for example, needed to spend more time away from home and work. This in turn affected the ability of whānau to support them, and often led to dwindling incomes and less resources to deal with the other financial costs involved in supporting a whānau member with cancer.

Many participants found themselves having to rely on others, such as the Cancer Society or the Lions, for travel assistance. In sharing travel with other patients, some participants were required to be away all day:

The only thing is he likes to go there, do his thing and come straight home. But they pick him up about an hour and a half early, then they have got to go and pick up some others and by that time it is about three o'clock. (Whānau 3)

The interviews showed that a lack of information about transport options could lead to some patients being unable to attend their treatment appointments. One socially-isolated participant (Patient 7) who had no whānau or other support, was not offered any assistance at the beginning of his treatment. This participant subsequently had no choice but to travel by public transport to his daily hospital appointments. After finding the public transport system difficult to navigate and expensive, Patient 7 was reluctant to continue with his treatment:

...cost me about twenty bucks and I said nah, I am not coming in there. So that is that new thing, those ambulance things. They come and pick you up... It is a new thing... if it wasn't for them I wouldn't have gone. I would just say oh bugger you. (Patient 7)

Those participants who had access to a reliable car and someone available to drive them still encountered problems with travel time and parking when attending their hospital appointments:

... it was a big stress because you had to find a car park...

and it is like 20 minutes driving around going in and out

because otherwise you start paying after half an hour.

And it came to a point where I was so stressed that

(partner) would have to drop me off at the front door

and I would have to sit in there or I would lose my spot in

the hospital. And I was worried that I would be going in

without him. (Patient 10)

Participants reported needing financial assistance but there appeared to be little

financial support available. Assistance for patients and whānau was offered

inconsistently and generally centred on specific supports such as transport.

Information about benefit entitlements and mobility cards, for example was

seldom offered to participants. In some instances, patients gained information

about their entitlements but encountered unhelpful staff when applying for their

subsidies. One patient described difficulties in engaging with providers of a travel

allowance she was entitled to for her cancer treatment:

And the shit that I got from the cashiers for the travel

allowance. They acted like it was their own money that

they were forking out. (Patient 1)

Patient 1 recounted feeling that she had to behave differently and change her

attitude in order to obtain the benefits she was entitled to. She described feeling

that she had to become an “ugly person”, demanding her entitlements and

treating hospital staff aggressively, the way that she felt they were treating her.

The cancer care journey also impacted on income through time taken off work by

participants or whānau. In general, participants described their employers

supporting them by offering time off for appointments, treatment and recovery and also leaving positions open over extended leave:

Work, they let me take my time off. They paid me right up. They were really, really good. (Patient 5)

Not being able to work had a negative effect on the wellbeing of some of the patients, who were used to providing for their families and unaccustomed to resting:

You know he'd just bloody moan and carry on "all I want to do is get back to work" I said well you have got to get better first ...and that is when everything started going downhill mentally with him. It was hard for him because he has never really had a day off work. He is that type of guy. (Whānau 3)

4.5 Summary

There were three distinct phases apparent throughout the interviews: the events that led to a participant being diagnosed with cancer and offered treatment options; the participant's experience of treatment; and the experience of follow-up after treatment ended. Some participants went straight to their family doctor when they had cancer symptoms, although some experienced delays due to a poor relationship with the GP or an inability to pay for the service. Other participants, all women, had their cancer detected through participation in cancer screening programmes.

There were some delays in treatment, and difficulties for participants in juggling many other aspects of their lives as well as engaging with numerous staff. For

the most part, however, participants appeared happy with the timing and delivery of their treatment. There were many gaps in support for participants after treatment. For those with a good GP relationship, follow-up appeared to be more consistent. Participants who were under the care of their local hospice were also well looked after. For other participants, there was little follow-up at the end of their cancer treatment journey and follow-up appointments with the specialist could be too short and time-pressured to adequately discuss concerns.

Three interrelated themes that ran across these three phases of care emerged through the analysis of the interviews. These were the experience of support, the continuity of care, and the wider determinants of health, in particular, the impacts of geographic distance and income.

Participants' support needs included practical and emotional support at appointments and at home. Importantly, participants also needed support in obtaining and understanding information about their treatment and services available to them. Whānau took the lead in support for most participants, but not all patients had large and supportive whānau who were able to provide support. In these instances, support was also provided by a number of others such as Māori health providers, GPs, the Cancer Society, and hospices. Some participants described their Māori health provider in the same ways that they talked about their whānau, in that there was a comfort and familiarity expressed, alongside around-the-clock support.

Having good support was crucial in gaining and deciphering information about cancer treatment. Many participants had accessed support from the Cancer Society, primarily in the form of transport. Some of the women patients had benefitted from the *Look Good Feel Better* workshop, which provided a good laugh and pick-me-up, at a time when it was needed.

There were numerous appointments to attend and understand throughout the cancer journey. Patients and whānau needed to engage with many different nurses, doctors and other hospital support staff. Provision of information about cancer and available support was variable and did not appear to be shared in a planned fashion. Those participants who had an amiable relationship with their GP appeared better equipped to work through and understand their cancer treatment, as well as accessing follow-up.

Travel and a lack of financial and other resources presented challenges for participants in accessing their cancer care. The need for financial assistance for participants was pressing but sources of financial support were limited and offered in an ad-hoc way. A lack of information about available support contributed to a daunting cancer treatment experience for some participants.

Chapter 5

Case 2: **Community**

5. Roles and backgrounds

The boundaries of the community group (Case 2) have been outlined in the methods section of Chapter 3. In brief, Case 2 is comprised of people who work with patients and whānau at the *care giving* level, which is at the interface of community care. Case 2 was made up of people who work with patients and whānau in primary health care and hospice settings, namely: two community health workers; two hospice Māori Liaisons; two practice nurses; two general practitioners; and a cancer care co-ordinator. All participants except the two GPs identified as Māori.

Community 1 is a cancer care co-ordinator based in a Māori health provider organisation in the greater Wellington area. Her role involves supporting patients and whānau to access cancer services, improving communication, knowledge and information about cancer, supporting Māori community development initiatives for cancer, improving the delivery of health promotion and education, and working collaboratively with other providers to ensure continuity of care for whānau with cancer. Community 1 was also instrumental in making KOETI, a cancer information DVD produced by Māori for Māori and funded by the Cancer Society.

Community 2 is a practice nurse at a general practice based within a Māori health provider organisation in the greater Wellington area. Previously, she worked with the Cancer Society on a research project asking whānau about their cancer treatment experiences.

Community 3 is a Māori Liaison at a hospice in the Wellington region. She described her role as Māori whānau support for patients and whānau under hospice care. She has worked in her community for many years and has

extensive networks with community organisations including Māori health providers.

Community 4 is a Māori Liaison at another hospice in the Wellington region. She has spent more than 20 years working as a nurse in Australia. She described her role as threefold: education, including cultural safety for the organisation; relationship-building with iwi and Māori health providers; and whānau care.

Community 5 is a general practitioner at a practice in the Wellington region. The practice is in an isolated part of Wellington and has a high percentage of Māori patients. Community 5 has recently returned to Aotearoa after working in England in general practice and palliative care.

Community 6 is a community health worker based in a Māori health provider organisation. Her work is primarily concerned with supporting patients and whānau with asthma and respiratory issues with, for example, transport and advocating for social needs such as housing and benefits. However, some patients also have cancer, and she has supported these whānau through their cancer treatment and palliative care journeys.

Community 7 is a practice nurse at a general practice in the Wellington region. The practice was set up by a trade union in the 1980s to serve low-income patients and whānau. Community 7 has had many years working as a nurse in a hospital setting, including short-stay and medical wards.

Community 8 is currently a medical officer at a hospice in the Wellington region; however, she has worked as a GP in the same community for over a decade.

Community 9 is a community health worker based at a practice in the Wellington region. The practice is located next to social housing and serves whānau with

limited resources. Community 9 describes her role as being to assist whānau to access health and social services.

5.1 The role of whānau in cancer care

...it is really important that their whānau are there and their extended family. That is the most important. Because that helps them get better. (Community 7)

Participants' discussion of the cancer journey almost always centred on the journey of the whānau, rather than individual patients. Whānau were described as diverse, in that they could be very large groups from multiple generations, or a partner, son, daughter or sibling as sole carer. Whānau could also encompass friends, neighbours and workmates.

Whānau were an invaluable piece of the cancer control puzzle, providing support, navigation, care, and even championing cancer prevention by sharing their stories within their wider communities. Participants described some examples of patients they had engaged with who were estranged from whānau, but for the most part, patients described by the study participants had whānau involved in their lives and their cancer care.

Where are your whānau?

For some of the patients cared for by participants, whānau connections had been severed and others simply chose not to involve whānau in their cancer journey. One participant described a variety of reasons why a patient may not want their whānau involved in their care:

I think for some people, having lots and lots of people in the house connected to them is difficult. I guess there are lots of levels of understanding and need out there. With the amount of people who are disconnected or are engaged with their iwi and their culture in different ways.

(Community 4)

Māori participants were proactive in helping to connect patients with their whānau when able. These participants recognised the importance of whānau, and they were at pains to try and re-establish whānau links for their patients, or communicate the need for more whānau input. In one instance, a hospice Liaison described challenges in helping kaumātua to accept help from their families. Some patients did not want to become a burden but once the lines of communication were open, whānau often mobilised to provide support. A Māori Liaison summed up how seemingly disconnected whānau came together when the need was great:

But when it comes down to the nitty gritty they are all around. They are all around. (Community 3)

Participants described some Māori patients who, for different reasons, did not have whānau with them along their cancer journey. In these cases, Māori health providers had stepped into the whānau support role. One community worker described taking on the role of whānau for a patient who had died:

... just after he died we sat with him and we stayed up there until a family member arrived which was about six hours later. (Community 6)

‘The whānau machine’

For most Māori patients who were cared for by our participants, whānau were integral to wellbeing and were described as a ‘machine’ that would kick into action, providing companionship and support, at times of crisis such as cancer treatment. When reflecting on her work as a GP, one participant described how after a cancer diagnosis, whānau often took charge and became very organised in caring for their own:

They have phone numbers and they have their cards and they come with their folders and things. And that is our patients. You know we are not used to that. To people being organised. But I think that is what happens. Yeah.

(Community 8)

Participants described a sense that when whānau were strong, they preferred to ‘get on with it’ and provide good care. It was thought that the practical, emotional and spiritual support provided within whānau was not always present for families from other cultures such as Pākehā. One participant outlined ways that whānau are expected to provide support:

Māori are really good on supporting people who are unwell and when there is a crisis. So you know we do tangis and we just have got this thing and we are into action and you know you need kai and you need this and this and this. In terms of that I actually think Māori do really well.

(Community 2)

Another participant described whānau resilience, with multiple members providing palliative care that was different to the example of an isolated couple:

Because I think once a Māori person or Māori whānau have an understanding that this is end-of-life, they are this unwell, I think perhaps Māori whānau adjust more resiliently than others. This is how it is. This is our role. This is what we need to do and these are the people we have got to do it with. (Community 4)

Some whānau could access resources that would not usually be known to families from other ethnicities. A practice nurse gave the example of whānau contacting other relations around the country for accommodation and support, as well as accessing marae resources:

And Māori are pretty resourceful. They have whānau all over the place really...You know, I mean it is a big ask but you know, or marae around the area, they can help out with things like accommodation and things like that. So it is just I suppose knowing where to go. (Community 7)

Participants talked about how, for many Māori, once whānau heard about one of their members having a cancer diagnosis, treatment or palliative care, it was normal to expect that whānau would support each other. This certainty that whānau would come to support patients was outlined by a practice nurse, who described whānau presence as an “ancient practice that kicks in for dying”. The example she gave was for palliative care at home:

I just see a massive machine that moves into action
whether you like it or not, you are going to have people
camping out in your back garden, in your shed there is
going to be a big cook house set up. That is how it is going
to roll... and there is this whole, I don't know ancient
practice that kicks in for dying. (Community 2)

Another participant further described the inevitability of whānau pouring into
the hospital setting to support patients, and raised another aspect of this,
namely that hospital staff were not always equipped to comfortably host
them, both in terms of accepting and welcoming their presence, and also
having practical skills to accommodate whānau groups.

When hospital staff did not have extended whānau themselves, it could be
challenging for them to understand why so many people were coming in to
support patients. One practice nurse reflected on her time working in the hospital
and described the potential for whānau groups to be very large, which could be
contrasted with the small nuclear families of some hospital staff:

Yeah. But for us whānau is not just Mum, Dad and the
kids. You are talking grandparents, you are talking aunties,
uncles, cousins, nieces, nephews, it is the wider whānau
and that is what...they still don't get that...Yeah, it is
because in their world it is always just your immediate
family. And immediate family don't even think of
grandparents. They don't think of brothers and sisters. It
is mum, dad and the children. That is it. (Community 7)

Wider whānau contributions to cancer prevention

As well as whānau supporting patients and each other, interviewees described individual patients and whānau members who were pivotal in helping others to access cancer care services. A GP outlined, for example, how some whānau have encouraged others in their communities to engage with screening services, by demystifying screening procedures:

And so if people can, if family members can say look it is nothing, no it is not fun but it is no big deal to have a smear test, that is a really powerful motivator for people to do it. If they know someone else that has done it and they say it is nothing to worry about, they are much more likely to participate.

(Community 5)

As well as health promotion and screening initiatives, whānau were also central to encouraging others to access hospice services, which will be reported in the hospice section of this chapter.

5.2 Whānau support needs

Whānau were described in the context of supporting patients, but also as people who had support needs of their own along the cancer journey. Whānau needed provision of good information, alongside practical and emotional support. Knowing that whānau were being looked after was important to patients, as described by this participant:

And because do you know, people on the cancer journey tend to worry about other members of their family too.... Yeah so it is not about just the one person, it is about everyone that is there.

(Community 6)

Travel to cancer treatment centres

When community participants reflected on the needs of patients and whānau undergoing cancer treatment, the struggle to travel to treatment centres featured strongly in their discussions. Travel could be problematic for both urban and rural whānau. For those living in isolated geographic areas, travel and accommodation were needed. Meeting the criteria for hospital accommodation could be problematic. A cancer care co-ordinator, for example, described a 100-kilometre cut-off for staying at hospital residences, which excluded some whānau.

Transport issues were not unique to rural areas. Participants from the city also described transport as a barrier for the cancer patients and whānau in their care. People with cars had to understand where to go and where to park, as well as having enough money to pay for petrol and parking. Those without cars had to rely on inconsistent shuttle services or public transport.

A community health worker described a cancer patient in his eighties who was unable to arrange hospital transport and was instead taking public transport to the hospital. There was, however, no bus stop near his home. This participant had noted that hospital shuttles were available for travel to dialysis and had advocated on behalf of the patient to try and arrange a hospital shuttle for cancer treatment.

Financial issues for whānau throughout cancer treatment

In addition to transport issues, participants described financial stresses for patients and whānau as they entered the world of cancer treatment. Whānau could have the main breadwinner undergoing treatment, or a number of whānau members might have to take time off work to provide childcare, transport or support. A community worker described worries for patients when their income

dried up. Additionally, a hospice Māori Liaison described the financial burden for whānau when a number of whānau members took on the care responsibility but were not receiving any care benefit to supplement their income:

they have to take time off work to, maybe be on a roster system to come to the hospice sometimes or be at home, taking care. A lot of them are not interested in applying for any benefit so that puts a lot of pressure. (Community 3)

This section has presented participants' views about whānau support needs throughout the cancer journey. The work of primary health care providers in providing advocacy to help address these needs is outlined in the following section.

5.3 Advocacy

Or we might be filling out caregiver forms for the family to look after them. So there are other things that we might still be doing, without necessarily being, you know so much medically for them. (Community 5)

Participants described providing advocacy for cancer patients and whānau in engaging with other organisations. These advocacy services were undertaken by Māori health providers, community workers at GP clinics and hospice liaison workers. The agency that came up most often as an example of an organisation that required advocacy for patients to engage with was WINZ. This agency provides benefits and financial assistance to people in need and for many of the cancer patients that our participants worked with, having cancer treatment put them in a position where they required government financial assistance for the first time.

Engaging with WINZ appeared to be daunting for most of the cancer patients that the participants worked with. There were many examples given by participants of people from their communities struggling to access the benefits they were entitled to, with an added barrier being not having a regular caseworker. In one example a community health worker expressed frustration when recalling her experience of supporting a cancer patient at WINZ who was trying to change from a sickness benefit to an invalids benefit:

We had to go there, we had letters from the doctors that we sent to WINZ. But they would not, it was as if they didn't believe that it was letter from the doctors because we took them in and they said well you look fine. I know! (Community 6)

A hospice Māori Liaison described a similar encounter with WINZ as she worked with a hospice patient to gain a carers benefit for a whānau member:

I was really angry because they were treated as if they were wanting to get something extra from the government... I have had to go with them and it just makes them feel like they are criminals because they are applying for a benefit and then they have the third degree about things. And yet all they are going in there to... so some member of their family can receive support. (Community 3)

Participants also described meetings with Housing New Zealand, a government agency that provides social housing. A community worker from a Māori health provider organisation recalled an example of a very ill cancer patient with poor mobility being refused an appropriate house:

She was having chemotherapy and she couldn't get up and down the stairs anymore, for a transfer to a single storey house and they wouldn't transfer her... Yes, it was absolutely appalling and she had to stay in that house until she passed away. (Community 6)

As patient advocates, primary health care providers also distributed information about cancer and its treatment, as well as referring patients and whānau to the appropriate support services. These will be explored in the following sections.

5.4 Information

Participants agreed that patients and whānau should have access to good information about all aspects of cancer including prevention, screening, diagnosis, treatment, survival and palliative care, as well as practical information such as cost, location and time. The complexity of cancer treatment was likened by one participant to navigating the legal system, and this participant thought it was unreasonable to expect people to understand all aspects of their journey.

Another participant had been part of a project that aimed to help Māori understand what to expect along their cancer journey. Instead of written material, a DVD called KOETI - the same name as the Māori support programme, was funded by the Cancer Society and produced by Māori for Māori, providing knowledge about the cancer journey.

...it is not that the information isn't there with the Cancer Society stuff but this is, you know we have put waiata (song) and karakia and we did do a DVD, we interviewed survivors and asked them to share their story. And we did it at the marae and where ever they felt comfortable.
(Community 1)

The KOETI DVD had served as a valuable resource for a Māori Liaison who had used this information tool in supporting a socially-isolated Māori man in hospice care. By watching KOETI together, they were able to learn more about the cancer journeys of whānau and feel better prepared and less alone.

Participants discussed the need for the right information at the right time, and cautioned against overloading patients and whānau with too much information. Two practice nurses described the need to keep clinical information concise:

Yep, what is on top. This is who you contact if you want to ask some more questions. Just keep it simple really and patient led, patient driven. Not dumping with a whole lot. (Community 2)

I think as a clinician you need to give them concise information but in a shortened version. Not too flowery and not too long. Short, to the point. This is it - if you want to know more, this is how you can access more information. (Community 7)

As well as a need for information about cancer and treatment, participants highlighted how practical information is often required such as whether services were free, and their opening hours. The context around how and when patients received information was also raised. It was explained, for example, that getting the right information to patients at the time of discharge from the hospital relied on the communication skills of individual clinicians who worked within a large hospital system. This meant that individual clinicians needed to access the right information from within their organisation and communicate this to the patient

within a limited timeframe. One participant described how this could lead to patients 'slipping through':

And then they will go home and I will think oh shit I should have given them this, or you know, this is a really good phone number that they could have rung. And I guess that is how people slip through but when they reappear again it is like ok... So I suppose as a clinician you need to know how to access all the information and the right people to come and talk to your patient... (Community 7)

5.5 Support services

Yeah you can't replace, the best doctor in the world, the best care, the best treatment, but I think nothing can make up for having those other supports as well.
(Community 5)

Participants were divided on whether patients and whānau are always able to access the support services that they need. Participants fell into two groups regarding the services offered by the Cancer Society, for example. The cancer care co-ordinator had a close relationship with the Cancer Society at both regional and national levels and was able to refer patients and whānau to many different services. Similarly, participants who had been involved with KOETI were well-informed about Cancer Society services and how to access them. However other participants had a lack of understanding about what the Cancer Society offers and the ways in which patients could access their services.

Support from the Cancer Society

The Cancer Society offers a range of support services to patients with cancer.

Some participants had a good relationship with their local branch and were able to confidently refer to services, but others were unclear about the services available. It was noted that it is difficult to know how many people had been referred to the Cancer Society, as this information was not generally recorded within general practice. Further, participants recognised that patients and whānau were not all the same, with some choosing to access a number of support services and others preferring not to. This was highlighted by a Māori Liaison:

So there are some people that seem to access lots of services, you will see them at a cancer support group, at a bereavement group... you know at their appointments and they will be anticipating the day unit. There is other people who are more insular. (Community 4)

A GP explained how patients are seldom diagnosed with cancer by their primary care provider and usually referred to the hospital for a diagnosis. Because of this, GPs do not often have information about support services available, including those offered by the Cancer Society.

This is the thing, because we basically are involved in the initial identification and then refer, and usually they don't even have a definitive diagnosis. That is why we are referring them. But we are never, well not never, but rarely are we the ones telling them that they have cancer and providing that kind of information. (Community 5)

An example of the variation in participants' understandings of support services available to their patients related to the Cancer Society's helpline. Some participants were aware of this service and encouraged patients and whānau to call the number if they had any queries:

From my perspective there is so many people out there that can help, and you have got that 0800 number for cancer! You know I always say to people ring that 0800 number. (Community 2)

Other participants had not heard of the service.

Cancer support group by Māori for Māori: KOETI

The KOETI programme was outlined in Chapter 3. Participants who had involvement with KOETI were very positive about the benefits of the programme which included immediate support, knowledge and confidence, as well as lasting connections and benefits. A practice nurse had been involved with KOETI and described it as a great space for support and making connections with others. She also alluded to the companionship that grew from patients staying together at Margaret Stewart House, a house for cancer patients from out of town having treatment in Wellington:

Kia Ora e Te Iwi is a great space and they like to hear, even the quiet ones, to hear how the other ones got on. And they just feel so validated about how they got on what they had been through... and they loved talking about the people they met in Margaret Stewart House.

Yes.

And they were oh I wonder what happened to that boy and the beauty of that is that they have got all the different ages staying in the same house so they can all support each other and just this whole little unique sub culture and they all get it.

(Community 2)

This 'sub culture' was also described by the cancer care co-ordinator who demonstrated how support between patients that evolved by attending the KOETI programme could last into the future. These supportive relationships could have spin-off benefits such as patients helping each other to access other resources, for example mobility scooters.

5.6 Funding and organisational kaupapa

You can't go in with blinkers on and be referred for something and actually you can clearly see something that is identified as needing. You can't just turn a blind eye. It is not what we do as Māori. (Community 9)

When describing the activities of Māori health providers in cancer control, participants agreed that funding was tight, accountability stringent, and kaupapa broader than in mainstream organisations. Māori health providers often went above and beyond what they were funded to do in order to provide wrap-around services for whānau. Māori individuals within mainstream organisations also described reaching out to other Māori and offering additional support. Māori participants felt that there was no choice; as Māori practitioners, they would make sure that whānau were looked after rather than choosing not to notice when there were broader needs, as described in the quotation at the beginning of this section.

An example was provided by a cancer care co-ordinator who provided assistance to a disoriented, elderly woman transported to the hospital for cancer treatment. Although the woman lived beyond the boundaries that would enable the co-ordinator's Māori health organisation to be funded, the co-ordinator did not hesitate to support the patient:

They didn't tell her they were coming a day early so she has had to leave with literally her nightie on because there is nine other whānau waiting in the van to go to (name of town). And so she has got the clothes on her back and her toothbrush. Because they do their own kai so she has got no food and no support. So I just say give me twenty minutes. Give me twenty minutes and I will be up there to help our kuia. (Community 1)

This participant was clear that the woman was 'somebody's nanny' and stranded in an unfamiliar place, which took precedence over any funding obligations. However, she was mindful that these types of activities were plugging a gap and were not sustainable. They required change at a systemic level:

Always because we work for Māori health providers or iwi organisations we always go above and beyond the call of our service. But like I said to our workmates, it is about getting smart otherwise we are just going to burn ourselves out. (Community 1)

It was pointed out by a number of participants that there was a delicate line between wrapping around whānau to help, and disempowering whānau by well-intended actions in taking over and doing too much:

Because Māori will assume that you are a Māori health provider that you have all the same skills as that person down the road. And you don't, because you are a community health worker. And they think oh yeah this is great, I have got her running around after me. Actually, that person can be doing you a huge disservice. (Community 2)

And he said good hearts and meaning well will only take us so far. If you don't have the skills or the capacity or the knowledge or the ability to move this whānau forward, get out... Because I am sitting there and (silence) you know you actually become part of the problem. You know we want to empower our whānau. We want them to move forward. We don't want them to be stuck there, stuck there, stuck there. (Community 1)

Participants agreed that Māori health providers and funding for Māori initiatives were not adequate to cover the services that were provided. One participant described the need to develop and fund qualified Māori health workers to deliver high quality programmes:

And the DHB expect all these outcomes and things but they are not prepared to fund highly qualified people within that. And there is not the resource within the Māori workforce often to hire well qualified ... We need to have well-qualified managers and well qualified social workers and experienced nurses in long-term conditions to be in these Whānau Ora programmes.

(Community 2)

Whether they obtain their primary health care from a Māori health provider or mainstream GP clinic, the first step on the cancer journey almost always takes place in primary health care for Māori cancer patients. The importance of having an established relationship with a primary health care provider to facilitate access to cancer detection, care and support is outlined in the following section.

5.7 Relationships between whānau and primary health care providers

... we wrap around as much as we can sort of thing and hopefully we can if people get to know us over a period of time then they feel comfortable coming to us. (Community 8)

A central theme throughout the interviews was the importance of patients and whānau having a connection and on-going relationship with their primary care provider which helped with access into and through cancer prevention, screening and support. Factors influencing these relationships included the local knowledge held by the primary health care provider organisation, such as knowing about community events and family circumstances. Additionally, financial cost, location and a welcoming environment by the provider were seen by participants as crucial.

GP rapport and availability

All participants felt it was important for patients and whānau to have a good relationship with the people who provide their health care, in terms of understanding and accessing care. For patients who had a regular GP, relationships could be built over time as the doctors and whānau got to know each other. One GP described how good rapport and a long-standing

relationship with patients helped ensure continuity of care, such as staying in touch with patients when they were referred to the hospital:

And then I might get a letter and give them a call and just ask how they are going and that sort of support. So just letting them know that we are still there... (Community 8)

In order to establish a relationship, it was helpful for whānau to see the same doctor, but this was not always possible due to limited clinic times or staff turnover. One GP highlighted how “chopping and changing” doctors at a GP clinic could cause frustration for patients who wanted a regular GP. Another participant described how in some areas it was not possible to have a regular GP, due to the local clinic times and financial cost.

It was thought that an established relationship between health providers and patients was of paramount importance for Māori to be able to let providers know if their needs had not been met. An example was provided of a complaint from a grieving whānau member which would not have been identified by the standard complaints policy. In this example, the relationship between whānau and a trusted person from the hospice was critical in order to address the complaint:

It doesn't matter that we have got a complaints policy. It doesn't matter. Because that person there, that Māori person there is not going to use it. Because unless they have got that relationship with somebody, that is just not going to happen for them. (Community 4)

GPs agreed that patients and whānau often felt more comfortable discussing issues around accessing health services such as transport with someone they have a long-standing relationship with, such as a community worker, for example:

Because there are so many different obstacles. It can be transport, it can be a lack of understanding, it can be didn't like the doctor. It can be just a million things. And they are not always going to be able to tell us. Whereas they are more likely to tell the community worker...Someone they are involved with.

(Community 5)

Once trust was built with a primary health care provider, participants thought that other services could be better accessed by whānau. A Māori Liaison outlined, for example, how having a good relationship with a Māori health provider improved access to other health services:

So if they have a connection to a Māori health provider, you know chances are they have got a connection to cancer support groups and there may be a grief group and then other organisations with those Whānau Ora people and stuff like that that can help them get the best of the health system. (Community 4)

Local knowledge by primary health care providers

Relationships between patients, whānau and health providers were enhanced by the local knowledge of the provider. Local knowledge included informal networks or community knowledge of sports events, family news and school occasions. This was outlined by a GP who described the inside knowledge of the reception and nursing staff at their clinic:

A lot of the staff here, the non-clinical staff but the nurses as well, live in (name of place) and they have lived here for a long time and they have a lot of community knowledge so often the nurses or reception will know a lot about someone's circumstances and us doctors we don't have any idea. (Community 5)

A community worker showed the high levels of trust she shared with vulnerable people in her community when she described having keys to people's homes, which, in the following example, helped the ambulance crew to enter:

And that night that he went, he, the ambulance rang to say they couldn't get in, because we have a spare key, I often have keys to people's houses and they need to get in.

(Community 6)

The right environment to welcome whānau into primary health care services

Participants agreed that it was important for whānau to feel welcomed at their primary health care organisation. A welcoming reception included the physical location and environment, cost, and importantly, the person behind the counter. GPs in particular stressed the importance of good reception staff who had the skills to help people feel welcome, but also had vital local knowledge that helped with identifying who patients were connected to, and reasons why they might not be contactable.

One participant highlighted how simply decorating a space to be hospitable was not enough, and environments needed to have meaning for Māori to be properly

welcoming, which meant stories behind the taonga, hearing te reo Māori spoken and seeing other Māori, for example:

I think more for me, more authentically, Māori people want to see other Māori people. Māori people want to hear a bit of reo. It is a bit thin or empty to go and buy bits and bobs of artwork. (Community 4)

Participants felt that the location of services also made a difference to whether people felt welcome. A GP described their practice being located next to social housing for ease of access and a cancer care co-ordinator instigated moving a course for Māori with cancer to different marae around the region.

Cost was another factor raised by participants regarding whānau access and connection to their health care provider. A GP stressed the need for financial costs to be kept low in order to enable whānau to see the doctor:

When you have a cost involved in seeing the GP, which is the case, that in itself is an obstacle to people coming. They are not going to fork out for all these transport costs and other things associated with their care. They are not really going to come to a GP as well, on top of all of that. (Community 5)

The complexity of navigating through the many steps involved in cancer treatment is examined in the following section.

5.8 Continuity of care throughout the cancer journey

You know a recent one there was about sixteen agencies working with the whānau but no one knew what anyone was doing. (Community 9)

Participants were asked a broad question about how they think the cancer journey is working for Māori. One of the main themes that came from participants' discussion was the many different people and services that patients and whānau are required to engage with as they are screened, diagnosed and treated for cancer.

GPs were mindful of the treatment journey ahead for their patients, but also acknowledged that they referred patients to secondary care, and often did not see them again until after treatment. Participants reflected that their patients could experience a lack of confidence if they had a good relationship with their primary health care provider and suddenly found themselves in a hospital environment:

Especially if you have got a good relationship with your primary health care team and then all of a sudden you end up in hospital with a secondary team it is quite daunting really.
(Community 7)

Cancer navigator roles

When participants reflected on the complexity of the cancer journey, they often described the need for someone to guide whānau through from diagnosis, through treatment, and even on to survival or palliative care. A GP talked about the overwhelming nature of receiving information about a cancer diagnosis and treatment, and the need to have a support person to help digest information:

I think that having somebody there with you, who can support you and also potentially demystify some of those things, is really, really helpful. And it is great if they have someone like that in their family. But a lot of people don't. (Community 5)

As well as helping whānau navigate through the cancer care system, a GP talked about the potential for broader whānau education stemming from a navigator role. If a support worker or navigator were working with whānau, there were opportunities for example, to provide cancer prevention information and initiatives.

Participants' kōrero about continuity of care highlighted the large number of people and organisations involved in cancer care. The significance of these cancer care providers communicating with each other is investigated in the next section.

5.9 Communication and relationships between providers

Participants were asked about communication between primary and secondary care in referrals and sharing information about patients with cancer. This conversation often developed into wider kōrero about relationships and communication between different health and service providers, spanning GP practices, Māori health providers, hospices, and support services such as the Cancer Society and food banks. The theme of communication and relationships between providers fell into four parts: first, the recognition that primary health care providers are often at a distance when patients are diagnosed with cancer,

and rely on communication and information to be 'kept in the loop': second, systems of record-keeping and time it took to share and access information; third, the importance of relationships between different health providers, which included organisations knowing about each other's kaupapa, but also enabling the sharing of information about the treatments and supports that patients were receiving; and finally, the reliance of these relationships on particular individuals or champions within organisations.

The distance between primary and secondary care

Participants from GP clinics described being "out of the loop" when one of their patients had a cancer diagnosis. It was rare for GPs to make a cancer diagnosis, and they generally referred patients to the hospital where the cancer team then managed the treatment. It was therefore important for primary care providers to have information about how their patients were getting on. A practice nurse described a gap in information when GP practices assumed that particular treatments had been received and supports put in place, without having this information:

So once they are under the cancer care team, there is a massive team wrapping around them so they are only going to come in for sort of GP follow-up... So we are sort of out of the loop. And that is when there is potentially going to be a gap and it may be assumed by us by the time they have come back and they have had all those operations and tests and that they have been linked in. (Community 2)

Sometimes gaps could be filled by a community worker with good community networks. One participant described people coming "under the radar" after hospital discharge which enabled her to follow-up and check on how the patient

was coping. This kind of follow-up appeared to be opportunistic, however, and participants described a need for better sharing of information between primary and secondary care.

A practice nurse who had worked in a hospital setting was surprised by the lack of information-sharing when she started working in primary care. She described being ill-informed about patients entering or being discharged from hospital:

And it is kind of like where is the liaison between the secondary care to the primary care? You know us as primary care nurses and the GPs, they need to know what is going on with their patients. Even though we have a lot of patients we still need to know what is going on and we usually find out after the fact. Which is kind of yeah, not the best. (Community 7)

A GP outlined how there were many aspects to cancer treatment, such as physical, emotional and family support, which were not always communicated from the hospital back to the GP. Psychosocial issues, for example, were not always as well reported as details about treatment:

...so we will know what kind of chemotherapy they have had and what their white cell count is but we won't know necessarily how they are dealing with things or what is happening with them or how they are dealing with their family and all that stuff. (Community 5)

Some participants described gaps in communication between primary care and the hospital regarding patient treatment. One GP outlined the potential for information to be lost. She gave the example of test results coming through to

their general practice and being unsure of whether they had also gone to the specialist.

Record-keeping and sharing

The logistics of accessing information about patients varied for the participants. There were inconsistencies in what was available from different hospitals, resulting in some patient correspondence being accessed electronically and others having to wait for information to arrive by post. One GP outlined the time it took for hard copies of clinic letters to arrive:

So there is a big delay and I suppose that is because of them being transcribed and then typed and then signed so there is a delay in that...So sometimes we are waiting two to three weeks for some of these things. Which in a lot of ways doesn't matter but in some circumstances it is a real problem. (Community 5)

Information-sharing systems appeared to be improving, but the systems were only as good as the people using them. Equally important to medical notes and test results, were the relationships between different care providers, which will be outlined below.

Relationships between organisations

The importance of primary health care providers building relationships with hospital staff, such as the oncology nurses, registrars and cancer care co-ordinators, was often raised. Knowing people at the hospital, or trusting that there would be a helpful person on the end of the telephone line meant that participants from primary health settings felt comfortable calling for advice or information about a patient. A practice nurse described feeling happy to call the hospital to rectify any gaps in information:

I think for us as a service we are often, I know myself, oh no, all of our team members, we wouldn't hesitate to ring and say hey we understand that you saw blah blah but we have not received any report or... (Community 7)

Participants referred to their work as part of a bigger picture, with other organisations also playing a part. The need for organisations to have good relationships with each other was critical for referring patients and whānau to other services. Relationships between a GP practice and budget advice services meant, for example, that a community health worker would not hesitate to refer whānau who could benefit from the service.

Participants' kōrero about hospice often focussed on the strength of hospice relationships with other providers. Hospice is described in more detail in a later section of this chapter, but the discussion pertaining to hospice relationships is outlined here. Strengthening relationships with other health and social service providers was a high priority for hospices, and this was exemplified by a Māori Liaison who highlighted her role in education throughout the community with different groups, cementing relationships between organisations:

Strategically we have got this thing called the enhanced community model. So more about having lots and lots of sharing with other organisations. Sharing groups with other organisations. Getting more community groups and projects and stuff to happen on hospice grounds. (Community 4)

In addition to education and relationship-building, hospices' relationships with other organisations meant that their net could be cast widely to enable provision

of services to support whānau. A Māori Liaison at another hospice described practical support that was enhanced by her networks, in particular with a Māori health provider organisation:

I have got a big crowd down the road (name of Māori health provider). So if I need support for any of our patients that is where I would go to support whānau and all the maraes throughout the Hutt Valley, my networks go through there... Yeah being affiliated with health services is a big help in my job. (Community 3)

Participants who worked outside hospice also shared this confidence in good communication and good relationships between hospice and other providers. A GP outlined how the hospice was only a phone call away to address any queries about patient care and she described calling for clinical advice.

Relationship champions

The need to trust people from other organisations tied in with theme of 'champions'. Participants often described individuals from other organisations who made a difference by going out of their way to assist, were innovative, or were simply approachable. The cancer care co-ordinator at a rural hospital was described by one of the practice nurses as such a person:

So she has done some education with our GPs, she has identified who she is. She has let us know clearly about the pathways and the time expectations for the cancer patients and she is freely available. (Community 2)

A cancer care co-ordinator also described a champion in a new oncologist who was motivated to participate in and support Māori-led initiatives such as attending the KOETI pilot programme:

We were in the marae and I said to her great, I am glad that you felt that way. And she said we don't have the opportunity at clinic to talk to them about things other than the disease, other than what treatment we will put them on, other than do you have any side-effects and what can we do for you. So she says please, please invite me to come to your next one (KOETI).

(Community 1)

Participants agreed that good communication about patient care and support stemmed from robust information systems and strong relationships between organisations, and between individuals within organisations. The next section explores participants' perceptions of some care providers' reluctance to share patient care with other organisations.

5.10 Gatekeeping

Come on. They got the email and they saw the Māori word and they didn't know what to do with it and so they just deleted it! So you know, that is challenging. (Community 1)

Theme of 'gatekeeping' encompassed kōrero about organisations or individuals within organisations choosing not to accept the expertise of another service, or failing to refer patients to other services which could benefit them. The examples given pertained to service providers resisting referral to others, and non-Māori

providers or individuals not recognising their limits when caring for Māori patients and whānau, resulting in unmet need.

Referring patients to other service providers

One participant (who does refer patients to other providers and support services), reflecting on her GP work, described how when it was time to refer a patient to the hospice, there could be mixed feelings as a care provider, surrendering a long-term relationship in order to ensure the patient and whānau receive the best care at the end-of-life:

So I tend to just refer more when you are just feeling like this person needs more than you can offer. And that is for their sake I think. The last thing you want is for someone who is palliative to end up in hospital. (Community 8)

Other participants described situations where they perceived that a GP had not referred patients to the hospice or to Māori cancer care co-ordinators, which potentially prevented patients accessing care from specialist care or support services. A Māori Liaison reported informally supporting patients in the community who were not referred to a hospice care plan and were still under the care of their GP. Furthermore, a cancer care co-ordinator encountered resistance by frontline GP staff in even accepting information about their service, let alone generating patient referrals:

...so you know we revamped our resources, we picked practices to target because you know we can't even get past the practice nurses because they are the gatekeepers of their GPs. And if you get a nice practice nurse you might be lucky if she will put our pamphlet in their little rack. Oh sorry we are too busy. And all of that. (Community 1)

The same participant outlined how addressing inequalities for Māori on the cancer continuum required leadership at management level in engagement with GPs, rather than having Māori cancer co-ordinators knocking on doors and being for the most part ignored:

I believe that was a key job for a project equity manager to be, as opposed to the Māori cancer co-ordinators... so you know I just said it is a bigger issue that needs to be addressed at a higher level. So slowly things are happening. But as far as communication goes I mean I have great communication with our own GP clinic. Others - there is none. (Community 1)

Referring patients to appropriate individuals within the same service

Gatekeeping could occur at an organisational level and also at an individual level within the same organisation. A Māori Liaison described unmet need that resulted when carers within her own organisation perceived that they were able to provide the best care for Māori patients and whānau, without involving the Māori Liaison. This participant described other Māori health workers encountering similar resistance from colleagues:

And I think some of our Pākehā colleagues could recognise what their limits may be. There may be times that they can't assist... a Māori counsellor...she said you know (name), twice in her whole career has she ever heard, has she been asked by a Pākehā counsellor – I have got this Māori person with me. I am not sure, I don't know if I can do what he needs, can you talk to him or can you take him on. (Community 4)

A nurse reflecting on her work within a hospital also described reluctance by non-Māori colleagues in accessing the support available for Māori from the hospital's Whānau Care Services:

I think my colleagues were a bit, how should you say
it, um not embarrassed but just a bit wary of asking
Whānau Care Services for, well didn't know what
they dealt with or how they did things. I think they
looked at it more as if you need a blessing, you ring
Whānau Care. That kind of thing. (Community 7)

When general practices, hospice or hospital staff were reluctant to acknowledge the need for Māori input into their care, or to refer to Māori services, it was questionable whether they possessed the awareness to provide culturally safe care. This will be reported in the next section.

5.11 The provision of culturally safe care

*And don't lump everybody all in that same basket.
Everybody does things differently. Somebody might
come in, they might look very Māori but don't have
anything to do with their Māori side at all. Or you might
have someone that is very Pākehā looking and is very
strong in their Māoritanga (Māori culture). (Community
7)*

Participants were asked what they thought about cultural safety throughout the cancer journey for Māori patients and whānau. There were various levels of

understanding and discussion about what made care culturally safe, and how best to deliver care in a way that was safe.

A practice nurse described minimal cultural safety training when she worked at a large urban hospital, with most hospital staff considering that it was not important:

You do your generic cultural safety training when you first start at the hospital but there is no on-going stuff...You tick your box, that is it, you have done that. That is part of my orientation. But it is not, yeah an on-going thing. (Community 7)

A number of participants reflected on working alongside people in health settings who 'don't get it' regarding the need for culturally safe care. A Māori Liaison gave an example of ignorant comments being made in public at executive level, and the need for recognition of cultural safety at governance level in order to make change:

You know I have heard a Chief Executive of hospice say oh we are a multicultural society. It is not a bicultural society. In his firm English accent... So lots of people just don't get it. And there are organisations out there that are wanting to get it, but still have no Māori at governance level, have no Treaty of Waitangi training for anybody in their organisation, yeah they just haven't got the depth of making the knowledge stay.

(Community 4)

At the service delivery level, a participant described an underlying sense of resistance from non-Māori staff when accommodating large whānau groups in

the hospital. Instead of doing their best to welcome whānau, staff were known to express exasperation:

I think it is more for whānau, extended whānau and
how people treat the extended family coming in. Not
like (sigh) oh those people. (Community 7)

Based on her experiences as a nurse in Australia, a Māori Liaison thought that culturally safe care in Aotearoa was much better on both individual and systems levels. She expressed delight at how staff within her organisation in Wellington responded positively to her teaching about rongoā at the hospice:

I wasn't sure about including rongoā the first time
that we did it... but they absolutely loved it. ..So there
is a good portion of, more reflective, more ko wai au,
(what do I bring to this) and how their own
experiences, is still part of rongoā, it is still part of the
healing that they bring to the work that they do.
(Community 4)

Participants agreed that there was still work to do in improving culturally safe care for Māori with cancer. 'What do I bring to this', described in the quotation above, forms a big part of cultural safety, in that the care provider's self-awareness and reflection on their own culture is important. A practice nurse shared examples of non-Māori nursing staff at a hospital lacking this self-awareness, and described an ingrained sense of grievance by non-Māori staff who thought cultural safety gave special treatment to Māori at the expense of non-Māori.

Despite having the right to equitable health services, the examples given by interviewees suggest that Māori cancer patients continue to be provided with care

that did not acknowledge cultural identity. The following section unpicks the apparent disconnect between Māori expectations of health services and the culturally-laden assertive attitude required in order to gain health information and services.

5.12 'Being in front': The attitude required in order to access cancer treatment and resources

I guess it is a little bit of a squeaky wheel isn't it, if you don't hear from them then you assume that everything is ok isn't it, things are ok, which is not necessarily always the case. (Community 8)

When describing different aspects of the cancer care journey, participants often mentioned a sense of reluctance by Māori to push aggressively for services and information, which could result in some whānau missing out. Some Māori participants explored this in greater depth, and described hesitancy in demanding services, which stemmed from generations of not being listened to by health care providers and others in positions of power. Participants described how other patients, often non-Māori, who had more of a sense of entitlement, questioned doctors and were assertive in their dealings with the health system, whereas many Māori did not want to bother anyone:

I suppose being in front, you know sort of get me the doctor, I think our Pākehā patients tended to be more, I want the doctor here now, tell me what is happening. Yeah, they (Māori) tend to sort of wait for the doctor to come and they will tell you, well we will see what the doctor says. (Community 7)

Insisting on particular services, information or standards of care could be an uncomfortable undertaking for some Māori patients and whānau. Participants talked about Māori not wanting to 'bother' anyone or behave in a way that could be seen as rude. A community health worker talked about whānau reluctance to cause trouble impacting on access to information:

And I don't think, sometimes a lot of Māori don't go out and look, don't... yeah they don't go out and look for information. They just don't want to be pains to anybody. ..You just don't want to be a pain or a nuisance to anybody and hope like hell that it goes away. (Community 6)

Another Māori participant discussed her thoughts on what was behind not wanting to be a 'nuisance', by reflecting on her own experience of the reactions of others when Māori do put themselves forward to request information or services:

I think it is a humbleness that they get and I suppose as you were growing up being Māori you kind of feel not to question things because of, whether the reaction you get from people around you. I don't know. It is kind of ingrained in us I think as you are growing up so you don't tend to ask those questions it is sort of, ok the doctor knows best. And that comes from generational things as well. (Community 7)

It was felt that by not being a 'squeaky wheel' as described at the beginning of this section, patients and whānau may not always receive the same information and services as those who were pro-active in pushing for services. In this way, the cancer control system was not necessarily as responsive to Māori as it was for others.

One part of cancer care that stood out due to their work towards improving their services for Māori was the hospice movement. The changes that had been made throughout palliative care service provision are described in the following section.

Palliative care

*...you know there is that mind-set out there too
especially when it comes to palliative care you know
that our whānau go there to die. Hospice has been
working really hard to change that. Really hard.
(Community 1)*

Participants were asked about how they thought palliative care was working for Māori with cancer. Most participants talked about hospice and their kōrero related to three issues. First, participants described a long-standing stigma attached to hospice, in that whānau often perceived that hospice was a place where people go to die. Participants thought that this perception was slowly changing as whānau shared their positive stories and hospice worked with other health and social service providers to provide education about their services. Second, participants talked about hospice embracing whānau in patient care, and also looking after whānau by providing practical, spiritual and emotional support. Third, participants described respite care for whānau, where patients could be looked after in the inpatient unit to give whānau a break.

Historical hospice stigma held by Māori

Participants talked about an historical stigma attached to hospice care, with its role of support and care in the community for patients and whānau not well known. A Māori Liaison outlined some assumptions that people have before they learn about hospice:

...some people don't know what is possible or they assume it is that building where you go to die in town. So they are not aware of a lot of the community stuff that can go on or what they can have access to beforehand. (Community 4)

The same participant described whānau hesitation in accessing hospice services before learning that they were also welcome to stay at the inpatient unit:

So sometimes it might be tikanga or cultural practices that they are not sure what they can do there. Some people are fearful about the number of people that are going to be in with them and if that is going to be ok for them to stay over because they want to be with their people, so they worry about that. (Community 4)

Another concern highlighted by a Māori Liaison related to how some patients preferred their personal cares be undertaken by whānau, which could be accommodated by hospice:

I think he just felt really secure here, and there is no worries with the family looking after him. Because as you know personal care plays a big part with everybody eh who is being looked after with their personal care. They are still a bit whakamā [shy] about who is going to look after my tinana [my body].

(Community 3)

Whānau inclusion in palliative care and positive whānau stories about hospice

Interviewees described positive whānau experiences as being at the forefront of changing negative perceptions of hospice. A community worker relayed the

surprise and happiness from one patient who could continue socialising in the places they enjoyed:

I have heard reports of, that actually the sort of comment
oh I don't know what I was worried about! You know the
great team and there was one instance where oh they
said I was allowed to go to the pub! (Community 9)

Participants agreed that once under hospice care, patients and whānau were looked after well. In particular, whānau were involved in care and importantly, also supported by hospice. The Māori Liaison from one hospice outlined practical measures that had been undertaken to properly accommodate and welcome whānau:

I think previously there has been a real challenge for
families and for staff. My experience now, I have talked
to Māori people and whānau and now people coming
into the hospice have been really, really happy. They
have felt well-tended to. We do have a flat that whānau
can come and stay in. If we can manage to have family
stay in the same room we can.... From what I hear now
we do quite well with large groups. (Community 4)

A practice nurse outlined how Māori experiences of palliative care could be very positive when whānau were pivotal in patient care. She described 'beautiful care' with kaumātua being looked after 24/7. The presence of many different people providing support and care could be challenging for non-Māori palliative care nurses who were not used to such large and interactive whānau groups:

Family will have shifts to make sure there is always someone there. That can be quite, I do think that can be a bit intimidating for some of our palliative nurses who are... you know? They have got to come in and they have got all these hordes of people and who are you? Who are you connected to, there is a bit of that and mmmm they are not used to that. (Community 2)

On the other hand, for some whānau, caring for their loved ones could be extremely exhausting, and participants recounted experiences of encouraging patients and whānau to accept respite care from hospice. A Māori Liaison illustrated how whānau often did not know what to expect when caring for their loved ones:

Yeah is a hell of a burden. Some people don't know what that is going to look like. They don't know how hard that is going to be. They don't know how tiring that is going to be. (Community 4)

A community worker summed up the energising that whānau often required when they were on the palliative care journey, by describing the need to 'just blah'. Caring for a loved one could be all-consuming, and whānau needed to take the time to also look after themselves:

But yeah from what I have heard of those who have engaged with hospice it has been really positive, and for the carers that has given them time for the respite. Given them time just to blah. Time to themselves and to do a couple of other bits. Time for the loved one to be taken care of as well. And it is a biggie. (Community 9)

Hospice relationships with other organisations promoting awareness of the service

A Māori Liaison described the work that their hospice has been undertaking with other organisations, including inviting health workers from both Māori and mainstream organisations to hospice grounds for inter-sectoral meetings. Such encounters helped to raise awareness of hospice services and assisted people from outside the hospice movement to feel comfortable about referring patients. This focus on building relationships and learning about hospice kaupapa was considered very helpful by participants who worked in primary care, and it assisted them in dispelling the fears of hospice held by their Māori cancer patients and whānau.

As well as building relationships with Māori organisations, hospices had implemented Māori Liaison roles, and developed Māori service plans in order to better respond to Māori patients and whānau. Māori service plans recognised the need to expand the Māori workforce. The lack of Māori care providers throughout the cancer journey will be described in the next section.

5.13 The Māori cancer care workforce

We had one Māori palliative care nurse between here and Wellington. One. (Community 1)

Participants talked about there being very few Māori in the cancer care and support workforce, both paid and unpaid. The quotation above exemplifies the lack of Māori oncology staff, but this was also described by other participants regarding all parts of the cancer continuum. A Māori Liaison said that for a time there was only one Māori person working at their hospice. The steps this hospice had taken to increase the Māori workforce and representation at governance

level were strides ahead of many organisations. Even so, the participant who shared her kōrero regarding the Māori workforce at her hospice talked about the challenges for small groups of Māori to constantly push for change:

Because especially as we are so few in numbers in workforce and so few in numbers of patients. To get the support at the top levels, to keep them aware or to keep an issue on the table, you know that is really important. But you can find, like I am finding at the moment I am just a bit battle weary. Because there is so many different parts of life where you have to keep Māori on the table.

(Community 4)

This participant described pressure for her to represent Māori on different governance boards, in relation to her work but also in other aspects of her life. This overlap between work and home life for Māori resonated with participants' descriptions of organisational kaupapa, and Māori care providers going above and beyond what is in funding contracts to provide the services needed by whānau.

These additional layers of pressure for the Māori cancer care workforce meant that there was even more need to increase this workforce, and some participants described a 'loosening up' required in order for this to happen, in particular, for recruiting Māori volunteers into hospice. A participant outlined how stringent training requirements deterred Māori from training as hospice volunteers, and suggested alternative ways of recruiting and training to boost the Māori volunteer workforce.

Some participants talked about the benefits of Māori health workers getting together and supporting each other. Not only was this good for the workers themselves to feel supported, but it also facilitated strong networks which helped workers to connect patients and whānau to the right services.

But it is so important that there is a strong, you know Māori healthcare workers network out there so that we know who is who and who is doing what.... and it is a much quicker, faster way of getting the right people for the right care than going through normal channels. (Community 4)

However when Māori sought each other's company to share and support their work, there could be resistance from non-Māori colleagues:

And so some of our non-Māori workers were saying hey what makes you fullas so special? And I am like hey just get over it will you? I said because when we are in a forum where we don't have to justify ourselves, we can actually just talk openly about what is happening among ourselves. (Community 1)

Participants agreed that for many Māori patients, there was a sense of comfort in having a Māori person providing their care. This involved unspoken communication, and an added level of understanding for many of, for example, tikanga practices. A practice nurse reflected on her own whānau experience supporting her mother in a hospital setting. Having Māori nurses look after them made a world of difference:

They kind of just, the Māori nurses tended to look after us more than the, what the Pākehā or the you know, the other people did. So yeah they will do stuff to help if the need does arise and I think too, you just do it. You have to. (Community 7)

This was reiterated by a community health worker who described a level of comfort for many Māori patients and whānau to have a Māori person caring for them, and in particular, a need for connection at a time that can be stressful:

We respond well when we see a fellow whānau member within. Particularly, you know it is very stressing and a significant thing to be happening. And I think we, there is some instinct of connection eh. (Community 9)

5.14 Summary

The diversity, importance, needs and contributions of whānau were at the forefront of participants' reflections on the cancer journeys of Māori patients. Participants acknowledged that some whānau were strong and others barely coping, with some people choosing not to have whānau know about or support their cancer treatment. When people were disconnected from their whānau, Māori health providers often stepped into the whānau role, providing transport, advocacy and support to cancer patients. For many Māori, whānau were described as a machine that organised, supported and cared for their loved ones throughout the cancer journey. Even well-resourced whānau could feel the strain of caring for patients and each other.

Transport, financial and housing needs were highlighted, but whānau were also described as champions of cancer control. Participants gave examples of whānau encouraging others to attend cancer screening, demystifying cancer treatment and sharing their positive hospice stories. These contributions to cancer control were important and one participant identified the potential for whānau to take more of a facilitation role in programmes such as KOETI.

Participants described their advocacy work in connecting patients and whānau with other services, but were divided on whether support services were accessed adequately. Cancer diagnoses are not usually made at the primary health care level, so participants were not always in a position to disseminate information about support services available. Participants who had good relationships with the Cancer Society were confident that support and information such as the 0800 Cancer Chat number were available to whānau. Others were unclear on what was available and whether services were being used. A community health worker cited examples of patients falling through the cracks, missing out on transport options or not meeting criteria for support.

Participants highlighted the many health care staff that whānau engage with when accessing treatment services and the need for good information about their treatment and care. The KOETI DVD was described as a good resource and participants stressed the need for patient-centred information, listening to patient and whānau information needs, and not overloading people with too much information. It was recognised that Māori may not push for cancer information and services as much as non-Māori, and by not wishing to be a nuisance by questioning and insisting on services, Māori could miss out.

Participants agreed that whānau having a good relationship with their primary health care provider was advantageous for accessing cancer prevention

initiatives, screening and support throughout treatment, as well as survival and palliative care. Connection with a primary health care provider hinged on good rapport and long-standing relationships between whānau and their provider, although this was not always possible in some locations due to staff turnover or scarcity of primary care services such as general practices. Good relationships also relied on the primary care provider having staff with local community knowledge, such as of family circumstances. Also important was a welcoming provider, with location, frontline staff and cost impacting on whānau feeling welcome.

Relationships between cancer care organisations including primary care, treatment and support services were described by participants as paramount to delivering good services. Four aspects of communication and relationships were discussed: primary health care providers often being out of the loop after a cancer diagnosis; the importance of relationships and information-sharing between organisations; the reliance of these relationships on particular individuals or champions; and finally, the variation in systems of record-keeping and the time it took to share information, such as test results or hospital discharge forms. Participants also described gatekeeping when relationships were not working, such as when organisations did not refer patients and whānau to other services that could help, or when individuals within organisations failed to see that they were not meeting Māori needs.

Participants had various experiences and understandings of culturally safe cancer care, with some emphasising that cultural safety is a fundamental part of their care, and others describing a tick-box approach by their organisation. Māori participants and those who worked for Māori health providers described a Māori kaupapa of meeting need, rather than sticking rigidly to contract obligations.

There was recognition that this approach was not always sustainable and that, despite goodwill, Māori staff were at risk of being burnt out.

Participants thought the historical stigma and fear attached to hospice was changing. This was due to the positive stories of whānau who had experienced the service, and the work of hospice in engaging and building relationships within their communities. Hospice's responsiveness to Māori was seen to be going in a positive direction, with leadership at governance level and, in particular, the Māori Liaison roles being implemented.

It was thought that more Māori were feeling comfortable about accessing hospice services, but that the Māori workforce in hospices, and indeed throughout the cancer control continuum, must continue to grow.

Chapter 6

Case 3: **Managers**

6. Roles and backgrounds

The boundaries of Case 3 -the Managers, have been outlined in the methods section of this thesis. In brief, Case 3 is made up of people who work at the *take care of* level, which involves managing services, staff and administration of funding contracts.

Seven managers took part in the study. They came from different organisations that support patients and whānau along the cancer journey in the greater Wellington region. The managers came from four Māori health providers, whānau services at a hospital, and two hospices. Participants had a wide range of different backgrounds, with many working in service provision such as nursing or community work before their management role. In this way, Case 3 participants were able to reflect on their experiences with patients before moving into their management roles, but there was also some overlap with some participants still working directly with whānau when the need arose. What set this case apart from Case 2 (the community participants) was the participants' additional management perspective, in that they were involved with funding, and relationships with other organisations and funders, as well as patients and whānau.

Manager 1 is a Palliative Care Nurse Specialist Educator at a hospice who has worked in the hospice movement for approximately 25 years. Her role within the hospice encompasses education and liaison, disseminating palliative care philosophy, and supporting health professionals and providers who care for dying people, such as aged care and primary health care. Manager 1 was able to contribute to the study based on her extensive hospice nursing experience and current managerial overview.

Manager 2 is Kaiwhakahaere (manager) at Mana Wāhine, an organisation for six Māori health providers which supports women to attend breast and cervical screening appointments. Mana Wāhine provides education, information, and practical support such as transport. Manager 2 co-ordinates the providers, trains kaimahi (workers), and fulfils contract obligations by completing monthly reports to the National Screening Unit (NSU). Previously, Manager 2 had extensive experience supporting women as a kaimahi for Mana Wāhine.

Manager 3 is the Manager of Whānau Care Services at a hospital. She has worked in the hospital for more than 25 years and has managed the Whānau Care Service for six years. Whānau Care Services provide a wide range of support to patients and whānau who are receiving hospital care. They also support and train staff to work with Māori such as in matters of tikanga.

Manager 4 oversees a number of groups within a Māori health provider organisation including a whānau ora nurse clinic team, sexual and reproductive health training programme, Mana Wāhine, injury prevention, an outreach diabetes service, and an outreach immunisation service. She described her role as supporting the kaimahi to do their jobs properly and meet contract requirements. Manager 4 also works directly with whānau after-hours or where further support is needed.

Manager 5 runs an asthma clinic within a Māori health provider organisation. Although the focus of her group is asthma and respiratory, the work has a whānau ora focus so that other health and social issues within whānau are addressed. Manager 5 has run the service for 17 years and has a close relationship with the kaimahi and the whānau who receive the services.

Manager 6 is the Chief Executive Officer of a hospice which involves strategic work and the overall day-to-day management of the organisation. Manager 6 described her role as ensuring that the focus remains on the beating heart of the organisation -patients and family. Before her hospice role, Manager 6 had extensive senior and executive public sector experience in Māori health.

Manager 7 looks after five teams based in a Māori health provider organisation. These include outreach services, Mana Wāhine (women's health services such as cervical screening), Tamariki Ora (children's health services including immunisations and Well Child checks) and Whānau Ora (family health services encompassing a wide range of health and support services). Manager 7 was also able to contribute to the study with her previous experience as a kaimahi in Whānau Ora.

6.1 Continuity of care

There is a little bit of discomfort or lack of confidence because again I guess it is that consistent contact or relationship that you feel you can engage with to say well how do I do this? Or what happens next? (Manager 5)

Participants were asked in broad terms how the cancer journey is working for Māori. One of the major themes to emerge from this kōrero was the need for continuity of care. Participants described multiple pathways and people involved in each patient's cancer care. Without a consistent support person to walk alongside patients and whānau, understanding cancer care could be difficult and confusing. This confusion ranged from understanding the diagnosis and treatment options, through to keeping up with appointment

times, places and practical issues. Participants agreed that there was an onus on the individual patient to navigate their way through the myriad of different appointments:

Often it just is reliant on the client knowing what needs to be done. When, who, how and where, so they kind of have to manage themselves. Manage you know, the pathway.

Manage all the different interventions and the people that they are going to have to intervene with. (Manager 4)

A lot of responsibility is put on the patient which in some areas is good, but when you are really unwell and quite vulnerable you aren't the best person to manage that.

(Manager 3)

Engaging with multiple health professionals led to some patients and whānau feeling unsure about who to contact when they had questions or concerns:

.. who do you listen to? Them or them? They are the specialist, they are the general practitioner so who do you listen to? (Manager 4)

Because people have often been through the health system where they have had at least six health professionals, they have had a GP, they have had an oncologist, they have had an on-call doctor, they have had their surgeon and sometimes they think I don't know who to ring. (Manager 1)

Participants agreed cancer care was often complex because there were different parts of treatment to co-ordinate. Part of navigating through cancer screening,

detection and treatment was the need to secure an appointment at a time when whānau were able to be at the hospital. Interviewees' thoughts on the reception that patients and whānau received at hospitals, as well as the flexibility in appointment times, are outlined in the following section.

6.2 Flexible appointments and a welcoming reception

And I always say to them you know if it is not possible for you to get to that appointment, for whatever reason, don't ever think that I am not going to bother. Because we can always rearrange an appointment to get you there. Just keep in the back of your mind that it will be a journey. (Manager 7)

Interviewees talked about three areas that impacted on the ability of patients and whānau to attend hospital appointments. First, it was important for patients to understand that their appointment existed, and the reasons why it was vital that they attend the appointment. Second, participants described the need for flexibility in appointment times to cater to whānau needs such as work, childcare or dealing with co-morbid conditions that could hamper mobility. Third, an important issue raised by participants was the apparent lack of follow-up appointments once cancer treatment had ended.

Barriers for patients and whānau to attending hospital screening and treatment appointments

Participants described difficulties for patients in attending cancer screening and treatment appointments. It was emphasised that if a patient did not attend (DNA) a hospital appointment, this did not necessarily mean that they were disinterested in their health or did not want treatment. One participant outlined recent work

which found that patients who failed to attend their appointments cared about their health, but were often not well-informed about their illness:

And we have just been recently been doing a DNA (did not attend) project and interviewing patients that DNAed a lot and all of them thought their health was important, contrary to popular belief. So people believe that patients don't, you know? But they all did! But the degree in which they understood their condition... and the implications for them and their family wasn't always well understood. (Manager 3)

As well as not always understanding the gravity of their illness, participants also described many other reasons why patients may not be able to attend appointments, including whānau commitments, work, childcare, timing, or previous bad experiences:

Because so many of them, they want to put their family first. You know they will put everything else before themselves... And then the other part of that I guess is that some of them are transient so you know they go off to other places and you can't find them. But you know a big barrier is past experiences, especially for cervical screening. I am sure you have heard some terrible stories. (Manager 2)

Hospital responses to access barriers

Participants spoke positively about the flexibility of appointment times at hospitals for patients undergoing cancer care. It was also noted that there was a Māori receptionist at one of the hospital departments, and seeing a Māori face put many patients at ease. It was also noted that this receptionist was often the only

Māori staff member throughout the cancer treatment journey, which will be further outlined in the Māori workforce section of this chapter. Participants described the diversity of patients and whānau resulting in different needs for appointment times. Some patients, for example, needed to continue working throughout their treatment, so were able to schedule treatment times that worked around their employment hours:

He would get the last appointment, the latest appointment that he can so that he could do as much work as he can. Then he would go and get his treatment and then he would go home and start early and stuff like that. (Manager 4)

Other patients were unable to attend early appointments due to mobility or childcare issues. However it was thought that patients were able to arrange appointment times that were appropriate and there appeared to be some flexibility in booking appointments:

Appointments times...they used to make an appointment at stupid hours and mum has probably got 4 or 5 kids at home, well they are not going to turn up to an appointment at 3 o'clock in the afternoon. But you know we have quite a good relationship with them, you know the booking system and so we are able to say no, that is not going to work for that client. (Manager 7)

It appeared that those who provide cancer treatment services were conscious of facilitating ease of access into their service. The participant from Whānau Care Services praised the efforts of Oncology Services in encouraging Māori to attend by making their reception area welcoming and appointment times more flexible, including night clinics.

A welcoming Whānau Care Services reception area was strategically positioned at one of the hospitals. It was observed that the physical location of Whānau Care Services had contributed to increasing the number of whānau who accessed them. By having a visible position near the entrance, whānau were made aware of the service and able to easily pop in:

They walk in, they see the pounamu (greenstone), they see Cultural Care, and we see a lot of them that just come to reception.

Do they self-refer?

They self-refer. Often though they don't know what they are referring for, and it may not be, not to say there is anything wrong with that but it is just the fact that they want to engage. And if they identify that they need support but they don't know what it is they need support for. You couldn't get a better referral. (Manager 3)

‘After that is when it falls over’: A lack of appointments at cancer treatment follow-up

Although participants agreed that appointment times throughout cancer treatment were, for the most part, flexible and welcoming, one participant noted that once patients had completed their cancer treatment, outpatient follow-up care was not as accessible, with poor communication and long waiting times:

... most of them, you know you are left waiting for longer than 30 minutes. They are not being informed why they have had to wait so long. Other women, or other people that have come before them and they get seen before them. And actually a couple of the ladies have just given up and said stuff yous I am not coming back. (Manager 3)

Additionally, booking an appointment with a community nurse for post-surgical care was also noted as not always being streamlined or accessible:

So you know they have had their surgery, and then they are sent home and I think it is that time, after that is when it falls over. You know it really does go phhhht. So you have got the community nurses that are supposed to come out and look after their wounds and you know sometimes they cannot be very helpful you know in terms of times of them being seen. (Manager 2)

The previous sections have outlined participants' views on availability and flexibility of different hospital appointments for cancer patients. The issue of appropriate information being available to Māori with cancer is canvassed in the following section.

6.3 Appropriate information for Māori with cancer

I think sometimes it is just not enough to put a Māori face on a pamphlet. You know? And I find that I see that happen a lot. But sometimes they need to come out and ask the people who use those resources, actually are they useful resources for them? Are they appropriate? I don't know if they do that.
(Manager 5)

A common theme to emerge from participants' discussion about patients interfacing with their treatment providers, and whānau being supported, was a need for better information. There was agreement among participants that current information given to patients was not always appropriate, for two main reasons. One reason was that the information often addressed clinical issues

rather than the issues that whānau wanted to know about. The other was a lack of Māori-focussed presentation of information, which related to the need for someone to talk to as well as written material. One participant described the clinical focus of colposcopy information:

You get a little booklet, it is very clinical. I said to the nurses you know can you reword it a little bit, to be a bit more....you have got to have the cold facts of the procedure but if you want the woman to attend you need to have, you know more lay terms...a nice and easy way to understand...But when they see that booklet, if they see the booklet, it is not very inviting. (Manager 2)

Participants reflected on questions that whānau had when going through cancer treatment which were not generally addressed in the information available to them. These included practical matters such as how whānau could safely lift family members, or where to go for after-hours care.

Furthermore, participants described a need for information that would give whānau an overview of all the resources available to support them through their cancer treatment, including how to talk to children about cancer, issues regarding sexual intimacy, or managing energy levels.

It also appeared that information given to patients was inconsistent, with some patients given information on things like accommodation and travel options, and others not given any information at all. A participant from a Māori health provider organisation described the need for a helpline for cancer patients who had questions about their illness or treatment. She was not confident that cancer patients and whānau in her community knew about or felt comfortable accessing the Cancer Society's 0800 cancer chat line. Participants thought

that information provided to cancer patients should be better tailored to Māori. This included more Māori-focussed information, but also for some information to be provided in face-to-face discussion:

The information that the Cancer Society provides is really useful, my understanding and experience in many whānau is that they don't necessarily read it... my sense is that we should have face-to-face kōrero as well as the written resources. Because sometimes you just want an answer there and then. You don't want to read the whole book or you know navigate your way through a book to find the answer for a question which is clearly important, that is what is on that person's mind. (Manager 4)

Information was primarily described in the form of printed material, but Whānau Care Services also highlighted an information DVD which was developed by the Blood and Cancer Centre at the hospital, and included information about the support that was available from Whānau Care Services. Being part of the information DVD led Whānau Care Services to further develop their knowledge about how to help whānau digest information regarding their treatment journeys:

But I thought the visual was a good start as opposed to brochures, you know because the paraphernalia that comes out of this organisation, even as an employee, it is sometimes difficult to understand what the objective of the information is. (Manager 3)

This section has showed that information available to whānau was not always accessed and did not address the practical issues related to getting on with life

before, during, and after cancer treatment, such as financial and whānau support. Tied in with the content of written and multi-media information about cancer was the mode in which it was delivered, namely how effectively the cancer service provider communicates information to patients and whānau. Discussion about the differences in communication style of those providing the care will be reported in the next section.

6.4 Communication between those giving and receiving cancer care

And you know in the back of my mind I am thinking you know some people can be really skilled at what they do, but they don't have people skills. So you know, so sometimes you just have to step up and support our clients. (Manager 7)

Participants identified variation in interpersonal skills and ability to impart information between different individuals who provide cancer care and support. It was thought that this inconsistency impacted negatively on the ability of patients to understand their care. On one hand, participants described instances of clear communication experienced by patients and whānau, with a phone number provided to call with any questions:

The breast care nurses are excellent at (name of hospital). They have been really good. They explain things very well and the surgeons, they are good too in their way... At the time of these assessments the breast care nurses give their card and their assurance that they can be contacted at any time if they have got any questions. (Manager 2)

Conversely, participants described instances where there was a perception by patients and their support people of poor communication by cancer care providers. This included hurried consultations, patient notes not having been read, and impolite behaviour. One participant outlined her experiences of supporting patients where specialists did not appear to be actively engaging:

Many times I have sat with clients that I have supported to the specialist. And the specialist will be sitting at his desk talking away (faces computer) not actually engaging with the client and they will go oh yes you have got (typing) use some big word.

And I will say to them excuse me you need to be talking to your client. And they will look at me in such a dirty way as if to say I am talking to the client. But they are not. (Manager 7)

Participants shared examples of poor communication between doctors and patients occurring for a variety of reasons. A participant from a Māori health provider organisation recounted one of their community workers supporting a hearing-impaired, elderly man to his oncology appointments. This example highlighted the importance of having a support person accompany patients to assist in understanding what was being communicated:

Just was grateful for whatever support or information he was given, and was a bit deaf as well which made a huge difference because he didn't really hear anything. So the first time that our community health worker went she told him so much stuff that he was in a real... I don't even think he knew what type of cancer he had because he would, he was the sort of person who would just nod his head and say nothing and just nod his head and stuff. (Manager 5)

It appeared that oncology staff were also mindful of having appropriate support people accompany patients in order to enhance communication. The participant from Whānau Care Services described a recent project by her group with oncology staff about communicating cancer information to patients and whānau. Despite the delivery of diagnoses being an everyday occurrence for clinicians, there was awareness from oncologists in the project that patients and whānau did not always understand what was being said at the time of the consultation, and that having appropriate support was vital to ensure that messages were understood:

... the oncologists were saying well that is what we do all day, is give bad diagnoses... It was like well how do we ensure that they have the support around them when they are giving that information and then that continuum about, so they actually know what it means and they know the implications that it has.

(Manager 3)

The examples from participants showed that continuity of care, communication and understanding were enhanced by having a trusted support person along the cancer care journey. The next section outlines how these needs are currently being fulfilled by Māori health providers and others.

6.5 The ‘bridging’ role of Māori health providers

So we will take them over there and introduce them and get them all going with the Cancer Society. (Manager 2)

Participants from Māori health provider organisations highlighted their work in providing continuity of care and improving patient and whānau understanding of cancer. This was achieved by Māori health providers bridging between patients,

whānau, the health workforce and other support services. Similarly, participants from hospices described bridging between patients and other community organisations, and the participant from Whānau Care Services emphasised the benefits of establishing relationships with whānau at the hospital early, so that they could provide support if and when it was needed.

Three issues were identified that impacted on the ability of providers to bridge effectively between patients, whānau, and cancer care and support services. These mainly applied to Māori health providers but to some extent were also relevant to the other participants. First, health providers needed to have established trust and good rapport with patients and whānau. Second, good relationships between health provider organisations and cancer care providers were required so that those supporting whānau could effectively inform and support patients as they entered and received treatment. Finally, the work involved in helping patients and whānau navigate the cancer treatment pathway needed to be recognised and appropriately resourced.

The value of trust and rapport between Māori health providers and whānau

I just think it has been positive for the whānau member with the cancer to have someone who they know, who understands their ways and is familiar with tikanga and things. To be able to have that person to talk to and also to advocate for them as well you know with some of their care. (Manager 5)

Māori health providers often had long-standing relationships with whānau in their communities, and as such were well-placed to provide information and support for cancer prevention, screening, treatment, survival and palliative care. As described by this participant, trust was vital in helping whānau to overcome fear

of services such as hospice, or to engage with a mainstream support organisation such as the Cancer Society:

If we know that whānau are not going to go in and see the Cancer Society or they are not being provided with the level of care they need in the community then there is a huge gap there. And it is a gap that has to be filled by Māori providers who are probably already known to those families. They trust them. (Manager 5)

And you know all of our families have gone on to access (name of hospice) care... and it is just explaining to them, taking that fear away, people who they know and trust. Like the community health worker. They already know her, you know they trust her. She has been able to take them to visit and they have been able to have care in their own home, it is not about putting them into an unfamiliar place, you know they still have choices. (Manager 5)

Māori health providers were also able to walk alongside patients and explain what was likely to happen at appointments, as described by this participant in the context of breast screening:

But you know it is not just about transport, it is about also that time to tell them what is going to happen at their appointment ...also you know we can go right into the room with them. (Manager 2)

As well as Māori health providers using their local knowledge to support patients and whānau, Māori Liaisons within mainstream providers such as hospice also

used their local knowledge to link whānau with services and provide practical support such as helping accommodate large whānau:

And (Māori Liaison) used to go and, she'd, because they had contact with all the maraes... If the big family come, well we can go there for the beds and the mattresses, or we have got this big family coming down. (Manager 1)

With their community networks, Māori health providers were in a unique position to ensure that whānau were able to receive health services. Their efforts were often outside the square, as outlined by this participant in an example of actions to engage women in cervical screening:

They don't want to be seen coming in to the practice...so we will take our smear taker to the home. And they go oh well I have got four kids, and so our kaimahi, our community worker will go with them. And she will look after, entertain the kids for twenty minutes or so while the smear is happening. Whatever it takes. (Manager 7)

Participants shared examples of bridging between patients and cancer care by talking with them before appointments about what to expect, accompanying patients to consultations, and debriefing afterwards. As shown in the following example, debriefing provided an opportunity for patients to clear the air and ask questions that they may not have felt comfortable asking during the consultation:

And then we use the opportunity of leaving the hospital to the time we drop them at the door to go over what has just happened...even though you are getting all the pamphlets and the booklets and all that as well... it is the other kōrero that the doctors etc. are giving to you at the same time. (Manager 2)

Māori health providers described how an on-going relationship was vital for patients to feel comfortable in asking questions, and for the support person to provide continuing information and assistance. The participant from Whānau Care Services also stressed the importance of establishing relationships with whānau early in their treatment journey so that if, and when, help was required, whānau would feel more comfortable receiving support from the service:

And what we promote is that we engage with them early from our service and once that situation changes then they feel comfortable contacting us. (Manager 3)

Relationships that affect the bridging work of Māori health providers

Participants raised two issues that impacted on the work of Māori health providers and others who facilitate access to cancer care for Māori patients and whānau. First, participants talked about the need for sharing of information between primary care and the hospital. Two participants reflected on the lack of information-sharing around breast and cervical screening:

They don't seem to share their information, so you know this one doesn't know what this one is doing, where the woman is at or what her needs are so yeah and I don't know if that is about privacy you know and those sorts of issues. (Manager 2)

Now because Mana Wāhine is not a GP service, what will happen is that the results from that clinic report is sent back to her GP. And they leave out the smear taker. And so then we are kind of left out of the loop. (Manager 7)

The second issue related to the inconsistencies in the ways that hospital staff reacted to having a person from a Māori health provider organisation supporting patients and whānau to screening and treatment appointments. The support role of Māori health providers was not always recognised by hospital staff. When it came to relationships with breast cancer screening providers, one participant from a Māori health provider organisation described examples of not always being appropriately acknowledged by screening programme staff:

Because we are actually part of the screening programmes, Mana Wāhine...and we get treated or acknowledged when we wear our badge. And if we forget to wear our badge they sort of look at you and think oh why are you here? (Manager 2)

Another participant described resistance from clinicians to her support at specialist appointments:

... and we get there and they go oh no we only want the client. And the client will go but I want Aunty to come with me. And they go oh but the specialist needs to talk to you. (Manager 7)

Participants agreed that relationships between those supporting patients and whānau on the cancer journey, and those who provide cancer services, were built

over time. This participant outlined the importance of face-to-face meetings in building trust between organisations:

But it takes that relationship and communication and trust before anything will work. We could give pamphlets, we could drop pamphlets a hundred times over but they mean nothing unless there is explanation and establishing of that relationship. (Manager 1)

Positive relationships between organisations had a positive effect for patients and whānau in that information about services was available and shared. In particular, the two participants from hospices outlined their focus on building community networks which helped to demystify their organisation. One hospice actively promotes bringing other organisations in to their inpatient unit for meetings, alongside participation in a wide range of community events:

And combined with building networks with Māori providers, rongoā healers and we have been doing this thing of, (name of Māori Liaison) has been bringing different groups in to run sessions to show how we run our services and get to do a little tour. So you start to see the place, they see the place in a different way. (Manager 6)

Another hospice participant described the reciprocity between her hospice and a Māori health provider organisation in understanding and promoting each other's work. Additionally, the same participant emphasised the benefits of participation in meetings with other organisations, in that people from different groups got to know each other informally which facilitated better care for patients:

We started a palliative care interest group...and that is for hospital staff, hospice, aged care, anyone just who have got an interest... and it is really nice because everyone is you know hi hi hi and did you hear about that course next week, it would be great if you could send a couple of caregivers and it is just that type of liaison. (Manager 1)

The benefits of relationships between people from different organisations also applied within a large organisation such as the hospital. The participant from Whānau Care Services observed the value of building awareness and understanding of their service within the hospital and improving engagement with staff in order to improve the cancer care pathway for patients and whānau.

Māori health providers were also pro-active in developing relationships with other organisations, which benefitted patients and whānau. This included establishing links with hospices, other primary health care organisations and hospital departments.

Established relationships between organisations helped facilitate good communication when services required improvement. One participant described a situation where a nurse from a mainstream organisation had inadvertently provided culturally unsafe care in the home of a Māori patient. The patient did not feel able to tell the nurse but was able to tell the community health worker from a Māori health provider organisation who then addressed the issue with the mainstream organisation. The outcome of this was that all nurses at the mainstream organisation were reminded in their training about the way they approach care. This example showed how the relationship between the Māori health provider organisation and other organisation was pivotal in being able to address the important issue of cultural safety.

The inadequacies of funding models in acknowledging the work of Māori health providers in cancer care

I see us as bridging relationships that could help improve some of the outcomes later between secondary services... but I think alongside that we need to be resourced to do some of that work and we are not. (Manager 5)

As described throughout this chapter, Māori health provider organisations play an important role in supporting patients and whānau throughout the cancer journey. Interviewees described different aspects of their work being funded or not funded. First, participants were not confident that their funders recognised the value of the work they undertake. The Māori health provider workforce, for example, was limited by the staff training and resources provided by their funders. Manager 2 outlined how Māori-specific training had been discontinued by the NSU and replaced by a generic mainstream training alongside mainstream organisations.

As well as a lack of cohesive training for staff by funders and government administrators, participants pointed out that much of the bridging work provided by Māori health providers is not acknowledged by funders. A participant who manages screening services for women described a tick-box report requirement by funders, rather than a bigger picture of the efforts required for women to make it to screening appointments. One example given was that Māori health providers were not paid until a woman had actually attended screening:

...at the end of the day, unless there is an outcome we don't get paid. And you can rock up to a place, all the appointment is organised and mum has decided something more important has come up and so we are just, ok back to the drawing board, try and re-engage her again, see what else we can set up. (Manager 7)

Other bridging work was not funded at all. In the following example, a participant describes her previous work as a kaimahi accompanying doctors on home visits. She highlights the importance of what she calls the "intermediary between clinical and whānau":

But often I have supported our doctor on home visits... but it is just that relationship, knowing he is on a clinical journey and for us, they kind of see us as part of the whānau and being that intermediary between clinical and whānau. So yeah I think there is a role there because we just, we just go and do it. But we are not funded to do it. (Manager 7)

In another example, a participant described the lack of resourcing behind KOETI:

Why would you develop a training programme for Māori but actually there is no funding to actually deliver the training? And I think that is what, that keeps happening and that is frustrating. It is like we do the training because we know there is a need but actually it is not acknowledged in any way. (Manager 5)

The potential for cancer navigators to assist Māori patients and whānau experiencing cancer

When participants described the bridging work that they undertake between patients, whānau and cancer services, the concept of cancer navigators was raised. Cancer navigators are defined in the background section of this thesis. Interviewees discussed the complexity of developing any future cancer navigator role for their community. This encompassed the challenges of being a non-clinical person seeking information from established cancer care teams, requiring a special person who could build rapport with the cancer care providers and also build trust with the patients and whānau engaging with the service. Additionally, one participant saw a cancer navigator role extending to the wider needs of whānau, in particular pertaining to cancer prevention:

But the other part about supporting and informing whānau.

That should be still happening. Part of the navigator role is about maybe helping to transform the whānau. So you don't want to wait for a daughter or mokopuna to get cervical cancer you know? All those sort of things. How do you do that?

(Manager 4)

The participants who supported patients and whānau throughout their treatment appeared to be providing an informal cancer navigation service already, and some were keen to develop this further:

. And I mean we are a relatively small organisation and we have only got nine staff, and we have provided some really comprehensive care over the years for whānau with cancer. And to the point where the staff want to develop a service where we can properly support whānau through that journey. (Manager 5)

This section has presented the views of participants regarding the work of Māori health providers and others in facilitating access to cancer care for Māori. This work, described as 'bridging' was based on established community links and long-term relationships with whānau. The vital role of whānau as patient carers and as people who also need support along the cancer journey is described in the following section.

6.6 The role of whānau throughout the cancer care journey

90-95% of care is actually done by families, not health professionals. And we might think we do a lot by having a half hour visit once a week, but in fact the caring is done 24/7 by families. (Manager 1)

Participants were asked how whānau and patient carers are supported throughout the cancer journey. Three main themes emerged from this kōrero. One theme reflected on diverse whānau dynamics, ranging from patient concerns about aspects of their cancer care putting stress on their whānau, to whānau not being told about the cancer at all. The second theme related to ways in which organisations had identified and worked on their approach to including and supporting whānau in their services. The third theme came from the Māori health provider participants and pertained to their overall whānau ora focus, in that wrapping around whānau, rather than individual patients was a foundational kaupapa of their organisations.

Different whānau needs

Participants commonly described patients putting the needs of whānau first in their concerns about their cancer treatment. These ranged from financial

concerns to practical issues such as school drop-offs, as described by this participant:

... You know, shit how are they going to survive... How am I going to get my daughter to school... just a whole lot of practical things. I have always paid the bills...I have always worked, why can't I work? So there is a whole lot of issues just with whānau. (Manager 4)

Participants also agreed that different patient and whānau dynamics impacted on how well they, as an organisation, were able to support whānau. Some patients were very open with their whānau and welcomed whānau support, and others, for differing reasons, chose not to share news of their cancer diagnosis or treatment with whānau. This affected the ability of care providers to communicate with whānau:

They can have those discussions and you know I know that (name) our community health worker has been able to talk with the whānau because he has been unable to tell his whānau because he doesn't want to you know bother them. (Manager 5)

Organisational responses to whānau

Participants from mainstream organisations such as hospice and the hospital shared stories of how their organisations had improved the way they include and support whānau. The first part of this was training staff to recognise the importance of whānau involvement in the cancer care journey, as well as understanding how to support large whānau groups. One participant from a hospice outlined how caring for patients from whānau groups could be daunting

for staff who did not necessarily come from cultures where large, interactive families were the norm. In one example, she illustrated how the hospice had recognised the need to accommodate the younger members of whānau:

... the role of children in, as family and family visitors...Children were part and parcel, death and dying was not separated out from the children...So that if you get a couple of robust kids running up and down the corridor, for our Pākehā staff, sometimes were quite horrified by children running up and down the corridor (gasping noises) stop that! And how do we deal with this? (Manager 6)

The hospice from this example had responded to this need by training staff and also implementing strategies to accommodate whānau appropriately, including development of a visitor's guide and identifying key spokespeople within whānau for staff to consult. These actions facilitated further practical measures so that the hospice could better support patients and whānau:

Looking at getting the family or the spokesperson or a small group to sort of determine who is going to be sleeping where, how they could take shifts, who else is going to be looking after other members of the family, which members might be staying in the family flat...and who is looking after the children.

(Manager 6)

Further, resources had been made available for whānau such as booklets containing karakia, hīmene (hymns) and waiata. Resources were also developed for staff, such as tikanga guidelines for interacting with patients both

in the inpatient unit and in family homes. Importantly, cultural safety education was on-going for staff.

The positive effects of staff training were also evident when another participant described hospital staff training in the importance of whānau participation in patient treatment, alongside practical tools to plan for large whānau groups:

... and questions from that like: well where are we supposed to fit them all in that small room? ...So giving them some tools to manage that is useful. And just, Māori patients felt better at the start of just positively affirming ourselves as opposed to negatively and that made it feel like they could ask more questions, like they were respected and opened up the patients' perspective, the opportunity of engaging with people as well.

(Manager 3)

Positively affirming Māori patients by genuinely accepting and including whānau in patient care had further benefits by clarifying who defines whānau, and different parts of the whānau role such as identifying patients:

Part of our education is that whānau and visitors are not the same, and that whānau is the extension of the individual and defined by the individual... like you know when someone goes into theatre they need to have whānau there so that you can authenticate and identify the patient in the operation so that with people warming to the concept of how whānau are supported. (Manager

3)

Whānau ora

Other participants talked about supporting whānau in a wider context beyond the particular patient's cancer journey. This included broader determinants of health such as education and housing. Participants from Māori health provider organisations described their whānau ora approach, in that they not only worked with the patient, but also supported the whānau on the cancer journey and other aspects of their lives. By assisting whānau to realise their aspirations, the Māori health provider organisations were also improving health literacy.

A whānau ora approach was articulated by a participant from a Māori health provider who emphasised the importance of finding out from whānau what was important to them regarding the cancer treatment pathway. She described how Māori health provider organisations had been listening and responding to whānau for many years:

See it is interesting about this thing -don't want to be told what to do, but what would be more important is have them listening to the whānau first, is that commitment to listen to what the issues are and also deal with all the issues and not just some of it or what is perceived to be the most important and so we are in a position to, albeit with nurse clinics and stuff and we are in a position to provide, always have been really to provide a holistic view and ear for whānau. (Manager 4)

Although interviewees reported pockets of activity regarding responses by cancer care providers to the needs of Māori cancer patients and their whānau, the bigger picture of engaging with the health system was daunting for many whānau. In particular, the onus on individual patients to advocate for themselves ran counter

to the concept of whānau ora. The incompatibility between the apparent need to ‘stand up for your rights’ and the ways in which whānau quietly and respectfully engage with health providers, is reported in the next section.

6.7 Equitable access to treatment and resources

Māori get a different deal to non-Māori in terms of the cancer pathway.

But at the end of the day, Māori, they are grateful for anything they get and there is no time to be sceptical or ungrateful so they behave with lots of humility. And for somebody like me who observes that, I want to be the opposite because I don't think that they are getting the service that they should be getting. (Manager 4)

An overarching theme from the Case 3 interviews was that Māori do not always receive the treatment, resources and support that they are entitled to along the cancer journey. This related to attending appointments; free services, such as transport offered by the Cancer Society; or Lions Club after-hours care; telephone support; and more. Underlying this theme was the onus on individual patients to advocate for themselves and navigate their way through the cancer journey. This had several problems for the whānau that participants' organisations supported.

First, patients and whānau were not always informed about what they were entitled to in the first place. As described in the information section, information packs, verbal communication about treatment, and support appeared to be offered in an opportunistic and inconsistent manner.

Second, the pro-active, confident approach towards service providers that was required of individuals was often at odds with many whānau who did not operate in this way, and were reluctant to push for services or be seen to be overly aggressive or causing trouble:

Because they don't tell them, a lot of these government agencies don't volunteer information. So whānau don't push them and often they miss out on what they are entitled to.

(Manager 5)

Additionally, undergoing cancer treatment was stressful and often patients and whānau were at their most vulnerable. Participants described patients and whānau being grateful for any treatment rather than demanding particular services:

But a lot of it is teaching the whānau how to you know just basically insist on your rights. See if you don't know your rights, your basic core services, how do you know what you should expect, stuff like that. But you know whānau experiences haven't had good experiences so why would they expect anything else?

Eh? Let's just get it over and done with. (Manager 4)

Not wanting to trouble anyone was another reason why patients and whānau were not always pro-active in seeking help. In one example, a participant described hesitance by whānau to access after-hours advice, resulting in a weekend of discomfort:

And often even for us they might wait, like it might have happened on a Friday when they have got diarrhoea but they waited until Monday to ring and ask us, and you know so they have been sick all weekend. I think well that is terrible.

(Manager 5)

The onus on individuals to contact support services, push for what they were entitled to and ensure they could make it to their appointments, disadvantaged

some whānau. For many of the patients and whānau that our participants described, there were many day-to-day issues to deal with before being able to follow-up their treatment or support options. Participants agreed that there was variation among the whānau that their organisations supported, with some whānau being experienced, confident and pro-active in dealing with health services, and others grateful for any care and help that was offered:

Some people know a lot ... often it is because they know the process. Because they have had another whānau member with cancer. And then it could be, you know then we have also had someone who has worked in the health area so she has an idea of what she needs and what she is entitled to. But to the other degree we have had a kaumātua who just asked for nothing and pretty much got nothing as well. (Manager 5)

Contributing to the reluctance in pushing for services was misunderstanding and fear of cancer, which was also perceived by participants as a barrier for Māori accessing cancer services. An example of this was conceptualising cancer as a death sentence, even before diagnosis:

Or sometimes I don't even use the word cancer because someone else has used the word cancer and then straight away they think that they are going to die. (Manager 7)

Fear of cancer was also observed to be an obstacle for patients and whānau considering support from the Cancer Society. For the same reasons, the patients and whānau supported by participants also feared hospice. Participants described a stigma attributed to hospice, but conversely it was whānau who had

benefitted from hospice services that were part of changing the perception of hospice by sharing their positive experiences with others:

... well there is various perceptions but engaging somehow that means that death is relatively close as opposed to the fact that palliative care can be quite a lengthy journey.

(Manager 3)

I do believe there is that, part of it is the advocates on behalf of our service have been Māori themselves talking amongst themselves and that has helped from their perspective in decreasing that fear barrier about coming into hospice. Whether it is as an inpatient in the unit or into the service where it is in the community. (Manager 6)

This section has explored how Māori do not always receive the cancer care services they are entitled to. Contributing to the disconnect between Māori expectations of health services, and the assertive attitude required in order to access services, were fear of cancer, and practical barriers such as transport issues. One way of aligning Māori expectations of health services with the services available is to have more Māori working in health care and for all care to be delivered in a culturally safe manner. This will be outlined in the following section.

6.8 Changes to the cancer care workforce

It would be nice to see some more kanohi Māori in different places, like the Cancer Society. But everywhere, you know? Not so much providers but in the other, in these other places, in the hospital.
(Manager 2)

When participants talked about patients and whānau moving through their cancer care, they expressed a need for a greater Māori presence in the cancer care workforce, alongside the need for all staff to provide care that was culturally safe. This encompassed screening staff, clinicians, administration staff and volunteers at support services.

Having a Māori face welcoming patients and whānau was regarded positively by participants. As noted in a previous section of this chapter, a number of participants mentioned a Māori receptionist who was sometimes rostered on at different cancer services in the hospital. Her presence was observed as immediately putting many patients and whānau at ease. One participant described the positive benefits for Māori patients engaging with Māori staff, such as the unspoken communication with someone from your own culture:

I think that there should be a lot more Māori employed and engaged in those sorts of roles for Māori whānau. The stuff that I have experienced so far is all the different parties, all the different pathways is the lack of Māori faces in those pathways. Or the lack of somebody where you just have to look and you don't have to communicate at all and you know what the other one is thinking. (Manager 4)

Although participants agreed that having Māori faces along the cancer journey was comforting for patients and whānau, they also noted that there were few Māori staff at the hospital. The need to have a greater Māori presence along the cancer care journey was often fulfilled by having a support person from a primary care organisation such as a Māori health provider. One participant explained the positive difference that a Māori support person could provide, such as the knowledge to carry out tikanga practices:

It makes a big difference for them to see a Māori face somewhere along their journey. And if that can't be in the secondary care setting in some of those other places, to have someone walking alongside them into those places I think makes a big difference. And I know that sometimes they want a karakia and things before they go in for the appointments so that is the sort of difference I think it can make to help settle them.

(Manager 5)

The same participant also described the comfort that patients drew from having a Māori support person. This ranged from being able to have discussions that they would not be able to have with non-Māori staff, through to generally being more comfortable having someone familiar with tikanga to undertake their personal care such as washing:

And the way he was brought up, he is an old man and he was brought up I suppose is steeped in Māoridom (the Māori world) and so he was very private about himself and he just felt comfortable I think about having a Māori nurse to wash him.

(Manager 5)

Another participant from a Māori health provider organisation described spending time with Māori patients who had travelled from out of town and did not have any other support. This example shows how having a Māori support person, even if there was no previous relationship, was appreciated by patients:

So sometimes you find yourself picking them up or dropping them off, or you know going for a coffee or something, take them out for lunch and often it doesn't matter that they don't know you. It is just that Māori face that is what they tell you. Oh it is so nice to see another Māori dear. You know things like that. (Manager 4)

Participants from mainstream organisations were mindful of increasing the number of Māori staff in their workforce. The managers from two hospices described their organisations Māori Service plans, and how these influenced workforce development. In particular, both hospices had developed a Māori Liaison role. A Māori Liaison provides practical assistance and community knowledge, together with education and collaboration with other providers, to improve Māori hospice access and care. Despite these successes, there were still enormous difficulties in recruiting Māori into the palliative care workforce due to other areas of care being more appealing to the Māori health workforce:

...when I am talking to Māori groups, I often refer to the fact that we are the sunset service. Whereas...for Māori going in to training, whether it be nursing or medical, they prefer the sunrise services, paediatric care, maternity care, health prevention...or they do prefer a more community based health approach. (Manager 6)

As well as articulating the need to grow the Māori workforce, the same participant described the need to collect data about patients and services to support the Māori service plan:

We have got a Māori Service Plan, we have got a Māori board member. How many Māori staff did we have? We had one, who was a registered nurse, she has since left. Right. How many Māori patients do we have? Hmmmm? Interesting... It is all very well having a Māori service plan but if we are not really looking at who our Māori patients are, and where they are and what is happening to them, how are we going to be able to measure what it is that we do and don't do?

(Manager 6)

Participants highlighted the importance of consistency in the values of individuals within the teams that cancer patients encountered; of having a good team kaupapa, instead of relying on individuals:

Some good cohesiveness within that team and delivery so it doesn't matter who, but the values are the same, the kaupapa and the way you deliver stuff has to be the same, not per individual. So it wouldn't matter if you were a bit of a grumpy so and so or if you were a bit reserved or if you were so out there. It wouldn't matter what type of personality. But you had a service that demanded that you had these values and you work this particular way. (Manager 4)

For the most part, participants described dedicated and excellent staff providing cancer services. There were, however, also examples of very poor service which had a lasting effect for patients and whānau, and discouraged further engagement with health services. In the following example, an older

patient was treated very badly at a mobile screening unit:

There was a wahine lady who is elderly who... has mobility issues ...

and they had notes to say that she had trouble getting to the bus...

And the day she arrived she was mistreated from the time she tried to walk up to the bus, because the woman was standing there with her hands on her hips saying what is wrong with you? (Manager 2)

Examples like these showed the importance of mainstream organisations ensuring that their staff were trained to care for patients in a culturally safe manner. Participants agreed that it was vital for all staff to understand how their own cultural beliefs and ways of doing things impacted on their care practice. In one example, a participant from a Māori health provider organisation described a situation where a patient felt culturally unsafe because of the actions of a nurse from a mainstream organisation:

The nurse unknowingly took his bandages off and put them all on the kitchen table. And he was really upset about it but he didn't want to tell them but felt comfortable to tell the community health worker to ask if she could ring and explain that that is tapu for him. And he would prefer to have a plastic bag that he could put it all in...And they were fine, it was done because they didn't know. But you know I think, I don't know what he would have done otherwise. You don't know whether he would have felt comfortable to tell them. (Manager 5)

6.9 Summary

Participants agreed that there were many people to engage with along the cancer journey, and patients and whānau often found this difficult due to confusion about who to talk to, alongside inconsistencies in communication from different individuals. Māori health providers offered continuity of care by providing support at consultations, taking notes and debriefing afterwards. They were also able to ensure that patients and whānau could access wrap-around services such as financial assistance through WINZ, and referrals to the Cancer Society. Additionally, Māori health providers were in a unique position to understand and respond to cultural and spiritual needs. Their local knowledge meant that they appreciated the diversity within their communities, and the needs of different whānau.

The bridging work undertaken by Māori health providers which assisted patients and whānau to connect with cancer and other services relied on their local knowledge and established relationships with whānau in their communities. Bridging between patients, whānau and cancer services also required relationships between organisations so that information about services could be shared and services improved. Much of the bridging work that is being carried out by Māori health providers and others resonates with the example of the cardiac navigator role that sits within Whānau Care Services. To properly establish cancer navigator roles would involve dedicated resourcing and staff who were able to work with both clinical teams and patients/whānau. Information for patients and whānau also required improvement, including more Māori-focussed information and people to talk to about the information.

Although communication between primary and secondary care was not seen to be consistent or timely, participants who supported patients and whānau through their cancer treatment noted that hospital departments were endeavouring to be more accessible by working on their reception areas, arranging different clinics and importantly, providing flexible appointments. This was helpful to diverse whānau, who had different work and family commitments and schedules. Despite flexibility of appointments, some whānau still struggled to navigate their way through the cancer care system. The onus on individual patients to understand, organise and push for the best care did not always align with whānau expectations of the service. Many whānau who the participants' organisations supported did not want to cause trouble and were grateful for any health service. Others were proactive and confident in questioning and making decisions, often based on past experiences from whānau members moving through cancer treatment.

The greatest breakdown in care provision appeared to be at the conclusion of cancer treatment, where there was no transition back into primary care. At this stage of the cancer journey, patients and whānau relied on visits from community nurses who had poor availability, and there were also reports of long waiting times at outpatient clinics.

The need for a greater Māori presence in the cancer care workforce was noted by participants. Further, more training for all staff in cultural safety would help Māori to feel comfortable with the service. Having a support person from a Māori health provider organisation was often cited as serving to put patients and whānau at ease. It was considered that community workers from Māori health organisations were able to help with matters of tikanga, such as karakia before consultations, as well as improving access, communication and understanding of the cancer journey.

Chapter 7

Case 4: **Policy**

7. Roles and backgrounds

Cancer control in Aotearoa is outlined in the background section of this thesis. In brief, key organisations involved in cancer control are: Cancer Control New Zealand, including the Palliative Care Council of New Zealand, Ministry of Health, New Zealand Cancer Control Steering Group, New Zealand Cancer Treatment Advisory Group, New Zealand Regional Cancer Networks Group and Regional Cancer Networks, and stakeholders such as the Cancer Society.

The policy case comprised interviews with eight representatives from some of the organisations involved in cancer control policy and implementation. One of the interviews was a joint exercise with two participants from the Cancer Control Network (**Policy 4** and **Policy 5**). It was important to also include at least one participant who was involved in managing the funding contracts of primary health providers as this was an area identified from interviews with community and management participants, which required an additional perspective.

Policy 1 is the National Manager for Supportive Care based at the National Office of the Cancer Society. As outlined in the background section of this thesis, the Cancer Society was established in 1929 and is the main provider of cancer information and supportive care in Aotearoa. The Cancer Society has six autonomous divisions around the country and a National Office. Policy 1 works closely with Cancer Society divisions, government and non-governmental organisations.

Policy 2 is a Senior Analyst at Cancer Control New Zealand but the main focus of his work is for the Palliative Care Council of New Zealand. The Palliative Care Council of New Zealand was established in 2008 by Cancer Control New Zealand. Its aim is to provide independent strategic advice to the Minister of

Health on New Zealand's performance in providing palliative and end-of-life care across all life limiting illnesses. Policy 2 describes his work as involving policy analysis, research and reviews, and developing develop reports and recommendations which the Palliative Care Council endorses before providing to the Minister of Health as advice. Before working in policy, Policy 2 was a registered nurse, mostly working in cancer care, including six years as a clinical nurse specialist and nurse educator, nurse lecturer, and co-ordinator of a postgraduate nursing course in cancer care at Victoria University, Wellington.

Policy 3 is the General Manager of Cancer Control New Zealand (CCNZ). CCNZ is described in greater detail in the background section of this thesis, but in brief, CCNZ was formerly the Cancer Control Council, which was established in 2005 to monitor and evaluate the cancer sector under the Cancer Control Strategy. Cancer Control New Zealand provides strategic advice directly to the minister as well as the wider cancer control community. Policy 3 described the role of his organisation to report and advise directly to the minister and board with a focus on monitoring and evaluation, and comparing Aotearoa with international cancer control. Policy 3 has over 20 years of clinical nursing experience in cancer and mental health.

Policy 4 is the Service Improvement Facilitator – Inequalities, at the Central Cancer Network. The Central Cancer Network is one of four Regional Cancer Networks established in 2007. The aim of the network is to work across organisations and boundaries to promote a collaborative approach to service planning and delivery. This is achieved by linking cancer services across DHB areas, strengthening existing collaborative arrangements and developing new collaborations (Central Cancer Network, 2007). The Regional Cancer Networks are described in greater detail in the background section of this thesis. Policy 4 has a background in public health, health promotion, tobacco control and mental

health, and has worked in kaupapa Māori services as well as NGO, DHB and regional public health organisations.

Policy 5 is the Network Manager of the Central Cancer Network, providing leadership for the overall planning and delivery of the work programme for the network. She comes from a radiation therapy and management background and has worked in the cancer field for the past 20 years.

Policy 6 holds a policy position at a DHB in the Wellington region. Policy 6 described her role as looking at cancer services and how they work, alongside working with systems to make things work better. Her role was set up as part of the DHB's Cancer Action Plan in response to findings from a survey mapping cancer patients' journeys (Doherty & Associates, 2006). Previously, Policy 6 worked as a cancer nurse for fifteen years, a staff nurse in the inpatient cancer ward, a nursing team leader, and in community cancer nursing.

Policy 7 maintains several different roles at a division of the Cancer Society. Her interview was included in the policy group as she is the Assistant CE but she also manages support and information, staff training and staff management. Policy 7 was pivotal in introducing the Living Well programme to Aotearoa and in setting up KOETI.

Policy 8 had recently left her position as a Senior Portfolio Manager at the National Screening Unit (NSU). In this role, Policy 8 was responsible for the development, management and monitoring of nationally-organised population-based screening in New Zealand. Previously, Policy 8 worked in the private sector in research and evaluation. One of her projects involved the evaluation of health promotion services for Māori and Pacific women. Another involved resource development of screening material for Māori and Pacific women and an audit contract of the cultural components of the audits of screening and

colposcopy providers. In this way, Policy 8 had established relationships with many Māori health providers and was familiar with the work that they undertake.

7.1 Organisational engagement with Māori

Well we know from research and anecdotal evidence that the Cancer Society has been for some time seen as a white, middle class organisation. We are aware of that and we are trying to address that, so we have over the last few years, quite a lot has happened in that area. (Policy 1)

When reflecting on organisational kaupapa and allocation of funding, there was substantial discussion from participants regarding Māori responsiveness. This encompassed organisations meaningfully engaging with and responding to Māori cancer contributions and needs. The ways in which organisations responded to Māori were different across the cancer control spectrum. There were differences, for example, between governmental and non-governmental organisations in recognising and funding projects that would reach Māori. Some non-governmental organisations such as the Cancer Society had historically employed a 'one size fits all' approach to information and service delivery, which as illustrated in the quotation above, had resulted in the exclusion of Māori and other groups.

Participants identified government agencies and cancer initiatives that had an inequalities focus, but some also highlighted the gap between policy aimed at addressing inequalities, and the limitations on funding to enact these policies.

Government commitment to addressing inequalities

Participants agreed that resources for cancer screening, detection, treatment, supportive care, palliative care and survival were limited, and funding needed to

be used effectively. Policy 6 raised an important aspect of policy and funding, in that the rhetoric of central government did not always translate into tangible funding for health providers. She gave the example of the recommendation for cancer navigators in the *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand* document (Ministry of Health, 2010a):

And certainly the document, the Guidance on Support for People with Cancer... that strongly emphasises those roles. But once again to see how they would envisage those developing within current capacity is where the difficulty lies I guess....from government, at every level there is a lot of talk about addressing inequalities, but if there is any actual commitment to it I think those (cancer navigators) are the types of things that need to happen. So how you get from one to the other I am not sure. (Policy 6)

Participants thought that it was important for non-governmental organisations to develop and improve their Māori responsiveness. The Wellington Division of the Cancer Society was mentioned by a number of the participants for the work they had done to implement a Māori service plan. As set out in the following section, Policy 7 described how the Wellington Division of the Cancer Society went about developing their plan and highlighted the road blocks thrown up by some Cancer Society members who resisted any moves towards Māori responsiveness.

Example of a non-governmental organisation's commitment to addressing inequalities: Development of a Māori service plan by the Wellington Division of the Cancer Society

In the mid-1990s, in collaboration with a Māori health provider organisation, the Wellington Division of the Cancer Society undertook a national survey of

the support needs for Māori with cancer. The survey was undertaken to provide background for the KOETI programme which is described in Chapter 2 and also briefly in a further section of this chapter. Carrying out the survey became a catalyst for highlighting the lack of knowledge of some Cancer Society members. Policy 7 recounted, for example, another division of the Cancer Society initially refusing to take part in the survey, perceiving it to be racist. Policy 7 went on to outline further resistance to the survey. She talked about members of the Cancer Society fighting against the survey, and cited examples ranging from misunderstanding of the Treaty of Waitangi, to racism:

One of the dreadful things that happened was that there were people within the organisation that said well why would you do that? It is not our business. That is the business of central government. You know we are a not-for-profit organisation, we don't have to honour the Treaty. Really. This all happened.

(Policy 7)

...we had some fundraising groups, they were called ladies auxiliaries or women's auxiliaries that you know, fundraised in the community. We had two of them disband as a consequence of the division funding that piece of research. It was called the Pataki report (Pataki Associates, 2002). On the grounds that it was appalling that our executive had approved that funding because of all the hand-outs that Māori get. (Policy 7)

Despite some opposition from within their organisation, the Wellington Division of the Cancer Society completed their survey and the resulting report was used to help develop a Māori service plan. This guiding document was recognised by

other participants. Participants from the Central Cancer Network, for example, outlined how they had been able to work with other Cancer Society divisions to improve their responsiveness to Māori:

And that has been adopted, the principle of it has been adopted at the national level to be moving into that space ...so within our network we have got the two divisions, and they have been looking at how they can improve that, using the principles from that piece of work. You know it is things like that about having the non-government organisations being more culturally responsive. So that is coming. I think there is a way to go with that but it is happening. (Policy 5)

The Wellington Division of the Cancer Society continued to champion Māori responsiveness. When the division funded the Blood and Cancer Centre at the hospital to produce an information DVD for patients, for example, they ensured that Whānau Care Services (who operate within Capital & Coast DHB) were included in the content.

This section has shown that both government and non-governmental organisations face different challenges in responding effectively to Māori cancer care contributions and needs. As non-governmental health service providers, Māori health provider organisations also face challenges in delivering services to their communities and as outlined in Chapter 2, their role in cancer care is varied and somewhat invisible. Policy participants' awareness of the current and potential cancer care work of Māori health providers is canvassed in the following section.

7.2 The role of Māori health providers in cancer care

It is actually quite a hard question because I really don't know what they do. I would actually be interested to know what they do in relation to palliative care because it is one question that we have that I wasn't able to answer. (Policy 2)

Participants were asked what role they saw for Māori health providers in cancer control. As shown in the quotation above, some participants were not aware of the breadth of the work currently undertaken by Māori health providers. Policy 8 was able to reflect on her relationships with Māori health providers whom she contracted as ISPs to provide screening services. Policy 4 and Policy 5 had also worked with Māori health providers in implementing their inequities projects. For the most part, participants reflected on the need for cancer navigator or co-ordinator roles that could be filled by Māori health providers. There were some examples cited of work already being done by Māori health providers in this area, but most of the discussion centred on what could happen in the future.

Participants thought that Māori health providers were well placed to help navigate patients and whānau through their cancer screening and treatment. A participant from the Central Cancer Network described how, for example, one provider had utilised the established relationships of community health workers within their areas to extend to information about cancer:

... up-skilling those community workers which are the ones that have that relationship with the families. So you know if you can do that without bringing someone else in over, you know. That complexity of those different relationships type thing I can see that being very valuable. (Policy 5)

Interviewees outlined how the cancer treatment journey was multifaceted, with many different layers of complexity such as numerous clinicians to engage with, information to process, travel and family issues. Participants described the need for a cancer navigator-type role to assist with supportive care needs:

... particularly if you live outside the main centre you have to travel as well and you might have family who need someone to help sort out their social situation or parent or child is away in one of the cancer centres in a different city. (Policy 2)

Participants thought it was important for cancer navigator services based within Māori health organisations be linked formally to other mainstream services. This served two purposes. First, the role of the navigator was seen as a mechanism for providing information to other organisations. This would help educate mainstream primary health care providers in both the needs of Māori cancer patients and whānau, and the Māori support services available in their communities. Second, being linked to other organisations would promote facilitation of referrals to the navigator service. One participant highlighted how mainstream service providers were often not aware of a Māori service in their area, or were reluctant to refer:

And the other part of the equation of course is making the service providers aware that that support is available and that is certainly something that we need to be working on locally because a lot of people wouldn't be aware of those services being available so although they are there, they are not necessarily used as much as they could be. (Policy 6)

There was some work being done to remedy the gaps in information and lack of

referrals between mainstream organisations and Māori health providers. Policy 6 described workshops that were being held in the Wellington region, informing mainstream providers of the work by Māori and Pacific providers in the area of cancer support:

... information workshops have been held for providers to inform them about what happens for Māori and Pacific providers basically, in the area. And to inform them about the cancer pathway and I guess that is making their ability to support more effective but we, there isn't any system yet by which people automatically are referred to them or are asked if they would like to be referred to that support. (Policy 6)

Workshops such as those outlined in the example above were useful in facilitating opportunities for those working within cancer care and support to learn about each other's services and develop good relationships so that patients could be confidently referred to different services. The importance of these relationships between different service providers throughout the cancer continuum will be described in the following section.

7.3 The value of good relationships between organisations

So most of the time I am bringing everyone around together and saying actually, we all need to be working together, because this is only going to work if we are all talking the same talk here. (Policy 8)

Participants consistently highlighted the critical role that relationships between organisations played in cancer control. Organisations included primary care service providers, secondary and tertiary services at the hospital, hospices, and organisations that provide support and information such as the Cancer Society. Relationships also included those organisations connected through funding contracts and service provision, such as DHBs, independent service providers (ISPs), and the Ministry of Health.

Participants thought that for service providers, the benefits of good relationships included knowing what each other were doing at each stage of cancer care from prevention, screening, diagnosis, treatment, and survival through to palliative care. By understanding what services were being delivered and what information was being developed and disseminated, organisations could compliment and support each other and importantly, share initiatives that were working well, or learn from things that did not work as well as expected. This theme was particularly prominent among the interviewees who work for the Central Cancer Network, as their role involves developing and implementing cancer control policy, and part of this was bringing together service providers to consider inequities in cancer service provision.

Participants from the Central Cancer Network described a focus of their work in bringing together organisations who provide cancer care and support. This had resulted in collaborative work plans, Māori equity advisory groups, and on-going relationships that benefitted other projects. One participant specified the role of the network in facilitating relationship-building, rather than trying to dictate direction:

So our role is to go and work with them and try and help them to identify some of the gaps and then to enable them to create some action in their area which is relevant for them. (Policy 4)

The work of the Central Cancer Network had an equity focus, specifically addressing inequities for Māori engagement with cancer services. An important aspect of addressing inequities was linking health providers and iwi. Policy 5 described bringing cancer service providers together in a marae setting to build relationships between each other and with tangata whenua:

...so there has been a focus on demystifying cancer for Māori patients which are like a road show that you can take out to a, generally into a marae setting and deliver that about cancer, cancer services and the cancer pathway so it informs your community, it informs, you bring your cancer service providers together in the same day so therefore all those relationships are built with that particular marae that you are working with. (Policy 5)

In another example, Policy 4 outlined how bringing together Māori clinicians and researchers for an equity advisory group on a bowel cancer screening project had benefitted other screening projects by cementing relationships and creating a structure for future advice:

And then from there, because there are around certain issues like lung cancer and tobacco control that there isn't a Māori go-to group really. And that can actually speak for and behalf of those issues. Yeah so there is a lot of potential there and to be a vehicle for other government agencies and other sectors in health to also plug into if we have the right people around at our table. (Policy 4)

Participants from the Central Cancer Network were pleased with how fostering relationships between different organisations enabled them to see what each other were providing, which had in some instances resulted in collaborative work plans. Cervical screening providers in one region, for example, had collaborated to plan and deliver initiatives together. Policy 4 described the beginning stages of this collaboration, with a meeting organised by the Central Cancer Network:

...they were working down the road from each other with a similar contract or the same, not even knowing that each other existed. So it is about having everybody in the same room and saying hey we have been doing this, we have been doing that and identifying all of those areas, those weaknesses and then at the end of this meeting everybody decided oh well we actually need to work together, to collaborate. (Policy 4)

Participants recognised that building relationships between cancer service providers and communities took time and resourcing, as well as motivated individuals who were able to keep the momentum going. Policy 1 described the many different people who needed to be on board and the practical challenges of even being able to find the time to meet:

... the oncology treatment centre staff, the social worker, the physio, the nutritionist, all of us are going to be talking about it together... The other thing is, everyone is so busy in their day job that to sit back and address what are really tricky issues is, you know it just doesn't happen...I mean the oncologists are hugely busy with the clinics...the radiologists are the same, the radio therapists. Everybody is busy. We are all busy. (Policy 1)

There was also recognition of the need for individual ‘champions’ within organisations to build links with other organisations and continue to drive forward with relationships. For a participant from the Cancer Society, it was important to have staff who had flexibility and creativity in making links and keeping people informed:

So the ones that are working more creatively are doing so because they are outgoing and personable and smart about meeting people and making links and keeping people informed. (Policy 7)

In another example of an individual champion, Policy 8 described a DHB manager who made it a high priority to bring together people from different parts of the cancer screening service to promote relationships and collaboration:

... she runs these quarterly meetings, that everybody in breast and cervical screening comes along ...because she believes that you should be dealing with it in a holistic nature and you know it is about the women and this is what makes services better for women. (Policy 8)

Participants agreed that it was important to have Māori ‘at the table’ for multi-organisational meetings, to have a Māori voice and to collaborate on projects. One participant highlighted a barrier to these relationships, however, in that Māori health providers had sometimes been seen as ‘not cancer-related’ and therefore overlooked.

Participants from the Cancer Society, both at national and divisional levels, were explicit in describing the need for good relationships between their organisation and Māori health providers. The participant at national level (Policy 1) explained that there were different divisions within the Cancer Society, with some having

good relationships with Māori health providers and others still in their infancy. She noted an example of a Cancer Society division on the East coast where cancer information was being disseminated in a marae setting, which promoted relationship-building between the Cancer Society, Māori health provider and community.

The ability of organisations to develop and sustain relationships with each other also impacted on funding decisions. A participant from the Cancer Control Council described the need for a group submitting a palliative care funding proposal to have links with their cancer centre for support:

But one of the things that I wanted to see was that that provider had a good link with the cancer centre because for one thing they need to know what is going on with the patients and they need to get good referrals and good information and communication. But they also need someone to go to if they pick up that this person is having a problem. And so it needs to be good two-way communication there and support. (Policy 2)

Policy 8 described the importance of good communication and relationships between DHBs and ISPs in cancer screening. Policy 8 had noted a breakdown in relationships between the two over a number of years which she attributed to staff turnover and a loss of momentum in keeping contact. In their role as a funding administrator, Policy 8 had found that it could be time-consuming being a “referee” in the relationship between the two services. The importance of communication between the NSU, DHBs and ISPs is further reported in a later section of this chapter that focuses on funding contracts. Communication between organisations also relates to the following section which explores sharing of information between primary health care providers and the hospitals.

7.4 Information-sharing between primary and secondary care

So it is good that that stuff is coming out now, so that GPs will know what to do but there also has to be the other side where secondary care is responsive to referrals and providing information as well. And there are still occasional people who fall through the gaps. They say I have been missed, and there needs to be a way to make sure that doesn't happen. (Policy 2)

Participants were asked what they thought about communication and sharing of patient information between primary and secondary care. Their discussion related to two issues: first, the perception by some participants that GPs missed out on information about their patients' care once referred to a cancer treatment centre; and second, the systems in place for primary and secondary care to talk to each other, and, in particular, the variation in information technology (IT) systems throughout the country. One interviewee also raised the issue of information system users having an inadequate understanding of privacy legislation.

Referral pathways

Participants from the Cancer Control Council thought that for the most part, GPs were doing a good job of passing on patient information to the hospital, but that the information flow back again could be slow or non-existent. Policy 2 outlined work by the New Zealand Guidelines Group in informing GPs of reasonable timeframes for cancer care and referral pathways (New Zealand Guidelines Group, 2009), but thought that GPs are often ill-informed once they refer a patient to the hospital.

Policy 3 stressed the importance of GPs being kept informed on patient progress throughout their treatment. He agreed that communication from GPs to hospitals appeared to work well, but that the information back from the hospital to the GP was lacking:

There is a sense, and I think that is where the communication needs to be a lot better, in the fact that you communicate to the hospital when you get your patient into the hospital but the communication coming back from the hospital seems to be varied. (Policy 3)

Policy 7 outlined why GPs needed information about what had been happening for their patients in hospital:

...a letter that goes to the GP – which they say always happens, but we know doesn't always happen... so the GP has that, so that in six months' time, if you go back to your GP for whatever, that he has this whole history of what has gone before and that the discharge plan also includes a whole lot of information that patients need to know in terms of referral of medications, what do they do if something goes wrong. (Policy 7)

Compatibility and development of Information Technology (IT) systems

Participants agreed that current IT systems containing patient cancer care information were variable throughout the country, with some areas facilitating online information-sharing and access by primary and secondary care, and others having different systems that were accessible only by the hospital, and vice versa. A number of participants described many different record-keeping arrangements by various organisations:

Hospices run a different IT programme to what GPs run. But then nobody runs the same sort of system as the hospital.

We have got twenty district health boards and most of them are running different IT systems. Well to fix that, to fix that communication we need to invest into our IT system. And be really upfront that the GP will be able to see what is happening. (Policy 3)

Participants were divided on the way forward for consolidating IT systems. Some acknowledged that the system was not perfect, but that it would take a phenomenal amount of time and resourcing to implement a national system. One participant described the potential for a “Novopay-type outcome”. (Novopay is a nationwide, web-based school payroll system that attracted substantial media attention in Aotearoa when it was introduced in 2012 and caused significant errors in the salary payments of thousands of primary and secondary teachers throughout the country over a 12-month period (Lovegrove, 2013; Shuttleworth, 2013)).

Others saw a nationally-accessible IT health system as a high priority. One participant thought that since Aotearoa was not a large country, it should be possible to implement a national information system. He saw many potential benefits in this, not the least, information-sharing between primary and secondary care:

... because of the way their DHB works, all their GPs are part of the DHB. They all have the same system so they can all access patient information anywhere on the coast, the same information for the patient. But if you are, say a patient from Auckland DHB and you are visiting Dunedin and you get sick, they can't help you. (Policy 2)

Another participant outlined improvements between Wellington, Wairarapa and the Hutt Valley hospitals so that each could view the other's records:

...there has been a system developed in IT so that Wellington and Wairarapa and Hutt can all link into each other's 'Concertos' (a type of patient information management system). So from the Hutt we can go into a patient in the Hutt and look at the Wellington records and the Wairarapa records. So we can't access and write in or alter those records at all but they can be looked at...So that will make a big difference in communication across the DHBs. (Policy 6)

Accessing individuals' screening information from the national cervical screening register was also problematic for health workers. Primary health care providers were not able to access register information directly. The participant from the NSU described how primary health care providers wanted to know women's screening status in real time, but had to telephone the registry:

... primary care want immediate access to it and at the moment they don't. They have to go through the actual register staff. And they want to know real time, quickly. And if they caught the woman at a festival or somewhere, they want to know. Even in primary care if she comes in for a 15 minute appointment, even if they just have ready access to see whether, where she is at. (Policy 8)

Tied in with IT systems was the understanding of people working in the health system of appropriate information-sharing. Policy 2 considered that a barrier to sharing information was the lack of understanding by people employed in both primary and secondary care on privacy and legal implications:

... what is going on around the country is that IT systems weren't being used properly... people were not using the Health and Privacy Information Act or the Health Information Privacy Code properly. They were using it as a barrier rather than to facilitate information-sharing. (Policy 2)

This section has presented the views of interviewees regarding barriers to information-sharing between health service providers, and the many different IT systems involved in capturing cancer patient information that are often not compatible. One area of cancer care in particular where information was not readily available was palliative care. It appeared that information was not collected consistently across the country and this hindered policy makers in obtaining a bigger picture of palliative care service provision in Aotearoa. Participant views about these issues are described in the following section.

7.5 Regional variation of palliative care provision

Because at the moment it is, access is widely varied across the country... but other places like Tairāwhiti, they have a hospice service there but it is a fairly small service compared to their population. (Policy 2)

Not all participants had experience of palliative care. Policy 2 could speak from his Palliative Care Council role and was able to outline much of the palliative care policy work that was being undertaken at the time of these interviews. Policy 3 also had some knowledge of palliative care policy. The two participants from the Central Cancer Network were aware of palliative care initiatives that were being undertaken throughout their region.

As shown in the quotation above, kōrero about palliative care centred mainly centred on regional variation, in that some areas, such as Wellington, had hospital, general practice and hospice care available, whereas other locations, particularly rural areas, might require patients and whānau to travel large distances and stay away from home for palliative care. However, it was difficult to measure regional variation as it appeared that national data on palliative care was not collected, and this was a priority for the Palliative Care Council. Policy 2 described the need to investigate what palliative care services are available on a national basis and had begun some work to examine this. He outlined how Hospice New Zealand has undertaken a member survey but aside from this, little was known about palliative care nationally. In addition, Policy 2 explained the challenges of collecting information from palliative care providers including hospices and DHBs:

And it is not actually that easy to get this data because they all do different things and collect information differently, and report it differently. Some of them have really good IT systems and some of them don't. So it is quite challenging. (Policy 2)

Participants thought that once the extent of palliative care provision in Aotearoa was established, a better picture could be drawn of what palliative care services were in place to meet a growing need. Policy 3 reflected on an ageing population, and recognition that palliative care is an essential part of care rather than a 'nice to have'. It was agreed that for most patients, generalist palliative care would meet their needs but relationships between generalist and specialist palliative care providers, such as hospices and GP practices, were crucial in order for primary care providers to be supported in their palliative care provision.

The other part of palliative care that was described by one of the interviewees, related to cultural safety. Policy 5 described an evaluation underway of the cultural appropriateness of the Liverpool Care Pathway for the Dying Patient (Liverpool Care Pathway). At the time of this research, the Liverpool Care Pathway was the best practice clinical model designed to improve the quality of end-of-life care (Ellershaw & Wilkinson, 2011). Because the pathway was developed in the United Kingdom, it was not known how appropriate it would be for Māori. The evaluation therefore focussed on gaps in the Liverpool Care Pathway regarding cultural identity and needs. Policy 5 also discussed the positive influence that Māori Liaison and kaiawhina (assistant) roles had in encouraging and looking after Māori in hospice care, but stressed the need for a more co-ordinated approach:

So a number of kaiawhina type roles that have been put in around palliative care which I think are very effective in the areas that they are in. But again it is pockets of investment and pockets of activity. It is trying to get a bit more of you know co-ordinated, equitable approach around these things really.

(Policy 5)

This section has explored policy participants' insights into the regional variation of palliative care in Aotearoa and the lack of consistent information about palliative care service provision. Despite these barriers to informing policy, there was agreement that palliative care catered to whānau needs as opposed to treating individual patients. This whānau focus, alongside a co-ordinated and equitable approach to service provision described in the quotation above, is further examined in the following section which canvasses participant views on the place of whānau ora in cancer care for Māori.

7.6 The place of whānau ora in cancer care for Māori

And what we are realising is it is not just the people with cancer that we need to talk to, it is whānau members and the health providers that are working for them. (Policy 1)

Participants talked about whānau ora in two contexts: first, the importance of whānau wellbeing throughout the cancer journey; and second, the Whānau Ora Initiatives, which will be described in the next section of this chapter.

The needs of whānau experiencing cancer

Interviewees shared examples of whānau needs for Māori experiencing cancer. There was a lot of discussion about how the health system historically has not been oriented towards whānau, and has instead been focussed on the patient. Policy 2 described findings from *The Voice of Experience* survey (Cancer Control Council of New Zealand, 2010) which showed that cancer patients wanted more involvement of whānau in decision-making, as well as having whānau and living situations taken into account when doctors outlined treatment plans.

One participant described the many difficulties that some whānau faced in day-to-day living which negatively impacted on their ability to access health services. Something as simple as participating in a cervical screening programme by attending a smear appointment could be very difficult for many women. Policy 8 described these sorts of challenges for women who were burdened with lives so chaotic that they were barely surviving:

Like if they work in a factory and they work 7 to 7 then there is no way they are going to get to colp (colposcopy)... but, the main thing that I think, that they tell me stops them from accessing the services, is what someone said to me is personal chaos. That their lives are just under the survival, just sitting on the edge of surviving in daily life. That a blip and they just crash and yeah, the car runs out of petrol, just can't cope with the rest of the world...you know all of the providers talk about that and as soon as I say personal chaos they say exactly. That is exactly it. (Policy 8)

Two examples were provided of organisations that put whānau at the forefront of care. First, participants agreed that palliative care was strides ahead of hospital care when it came to looking after the whole whānau instead of the individual patient:

So I think it is a bit different. In an acute setting in a hospital you tend to be predominantly focussed on the patient...and their journey but palliative care is much more holistic so yeah the whole family would normally be included as a, just a way of doing things. (Policy 2)

The second example of healthcare that welcomed and included whānau in patient care was paediatrics, and in particular, Starship hospital in Auckland which had designed their buildings to accommodate and support whānau:

I have never ever seen a service that is so family orientated. Right down to a family, rather large, it is about the size of this boardroom. What they term a family room and it has got a kitchen you know where the families can go. (Policy 3)

7.7 Administration of cancer service funding

contracts

I was trying to think how to make this, how to recognise what they do. And I thought if you have got say 10 Māori women who have never been screened before who have high grade, and who you get to colp(colposcopy) and treated and back in the programme, the cost savings to the health system, you know for 10 women who could have died of cancer, I think that Māori health provider has earned really just in one year with ten supports. (Policy 8)

Not all participants were involved in the administration of funding contracts to primary health care providers. Of the interviewees who were able to talk about funding and contracting, those from the Central Cancer Network described funding available for activities related to their work. Additionally, Policy 2 had been involved in funding decisions regarding palliative care and Policy 8's role involved extensive contract administration and management. When these four participants talked about funding, their discussion focussed primarily around three areas: contract expectations and reporting; communication; and funding instability.

Contract expectations and reporting between funders and providers

In her role as a Senior Portfolio Manager at the NSU, Policy 8 manages multiple contracts with ISPs and DHBs for health promotion and breast and cervical screening programmes. Māori health providers are counted among the ISPs. Policy 8 outlined the current contracting environment for breast and cervical screening. ISPs receive bulk funding for invitation and recall into screening

programmes. This funding covers health promotion activities in the community, such as running or participating in community events like galas and field days. The NSU also funds opportunistic smears through DHBs which contract out to PHOs. Additionally, the NSU pays ISPs directly for smears. The payment recognises the extra work involved, such as a Māori health provider visiting a woman or providing transport:

So we have two different rates and then we pay about \$157 or something for the support to colposcopy. But like I said that \$157 will only be paid when they take the woman to colposcopy. So if it takes, she just drops around and picks her up and takes her they get \$157, if she spends ten times coming to see her, she gets \$157. (Policy 8)

Policy 8 stressed that the main focus of her job was developing relationships with the ISPs and helping them to undertake their contracts, rather than the 'policing' of contracts:

And that is the kind of service development support role I think that we have in contract management rather than a punitive, you haven't done A, B and C as set out in your contract. I think it is you know developing them, helping them understand what we need. Helping them get, well giving them the information that they need to do the jobs. (Policy 8)

The NSU seeks to provide the opportunity for all eligible people, particularly those who are Māori or Pacific, to take part in organised screening programmes that best meet their needs. Policy 8 outlined working with regional services to make

sure the register is working well in their area, including implementing prioritised health promotion activities for Māori, Pacific and Asian women:

They can do it for the whole population, but they must target those women as our priority women, and then obviously they have been really proactive in the community, getting primary care together, linking up people, linking colposcopy with the ISPs which is really important too, all of that sort of stuff.

(Policy 8)

Policy 8 outlined the challenges in appropriately funding Māori health providers in a way that recognised the background work that goes into getting women to cervical screening, colposcopy and breast screening. She gave the example of a rural ISP transporting women to assessment and treatment. In this example, women required transport from Waikato to Tairāwhiti, which was almost five hours of driving each way.

... if you are going to go that far, chances are she is going to want to take her whānau or she doesn't want to go because she doesn't want to leave them...But how do you fund that?

...Working out what would be best, how can we value that time but still make it sustainable in terms of funding. (Policy 8)

At the time of the interview, the NSU were in the process of consultation to change the way they fund health promotion and screening. Instead of funding ISPs directly, the NSU were planning to allocate all funding to DHBs for administration. This was considered by the NSU to be a more effective way of administering funds:

Because they have that, DHBs have a lot more flexibility to move money quicker than us, like the Ministry takes so long, to do things, to get there are sign off processes and stuff like that but also DHBs have the local knowledge and most of them have direct contracts with Māori and Pacific providers anyway. (Policy 8)

On the other hand, by channelling all funding through DHBs, it was not clear whether ISPs, including Māori health providers, would be guaranteed future funding:

The risk I think will be I think we fund generous contracts, relatively generous and I am not sure that DHBs will do the same things or that we can ensure the money goes to the ISPs either, so I mean that is something that the Ministry has to think about, whether it is ok with that. (Policy 8)

The Central Cancer Network had provided a small amount of funding to different providers for their own cancer control initiatives and found that providers had used their funding in diverse and innovative ways. They outlined the ability of different providers to deliver programmes on a shoestring budget:

... just on the demystifying cancer programme, some of them took a community focus to it, so getting the information out to the communities. But Whanganui took a workforce focus on it, so used that same sort of process but used their community workers, the whānau ora workers out in the community to up skill them about cancer. (Policy 5)

Another aspect to managing funding contracts was the ability of ISPs to report on the work that they were doing. As well as ticking the boxes to show how many women had been screened, Policy 8 talked about ISPs wanting to share more contextual information about the work that they do. From the perspective of the funder, hearing women's stories could be very helpful in providing information to the Minister of Health and could impact on future policy:

Because I think things like that, those little stories, they can go up to the Minister when we talk about, if we need approval from someone to review these or continue them or whatever, when we have got little bits of information it becomes a story, we can tell the story of what these services are. (Policy 8)

Policy 8 pointed out that although sharing the stories of women who were supported to screening was a useful tool in alerting policy makers to the importance of such work, but the breadth and depth of the work undertaken by ISPs in the community was not necessarily reflected in the narrative section of their reports:

I mean I liked reading it because I think it is useful, but it is just how do I turn it around and share it wider so that people understand...But the other thing is, reports themselves are often quite useless, because people don't really know what to write and often these providers are, their strength is the women and the community networks and not necessarily report writing. (Policy 8)

Policy 8 had worked at making reports to and from providers a useful exercise for both the providers and the funder. She described efforts to improve the

reporting process so that information and feedback were a two way street between the providers and the funder. Policy 8 thought that there were differences between DHBs and ISPs in their expectations of the NSU as a funder. She described, for example, Māori health providers considering that the NSU are 'takers of information' who provide little feedback, but the DHBs were more accustomed to managing funding contracts and clearer on what to expect from the NSU:

The DHB providers are more used to that role too because they contract and the ISPs were just like wow, I didn't know you could give us anything that is useful...But, yeah I think it was something, yeah I was trying to improve it, so it would be useful to them too. (Policy 8)

The importance of communication between funders and providers

Participants involved in funding contract management described the importance of communication between funders and service providers. Communication between DHBs, ISPs and the NSU was important, for example, so that all parties were clear on what the funding covered, such as expected numbers of patients to be supported to screening. When ISPs did not understand their contracts, there could be a resulting lack of support for women.

Policy 8 illustrated how a funding misunderstanding had been rectified during a meeting about colposcopy contracts. She outlined how the funding for support to colposcopy contract had a minimum of support for 10 women, but that this could be increased for providers supporting more than 10 women. Policy 8 had discovered, However that one of the ISPs was operating on the basis that there was a limit of 10 women they were able to support under the contract:

... and all this time they thought of that as a limit rather than a base, a bottom amount so they weren't, they were trying to ration them out. (Policy 8)

As well as communication between funders and service providers, communication between DHBs and ISPs was crucial so that organisations could appreciate each other's kaupapa. Policy 8 described, for example, a 'disconnect' between some DHBs and ISPs in that DHBs did not always appreciate the breadth of the work that ISPs do with their communities, or understand why a community health worker would not be available to support a woman to attend a colposcopy clinic:

Like the sort of feedback that I would get from colposcopy clinics is that they would say we have ten high grade Māori women that need to be picked up, and we ring the ISP and they say sorry we are too busy, we have got a festival on ... And you know often ISPs' complaint is that they don't get the referral until 9'oclock in the morning of the time and that woman has got an appointment at 11'clock and they are like we are not miracle workers either, if you can't get hold of her, not sure what you think we are going to be able do. (Policy 8)

The Whānau Ora Initiatives

The Whānau Ora Initiatives are described in more detail in Chapter 2 of this thesis. The interagency collaboration that the initiatives facilitated was recognised as an example of improved communication between organisations. Participants from the Central Cancer Network welcomed the Whānau Ora Initiatives as they had seen how ineffective organisations could be when they did not work together:

Because we see some of the problems of like not everybody working together and that is one of the main reasons for the Whānau Ora framework, is health providers not working together at all. By working with the local cancer network is a project for all of them to work on, and it is around reducing inequalities. (Policy 4)

The following section steps away from funding administration and focusses on the views of participants regarding the information and support services available to patients and whānau experiencing cancer. The importance of inclusive, timely and appropriate information for patients and whānau will be outlined.

7.8 Information for cancer patients and whānau

I think we need to be investing more into multi-pronged attacks on communication. I think we have a tendency to put one message out there and all we do is translate that message into different languages. (Policy 3)

Participants were asked if patients and whānau were able to access the information they needed throughout their cancer journey. This included clinical information as information about support services available. There were two parts to this discussion. First, participants talked about the need for information delivery that is specific to Māori. Examples were given of information delivered face-to-face in support groups or information sessions. Second, participants discussed the timing, accessibility and suitability of written information available to patients and whānau at different stages of their cancer journey.

The need for Māori-specific delivery of information about cancer

So I suspect that might be some of the issue around why Māori present late, because they don't get good quality, easy to understand information and delivered to them in a way that they feel comfortable. (Policy 2)

Participants agreed that a 'one size fits all' approach to cancer information was not adequate for reaching all Māori. Information initiatives that had been developed by Māori for Māori had been received well and these were being shared between networks:

They did development of Kite (basket) Ora (wellness) which is a Māori information package for cancer patients. And again they have developed that up with their funding but all of the other regions are now looking to adapt and adopt components of that because they have seen it as an excellent resource. (Policy 5)

There was discussion about the suitability of face-to-face exchange of information rather than distribution of written information to Māori cancer patients and whānau. Two examples were given of face-to-face support and education programmes. One example was information evenings for Māori men about prostate cancer which was part of a sports training programme. This was delivered by Policy 2 from the Cancer Control Council. The other face-to-face programme for Māori was KOETI, which is described in detail in Chapter 2.

Example 1: The Tane Triathlon hui

Although his work is primarily in policy, Policy 2 outlined other work facilitating hui which delivered prostate cancer screening information to Māori men who were

part of a sports group. Policy 2 described how this hui filled a gap in men's knowledge about prostate cancer:

They have all been marae-based... and as a part of that they build up to it over a couple of weeks, doing exercise and they have a series of evening presentations as well and I guess the thing that struck me from that out of all those things would probably be, there was not a huge amount, maybe 40 men, none of them really have a good understanding about what their prostate was, what it did, but also about prostate cancer. So for almost all of them it was news, real brand new news. (Policy 2)

By getting the information in a safe environment, related to a sporting activity, hui participants were able to ask questions and share experiences:

At one of them, we had a guy who had prostate cancer treatment so he talked a bit about his story and he was a normal bloke saying what it was like so that was good as well. (Policy 2)

Policy 2 felt that face-to-face hui were a good way for Māori to access information about cancer prevention and screening. In this example, the triathlon group facilitated a comfortable environment for Māori men, who in this participant's opinion did not always go to the doctor if they had concerns about their health. He acknowledged that this form of information distribution was resource-intensive; however, it did have the benefit of being shared beyond the hui, by the attendees, with their whānau and friends:

...but there is a lot more than just 40 men who need to know about it. But if they go out and spread it to their mates and stuff, yeah. (Policy 2)

Example 2: KOETI

The other example of face-to-face education and support was KOETI, the kaupapa Māori educational and support programme for cancer patients and their whānau. Participants from the Cancer Society were able to describe in detail the introduction of the Living Well programme and the subsequent development of KOETI. Other participants were also aware of the programme.

Policy 7 described introducing the Living Well programme from Australia in the 1990s and how this was used as the basis for developing an education and support programme for Māori. Both the Living Well and KOETI programmes are described in greater detail in Chapter 2. Policy 7 outlined how introducing the programme sparked a chain of events that promoted awareness within her division of the need for meaningful collaboration between Māori health providers and the Cancer Society and, in a particularly reflective comment, showed the tendency of mainstream organisations to assume they know what is best for Māori instead of listening as equal partners:

... there was a hui that was here with Māori providers and the outcome of that, it was kind of like here is this fantastic programme and we think, we think this would be fantastic for you. And it was well actually, this is not going to work for us and actually there is a first step. That is very nice of you but it is a first step and one of the things that would be interesting to know is actually what Māori need. (Policy 7)

The Wellington division of the Cancer Society heeded this advice, and funded research examining the needs of Māori with cancer (Pataki Associates, 2002). Armed with findings from the research they were then able to collaborate on developing the KOETI project. This evidence base to inform the programme had also benefited the Cancer Society at national level. Policy 1 outlined, for example, how being part of the developmental process for KOETI had raised awareness within the Cancer Society of access and barriers to services for Māori:

So we have done quite a lot of work with Māori particularly around the Living Well programme. That has alerted us to the wider picture of why people might not be accessing services and it is not just for cancer, it is accessing medical care and the taboos that are around the, you know being ill and who to talk to and what to do about it. (Policy 1)

This awareness had led to a focus on Māori responsiveness, and other Cancer Society divisions were following Wellington Division's lead of developing Māori service plans. Policy 1 was explicit in describing their organisation as a mainstream one that cannot speak for Māori, and that the KOETI programme was intended to be by Māori and for Māori:

So they take the programme and it will become whatever it needs to be in whatever iwi, hapū, Māori provider, wherever it is. And that is the model. So we want Māori to understand that they can access us and we will guide them to where they need to go, or we will be working with the Māori providers, sharing our expertise in an appropriate way. (Policy 1)

There were differences between the Living Well and KOETI programmes that made the latter a safe space for Māori. Policy 1 described a different comfort zone for those who attended the Living Well programme, in that it was more structured and had the same people attend from the first session to the last. However, the Living Well model did not necessarily fit with all groups and there were differences in the way KOETI was delivered that made it more acceptable to Māori. Policy 1 described the importance of karakia and mihi (introductions) for KOETI that was not present at the Living Well programme, as well as flexibility in attendees:

Whereas the Māori version, KOETI, it is just so different. It might be Auntie who comes the first time to check it out. Thinks it is great, brings the person that has got cancer along the next time. They might not be able to come to the third session, so a whānau member comes on their behalf and they share the information. (Policy 1)

Another example of how the Cancer Society came to realise differences in requirements for delivering a programme by Māori for Māori was the place of kai in the KOETI programme. This provided a shift in thinking for the Cancer Society as they moved from 'tea and biscuits' to realise the critical role of kai in hosting Māori gatherings:

In the non-Māori version you know, you have tea and biscuits. The Māori version you have lunch or dinner, depending on what time of day. And that is not negotiable. It is the sharing of kai and so on that actually gives the group its essence of trust. So we have learnt that. We used to look at budgets and think they are not having five hundred dollars of food, don't be ridiculous, we could do it for \$50. Now we have understood that that is not negotiable. That is about acknowledging what needs to happen. (Policy 1)

Participants also discussed how patients and whānau were not all the same, with different preferences and needs. Thus, support and education programmes such as Living Well and KOETI did not appeal to everyone:

For some people going to a group with other people would be the last thing they would want to do. But for other people it is a blessing and a lifeline for them. So how do we best get those links for each person to ensure that they get where they need to go. (Policy 1)

Timing and content of information

Information relevant to screening, detection and diagnosis

There was discussion about the role of cancer information in dispelling fears, especially at screening and detection. The participant from the NSU (Policy 8) described patient misunderstandings and fears around screening, such as that any abnormality might be seen as a cancer diagnosis:

Because that is another thing, a lot of people don't actually understand that. They either think that having a smear is, just the process is enough, not that there is a result that comes out, that you have to do something. And then if they do have an abnormality, even if it is low grade, they think they have got cancer, and they are having cancer treatment, not pre-cancerous stuff. So there is a lot of misunderstanding about that. (Policy 8)

Although not specific to Māori, participants agreed that people had different information requirements at all stages of the cancer journey, and often did not want to be overloaded with information at the time of diagnosis. One participant

talked about patients being bombarded with information packs that were never opened:

Yeah so I think the main thing for us is understanding that some people want information and some people don't. And we have done a lot of work to put good information in the treatment centres so that everybody can be given a pack that has got everything in it and then we discover that the people, you might see them six months later, and you say did you know and you were given this pack and I don't know where the pack is, I couldn't open it. (Policy 1)

Lessons learned from giving too much information to patients had resulted in a patient-centred approach for the Cancer Society. This meant giving the right information at the right time for each person, which posed problems for an organisation that relied on patient referrals or on having patients opportunistically pick up a brochure or take note of the 0800 number from the hospital.

Participants agreed that less is more when it came to giving information to cancer patients and whānau. Policy 6 reflected on her time in a lung cancer support role and how a one-page information sheet with links to different services worked well:

But the Cancer Society does really good packages on each cancer diagnosis. And when I was doing that lung cancer support role I would take those with me but they were too much for people. So they also do a really good leaflet that is just a page which outlines what is available. I think it is better to give just that page and then let people know as they go along what is available. (Policy 6)

Information for people experiencing cancer treatment

The Cancer Society is the main providers of cancer information in Aotearoa and their information services are outlined in Chapter 2. Getting the word out about the services available from the Cancer Society was described as a challenge by one participant, who thought the 0800 phone number was becoming more popular:

So the challenge for us is the same as it has always been. It has been having people know what we have. What our wares are and how to access them when they need to. And more and more for all of our services we see the portal being the cancer information service. The 0800 cancer information service. (Policy 7)

Another resource available to cancer patients and whānau in the Wellington region was a directory that had been developed with an inequalities focus by one of the study participants (Policy 6) with funding from the Central Cancer Network.

So that directory was developed particularly from the point of view of trying to address inequalities so it has got all the Māori health services and the Pacific health services. It has got Mana Wāhine, all those sort of services across the three DHBs. (Policy 6)

The directory had been distributed to general practices, Māori health and Pacific health providers and was also available online. The Central Cancer Network had also developed a regional directory of cancer services which linked into the local directory online. Policy 6 had feedback from providers who used the directory but it was difficult to measure how much the directory was being used by cancer patients and their whānau. Policy 6 thought the directory

was less confronting for patients and whānau than information from the Cancer Society, as some patients were afraid of the word ‘cancer’ and not ready to engage with the Cancer Society.

Information available to patients and whānau after cancer treatment

In addition to ‘Cancer Chat’, ‘Cancer Connect’ and directory information, the Living Well and KOETI programmes were described as informative as well as supportive for patients and whānau after cancer treatment. Importantly, information gained by patients and whānau about a range of cancer issues was often shared by whānau with the wider community.

All the interviewees agreed that patients and whānau needed the right information at the right time, covering clinical questions through to support services. The provision of supportive care is outlined in the next section.

7.9 Supportive care

I mean the thing about supportive care is we see the impact of cancer. It is not just about the physical condition. It impacts on every aspect of your life, so we use the Te Whare Tapa Whā model of the four pillars of the whare. And we acknowledge it is not just the person with cancer it is the whānau, whoever is, their lives have changed too. (Policy 1)

Supportive care during the period of cancer treatment

Supportive care in the context of cancer services has been defined in the background section of this thesis. In brief, supportive care encompasses essential services to meet the holistic needs of cancer patients throughout their experience with cancer (Ministry of Health, 2011a).

Although Policy 8 described supportive care in the work that ISPs (including Māori health providers) undertake by visiting and providing transport and support to whānau, for the most part, participants thought that the Cancer Society is the main provider of supportive care for cancer patients and their whānau in Aotearoa.

In addition to the services provided by the Cancer Society that are outlined in Chapter 2, at the time of interviewing, two divisions of the Cancer Society offered community liaison nursing services wherein oncology nurses provided home visits to patients, providing nursing services and also helping with practical needs such as meals and housework. Policy 1 described this as similar to a district nursing service. Other divisions had a community liaison person able to visit patients and link them with any services that they may have required.

Another part of supportive care was counselling, which for some Cancer Society divisions meant counsellors on site, and for others, connecting patients with cancer-related counsellors. Some divisions also provided massage services, support groups, art groups, exercise groups and other wellbeing related activities.

Interviewees agreed that the cancer treatment journey took its toll on whānau, and appropriate supports were not always available or accessed. The importance of those providing treatment to cancer patients finding out about the support needs of each whānau and linking them with the appropriate services was outlined by most participants. Policy 2 and Policy 3 from the Cancer Control Council described the findings of their patient survey *The Voice of Experience* (Cancer Control Council of New Zealand, 2010). The study is described in greater detail in Chapter 2. The report identified gaps in emotional support and information for patients, including psychosocial support. Findings from the study

also led to the Ministry of Health working on a supportive care guidance plan, as described in Chapter 2.

Policy 7 identified a barrier in accessing supportive care in that social workers at her local hospital were not well enough resourced to identify and respond to patients' supportive care needs, yet referrals to the Cancer Society were sometimes overlooked in lieu of hospital psychological services, which could lead to a very long wait:

...if there are major psychological concerns then people may be referred to the psych team, the psych liaison team, where the waiting list is three months. One of the reasons that I came to this job in the late eighties was to make a change in that. And that is still happening. It is still happening that if you have normal distress associated with your cancer diagnosis, that you will be referred to a psych liaison team. Well they should be referred here actually. (Policy 7)

Supportive care after cancer treatment

Participants identified a gap in supportive care in the period after cancer treatment ended. From their experience of working in cancer policy, participants reported finding little research about the needs of cancer patients at this time. Additionally, participants thought that development of a referral system from the final stages of cancer treatment to supportive care in the community was still in the planning stages.

Participants agreed that cancer treatment could be all-encompassing for patients and whānau. Policy 1 outlined the focus on getting through cancer treatment for patients and the need for someone to refer to at the conclusion of

treatment. At the time of interviewing, both the Cancer Society and the Central Cancer Network were beginning projects to identify the best ways to refer patients to support services after treatment. As well as the local Cancer Society division, patients could also be referred to their GP, but there did not yet appear to be a referral process in place:

Now where that person is, we are having those discussions now.

Is it the GP, is it the practice nurse? Is it the Cancer Society? Is it someone else who is sitting in the cancer centre but doing a different job? We are not sure. But we know we need to get that link right. The link back to the GP is essential. (Policy 1)

Some participants were unsure of how the referral after treatment should work, due to GP workloads and patient time. Policy 2 questioned the need to connect with the GP after cancer treatment had concluded, if the patient could talk through any issues with someone from the Cancer Society:

I guess they should be referred back to their GP, but I don't know what the GP is going to do. Because they are really busy. They are not going to sit down for 15 minutes with someone who doesn't really have any health issue apart from that they might be concerned or just want to talk about stuff. And I guess in that respect the Cancer Society is probably one organisation that does offer some really good support for those people with their support groups, counselling, that kind of stuff. (Policy 2)

Participants thought that much of the current cancer-related research was focussed on clinical trials or patient experiences of treatment and palliative care, but the period after treatment appeared to be largely neglected in the

literature. Both participants from Cancer Control New Zealand highlighted the need for more research in this area, particularly around depression and psychosocial needs. Policy 3 recounted an example which highlights the fear and uncertainty for those without appropriate supportive care:

And she said you know I miss seeing everybody in the hospital and, because you do build a relationship with people. And I said so what is it like, being at home and she said well it was quite frustrating because she says I sit in my lounge and I look at my tatty curtains and I think they need to be replaced but what is the point of replacing them when I could relapse and I won't ever get to use them. (Policy 3)

There was some discussion about patient diversity, in that people had different needs once their treatment had ended. Participants agreed that some patients did not wish to engage with any further information or support services, whereas others might benefit from on-going support. The Cancer Society was working to link patients better to the services that could help them. Policy 1 was mindful that patients' lives had often worked around multiple hospital appointments and, for some patients, it was helpful and comforting to have the continuity of an appointment arranged in the community post-treatment:

So it is more about, we think maybe it is about not this is your last appointment, but your next appointment is in the community. And if you go along to see so and so in two weeks time, they will see how you are going and talk through with you the options that are available. (Policy 1)

Policy 7 emphasised the excellent psychosocial support that was available through their Cancer Society division, but thought there was much work to be done in cancer treatment centres linking patients to these supports after their treatment:

...if there was effective post treatment planning, or during treatment planning that was a linking with, and this is where your next appointment is, it is with the Cancer Society and they will do that. Because we are the ones that can do that. And I suspect that what happens is that their focus isn't on the patient beyond treatment because they have got all of these new ones coming in their door. And their focus is not that.

(Policy 7)

Work was underway within the Cancer Society and the Central Cancer Network to promote better links between cancer treatment centres and those who could provide care in the community after treatment.

7.10 Summary

Participants agreed that there were many challenges for policy makers and funders in improving Māori responsiveness throughout cancer care. There were differences between non-governmental organisations and government agencies in understanding obligations to Māori as partners in the Treaty of Waitangi.

Despite resistance from its own members, the Wellington Division of the Cancer Society had led the way for cancer-focussed non-governmental organisations in developing a Māori service plan, and funding the development of KOETI.

Government agencies had a commitment to equitable access to cancer care and resources, but funding did not always match need. This was shown in many

examples including that of the cancer navigator recommendation in the *Supportive Care for Adults with Cancer in New Zealand* (Cancer Control Council of New Zealand, 2010) document that had not been implemented nationally.

The work of Māori health providers was sometimes misunderstood by other providers such as DHBs and indeed, not all of the participants interviewed were familiar with what Māori health providers do. Some participants had a funding contract relationship with Māori health providers and the Central Cancer Network participants had been involved in funding and building relationships between providers. Discussion of the role of Māori health providers centred on their ability to support whānau throughout the cancer journey and their strength in having established relationships within their communities enabling whānau to connect with services to help them through cancer screening, detection, treatment, palliative care and survival.

Participants described a cancer navigator-type role which would facilitate information-sharing with other organisations, as well as helping whānau to access services. It was noted that there was not currently a referral system to Māori health providers, and future work was required in building knowledge and relationships between provider organisations.

Participants consistently highlighted the critical role that relationships between organisations played throughout cancer control. Whānau Ora, a new interagency approach to providing health and social services, promoted such relationships, as did the work by the Central Cancer Network in bringing organisations together to collaborate on future work. However as well as recognising the importance of certain motivated individuals who were able to keep the momentum going, participants recognised that building relationships between cancer service providers and communities took time and resourcing.

Alongside the need for good working relationships between organisations, participants identified communication and sharing of information between primary and secondary care to be an area of importance in cancer control. Participants discussed inconsistencies in IT systems and understanding of healthcare workers in information privacy. When patient information was not shared adequately, patients could fall through the gaps, miss out on treatment, or not have follow-up services in place at the conclusion of their treatment.

Interviewees who were able to reflect on palliative care for Māori, described regional variation in palliative care service availability and the added complication of nationwide statistics on palliative care access not being available. Participants thought that once the extent of palliative care provision in Aotearoa was established, a better picture could be drawn of what palliative care services were in place to meet a growing need. Participants agreed that palliative care provided more support to whānau than hospital care which was focussed on the individual patient.

Participants talked about whānau ora in two contexts: first the importance of whānau wellbeing throughout the cancer journey and second, the Whānau Ora Initiatives. Participants agreed that the health system often focussed on the individual patient, but whānau could be under enormous pressure with financial, housing and education needs also requiring attention. Hospice and Starship children's hospital were described as examples of health services which accommodated the needs of whānau and made them feel welcome and cared for. The interagency collaboration facilitated by the Whānau Ora Initiatives was thought to be advantageous in terms of providers' ability to work alongside other agencies to address multiple whānau needs.

Four interviewees were involved in administration of funding contracts.

Successful funding contract relationships relied on good relationships between funders and providers, and between the providers themselves. For non-governmental organisations such as the Cancer Society, goodwill from the public also meant funding had to be carefully managed. There was a gap between policy and funding in that resources were limited and this sometimes resulted in good cancer care or prevention initiatives not being retained due to a lack of sustainable funding.

The timing, accessibility and suitability of written information for Māori patients and whānau were important, if people were to understand their care and support options. Face-to-face information delivered in comfortable spaces such as KOETI, and forums such as the Tane Triathlon groups, were thought to be very successful in reaching workshop participants and their wider families and communities.

Cancer information included supportive care, which is for the most part delivered by the Cancer Society. The need for those providing treatment to cancer patients to recognise what support is necessary and to link patients with the appropriate services was voiced by most participants. Supportive care was inconsistent throughout the country and often related to how well the particular local Cancer Society branch was resourced.

Interviewees identified a major gap in supportive care in the period after cancer treatment ended. There was little research about the needs of cancer patients during this time, and a referral system aiming to ensure that follow-up was initiated was currently in the planning stages. Whether patients should be referred to their GP or to their local Cancer Society was being debated by the Cancer Society and the Central Cancer Network.

Chapter 8

Discussion

8. Discussion

The discussion is framed by an ethic of care model which recognises the diversity, contributions and needs of whānau throughout the cancer journey as a *personal* and *social* journey of care. This journey needs to be understood in relation to *organisational* and *political* care ethics which emphasise cancer prevention, detection, treatment, palliative care and survival. The study research questions: (1) *what helps patients and whānau to access and receive cancer services*; (2) *what is the role of primary care, which includes Māori health providers and mainstream providers, in facilitating access into and through cancer care services*; and (3) *does current cancer control policy adequately address Māori needs*; are also considered in relation to the key themes arising from the study. Finally, the strengths and limitations of the research are identified.

Adapted ‘Circles of personalist care ethics’ model

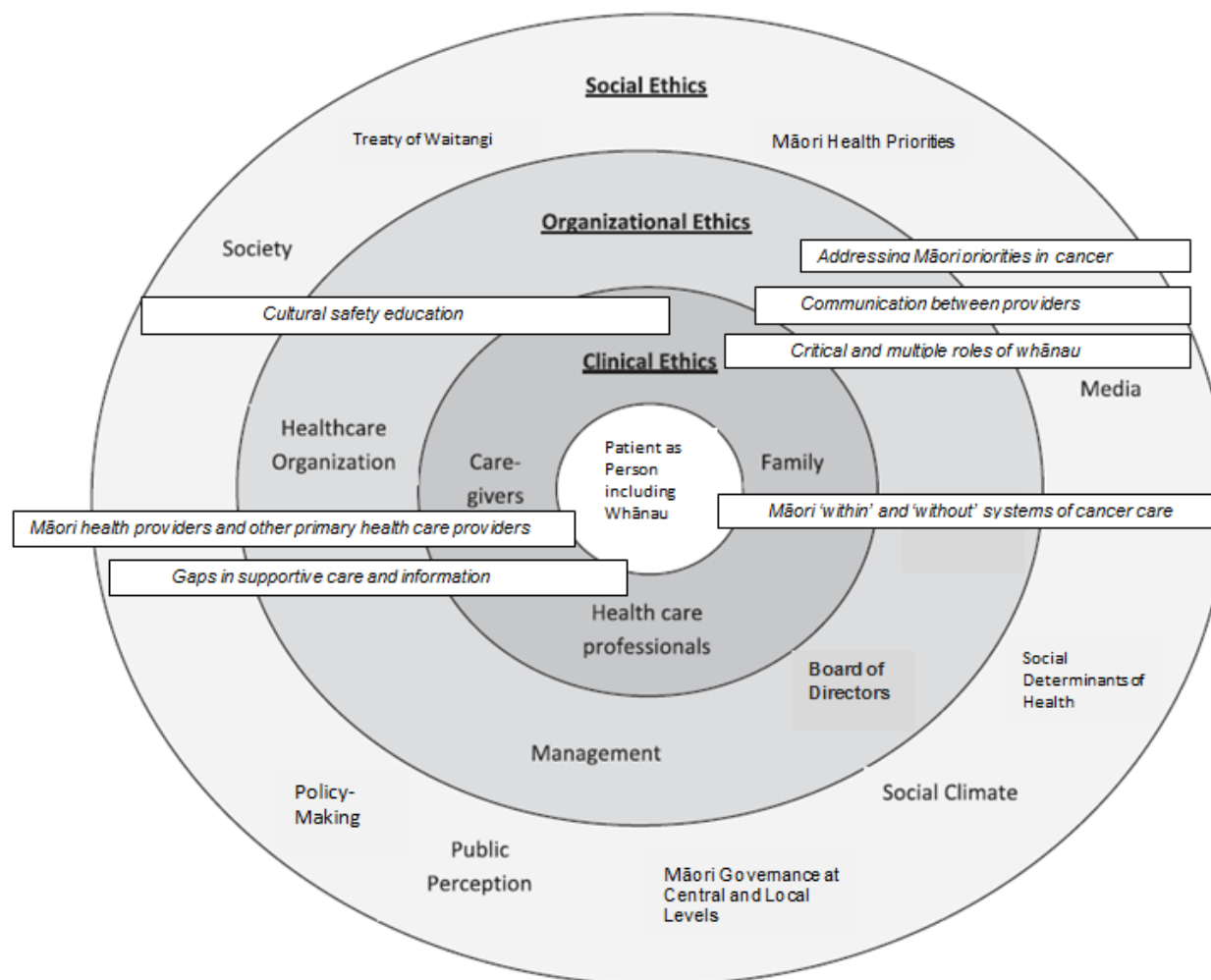
Denier and Gastmans (2013) Circles of personalist care ethics model (Appendix 10) was introduced in Chapter 3. The model uses *patient as person, clinical, organisational, and social* ethics in order to examine systems of care and how the different components of care interact and relate to each other. The four cases comprise the perspectives of care receivers (Case 1, patients and whānau), care givers (Case 2, community), those who take care of (Case 3, managers), and care about (Case 4, policy), which fit within each of Denier and Gastmans (2013) four care dimensions. Not unexpectedly, there is some overlap. For example the management case shared both their *clinical* and *organisational* perspectives. Additionally, no matter which group the participants were part of, all came from families or other whānau groups and many shared stories from their own whānau cancer experiences. Such ‘blurring of the lines’ adds richness to the data and acknowledges

participants' immersion in what Barnes (2006) refers to as the "universality of human relatedness" (p. 151). This is discussed in greater depth later in this chapter.

Denier and Gastmans (2013) model was adapted (Figure 2) to assist in structuring the comparative analyses in the following ways. First, historical determinants such as colonisation, factor in *social ethics*, with the rights of Māori to equitable health outcomes and governance, under the Treaty of Waitangi, alongside the recognition of Māori health priorities, featuring prominently. Second, social determinants of health such as income, education and housing were added to the *social ethics realm*. Third, whānau were added to the *patient as person* circle, acknowledging that many Māori engage with health systems as part of a collective rather than as individual patients. Additionally, the four levels of care ethics fit with the study's case boundaries which were based on Tronto's (1998) ethic of care framework. However, where Denier and Gastmans (2013) model diverges from this thesis is its goal of 'cultural sensitivity' in care, within a multi-cultural context. Instead, I apply the educational theory of 'culturally safe' care (Ramsden, 2002), within a bi-cultural context, as is relevant to the setting of Aotearoa and the Treaty of Waitangi. Finally, the seven key themes identified from the study are shown in the adapted model:

- Critical and multiple roles of whānau
- Māori 'within' and 'without' systems of cancer care
- Cultural safety education
- Gaps in supportive care and information
- Māori health providers and other primary health care providers
- Communication between providers
- Addressing Māori priorities in cancer.

Figure 2: Circles of Personalist Care Ethics applied to study themes (adapted from Denier and Gastmans, 2013)



Critical and multiple roles of whānau

The starting point for considering the cancer journey faced by Māori begins with a shared understanding of the importance of whānau throughout cancer care and support, and how each whānau is different. Connection and care are recognised as intrinsic parts of whānau life. Particular to the whānau theme is the need for care givers, those who take care of and care about, to recognise the strengths of whānau in providing care. Denier and Gastmans (2013) approach this awareness of collective ownership of care by describing “autonomy as a relational value” (p. 41) whereby whānau interdependence is considered a strength.

This strength in interdependence has been previously described by Durie (1994) who pointed out that for many whānau, pursuit of individual success and looking out for oneself, instead of the collective, is seen as a sign of immaturity. The united strength of whānau has been compared to other collective-based cultures in Aotearoa such as Pacific Island and Korean families (Frey et al, 2013; Te Momo & George, 2013) and across Indigenous experiences internationally (Shahid & Thompson, 2009).

The interconnectedness of the relationships between elements within the *patient/whānau* and *social ethics* spheres is also important. In particular, the way that media influences public perceptions, and the influence of public perceptions on policy, within a social climate which supports and values ‘independence’ over ‘interdependence’ (Sevenhuijsen, 2004).

In Aotearoa, the foundation of support provided by whānau sits outside the societal expectation of living as the ‘independent majority’ (Barnes, 2006). Day to day challenges for whānau experiencing cancer show that despite the existence of the He Korowai Oranga framework (Minister and Associate Minister of Health,

2002), and the Equity of Healthcare for Māori framework (Ministry of Health, 2014b), interdependence as a strength of whānau is not celebrated, supported or even acknowledged by most mainstream health services in a tangible sense. Instead, there is a focus on autonomous, assertive individuals who have the ability and resources to engage with ‘patient portals’ (Minister of Health, 2016b; Ministry of Health, 2014c, 2015d) and the confidence to identify and access the preventive, diagnostic and treatment services that are available in their geographic areas (Ministry of Health, 2014c).

Collectives such as whānau, can be seen by clinicians as unwieldy groups who take up too much consultation time, and who are less compliant with medication (McCreanor & Nairn, 2002). Thus, as pointed out by Moewaka Barnes (2008), despite being Treaty partners with the Crown, Māori are still defined as “different and in need of development” (p. ii). This research has found that the ‘deficit approach’ to Māori cancer care is prevalent throughout the *clinical, organisational* and *social* spheres of care ethics.

At the same time, whānau diversity including size, strength and resources, varies. Whānau range from large and multi-generational groups to small families or one isolated carer such as a partner, child or sibling. Some whānau are strong and united, but others do not have the skills or resources to look after each other. Some patients are disconnected from their whānau. Participants from the community case described going to great lengths to re-connect patients with their whānau in order to better navigate the cancer treatment journey.

Properly looking after whānau can sometimes take effort and diplomacy, for example, interviews with palliative care workers by Oetzel and colleagues (2015a) showed that caring for large whānau groups could be difficult, especially when whānau were not in agreement on the best course of treatment for their

loved one. But these kinds of difficulties for the health system and those who work within it are not valid reasons for complacency.

Factors such as racism at institutional, system and personal levels (Jones, 2000; Robson, 2008), and other on-going effects of colonisation such as intergenerational poverty (Cunningham et al, 2002; Smith, 2012), have a huge effect on some whānau where getting through the day is an achievement, and negotiating a complex cancer service environment is an impossibility. Māori health providers are pivotal in working alongside whānau who live in vulnerable situations such as these. Barnes (2006) theorised that people can be in positions of both vulnerability and strength. Further, Barnes (2006) has described the artificial and polarising labels imposed on groups as either 'needy' or 'normal' when considering care, with most of the population considered an autonomous majority, neither needing nor providing care. According to Barnes (2006) and Tronto (1993), everyone needs care at some time in their lives and this need for care is not a weakness or a shortfall.

As well as playing a role in cancer care, whānau can also be information disseminators, for example sharing their positive experiences of hospice, which contributes to dispelling myths and fears about hospice in their communities. Whānau act as 'agents of change' (Ripia, Allan & Te Momo, 2012) and make a positive contribution to Māori health and wellbeing through these health promotion activities. Participants from the policy case did not raise these kinds of whānau cancer control contributions to the same extent as those who worked with whānau did, suggesting that this important contribution at the flax roots level, may not always be recognised by those who inform and create cancer policy.

Patients can be advantaged in being supported throughout their cancer care when they are part of a strong, well connected and resourced whānau who are

able to participate in patient care. When whānau are connected to different relations around the country, for example, they are sometimes able to source accommodation and transport. For many whānau there is no question that when someone is ill, it is time to step up, be present, and provide assistance. This knowing what to do when someone is ill is a strength for whānau, but often at odds with the facilities and staff at treatment centres, highlighting the disconnection between whānau expectations of health services and what is available from the system of care.

At the outset it was expected that the cancer care journey for Māori would involve more than individual cancer patients and that whānau would play a big part. What this study has added to the existing Māori cancer care literature (Cormack et al, 2005; Dew et al, 2015; Egan et al, 2014; Frey et al, 2013; Hill et al, 2013; Pitama et al, 2012; Robson & Ellison-Loschmann, 2016; Robson & Harris, 2007; Robson et al, 2010; Slater et al, 2016; Thomson et al, 2009; Walker et al, 2008) is the wide ranging role of whānau across cancer care, in support, information dissemination and health promotion, and how whānau contributions to cancer care are not reflected in health policy.

In the context of cancer care, many Māori whānau are indeed different to the 'independent majority', and this is something to be celebrated. The 'whānau machine' described in this study was shown to provide immediate practical support and also spread information about cancer prevention and services within wider communities. But it is the system of care, as it continues to privilege the mainstream, not whānau, which is in need of development.

Māori 'within' and 'without' systems of cancer care

Successfully navigating through the cancer care system appears to require a certain attitude and adoption of a sense of entitlement, yet many of the

participants in this study described Māori whānau not wanting to be a nuisance or bother anyone. Participants described this attitude as ‘pushing for care’ or being ‘out in front’. However; insisting on particular services, information or standards of care, requiring a pro-active and confident approach is often at odds with many whānau who do not operate in this context. Reid and colleagues (2000) named universalism as a structural barrier to health care. For this study, universalism was expressed in the inherent values apparent within cancer care services which are incongruent with the values of many Māori.

This misalignment between health system expectations of patient attitudes and Māori expectations of the health system has been explored in a large study involving focus groups with Māori accessing primary care (Jansen, Bacal & Crengle, 2008). The authors explained that manuhiri (or proper behaviour when interacting with new people in a new environment), alongside noho whakaiti (to be appropriately quiet and watchful when in the presence of someone of higher status), can lead to confusion and miscommunication between Māori whānau and their healthcare providers (ibid). This has also been identified by Boulton and colleagues (2013), whose focus groups with Māori nurses showed that patient needs were less likely to be revealed or met when there was a lack of trust between the health service provider and receiver. Thus, a Māori approach to health services can be different to the mainstream, and to quietly and respectfully listen and accept care can potentially lead to support and information simply not being offered or granted. This finding is supported by Oetzel and colleagues (2015b) recent qualitative work on end-of-life care for Māori, where Māori experiences suggested that: “those who stayed quiet did not receive the best possible care” (p. 765).

A naive suggestion might be for Māori whānau to simply speak up, demand answers and therefore receive better service, just like their Pākehā

counterparts. However, culturally bound, respectful behaviour is also overlaid with knowledge about the collective whānau experiences reaching back to the period post the signing of the Treaty of Waitangi. This study found that whānau may hold the experiences of many generations in observing the negative reactions of others when patients dare to ask questions and demand the best service. When *social ethics* is also incorporated into this idea, relentless media messages relaying that Māori who ask questions are ‘troublemakers’ (McCreanor, 2008; Nairn, Moewaka Barnes & Borrell, 2012) makes speaking up even more uncomfortable. In this way, it is understandable that Māori cancer patients and whānau are likely to exercise caution when engaging with health systems for their cancer treatment.

Policy participants did not focus on individual ‘pushing for care’ to the extent of the other three cases but instead, approached barriers to care from a broader systems perspective. Thus, how organisations and those who work within them could be more responsive to Māori (*clinical* and *organisational* ethics spheres) so that accessibility to and through the services could be improved, was seen as a priority.

Examples of organisations that were working towards meeting whānau needs included hospice and the Cancer Society. Hospices have developed Māori service plans which involve strategies to welcome and look after whānau by providing practical, spiritual and emotional support, as well as strategies to increase their Māori workforce. Participants also described excellent and accessible after-hours care that provided confidence to whānau, and respite care when whānau needed a break. Māori Liaison roles have been implemented at hospices in order to better respond to Māori patients and whānau, help connect the wider community to hospice and provide education about hospice and culturally safe care. Working with a Māori health provider,

the Wellington division of the Cancer Society had funded and helped design the KOETI programme as a counterpart of the Living Well programme (Jasperse, Herst & Kane, 2012; Kane et al, 2014) in order to increase Māori participation in supportive care programmes.

The primary health care access literature leans heavily towards the importance of relationships between patients and their GP (Arend et al, 2012; Lin et al, 2014; McCreanor & Nairn, 2002; Penney, Moewaka Barnes & McCreanor, 2011; Raja et al, 2015; Shoen et al, 2011; Slater et al, 2013; Steiner et al, 2008; Walton et al, 2013). However, this study raises the need to include frontline staff in this discourse. To have a respected member of the community who is known to whānau, and who possesses local knowledge, as the first point of contact in primary care would help in building trust and facilitating better access to cancer care for Māori. Neuwelt and colleagues (2015) showed that reception staff can be marginalised as part of practice teams as they are not part of the medical team. Findings from this study show that GP practices can benefit from recognising the abilities and responsibilities of reception staff.

The quality of communication between clinicians and whānau is variable. Some patients and whānau in this study struggled to understand what their clinicians told them, but there was also evidence of oncologists, radiologists and others within cancer treatment centres who were excellent communicators. The ability of those in secondary care to communicate information effectively has been shown to assist patients to cope better with their cancer (Epstein & Street, 2007). International evidence shows that communication between patients and those who provide cancer treatment services has potential for improvement (Arora et al, 2009; Hack et al, 2012; Jones et al, 2011; Venetis, Robinson & Kearney, 2013).

Poor communication by clinicians may be due to a lack of formal communication training (Bertakis, Roter & Putnam, 1991; Fallowfield & Jenkins, 1999). Others dispute the need for such training, for example Mendick and colleagues (2015) found that breast surgeons considered observation and mindfulness to be equally important. This study adds that having a good support person alongside whānau can ameliorate poor communication by clinicians.

The interface between whānau and those tasked with their care is not always positive or encouraging of whānau involvement. Both the community and management participants, for example, observed that when whānau appeared en masse to support and care for their whānau member at the hospital, non-Māori staff did not always understand the importance of their presence and were not welcoming. Indeed, the experiences of these participants had been that many non-Māori staff appeared to consider whānau attendance to be an inconvenience. These cases thought that training was required at the *organisational* and *clinical* ethics perspectives to enable staff to properly and respectfully accommodate whānau.

At the healthcare system level (*organisational ethics*), there are other people who can play a part in improving the system of cancer care for Māori. These are the people in senior and executive roles who keep Māori issues on the table, and people who prioritise these issues at governance level within their communities. Those who work at the healthcare governance level face both organisational and political constraints in their policy and governance work. Panoho's (2014) research, for example, showed that many DHBs have their Māori positions vacant for long periods, and that Māori have to work twice as hard at governance level to have Māori issues heard. At a wider healthcare system level (*social ethics*) there are people who design and/or implement

policy work such as He Korowai Oranga (Minister and Associate Minister of Health, 2002) and the Whānau Ora Initiatives (Te Puni Kōkiri, 2015). Came's (2014) interviews with Māori policy makers has shown that to prioritise Māori issues is challenging, with Māori voices almost always a minority at policy level.

Assisting policy makers by providing robust evidence is the growing body of researchers who, in their own words: “monitor and evaluate Crown action and inaction” (Reid & Robson, 2007, p. 3) on health and other systems, processes and outcomes, and their effects on Māori (Cormack et al, 2005). In the *social ethics* realm, Māori are growing in numbers as health providers but also as researchers and policy makers. However there is still much to be done in terms of expanding the Māori health workforce. A report monitoring the number of Māori in the health workforce (Ratima et al, 2008), for example, found that the Māori health and disability workforce is slowly increasing, but that Māori predominantly hold the less skilled jobs such as service workers, and are poorly represented in professional occupational categories such as surgeons.

Further, it appears that simply training a Māori health workforce is not enough to ensure that Māori are able to find employment in the health sector. A Radio New Zealand report shared the stories of Māori nurse graduates who were unable to find employment at the conclusion of their studies (Bootham, 2014). At the time of the report, the National Council of Māori Nurses was working alongside the national body of the NZ Nurses Organisation to set up a workforce group to address these issues.

As well as increasing Māori representation in the paid health workforce, this study found that the volunteer workforce within mainstream cancer care also lacks Māori representation. A great deal of cancer work is undertaken by

volunteers, for example in hospices and organisations such as the Cancer Society. But despite Māori undertaking a vast amount of volunteer work (Statistics New Zealand, 2011; Te Momo & George, 2013), organisations that provide cancer care appear to be failing to attract Māori volunteers. One hospice in the study had responded to this by looking at ways to make their volunteer training more compatible with Māori ways of working. In trying to represent all parts of the community in the volunteer workforce, these approaches are consistent with work internationally which attempts to recruit volunteers in innovative ways (Morris et al, 2013).

In terms of communicating information to a wide range of cancer patients, a workforce made up of predominantly non-Māori volunteers may not always adequately reach Māori. Based on what has been documented regarding the variety of views, perceptions and prejudices held by mainstream Aotearoa (McCreanor & Nairn, 2002; Nairn, Moewaka Barnes & Borell, 2012; Pack, Tuffin & Lyons, 2015), it is likely that volunteers vary widely in their ability to engage with whānau in a culturally safe manner.

Cultural safety education

A range of social determinants of health such as experiences of poverty and racism, alongside poor education and employment outcomes, lead to many Māori being at a disadvantage before even contemplating a step through the door of their primary health care provider clinic (Te Karu, Bryant & Elley, 2013). These disadvantages must be taken into account when thinking about access into and through health care. To lay the blame solely on the health sector, in Durie's words: "implicitly places an unfair burden on the health sector as a panacea for the ills generated within wider society" (Durie, 2011, p. 287). But the way that health systems and those who work within them look after Māori cancer patients and whānau could be improved. A shift in focus

from cultural competency, to cultural safety in delivery of health services, would align the values of each organisation much better with Māori expectations of their services.

The starting point for this part of the discussion centres on the right of all patients to receive cancer care regardless of their cultural identity. It is clear from the study that patients and whānau do not always experience this right. Indeed, similar findings have been reported regarding the health system engagement experiences of Indigenous people in Australia (Carrick et al, 1996; Condon et al, 2006) and Canada (Brascoupe & Waters, 2009; Shah & Reeves, 2012). This study identified a need for those providing cancer care services to create space for whānau to be positively affirmed as Māori rather than being seen as a problem. This extended to hospital staff welcoming whānau and including them in care, instead of considering the presence of large whānau to be a nuisance.

For over 20 years, cultural safety education has been integral to one part of the *clinical* workforce - nursing and midwifery training. Other areas of the medical workforce have a cultural competency focus (The Royal New Zealand College of General Practitioners, 2007) and people who work within the *social ethics* realm, including those who plan, manage and administer cancer care policy, do not have to undertake any cultural competency or cultural safety training at all (Came, 2014).

In order to provide an open minded, non-judgemental workforce who do not blame the victims of historical and social processes for their current situation (Ramsden, 2002), cultural safety education must extend to all health workers, as it has to physicians in Canada (Klopp & Nakanishi, 2012) and frontline health workers in Australia (Shah & Reeves, 2012).

The current cultural competence focus with an arbitrary cultural safety choice in Aotearoa is not sufficient to ensure that all healthcare staff are able to practice in a culturally safe way. This was shown in a recent study that found a minority of staff had undertaken cultural safety training within 15 DHBs and 19 PHOs in Aotearoa (Sheridan et al, 2011).

Efforts by different organisations to provide culturally safe cancer care are positive, but fractured. Māori liaison roles at hospices, for example, are improving Māori access to, and experiences of, hospice care. However these types of roles are not consistent across cancer care services, and policy participants in this study identified the need for a more co-ordinated, equitable approach to culturally safe care across the cancer control spectrum.

The implementation of cultural safety beyond nursing and midwifery in Aotearoa would require, in particular, commitment from doctors to recognise its importance and include cultural safety education as a core component of their training. Thanks to Ramsden and others, who introduced the concept of culture as a positive resource for health and education institutions (Ramsden, 2002), the hard work has already been done in providing a robust, evidence based cultural safety foundation. It would not be difficult for doctors to adapt cultural safety education to meet their training needs.

The evidence suggests that the current cultural competency focus within medicine is not adequate in caring for whānau. Reviews of cultural competency interventions across a number of countries including Aotearoa, question whether cultural competency in health practice has any benefit for Indigenous populations (Clifford et al, 2015; Dew et al 2015; Truong, Paradies & Priest, 2014). In fact, cultural competency may be harmful (Dew et al, 2015; Paul, Hill & Ewen, 2015). Recent work by Dew and colleagues (2015) for

example, points out how cultural competence is a mono-cultural form of healthcare delivery where cultural dissonance is ignored. Further, Paul and colleagues (2015) describe cultural competence as reducing complex historical and social processes to a technical skill. Indeed, the current study findings suggest that by ticking off a checklist of cultural knowledge rather than examining the inherent power and control between clinicians and patients, cultural competence merely places Indigenous patients under the colonial gaze (Smith, 2012) once again.

Perhaps it is easier for doctors in Aotearoa to leave cultural safety to the nursing team, and themselves merely tick off a 'cultural' checklist, than to meaningfully examine the way that a health system and those who work within it, privilege some patients and exclude others. But there is a responsibility on doctors to take into account the generations of racism, oppression and poverty experienced by Indigenous and other minority groups, and how these manifest in health outcomes (Bassett, 2015). In Bassett's words: "It is the daily context where a person lives, grows, works, loves, that most importantly determines population health, and for too many of us poor health" (p. 1). According to Bassett (ibid), the time has come for all doctors to actively resist the systemic oppression faced by the most vulnerable.

Cultural safety is important as a care practice, which fits within the *clinical ethics* realm of Figure 2. However for cultural safety to be appropriately implemented, it must also be a focus of *organisational ethics*, at both management and governance levels, and given overall direction from the *social ethics* level. But the lack of commitment to system-wide cultural safety education in Aotearoa leads to questions about the priorities of those who influence, design and implement health policy. In particular, if health inequities for Māori are to be properly addressed, there must be a paradigm

shift from placing responsibility on individuals for access into and through health systems, to the systems themselves working in a way that provides culturally safe care. To shift from a cultural competency approach to cultural safety education for all health practitioners in Aotearoa would mean that health systems must shift accountability for healthcare away from the patient, while also shifting the power to decide whether the service is culturally safe to the patient (my emphasis).

Cook and colleagues (2014) provide an example of this shifting of accountability when they describe cultural safety and comfort during gynaecological examinations. The authors highlight that if Māori women do not attend their appointment or return to the service, organisations providing the service must reflect on the way they provide care.

Ramsden (1997) described what is involved for health service providers to take responsibility for culturally safe care. These actions include identifying barriers to care and working towards eliminating them. This contrasts the option which is much easier for the organisation, namely to push responsibility back onto the individual who did not attend, and focus instead on individual health behaviours (Cook et al, 2014).

This shifting of accountability of care to the health system must also be driven by the priorities at *social ethics* level. However, the current focus on individual health behaviours fits neatly with the neoliberal view of 'personal responsibility' (Ryall, 2007) which has been working its way into health policy over the last thirty years. While 'personal responsibility' continues to permeate health policy in Aotearoa, the challenges to health systems instead of individuals presented by cultural safety, are unlikely to be addressed.

Gaps in supportive care and information

Patient and whānau support needs throughout the cancer journey include emotional, spiritual and practical support. In terms of *clinical ethics*, it is important for those working with whānau to provide support to patients in acquiring and interpreting information about their illness, as well as information on other available supports, particularly financial.

There is a lack of appropriate support for whānau throughout the cancer journey, and referral processes for linking patients and whānau to supportive care appear to be erratic. The gap in supportive care services for Māori experiencing cancer (Cormack et al, 2005; Murphy et al, 2010; Nesler & Wharerau, 2011; Slater et al, 2013; Walker et al, 2008) is shared by Indigenous people throughout the world (Cavanagh et al, 2015; Doorenbos et al, 2010; Hodge et al, 2012; Whop et al, 2001) and signals a collective weakness across *clinical*, *organisational* and *social ethics* in placing multiple whānau needs at the centre of care (*patient as person*). Evidence such as *The Voice of Experience* (Cancer Control Council of New Zealand, 2010) patient survey must be incorporated into cancer policy in order to properly address gaps in emotional support and information, including psychosocial support.

The supportive care services delivered by Māori health providers to whānau is undertaken outside the parameters of their funding contracts. This lack of funding can be positioned across the *organisational* and *social ethics* domains (Figure 2), with responsibility for sustainable funding not currently taken at the policy level, and Māori health providers stretching their resources to provide these services. It appears that there is recognition at the policy level of the need for sustainable funding. The Ministry of Health (2011a) have noted, for example, that clearer and more flexible funding

structures are required to support improvements in supportive care service delivery. One example is the identification of responsibility for funding supportive care access within cancer treatment regions, which will help to ensure that DHB boundaries do not impede service access.

However, 'on the ground' at *organisational* level, supportive care programmes that are inclusive to Māori, lose their momentum. The KOETI programme is an example of a formal supportive care programme that did not have a sustainability component built in, and has not rolled out nationwide over time. There is now an urgent need for a supportive care structure that is appropriate for Māori, and a programme where Māori in any part of the country can come together, share and learn about life with cancer, with others in their communities. Like other Māori health provider services, participation in a supportive care programme will facilitate access to further services for whānau. As shown in the KOETI example, any such programme must have a sustainability component built in. Approaches to programme sustainability could be explored through recognition of supportive care as a core component of cancer service provision.

Egan and colleagues (2014) reported that people sometimes feel that their cancer was not serious enough to warrant supportive care, or felt reluctant to associate themselves with the Cancer Society. However, our previous work with patients and whānau showed that for people who have a strong relationship with their primary health care provider, such fears can be ameliorated by accepting referrals and information from a trusted person such as a community health worker, nurse or doctor (Slater et al, 2013). This finding concurred with the literature that having a trusted primary health care provider helps with accessing and processing health information, as well as awareness of, or referral to the supportive care services that are

available (Arend et al, 2012; Lin et al, 2014; Shoen et al, 2011; Walton et al, 2013).

The time when cancer treatment concludes is a particular area where supportive care is lacking. This stage of the cancer journey is also understudied in the literature (Burhansstipanov et al, 2001; Cavanagh et al, 2015; Doorenbos et al, 2010; Gottlieb & Wachala, 2006; Hodge et al, 2012; Warson, 2012; Santos et al, 2001), particularly in Aotearoa (Jasperse, Herst & Kane, 2012; Kane et al, 2014).

At the time that interviews were undertaken for this study, dialogue was beginning at the *social* and *organisational ethics* levels regarding the best place to refer patients for supportive cancer care at follow up and survival. Internationally, Campbell and colleagues (2002) place the follow-up care role firmly in the hands of primary health care. Findings from this study have shown that Māori health providers are already fulfilling this role by 'hanging in there' for whānau at the conclusion of cancer treatment. As will be described in a later section, it is important that this work is recognised and sustainably funded.

Cementing relationships between mainstream support organisations and Māori organisations enhances access to mainstream supportive care services for Māori. These kinds of relationships have also been reported internationally by Whop and colleagues (2012) who emphasised how relationships between mainstream support services and Indigenous organisations are critical in meeting the supportive care needs of Indigenous cancer patients, with further efforts required to strengthen these relationships.

With Māori over-represented in cancer incidence and mortality, it seems reasonable to assume that information about cancer and supportive care services should be especially accessible to Māori. However, cancer information is not distributed or understood adequately. This inconsistent availability of cancer information is noted in the New Zealand Cancer Health Information Strategy (Ministry of Health, 2015d). The Strategy's response includes:

Supporting improvements on the quality and range of information available to patients, such as patient portals and shared care plans that will make it easier for patients to access their cancer information, engage actively in their health care and be effectively supported by a multi-disciplinary team. (p. 2)

The Strategy does not outline how people with limited access to technology, poor literacy or rural isolation will benefit from patient portals. Thus, the *social ethics* elements of society, public perception and policy making (Figure 2) value the 'independent majority' (Barnes, 2006). Again, the neoliberal approach which places responsibility on individuals for gaining information, is present. Although framed as making life easier for patients, it must be asked who these patients are, and importantly, who they are not.

The individual responsibility approach ignores those who will be inevitably left behind, and the evidence shows that those who have been left behind in cancer care, are Māori (Robson & Ellison-Loschmann, 2016). This focus on individual access to technology for information is also apparent in the recent New Zealand Health Strategy (Minister of Health, 2016a).

Face-to-face communication is very effective in communicating cancer information to Māori. But there is a gap in provision of cancer information that is relevant to Māori, covering practical issues whānau want to know about, rather than solely clinical information. “Putting a Māori face on the cover” is not enough to ensure that information is appropriate to Māori and the use of imagery is sometimes confusing. Research has shown that printed information is often drafted without consultation with the groups who will read it, and lacks the content that will engage or inform Māori (Batten & Holdaway, 2012; Rauawaawa Kaumātua Charitable Trust Research Project Team, 2014).

Māori health providers and other primary health care providers

Since their nationwide implementation three decades ago, Māori health providers have increased and improved access to health services for Māori in a range of ways (Cormack et al, 2005; Maniapoto & Gribben, 2003; McLeod et al, 2011; Slater et al, 2016; Slater et al, 2013; Walker et al, 2008). Findings from this study were consistent with this literature, but they also raise questions about the sustainability of the cancer care work undertaken by Māori health providers. Māori health providers are involved in all parts of the cancer control continuum. Our recent nationwide survey showed that Māori health providers contribute to cancer prevention, screening and care by delivering a wide range of programmes including health promotion, advocacy, information and support, alongside clinical care (Slater et al, 2016). Indeed, the current study also found that Māori health providers offer continuity of care by providing support at consultations, taking notes and debriefing afterwards. Additionally, Māori health providers are in a unique position to understand and respond to cultural and spiritual needs. Their local knowledge means that they appreciate the diversity within their communities, and the needs of different whānau.

Māori health providers also play an important role in facilitating access to mainstream health services. They often accompany patients to cancer care services, and patients describe their Māori health provider with the same comfort and familiarity as they would whānau. This unofficial cancer navigator role is not recognised at *social ethics* level.

The work of Māori health providers is inseparable from Māori development. For example, Ratima (2001) has outlined how Māori health promotion represents far more than routine dissemination of health and lifestyle messages. She describes Māori health promotion as: “a process of enabling Māori to increase control over the determinants of health and strengthen their identity as Māori, and thereby improve their health and position in society” (Ratima, 2001, p. 4). In this respect, health promotion carried out by Māori health providers not only contributes to cancer prevention, but also promotes positive Māori development, as shown in the Tane Triathlon forum (Te Puni Kōkiri, 2013) for example, and cancer prevention messages distributed through netball networks (Manchester, 2004).

Initiatives such as these not only deliver cancer prevention messages, they positively affirm participants as Māori, and provide a forum for Māori people to share cancer stories with each other. Other forums for reaching Indigenous and minority ethnic groups have been successful overseas, with church based programmes shown to assist Pacific people (Aitaoto et al, 2007), Latinos (Allen et al, 2015; Castro et al, 1995;) and Hawaiians (Ka'opua, 2008) in receiving health promotion messages and improving access to cancer screening.

This study's findings concurred with the literature regarding the local knowledge and innovative methods that Māori health providers employ to enable people in their communities to access health services (Cormack et al,

2005; Russell [Pere], Smiler & Stace, 2013; Slater et al, 2013, Slater et al, 2016; Thomson et al, 2009; Walker et al, 2008). The importance of local knowledge and social networks in assisting cancer screening to reach a wide range of women has also been shown internationally (Carrick et al, 1996; Lam et al, 2003).

Community driven health promotion and cancer screening initiatives by trusted community health providers are successful in reaching Māori. But the people providing these programmes and actions often do this work beyond the realms of their paid work. This signals a failure of policy in the *social ethics* realm to recognise the work that needs to be done in order for Māori to be cared for adequately.

Feminist theorists have highlighted how institutions and practices are often based on a fundamental assumption that women's unpaid work will provide most of the caring and servicing necessary for society's overall functioning (Balbo, 1987, Barnes, 2006; Tronto, 1993, 2010). In the context of this study, it is often the unpaid labour of Māori health providers that connects people to the cancer care and services they need.

For almost 30 years, Māori health provider organisations have been funded to provide primary health care services. Our nationwide survey of Māori health providers (Slater et al, 2016) showed that the vital work Māori health providers undertake in cancer care has a high degree of invisibility. With no publically available information on the Ministry of Health website, and no directory of Māori health provider services, it is no wonder that one of the policy participants in this study did not know what services Māori health providers deliver in cancer care.

This study showed that there is massive potential for Māori health providers to deliver substantially more than they are currently able, in cancer care and also in the work they do in linking patients and whānau to wider health services. For far too long they have been advocating, transporting and navigating the cancer journeys of whānau in their communities and doing this on what one participant described as 'the smell of an oily rag'.

The call to properly resource Māori health providers is not new. Lavoie (2003) compared Indigenous health provision funding models and realities between Aotearoa, Australia and Canada and found that Māori health provider contracts were more fractured and less sustainable than their counterparts in the two other countries. Another study found limited scope for Māori health providers to negotiate with funders, resulting in the values and principles that set Māori health providers apart from mainstream services not being recognised within their contracts (Boulton, 2005). A survey of 56 health providers found that compared to mainstream health providers, Māori health providers are heavily financially audited and hold shorter term contracts (Came, 2014). Undeniably, the available evidence points to Māori health providers being under-funded, over-regulated and under-evaluated (Boulton, 2005; Came, 2014; Lavoie, 2003; Matheson, 2013).

It appears that Māori are not the only health providers who are required to put a great deal of effort into obtaining and sustaining health funding contracts. Recently, Pacific health provider participants in a study of cervical screening in South Auckland also described limited funding and frequent changes to funding rules (Foliaki & Matheson, 2015). After lengthy attempts to obtain funding information from Capital and Coast DHB (CCDHB), Matheson's (2013) example of less than 1% of CCDHB funding going to Māori and Pacific providers combined shows that the funding Māori health providers receive in

this area is currently negligible. It is simply not enough funding to sustainably deliver the services that are currently being provided, and it is certainly not enough to build stronger relationships between organisations so that Māori health providers and other primary health care providers can make a consistent contribution to cancer control.

Another layer of difficulty in sustainably providing these services faced by providers has been articulated by Te Momo and George (2013), who tie together the “decline in government funding to deliver a social service, the increase in clients requiring a type of social service, and the struggles for these communities to provide a largely unpaid service” (p.1). This decline in government funding is related to the fiscal restraints that are commonly cited throughout recent health policy, including the NZ Cancer Plan (Ministry of Health, 2014c) and the New Zealand Health Strategy (Minister of Health, 2016a), implying that with scarce resources, there is no funding for ‘extra’ services. But fiscal restraint is not a credible reason for continuing to expect Māori health providers to engage in unpaid activities. As shown internationally, a lack of resources is a major constraint on any programme but there are many examples where substantial improvements in population health have been achieved by prioritising health development (Gruen et al, 2008).

Māori health providers have always had to fit their services into whatever funding contracts were available to them (Russell [Pere], Smiler & Stace, 2013). It appears that there has never been an overall plan for sustainable funding to recognise the work that Māori health providers undertake, and instead, piecemeal contracts have supported some, but not all, of their work (Boulton, 2005). The refreshed New Zealand Health Strategy’s Roadmap of Actions (Minister of Health, 2016b) describes a commitment to reviewing funding, contracting and accountability arrangements for maternity and Well

Child services, as well as building capacity across health and social service providers: “to promote sustainable options and choice within communities” (p. 16). If this action point were to actively engage with the breadth of work undertaken by Māori health providers, a sustainable future for these unique services might be a possibility. Some suggestions on how this could work have been developed by Gruen and colleagues (2008) who emphasise system components being well defined for sustainable planning.

Until these issues are properly addressed at the *social ethics* level by planners and funders, it is difficult to see how the work Māori health providers currently undertake, drawing on their resources at *organisational* and *clinical ethics* levels, can continue. But there may be hope. As this study was being undertaken, the Whānau Ora Initiatives were being rolled out across Aotearoa. At the *social ethics* level, this new funding model recognises Māori health priorities and sees whānau interdependence as a strength. For the first time, there is an opportunity for the whānau ora kaupapa that Māori health providers have always had, to be appropriately resourced, supported, and evaluated.

The Whānau Ora Initiatives (Te Puni Kōkiri, 2015) are relevant to this research for two reasons. First, there is now the potential for Māori health providers who are part of Whānau Ora collectives to be appropriately funded for the work across sectors that they have been undertaking for many years. Second, the focus of the initiatives is on realising whānau aspirations and building on whānau strengths, instead of health and social services acting independently as ambulances at the bottom of the cliff.

The recent Te Puni Kōkiri (2015) report of Whānau Ora noted that one of the drivers for funding the initiative was concern by the Minister for Māori Affairs that Māori health and social service providers were compromised in their

whānau ora approach by “fragmented sectoral approaches and an alignment with funder expectations rather than actual whānau needs” (p. 19). This implies that under the Whānau Ora Initiatives, funders will recognise the work undertaken by Māori health providers, rather than relying on providers to stretch their resources in order to support whānau appropriately. Boulton and colleagues (2013), for example, have shown how one Māori health and social service provider was able to consolidate their many small contracts into a single Whānau Ora contract. In this way, appropriate resources were in place to enact the whānau ora focus of the work that had always been undertaken by the provider.

By changing the way services are funded, promoting collaboration across sectors and firmly rejecting the Māori deficit model in favour of supporting whānau aspirations (Ripia, Allan & Te Momo, 2012), the Whānau Ora Initiatives present exciting opportunities in cancer care for Māori. This model of health and social service delivery could address inequities in cancer outcomes in a number of ways. First, by facilitating better Māori access to, and in some instances, provision of, the many different parts of the cancer care continuum, including health promotion, screening, diagnosis, treatment, palliative care and rehabilitation.

With the right momentum, the Whānau Ora initiatives could represent a vehicle for provision of Māori-driven services that overlap across sectors in areas of cancer care, which are currently based in the mainstream. This research has identified, for example, a need for sustainable Māori supportive care services. The Whānau Ora Initiatives provide the opportunity for supportive care programmes to be built into Whānau Ora funding contracts.

Successive governments have offered many different approaches to rectifying health inequities between Māori and non-Māori over the years, but most of these have been theoretical in nature, and have not had solid funding structures behind them. Those delivering the services have had to adapt the way that they work and stretch resources in order to fit the kaupapa of the day. Despite the words ‘inequities’, ‘participation’, ‘partnership’, ‘protection’ and ‘whānau ora’ being constant within policy documents over recent decades, the Whānau Ora Initiatives represent the first policy that is closely aligned to Māori health approaches as a whole.

However, potential risks for the Whānau Ora Initiatives have been identified. Ratima and colleagues (2010), for example, fear that “the relocation of Māori health promotion efforts within Whānau Ora initiatives may be a risk if the approach does not prove to be politically durable” (p. 4). Indeed, this policy was driven by the Māori Party, and thus, it relies on their continued existence. Therefore, to future-proof this new health and social service provision model, robust and on-going evaluation of the Whānau Ora Initiatives is critical in providing evidence of its outcomes. Returning to the adapted circles of personalist care ethics (Figure 2), this will require commitment across all four realms of care, with planning and funding at *social ethics* policy level, co-operation at both *organisational* and *clinical* levels, and at the *patient as person* level, active participation in evaluation by whānau receiving the services.

Not all Māori are able, or wish to access Māori health provider services. For this reason, the roles of both Māori and mainstream primary care are critical in linking Māori with cancer care. This section has discussed Māori health provider contributions to cancer care specifically. The following section considers the role of primary health care generally in cancer care for Māori.

Findings from the study align with the literature showing that primary care is integral to service access, continuity of care and information throughout the cancer care journey (Burge et al, 2003; Kendall et al, 2006). As the first point of connection with the health system, primary care affects all parts of the cancer experience such as prevention, early detection, access to specialist treatment and supportive care (Campbell, MacLeod & Weller, 2002).

Lasting relationships with primary health care providers are particularly relevant to cancer care with long term relationships between providers and families recognised as the foundation of community cancer care (Aubin, 2011; Halkett et al, 2015; Jiwa, McManus & Dadich, 2013a; Kendall et al, 2006). Recent work in Australia found that this foundation relies on GPs having good knowledge of evidence based practices, and also cancer literacy by the patient, which may be different for Indigenous people (Jiwa et al, 2013a; 2013b; Ministry of Health, 2010b; Rauawaawa Kaumatua Charitable Trust Research Project Team, 2014).

In addition to individual GP and patient factors, findings from the current study highlight difficulties in accessing a regular GP who can treat individuals within the bigger picture of their families and communities. These difficulties include limited clinics in some areas, high staff turnover and different doctor priorities, all of which contribute to GPs not being as accessible as they once were.

Further, financial barriers have been shown to inhibit the ability of people to access primary care (Cumming & Gribben, 2007; Matheson, 1992). The Primary Health Care Strategy aimed to remove barriers to primary care by signing up patients to PHOs and reducing the cost of seeing a GP (Boulton, 2005). But the current study found that Māori continue to face barriers to accessing a regular GP. Nonetheless, it appears that cancer patients who do

have a regular GP, want continuity of care from their GP throughout their cancer treatment, for cancer related issues as well as co-morbidities and the health issues of family members (Anvik, Holtedahl & Mikalsen, 2006; Halkett et al, 2001).

A lasting relationship with a primary health care provider is dependent on cost, location (Cumming & Gribben, 2007), availability of GPs (Jiwa et al, 2013a) and the ability of the primary health care provider to build rapport with patients (Cram, Smith & Johnston, 2003; Crengle et al, 2005; McCreanor & Nairn, 2002; Penney, Moewaka Barnes & McCreanor, 2011). These are all factors that individual patients cannot control, and must be addressed at a systems level.

Communication between providers

Findings from this study concur with the literature regarding the need for improved communication between all health care providers throughout the cancer continuum (Anvik et al, 2006; Jiwa & Dadich, 2013, Spiegel et al, 2010). At the *organisational ethics* level, the finding that GPs are swift in referring patient information to hospitals, but information flow from the hospital back to the GP is inconsistent, has also been noted in an Austrian study which found that despite cancer patients placing importance on communication between their GP and the hospital, often the information exchange was insufficient (Spiegel et al, 2010). The negative implications for this poor communication were articulated in a recent Australian review of communication between primary and secondary care for cancer patients (Jiwa & Dadich, 2013). The review found that where information relayed between the two is poor, patient outcomes were compromised.

Other studies have shed light on why this lack of information-sharing might occur, by suggesting that specialist cancer treatment providers may withhold information depending on their perceptions of the role for primary care throughout different stages of cancer care (Aubin et al, 2012; Sisler et al, 2012). A Canadian study, for example, found that preferences regarding the extent of GP involvement in cancer care differed between GPs and cancer specialists at various stages of the cancer journey. Specialists considered that GP involvement was not important during cancer diagnosis and treatment, but vital at advanced stages of cancer care (Aubin et al, 2012).

Doctors in a German study responded to these kinds of perceptions held by cancer treatment providers by working to address gaps in communication. These GPs built relationships with cancer treatment providers to promote better communication, and therefore better informed patient care (Dahlhaus et al, 2014). This kind of relationship building is driven in Aotearoa by the Regional Cancer Networks.

The Regional Cancer Networks work at the *social ethics* level to facilitate positive communication between providers at the *organisational* and *clinical ethics* levels. The aim of better communication between all health service providers in cancer care has been a pivotal role of the Regional Cancer Networks in encouraging different parts of the cancer control workforce in Aotearoa to talk to each other (Herbert & Peel, 2010). Indeed, findings from the current study found that the Central Cancer Network has assisted some primary health care providers in knowing what each other were delivering, and sharing examples of successes and mistakes. This study found that such communication required ‘champions’ – people who had the skill to connect with others, and keep up momentum in relationships and communication between their organisation and others.

A recent review of Regional Cancer Networks (Herbert & Peel, 2010) found that cancer control stakeholders “accept the benefits of working collaboratively via the Regional Cancer Networks and hence have a sense of commitment to the networks” (p. 9). However, the review considered that stakeholders did not yet feel collective ownership of the networks. The report acknowledged that not all stakeholders have been reached by the networks and named DHB funding and planning teams and importantly, the primary health care sector, as those requiring more engagement.

It is vital for primary health care providers to be actively engaged in Regional Cancer Networks, as primary care providers are often cut off from patients after a cancer diagnosis. Yet, when primary health care providers have long established relationships with patients and whānau, they are in an excellent position to provide information and guidance throughout all stages of the cancer journey.

Findings from this study agree with the literature that Māori health providers play an important role in facilitating access to mainstream health services (Cormack et al, 2005; Walker et al, 2008). However the findings also showed that this was not recognised by mainstream health providers. While Māori health providers refer, transport and even accompany and support patients and whānau to screening, treatment and other cancer care services, the mainstream services are less active in referring patients to Māori health providers.

McCreanor and Nairn’s (2002) study of general practitioners considered what might be behind this apparent gatekeeping. The authors report that doctors who took part in their qualitative study were ambivalent about Māori-driven

health services or programmes, which often stemmed from resistance to political or cultural dualism and competition between services.

This current research highlights the importance of the Regional Cancer Networks in getting everyone around the table to ensure that the types of assumptions outlined by McCreaner and Nairn (2002) above, are dispelled. Having faith in the services each provider offers can foster the development of meaningful relationships between providers so that referrals between services can be confidently made.

Of note is that the Regional Cancer Networks review outlined earlier, observed that limited resources were a barrier to the implementation of the activities of the networks (Herbert & Peel, 2010). As reported previously in regard to the funding allocated to Māori projects (Came, 2012; Matheson, 2013), when funding is limited, there is potential for Māori-focussed activities to be passed over in favour of a universal approach. Thus, it is important that in times of fiscal restraint, the Regional Cancer Networks do not lose their inequalities focus by quietly disestablishing their inequalities manager positions. In terms of *social ethics*, this implies that the Ministry of Health must increase funding to the Regional Cancer Networks, in order for the networks to recognise Māori health priorities.

A further barrier to communication between cancer care providers is the availability of IT systems that promote collaborative, integrated care. Different patient record systems are not always compatible or available. The Cervical Screening database, for example is not available at GP clinic level, and there can be different record-keeping systems at hospital, GP and hospice levels. Hospice presents its own problems with ethnicity data not routinely collected nationwide, and indeed the literature shows that collection of ethnicity data

has been problematic at all levels of healthcare in Aotearoa for a long time (Curtis, Wright & Wall, 2005; Te Rōpū Rangahau Hauora a Eru Pōmare, 2000).

This problem is not unique to Aotearoa. The need to prioritise and improve the collection of ethnicity data was recently stressed in an international study of Indigenous people's health (Anderson et al, 2016). The authors noted that this data is vital to policy accountability in informing decision making, monitoring outcomes and influencing resourcing priorities. Therefore, the collection of consistent and robust ethnicity data is critical in informing health policy. Equally, at the *social ethics* level, priority must be given to ensuring that organisations are educated in how to collect reliable ethnicity data. At a *clinical ethics* level, this means including reception and administrative staff, as well as clinicians, in rigorous training for ethnicity data collection. There is also a responsibility on policy makers to respond to the health service needs presented by the data, with appropriate resourcing.

The issue of consolidating different IT systems so that cancer care providers can better share information is addressed in the New Zealand Cancer Health Information Strategy (Ministry of Health, 2015d). The strategy provides an overview of the complexity in cancer information, with screening, GP, diagnostics, oncology, and many other stakeholders capturing cancer data. Additionally, the strategy cites more than 30 current projects at national and regional levels which are designed to improve information quality and accessibility. The strategy describes progress being made, acknowledging that although patient records are currently not comprehensive, electronic and accessible for different providers, there are some successes in standardising data. An example is cited in clinical data repositories in standardising and linking information across DHBs (Ministry of Health, 2015d). Explicit in the

strategy is the need for more collaboration between primary and secondary care, and government and non-governmental organisations in achieving better information-sharing. One of the purposes of the New Zealand Cancer Health Information strategy is to enable the NZ Cancer Plan (Ministry of Health, 2014c), which alongside other cancer control policies, is discussed in the following section.

Cancer control policy in Aotearoa

Cancer related policy in Aotearoa is losing the equity approach that was articulated in the early 2000s (Blakely, Simmers & Sharpe, 2011). The NZ Cancer Plan (Ministry of Health, 2014c) alongside the New Zealand Cancer Control Strategy (Minister of Health, 2003), and the Māori Health Strategy -He Korowai Oranga (Minister and Associate Minister of Health, 2002; Ministry of Health 2014e), provide the main policy drivers for cancer control in Māori. It should be noted that the refreshed New Zealand Health Strategy (Minister of Health, 2016a, 2016b) was released as this thesis was being completed. Although the two documents informing the refreshed Strategy acknowledge the special relationship between Māori and the Crown, and indeed, the Future Directions part of the Strategy describes “shifting the focus on individuals to a wider focus on the family and whānau” (Minister of Health, 2016a, p. 14) there is little indication of how Māori health providers will play a part in this, and how sustainable, adequate resourcing will address Māori cancer priorities.

A recent review of the literature on Māori access to cancer services concluded that there is good strategic and policy recognition of the need to reduce Māori health care cancer disparities (Cram, 2014). The report cited the Ministry of Health’s Briefing to the Incoming Minister of Health and the Ministry’s Statement of Intent, alongside DHB Māori Health plans as providing a good platform for improving Māori access to cancer services and the reduction of

Māori cancer morbidity and mortality. These positive intentions are also expressed in the refreshed New Zealand Health Strategy (Ministry of Health, 2016a, 2016b), which gives an example of enacting the Treaty of Waitangi principle of the Strategy to lead the training of health staff and board members.

Other authors have shown that these kinds of strategies do not always translate into practice, and have provided examples of such plans playing out quite differently when implemented (Boulton, 2005; Came, 2014; Panoho, 2012). For example, despite the New Zealand Public Health and Disability Act 2000, requiring Māori DHB representatives at governance level, recent research has shown that many of these positions go unfilled for long periods, and that Māori board members struggle with a scarcity in the bicultural knowledge of other board members (Panoho, 2012). Panoho reported that Pākehā board members appeared to manage Māori issues with a deficit approach as opposed to one that valued equitable relationships.

Panoho (2012) adds that for equitable relationships between Māori and the Crown to be enacted, more accountability is required from DHBs to prove that they are meeting their obligations to Māori under the Treaty of Waitangi. Came (2014) agrees that DHBs do not currently function well enough, and shows the hurdles that exist for this to change, within a wider framework of flawed health policy development. Using critical race theory she unpicked the way that policy makers interact with each other and pinpointed parts of the policy cycle where institutional racism can be identified. Came identified five sites of institutional racism within health policy making that contribute to the health inequities between Māori and Pākehā including: the way decisions are made; evidence is used; cultural competencies; consultation processes; and the influence of the Crown in filtering policy (ibid). Panoho (2012) and Came's

(2014) contributions show that there is much work to be done in shifting the way health policy is written, implemented and made accountable so that Māori can enjoy the same level of health as the rest of the population.

Unacceptable ethnic differences in cancer mortality are driven by inequities in access to cancer services which were identified over a decade ago by Cormack and colleagues (2005). A pivotal part of the NZ Cancer Plan (Ministry of Health, 2014c) attempts to address access issues through its nationwide implementation of cancer navigator positions. Overseas, cancer navigators have had success in improving cancer journeys (Ashleigh Guadagnolo et al, 2011; Meade et al, 2014;) and the international literature shows that the role of the cancer navigator is particularly important for linking Indigenous people and those living in poverty with cancer treatment, support and information (Braun, Kagawa-Singer, & Burhansstipanov, 2012; Paskett et al, 2011; Petereit et al, 2008; Whop et al, 2012a; Wilcox & Bruce, 2010). Indeed, by facilitating access to care, Cram (2014) has described cancer navigators as buffering Māori from a health workforce that lacks cultural competence.

Cancer navigator roles are argued to enhance continuity of care by providing consistency and better access to information (Braun et al, 2012). Findings from this study show that Māori health providers have been helping patients to navigate their cancer journeys for a long time. This was also reported by Māori health providers in our recent nationwide survey (Slater et al, 2016), and by cancer patients and health providers in other studies (Cormack et al, 2005; Walker et al, 2008).

The role of the cancer navigator in Aotearoa is yet to be properly rolled out nationwide and there is work still to be done establishing the scope and location

of cancer navigator work. This has also been debated in the literature (Blakely et al, 2015; Collinson et al, 2013). Recent work by Blakely and colleagues (2015) suggested that hospital based cancer care co-ordinators could be cost effective in reducing time and increasing coverage to effective treatments for patients with colon cancer. Additionally, one point of contact could relieve pressure on the cancer care team regarding communication and also reduce patient anxiety in understanding their care (Collinson, 2013). This current study added that there was potential for cancer navigators based within Māori health provider organisations to provide broader whānau education in cancer prevention.

One of the initiatives linked to the Faster Cancer Treatment target in the NZ Cancer Plan (Ministry of Health, 2014c) is the New Zealand cancer nurse co-ordinator programme. This includes establishing 60 cancer nurse co-ordinators who work as part of each cancer treatment team and provide a link between patients, whānau and health care providers in order to improve access to cancer treatment and support services. An evaluation of the cancer nurse co-ordinator programme is in progress, with on-going review until December 2015 and a report due in mid-2016. An interim evaluation report shows that relationships within DHBs for the nurses are still being formed, but patients who access the service are positive about their care (Litmus Limited, 2014). It is not known how many, if any, of the cancer nurse co-ordinators are Māori, or have established links with primary health care providers, including Māori health providers.

The NZ Cancer Plan (Ministry of Health, 2014c) outlines three delivery models for cancer navigators which cover both the community and hospital based nurse co-ordinator roles. First, cancer nurse co-ordinators are specialist nurses responsible for care of patients in a particular tumour stream. It is clear that

these nurses are based within the treatment centres where they are part of a multidisciplinary team. Findings from this study raise the need for these nurses to be culturally safe in their care and that they are able to help whānau to feel welcome, whether whānau is one support person, a large group or a community worker from a Māori health provider.

The second delivery model for cancer navigation in the Plan comprises generalist specialist nurses who are responsible for co-ordinating the care of patients considered most at risk of experiencing problems with care co-ordination throughout their region. Furthermore, population focus specialist nurses are tasked with reducing barriers and will work with Māori and other populations who are considered hard to reach. This approach is counter to the strong message in the Māori cancer access literature regarding trust and long-term relationships facilitating better access to cancer care (Cormack et al, 2005; Reid et al, 2016; Slater et al, 2013, 2015, 2016; Walker et al, 2008). The number of intended population focus specialist nurses is not made clear in the Plan, nor is the manner in which they will engage with communities in the way that primary health care providers, particularly Māori health providers currently do.

Findings from the current study found that there is an additional step in reducing barriers and ensuring timely access to cancer treatment before Māori whānau can engage with the generalist specialist nurse or the population focus specialist nurse. This step is currently filled by Māori health providers, and to some extent also by some mainstream primary health care providers in their facilitation of access to cancer care services. It is unlikely that the population focus specialist nurses will have a long-standing relationship with whānau, be able to assist with transport, childcare, and have the kind of trust that is almost interchangeable with whānau.

8.1 Study limitations and strengths

Limitations

This section discusses the limitations and strengths of the study. The first limitation is that this is a small study, set in a fixed geographical location at a particular point in time, therefore findings are not generalisable to the entire population. However the study findings have theoretical generalisability as many of the findings resonated with similar qualitative studies in different parts of Aotearoa (Cormack et al, 2005; Egan et al, 2014; Walker et al, 2008,) and it is possible and indeed likely that cancer patients, whānau, care providers, managers and policy people within a wider context will share some of the thoughts and experiences from the study.

The study design meant that community, management and participants were assigned to particular cases depending on their current job, and patients and whānau, regardless of their occupation, were grouped together. But the participants must also be recognised as human beings as well as the roles they fulfilled for this study. In this way, community, management and policy participants often reflected on their own personal experiences of health system engagement or shared stories from their own whānau. At the same time, patients and whānau sometimes reflected on their work. Rather than this being a hindrance to the study, it added a richness to the data. Barnes (2006) has called this overlap in roles the *universality of human relatedness* (p. 151).

Certainly, the ethic of care framework outlined by Tronto (1993, 1998) recognises that the boundaries between the four cases: the care about; care for; take care and care receivers, are artificial, in that everyone needs to be cared for at some point in their lives. Further, the need for care should not be seen as a weakness, or indeed to plan, manage or undertake care should not be a burden. By

choosing a case study approach, differences in experiences and views were identified between the four cases in this study, but similarities were also found.

Another limitation to the study was that there were no participants who were currently working at cancer treatment centres. The contribution of people who work for cancer treatment centres would have added further insight from those who provide cancer care services, in particular, regarding the communication between patients and clinicians and sharing of information between primary and hospital care. However despite repeated attempts to contact the people who could give permission for me to invite cancer treatment centre workers to participate, I was unable to contact these people.

I met individual radiologists and oncology nurses but they were unable to participate without the permission of their employers. To compromise these workers by asking them to be interviewed outside their workplace would have breached the ethical approval for this study which I was not prepared to do. Therefore, people from this area were not included in the study. However as outlined in the paragraph above regarding the overlap between different roles, two of the policy participants had extensive experience working in cancer treatment centres before their policy roles, and both reflected on this work throughout their interviews.

A final limitation was the time constraint in undertaking this project which did not allow time to consult with study participants on the study themes and draft results. Although participants had the opportunity to review their transcripts, they were not included in any further development of the study and their input would have enhanced the study findings.

Strengths

A foundation of feminist research practice is self-reflection (Olesen, 2011). Therefore, I kept a reflexive journal throughout the study which enabled me to document insights as well as record modifications as the research evolved. This reflexive approach was based on a workshop I attended that was taught by Goodrick (2011), who emphasised the value of a journal in assisting researchers to clarify values and experiences and track decisions. As well as being conscious of my own bias, a further guard against researcher bias was the process of researcher triangulation.

Work by Māori researchers has raised two important issues that must be considered when discussing the limitations of this study. One is the issue raised by Kiro (2001) regarding Māori middle class concerns being projected onto the whole population. My reflexive journal logged my own concerns in projecting my world view onto the study findings. For example, when the multiple and critical role of whānau theme began to emerge, I worried that I was romanticising whānau and ignoring the realities of many whānau who were not able to care for their own as they navigated through cancer treatment. Further, I feared that to hold whānau up as an important and overlooked conduit for public health messages to the community, it could be implied that whānau who did not fulfil this were somehow failing their whānau role.

Nonetheless, after reading and re-reading the transcripts, and talking through the emerging themes with others members of the team, as well as becoming more and more familiar with the related literature, my confidence grew that the role of whānau and the strength in whānau was in fact a pivotal message from the study findings. Any failing did not sit with whānau, it was with the systems that had failed whānau, and indeed, there was a light at the end of the tunnel in the

Whānau Ora Initiatives, which for the first time encouraged across sector collaboration to help whānau to realise their own goals. I hope that the discussion has communicated this important point.

The second issue was raised by Walker and colleagues (2008) who described patients and whānau expressing *considerable gratitude for very limited care* (p. 33) which must also be unpicked for this study. As was described in our study of Māori hospice experiences (Slater et al, 2015), in the context of research showing that Māori do not receive the same standard of health care service as non-Māori (Robson & Harris, 2007; Hill et al, 2013), as research participants, Māori may therefore express appreciation or gratitude for care that is not responsive to their needs.

However patient and whānau participants in this study raised a number of issues regarding information, whānau support, cultural safety and systems engagement where appreciation was not expressed. Furthermore, the case study approach included a variety of people from different organisations within the four cases.

This strengthened the study as participants could speak from their own perspectives. Community, management and policy participants were not the recipients of cancer care and support services in this study and therefore were not in a vulnerable position of potentially feeling as if they should express appreciation or gratitude for services.

Chapter 9

Conclusions

Far too many Māori die from cancer, despite the availability of treatment and supportive care services that could have prevented many of these deaths and improved quality of life. Findings from this work indicate that the systems Māori are required to engage with throughout the cancer journey continue to be universal, with an assertive approach required by patients and whānau in order to receive and understand information about their illness and treatment, as well as entitlements such as travel and accommodation.

Care is an intrinsic part of whānau life and whānau also play an important role as health promoters, sharing their stories of cancer with their communities. Many whānau operate as interdependent collectives rather than as independent patients. For Māori as individual cancer patients to question cancer care providers and demand particular services can be an uncomfortable undertaking. If there is a genuine commitment at health process and health system levels to ensuring less Māori people die from cancer, the existing delivery of cancer care must change. A mechanism to unlock the power relations inherent in caring is the implementation of cultural safety education throughout the entire health workforce to replace the current focus on cultural competency.

The system of care faced by Māori with cancer includes the universal health service approach (Reid & Robson, 2007), with limited ethnic composition, communication skills and cultural safety education of the health workforce, at reception, clinician, managerial and governance levels, as well as broader functions such as funding, location, flexibility and availability of services. The system of cancer care extends to: health promotion; screening; detection; diagnosis; treatment; palliative care and rehabilitation, in addition to the information and supportive care services available throughout each of these stages.

The ethic of care framework was useful in this study for examining the system of care faced by Māori with cancer, and has brought into focus how the interdependence of whānau is a strength. The framework has also highlighted the need for people working in the *care for*, *care about* and *take care of* levels to understand that they are part of a health care system that privileges the mainstream, at the expense of Māori. Many people at community, management and policy level are working to change the way the health system engages with Māori, but without a solid commitment to health equity from those who lead central government, DHBs and health providers, these efforts are not cohesive across the system as a whole. This complacency from successive governments is unacceptable when there are robust tools that could be properly enacted such as the Equity of healthcare for Māori framework (Ministry of Health, 2014b).

The role of primary health care, particularly that of Māori health providers, in facilitating access to cancer care, must be at the forefront of cancer policy. Primary care performs a vital role in cancer care by facilitating access to services, and providing continuity of care and information that is person-centred throughout the cancer care journey (Burge et al, 2003; Kendall et al, 2006). For almost 30 years, Māori health providers have facilitated access to mainstream health services (Crengle, 2000, Slater et al, 2016). Māori health providers have used their local knowledge and established relationships within their communities to provide health promotion activities grounded in positive Māori development, and provided continuity throughout cancer treatment and rehabilitation. Māori health providers also deliver supportive care services to whānau experiencing cancer, but for the most part, supportive care services are provided by the Cancer Society. Good support assists with receiving and digesting cancer information, however information about cancer does not always align with Māori world views. Information is not consistently distributed or always understood by whānau.

The long established relationships, high degree of trust and whānau ora approach that Māori health providers have within their communities is pivotal in helping Māori to access cancer care services. Māori health providers 'hang in there' for whānau which is of particular importance after the conclusion of cancer treatment, when follow-up care is lacking. However Māori health providers' whānau ora approach to care has not historically been adequately recognised or funded. The Whānau Ora Initiatives may provide scope for Māori health providers to be recognised and funded for the work they do across sectors. This study showed that whānau are the key to positively affirming Māori access to cancer care and support services. Investing in better and sustainable supportive care for whānau, including support groups, would gather momentum in dispelling myths and fears about cancer, treatment, hospitals and hospice, thereby improving Māori access into and through cancer care.

The establishment of the Regional Cancer Networks has helped facilitate communication between primary and secondary care, and also improved communication between primary health care providers. There is room for improvement however, in collection of ethnicity data, compatible and timely medical records and IT systems to facilitate better informed service provision and information-sharing. It is important for the Regional Cancer Networks to continue their inequalities focus by maintaining their inequalities manager positions. In terms of *social ethics*, this implies that the Ministry of Health must increase funding to the Regional Cancer Networks, in order for the networks to recognise Māori health priorities.

There are great challenges ahead for those working to address Māori priorities in cancer care, as cancer related policy in Aotearoa appears to be losing the equity approach that was articulated in the early 2000s (Blakely, Simmers & Sharpe, 2011). The specific equity focus that was articulated in the New Zealand Health

Strategy (Minister of Health, 2000), the Primary Health Care Strategy (Minister of Health, 2001), the New Zealand Cancer Control Strategy (Minister of Health and the New Zealand Cancer Control Trust, 2003), The New Zealand Disability Strategy (Minister of Disability Issues, 2001), the New Zealand Palliative Care Strategy (Ministry of Health, 2001) and He Korowai Oranga, Māori Health Strategy (Minister and Associate Minister of Health, 2002), have been watered down in the NZ Cancer Plan (Ministry of Health, 2014c) and the updated New Zealand Health Strategy (Minister of Health, 2016a). The contribution of Māori health providers, and the Equity of Healthcare for Māori framework (Ministry of Health, 2014) should be at the forefront of both the NZ Cancer Plan (Ministry of Health, 2014c) and the New Zealand Health Strategy (Minister of Health, 2016a, 2016b).

The development of cancer nurse co-ordinator roles within DHBs has the potential to improve access for Māori with cancer to appropriate services, but only if the navigators have good relationships with Māori health providers and other primary health care providers who have local knowledge and established trust within their communities. It is also critical for the cancer nurse co-ordinators, alongside all health practitioners, to be culturally safe in their care.

Findings from this study support a more strategic approach in order to improve the whole cancer continuum. Acknowledgement of the different support and quality of life needs of Māori is required, as well as the development of genuinely integrated models of care, consistent with a Māori-centred approach that addresses priorities for Māori. These include integration of primary and secondary cancer care, supportive care, survivorship and palliative care services and most importantly, recognition of the importance of whānau ora.

Many of the issues raised by the study are not new. The need for culturally safe care by all health practitioners, adequate recognition and funding for Māori health providers, and better access into and through cancer care for Māori have been described as urgent priorities for a long time (Cormack et al, 2005). But they have never been adequately addressed through government policy. Despite successive governments reframing their commitment to Māori health, outcomes continue to be poor. There will be increasing numbers of Māori with cancer in the future, including increased numbers of those with highly fatal cancers, as well as cancers requiring more long term management and support (Robson & Ellison-Loschmann, 2016). This has implications for the health system in general, and particularly for providing culturally safe cancer care and support for Māori.

The implications of not addressing systemic barriers into and through cancer care for Māori are wide and will affect many whānau. Findings from this study raise questions about the sustainability of the work that Māori health providers already undertake in cancer care, and pin substantial hope on the Whānau Ora Initiatives to push forward in recognising the breadth of this work. If cancer control in Aotearoa continues on its current universal path, it is likely that cancer screening, detection, diagnosis, treatment, supportive care, palliative care and rehabilitation services will not reach whānau and Māori will continue to die from cancers that could have been prevented or treated. Can we really go on like this?

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The role and potential of community-based cancer care for Māori in Aotearoa/New Zealand

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ABSTRACT

AIM: To investigate the contribution to cancer care and prevention by Māori health provider organisations (MHPs) in Aotearoa/New Zealand.

METHODS: A nationwide postal survey of all MHPs (n=253) was undertaken in 2011. The response rate was 55%.

RESULTS: We found that MHPs are delivering a wide range of programmes including cancer prevention services focussed on health promotion, advocacy, information and support. MHPs identified financial hardship, transport difficulties, and lack of information as the greatest barriers to cancer care. Culturally safe care by mainstream providers would improve cancer service provision overall. The importance of trust and long-term relationships, with a focus on families rather than individual-based care, was highlighted.

CONCLUSION: These findings could lead to substantial improvements in quality of life for Māori cancer patients. This is the first study to show how indigenous health providers contribute to cancer care and prevention in Aotearoa/New Zealand.

There are stark differences in cancer incidence and survival across ethnic groups in Aotearoa/New Zealand (Aotearoa), with Māori carrying a disproportionate cancer burden.¹ Māori have an approximately 20% higher age-standardised incidence rate, and a 72% higher age-standardised mortality rate for cancer overall compared to non-Māori.² Additionally, quality of life differs between Māori and non-Māori from diagnosis through treatment, recurrence and survival.²

It is well established that there are challenges in accessing health care for Māori at all levels of service provision.³⁻⁶ Access to care has a substantial impact on cancer outcomes,⁷ yet the evidence suggests that mainstream systems of cancer care are substantially less responsive to Māori than non-Māori.⁸

Māori health providers (MHPs) were established in Aotearoa in the 1990s following radical public sector reforms. New funding models enabled MHPs to compete with other providers for health

service contracts.⁹ MHP values and ways of working were different to mainstream health providers and their services were available to all ethnic groups. One of the most important roles of MHPs was to enable people to access health services. MHPs used Māori models of wellbeing, positive Māori development and Māori philosophical and practical approaches.¹⁰ However, health service contracts focussed on individuals and illness, which was inconsistent with Māori worldviews, emphasising holistic wellbeing and collective approaches to health for the whole whānau (family).¹¹ Despite these challenges, the number of MHPs has increased and their main focus is primary health care services relating to prevention and lifestyle issues.¹² Some MHPs offer general practitioner (GP) services and some do not, nonetheless MHPs play a major role in facilitating access for Māori into mainstream health care. This means that even if the MHP does not have its own GP service, regardless, appropriate onward referral (to primary health care

clinics/services in their areas), for those patients requiring this, is a core feature of the work that MHPs were set up to do. This facilitation remains important given that, as a diverse population, not all Māori access MHPs and all secondary care services are within the mainstream health care system.¹³

The establishment of MHP services coincided with the development of cultural safety education. Cultural safety programmes were developed in response to growing evidence of disparities in a range of health outcomes between Māori and non-Māori.¹⁴ Cultural safety shifted responsibility back on institutions and health workers to address their performance in meeting the health realities of Māori, including access to care.¹⁵

The Medical Council of New Zealand and most District Health Boards (DHBs) have a cultural competency requirement, which is different to cultural safety. Cultural safety makes explicit the role of power in the nurse/midwife relationship with clients. Thus, the definition of 'good' care is placed in the hands of those receiving it. Cultural competency is less concerned with power and focuses more on the ability of clinical staff to engage respectfully and reflectively with people from different backgrounds.¹⁶

Primary care plays a key role in facilitating access to services, continuity of care and information that is person-centred throughout the cancer care journey.^{17,18} As the first point of connection with the health system, primary care influences cancer prevention, early detection, access to specialist treatment and patient support following discharge from hospital.¹⁹

There is some research showing that as primary care providers, MHPs have a distinctive approach to cancer care.²⁰⁻²⁵ The trust and rapport that MHPs have within their communities enables engagement with mainstream cancer care and support services. Additionally, these relationships enhance MHP driven cancer prevention activities (for example, smoking cessation). There is evidence that MHPs are effective at providing cancer screening²³ and support throughout cancer treatment.^{22,25}

MHPs have been providing primary care services for decades, but information about of their services, particularly in relation

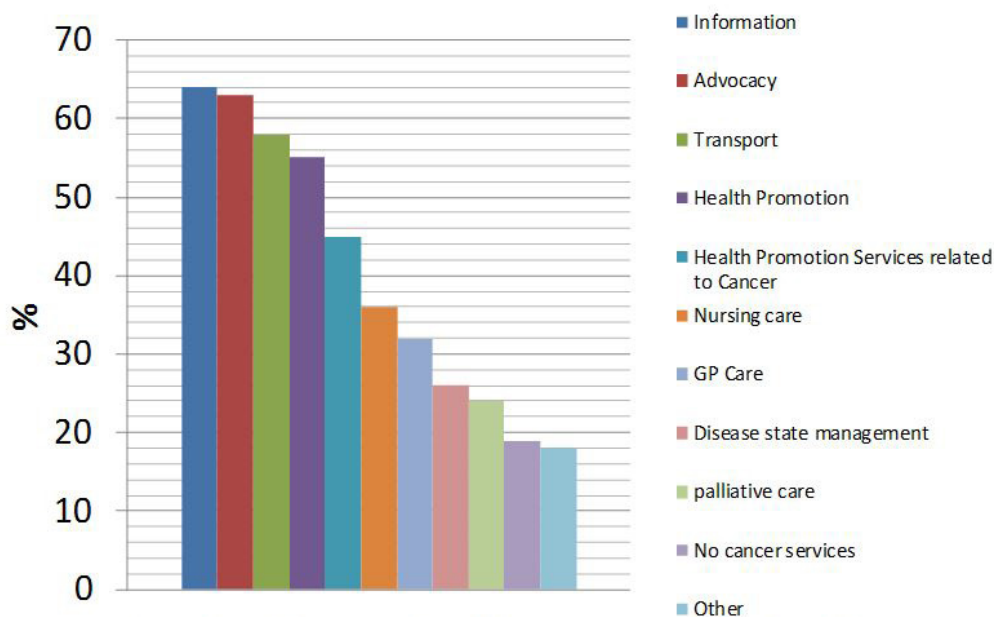
to cancer, is scarce. There is evidence that MHPs have a wealth of local knowledge from their communities regarding the causes of disparities for Māori including access to and through cancer care.²³ This study aims to explore how MHPs facilitate access to cancer screening, diagnosis, treatment, support and palliative care services. Through identifying the services MHPs provide there is potential to build on strengths and help address unacceptable ethnic differences in cancer incidence, mortality and quality of life.

Methods

This paper describes a survey of MHPs current role in cancer care. It examines the potential for further services, and explores MHP perspectives on what is impeding or assisting their communities in accessing services along the cancer journey. The study was approved by the Health and Disability Ethics Committee (MEC/09/11/131).

In 2011, we undertook a nationwide postal survey of all MHPs in Aotearoa. As discovered by other researchers,²⁵ there is no publicly available database of MHPs. MHPs can list their organisation on the Ministry of Health website, but this is not comprehensive with 66 MHPs listed at the time this paper was written.²⁶ For this study we therefore used publically available directories and networks in order to identify MHPs. Using this approach, 253 MHPs were identified.

The survey questionnaire was developed based on the Te Huarahi o Nga Tangata Katoa study, which investigated cancer service availability and experiences of patients and providers.²⁷ Our questionnaire explored services MHPs are currently delivering, including core services, types of support for cancer patients and whānau, and also health promotion, screening and other services which help with cancer prevention. Providers were asked to consider barriers to care for people who do not access cancer detection and diagnostic services, and what would help people with cancer and their whānau at all levels of cancer care and support. Finally, MHPs were asked if there were additional cancer care services that they could provide if funded.

Figure 1: Services for people with cancer and their whānau delivered by MHPs.

The questionnaires were sent to each provider together with a covering letter, information sheet and post-paid reply envelope. The information sheet outlined the aims of the study and explained that completion of the questionnaire implied consent. Non-responders were sent a follow-up survey, and contacted by telephone with a further survey sent on request. Data were entered into a Microsoft Access database. Analyses were undertaken using the statistical software package SAS and involved simple tabulations and percentages. No statistical tests were applied. Microsoft Access was used to group the data in the open text fields.

Results

Of the 253 questionnaires sent out to MHPs, 119 (47%) were completed, 23 (9%) declined (of these, four organisations provided information about the services they provide), 37 (15%) were ineligible (return to sender, organisation no longer exists or is not a MHP). There were 74 (29%) non-responders. These included organisations that were sent the questionnaire and followed up with a telephone call, but did not complete the survey, and organisations that were sent the questionnaire twice but not able to be contacted by telephone. After subtracting the ineligible, the overall response rate was 55%.

The survey was answered by people from a range of positions within the MHP organ-

isations. Over half of the respondents were Kaiwhakahaere/Chief Executive Officers and managers (15% and 37% respectively), but the survey was also answered by nurses (10%), community health workers (8%), project/programme co-ordinators (8%), GPs (6%) and administrators (2%). Other respondents (9%) included team leaders, group responses, liaison positions and a counsellor. Six respondents did not provide their position within the organisation.

MHPs varied in size, ranging from individuals providing one health service, to large organisations with multiple premises, delivering up to 20 health service contracts. Respondents were asked to show the health services they offered, whether funded or not. Health promotion services were the most commonly provided health service. More than half of the respondents reported providing child/youth health, older people's health, community outreach, social services, infant health, mental health or nursing services. Services that were provided the least were disability support services and rongoā (Māori medicine).

Cancer services

Respondents were asked about the services they provide for people with cancer and their whānau (Figure 1).

Information (64%), advocacy (63%), transport (58%) and health promotion (55%) were the most commonly reported cancer services, while health promotion services related to cancer (such as Aukati Kai

Table 1: Reasons for delay in accessing services for cancer detection/diagnosis.

	Screening services		Primary Care presentation with symptoms	
	(n)	%	(n)	%
Limited information	88	74%	73	61%
Financial barriers	98	82%	99	83%
Provider issues such as no GP or not registered with a Primary Health Organisation (PHO)	57	48%	54	45%
Lack of cultural safety	59	50%	57	48%
No Māori health workers	52	44%	49	41%
Fear of cancer diagnosis	-	-	112	94%
Fear of misdiagnosis	-	-	43	36%
Fear of treatment	-	-	91	76%
Reluctance about talking to the doctor about other health issues	-	-	83	70%
Delay in referral to specialist	-	-	50	42%
Other reasons	48	40%	24	20%

Paipa—a quit smoking programme) were reported by 45% of respondents. Respondents also reported provision of nursing care (36%), GP care (32%), disease state management (26%), and palliative care (24%). Almost 20% of providers reported no cancer service provision and 18% described other support and services including support for whānau, respite care, counselling and psychotherapy, support group programmes, funeral support, celebrations, rongoā (medicine) and accommodation (Figure 1).

In an open question, respondents were asked what services were of most benefit to people with cancer and their whānau. Most often, *by Māori for Māori* health and support services were described (33%). Specifically, respondents indicated the trust that people have in their MHP, cultural support, holistic healing, access to rongoā and mirimiri (massage), and wrap-around care that is often available after hours.

Advocacy and practical support were also outlined (27%), including transport and support for clinician and other appointments such as welfare agencies and electricity companies. Clinical services were identified (20%) including oncology departments, specialists and community nursing care. Palliative care was also

noted (18%), with both palliative care and hospice care specified.

Respondents were asked to choose from a list of reasons why some people might delay accessing a service for early cancer detection or diagnosis. These included screening services and also primary care services such as a GP.

Findings related to delays in accessing cancer screening services indicate that financial barriers and limited information were the main reasons for delay. Half of respondents cited a lack of cultural safety by the screening provider, and provider issues such as not having a regular GP or not being registered with a PHO. Almost half of respondents thought an absence of Māori health workers at the screening provider contributed to delays. Other reasons were also described including: practical issues such as lack of transport and difficulty juggling childcare or time off work; and wider issues such as feeling whakamā (shy or embarrassed), denial and fear of diagnosis (Table 1). Information about accessing screening services due to fears of misdiagnosis, treatment or referral delay was not collected as it was seen as less relevant for asymptomatic people.

Findings with regard to delays in presenting at a primary care provider for

cancer detection or diagnosis, suggest that fear of diagnosis, financial barriers and fear of treatment were thought to be key reasons for delay. Additionally, many providers thought that reluctance about talking to the doctor about other health issues, such as diet or smoking, would contribute to delays. Limited information about cancer detection was also considered a factor. Almost half of respondents cited a lack of cultural safety by the primary care provider, while less than half thought that provider issues, such as not having a GP, a delay in referral to a specialist or no Māori health workers at the primary care provider, contributed to delays. Lastly, a fear of misdiagnosis was considered a contributor to delaying access to early cancer detection (Table 1). Just under a quarter of respondents listed other reasons. As with the delay in accessing screening services, these included practical issues, such as taking time off work, childcare and also worrying about the future, such as how to cope financially. Respondents also indicated that people might feel shy about seeing a doctor when they have symptoms, and fear of death, or fear of treatment based on the experiences of others.

In an open text question, providers were asked if they could identify any issues about, or barriers to, services for people with cancer. A quarter of respondents did not have any issues or barriers to identify. One respondent did not know, and data were missing for two respondents. Most respondents (70%) listed issues about, or barriers to services for people with cancer. Answers were similar to those shown for screening and presentation to primary care with symptoms in Table 1. Most commonly cited were transport and access issues. Additionally, a lack of appropriate information for people with cancer was described. This included information about diagnosis and treatment, and also information about support services available.

Financial costs were also reported as barriers to care, with time off work, childcare costs and accommodation adding financial pressure to whānau. Respondents also identified a lack of culturally appropriate services, for example cancer care staff pronouncing names correctly.

Respondents were asked if palliative care was readily available in their communities.

Over half of the respondents (63%) thought it was, and 26% thought it was not. Eleven per cent of respondents did not know. Half of the respondents (n=60) identified issues or barriers to palliative care. Of these, location and travel were the main barriers, with many living in rural communities. Related to this were the responses of a smaller number of respondents who specified poor resourcing for community nurses in their area to provide palliative care services for whānau at home. A need for culturally safe palliative care services was described, and suggestions for improvement included acknowledging and improving cultural safety, having more Māori faces within palliative care service delivery, and a need for te reo Māori (Māori language), and karakia (prayer) to be available. A small number of respondents indicated reluctance by Māori to use hospice services due to associating the hospice with death.

Providers were asked if there were additional cancer care services that their organisation could provide, if funded. The question specified services that are currently not easily available or accessed in their communities. Over a quarter (32%) of respondents said there were no cancer care services that their organisation could provide. For many, this was due being a small provider with few contracts and resources. A small number (7%) of respondents did not know if there were cancer services they could provide, and over half (61%) answered positively. Of these, the services listed most were Māori-focussed cancer care services. These included support for whānau, Māori cancer support nurses, Māori focussed psychotherapy and counselling, and culturally appropriate home help. Respondents also listed 24-hour nursing support, mirimiri and rongoā, cancer resources and information specific to Māori.

In addition, the need for dedicated cancer navigator positions was highlighted. Support and advocacy, from diagnosis through to survival or palliative care, were emphasised. Respondents also listed provision of palliative care, appropriate funding for transport services rather than relying on volunteers and mobile nursing teams to access whānau in isolated areas.

Discussion

This study is the first national survey of MHP cancer services. Four key areas were identified in our findings. The first is the largely unacknowledged, wide ranging cancer services that MHPs currently provide and the additional services that they would like to provide if adequately funded. Second, a number of barriers to and through cancer care for Māori were identified, such as financial and transport issues. Third, a continuing need was shown for culturally safe care by all services for Māori with cancer. Finally, the importance of trust and long-term relationships with a focus on families rather than individual-based care was highlighted.

Our list of MHPs was compiled from publicly available directories and networks. It is likely that in addition to our non-respondents, a small number of organisations were not surveyed, although it is impossible to count how many were missed. In 2009, the Ministry of Health estimated that there were approximately 275 MHPs,²⁸ but only a quarter of these are listed on their website.²⁶ This raises questions about why MHPs and their work are effectively invisible, with little information available about their contributions, and few evaluations of their work.

A response rate of 55% for this survey is acceptable. It is comparable to the 46% response rate yielded in a recent cross-sectional postal survey of GPs in Aotearoa.²⁸ Our efforts to increase the response rate included sending out the questionnaire up to three times and following up by telephone. We acknowledge that there may be non-response bias in this study with those organisations not providing cancer services feeling that the survey was not relevant and thus not completing it, however four declines provided information about the services they deliver and these did not differ markedly from the services reported by the respondents. Additionally, there may be some recall bias where MHPs have reflected on the services they offer or barriers experienced by those in their communities.

Results showed that MHPs contribute to cancer prevention, screening and care by delivering a wide range of programmes, including health promotion, advocacy,

information and support alongside clinical care. In terms of contributing to cancer prevention, a high proportion of MHPs in our study provided health promotion services to their communities. The context of this work is important as Māori health promotion goes beyond delivering health and lifestyle messages. Ratima describes Māori health promotion as:

*a process of enabling Māori to increase control over the determinants of health and strengthen their identity as Māori, and thereby improve their health and position in society.*³⁰

In this way, the work that MHPs undertake in health promotion not only plays a central role in cancer prevention, but also contributes to positive Māori development.

Almost half of the MHPs in our study reported providing cancer screening services. Building trust, long-term relationships and practical assistance have been shown to increase cancer screening rates.^{20,21,25} Our study demonstrated that many MHPs provide practical assistance, such as transport, advocacy and after hours care, but also link families with other services, such as the Cancer Society of New Zealand, hospice or Māori rongoā practitioners.

The coordination of care for Māori has been identified as a major area requiring further work.²⁰ Literature has shown that cancer navigator roles have succeeded in facilitating improved cancer care in Aotearoa,^{21,31} and internationally—particularly for indigenous populations and those living in poverty.³²⁻³⁴ The current study, and our previous work with cancer patients,²⁴ suggest that MHPs have been delivering informal cancer navigation for some time, but there is evidence that they are inadequately funded to do this work.³⁵⁻³⁸

Attempts to gather health funding information from Crown funding agencies have proven problematic.^{35,36} Studies asking MHPs directly about their contracts have offered more insight. Lavoie found that MHPs were restricted by narrowly focussed contracts which did not reflect the work carried out.³⁷ Other studies have found limited scope for MHPs to negotiate with funders,³⁸ and MHP contracts to be short

term and audited with a heavy financial focus compared to their mainstream counterparts.³⁵ Indeed, the available evidence suggests that MHPs are underfunded and over regulated, but their process outcomes are under evaluated.³⁵⁻³⁸ Without these issues being properly addressed by funders, it is difficult to see how the work of MHPs can be acknowledged and supported.

Financial struggles and travel featured consistently in our results as barriers to cancer screening, diagnosis and treatment. Health care reforms, beginning in 1999, aimed to improve primary care access in Aotearoa. By signing up to a PHO, the cost of GP consultations was reduced and some services were free.³⁸ However, findings from this study suggest that in addition to many Māori not having a regular GP or being signed up to a PHO, other barriers, such as the cost of travelling to appointments, still remain.

A lack of appropriate information was also a barrier to cancer services for the communities served by MHPs. This finding is consistent with work by Walker et al, who encourage more information and resources tailored to whānau and MHPs,²¹ and Cormack and colleagues, who recommend Māori-specific resource material about cancer and cancer service options for individuals, whānau and communities.²⁰

Our results suggest that fear is a major contributor inhibiting access to primary care services and potentially a cancer diagnosis. Fear of cancer, particularly by indigenous populations, has been documented internationally.⁴⁰⁻⁴² Our previous work found that having a trusted community health worker, nurse or GP can help alleviate these fears.²⁴ Further, persistence by MHPs in contacting and encouraging Māori to attend primary care services has been shown to ease fears about cancer screening,²² diagnosis and treatment.²¹

Despite 66% of respondents believing that palliative care is available to Māori with cancer, and 24% of the MHPs delivering palliative care services, our results showed that MHPs are not confident their communities can always access the palliative care services they need. For some, this was due to living in remote locations. For those in

areas where palliative care services are available, more Māori staff and improved cultural safety in hospices to encourage access was suggested. This aligns with findings from Frey et al, who additionally found a lack of awareness amongst Māori and other groups around palliative care service availability.⁴³

MHPs in our study considered that shyness, or reluctance to discuss other health issues, impacted on Māori with cancer symptoms consulting a doctor. This finding suggests a current gap in comfort and rapport with mainstream primary health care providers which has also been described in other studies.^{25,44-46} There is more work to be done within mainstream health systems and those who work in them to improve cultural safety. Approximately half of the MHPs who took part in this study consistently reported a lack cultural safety as a barrier to all cancer services, from prevention through to screening, primary, and hospital care.

Progress is being made. Our study supported previous findings that whānau play a critical role in relation to facilitating Māori access to cancer care services.^{20,27,47} Whānau Ora, a new interagency approach to providing health and social services in Aotearoa, may offer better outcomes. The Whānau Ora initiatives encompass a philosophical approach, model of practice and measurable outcomes for health and social services.⁴⁸ At the time of this survey, Whānau Ora provider collectives were being established and early reports on Whānau Ora progress are scarce but positive. Boulton et al, for example, have shown how as a Māori-centred framework, Whānau Ora has positively changed ways of working and integration of contracts for a Māori health and social service provider.⁴⁹ Although not all MHPs will be part of Whānau Ora collectives (at the time of writing there were 34 Whānau Ora collectives),⁵⁰ Whānau Ora represents an opportunity to be appropriately resourced for the wide range of MHP services that overlap across sectors. Thus, the Whānau Ora approach should be considered as central to any framework for an integrated cancer care journey for Māori.

Competing interests:

Tania Slater, Maureen Holdaway, Anna Matheson and Lis Ellison-Loschmann report grants from Health Research Council of New Zealand, during the conduct of the study.

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ORIGINAL SCIENTIFIC PAPER

QUALITATIVE RESEARCH

'It's whanaungatanga and all that kind of stuff': Maori cancer patients' experiences of health services

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ABSTRACT

INTRODUCTION: There are unacceptable ethnic differences in cancer survival in Aotearoa/New Zealand. For people with cancer, quality of life and survival are shaped by access to care, but research on Maori access to, and through, cancer care is limited. Internationally, research has shown that primary care plays an important role in providing patient-centred, holistic care and information throughout the cancer care journey. Additionally, Maori health providers provide practical support and facilitate access to all levels of health care. Here we describe the cancer journeys of Maori patients and whanau and identify factors that may facilitate or inhibit access to and through cancer care services.

METHODS: Twelve Maori patients affected by cancer and their whanau (family) in the lower North Island took part in face-to-face semi-structured interviews exploring their experiences of cancer screening, diagnosis, treatment, survival and palliative care.

FINDINGS: Three key areas were identified that impacted upon the cancer care journey: the experience of support; continuity of care; and the impact of financial and geographic determinants.

CONCLUSION: Primary care plays a key role in support and continuity of care across the cancer journey. Alongside interpersonal rapport, a long-term relationship with a primary health provider facilitated a more positive experience of the cancer care journey, suggesting that patients with a 'medical home' are happier with their care and report less problems with coordination between services. Positive, long-standing relationships with general practitioners and Maori health providers assisted patients and whanau with the provision and understanding of information, alongside practical support.

KEYWORDS: Cancer; family; health services, indigenous; Maori health; primary health care cancer

Introduction

There are unacceptable ethnic differences in cancer survival in Aotearoa/New Zealand. It has been documented that Maori have an approximately 19% higher age-sex-standardised incidence rate and a 78% higher age-sex-standardised mortality rate for cancer overall, compared to non-Maori.¹ Stage at diagnosis and presence of comorbidities have not been found to fully explain survival differences between Maori and non-Maori.¹⁻³

As well as having significantly higher cancer mortality rates, quality of life differs between Maori and non-Maori at all stages of the cancer

journey.⁴ However, few studies have included the voices of Maori with cancer and their whanau in order to pinpoint factors that facilitate or inhibit access to, and through, cancer care services.

A number of studies have highlighted difficulties in access to health care for Maori at all levels of service provision.⁵⁻⁹ The term 'access' has been defined as the timely use of personal health services to achieve the best possible health outcomes.¹⁰ Access may be conceptualised in terms of whole systems that operate at the structural, clinical/treatment and patient levels.^{3,8,11} For people with cancer, quality of life and survival are shaped by the interaction between and across all of these levels that impact on access through, as

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well as to, health care services.¹¹ Research to date on Maori experiences of access to and through cancer care is, however, limited.^{8,12} One such study advocates for improved communication and information, better resourcing for Maori providers and whanau, use of cancer navigators, more coordinated service delivery, changes in mainstream services and cultural competence training for all health workers.¹²

Internationally, research has shown that primary care can play an important role in providing patient-centred, holistic care and information throughout the cancer care journey^{13,14} and for those with complex needs.¹⁵ ‘Medical home’ is a concept that encapsulates primary care practices where clinicians are accessible, know patients’ medical history, and help coordinate care.¹⁵ Interpersonal rapport between general practitioners (GPs) and patients has been identified as important in enabling Maori to access health care.^{16,17} However, studies have shown that many Maori do not experience good rapport with a primary health care provider,^{9,18,19} and further research has highlighted areas where good rapport is also lacking with other practice staff, such as those managing reception.^{12,20}

Primary care services delivered by Maori—ranging from Maori-specific services through to advocacy in engagement with mainstream providers—has increased in recent decades.⁸ Maori providers have also played an important but unrecognised role in the provision of primary cancer care, through the implementation of health promotion programmes, such as Aukati Kai Paipa and Healthy Eating Healthy Action.^{21,22}

Patients who are looked after by Maori health providers report satisfaction with cost, cultural acceptability, convenience of location,²³ and empowerment and comfort, which is enhanced by a setting that prioritises a Maori worldview, alongside practical support.¹² However, most Maori still access mainstream health services,²⁴ which are much more numerous than Maori provider organisations. Ethnic differences in cancer survival suggest that current approaches to cancer care delivery are not responsive to Maori, although the reasons for this are unclear. This research aims to describe the cancer journeys of

WHAT GAP THIS FILLS

What we already know: As well as having significantly higher cancer mortality rates, quality of life differs between Maori and non-Maori at all stages of the cancer journey. Few studies to date have documented the care experiences of Maori cancer patients and their whanau.

What this study adds: Longstanding relationships with primary health care providers are key to continuity of care for cancer patients and their whanau. These relationships, alongside good interpersonal rapport, facilitated positive experiences and informed choices about treatment and other supports throughout the cancer care journey.

Maori patients and whanau and identify factors that may facilitate or inhibit access to, and through, cancer care services.

Methods

This research explores the experiences of 12 Maori patients and their whanau affected by cancer. A qualitative approach, using face-to-face, semi-structured interviews was considered appropriate for this study, to capture an in-depth understanding of the cancer journey from the point of view of the participants.²⁵ The method selected does not lend itself to the results being generalisable outside of the geographic areas and the group of participants in this study.

The study team was composed of members from two Maori health provider organisations and researchers from Massey University. The study was approved by the Health and Disability Ethics Committee (MEC/09/11/131). Inclusion criteria were Maori with a cancer diagnosis, from enrolled populations in two Maori provider organisations in the Wellington and Wairarapa regions. Whanau (family) of the person with cancer were also welcome to take part in the interviews. Potential participants were identified by the Maori health providers who recruited participants and gained their written, informed consent. Interviews took place between May and November 2011 and were conducted by two Maori health workers (CD and HT) from one of the Maori health provider organisations, at a time and location chosen by the participant.

Interviews were recorded digitally and transcribed verbatim by one of the researchers. A the-

matic analysis was carried out on the interview transcripts. This involved identifying, coding and categorising the primary patterns in the data.²⁶ The analyses were undertaken in three parts. Firstly, two researchers independently carried out preliminary coding of the transcripts by hand. Secondly, the researchers compared and discussed the emergent themes with each other and then with one of the participating Maori health providers. Thirdly, qualitative analysis software NVivo (QSR International Pty Ltd, Doncaster, Australia) was used to help organise the thematic codes.

Findings

Participants were Maori, and ranged in age from mid-30s to mid-70s. All had experienced cancer in the last five years, with the exception of one participant who was a cancer survivor for more than 20 years. Participants had been diagnosed with a range of cancer types, including breast, cervical, prostate, uterine, lung and laryngeal cancers.

Three distinct themes were identified from the interviews as being key areas that enabled or inhibited the cancer care journey for study participants.

These were: experience of support; continuity of care; and wider health determinants, specifically geographical distance and income.

Experience of support

Participants' needs included emotional support at appointments and at home in the long term, as well as practical support, such as getting to and from appointments, and acquiring and interpreting health information and types of financial assistance available. Support organisations utilised by participants included Maori health providers, GPs, hospitals/district health boards (DHBs), the Cancer Society of New Zealand (CSNZ), Lions Clubs (charity organisation) and hospices.

Whanau support was discussed frequently. Whanau provided personal and emotional support through the journey at all stages. This support came primarily from one family member

who themselves often experienced stress from being in this role. Occasionally time off work was required, impacting on household income.

My husband and I argued. The stress, you know he had to take time off his job to do it. You know when I had breast cancer he actually gave up his job to take me to my treatments. (#5)

Stresses accumulated for whanau in a support role. However, there was no discussion of whanau taking breaks or getting support for themselves, with a few participants referring to 'burnout' of their supportive whanau.

Another whanau role was in helping patients decipher information they received from health workers. Participants who did not have whanau or personal support appeared to be at a disadvantage with regard to both receiving and understanding information about their care. Maori provider organisations often filled this gap, as well as providing help to whanau.

When I was searching for the turbans she [Maori Provider] actually rang up the CSNZ and you know I could have done it but I wasn't even thinking about that. (#7)

Maori providers also acted as facilitators of information for other available support, provided companionship, and assisted with practical and logistical needs, such as attending appointments or finding out where to park cars at the hospital. Maori health providers and whanau were discussed in similar ways by participants. There was trust, comfort and familiarity expressed, as well as knowledge that participants could make contact at any time if needing support—especially when at home.

It is the companionship eh. I mean yeah, you know if it is [a Maori Provider] come on, let's go in there and I will shout you a cup of tea or I go, I say to [Maori Provider] let's go to Petone and look at some fish heads, you know, because there is a fish factory there. (#12)

...all those kind of things that you expect from a Maori service you know and it's whanaungatanga and all that kind of stuff. (#7)

There was substantial discussion of the relationship with GPs, notably where participants had either a long-standing relationship with a family GP, or had never had one, or had 'lost' this relationship. Of the 12 participants, seven had a regular GP. Of these, five described positive relationships, while one participant experienced a long history of unhappiness and distrust in her GP, and another had only visited the family GP once in 20 years. The remaining five participants did not have a regular GP and would see whoever was available at their local clinic, attend after-hours medical centres, or not seek medical care until reaching a crisis point.

I just go to whoever is available when you ring up. (#7)

Participants with a positive, long-term GP relationship tended to highlight the importance of this history.

Same GP, yeah. She has got two files that thick. And she was the one that um, when I first was diagnosed she sent me to a specialist. So there was no shilly shallying. (#12)

The DHBs and hospitals provided a number of services ranging from access to specialists and outpatient care through to district nurses but also petrol vouchers, parking, ambulance/taxi services, and other home help assistance. Interactions with specialists were mostly described positively. These interactions often followed a period of uncertainty for participants, with the specialist providing much anticipated answers or options. It was, however, frequently expressed that appointment times were not long enough, which was also raised in regard to GP visits, and that there was not often the opportunity or 'space' to ask questions that participants might have wanted to ask. It was in these situations where personal support was described as invaluable.

Continuity of care

A common thread throughout the interviews was the numbers of individuals involved in a person's cancer care. Although participants spoke positively about many of their interactions with health workers, the overall impression was one

of numerous organisations, specialists, doctors, nurses and administrative people involved in the process of care. Difficulties in maintaining relationships with ever-changing staff led to gaps in information and support.

When I was going through some treatments you know you get people coming around you introducing themselves and you are like well hold on, I am not really worried about you right now, I have got to focus on myself so you know come and see me when I am at home, when I am all alone, when there is nobody there to help me. (#1)

Having a positive and long-standing relationship with a GP throughout the cancer care journey was beneficial and facilitated positive experiences of support and follow-up.

Yep, yes, she [GP] is the one that's been putting me on to different people. (#2)

Barriers to accessing information were articulated by participants as an outcome of both inadequate support and a lack of long-term relationships with primary health care providers. Information provided (or not provided) to participants about available support and resources was inconsistent and appeared to be shared in an opportunistic rather than a planned fashion. This included information about the cancer itself (cancer/treatment/follow-up) but also travel/accommodation, support and financial assistance. The availability of information appeared strongly dependent upon the nature of support a patient had at particular moments through the cancer care journey.

And then the chemo came in and I just got lost, absolutely lost. And I just got all these appointments like you have got to be here, you have got to be here, but if it wasn't for [Maori Provider], I wouldn't know where I was going. (#7)

They offered me a tablet. What was that for? Well I couldn't get at, grasp what he was on about, you know? (#11)

Wider determinants of health

Distance to services and financial constraints, within a wider context of determinants of health,

were the main barriers to care described by participants. Participants' experiences of travel to appointments, even when distances were close, were difficult. With greater geographic distance, this was even more significant. For example, for those living in the Wairarapa (compared to those living in Wellington/Hutt Valley/Porirua) the impact was greater in terms of more time away from home and work and, therefore, in both the ability of whanau to support them and also in losses to income and the other financial costs involved. Dependence upon others for logistic and financial assistance with travel meant that the conditions of travel were less than ideal, with many participants describing having to be away all day, even for a brief appointment, or being in situations that they felt compounded their stress levels.

The financial burdens it puts on you. Because I had to travel from [locality] to [locality] every day... for five weeks for radiotherapy... And the stress, just in that alone. (#1)

The need for financial assistance for this group of participants through the cancer care journey was often critical, but sources of financial support were limited and opportunities for assistance offered in an inconsistent way. For example, little information was freely available about benefit entitlements and mobility cards. Income was also affected through time taken off work by participants or whanau. In general, employers were very supportive and offered time off for appointments, treatment and recovery and also kept positions 'open' or extended leave entitlements. However, the impact on income was still substantial and there was often little support offered to address this.

Discussion

The main limitation of the study is that it presents the experiences of a small group of participants only and is confined to cancer services within specific geographic areas of Aotearoa/New Zealand. However, few studies to date have documented the experiences of Maori cancer patients and their whanau regarding facilitators and inhibitors to cancer care. The current study emphasises some important and understudied areas within levels of cancer care.

In relation to the theme of experience of support, the results highlight the critical role of information and how the quality of, and response to information is interrelated with the support structures of patients, with Maori provider organisations and GPs being central to this. Support was also relevant for whanau, both during treatment of their family member with cancer but also on discharge home and in terms of adequate follow-up care and services.

The availability of personal support to patients was variable but was considered crucial for making sense of information and advice provided throughout their cancer journey. Whanau and Maori health providers often filled this role and importantly, in some instances, so did relationships with GPs. While the results concur with other literature that 'rapport' is important within face-to-face contacts,¹⁷ in terms of the identified theme of continuity of care they also show that, alongside rapport, a long-term relationship with a GP facilitated a more positive experience. Other work in Aotearoa/New Zealand has also found that having a regular primary care provider is associated with better quality of care,^{9,27} and international studies similarly show that patients with a 'medical home' are happier with their care and report fewer problems with coordination between services.^{15,28} The concept of 'home' in the context of primary care resonates with the historic family doctor who looked after multiple family generations and was able to treat individuals within the bigger picture of their families and communities. Lasting relationships with primary care providers are particularly relevant to cancer care, with ongoing, personal contact recognised as the foundation of community cancer care.¹⁴ There is little literature on how to develop long-term relationships between primary health care providers and patients in Aotearoa/New Zealand. Lacey et al.'s Hui Process Framework¹⁷ identifies key elements to assist long-term relationship building between health practitioners and Maori, including establishing rapport, active engagement and developing trust.

The current study was developed based on work in the United Kingdom²⁹ that recognises that primary care is the first level of contact and entry point into the health system, and that nearly all

the priorities for cancer services are affected by actions in primary care—reducing the risk of cancer, early detection, faster access to specialist treatment, and improved support for patients living with cancer. Additionally, focus on the health and wellbeing of the family is the crux of the Whanau Ora policy that was recently introduced in Aotearoa/New Zealand and that emphasises building long-term relationships that enhance whanau capabilities and realise whanau aspirations.³⁰ Maori have long advocated the value of a Whanau Ora approach to health care, and this approach forms the basis for He Korowai Oranga, the Government's Maori health strategy.³¹ Whanau have a critical role in relation to facilitating Maori cancer patient access to cancer care services.^{8,32,33} Thus, the Whanau Ora approach will be central to any framework for integrated cancer care for Maori. The Whanau Ora Cancer Care Coordination Project³⁴ considered the development of culturally responsive models of case management to improve the delivery of cancer control services in the Waitemata area. In their development of a model for reducing cancer inequalities among Maori and Pacific people, the project identified the need for care coordination across health care settings and throughout the personal cancer care journey of the person and their whanau.

The importance of appropriate, timely access and information for patients and whanau in this study is mirrored in other studies and policy initiatives in Aotearoa/New Zealand and internationally.^{8,11,12,35} Advocacy and cancer 'navigator' roles have been identified as being key positions required to facilitate and assist people in negotiating the complexity and range of cancer services.³⁴ Cancer navigators have had success in improving people's cancer journeys overseas,^{36,37} with some provisional work done here in Aotearoa/New Zealand regarding their effectiveness suggesting similar results.^{12,38} Cancer navigator roles were part of the Community Cancer Support Services Pilot Projects, which were evaluated in 2010 and were found to impact positively on the cancer journeys of patients and whanau, while also aiding health and social service providers.³⁸ Our study findings suggest that Maori health providers are already providing informal cancer navigation. This begs the question of whether they are

recognised and resourced appropriately to do this important work.

As well as delivering information in a consistent and timely fashion, it is important that the content of the information is meaningful to the receivers. Cormack and colleagues recommend high quality Maori-specific resource material about cancer and cancer service options for individuals, whanau and communities.⁸ Our study echoes findings by Walker et al.¹² who advocate for more information and resources for whanau and Maori health providers, alongside changes to mainstream health provision, such as flexible appointment times.

Where wider health determinants impacted on access to, and through cancer services, participants received ongoing support from Maori health providers that went beyond medical care and included emotional support and appropriate practical and logistical support for the whole whanau. Similar findings have been reported in the literature,^{8,12,23,39} including one study of a GP population that showed Maori breast screening participation rates rose from 45% to 97%.⁴⁰ In that study, barriers to participation were reduced through better information, phoning women to confirm appointments, helping with transport and coordinating appointments for women from the same household. The authors suggest that these strategies can also be used by mainstream organisations to improve screening participation by Maori.⁴⁰ Examples of mainstream providers adapting their services to reduce barriers include offering flexible appointment times, providing other types of assistance relating to complex care needs, such as smoking cessation advice at screening clinics,³⁹ and providing cultural safety training for all staff.⁴¹ Enhancement of mainstream services at all levels of health care delivery to better meet the needs of all those they serve is important if we are to effectively address the unacceptable ethnic differences in cancer survival.

In summary, as well as appropriately supporting and resourcing Maori health providers, these findings suggest there are also lessons for the practice of mainstream GPs, particularly in fostering not only rapport but also prioritising

long-term relationships with patients that build up a history of care. In this way, primary care services are key facilitators for access to, and through, cancer care services. The cancer journeys described in this study highlight the critical role of GPs and Maori health providers in terms of providing consistent information and enabling continuity of care for Maori with cancer.

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“They see the place in a different way” Māori cancer patients, families, community and hospice views of hospice care.

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ABSTRACT

Despite poor cancer survival statistics, Māori do not readily access hospice services. This study aims to explore how hospice services respond to Māori by investigating the different influences and interactions between three perspectives of hospice care. We conducted a Māori-centred, cross-sectional qualitative study by undertaking semi structured interviews with hospice patients and whānau (families) (n=8), hospice representatives (n=4), and representatives from three Māori health provider organisations (n=5). The study found that negative perceptions of hospice are being changed by hospices' relationships with other organisations and positive stories from whānau. Whānau involvement, continuity of care and after hours care with a greater Māori workforce and a further emphasis on culturally safe care are critical for this work to gain momentum. Findings can be of use to further develop quality of care indicators that reflect the perspectives of patients and whānau, and those who provide their care.

Keywords

Māori, Indigenous, hospice, cultural safety, family, workforce,

INTRODUCTION

Palliative care is not always responsive to Indigenous needs. For example studies in Australia highlight the inadequacies of proximity, resourcing and cultural safety in palliative care provision (Shahid, Bessarab, van Schaik et al, 2013, McGrath et al, 2007), and Canadian studies highlight the need for culturally safe palliative care in small and often invisible Indigenous populations (Castleden et al, 2010; Johnston et al, 2013).

Māori, the Indigenous people of Aotearoa/New Zealand (Aotearoa) make up approximately 15% of the total 4.5 million population, together with peoples of Pacific origin (7%), European (77%) (primarily from the United Kingdom and Europe) and Asia (12%) (Statistics New Zealand, 2013). Income, education, housing and employment are well recognized as key determinants of health (Smedley et al, 2002). The differential distribution of deprivation, living standards, and employment status by ethnicity in Aotearoa have consequences in terms of access to care and health outcomes (Durie, 2004; Robson, 2008) with Māori, Pacific and low income groups experiencing the greatest levels of unmet health need compared to other population groups (Robson, 2008).

The recognised complexity involved in the provision of cancer services highlights the importance of access throughout the entire cancer care pathway with differences in health care access likely to be important mediators of cancer survival disparities (Smedley et al, 2002; Cormack et al, 2005). Cancer incidence and mortality rates remain unacceptably high for Māori compared to non-Māori. In 2011 the Māori mortality rate was 72.1% higher than the non-Māori rate (Ministry of Health, 2014). Thus, urgent attention to improving Māori cancer outcomes is needed.

For many Māori, collective approaches to decision making, involving discussion and input from multiple family members remains as important as individual choice when considering health care options (Durie, 2004). Whānau (family) are therefore often seen as pivotal in both contributing to decisions around treatment options as well as the provision of patient care, especially at the end of life (Bray and Goodyear-Smith, 2013). Such collective approaches to healthcare are not always congruent with biomedical worldviews, where a more individualised focus is common (Wilson and Barton, 2012).

Palliative care, of people who are dying from active progressive diseases or other conditions that are not responsive to curative treatment (Ministry of Health, 2001) is an important part of cancer care in terms of maintaining optimum quality of life. However, like other mainstream health services in Aotearoa, specialist palliative care offered by hospices has not traditionally been responsive to Māori needs. This may be due to hospice services reflecting the European cultural norms represented by their workforce, including different ways of showing respect, spirituality and care preferences (Ramsden, 2002).

Hospices in Aotearoa are independent, charitable organisations that provide free care and support to people with life-limiting conditions and their whānau (Hospice New Zealand, 2012). The modern hospice movement was championed by the work of Dame Cicely Saunders, whose concept of ‘total pain’ refers to multiple aspects of a person rather than solely their physical pain and in this way, finds common ground with Māori models of wellbeing. For example, both Saunders ‘total pain’ (Saunders, 2000) and Durie’s Te Whare Tapa Wha model (Durie, 1994) encompass physical (Taha tinana), spiritual (taha wairua), psychological (taha hinengaro) and family

(taha whānau) needs. Nonetheless, Māori appear to be under-represented in hospice uptake. For instance, a recent review of ethnicities represented within a Wellington hospice found that just 6% of patients identified as Māori (Taylor et al, 2011). National data on hospice usage by ethnicity is not collected and there are only a small number of studies that explore Māori hospice experiences. For example one study highlighted misconceptions shared by the general population about hospice care signalling that death is imminent, and suggested a need for more public awareness about hospice, particularly for Māori and Pacific people (Bray and Goodyear-Smith, 2013). Another study found patients and families experienced hospice services as mono-cultural (Bellamy and Gott, 2012) and that lack of ethnic representation amongst hospice staff and concern that the hospice would exclude family from the care process were also factors affecting patient engagement with hospice services (Frey et al, 2013).

We found two studies centred solely on Māori hospice experiences. One recommended that hospice should develop information to address negative perceptions of their services; that staff be encouraged to have *genuine respect, interest, and compassion toward Māori*; and that whānau be recognised as integral to the caring process (Taylor et al, 2014). The other study described how using the concept of Whānaungatanga (networks and social interaction based on the models of the extended family (Durie, 1994)) enabled Māori to be more actively engaged in hospice services (Cottle et al, 2013).

In order to examine the system of care, we explored Māori experiences of hospice care from three significant perspectives: patients and whānau; hospice care providers; and Māori health providers in one region of Aotearoa.

METHODS

For an in-depth understanding of what it is like to enter, deliver and receive hospice care from the viewpoint of the participants, we selected a Māori centred (Cunningham, 2000), qualitative research approach (Green and Thorogood, 2009). Semi-structured, face to face interviews were undertaken with hospice patients and their whānau; hospice service providers; and organisations involved in the care of Māori with cancer.

In total, 17 interviews were undertaken. All patients and all but one of the hospice and non-hospice health providers self-identified as Māori. Patients and whānau shared their perceptions and experiences of hospice care while providers were asked about how different aspects of hospice care are currently working for Māori and if/how these could be advanced and improved.

The study team was comprised of collaborators from two Māori health provider organisations and Massey University. The study was approved by the Health and Disability Ethics Committee (MEC/09/11/131) and forms one component of a larger study currently being undertaken which focuses on approaches to integration across primary, secondary, tertiary and palliative cancer services to improve the co-ordination of care for Māori experiencing cancer (Slater et al, 2013).

For the current study, the inclusion criteria for patients and whānau were Māori hospice patients with a cancer diagnosis. Inclusion criteria for the providers were either Māori liaison or other senior and executive positions based in hospices in the Wellington region, or Māori health providers working in either primary or secondary care services from the greater Wellington region. They included three managers and two community workers from Māori health provider organisations and secondary care services.

Potential patients and whānau members were identified by hospice Māori Liaison workers. They were provided with an information sheet about the study and if interested, follow-up was initiated by the research team. Interviews took place between May and November 2011 and were conducted at a time and location chosen by the participants.

Providers were identified by word-of-mouth. Providers were contacted by one of the Massey University researchers to ascertain their interest and provide them with more information about the study. All participants provided written, informed consent to take part in the study.

Interviews were recorded digitally and transcribed verbatim by one of the researchers. In order to compare across perspectives, a thematic analysis was carried out on the transcripts, involving identification, coding and categorising the primary patterns in the data (Patton, 2002). There were three stages in the analyses process. First, two researchers independently carried out preliminary coding of the transcripts. The researchers then discussed the emergent themes with each other and

one of the Māori health providers. Thirdly, qualitative analysis software *NVivo* (NVivo qualitative data analysis software, 2012) was used to help organise the thematic codes.

RESULTS

A total of 17 interviews were undertaken: eight joint interviews with patients and whānau; four hospice service providers; and five Māori health providers. The three central themes that emerged from the interviews were: the changing perceptions of hospice; the experiences of hospice care; and service responsiveness to Māori patients and whānau.

Changing perceptions of hospice

Participants from all three groups described an historical stigma attached to palliative care, specifically that the hospice was a place where very sick people go to die. Hospice care was often associated with staying in the inpatient unit, instead of support and care in the community.

Participants outlined how perceptions about hospice were being changed on two fronts. First, those working for hospice were bringing about change in the community by working with groups and individuals to demystify hospice care. Second, whānau who had been looked after by hospice shared their positive experiences with others which helped patients gain a positive impression of their hospice referral, for example:

But I have heard that it is a wonderful place (patient 1)

Participants who worked for hospice believed that perceptions were shifting, with more Māori understanding that hospice could provide care at home. Additionally, there was increased understanding that patients could return home after an inpatient stay.

Hospice service providers stressed the importance of building relationships with the wider community, including iwi (tribes), Māori health providers and general practitioners (GPs). One participant described how information alone was not enough to encourage people to learn about hospice:

But it takes that relationship and communication and trust before anything will work. We could give pamphlets, we could drop pamphlets a hundred times over but they mean nothing unless there is explanation and establishing of that relationship. (hospice service provider 3)

Another participant outlined practical steps hospice had taken to build links within the community and the benefits of these in changing the way others see hospice:

And combined with building networks with Māori providers, rongoa (medicine) healers... (Māori Liaison) has been bringing different groups in to run sessions to show how we run our services and get to do a little tour. So you start to see the place, they see the place in a different way. (hospice service provider 2)

Those working for hospice observed that physically welcoming community organisations into hospice buildings for training and meetings fostered a positive view of hospice. Additionally, whānau who experienced hospice services first-hand helped to ‘change the mindset’ of the wider community. Hospice service providers

thought that as more whānau shared their experiences, conversations about hospice were changing from fearful to being more positive and encouraging.

It was also thought that having more Māori staff within the hospice would greatly help in identifying the types of support and assistance which might be most useful for Māori patients and whānau. Participants highlighted the challenge of recruiting Māori to work in palliative care, which historically has not been a specialty area where many have chosen to work.

Participants felt that the presence of a Māori staff member would have helped with the care of Māori patients in many instances due to comfort and familiarity. In some cases, Māori health providers had ‘loaned’ one of their own nurses to work alongside the hospice nurse. This collaborative model of care resulted in the adoption of a more culturally appropriate practice when disposing of used bandages.

Volunteer services such as serving meals and providing transport are also central activities of hospice care. One hospice service provider noted that Māori do a vast amount of volunteer work within sports groups and whānau activities, but hospices are failing to reach potential Māori volunteers. Participants agreed that more creative approaches by hospices were needed. For example one participant described the need to “loosen up” on identifying volunteers as informal support for patients and whānau:

Mary needs someone to sit with her husband once a week for an hour so she can go out for dinner. If three other people on that street knew that was happening they would happily go and do that. (hospice service provider 4)

Hospice experience

Patients and whānau reported positive experiences of hospice care. For the most part, this was due to the skills and expertise of staff. Participants frequently recounted how staff were consistently helpful, as described by this participant:

They helped you as soon as you walked through the door. (patient 4)

Patients and whānau responded with a sense of confidence. One participant described this feeling as ‘taking a break from dying’.

Patients and whānau also reported positive experiences of continuity in their hospice care, in particular, knowing who to contact after hours. This was a substantial improvement from the after hours care they had received at the hospital before becoming hospice patients. Patients and whānau recalled long waiting times at the hospital emergency department, and having to retell their story to multiple clinicians when they were in a great deal of pain and distress. In contrast to hospital care, experiences of hospice care were very positive. Those who worked for hospice described the importance of easy communication between hospice staff, patients and whānau. Both patients and whānau expressed feeling more confident due to the communication and expertise of hospice care, and felt reassured by knowing hospice was a phone call away at any time of the day or night.

The support that whānau felt they had from hospice was part of the wider inclusion and support fostered by hospice services. The importance of whānau themselves being looked after and recognition of their integral role in the care of patients was described by this hospice worker:

90-95% of care is actually done by families, not health professionals. And we might think we do a lot by having a half hour visit once a week, but in fact the caring is done 24/7 by families. (hospice service provider 3)

Many participants described the benefits of hospice providing respite care so that whānau could have a break. Additionally, the financial strain from taking time off work took its toll on whānau and financial assistance was not always accessed due to not knowing what was available.

Service responsiveness

A range of whānau care approaches were described by participants, from large families with multiple members, through to one isolated partner as sole carer. Those who worked for hospice highlighted the importance of working with whānau to provide care and support at home but also encouraging patients and whānau to enter the inpatient unit when appropriate, such as when a medication review was necessary or suggesting the option of respite care. Hospice service providers also described how they had improved their approach to accommodating whānau within inpatient units. For example, properly looking after large families meant that practical measures needed to be implemented such as the provision of beds and cooking facilities for whānau. Other strategies have also been developed for whānau using hospice services. One participant described the importance of identifying a key spokesperson within whānau to assist with organising visitor shifts or establishing how many people could stay, as well as making sure children were entertained.

The efforts of hospice management and staff to accommodate whānau were noted by patients and whānau. For example one patient reflected on the changes hospices had made for whānau:

'.. it's amazing...they have rooms there for family to stay over if they need to and you know they're sort of like, more open too. Whereas, once upon a time it was just so European-ised. It's like you'd only have one or two visitors at a time. But now... the hospice recognise and understand whānau as big. (patient 2)

As well as including whānau in patient care, hospices offered whānau services such as spiritual support, or the provision of physical areas set aside to relax and reflect. One patient outlined how multiple family members had counselling and space available to them while another described the positive effects of counselling for her grandchildren in understanding what was happening to their koro (grandfather). Additionally, assistance was available for practical issues such as applying for a benefit or arranging a funeral.

Participants acknowledged that although improving, not all of their experiences of hospice care had been culturally safe. In one example a Māori health provider acted as a facilitator between a patient and the hospice when an issue of cultural safety arose:

...he was really upset about it but he didn't want to tell them, but felt comfortable to tell the community health worker to ask if she could ring and explain that that is tapu (sacred)for him... and the (hospice) nurse rang up and said thank you for letting us know that because you know they would hate to offend him. (Māori health provider 1)

Participants described the need for hospice care to meet the diverse realities of Māori, for example not making assumptions about whānau or tribal connections and instead finding out about the preferences of patients:

And all iwis are different. All tribes are different for their own beliefs and what they do in their own tribes. So it is just about observing and just being cautious basically. (hospice service provider 1)

One participant summed up the necessity for culturally safe care by stressing the need for hospice workers to:

Look after families the way they want to be looked after (hospice service provider 4)

Another mechanism to support the work of hospice is through the use of policies which can not only provide guidelines for standards of care, but may also be used to facilitate change. For example one participant described the importance of the Māori service plan being supported at both management and service delivery levels with the overall challenges recognised:

So there has had to be change at strategic level, at management level in order to recognise that this is what you have got to do (hospice service provider 4)

The Māori liaison role, specifically arising from policy initiated by some hospice services, exemplifies this through practical assistance and community knowledge, together with education and collaboration with other providers, to improve Māori hospice access and care.

DISCUSSION

Having access to hospice services can create confidence in palliative care at a critical stage in the cancer journey and may contribute to improved quality of life. Our findings show that relationships between primary health care providers and hospice service providers are critical for encouraging Māori to access hospice services. Hospices provide specialist palliative care and guidance, but, understandably they do not have the same long lasting relationships with whānau as has been shown with primary health care providers (Crengle et al, 2005; Jatrana and Crampton, 2009). Our previous work with Māori cancer patients and whānau suggested that positive, long term relationships with GPs and Māori health providers assisted whānau in effectively accessing care, and gaining practical support (Slater, et al, 2013). Accordingly, primary health care providers play a vital role in referring Māori patients to hospice care, and endorsing the work of hospice to other health and social service providers. Actions such as these help alleviate the misconceptions identified by Bray and Goodyear Smith (2013) for example fears around hospice hastening death, or that whānau will not be allowed to care for their own family member once under hospice care. Our study also demonstrated that primary health care providers can deliver and facilitate on-going care for cancer patients. It is important that this work is recognised at the policy level and appropriately funded.

In addition to hospice and primary health care providers building community trust in hospice services, confidence in hospice relies on patients and whānau feeling empowered in their care. Palliative care in Aotearoa is primarily guided by the New Zealand Palliative Care Strategy (NZPCS), and also informed by other key policy documents (Ministry of Health, 2001; Ministry of Health, 2003). The NZPCS holds

the vision: *“All people who are dying and their family/whānau who could benefit from palliative care, have timely access to quality palliative care services that are culturally appropriate and are provided in a coordinated way”* (Ministry of Health, 2001). The strategy describes culturally safe care only in the context of employing hospice staff.

Culturally appropriate care and culturally safe care are two different concepts with cultural safety making explicit the role of power in the clinician relationship with patients. Thus, ‘good’ care is defined by those receiving the care, not those who provide it (Ramsden, 2002). This resonates with Bellamy and Gott’s (2012) work showing the importance of learning from patients and their whānau about what they regard as appropriate care.

Our findings suggest that further work at the service level would be beneficial for both encouraging Māori to use hospice services as well as increasing opportunities for more Māori health workers to enter the palliative care area. Hospice workers cited mechanisms that could facilitate change such as strategic Māori health or service plans aimed at workforce and policy development and furthering knowledge of hospice services in the community. They also highlighted the need for systemic changes including more rigorous collection of ethnicity data, and growing and valuing a greater Māori workforce.

Frey et al (2013) recently raised concerns about the ethnic representation of hospice staff resulting in a perception by patients and whānau from non-Western cultures of mono-culturalism. Hospice and Māori health providers in our study agreed that both

the paid and volunteer Māori hospice workforce must continue to grow. Having hospice volunteers and staff that represent *all* of the community is consistent with findings from a British study (Morris et al, 2013). In order to achieve greater Māori representation in the hospice workforce, flexibility in the way that hospices operate may be required such as providing volunteer training for whānau groups, or being more innovative in the ways in which volunteers are recruited.

Whānau are pivotal to patient wellbeing in the care of dying patients (Bellamy and Gott, 2012; Cottle et al, 2013; Frey et al, 2013; Taylor et al, 2014). Our participants described the diversity that constitutes ‘whānau’ and the need for providers to be respectful and adaptable to cater to the different needs and preferences of all of those who use the service. These findings demonstrated the importance of whānau also feeling ‘cared for’ by hospice while at the same time being recognised as carers themselves. As shown in a recent overseas study (Vedel et al, 2014), these findings can be of use to further develop indicators of quality of care, in this case Māori responsiveness, that reflect the realities of patients and whānau, and those who provide their care.

There are several limitations to this study. There were a small number of participants, all based in one region of Aotearoa. Therefore these results cannot be generalised to the wider population or to hospices nationwide. A further limitation of the study is one raised by Walker et al concerning the issue of patients and whānau expressing *considerable gratitude for very limited care* (Walker et al, 2008). It is well documented that Māori do not receive the same standard of health service

as non-Māori (Hill et al, 2013; Robson and Harris, 2007). As research participants, Māori may therefore express appreciation for care even when it is not responsive to their needs.

However, inclusion of non-hospice health care providers in this study is a strength as this group is able to speak from their own perspectives, outside of hospice services. Additionally, all but one of the participants in this study were Māori. In this regard, the study is particularly unique in providing insight into what it is like for Māori to engage with, experience, deliver and support hospice services, which provides a better understanding of the system of care.

CONCLUSIONS

Māori are entitled to equitable treatment, resources and support at all stages of the cancer care journey but historically, have been under-represented as patients and providers of hospice care. This study found that the key to changing Māori perceptions of hospice and ensuring better access to specialist palliative care lies in patients, whānau and health providers having trust and confidence in hospice services and facilitating opportunities for wider engagement with the community in order to promote the work and services offered by hospice care.

Resourcing to support an increase in the number of Māori in the palliative care and hospice workforce is also important. These findings support the need for the development of quality of care indicators that reflect the perspectives of patients and whānau, and those who provide their care.

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[Date]

[database ref]

[patient name]
[patient address]
[suburb]
[city]

**Centre for Public
Health Research**

Dear [patient name],

We have received your name and address from [Māori provider organisation]. I understand that a staff member from [Māori provider organisation] has told you about this study and that you have agreed to having your name forwarded to us so that we can give you some more information about the research. The Massey University Centre for Public Health Research is currently undertaking research to look at cancer care for Māori in New Zealand and one part of the study is focussed particularly on talking with people with a current cancer diagnosis.

We would like to invite you to participate in this research. It will involve an interview where you will be asked about your cancer care, treatment and support needs within the health system. The interview will take approximately 1 hour of your time and we would like to audio tape your interview. We are also interested in Māori priorities for cancer service delivery which includes those of family members or friends that may be assisting with your care. For this reason we would like you to identify one whānau member or support person who has been closely involved in your care that we can approach to also complete a short questionnaire.

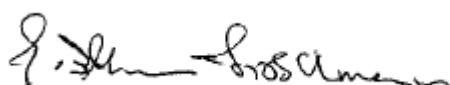
If you decide not to take part in the project, this will not affect your current and future medical management. The project is fully funded and there will be no cost to you. All information you give us will be strictly confidential to the research team. We realise that this may be a difficult time for you, but we would very much appreciate your taking part in our research. The more people who take part, the more valuable the results will be.

If you would like to take part in this project, please complete the enclosed consent. If you do not wish to take part, please tick the option 'No'.

If you have any queries or concerns about this project, you can contact me, Dr Lis Ellison-Loschmann, or Huia Tavite at Kokiri Marae Health and Social Services, on 920-1496.

Thank you very much for your time in considering taking part in this study.

Yours sincerely,



Dr Lis Ellison-Loschmann
On behalf of the "Māori and cancer – the role of primary care" team

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Dr Lis Ellison-Loschmann

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Māori and cancer – the role of primary care

Consent Form

Please send this consent form to us at our freepost address below or phone us to discuss your consent on 0800 866 277.

Centre for Public Health Research

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Dr Lis Ellison-Loschmann

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Request for Interpreter (please circle if required)

Māori	E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero	✓ Ae	x Kao
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- I have read the information brochure which explains details of the study.
- I understand that taking part is entirely my choice.
- I understand that I may contact the study centre to ask questions regarding the study at any time.
- I understand that I may decline to answer any particular questions.
- I agree to provide information to the researchers, and understand that this will be used for research purposes only.
- I understand that none of the published results will include any identifiable information.

This consent form will be held for a period of ten (10) years.

Approved by the Multi-region Ethics Committee:(MEC/09/11/131).

I agree to participate in the “Māori and cancer – the role of primary care” study: ☐ Yes ☐ No

Full Name: _____

Telephone: *(home)* _____ *(alternative/mobile)* _____

Signed: _____ Date: _____

I will provide the name of a family member/friend involved in my care: ☐ Yes ☐ No

I agree to have my interview recorded and the audio tape transcribed: ☐ Yes ☐ No

Patient and Whanau Interview Schedule.

Opening recap on what the study is about:

The Massey University Centre for Public Health Research is working with Kokiri Marae Health & Social Services on a research project looking at cancer care for Māori in New Zealand. We are talking to a range of different groups of people including those with a cancer diagnosis and their whanau, those working in DHBs who provide cancer services, cancer organisations like the Cancer Society of NZ) and Maori provider organisations. For this part of the study, we are wanting to talk to you about your support needs, as someone with cancer, within the health system and what you think are the priorities for cancer service delivery.

Do you have a regular GP that you see? How long have you been seeing them? Do other family members see the same GP as you? What is your relationship like with the GP? Do you feel like the GP has a good idea about your family situation?

Can you tell me about what you know about the type of cancer you have – what information have you been given? When were you diagnosed? Who told you you had cancer? How was that experience of being told? Who was with you when you were told?

Did you feel adequately prepared (in terms of knowing what tests and how long you would be in hospital) for going into hospital for your cancer treatment? What was good about your preparation? What would you have liked to know more about beforehand?

Did you have sufficient time to talk through treatment options and side effects with hospital staff before and during your treatment?

How well were your whānau and friends supported by hospital staff while you were undergoing treatment.

Did you receive any information about symptoms to be aware of and what to do, or how to manage possible side effects when you were discharged?

Did you know who was in charge of your care or who you could ring or contact if you had any queries when you were discharged home? What did you do or who did you contact?

Did you receive any follow-up from your GP when you were discharged from hospital? How soon after discharge did this occur? What sort of follow-up was it? Was it enough or would you have liked a different kind of support?

Have you had any information about adjusting to life after cancer treatment (relationships, employment, body image, loss of confidence, support groups)? If yes, from whom? Is there more or other information you would have liked?

If you have had a re-admission to hospital, how has this been for you? Are there other issues you think are important to consider when you require further cancer treatment both for yourself and your family/support people? (for the interviewer: think about “ did the person ever worry that they were disappointing their family by whatever choice it was they made regarding further treatment?”)

What support services have you been offered by anyone during the whole time since your cancer diagnosis? (e.g help with transport; support/advocacy at appointments; mobility stickers; help with changing appointments.....). Who offered or provided these services of how did you find out about them?

Have your whānau or support people given any information, either about your cancer and how to support you, or any information about cancer support services (for example – help with transport to the hospital for follow-up appointments) during the whole time since you have been diagnosed with cancer?

What kinds of support services are offered by the Māori provider organisation you attend? Are there other supports (practical or information) you would like to see offered (for yourself or your whānau/support people)? What are they?

Māori and cancer –The role of primary care

Information Sheet

Kia ora

My name is Tania Slater and I am a researcher and PhD student at Massey University. I am part of a team that is undertaking a study to find out more about pathways through care for Māori with cancer in New Zealand, and investigate the potential for primary care to help facilitate coordinated and therefore more effective cancer care for Māori.

The people on the study team are:

Lis Ellison-Loschmann, Senior Research Fellow, Centre for Public Health Research
Chris Cunningham, Director, Research Centre for Māori Health and Development
Teresa Olsen, Manager, Health and Social Services, Kokiri Marae
Cheryl Davies, Co-ordinator, Tu Kotahi Services, Kokiri Marae
Triny Ruhe, General Manager, Whaiora Whanui Trust, Masterton
Tania Slater, Research Fellow and PhD student, Centre for Public Health Research
Nicola Ehau, Director of Māori Health, Nelson Marlborough District Health Board
Cheryl Goodyear, Manager of Whānau Care Services, Capital & Coast District Health Board
Lucy Meldrum, Nurse Specialist, Palliative Care Services, Auckland District Health Board
Professor Mason Durie, Māori Research and Development
Maureen Holdaway, Research Centre for Māori Health and Development
Monica O'Reilly, Acute and Chronic Care, Hutt Valley District Health Board
Kate Gellatly, Te Omanga Hospice
Fiona Pearson, Assistant Divisional Manager, Cancer Society Wellington
Wayne Naylor, Palliative Care Council of New Zealand
Anna Matheson, Centre for Public Health Research
Professor Neil Pearce, Director, Centre for Public Health Research

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Venue of study:

The study is based at the Centre for Public Health Research, Massey University, Wellington Campus. The research is being done in collaboration with two Māori provider organisations -Kokiri Marae Health and Social Services, Seaview, Wellington and Whaiora Whanui Trust, Masterton.

What is this study about?

My part of the study involves interviewing people involved in cancer policy, cancer service providers and other organisations that support Māori with cancer. The purpose of these interviews is to create a more detailed picture of the factors that enable and constrain organisations to respond appropriately to individual and community level issues within their areas. Findings from this part of the study will contribute to the overall study, and also form part of my PhD thesis.

You have been given this information sheet because I would like to invite you to be interviewed for the study. Taking part in the study is entirely **voluntary**. You are under no obligation to participate.

What would participation involve?

Participation in the study will involve a face to face interview with me. You will be asked for permission to have the interview audio recorded. You will be asked about the services your organisation currently provides to people with cancer, including the care and treatment options available and the type of support services offered to people with cancer and their families. Interviews vary in length but we would expect it to take upwards of 45

minutes. If you prefer an alternative method, such as a telephone interview, this can also be arranged. Please be aware that all questions are optional. If you do not want to answer a particular question, you do not have to.

What happens to the interview information?

I will transcribe the interview, and you will have the option of checking and amending your transcript. You can choose to withdraw your transcript within a month of reviewing it. Remember that you have the right to decline to answer any particular question.

All information you give us will be treated with utmost confidentiality. We guarantee that you will not be identified by name or address in any publications or reports arising from this work. However, as the study is based in two specific geographical locations, it is possible that some people may be able to guess your identity.

The audio and text versions of the interview will be stored on a password protected computer and analysed in a qualitative software package called NVIVO. Consent forms will be kept in locked filing cabinets, which will be the responsibility of the Director of the Centre for Public Health Research. After 10 years, all the paper records will be destroyed.

The information you provide will have two purposes. The first is to inform the wider study about pathways through care for Māori with cancer in New Zealand, and investigate the potential for primary care, particularly Māori health providers, to help facilitate coordinated and therefore more effective cancer care for Māori. The second purpose is to contribute to my PhD study, which examines the role and potential of community care for Māori with cancer.

For more information:

Please feel free to call me or Lis Ellison-Loschmann at the Centre for Public Health Research to discuss any queries or concerns that you may have about the study. Our phone number is 0800 080 078. Lis is the principal investigator for the overall study and she is also one of my supervisors.

This project has received ethical approval of the Multi-region Ethics Committee which covers all of New Zealand (Ref: MEC/ 09/11/131).

If you have any queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate, telephone: Northland to Franklin 0800 555 050; Mid and lower North Island 0800 42 36 38 (4 ADNET); South Island except Christchurch 0800 377 766; Christchurch 03 377 7501.

Thank you very much for your time in considering taking part in this study.

We hope that with your help, we can find out more about achieving optimal cancer care for Māori in New Zealand.

Māori and Cancer –The role of primary care

Consent Form

Would you like an interpreter? Please circle if required

E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero ✓ x
Ae Kao

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- I have read the Information Sheet which explains details of the study.
- I understand that taking part is entirely my choice.
- I understand that I may contact the study centre to ask questions regarding the study at any time.
- I understand that I may decline to answer any particular questions.
- I agree to provide information to the researchers, and understand that this will be used for research purposes only.
- I understand that none of the published results will include any identifiable information, however it is possible that some people may be able to guess my identity.

I agree to participate in the Māori and Cancer study. ☐ Yes ☐ No

I would like to be sent a summary of the study results. ☐ Yes ☐ No

My telephone number is: _____ **mobile/alternative number:** _____

Signed: _____ Date: _____

Name: _____

Address: _____

*Please send this consent form to us using the post-paid envelope enclosed or phone us to discuss your consent on **0800 866 277***

KEY INFORMANT INTERVIEW SCHEDULE

This part of our study is looking at the role and potential of community based care for Māori in Aotearoa/New Zealand. I am going to ask you some questions about your role supporting/treating Māori with cancer. Some of the questions are quite general and others specific to Māori.

1. Can you tell me about your organisation, and your role within the organisation?
What is a normal day like for you? Who do you see? What concerns do they have?
2. How is the cancer journey working for Māori? (screening, diagnosis, treatment, survival, palliative care)
3. Do you feel communication between primary and secondary care is adequate?

Why/why not? How does it compare at different stages of the cancer journey (diagnosis, treatment, discharge, palliative care)

Where would you like to see improvement?
4. How is information received from secondary care?
Is it received in a timely manner?
5. Do you feel out-of-hours care is adequate?
Who provides it?
Do they have enough resources and patient information?
6. How are whānau and patient carers supported?
Transport, accommodation, meals, financial, childcare, respite, advocacy, someone to talk to
7. Survival -How are patients and whānau supported after treatment?
8. Do you have access to specialist palliative care advice for symptom management?
9. Do you have easy access to advice at all times? If not, does this affect decision regarding place of patient care?
10. Are there any areas in the cancer journey where you would like to see Māori providers playing a different role?

Circles of Personalist Care Ethics (Denier and Gastmans, 2013, p. 40)

