

E te tākuta, kei a koe te tikanga - A qualitative study of factors influencing treatment decision-making in cancer consultations with Māori patients and whānau

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Abstract

Aim

This research explores factors influencing treatment decision-making in cancer consultations with Māori patients and whānau (extended families) to ascertain if any of these factors could be contributing to cancer treatment inequities experienced by Māori.

Design

Māori centred research using case study and qualitative methods.

Participants

Five adult Māori patients who had recently received a cancer diagnosis participated in this study along with their whānau and three oncology specialists with whom they had a consultation where a treatment option was discussed.

Methods

Consultations were audio-recorded and soon after patients and whānau were interviewed. Specialists self-recorded a brief debrief using a prompt questionnaire.

Results

Within and across cases, a range of factors appeared to influence patients'/whānau treatment decision-making: comorbidity, disease and treatment factors. Whānau involvement and support was significant as was the specialist's treatment recommendation. They also identified positive experiences with the specialist. Specialists attended the consultation prepared to offer one medical treatment option in each of the cases studied and patient factors such as fitness for treatment, family history and symptoms appeared important to their treatment decision-making. Information shared by specialists with patients indicated comorbidity, disease, treatment and health care system factors such as multidisciplinary

team decision-making had influenced the development of the treatment option offered in the consultation.

Conclusion

This research provides valuable information about the range of factors that influence both specialists' and patients'/whānau treatment decision-making in cancer consultations. Whānau and specialists treatment recommendations appeared important to patients' decision-making and medical factors and patient factors to specialists'. In some cases, comorbidity requires greater attention given the impact it has on treatment decision-making.

While it did not appear as if any of these factors were likely contributors to cancer treatment inequities there were signs to suggest that health care system treatment decision-making processes could be improved. Further exploration for factors influencing treatment decision-making earlier in the treatment decision-making pathway may also provide clues to potential causes of treatment inequities.

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*Whāia te iti kahurangi ki te tūohu koe me he maunga
teitei*

*Seek the treasure you value most dearly: if you bow your
head, let it be to a lofty mountain*

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Chapter 1 – Introduction

Cancer is a leading cause of illness and death amongst indigenous people world-wide (Jemal et al., 2004; Paltoo & Chu, 2004; Sheppard, Chiarelli, Marrett, Nishri, & Trudeau, 2011; Soeberg, 2012; Valery, Coory, Stirling, & Green, 2006). Cancer inequities between indigenous and non-indigenous peoples are also evident worldwide (United Nations, 2009). In New Zealand (NZ) cancer is the second leading cause of death for Māori, accounting for nearly a third of all Māori deaths (Robson & Harris, 2007). Of all cancers, lung cancer is the leading cause of death for Māori women and the second leading cause of death for Māori men (Ministry of Health, 2015d). A higher burden of cancer is borne by Māori compared to the general population and Māori with cancer have higher rates of comorbidity than non-Māori (Hill, Sarfati, Blakely, Robson, Purdie, Dennett, et al., 2010; Ministry of Health, 2015a; Sarfati et al., 2009).

Comorbidities are a key determinant for treatment decisions and an important prognostic factor for long term survival from cancer (Hill, Sarfati, Blakely, Robson, Purdie, Chen, et al., 2010; Sogaard, Thomsen, Bossen, Sorensen, & Norgaard, 2013). Differences in treatment after diagnosis have been identified as a contributing factor to Māori experiencing poorer outcomes (Hill, Sarfati, Blakely, Robson, Purdie, Dennett, et al., 2010; Stevens, Stevens, Kolbe, & Cox, 2008). Thus, the focus of this thesis is on factors influencing treatment decision-making in cancer consultations with Māori, paying particular attention to comorbidities.

This research explores the research questions from the patients'/whānau and specialists' perspectives guided by a Māori centred research approach (Cunningham, 2000; Foster, 2003). Qualitative methods were used to gather, analyse and interpret the data. This research aims to contribute knowledge to inform the development of interventions designed to reduce health inequities for Māori. Furthermore, this research is exploratory as there do

not appear to be any studies which specifically identify factors which influence treatment decision-making in consultations with Māori.

Research aim

The aim of this thesis is to understand the factors which influence treatment decision-making in cancer consultations with Māori patients and whānau by asking:

1. What impact do comorbidities have on treatment decision-making in cancer consultations with Māori patients/whānau?
2. What other factors influence treatment decision-making in cancer consultations with Māori patients/whānau?

Researcher position

This thesis is based on work undertaken as part of a three year study (2011-2014) funded by the Health Research Council of NZ (HRC) the '*Cancer Care Journeys and Clinical Decision Making Qualitative study*' (C3 Qual). The C3 Qual study is part of a larger *Cancer, Comorbidity and Care (C3)* research programme led by Professor Diana Sarfati (Otago University). Clinical and Māori Community Oversight groups provided advice to the C3 research programme. The C3 Qual project was led by Associate Professor Louise Signal (University of Otago) and Professor Chris Cunningham (Massey University). Signal is also the primary supervisor of this thesis, with Lis Ellison-Loschmann (Massey University) as second. Other team advisors include Diana Sarfati, Kevin Dew, Lesley Batten and Maureen Holdaway. The C3 Qual study comprises four phases: (1) processes of clinical decision-making in multidisciplinary meetings; (2) decision-making in cancer consultations; (3) understanding the patient's cancer journey and (4) intervention development.

This thesis presents the experiences of five Māori cancer patients who were study participants in the second phase of the C3 Qual study. There were also 13 NZ European cancer patients who participated in this phase. I was responsible for developing the ethics application, the research protocol, information sheets, consent forms and questionnaires, with supervision and with input from other team members. I set up and led the data collection. In total I undertook 14 interviews (four Māori and ten NZ European patients), five of which were completed with research assistant, Virginia Signal. Analysis of the Māori participants' data for this thesis was undertaken by myself and overseen by my supervisors, Signal and Ellison-Loschmann. Team members Dew and Sarfati also cross checked data analysis.

Personal position

My interest in this research topic is linked to my personal experiences of cancer among whānau members and friends, and in my professional capacity as a public health practitioner with a nursing background concerned with achieving health equity for Māori.

I have the privilege of having two fathers, one of whom was taken by lung cancer at the age of 50. Mum, my sister, my Dad's GP, the district health nurses, whānau and I cared for Dad at home for the final few months of his life. The smell of cancer is never forgotten. The emaciated man resembling a concentration camp survivor, confined to bed, passed before the break of dawn one cold spring morning. He no longer resembled the quiet, animal loving, hard worker of a dad I remembered. That devastating experience is permanently imprinted on my brain and in my senses for time ever more, as no doubt it was for everyone involved. Over time a number of other family members have also succumbed to cancer.

While undertaking this thesis my sister (39 years) and a dear friend (42 years) were both diagnosed with breast cancer, further ensuring my personal connection to the topic. Thankfully they continue to fight the 'good fight' and it serves as a stark reminder that you just never know what may be waiting

around the corner. While a cancer diagnosis might feel like a death sentence, advances in screening and treatment gives us hope - and the diagnosis reminds us all of what is truly important, friends and whānau. I believe that my personal experiences enabled me to undertake this research with compassion, commitment and understanding combined with the respect that these participants, their whānau and specialists deserved.

My work in Māori public health has focused largely on health promotion, cancer screening, and primary care in the community. During that time I noted advances in cancer health promotion, prevention, early detection, and treatment. Yet, over the past few decades, cancer incidence and mortality rates continue to show that Māori experience a greater burden of cancer when compared to NZ Europeans. Why I ask myself are there persistent and unfair differences in health status between Māori in 'modern day' NZ that are unnecessary and potentially avoidable?

Therefore, when the opportunity to participate in the C3 research programme arose it seemed both a natural and logical pathway to pursue. The programme provided not only an opportunity to learn about the experiences of patients, whānau and specialists along the cancer journey but more importantly, the chance to identify interventions to address inequities. This thesis is undertaken to complete a Masters of Public Health from the University of Otago.

Te Tiriti o Waitangi

Te Tiriti o Waitangi (Te Tiriti), was signed in 1840 and is the founding document between the Queen of England (the Crown) and many of the indigenous tribes of NZ (collectively referred to as Māori). Te Tiriti was negotiated with many Māori Chiefs by representatives of the Queen and recognises Māori as the tangata whenua (people of the land) of Aotearoa/NZ (Ministry for Culture and Heritage, 2016). Te Tiriti contains three main articles: Article one, where Māori essentially conferred governorship to the

Queen; Article Two, protects Māori Chieftainship over lands, villages and treasurers and allows Māori to sell land to the Queen and Article Three, which guarantees Māori the protection of the Queen of England and the same rights as British subjects. Under Article Three, it has been suggested that Māori are therefore entitled to enjoy the same level of health as non-Māori (Reid & Robson, 2007).

Te Tiriti paved the way for large numbers of mainly English immigrants to settle in Aotearoa/NZ. Although Te Tiriti was designed to protect Māori, the Crowns' inability to honour it over time has resulted in detrimental effects on Māori. Examples include poorer health for Māori compared to NZ Europeans, loss of life from infectious disease and firearms, effects on education, employment, land, language and wairua (spiritual wellbeing) (Cram, Smith, & Johnstone, 2003; Durie, 1998; Kunitz, 1998; Sorrenson, 1956). Large scale settlement essentially disrupted fundamental elements of Māori life including food supplies, social networks and the economic base. Many of these factors are now considered to be social determinants of health.

In a modern context social determinants of health can be considered in three sub-sets. Firstly, the socio-economic and political context (the cause of the causes), secondly the social determinants of health inequities, and thirdly intermediary factors such as the health care system (Solar & Irwin, 2010). Social determinants of health have been found to contribute significantly to health inequities, more so than the health care system in some instances (Hosseinpoor et al., 2006).

In this thesis inequalities refer to *"the observed differences in health status between groups"* (Blakely & Simmers, 2011). Inequities are defined as:

"... differences which are unnecessary and avoidable, but in addition are considered unfair and unjust. So, in order to describe a certain situation as inequitable the cause has to be examined and judged to be unfair in the context of what is going on in the rest of society" (Whitehead, 1992).

Elements of health differences include social determinants of health such as income, housing conditions and social networks, alongside other factors such as 'natural, biological variation' (Marmot, 2005; Whitehead, 1992) which may also (but not always) contribute to the development of health inequalities and inequities.

British authority was later transferred to the NZ Parliament and while Te Tiriti is recognised by the NZ Government as evidenced in legislation such as the Treaty of Waitangi Act 1995 it appears to be absent from social policy legislation (Durie, 1994; Government., 2016). Consequently Te Tiriti is the only mechanism in NZ that Māori are able to call on to ensure their rights as the indigenous people of Aotearoa/NZ are being upheld. Māori have a right to equitable health outcomes (Robson & Harris, 2007), and it is particularly important that cancer inequalities between Māori and non-Māori are addressed. On the international stage the World Health Organization encourages member states such as NZ to recognise the rights of indigenous people (including Māori) to high standards of health.

Any study involving Māori decision-making must consider the cultural context. Durie (1994) describes how pre-colonisation, Māori had well established systems for treating ill-health at the individual and population level while also being cognizant of the importance of social, environmental and spiritual elements pertaining to both the individual, whānau (extended family) and hapū (kinship group). An important part of the Māori 'public health' system were Tohunga (traditional healers). Tohunga led activities to remedy physical signs and symptom which were often considered manifestations of spiritual imbalance (Leske, 2007; Voyce, 1989). Traditional methods of healing at the individual level often involved rongoā (herbal medicines), karakia (prayer), mirimiri (massage) and wai (water) (Cram et al., 2003; Durie, 1994; Institute of Environmental Science and Research Ltd, 2008). In part due to colonisation, Māori people now largely access health care services from the New Zealand health care system which is founded on

Western medical philosophy. Although Tohunga have become scarce in modern times, traditional healing practices continue.

While people who form the different iwi groups in Aotearoa/NZ are collectively referred to as Māori this is also where any sense of 'sameness' ceases. As Durie (1994) notes "*Māori live in diverse cultural worlds. There is no one reality nor is there any longer a single definition which will encompass the range of Māori life-styles*" (pg.214). Although Māori vary greatly in terms of their diversity, they are still Māori, and Durie (1994) reminds us of the relevance of culture to illness and treatment. Based on an examination of medical practice and hospital procedures pre-1994 he concluded that "*cultural heritage continued to shape ideas, attitudes, and reactions, particularly at times of illness*" for Māori patients (pg. 68).

When exploring decision-making in cancer consultations with Māori patients, it is important that it is inclusive of the whānau [family] context. In 2014 the Ministry of Health re-released He Korowai Oranga (Māori Health Strategy), which provides the framework for achieving the best health outcomes for Māori (Ministry of Health, 2014b). The strategy emphasises whānau ora (healthy families) and mauri ora (healthy individuals) as two of three key elements which contribute to pae ora (healthy futures for Māori). Recognition of whānau and a focus on whānau as a whole rather than individual family members has been emphasised more recently by the Whānau Ora approach led by Te Puni Kōkiri (Te Puni Kokiri, 2010) which now provides the main policy direction for health and social services in NZ (Provost, 2015). With a focus on building and strengthening capability within families together with addressing health care needs at the family level, Whānau Ora offers a unique opportunity for NZ to provide global leadership on how health services can be jointly improved for everyone and reduce health inequities.

Therefore, in the context of this thesis, individual patients and whānau are recognised as inter-connected and therefore collectively able to influence

cancer treatment decision-making. Recognising the diversity between patients and whānau means the ways in which decision-making occurs may vary.

When studying Māori decision-making it is important to understand the foundations upon which this may occur. Democratic voting for example was introduced into NZ as part of the colonisation process and continues to underpin many societal level approaches to decision-making. Shaw's (2011) study of democratic decision making describes how Māori decision-making, referred to as "*deliberative decision-making without democracy*", is at odds with Western based democratic decision-making (Shaw, 2011). The Kīngitanga (Māori King Movement) where decision-making occurs via rūnanga (assembly discussion) with tribal members seemingly aligns with deliberative non-democratic decision-making. In contrast the Ngāti Porou (East Coast Tribal grouping) Rūnanga recently held an election for Rohenga Tīpuna (marae and hapū clusters) representatives involving a democratic voting process (Te Runanga o Ngati Porou, 2015).

Policy and programme context

In response to the growing burden of cancer and the emergence of medical treatment able to improve patient outcomes, NZ like many other 'Western' countries has developed cancer control policy, plans and strategies the first of which was launched in 2003 by the Minister of Health (Minister of Health, 2003). The Cancer Control Strategy's objective of reducing the impact and incidence of cancer also linked clearly to the NZ Health Strategy (King, 2000). Cancer strategies aim to reduce cancer incidence, morbidity and mortality across the cancer spectrum and involve activities in the following areas: primary prevention, screening and early diagnosis, treatment and symptom control, rehabilitation and support, and palliative care.

Cancer has been prioritised by the NZ Government over the past few years. This is evidenced by the investment of resources to improve outcomes

through the delivery of higher quality services and care to people experiencing cancer (King, 2000, 2001; Minister of Health, 2003). The more recent programme of cancer related activities for government agencies is centred on a strategic framework for action contained in the NZ Cancer Plan 2015-2018 (NZ Cancer Plan) (Ministry of Health, 2014c). The framework has a focus on equity and requires, amongst other things, that **all** people, have timely access to high-quality cancer treatment.

The NZ Cancer Plan acknowledges that the impact of cancer is higher on Māori than the 'general' population and identifies He Korowai Oranga (Māori health strategy) as a guiding framework to improve outcomes for Māori (Ministry of Health, 2014b, 2014c). An Equity of Health Care for Māori framework (Ministry of Health, 2014a) sits along-side He Korowai Oranga and provides direction across three domains: leadership, knowledge and commitment. These domains are directed to three levels: the health system, health organisations and health practitioners, and contain practical strategies which can be implemented at each level to reduce health inequalities for Māori.

Increasingly over the past decade, evidence of cancer treatment inequities has emerged (Hill, Sarfati, Blakely, Robson, Purdie, Chen, et al., 2010; Hill, Sarfati, Blakely, Robson, Purdie, Dennett, et al., 2010; Hill, Sarfati, Robson, & Blakely, 2013; Robson & Ellison-Loschmann, 2016; Seneviratne, Campbell, Scott, Shirley, Peni, et al., 2015). Reducing treatment inequities is an important public health issue because they are essentially unfair and contribute to cancer deaths, an important factor to be considered in the multidimensional population approach required to improve outcomes. Additionally they breach the obligations to Māori under Te Tiriti. Recent activities to improve the quality of treatment in New Zealand have been led by regional cancer networks, and the Ministry of Health (MoH), drawing on specialist knowledge within working groups (National Bowel Cancer Tumour Standards Working Group, 2013; National Breast Cancer Tumour Standards Working Group, 2013).

The MoH led 'Faster Cancer Treatment Programme' is another example of activities focused on improving quality of care. The development of more than ten tumour standards is one example of a Faster Cancer Treatment Programme quality improvement activity (National Bowel Cancer Tumour Standards Working Group, 2013; National Breast Cancer Tumour Standards Working Group, 2013). Those standards are to be implemented by District Health Boards (DHB) at a regional level, and are to commence with DHBs reviewing services against the standards and implementing improvement strategies. Some improvement strategies are focused on equity issues and tailored to meet the specific needs of different population groups such as Māori who experience poorer outcomes. Unfortunately, while DHBs are expected to implement the standards, they are not mandatory. It is too soon to determine if the standards have been implemented as intended or if they will address cancer disparities experienced by Māori. If Māori do not benefit from the tumour standards at the same rate or better than others there is the perverse potential for inequities to persist or increase rather than decrease.

Internationally the United Nations (UN) and the World Health Organisation (WHO) have identified non-communicable diseases (of which cancer is a key one) as a major challenge and one that countries must act against to prevent, control and monitor (United Nations, 2012a, 2012b). An example initiative is "The Commission on Social Determinants of Health" (The Commission) which was established by the WHO to support tackling avoidable health inequities and the social causes of ill health (Commission on Social Determinants of Health, 2008). According to The Commission "*health inequities are the result of a complex system operating at a global, national and local levels*". Furthermore the Commission suggests that attention be given to social factors as determinants of health inequities and country specific policy must be used to address those social factors that underlie the determinants of health inequities if they are to prosper.

Cancer inequities

Mortality

In 2012, 7969 of all deaths for non-Māori were from cancer (age standardized 116.5/100,000) compared to 936 Māori deaths (age standardized 199.4/100,000) (Ministry of Health, 2015a). The difference in mortality rates between Māori and non-Māori is striking. Leading sites of cancer mortality for Māori are lung, female breast, colorectal, prostate, stomach, pancreas and liver. Lung cancer alone causes over 30% of all cancer deaths in Māori (Cormack, Purdie, & Robson, 2007; Robson, Purdie, & Cormack, 2010).

Survival

Māori adults have a greater risk of dying from cancer and poorer survival rates than non-Māori (Hill, Sarfati, Blakely, Robson, Purdie, Chen, et al., 2010; Jeffreys, Wright, t Mannelje, Huang, & Pearce, 2005; Robson et al., 2010; Signal et al., 2015; Stevens et al., 2008). Additionally, for some cancers, Māori are more likely to be diagnosed later, with more advanced disease (Robson et al., 2010) and have a greater likelihood of metastatic disease (Stevens, Stevens, Kolbe, & Cox, 2007) than non-Māori. Trends in cancer survival for the period 1991-2004 found Māori had poorer survival than non-Māori across 17 of 21 cancer sites and cancer mortality was on average 29% worse for Māori compared to non-Māori (Soeberg, 2012).

Explanations for persistent ethnic cancer survival gaps between Māori and non-Māori may include: access to cancer screening and tumor biology (for example in breast cancer) (McKenzie, Jeffreys, t Mannelje, & Pearce, 2008; Seneviratne, Campbell, Scott, Shirley, & Lawrenson, 2015; Seneviratne, Campbell, Scott, Shirley, Peni, et al., 2015), access to treatment influenced by increased prevalence of comorbidities such as cardiovascular and respiratory disease, all of which may impact on treatment outcomes, disease stage, diagnosis, prognosis and access to and co-ordination of cancer treatment services (Cormack, Robson, Purdie, Ratima, & Brown, 2005; Hill, Sarfati,

Blakely, Robson, Purdie, Chen, et al., 2010; Sarfati, Koczwara, & Jackson, 2016; Signal et al., 2015; Stevens et al., 2008). There is a dearth of knowledge about treatment decision-making in cancer consultations with Māori in NZ and with other indigenous peoples. Similarly, there is a scarcity of information about the impact comorbidities may have on treatment decision-making in cancer consultations. As a result both factors should be investigated further to ascertain if they contribute to persistent ethnic survival gaps between Māori and non-Māori.

Treatment inequities

Treatment inequities between Māori and non-Māori are evident across the entire treatment spectrum including time to treatment, treatment approach and type of treatment (Stevens et al., 2008). A recent study by Signal et al. (2015) found that Māori with stomach cancer had differential access to specialised surgical services for Māori compared to non-Māori (Signal et al., 2015). This study found Māori were less likely to be treated in a main centre (44% Māori vs 87% non-Māori), and were less likely to have their surgery performed by a specialist upper gastrointestinal surgeon (38% Māori vs 79% non-Māori). The authors suggest these findings should be viewed cautiously due to the small sample size ($n = 335$).

Māori have also been found to receive less treatment than NZ Europeans. A study comparing treatment of Māori and non-Māori with colon cancer found similar surgical treatment rates but Māori were less likely to receive adjuvant chemotherapy (Hill, Sarfati, Blakely, Robson, Purdie, Chen, et al., 2010). Two NZ studies of lung cancer also found that Māori diagnosed with lung cancer are more likely to receive palliative rather than curative treatment than NZ Europeans (Christmas & Findlay, 2004; Stevens et al., 2008). Adjusting for disease characteristics and patient comorbidity did not account for the differences found in these studies.

It is also concerning to note that although there have been improvements in cervical cancer incidence and mortality outcomes for Māori women

compared to non-Māori women, health inequities persist (Lawrenson et al., 2016; Ministry of Health, 2015d). Both breast and cervical cancer have good treatment options and are potentially curable if detected early. Health providers in McLeod et al.'s (2011) cervical cancer inequities study suggest improved treatment standards have helped improve outcomes for Māori women but that further work is needed and suggest work focuses on improving service accessibility (McLeod et al., 2011).

Comorbidity

Comorbidity is the simultaneous existence of disease in addition to the disease of interest (Feinstein, 1970). Māori with cancer experience higher rates of comorbidity and are more likely to have multiple comorbidities than non-Māori (Hill, Sarfati, Blakely, Robson, Purdie, Chen, et al., 2010; Hill, Sarfati, Blakely, Robson, Purdie, Dennett, et al., 2010; Sarfati, Tan, Blakely, & Pearce, 2011; Stevens et al., 2008). Comorbidities have also been found to influence cancer survival disparities (Hill, Sarfati, Blakely, Robson, Purdie, Chen, et al., 2010; Hill, Sarfati, Blakely, Robson, Purdie, Dennett, et al., 2010; Stevens et al., 2008) although little is known about how this occurs for Māori.

Comorbidities may increase the clinical complexity of treating cancer, resulting in less than optimal access to major treatments and reduced treatment effectiveness while also being an important influencing factor for survival from cancer (Extermann, 2000a, 2000b, 2007; Hong, Ambrosone, & Goodwin, 2015; Sarfati et al., 2016; Satariano & Silliman, 2003; Sogaard et al., 2013). The Institute of Medicine's (2013) report on delivering high quality cancer care indicates that specialists are not well skilled to manage patients comorbidities which may have an adverse effect on patient outcomes (Institute of Medicine, 2013).

Comorbidities can affect survival in a range of ways. Comorbidities may increase the physiological burden of disease on an individual and also indirectly affect treatment options, quality and effectiveness. Comorbidities may also influence the likelihood of an individual being offered active

treatment (Sarfati et al., 2009; Stevens et al., 2008). For example, in a NZ study of patients with lung cancer, Stevens et al. (2008) found patients with a Charlson score (a measure of comorbidity, with higher scores indicating higher comorbidity) of two or more were about half as likely to be referred to cancer treatment as those with a score of zero.

Recent studies suggest that those with comorbidity may be able to tolerate and benefit from advanced treatments (Hill, Sarfati, Blakely, Robson, Purdie, Chen, et al., 2010; Sarfati et al., 2009). For example, a NZ study of people with advanced colon cancer (stage III) found that 84% of those with a Charlson score of zero were offered adjuvant chemotherapy compared with 19% of those with score of three or more (Hill, Sarfati, Blakely, & Robson, 2009). Sarfati et al.'s (2009) NZ based study found a 60% reduction in excess mortality for those with high levels of comorbidity when they received chemotherapy treatment (Sarfati et al., 2009). This finding indicates that for some cancers the burden of comorbidity on cancer mortality may be modifiable.

Māori models of health

In response to frustrations with a health sector focused on biological dysfunction and a desire for perspectives which consider the person as a whole and interconnected (socially and ecologically), Māori models of health emerged from the 1970s (Durie, 1994; Ratima, 2001). They did so alongside other holistic and integrative indigenous models which also began to develop worldwide (Chino & Debruyne, 2006; First Nations Health Authority, 2014). Te Whare Tapa Whā (a four sided house) is possibly the most well-known Māori model of health (Durie, 1994). This model is holistic in its approach and consists of four dimensions of health: taha wairua (spiritual side), taha hinengaro (mental side), taha tinana (physical side) and taha whānau (extended family side). This model also seeks to emphasise traditional beliefs while remaining mindful of Western medicine. Pere's Te Wheke (the octopus) model of health focuses more on the family health perspective

(Ministry of Health, 2016) and incorporates similar domains to Te Whare Tapa Whā while adding additional dimensions such as mana ake (uniqueness of the individual, family and positive identity). There are also many which have been developed in the service delivery, mental health and policy areas (Durie, 1994; Ministry of Health, 2016; Pitama, Huria, & Lacey, 2014; Ratima, 2001; Te Rau Matatini, 2015).

The Waikare o te Waka o Meihana model (an indigenous framework) has arisen more recently to guide the training of new medical personnel in undertaking effective clinical assessments with Māori patients and whānau (Pitama et al., 2014). Māori models of health enable Māori to define the direction and exert control over understandings of Māori health. Māori models also provide a comprehensive approach to the range of responses needed in order to improve Māori health outcomes.

Astutely in 1994, Durie identified “...a lack of shared decision-making and limited recognition of Māori views” as one reason for Māori experiencing a sense of alienation and strained relationships with health professionals (pg. 74). In response, increasing numbers of organisational policy statements address culturally appropriate and holistic care by incorporating models such as Te Whare Tapa Whā and the Meihana models (Pitama et al., 2014) into training and practice.

The consultation

The primary purpose of the consultation following a cancer diagnosis is to provide an opportunity for specialists, patients and family members to come together to discuss the disease (symptoms, diagnosis), impact of the diagnosis and management/treatment options. Participants give and obtain information, which provides an opportunity for concerns to be aired. Consultations are also the place where specialists, patients and family members establish a relationship (Ministry of Health, 2010a).

The body of cancer consultation literature reveals that attention has largely focused on describing what occurs (communication, patient participation, decision-making, interactions) in the consultation (Brown et al., 2012; Gaston & Mitchell, 2005; Kunneman et al., 2016; Laidsaar-Powell et al., 2013; Scott, Entwistle, Sowden, & Watt, 2001; Shepherd, Tattersall, & Butow, 2007). In more recent times there has been a growing focus on interventions (e.g. communication training for specialists, patient aids) to improve the quality of consultations (Bernhard et al., 2012; Hacking et al., 2013; Kamal et al., 2011). While these studies provide insight and information useful for designing models of best practice for example, few studies attend to different cultural groups as part of their methodology or in their analysis. For example, Leppin et al.'s (2015) study into decision status concordance between patients and clinicians only included 3.1% non-white participants (Leppin et al., 2015). While the Arora et al. (2009) study of physician decision-making styles and patient psychological outcome had a greater proportion (26.2%) of study participants who identified as minorities, there did not appear to contain any analysis to demonstrate if there were similarities or differences between racial groups (Arora, Weaver, Clayman, Oakley-Girvan, & Potosky, 2009).

The lack of research in the cancer field inclusive of or centred on indigenous and racial and ethnic minority people, such as Māori is noted. The lack of cancer research on groups other than the 'general population' is also relevant for those with differing education levels, English as a second language or through having a disability - all of whom have the right to good care. While the generalisability of these findings as they apply to other population groupings is largely unknown, it is nonetheless important to emphasise the need for improved approaches to the quality and interaction exchange within consultations.

Approaches to care

The past twenty or so years have seen a move away from paternalistic approaches (where specialists assume authority) (K. Taylor, 2009), to

patient-centred care (Epstein & Street, 2007). The Institute of Medicine defines patient-centered care as: *"Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions"* (Institute of Medicine, 2001). An international study by Stewart (2001, p 445) involving clinicians and patients has described patient-centred care as care which:

(a) explores patients' main reasons for the visit, concerns, and need for information; (b) seeks an integrated understanding of patients worlds – that is, their whole person, emotional needs, and life issues; (c) finds common ground on what the patients problem is and mutually agrees on management; (d) enhances prevention and health promotion; and (e) enhances the continuing relationship between the patient and the doctor.

Mead and Bower (2000) identify five key dimensions of patient-centred care that have synergies with Stewart's (2001) description. The five dimensions are; the biopsychosocial perspective, 'patient-as-person', sharing power and responsibility, therapeutic alliance, and 'doctor-as-person' (N. Mead & Bower, 2000). More recent literature suggests cultural safety and cultural competence are key and underpin effective patient-centred care when considering the context of indigenous people (Ellison-Loschmann & Pearce, 2006; Lacey, Huria, Beckert, Gilles, & Pitama, 2011; Nguyen, 2008). Cultural safety and culturally competent health practitioners are important as the culture of indigenous people accessing healthcare is often different to Western culture dominated systems. Difficulties experienced by indigenous people may be overcome when doctors recognise cultural diversity, and acknowledge how their own culture and views may impact on the patient interaction. A positive outcome can occur when both parties have mutual respect for each other (New Zealand Medical Council, 2013) .

In the NZ context, legislation such as the Health Practitioners Competency Assurance Act (Government., 2003), the Medical Council guide for Conduct (Legislative and Ethical Standards and Guidelines) (New Zealand Medical Council, 2013) and Practice and Patient Code of Rights (Health and Disability

Commissioner, 1996) identify requirements important to patient-centred care and cultural competence. It is also important to note however, that cultural safety is different to other models which focus primarily on culturally sensitive or competent care (Leininger, 1996; Theunissen, 2011; Wilson & Barton, 2012) in two key respects. The first is with regard to the definition of 'culture', which in cultural safety encompasses any differences between the health professional and the patient including gender, religion, politics, sexuality, age and culture. The second major difference is that cultural safety overtly seeks to address the power imbalance which may affect the one-to-one interactions between health professionals and their patients. This is done through the training programmes of health professionals (which simultaneously also effect structural changes through education) whereby students are exposed (many for the first time in any of their education experience) to the history of colonisation and its effects on the health of Māori, in order to provide relevant context for how these effects continue to have impact today (Ramsden, 1997).

Treatment decision-making in the cancer context

Cancer treatment decision-making can be complex and is a key component of consultations involving patients, specialists and in many instances family, following the receipt of a cancer diagnosis (Doherty & Associates, 2006; E. L. Mead et al., 2013; Noble-Adams, 2012; Obeidat, Homish, & Lally, 2013; Pardon et al., 2010; Tranberg et al., 2015). Often cancer patients have many, rather than just one, decision to make in consultations (Mendick, Young, Holcombe, & Salmon, 2010) ranging from disease profiling and tests to inform treatment planning, through to participation in clinical trials, all of which add to the decision-making 'burden'. Patient-centred care requires patient values and preferences to be considered in addition to biomedical and treatment factors, adding further complexity to cancer treatment decision-making.

Over the past two decades patient participation in treatment decision-making with specialists has increased (Chewning et al., 2012). Over a similar period, significant advances in cancer treatments have occurred, some offering control and others cure, with an overall increase in the numbers of people who are now cancer 'survivors' (DeSantis et al., 2014). Correspondingly, there are also many more people who are having to participate in often complex treatment decision-making (DeSantis et al., 2014).

Prior to the consultation, patients in many instances have already made many decisions regarding screening, symptoms and diagnostic procedures (e.g. biopsy and scans), some of which may have involved partners and family. Diagnostic procedures will, in most instances, have been determined in collaboration with a general practitioner (GP) or specialist. Initial discussions about treatment options are also likely to have begun with health professionals (e.g. nurses, physicians, surgeons, radiologists) and family and friends prior to the consultation.

To determine best patient outcomes, information is required on a range of factors including the cancer (for example: size, location, genetic profile, hormonal status), the evidence base for treatment options, patient and family (health, comorbidities, values, preferences), treatment benefit (for example: tumour reduction or elimination), treatment risks (for example: short or long term heart damage), acute and long term side-effects and quality of life (Cancer Society of New Zealand, 2016; National Bowel Cancer Tumour Standards Working Group, 2013; National Breast Cancer Tumour Standards Working Group, 2013; Reyna, Nelson, Han, & Pignone, 2015). Patients and family may be offered one or a number of treatment possibilities with more than one treatment pathway to consider, including the option of deferring or doing nothing (Whitney et al., 2008). Each different cancer pathway has its own set of possible therapeutic effects and side effects to consider. Utilising a breast cancer scenario, potential possibilities might include choosing between treatments with similar outcomes (e.g. breast conserving surgery vs

mastectomy) or choosing which combination of treatment to have (e.g. chemotherapy and hormone therapy combined or chemotherapy alone). In addition patients and family may be asked to consider the order of treatments (e.g. chemotherapy followed by surgery or vice versa), all the while recognising they may also choose surveillance (watchful waiting) or to opt-out of treatment entirely.

For patients with metastatic, recurrent or terminal disease, additional factors may also be considered when making treatment decisions. Such factors may include how aggressively to treat the cancer and deciding to continue with or to stop treatment. Adopting a palliative care approach focused on maximising quality of remaining life is another option that might be considered in such circumstances.

The number and type of participants present in cancer consultations where treatment decision-making occurs is also increasing. At a minimum, the specialist and patient are present and this dyad (two participants) is commonly the focus of research. And, although often present with roles that influence care and decision-making, family members or important others attending consultations have only recently begun to be considered by researchers exploring activities occurring in consultations such as communication (Laidsaar-Powell et al., 2013). In recognition of the roles family can play Johnson et al. (2009) propose a family and patient approach to care in which family are considered a member of the 'health care team' rather than a 'visitor' (B. H. Johnson, Abraham, & Shelton, 2009). In addition, cancer nurse specialists are increasingly participants in cancer consultations and demand for their services grows as the number of patients increase and policy directions change (Ministry of Health, 2007). To date, there appears to be a paucity of NZ literature on the influence they have on the consultation and decision-making in particular, and there is very little work internationally which has focused on this area (Holloway, Baker, & Lumby, 2009; McCullough, McKinlay, Barthow, Moss, & Wise, 2010; McKinlay, 2001; Neufeld, Degner, & Dick, 1993).

Decision aids have evolved in many countries to enable quality decision-making in complex circumstances (International Patient Decision Aid Standards Collaboration, 2016; Stacey et al., 2014). Evidence based information is provided to patients using decision aids when there are preference sensitive treatment options to make (Adsul et al., 2015; Nicholas, Butow, Tesson, & Boyle, 2016). Decision aids take different forms and may be web based or may involve videos and pamphlets. Most often they are given to patients prior to the consultation and provide balanced information about the differing treatment options, their harms and benefits (Stiggelbout et al., 2012).

Research outline

This thesis is divided into five chapters plus appendices. Chapter one has introduced and outlined the thesis. This chapter has also presented background information regarding cancer inequities experienced by Māori along with strategic, policy and service developments relevant to cancer in NZ. An overview of consultations, approaches to care and treatment decision-making in the cancer context is also provided. Chapter two provides a critical review of the relevant literature pertaining to cancer consultations and decision-making by specialists, Māori, other indigenous people and racial and ethnic minority populations. Attention is paid to the role of participants including specialists, patients and whānau; communication; and decision-making approaches and models. Chapter three describes the methodological approach and methods utilised in this study to collect and analyse data. It outlines the Māori Centred Research methodology (Cunningham, 2000; Foster, 2003) which requires Māori participation, a Māori focus and tangible benefits for Māori that will result from the research. Chapter four presents the findings of the research for each of the five cases included in the study. Chapter five provides a discussion of the study's key findings in relation to the literature on this topic, identifies the strengths and limitations of this study and discusses the potential implications of this study on policy and

service provision. It also provides recommendations for further research in this area.

Chapter two - Literature review

This chapter presents a narrative literature review examining factors that influence cancer treatment decision-making in consultations involving medical specialists and Māori patients and whānau. A secondary area of interest explored was how comorbidity influences treatment decision-making in consultations involving specialists, Māori and whānau. An initial review found

- No studies which examined factors influencing treatment decision-making in cancer consultations involving specialists, Māori patients and whānau.
- No studies which examined how comorbidity influences treatment decision-making in cancer consultations involving specialists, Māori patients and whānau.
- A paucity of studies which examined factors influencing cancer treatment decision-making in the consultation setting with specialists and indigenous people.

Therefore, the review was broadened to include published literature examining factors influencing cancer treatment decision-making in indigenous populations, racial and ethnic minority groups from non-Western countries (e.g. Asia and the Middle East), not limited to the consultation setting. Literature was also reviewed to identify factors which influence specialists' cancer treatment decision-making. The aims of the literature review were to:

1. Describe decision-making in cancer consultation literature and treatment decision-making models relevant to cancer treatment decision-making.

2. Identify factors (including comorbidity) which influence cancer treatment decision-making by indigenous people and racial/ethnic minority patients.
3. Identify factors (including comorbidity) which influence specialists' treatment decision-making in cancer consultations.

Literature sources

Studies were identified using a search of electronic databases, including Medline (OvidSP), CINAHL, Cochrane and Google Scholar. Studies that reported the findings of original research which met the following criteria were included in this review: (i) published from 1972 to 2016, in the English language, and in peer-reviewed journals, (ii) investigated cancer treatment decision-making in indigenous, racial and ethnic minority populations and treatment decision-making by specialists. Systematic reviews undertaken overseas as well as studies and information sources using NZ literature were sought. The reference list of retrieved articles was hand-searched and advice sought from experts in the field.

Broad search terms were used to ensure all relevant articles were identified. Databases were searched with combinations of terms and variations of the following: 'decision-making', 'neoplasm', 'cancer', 'consult*', 'Māori', 'indigenous', 'aboriginal', 'ethnic', 'minority', 'clinician', 'specialist', 'physician', 'oncologist' and 'surgeon'. Studies were categorised and findings synthesised using narrative summary. Cancer was a prerequisite for inclusion of a study but it could also contain other conditions e.g. lung cancer and COPD.

Grey literature, not identified in the searches above, was sourced from NZ and international organisations. Unpublished literature was accessed via the Internet through searches of organisational websites using the Google platform. Search terms included 'cancer treatment decision-making indigenous' and 'cancer treatment decision-making Māori' and 'decision-making Māori'.

The majority of literature covered in this review was published in the past 15 years, perhaps indicative of the growing focus on patient centred care and shared decision-making in Western medicine (Institute of Medicine, 2001; Legare, Ratte, Gravel, & Graham, 2008; E. L. Mead et al., 2013; Tzelepis et al., 2014). Doctors who provide care are referred to by many names in the literature, some common examples include: clinician, physician, surgeon, oncologist along with their area of specialty. For ease of reading I mainly refer to them collectively as specialists in this review. Similarly a range of people who attend consultations with patients are referred to in the literature in various ways including family, companion, caregiver, carer and spouse. This group is mainly referred to collectively as 'family'.

Organisation of the literature review findings

Examination of the studies revealed themes, which were then assigned to either the specialist or patient/whānau depending on whose decision-making was most influenced. Two significant themes, decision-making approaches and models and communication overlapped considerably and are presented in dedicated sections.

Section 1: *Decision-making in cancer consultations, approaches and models* draws attention to studies that explore how these influence patients' and specialists' decision-making.

Section 2: *Communication* looks at how this influences decision-making by specialists and patients.

Section 3: *Factors influencing patients' decision-making* explores specialist, whānau/family, patient and medical factors (comorbidity, disease and treatment).

Section 4: *Factors influencing specialists' decision-making* explores patient, medical (including comorbidity, disease and treatment), specialists and setting/system factors.

Section 1: Decision-making in cancer consultations, approaches, models and styles

Decision-making in cancer consultations

Decision-making in cancer consultations has largely been studied from perspectives of: communication (Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005; M. Johnson, 2012; Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2012); information (Cavalli-Björkman, Glimelius, & Strang, 2012; Chouliara, Kearney, Stott, Molassiotis, & Miller, 2004; Eggly et al., 2006; Eggly et al., 2013; Gaston & Mitchell, 2005; Hack et al., 2012; I. O'Brien, Lambie, & Stacy-Baynes, 2009; Puts, Papoutsis, Springall, & Tourangeau, 2012); and decision-making (Back & Huak, 2005; Cordella, 2011; Denberg, Melhado, & Steiner, 2006; Dovidio & Fiske, 2012; El Turabi, Abel, Roland, & Lyratzopoulos, 2013; Elwyn & Miron-Shatz, 2010; Entwistle & Watt, 2006; Gaston & Mitchell, 2005; Guadagnoli & Ward, 1998; Joseph-Williams, Elwyn, & Edwards, 2014; Kimball et al., 2013; Laidsaar-Powell et al., 2013; Mendick et al., 2010; Mendick, Young, Holcombe, & Salmon, 2011; Salmon, Mendick, & Young, 2011; Shepherd, Tattersall, & Butow, 2008; van Ryn et al., 2011). Factors identified span across a range of levels including: systems, patients and specialists. Other bodies of work have focused on the components of decision-making models, definitions, characteristics, how to monitor and measure it and tools to aid or improve shared decision-making (Elwyn et al., 2012; Legare et al., 2010; McCullough et al., 2010; Scholl et al., 2011; Siminoff & Step, 2005).

A significant amount of decision-making in the cancer literature reviewed utilised qualitative methods to gather data including interviews, both semi-structured and face to face, observations and consultation recordings, focus groups, scenarios and telephone interviews (Cavalli-Björkman et al., 2012; Chouliara, Miller, et al., 2004; Mendick et al., 2010, 2011; M. A. O'Brien et al., 2013; Salmon et al., 2011). Some quantitative data collection methods were also used such as surveys and questionnaires (Eggly et al., 2013; El Turabi et

al., 2013; Hagerty, Butow, Ellis, Lobb, et al., 2005; Shepherd et al., 2008). Common qualitative methods of analysis were also undertaken when examining the data, including: framework analysis, inductive content analysis, constant comparison, cross case qualitative analysis, and some drew on discourse analysis, conversation analysis and interactional sociolinguistics (Cavalli-Björkman et al., 2012; Chouliara, Miller, et al., 2004; Cordella, 2011; Mendick et al., 2010; M. A. O'Brien et al., 2013; Salmon et al., 2011). Some innovative techniques were also undertaken including specialists reviewing video of their consultations (M. A. O'Brien et al., 2013). Perspectives of patients and specialists were commonly reported as they were most often the participants in the research, with family and other health professional's involvement occurring less often (Chouliara, Miller, et al., 2004; Laidsaar-Powell, Butow, Bu, Charles, et al., 2016; Laidsaar-Powell, Butow, Bu, Fisher, & Juraskova, 2016; McCullough et al., 2010; M. A. O'Brien et al., 2013; Shepherd et al., 2008).

General limitations of the literature reviewed include a significant proportion of the literature stemmed from research involving a limited number of cancer types, commonly breast cancer. Due to gender biases and treatment advances breast cancer may not be representative of all cancers. Little literature involved family members, important others or other health professionals such as cancer nurse specialists. Very little literature explored indigenous, racial or ethnic minority group perspectives. Some studies have recognised this limitation and are currently exploring methods to enable this (Brown et al., 2011). Given much of the literature regarding decision-making comes from the United States (Denberg et al., 2006; Puts et al., 2015) Canada (Hack et al., 2012; M. A. O'Brien et al., 2013) and the United Kingdom (El Turabi et al., 2013; Mendick et al., 2010, 2011; Salmon et al., 2011), generalisability and applicability to the NZ context requires careful consideration. Only one NZ study was found which reported a model of treatment decision-making in the cancer context (McCullough et al., 2010). Additional understudied areas identified include cancers other than breast

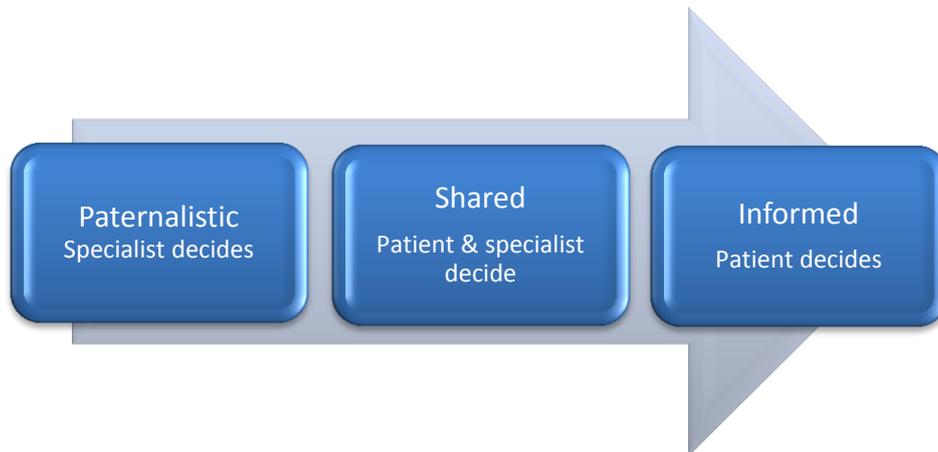
and specialists' cultural competency to undertake shared decision-making. Finally, and perhaps more important is the lack of research investigating system level issues that support and enable decision-making activities with the potential to address ethnic cancer inequities.

Decision-making models, approaches and styles

Over time there has been an increase in the use of decision-making theory and models in the literature. From a psychological perspective Reyna et al. (2015) describe decision-making theory which includes classical, computational and psychophysical theory (Reyna et al., 2015). Three key models of decision-making are commonly identified in the literature, paternalistic (specialist decides), shared (patient and specialist decide together) and informed decision-making (patient decides based on information provided) (Figure.1) (Charles, Gafni, & Whelan, 1997; Kon, 2010; Makoul & Clayman, 2006; Towle & Godolphin, 1999; Whitney et al., 2008). Key models largely focus on decision control. Epstein and Street (2007) suggest three stages - information exchange, deliberation and making the final decision occur regardless of who has control (Epstein & Street, 2007). Evidenced based patient choice is a decision-making model referred to less often in the literature (Whitney et al., 2008).

Disagreement is not uncommon in decision-making therefore one could suggest that when one treatment option has been offered by a specialist three decision outcomes are possible (Whitney et al., 2008). The first decision-outcome may occur when the patient and specialist make a consensus decision to accept a treatment option. The second decision-outcome could be a non-consensus decision (when the patient rejects the option/s offered by the specialist). The patient may or may not seek alternative options. Thirdly, the patient may choose to defer decision-making. The first two decision outcomes mentioned align with decision types identified by Whitney et al.'s (2008) two dimensional decision-making model.

Figure 1: Key models of decision-making.



In the NZ context, once a specialist has completed specialty training there appears to be a greater focus on professional development in areas related to treatment rather than topics such as communication and shared decision-making (A. Simpson, personal communication, 2014). Although not well evaluated, shared decision-making training programmes for health professionals exist in many countries (Legare et al., 2012) however none were identified in NZ.

Paternalistic decision-making

In the paternalistic decision-making model, also known as the parental or priestly model, the specialist decides what treatment is best for the patient (Emanuel & Emanuel, 1992). Within this model Emanuel and Emanuel (1992) describe how the specialist's approach may vary and move between seeking a patient's consent or, with a more authoritarian style, go so far as to inform the patient of the treatment that will be administered. Specialists operating under this model are often portrayed as the patients 'guardian' of health, and patients accept the guardian's treatment decision. While not currently a favoured model of decision-making in the cancer field, it may be appropriate in other circumstances where timely treatment is critical such as with a ruptured appendix.

Informed decision-making

Informed decision-making appears to have grown from a desire to expand informed consent in decision-making to informed decision-making involving informed choice (where alternatives such as watchful waiting are disclosed). An aim of informed decision-making is to ensure meaningful conversation occurs between the patient and specialist rather than the specialist simply informing the patient of treatment risks, benefits and alternatives (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999). This model has similar elements to shared decision-making discussed further on, but applies in situations where there is only one medically indicated treatment option.

Several approaches have been developed to measure informed decision-making (Braddock et al., 1999; Roter & Larson, 2002; Street & Gordon, 2006). Most approaches have evolved out of the United States using differing conceptual frameworks involving theories, patient participation, communication behaviors and informed consent. The methods used to assess informed decision-making capture both patient and physician elements and differ in complexity from 41 categories in the Roter Interactional Analysis System (a method of coding dialogue), to five in the Street Coding Method (Roter & Larson, 2002; Street & Gordon, 2006).

An Australian study of informed decision-making by 118 cancer patients with incurable disease found that while most were informed about treatment aims, less than half were informed about alternatives and a third were offered a treatment choice (Gattellari, Voigt, Butow, & Tattersall, 2002). More informed patients might be expected to make treatment choices aligned to best care. However this may not always be the case. In a prospective observational cohort study approximately one third of female newly diagnosed breast cancer patients with high knowledge scores chose mastectomy over breast conserving surgery despite an association with equivalent outcomes (Collins et al., 2009; Lantz, Zemencuk, & Katz, 2002). Informed decision-making cancer literature largely refers to the screening

context (Mullen et al., 2006). This may indicate a gap in the literature or that informed decision-making is less common in the cancer treatment context.

Shared decision-making

'Shared decision-making' is a term commonly used in the 21st century to describe a largely Western based decision-making model particularly attuned to those interested in providing patient-centred care (Barry & Edgman-Levitan, 2012). Shared decision-making sits on the decision-making spectrum between the paternalistic and informed models (Charles et al., 1997; Makoul & Clayman, 2006) (Figure 1). Shared decision-making can engender patients to express tino rangatiratanga (self-determination) with regard to their health and well-being and has the potential for family to participate in a meaningful way. Although there does not appear to be one internationally agreed definition of shared decision-making, it has been described as a model of decision-making that aligns to ethical principles, takes a patient-centred approach (Barry & Edgman-Levitan, 2012) and aims for decision-making that corresponds with patients wishes (Barton et al., 1996; Charles et al., 1997; Kon, 2010; Makoul & Clayman, 2006). According to Barry and Edgman-Levitan (2012, p. 780), shared decision-making is considered "*the Pinnacle of Patient-Centred Care*" due to its patient-centred approach where patient values and preferences are considered paramount.

Despite shared decision-making's growing popularity dissent remains regarding its applicability when the specialist presents only one treatment option. Charles et al. (1997) propose that several treatment options are required to undertake shared decision-making (Charles et al., 1997), however, patient-centred approaches to care would suggest the process of shared decision-making itself is of utmost importance rather than the number of options available or decisions made.

Literature on shared decision-making has grown exponentially since the 1990s (Blanc et al., 2014; Makoul & Clayman, 2006), seemingly in parallel to a time when many Western countries were moving towards greater

recognition of patient rights and autonomy. NZ for example established Patient Rights and enacted the Health and Disability Commissioner Act in 1994 (Health and Disability Commissioner, 1996), while in the United Kingdom (UK) there are an increasing number of shared decision-making reports and publications (Coulter, 2009; Coulter & Collins, 2011; Elwyn et al., 2010). The UK National Health Service has also established a website dedicated to shared decision-making for patients and health professionals as part of a *'Right Care Shared Decision-Making Programme'* which aims to, among other things, promote patient-centred care as part of a Quality Improvement Programme (National Health Service, 2016). Internationally, participants from 18 countries attended the Salzburg Global Seminar to consider the role patients can and should play in healthcare decisions and produced a statement in which clinicians are said to have an ethical imperative to share important decision-making with patients, and that patients have a right to participate equally in their care (Salzburg Global Seminar, 2011).

Despite the lack of consensus about characteristics which contribute to optimal shared decision-making (Brown et al., 2011), common themes are identifiable. Firstly, it involves at least two participants including the patient and specialist (but may also include family, friends and the wider health care team). Secondly, information is shared between the parties involved, with the specialist offering option/s and descriptions of benefit/s and risk/s. Thirdly, discussion occurs which may involve the patient expressing values and preferences, and building agreement about the preferred treatment. Finally, a decision is made about which treatment to proceed with (Barry & Edgman-Levitan, 2012; Charles et al., 1997). Opinions vary about whether the decision has to be mutually agreed (Charles et al., 1997; Legare et al., 2008; Makoul & Clayman, 2006).

Recognising that decision-making may take different forms in different situations, Kon (2010) describes a version of shared decision-making which encompasses models previously discussed and suggests they exist on a

“shared decision-making continuum” (Kon, 2010). This two dimensional shared decision-making continuum, involves a patient-specialist dyad and considers both who is driving the decision and who is taking responsibility. The goal of this model is for patient desires to drive decision-making which in turn will determine where they will sit on the spectrum. How realistic achieving this goal is in treatment decision-making consultations given time constraints, complex decision making compounded by comorbidities and a power dynamic that sits with the specialists is questionable.

In NZ, the New Zealand Medical Association and Medical Council (NZMC) (New Zealand Medical Council, 2013) advocate for the shared decision-making model. The NZMC gives clear instructions about the need for informed choice and consent which requires practitioners to undertake activities such as explaining to the patient his or her condition, options available and expected risks (New Zealand Medical Council, 2013). These essential elements align to both shared and informed decision-making.

Knowledge produced from shared decision-making research to date primarily privileges non-indigenous, white and racial majority groups, as is evidenced by the scarcity of literature reporting inclusivity of minority or racial groups in comparison to others (E. L. Mead et al., 2013). Given cancer disparities experienced by indigenous populations, a greater comorbidity burden and the need for culturally safe patient-centred care it is essential that specialists facilitate patient involvement in shared treatment decision-making that meets the needs of these populations (E. L. Mead et al., 2013).

Decision-making styles

Some studies have investigated factors that influence patients’ and specialists’ decision-making styles (Kaplan, Greenfield, Gandek, Rogers, & Ware, 1996; Weber, Solomon, & Meyer, 2013). A large survey involving patients and physicians by Kaplan et al. (1996) assessed personal characteristics associated with the likelihood of specialists involving patients

in diagnostic and treatment decision-making. This study found specialists' background, training, professional autonomy and practice volume influenced their decision-making style (Kaplan et al., 1996). More recent models have arisen, some due to perceived limitations with the Kaplan model and others which attempt to take a more holistic picture (Arora et al., 2009; Halkett, Arbon, Scutter, & Borg, 2005). Halkett et al.'s (2005) qualitative study involving women who had received treatment for breast cancer suggests specialists are influenced by factors such as *"the perceptions and expectation that they have of the women, their personal treatment preference, informed consent, their background training and knowledge of guidelines and protocols, and multidisciplinary clinics"* (p. 250). Arora et al.'s (2009) survey involving 623 cancer survivors determined specialists' decision-making styles by ascertaining information from patients about their interaction with the specialist, which were then linked with patient outcomes such as quality of life (Arora et al., 2009).

While there have been many studies which attend to patients' preferences for ultimately making the final decision (Arora & McHorney, 2000; Degner & Sloan, 1992; Hawley et al., 2007; Weber et al., 2013), less attention has been given to their decision-making styles. Of those studies which considered decision-making style, Pierce (1993) identified three decision-making styles among a group of patients with breast cancer. Firstly, 'the deferrer' (patient defers decision-making to another); secondly, 'the delayer' (patient delays decision-making until a clear preference is ascertained); and thirdly, 'the deliberator' (patient purposefully takes personal responsibility for making a quality decision) (Pierce, 1993). Pierce (1993) determined participants' styles by considering patients' perceptions of treatment options, how they coped with decisional conflict, how they engaged in information seeking, how they assessed risks related to treatment options, and their deliberation of options (Pierce, 1993).

Halkett et al.'s (2005) study mentioned previously developed a conceptual model of decision-making also involving women with early stage breast

cancer. The nature and level of patient involvement in decision-making in this study was found to be influenced by seven key issues: information provided, reaction to diagnosis, previous knowledge of cancer, urgency, support people, body image and demographics (Halkett et al., 2005). Finally, a recent qualitative study by Weber et al. (2013) involving largely Caucasian breast cancer survivors, identified five treatment decision-making styles: medical expert, self-efficacy, relationship embedded, inhibition, and constellation of information (Weber et al., 2013). Styles were differentiated by low versus high information needs, and 'self' versus 'other' preferences. Weber et al.'s (2013) study demonstrates the evolution of thinking to include elements such as relationships (where decisions were influenced by loved ones), and constellation styles (involving several influences). Pierce's (1993) early work provides useful insight to factors which may influence patient decision-making, however it appears limited to the patient physician dyad with a clinical focus. More recent studies in this field indicate that a broader range of factors may influence patient decision-making, and acknowledge the role family or important others play (Halkett et al., 2005; Weber et al., 2013).

In summary, decision-making has been increasingly studied since the 1990s, using both qualitative and quantitative methods. More recently thinking in this area has evolved in response to a greater drive towards patient autonomy and rights. Common models of decision-making include, paternalistic, shared and informed decision-making with the patient and specialist having differing levels of control and autonomy. A range of factors were found to influence specialists' styles including training, knowledge and volume of patients seen. In contrast patient styles were influenced by engagement, risk assessment, and more recent literature identified complexity and the role of family as influential.

Section 2: Communication

There is a very small body of literature pertaining to Māori and communication in the health domain. From the literature it is clear that

effective communication is vitally important and can be challenging for different reasons. Regardless of which stage of the cancer journey people are at, Māori patients and whānau value good communication (Cormack et al., 2005; Doherty & Associates, 2006; T. Walker et al., 2008). A number of communication factors were raised in Walker et al.'s (2008) qualitative study using focus groups and interviews with Māori cancer patients. Communication was identified as something which influences patients' emotional experiences, determines how informed patients feel about their disease, and that treatment and can also influence the whānau experience. Good communication could be as simple as asking the patient what they want to know, and was associated with aiding recovery and sense of support. Health professionals who were not responsive to patients' needs were more likely to be described as having poor communication similarly to those who were not forthcoming with information. Poor communication may limit patient access to both knowledge and essential support systems. For example, some people in this study reported using a range of tactics such as assertiveness to facilitate access to pain relief and basic care, while other patients found it difficult to know what questions to ask. Information deficits can ultimately result in treatment decision regret (T. Walker et al., 2008).

The context that communication about treatment decision-making occurs within also has the ability to influence decision-making. Patients attending consultations to discuss treatment have all experienced a period of uncertainty regarding their 'situation' and are likely attending the consultation to seek answers and/or a plan of action (Slater et al., 2013). The formal length of a consultation where treatment options are discussed in NZ is largely determined by hospital systems. Different specialties may also have different requirements, for instance medical oncology consultations are often scheduled for and take longer than radiation oncology consultations. In the hospital setting, specialists have power, within system constraints, to influence the length of time consultations take.

Some participants in Slater et al.'s (2013, p. 311) qualitative study of Māori cancer patients' and whānau experiences of health services identified that appointment times with specialists were '*not long enough*' and reported the same experience occurring in the primary care setting. These participants also noted that there was insufficient '*space*' and opportunity to ask questions and that it was difficult to develop and maintain relationships with multiple health professionals. The presence of comorbidities in addition to cancer may also increase the likelihood that more time is needed in consultations. These issues can result in gaps in patient information and knowledge, thereby influencing their ability to access support - potentially important factors in decision-making.

Information about cancer and treatment is often communicated, both verbally and in written form, to patients from a range of health professionals, including specialists and nurses pre and post consultations. In the consultation setting patients receive information from the specialist, support people/whānau present and in some cases nurse specialists (Slater et al., 2013; T. Walker et al., 2008). Specialists may also have additional information to communicate to patients with comorbidity as there is a greater risk of complexity regarding the diagnosis and treatment options. Other sources of information may include family, friends, colleagues, the internet (Dew et al., 2014) and Māori health providers (Slater et al., 2013; T. Walker et al., 2008). For treatment decision-making it is important that information is consistent, meaningful, timely (Slater et al., 2013) and produced in such a way that patients are able to understand it (T. Walker et al., 2008).

NZ's Ministry of Health (2010) defines health literacy as "*the capacity to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions*" (Ministry of Health, 2010b). While the main focus of this definition is on the patient's capability, it is clear that health literacy is important to treatment decision-making and thus more likely to be inclusive of both health care providers and patients.

Māori cancer patients with low health literacy may limit what information they share and want (Dew, Signal, et al., 2015). A recent review of health literacy by the Ministry of Health indicates a shift from a patient focus to one inclusive of the health care system, providers and practitioners in supporting patient access and understanding of health services (Ministry of Health, 2015b). A health literacy action plan template contained within the review report to guide service and organisational action to improve health literacy, further signals the important role providers have.

Who communicates information to patients is important, especially 'sensitive' information such as diagnosis (Dew, Signal, et al., 2015; Slater et al., 2013; T. Walker et al., 2008). Many patients prefer key information to be given by someone they trust, and ideally have an established relationship with. When accessing specialist care however, many 'sensitive' conversations such as those regarding treatment, occur between patients and specialists who have only just met. In Dew et al.'s (2015) qualitative study involving 19 Māori patients, poor patient experience with a 'junior' doctor's communication of the patient diagnosis resulted in a negative patient experience. Some patients prefer important information to be given by a senior doctor (Dew, Signal, et al., 2015). Given the seriousness of a cancer diagnosis for patients, the desire for this information to be given by a senior doctor may provide patients with a greater sense of trust.

Although there is a scarcity of literature that considers cultural influences on communication in consultations involving Māori specifically, there is some work which has been undertaken in other cancer settings. For example, a NZ study of ideal communication behaviours in the palliative care setting identified important cultural issues (Oetzel, Simpson, Berryman, & Reddy, 2015). In this study, non-Māori palliative care workers and kaumātua (elder/s with status) focused on avoiding prejudice and cultural mistakes. In contrast, whānau and Māori palliative care workers identified tikanga (correct procedure/custom) as important to upholding well-being and improving the quality of care (Oetzel, Simpson, Berryman, & Reddy, 2015).

A range of cultural concepts are identified in the literature as influencing communication between Māori and health professionals. For example, Māori holistic models of care were found to be in conflict with hospital care models by some participants in Walker et al.'s (2008) study. They described hospitals as only dealing with the physical and not the mental and spiritual elements of a person (T. Walker et al., 2008). Whakama (to be ashamed/shy) is another important cultural concept which can influence communication between Māori and health professionals. This can be further intensified for patients as often their concerns or issues are only able to be addressed by non-Māori health professionals who may lack the cultural competence to deal appropriately with the issue (Kidd, Gibbons, Kara, Blundell, & Berryman, 2013). Aroha (love/compassion) for the people is a key cultural concept that many Māori value (Durie, 1994; T. Walker et al., 2008). How specialists communicate with patients and whānau is one vehicle for expressing their aroha. It is important to understand cultural differences and important cultural values which may influence communication.

Whether communication is affected by congruence between the ethnicity of patients and specialists is uncertain. Some patients in Walker et al.'s (2008) study reported finding it easier to relate to health professionals who were Māori while the majority reported that the 'qualities demonstrated' were more important than ethnicity. Similarly, a NZ qualitative palliative care study identified greater communication challenges when palliative care workers were of a different culture to patients (Bellamy & Gott, 2013).

As mentioned earlier, whānau often attend consultations with their family member who are unwell and play an integral role in their cancer experience (Dew, Signal, et al., 2015; Slater et al., 2013; T. Walker et al., 2008). Walker et al. (2008) identified that whānau often act as advocates and found communication between patients and health professionals improved when whānau members played a central liaison role with specialists. Similarly the importance of whānau members aiding patients' understanding of information and facilitating interactions with specialists was identified in

Slater et al.'s (2013) study of Māori patients access to and through cancer services (Slater et al., 2013). In addition to the patient, whānau may be another valuable source of information on comorbidity and cancer in consultations.

However, it is important to acknowledge that there may not always be concordance between what the patient wants and the views of whānau. Differing views may lead to tension and pressure in relation to treatment decision-making (Dew, Signal, et al., 2015). Additionally whānau may be perceived as 'difficult' by some care workers (Oetzel, Simpson, Berryman, Iti, & Reddy, 2015). The appointment of a whānau spokesperson is one strategy identified in the literature to manage communication in conflict situations involving multiple whānau members (Oetzel, Simpson, Berryman, Iti, et al., 2015). Ultimately it is imperative that specialists, and indeed all health professionals, recognise that whānau may be present throughout the whole cancer journey and beyond, regardless of the outcome, and that they are therefore critical to include in communication. Being informed and connected to what is occurring with the ill whānau member enables whānau to carry out their role in a manner which maintains mana and protects patient dignity (e.g. avoiding misunderstandings). Patients without whānau or other support systems may be disadvantaged as they lack the additional support around receiving and interpreting information about treatment and care. Alternatively, they may seek support from other sources.

Establishing rapport with patients in consultations is core to communication, and a key objective of specialists which aids the development of a relationship and connection with the patient. Both Slater et al. (2013) and Lacey (2011) concur that developing rapport in face to face interactions with Māori is important (Lacey et al., 2011; Slater et al., 2013). Key components of rapport identified by Māori include the doctors taking time to listen, using understandable language, taking an interest in whānau health history, and engaging with the patient to deliver a collaborative style of healthcare (Cram et al., 2003). Health professionals and other health personnel (e.g.

receptionists) have not always established good rapport with Māori patients both in the cancer (T. Walker et al., 2008) and primary care fields (McCreanor & Nairn, 2002; Penney, Barnes, & McCreanor, 2011; Pitama, Ahuriri-Driscoll, Huria, Lacey, & Robertson, 2011). Specialists able to establish rapport with Māori patients and whānau may then be better able to ascertain issues of concern and assist to resolve them (T. Walker et al., 2008).

A number of key recommendations have been made by researchers to improve communication with Māori. Oetzel et al. (2015) suggests one way for parties to enhance communication is by the different parties sharing and ascertaining their respective preferences (Oetzel, Simpson, Berryman, & Reddy, 2015). Training health professionals to enhance their cultural competency skills is also identified by several studies (Lacey et al., 2011; Oetzel, Simpson, Berryman, & Reddy, 2015; Pitama et al., 2014; T. Walker et al., 2008). The development of Māori specific resources and receipt of good information in different forms is also identified as a strategy to improve communication (Cormack et al., 2005; Slater et al., 2013; T. Walker et al., 2008).

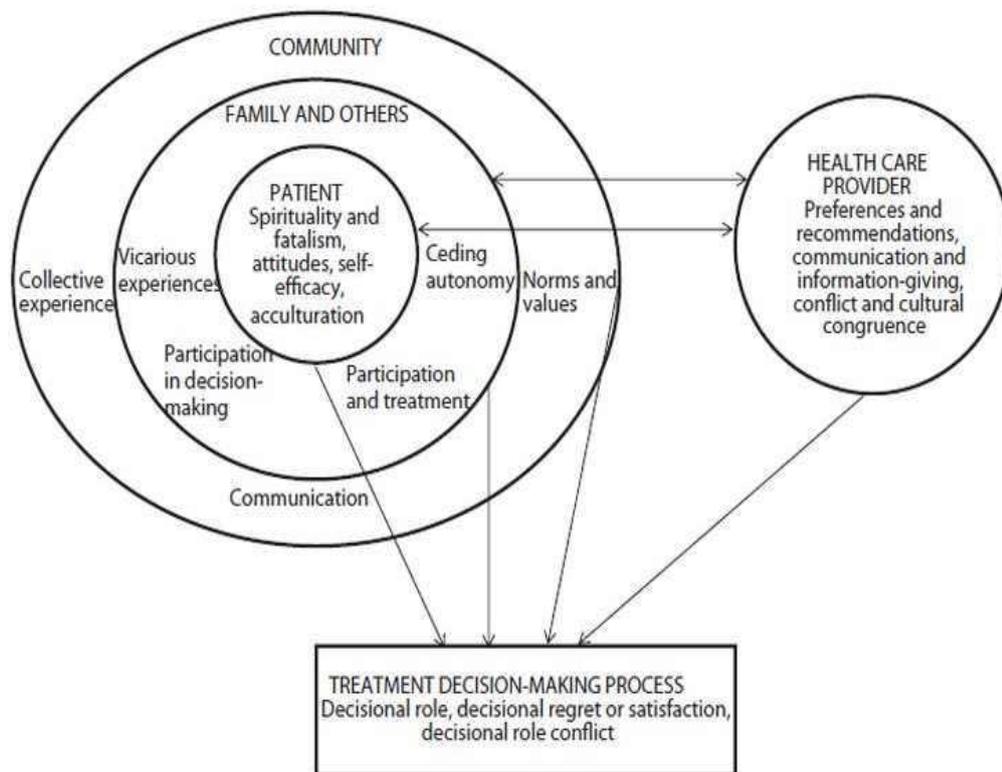
In summary, good communication is vital to enabling informed and appropriate treatment decision-making. Communication is influenced by many factors including time, system constraints and the ability to establish relationships and rapport. Patient comorbidity may add further complexity to information communicated to patients in consultations. Additionally it is important for specialists to be sufficiently trained to communicate with patients and whānau of different cultures.

Section 3: Factors influencing patient decision-making

This section considers literature pertaining to factors that influence patient decision-making. Māori models of health, outlined in chapter one, alongside Mead et al.'s (2013) conceptual model of shared decision-making (Figure 2) were drawn on to guide the presentation of literature in this section. Mead's

model was developed by refining major themes identified from a systematic literature review of racial/ethnic minority groups with cancer and shared decision-making (see figure 2). Internationally, there is a small body of literature focused on factors that influence indigenous, racial and ethnic minority patient treatment decision-making. The literature in this section is grouped into themes: whānau, specialist, patient and medical (including comorbidity), disease and treatment.

Figure 2: A conceptual model of influences on cancer treatment decision making among racial/ethnic and minority patients



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Note: (E. L. Mead et al., 2013, p. 19). Permission to use this image was obtained from corresponding author – A. Morris by email, 10/1/2017.)

Whānau

Whānau are important in the cancer journey. Their importance has been identified by a few recent qualitative studies investigating Māori experiences

of cancer (Dew, Signal, et al., 2015; Egan et al., 2016; Slater et al., 2013; T. Walker et al., 2008). In these studies whānau are attributed with playing a multitude of largely supportive roles. Slater et al.'s (2013) study of facilitators and inhibitors to cancer care access interviewed patients with a mixture of cancers and their whānau. Their study found support was often provided by one key family member who themselves could find the role stressful. A range of supportive roles and activities undertaken by whānau were identified across studies including: emotional support at appointments, transport, acquisition and interpretation of health information, and financial support (Egan et al., 2016; Slater et al., 2013; T. Walker et al., 2008).

Similarly to Slater et al.'s (2013) study, another qualitative study of roles and Māori experiences of cancer care identified whānau as important in the patient journey and providers of support, both physically and cultural (Dew, Signal, et al., 2015). Conversely however, whānau were also identified in this study as a potential source of tension regarding treatment particularly when whānau treatment preferences were in conflict with western medicine options on offer. For example, one whānau preferred traditional healing methods to chemotherapy and radiotherapy which were likened to "*poisoning and burning your body*". In this particular scenario the patient chose to compromise by accepting western medicine combined with some cultural healing practices like karakia (ritual chants, prayers) and aroha (love, concern, compassion) (Dew, Signal, et al., 2015).

As mentioned, providing support for un-well whānau member can also be a burden. The costs for whānau involved with caring for family with cancer were identified as significant in two studies, with some whānau incurring debt and even bankruptcy (Egan et al., 2016; Gott, Allen, Moeke-Maxwell, Gardiner, & Robinson, 2015). Costs associated with the provision of support were identified and found to occur at different levels including, personal, interpersonal, sociocultural and structural. Costs incurred by whānau were also reported as being both direct in the form of transport, food and medication and indirect (e.g. employment related) with little financial

support available from government agencies. Although this study did not solely focus on Māori, nearly 40% of the participants identified as Māori (Egan et al., 2016).

Whānau may also require support to facilitate their ability to assist their unwell whānau member although it is difficult to determine as published literature on this topic is sparse. Two interventions designed to support families and people with cancer during the assessment, diagnosis and treatment phases were identified in a recent literature review which explored factors that could improve Māori access to cancer services (Cram, 2014a). The two studies focused on native Hawaiian women and their families (Mokuau, Braun, Wong, Higuchi, & Gotay, 2008) and African American families with a parent who had cancer (Davey, Kissil, Lynch, Harmon, & Hodgson, 2012). The findings of these two studies suggest culturally responsive interventions are potentially effective, and can increase satisfaction and improve communication. In NZ the 'Kia Ora E te Iwi' kaupapa Māori based cancer support programme was developed to provide education and support for patients and whānau (Central Cancer Network, 2016). The programme was designed to improve cancer outcomes for Māori and was developed collaboratively by Iwi, Māori Health Providers and the NZ Cancer Society (Ministry of Health, 2015c).

Whānau however, may not always be able to provide support and alternatives may be sought. Two studies identified Māori health providers as acceptable substitutes for whānau, when whānau were unable to carry out their role. Māori health providers who often have established relationships with patients were seen to provide a sense of comfort, trust and familiarity (Slater et al., 2013; T. Walker et al., 2008).

While there appears to be an absence of literature that considers decision-making by Māori in relation to cancer, there is a small body of work in which it is considered in other health and related topic areas such as breastfeeding (Glover, Manaena-Biddle, & Waldon, 2007), death (Nikora, Masters-Awatere,

& Te Awekotuku, 2012) and research (Hope Tupara, 2012). These studies identify whānau as key to the decision-making process. For example, Glover et al.'s (2007) study of Māori women's breastfeeding decisions identified whānau as having a key role in decision-making. In this study, while women sought advice and support from whānau in decision-making and whānau were supportive, they did not appear to perceive they had a role in making the final decision, suggesting it was for the feeding mothers to make.

The role of family in regard to cancer care and decision-making has been broadened in light of the lack of direct relevant literature on the topic. Family have become more prominent in recent international literature. Several systematic reviews of decision-making support the notion that family are important and play a key role in cancer care including decision-making for indigenous, minority and non-Western peoples (E. L. Mead et al., 2013; Obeidat et al., 2013; Tranberg et al., 2015). These specific groups however do not appear to be homogenous with regard to the importance and role family plays in decision-making.

Connection to family was identified as part of a cultural theme thought to influence decision-making. In Tranberg et al.'s (2015) review involving five studies of Aboriginal and Torres Strait Islander people, cultural values relating to family and kinship were perceived to strongly influence responses to diagnosis and treatment. For some families, cancer was thought to have been caused by breaches of cultural traditions. Such situations had the potential to bring shame on the family. While for others, particularly those from rural and remote areas, members of the family felt responsibility for the person needing treatment and the patient in turn felt responsibility to the family. Regardless of these two factors, the availability of support was found to have a significant impact on treatment initiation and maintenance. This systematic review of factors influencing cancer treatment decision-making by indigenous peoples was limited in that only five qualitative studies were identified, furthermore all five studies pertain to Australian Aboriginal and

Torres Strait Islander people (Tranberg et al., 2015). Despite these limitations, families were identified as important to decision-making.

Mead et al.'s (2013) systematic review of shared decision-making among racial and ethnic minorities with cancer, identified 23 articles which utilised both qualitative and quantitative methods, the majority of which originated in the United States. Patients involved in the studies commonly had a diagnosis of breast cancer. Ethnic minority populations represented were African-American's, Latina (defined by language preference, English or Spanish), Asian (Chinese and Punjabis) and Jewish populations. Among these studies, low acculturated Latina and Asian peoples appeared to have greater family participation in decision-making than African Americans for instance. In addition to identifying that family plays an important role in treatment decision-making, this review also explored in more depth the roles and impact family may have on decision-making and treatment outcomes (E. L. Mead et al., 2013). Areas such as family participation, advocacy and communication were identified.

Decision-making at a whānau level (of which patient individuals are members) may appear complex to non-Māori who are unaware of the culturally bound traditions which underpin it (Richie, 1992). Many whānau form hapū (extended whānau) and many hapū form an iwi (tribe/extended kinship group) a Māori social construct. Whānau formation occurs as the result of people sharing common ancestry (whakapapa whānau) or a common purpose (kaupapa whānau). Many iwi are patriarchal while others, such as Ngāti Porou, are matriarchal (Mahuika, 1972).

Māori are described by Patterson (1992) as having collective principles and wealth and power are attributed to the whānau, hapū or iwi rather than the individual (Patterson, 1992). Roles and responsibilities of different whānau members may be determined by cultural traditions such as birth order. Tuākana (first born male child) for instance often inherit leadership roles while tēina (all but first born children) and pōtiki (youngest child) play roles

in decision-making designed to ensure honesty and thoughtfulness by the tuākana (Nikora et al., 2012).

Holistic care and nurturing are key roles attributed to whānau and consequences are apparent for whānau when there are role transgressions (Durie, 1994, p. 73). Durie (1994) suggests that Western aligned attributes such as self-sufficiency and self-realization are at odds with a Māori sense of health and that 'interdependence' rather than 'independence' is a healthier goal.

When considering the role of whānau in decision-making we must be mindful of societal changes affecting whānau. Changes include, Māori migration post World-War II, urbanisation and in more recent times immigration to Australia by many whānau in search of better living and working conditions. Many Māori are now separated geographically from their whānau, hapū and iwi (tribe). Adaptation to this separation has resulted in culture changes to birth and death rituals for instance. It is plausible to suggest that isolated individuals separated from whānau and living in urban settings may be more likely to adopt Western ways including individualist thinking and self-sufficiency.

Traditionally, collective decision-making is a phenomenon among Māori (Bishop, 1995; H. Tupara, 2009). Tupara (2009, p. 20) suggests this phenomenon "*always existed in Māori society*". Māori decision-making often occurred and still does in many instances in the context of hui (gathering of people). Inclusiveness is an important principle underlying the hui process, and hui may vary in size from a few whānau members to hundreds depending on the kaupapa (purpose for the hui). Many hui begin with karakia (ritual chant/prayers) and participants are provided the opportunity to kōrero (speak) and listen to the views of others. Discussion and debate on the kaupapa may occur until ideally a consensus is achieved (Nikora et al., 2012).

Processes associated with hui align somewhat to those ascribed to shared decision-making, discussed earlier. However, the shared decision-making literature does not appear to incorporate the potential for a consensus not being able to be reached, in contrast to hui, which do. For example, in hui when a consensus cannot be reached, decision-making may be deferred while the advice of experts (such as kaumātua) is sought. Other participants might withdraw as a form of protest or to avoid conflict (Nikora et al., 2012).

In her doctoral thesis and a retrospective qualitative case study of decision experiences of members involving three whānau kin groups participating in genetic research, Tupara identified four key processes considered critical to Māori decision-making (H. Tupara, 2009; Hope Tupara, 2012). Firstly, a hui is called; secondly, rangatiratanga (meanings including authority, ownership, autonomy) occurs; thirdly, manaakitanga (process of showing respect, generosity and care for others) is shared; and finally, kotahitanga (unity, togetherness, solidarity, collective action) is reached. Māori decision-making is largely a collective activity however not exclusively (Durie, 1994; Nikora et al., 2012). Individual autonomy is acknowledged and occurs in a manner which enables the integrity of the whānau to be maintained. In addition to personal attributes, authority and control, fears, values, beliefs, information and role-modeling are also identified by Tupara (2012) as factors which influence the Māori decision-making process.

The vision of He Korowai Oranga (Māori Health Strategy), mentioned earlier, is to achieve Pae Ora (Healthy Futures), a holistic state of health involving three interconnected elements: healthy individuals, whānau and environments (Ministry of Health, 2014b). The most recent iteration of this strategy aims to strengthen earlier versions by the addition of core components which have been woven into the framework (King & Turia, 2002; Ministry of Health, 2014b). Two core components of the framework are particularly relevant to decision-making. Firstly, Māori participation is identified as one of three principles, underpinning the relationships between the Crown and Māori with regard to Te Tiriti o Waitangi. This principle calls

for whānau to be involved in decision-making at all levels (planning, development and delivery) of health and disability services (Ministry of Health, 2014b). Secondly, knowledge (high quality information) is identified as a core component to support evidence-based whānau decision-making (Ministry of Health, 2014b).

Specialists

Mead et al.'s (2013) review identified how racial and ethnic groups respect specialists and identify them as authority figures. Of all factors identified as influencing patients' decision-making, specialists' treatment preferences and recommendations were found to have the greatest impact (E. L. Mead et al., 2013). Alternatively, this review also found the reverse was true. For example, if specialists did not advocate for a particular treatment then treatment uptake by patients was found to be less. Patients were also more likely to experience decision regret and dissatisfaction when they choose to relinquish their role in decision-making to the specialist.

To date, it appears no NZ studies have explored the influence of the specialist on patient treatment decision-making with Māori or other ethnic groups in NZ.

Patient

Mental and spiritual well-being

There appears to be little NZ literature on how mental, spiritual and emotional states may influence cancer treatment decision-making for Māori or others, and few studies internationally which specifically address this topic in indigenous, racial and ethnic minority groups (E. L. Mead et al., 2013; Obeidat et al., 2013; Tranberg et al., 2015). Of studies that did, spirituality (not prayer alone) was identified as an important coping mechanism, particularly for African Americans with cancer, and found to influence the decision-making process (E. L. Mead et al., 2013). Patient spirituality was

also linked positively to patient faith in specialists, relationships with providers, and compliance with treatment recommendations. Spirituality is considered a core element of key Māori health models such as Te Whare Tapa Whā mentioned earlier. In a recent qualitative study by Egan et al. (2015) spirituality was reported as important to Māori patients' understandings and experiences of cancer.

Attitudes

Patients' attitudes were also identified in Mead et al.'s (2013) systematic review as having the potential to influence decision-making. In this review conflict was found to intensify anxiety while findings from some studies suggest that adopting a 'positive attitude' was central to treatment decision-making for some. However, the definition or actions taken to express a 'positive attitude' by racial and ethnic groups varied. One group expressed this attitude by taking an active approach to decision-making while another ethnic group deferred treatment decision-making to specialists.

Fatalism and fear

Fatalism occurs when people believe an outcome is predetermined and they are powerless to change (Merriam-Webster, 2016). There is a paucity of literature considering fatalism and decision-making among Māori. However, fatalism was identified as relevant to decision-making in two key reviews involving indigenous people and racial/ethnic minority patients (E. L. Mead et al., 2013; Tranberg et al., 2015). Mead et al.'s (2013) review identified a study where patient decision-making was limited due to the perception that their cancer diagnosis and treatment outcomes were 'God's will' and they relied on prayer (E. L. Mead et al., 2013). Similar fatalistic views were found by Tranberg et al. (2015) in their review which identified cancer diagnosis could be linked to negative family experiences of cancer. In combination with cultural beliefs, cancer could be linked to retribution for broken laws and customs. Therefore, some thought nothing could be done in these circumstances and considered treatment to be pointless (Tranberg et al., 2015).

Not dissimilar to many other indigenous populations, Aborigine and Torres Strait Islander participants in the studies reviewed by Tranberg et al. (2015) considered the body as sacred and maintaining wholeness as very important. Even talking about cancer was discouraged in these cultures for fear “*it could make it happen*”(p. 7).

Fear of cancer and the unknown, like chemotherapy treatment for example, seems a ‘normal’ reaction for many. However, for some whānau a cancer diagnosis can also result in fear, not just for the affected individual but for themselves and the wider whānau (Dew, Signal, et al., 2015).

Medical: comorbidity, disease and treatment

No NZ literature was found which considers how medical factors such as, disease and treatment factors influence cancer treatment decision-making by Māori. International literature identified a few studies in Mead et al.’s (2013) systematic review pertaining to racial and ethnic minority groups which identified biomedical and treatment related topics (E. L. Mead et al., 2013; Tranberg et al., 2015). Specifically, concerns about disease recurrence, survival and treatment effects were found to be prominent in shaping treatment decision-making, particularly for Latina and African American women. These studies showed that in countries where treatment is not free, treatment costs are of concern and potentially influence decision-making.

Comorbidity was not identified as a factor influencing patient treatment decision-making in the literature reviewed.

In summary, there are a number of factors found in the literature that influence patient treatment decision-making including whānau, the specialist and patient factors such as their mental well-being and attitudes. Furthermore, international literature found disease and treatment factors were prominent in treatment decision-making by minority populations.

Section 4: Factors influencing specialists' decision-making

This section considers literature pertaining to factors that influence *specialists'* decision-making. Internationally, there is a small body of literature focused on factors that influence specialists' treatment decision-making. The literature in this section is grouped into themes: medical (including comorbidity, disease and treatment), patient, specialist and healthcare system.

Medical: comorbidity, disease and treatment

Cancer treatment planning is often a complex process and requires specialist consideration of a vast array of medical factors when preparing treatment options. A key goal of many treatment options is to maximise survival, while other goals often aim to lessen unpleasant treatment related side-effects.

The presence of comorbidities has been linked with treatment selection and lower treatment rates in cancer patients (Koppie et al., 2008; Sarfati et al., 2016). Hall et al.'s (2005) review suggests that to correctly determine best treatment, which he suggests has been inappropriately influenced by patients' age and comorbid illness, comorbidities must be integrated into treatment decisions by specialists (Hall, Jani, Ryu, Narayan, & Vijayakumar, 2005). Comorbidities were also identified in Shepherd et al.'s (2008) large survey of over 600 Australian cancer specialists as a factor which added difficulty to treatment decision-making. Specialists working with Māori patients are likely to encounter comorbidities often given the higher prevalence of common comorbid conditions such as diabetes and cardiovascular disease in the Māori population compared with NZ Europeans (Robson & Harris, 2007).

Patient cancer treatment management plans are often prepared by specialists in consultation with multidisciplinary teams (Ung, Campbell, Duplan, Ball, & David, 2016). Patient comorbidities have been identified as one reason for

multidisciplinary team treatment recommendations having not been implemented (Blazeby et al., 2006). In addition to multidisciplinary teams, specialists commonly utilise risk prediction programmes such as 'Adjuvant! Online' to determine if adjuvant treatment will be of benefit to patients (Ravdin et al., 2001). A recent review of 20 risk prediction models identified 'Adjuvant! Online' as the sole model which included patient comorbidity in calculations (Engelhardt et al., 2014). The lack of consideration of patient comorbidities by multidisciplinary teams and risk prediction models suggests specialists must define and determine if patient comorbidities influence the development of treatment management plans.

In addition to patient comorbidity specialists also consider disease and treatment factors. A triangulation study of treatment decisions involving eight surgical specialists in the UK treating breast cancer patients identified that treatment options were only presented when specialists considered there to be clinically equivocal options that maximized survival (Mendick et al., 2010). Alternative options were likely to be offered when 'best practice' was unclear, or when the outcome would not be significantly affected by choice (Mendick et al., 2010).

Specialists make many complex decisions about treatment and new knowledge regularly results in changes to treatment approaches. Specialist's beliefs about the strength of evidence underpinning treatments have been found to affect treatment selection (Showalter et al., 2012; Tariman et al., 2012). For example, a recent survey involving radiation oncology and urology specialists which aimed to evaluate beliefs and practices regarding adjuvant radiation therapy after radical prostatectomy found recommendations for radiotherapy varied by specialty (Showalter et al., 2012). This variation occurred despite the authors suggesting there is sufficient evidence from randomized control trials to support adjuvant radiation therapy after radical prostatectomy. The authors suggest future studies should define toxicity factors and identify specific patient groups that would benefit from adjuvant treatment to better guide specialists' decision-

making. The low response rate in this survey (20%), a disproportionate number of academic specialists in the response group, and limited consideration of training bias limit the generalisability of these findings (Showalter et al., 2012).

Other medical factors such as tumor type, cytogenetic profile and physiologic status were identified in Tariman et al.'s (2012) review as integral to specialists decision-making (Tariman et al., 2012). For example, cytogenetic profiles which identify node and hormone receptor status can assist specialists to determine, in combination with treatment algorithms, which chemotherapy regimen is likely to be of greatest value for patients when planning breast cancer chemotherapy and hormone therapy treatment. This review was limited to literature concerning 'older' (≥ 65 yrs) adult patients with cancer and some of the studies included have methodological flaws such as poor response rates.

Patient

A range of patient factors were found to influence specialist decision-making including; patients' living situation, education status, willingness to accept treatment (Cavalli-Björkman et al., 2012), comorbidities (Shepherd et al., 2008; Tariman et al., 2012), age (Tariman et al., 2012) and family (Back & Huak, 2005; Cavalli-Björkman et al., 2012; Laidsaar-Powell et al., 2013).

Cavalli-Björkman et al.'s (2012) qualitative study interviewed 20 Swedish oncologists and found that chemotherapy treatment combinations used for cancer patients were affected by patient living situations (Cavalli-Björkman et al., 2012). Fear of treatment toxicity for patients who lived alone underpinned oncologists' decisions to consciously use less combination therapy for these patients.

Families were identified in the literature as having the potential to influence specialists' treatment decision-making (Back & Huak, 2005; Cavalli-Björkman et al., 2012; Laidsaar-Powell et al., 2013), and they could either help or

hinder decision-making. In Cavalli-Bjorkman et al.'s (2012) study, some specialists reported that persuasive family could be challenging while others felt outnumbered (Cavalli-Björkman et al., 2012). Similarly, Laidsaar-Powell et al.'s 2013 review identified some specialists felt burdened by family participating in consultations (Laidsaar-Powell et al., 2013).

Specialists' perceptions and opinions of families vary. Laidsaar-Powell et al.'s (2013) recent systematic review of triadic medical consultations (involving three participants, often the patient, specialist and a family member) identified a number of family factors potentially able to influence specialists' decision-making (Laidsaar-Powell et al., 2013). Family were recognised as a helpful source of medical information (history, medications and symptoms) and important to treatment decision-making by specialists. However, their presence in consultations could also increase the complexity of the consultation with some specialists expressing concern that family may take time away from the specialist's ability to discuss important issues with the patient. Other specialists also suggested that family limit their ability to discuss sensitive issues with patients, while others considered family involvement compromised their ability to answer patients' questions (Laidsaar-Powell et al., 2013).

Other patient factors such as age were identified as influencing specialists' decision-making in another review which investigated specialist, patient and contextual factors that affect decision-making in older adults diagnosed with cancer (Tariman et al., 2012). This review, involving literature sourced from 1966-2010, identified how specialists' judgments of patient age could influence and bias their perceptions of patient life expectancy. Age bias for example was found to result in under-treatment for some older cancer patients, negatively impacting their prognosis (Tariman et al., 2012).

Specialist

Personal factors (e.g. values, beliefs and bias), emotional factors and professional expertise was identified in the literature as having influenced specialists' treatment decision-making. Specialists' values for example, appear to influence a vast array of treatment decision-making related factors (Dew, Stubbe, et al., 2015; Schildmann, Tan, Salloch, & Vollmann, 2013; Tariman et al., 2012) and are fundamentally important in decision-making. How their values are expressed may or may not benefit the patient, nor may they align to patient values and preferences (Winkler, Hiddemann, & Marckmann, 2011). Tariman et al.'s (2012) review identified specialist values and beliefs as factors which influence their perception of quality of life, who should be involved, and what information is important to consider in decision-making (Tariman et al., 2012). Attention to the expression of specialists' values is important to consider, as how values are expressed can influence the decision-making process and priorities aligned to treatment goals like length or quality of life, and ultimately health outcomes for cancer patients.

Some early studies identified that specialists believed they should have more decision-making authority than cancer patients based on their view that they were the expert (Beisecker, Helmig, Graham, & Moore, 1994). The type of decision-making, where patients play a minimal role and specialists largely decide, aligns predominately with a paternalistic decision-making model discussed earlier (Emanuel & Emanuel, 1992). Strands of this view appear to persist in contemporary studies where specialists articulated their belief that they determine the option/s offered to patients in consultations, therefore they control decision-making (Mendick et al., 2010). The consequences of paternalistic models of decision-making have been linked to under-treatment of cancer in older populations (Bouchardy, Rapiti, Blagojevic, Vlastos, & Vlastos, 2007), with the reasons for this being unclear.

The work of specialists may be highly rewarding, however it may also be stressful and demanding. Dealing with pressure situations is part of their daily life, and at times their emotional responses to these situations may affect their treatment decision-making. For example, a specialist may have to inform patients (with young children) they have a terminal illness (Koedoot et al., 2004). While having young children has been found to influence cancer patients perceptions of treatment factors (Lux et al., 2013), there appears to be little, if any literature which considers how treating patients with young children impacts on specialists.

Making life and death decisions involving toxic treatments can also affect emotions and stress levels (Shanafelt & Dyrbye, 2012). A Swedish study of factors oncologists consider when making treatment decisions, identified how their desire to please patients and family influenced their response to treatment demands (Cavalli-Björkman et al., 2012). At times oncologists would prescribe patients treatment even when they thought it had limited efficacy. And, although Salmon et al. (2011) note emotional talk may be absent from some consultations, many specialists describe their relationships with patients as being both personal and emotional (Salmon et al., 2011). Given the emotional toll working in cancer care can take, it is unsurprising to learn from Shanafelt and Dyrbye's (2012) review that psychological responses in the form of depression, anxiety and fatigue, collectively referred to as 'burnout' is high amongst specialists working in the cancer field.

Other personal characteristics such as ethnic bias, expressed sometimes as prejudice and/or discrimination (Dovidio & Fiske, 2012) are identified in the literature as influencing quality of care and decision-making by specialists (Smedley, Stith, & Nelson, 2003), at times despite their best intentions. Biases may be either explicit (conscious) or implicit (below conscious awareness). Cultural and racial differences between the patient and clinician may lead to differential treatment as could the gender of both the patient and clinician. These factors along with comorbidity, which is common among Māori (Hill, Sarfati, Blakely, Robson, Purdie, Chen, et al., 2010), are likely to

exacerbate clinical uncertainty for clinicians who are already dealing with highly stressful and complex decision-making situations. Literature in this area is limited but growing.

The literature regarding ethnic bias and specialists originates largely from the US and primarily concerns African American and Latino populations. Within this body of literature, ethnic bias is identified as a potential factor contributing to treatment inequities between African Americans and Latinos when compared with Whites (Baldwin et al., 2005; Dovidio & Fiske, 2012; Jessup, Stewart, Greene, & Minsky, 2005; Shavers & Brown, 2002; van Ryn et al., 2011). Ethnic bias may also impact on relationships (van Ryn et al., 2011), communication (Cooper et al., 2012; Martin, Roter, Beach, Carson, & Cooper, 2013), care (Cooper et al., 2012), and treatment decision-making (Alibhai et al., 2004; Smedley et al., 2003).

While ethnic bias has not explicitly been studied in the NZ cancer context, experiences of racial discrimination by health professionals have recently been reported. Harris et al. (2012) conclude from their analysis of 2006/2007 Health Survey data that *"Experience of racial discrimination in both health care and other settings may influence health care use and experiences of care and is a potential pathway to poor health"* (Harris et al., 2012, p. 1012).

Fatigued and burdened specialists are identified in literature reviewed by Dovidio and Fiske (2012) as being at increased risk of prejudiced and discriminatory practice (Dovidio & Fiske, 2012). These conditions are considered to limit specialists' cognitive abilities to control their own biased behaviour. While specialist biases are more likely to be implicit rather than explicit (Moskowitz, Stone, & Childs, 2012) the outcome for patients can be poor relationships with specialists (Blair et al., 2013) and disparate care (Blair et al., 2013; Dovidio & Fiske, 2012; Smedley et al., 2003). While some specialists may look to biological explanations for treatment disparities between ethnic minorities and Whites (Jessup et al., 2005), Dovidio's (2012)

review suggests other specialists (although not all) are increasingly acknowledging the contribution of non-biological factors to care disparities between different races.

Van Ryn et al. (2011) suggest a range of important setting factors have the potential to 'eradicate inequities in care'. She also recommends other strategies including reducing specialist cognitive load, universal guidelines, and improving organisational racial climates. Organisational racial climates refer to "*employees' shared perceptions of the policies and practices that communicate the extent to which fostering diversity and eliminating discrimination is a priority in the organization*" (Pugh, Dietz, Brief, & Wiley, 2008). Implementing quality improvement initiatives, designed to eliminate conditions and behaviors that contribute to the formation of inequities between ethnic groups, was also identified in the literature as an important strategy to address care inequities (van Ryn et al., 2011).

Other non-medical factors such as practice types, age, education, area of expertise and experience have also been linked to specialists' approaches to treatment decision-making (Lux et al., 2013; Schildmann & Vollmann, 2010; Shepherd et al., 2008; Tariman et al., 2012). Given many cancer services are situated in large hospitals with complex systems it is important that specialists providing care are able to 'work the system'. Shepherd et al.'s (2008) study mentioned earlier found the place of initial medical training and years of experience influenced how commonly system barriers were experienced (Shepherd et al., 2008). Unfortunately, this study did not include cultural differences or comorbidity as potential influencing factors in the analyses. Tariman et al.'s (2012) review also found experts in the field of Hodgkin's Disease were more likely to tailor treatment to individual patients than non-experts while academic specialists were more likely to use combined therapies (Tariman et al., 2012). Some limitations of this survey however were its response rate of 50%, few treatment choices for participants, and lack of recognition for how decision-making may have been influenced by the patient context.

Healthcare system

Two articles identified four system factors with the potential to influence specialist treatment decision-making. Mendick et al. (2010), identified that 'best practice' and multidisciplinary team policy determines most specialist treatment decisions (Mendick et al., 2010). Shepherd et al.'s (2008) study adds two further system/setting barriers to the range of factors which influence specialists' decision-making, specifically identifying insufficient time with patients and lack of information (Shepherd et al., 2008). Less experienced specialists in this study reported difficulties with system issues more often and the authors suggest this could be due to more experienced specialists' skill at 'working' the system and being more likely to take a patient-centred approach.

Many treatment decisions in cancer care are increasingly being made in teams by a range of healthcare professionals, commonly referred to as multidisciplinary teams (C. Taylor et al., 2010). This is also true for many cancers treated in the NZ secondary health care system and the Ministry of Health have developed guidelines to guide best practice in multidisciplinary teams (Ministry of Health, 2010a). Dew et al.'s (2015) study, involving specialists in ten NZ multidisciplinary cancer team meetings identified a broad typology of value positions taken by participants in expressing their decision-making preferences. These included utilitarian (treatment option considered patient population and use of resources to maximise benefits), paternalistic pastoralism (focused on patient good, patient not seen as best to make the decision), beneficent pastoralism (treatment to enhance patient well-being regardless of cost or management indication), patient empowerment (all information provided to patient, patient decides in discussion with specialist), procedural (protocol and process driven treatment) and clinician's self-preservation (specialist determines treatment based on interactions with patient) (Dew, Stubbe, et al., 2015).

In summary, a range of factors that influence specialists' decision-making were identified including patient factors (e.g. their family, living situation and age). Specialists have highly stressful jobs and some literature identified that personal characteristics, such as values, biases and experience were influential. Given the complexity of cancer treatment decision-making it is unsurprising to find that disease and treatment factors also influenced treatment decision-making. In addition to these, healthcare system factors such as multidisciplinary teams also feature increasingly in specialists' decision-making.

Summary

In summary, section one outlined relevant contextual information important when studying cancer treatment decision-making including approaches, models, types and styles. A number of studies attended to treatment decision-making in cancer consultations which commonly focused on communication, information and decision-making processes. Patient, specialist and system levels were explored along with methods to monitor, measure and improve decision-making.

Section two showed how important good communication is to inform treatment decision-making. The literature shows that communication in consultations where complex treatment decisions are often made may be affected by multiple factors including time, system constraints, cultural differences, comorbidities and relationship development.

Section three presented information about the range of factors found to influence patient treatment decision-making including, patients' mental well-being and medical factors such as disease and treatment factors. The importance of the specialist's treatment recommendation and whānau involvement in patient decision-making was identified consistently in the literature. However, there was a lack of literature able to be sourced considering factors influencing treatment decision-making in cancer

consultations involving Māori with cancer or other indigenous and racial and ethnic minority populations.

The final section reviewed a range of factors found to influence decision-making by specialists. This section found specialists could be affected by patient, specialists, healthcare system and disease and treatment factors. Similarly to patients there is a paucity of literature considering factors which influence specialist decision-making in cancer consultations. Additionally, little literature was found that investigates the views of or factors which influence indigenous or ethnic minority specialists decision-making or factors that influence specialist decision-making with indigenous or minority populations.

It is important that indigenous and ethnic cancer treatment inequities are addressed. Factors influencing treatment decision-making in consultations are important. However, literature which attends to these factors from the view of Māori or other indigenous peoples and ethnic/racial minority patients is scarce. Further research in this area is warranted.

Chapter 3: Methodology

Overview

This research examines how comorbidities and other factors impact on treatment decision-making in cancer consultations. A Māori Centred Research approach has been used to ensure that the research design, implementation, and interpretation are appropriate for Māori, ultimately contributing to increasing both Māori knowledge and the knowledge of those who provide cancer care services. Māori Centred Research places Māori at the core of the research and encompasses Western based research methodologies and methods. This thesis focuses on the five Māori participants and draws on case study methodology and qualitative methods to assist with design, data collection, analysis and interpretation of findings.

The methodology utilised in this study aims to enable the following research questions to be answered:

Research questions

1. What impact do comorbidities have on treatment decision-making in cancer consultations with Māori patients/whānau?
2. What other factors influence treatment decision-making in cancer consultations with Māori patients/whānau?

The research questions are concerned with the perspectives of patients/whānau and specialists. Consultations were recorded and patient/Whānau and specialists perspectives were sought. Patients/Whānau were interviewed and specialists recorded their own debrief.

This chapter begins by considering approaches to Māori research, and in particular, Kaupapa Māori Research and Māori Centred Research. These approaches identify ways of developing and contributing to the knowledge of

Māori and non-Māori with the view that it is used to enhance cancer care services for Māori. Māori Centred Research is also considered alongside case study methodology. The chapter concludes by providing a description of the qualitative methods employed in undertaking this research.

Māori research

This section aims to provide an overview of different methodologies used to undertake research with Māori and brings together the methodologies used to guide this research.

New research methodologies and frameworks have arisen in NZ in response to concern by Māori about how research is undertaken with Māori (Bishop, 1999; Smith, 1999; S. Walker, Eketone, & Gibbs, 2006). For example, Māori have questioned whose research agenda is advanced when research involving Māori is undertaken by non-Māori and what Māori control there is in this type of research. Kaupapa Māori research and Māori Centred Research are examples of research methodologies which have evolved in response to such concerns (S. Walker et al., 2006).

Māori centred research

Based on the premise that all research in contemporary NZ society has the ability to contribute to Māori knowledge, Cunningham (2000) proposes that research can be identified and grouped according to the ability of that research to contribute to Māori knowledge. Māori Centred Research is one of the groups identified by Cunningham (2000).

Taking a Māori Centred Research approach means placing Māori people at the centre of the research, being culturally mindful, and focused on generating gains for Māori development (Durie, 1996). At the same time, taking a Māori Centred Research approach requires the researcher to ensure that Māori are regarded as a diverse people. This approach acknowledges that Māori may both share things in common as well as have differences. This is referred to in contemporary society as

Matatini Māori or diverse Māori realities (Durie, 1995). Cunningham (2000) describes Māori Centred Research as, “*research where Māori are significant participants, and are typically senior members of research teams, research where Māori analysis is undertaken and which produces Māori knowledge, albeit measured against mainstream standards for research*” (p. 65).

Durie (1997) identified three primary principles to guide those planning a Māori Centred Research approach, *whakapiki tangata*, *whakatuia*, and *mana Māori* (pp. 49-50). These principles were interpreted and applied by Foster (2003) as:

- *Principle one: Whakapiki tangata* – meaning Māori are enabled, enhanced or empowered which results in research that is of benefit to Māori and that Māori are in control of (Foster, 2003).
- *Principle two: Whakatuia* – meaning integration, which involves using a ‘holistic approach that incorporates notions of relationships and inter-connectiveness’ between realms such as *taha wairua* (spiritual well-being) and *taha tinana* (physical well-being) as described in Durie’s (1997) *Te Whare Tapa Whā Māori* health framework (pg. 69).
- *Principle three: Mana Māori* – consists of notions of Māori power and control over the research in its entirety (design, participation, processes and findings) (Foster, 2003).

In addition to the guiding principles identified by Durie (1997) and Forster (2003), Cunningham (2000) attributes four key characteristics to Māori Centred Research. Firstly, Māori Centred Research is research which is controlled by ‘mainstream’ or those that are non-Māori and likely to be funded by the Crown, in contrast to *Kaupapa Māori* research which is controlled by Māori. Secondly, Māori are major participants in Māori Centred Research and likely to be involved in all facets, not solely as participants. The third characteristic involves the use of contemporary mainstream and Māori research methods. Finally, Māori Centred Research involves a Māori analysis (Cunningham, 2000).

In line with characteristics of Māori Centred Research, two common and one innovative qualitative methods were utilised to gather information for this research and generate knowledge to benefit Māori. Knowledge, which may be used to better understand why treatment differences occur between Māori and non-Māori, and ultimately result in better outcomes for **all** cancer patients (Sarfati et al., 2009; Sarfati et al., 2016; Stevens et al., 2008).

Baum (1995) argues qualitative research methods “*are well suited to studying complex public health situations*” (Baum, 1995). Discovering what factors influence treatment decision-making by participants in cancer consultations was identified as complex in the previous chapter. The use of qualitative methods in this study were particularly appropriate for two main reasons. Firstly, it aims “*to capture lived experiences of the social world and the meaning people give these experiences from their own perspectives*” Corti & Thompson (2004, p. 326). In this study this pertains to participant perspectives and meanings given to factors influencing treatment decision-making in the consultation (Corti & Thompson, 2004). Secondly, “*qualitative data can be used to explain the results of quantitative research*” (Liamputtong & Ezzy, 2005). This is particularly relevant for this study as quantitative data involving treatment disparities for instance between Māori and non-Māori was presented in chapter one, however the reasons for those disparities is not well understood.

The ‘*Best Outcomes for Māori: Te Hoe Nuku Roa*’ longitudinal household survey is one of the few publications identified which explicitly used a Māori Centred Research approach (Foster, 2003). On one level, the lack of published studies explicitly reporting a Māori Centred Research approach is surprising since there are a number of research projects in NZ undertaken that appear to ‘fit’ the Māori Centred Research description, for example work by Walker et al. (2008). This phenomenon may be due to the ‘normalising’ of Māori participation at all levels of research in ‘mainstream’ non-Māori research institutions, alongside growing numbers of Māori academics within these settings.

In addition to Māori Centred Research, an ethical framework founded on four tikanga (Māori protocols and practices) based principles, also provides valuable direction for this research (Hudson, Milne, Reynolds, Russell, & Smith, 2010). They are:

- Whakapapa (relationships) – undertaken by researchers when ‘connecting’ with research participants.
- Tika (research design) – involved the selection of Māori Centred Research and establishment of Community Māori Oversight Group.
- Manaakitanga (cultural and societal responsibilities) – attended to when gathering and disseminating data and results.
- Mana (justice and equity) – a key consideration in data analysis (Hudson et al.).

The use of Māori centred research in this study

A Māori Centred Research approach fits well with the work of this thesis for several reasons. Firstly, the setting within which patients and specialists participate in consultations to discuss treatment options is controlled by ‘mainstream’ or non-Māori. Secondly, the C3 research programme is led by the University of Otago and funded by the HRC, both controlled by non-Māori. Thirdly, Māori have participated in this research in a variety of roles including Co-Principal Investigator, as members of the research team, and as participants. Oversight and advice was provided by a small group of clinical specialists (clinical advisory group) including a Māori surgeon and a Community Māori Oversight Group consisting of Māori community, consumer, provider and cancer sector specialists. Māori participation in all facets of this research helped ensure approaches were valid for Māori.

The principles of Māori Centred Research were applied to this work in several ways. Supervision was provided by Associate Professor Louise Signal (University

of Otago) and Dr Lis Ellison-Loschmann (Massey University), one NZ European and the other Māori. At least one Māori researcher participated in interviews with each of the Māori participants. A second interviewer employed on the larger C3 Qual study assisted with arranging interviews and taking additional notes as required during the interview. In this way continuity was maintained for the data collection phase of the C3 Qual study, although as previously noted this thesis is only concerned with the response/information gathered from participants in the Māori consultations. I completed two of the Māori interviews with a second interviewer, and two alone. The analysis of Māori data was led by myself and reviewed by my supervisors and other leading team members.

Māori Centred Research principles were implemented in this study in the following ways. *Whakapiki tangata*: this principle related to the generation of knowledge not previously available for use by those planning and delivering cancer services to Māori. At an individual level Māori participants' dignity and confidentiality was strictly maintained and consent processes followed. Participation of the Community Māori Oversight Group, ongoing involvement of Māori researchers at all levels (design, data collection and analysis) and dissemination of research findings to both Māori and non-Māori organisations and communities ensured that the kaupapa (purpose for, principles) of Māori Centred Research was upheld.

Whakatuia in this research was expressed by the choice of case study methodology (discussed in detail below) drawing on multiple data sources. The consideration of several domains in the analysis is particularly suited to understanding the complexity of patients/whānau and specialists in the hospital setting. *Whakatuia* also ensured this research acknowledged that while the focus was on a single consultation where decision-making occurred at one point in time, both past, present and future factors were important and relevant to consider when researching cancer treatment decision-making.

The principle of *Mana Māori* in this research was addressed by Māori participation in the design of the research, the research team and Community Māori and Clinical Oversight Groups.

Research methods used to collect and analyse information were designed to occur in a manner cognisant of Māori culture. Methods used to gather information involved one primary research contact with participants throughout the research process. Initial research contact with patients and kanoi ki kanohi (face-to-face) interviewing was led by one lead researcher, face-to-face interviews and Māori researcher participation in interviews (at times together with a non-Māori researcher) enhanced opportunities to develop rapport, trust and respect with research participants.

The use of Māori researchers in the interviewing process was also important for a number of reasons. Firstly, a Māori researcher is more likely to be familiar with the Māori language and culture amongst the diversity of Māori living in NZ society aiding cultural competency. Secondly, there was greater potential for Māori researchers to find opportunities to share experiences with Māori participants, and the likelihood that they would feel comfortable due to having another Māori person to talk with. Training a new Māori researcher potentially increases Māori researcher capacity.

Reciprocity is an important element involved in building and nurturing relationships. A koha (an offering) was presented to participants in this research as a way of expressing gratitude and acknowledging the sharing of sensitive and personal information by vulnerable people during a stressful time with strangers (researchers). Participants' parking costs were also paid to acknowledge the additional time and costs incurred when participating in the interview.

A Māori analysis was led by a Māori researcher (thesis author) with advice and assistance from supervisors and key team members. The purpose of a Māori researcher looking at Māori data first was to ensure that data analysis was undertaken in a manner open to using an integrated approach to generate understanding consistent with a Māori world view. A Māori model of health, Te Whare Tapa Whā was drawn on to guide the analysis (Durie, 1994). This approach was informed by work undertaken in a large mainstream qualitative research

project where Māori sought to analyse Māori data (Cram, Phillips, Tipene-Matua, Parsons, & Taupo, 2004).

Case study methodology

A case study approach provided the overarching research strategy for this thesis. Case study strategy “*investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident*” (Yin, 2003) (pg. 13). In NZ and indeed internationally little is known about factors influencing cancer treatment decision-making in consultations with Māori or other indigenous and ethnic minority populations (E. L. Mead et al., 2013). Little is known about how cancer treatment decision-making may be affected by the context within which it occurs. In NZ consultations largely occur in hospitals founded on western medicine. Yin (2003) notes the explicit inclusion of context distinguishes case studies from other research designs.

Triangulation is a key feature of case study inquiry. Triangulation evolved in response to the position that no one single method could singularly solve a problem involving rival causal factors (Denzin, 1978). According to Denzin (1978), four types of triangulation can occur in research: theory, methodological, data and investigator triangulation. Additionally, case studies often employ “*in-depth data collection involving multiple sources of information*” (Creswell, 2013, p. 97). This study gathered information from three different sources, discussed later in this chapter.

Findings in a case study are developed by the researcher after triangulating data sources which are likely to have been gathered using different data collection methods (Yin, 2003). Data triangulation increases the likelihood that the reported findings will be comprehensive, wide-ranging and fully-developed (Denzin, 1978). Furthermore, Yin (2003, p. 7-8) suggests that case study research strategy is indicated when two further factors are present. Firstly, the extent of control the researcher has over the event, and secondly a focus on contemporary events in

which behaviours cannot be manipulated. In this study the researcher had no control over, nor ability to manipulate consultations.

Case study strategy in this research enabled the development of a greater understanding of what is potentially a complex phenomenon (cancer treatment decision-making involving two or more parties) within the context of where it occurs (public hospitals). Triangulation of three data sources also occurred in this study, in recognition of the fact that decision-making making is complex, and to ensure the views of the different participants were considered. This case study is both explanatory and exploratory in that it sought to understand and describe how comorbidity and other factors influence treatment decision-making in cancer consultations with Māori.

Methods

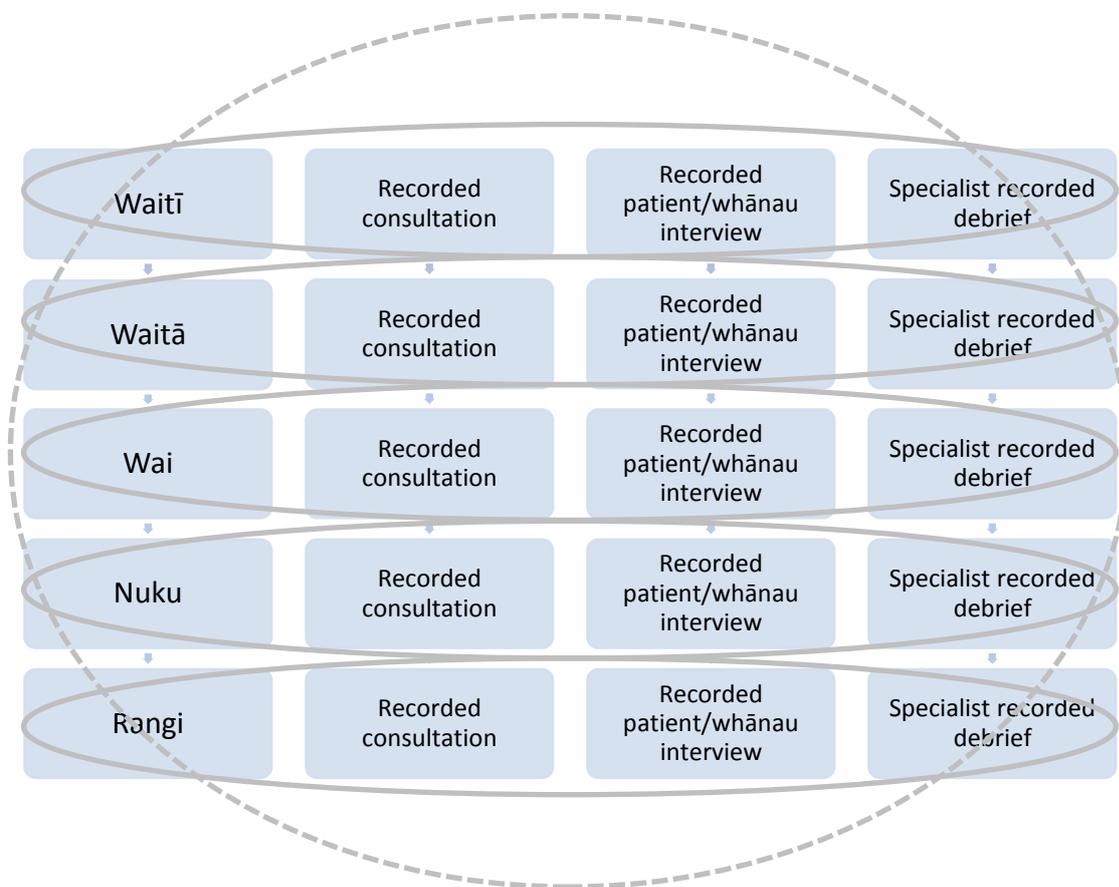
This research utilised qualitative research methods to seek ‘a deeper truth’ than is available in statistical studies alone, through ‘the systematic collection, organisation, and interpretation of textual material derived from talk or observation’ and through exploring the ‘meanings of social phenomena as experienced by individuals themselves, in their natural context (Malterud).

To capture a broad range of issues influencing decision-making, this research was undertaken with adult patients able to give consent, in different hospitals, with differing cancer types, with and without comorbidities, and who saw specialists offering one of two treatment modes (medical oncology and radiation oncology).

Differing qualitative methods of data collection that could be used to gather data about treatment decision-making in cancer consultations were considered and included: surveys, focus groups, interviews and observation. Survey options were discounted as so little was known about the topic of interest to inform the development of a meaningful survey. Focus groups were also considered, but thought to be inappropriate as participants would be in a particularly vulnerable state having recently received a cancer diagnosis, and thus may not have felt able to express themselves in a group situation. The timeframe between receiving a

diagnosis and discussing treatment options was also likely to be very short, in some cases only a few days, making the feasibility of organising a focus group that suited all patients virtually impossible. Three methods were chosen to collect data: (a) recording of consultations; (b) recording of patient interviews (post-consultation); and (c) specialist recording of self-debriefs (post-consultation) (Figure 3).

Figure 3: Structure of data sources for analysis



Note: Each case comprises three types of data. The within-case strand (grey bands) integrates the data within each case. The cross case strand (indicated by dashed outer circle) examines data from within each case as a whole.

Recruitment

Specialists

The C3Qual Research Programme Clinical Advisory Committee provided advice about how best to recruit specialists for this study. Four recruitment strategies were employed.

- Strategy one: At one hospital the Cancer Centre Clinical Heads of Department (HoDs) were briefed about the research by a Co-Primary Investigator and senior public health research doctor on the C3Qual research team. Each of the HoDs then verbally presented the research to their colleagues to ascertain interest. They also provided them with written information about the study and copies of the consent and demographic forms (Appendices A, B, C). Specialists then indicated their interest in participating in the research by either directly contacting the researchers or via their HoDs. Interested specialists met with the researchers to discuss the research in detail.
- Strategy two: At a second hospital a clinical specialist on the research team ascertained interest from colleagues in participating in this research. Several attempts to establish the research over a period of about a year at that hospital proved unsuccessful. This was primarily due to changes in support personnel for the clinical specialist at that hospital, and other specialist circumstances.
- Strategy three: In response to the failure of strategy two, strategy three was developed utilising networks amongst the wider C3Qual research team. At a third cancer centre hospital the Head of the Oncology Service called a joint meeting with interested team members and the research team. Researchers from C3Qual attended the meeting where a brief was provided about the study and specialists indicated their interest (or not) at the end of the meeting.

- Strategy four: A specialist recruited from strategy three who held outreach clinics in another city discussed the research with a colleague there and recruited that specialist to the study. A Co-PI from the C3Qual study then contacted the specialist to provide more information about the study.

All specialists were provided with an information sheet, consent and demographic forms which were developed in consultation with clinicians on the research team, led by the thesis author (Appendices A, B, C).

As a result of these recruitment strategies, 12 specialists from three hospitals agreed to participate in the C3 Qual research. Three of whom participated in the consultations with the five cases included in this study. Two of the three hospitals where the five consultations occurred provide a full range of cancer services (blood cancers, medical oncology, radiation oncology and clinical haematology), while one has a limited range of services (i.e. no radiation oncology services). Of the three specialists who participated in this study, one specialised in radiation oncology and two in medical oncology. All provided outpatient clinics at other hospitals in their region. Two specialists were female and one male, all three were of different ethnic groups and two trained abroad. None were Māori.

Individual tailoring of research processes for each specialist, cognisant of different treatment pathways and organisational processes at each hospital, was undertaken. Tailoring was also necessary as specialists had differing communication preferences and support available to them within their hospital. For example, one specialist preferred to communicate directly with the researcher during the data collection phase while another did so via other hospital personnel (research administrator and nurse).

The specialists were responsible for key research activities including: identifying patients eligible for the study from new patient clinic lists, recording consultations, and recording the specialist debrief as soon as possible after each consultation. Behind the scenes, invaluable support was provided by members of the department and hospital research services. They assisted with patient recruitment

and supported the specialists and researchers to successfully undertake the research.

On the advice of specialists who agreed to participate in this study, a strategy was developed to enable an appropriate response should any participants become upset during the interview process. This involved gathering resources from the Cancer Society and ascertaining contact details for community oncology support services.

Patients

As previously mentioned the role of specialists participating in this study included identifying patients eligible to partake. The following inclusion criteria were used by participating specialists to identify patients eligible for the research:

- patients who were 18 years of age or older
- of Māori ethnicity
- had recently been diagnosed with cancer and were going to discuss treatment options at their next consultation (except in the case of lung cancer where they may have had a provisional diagnosis).

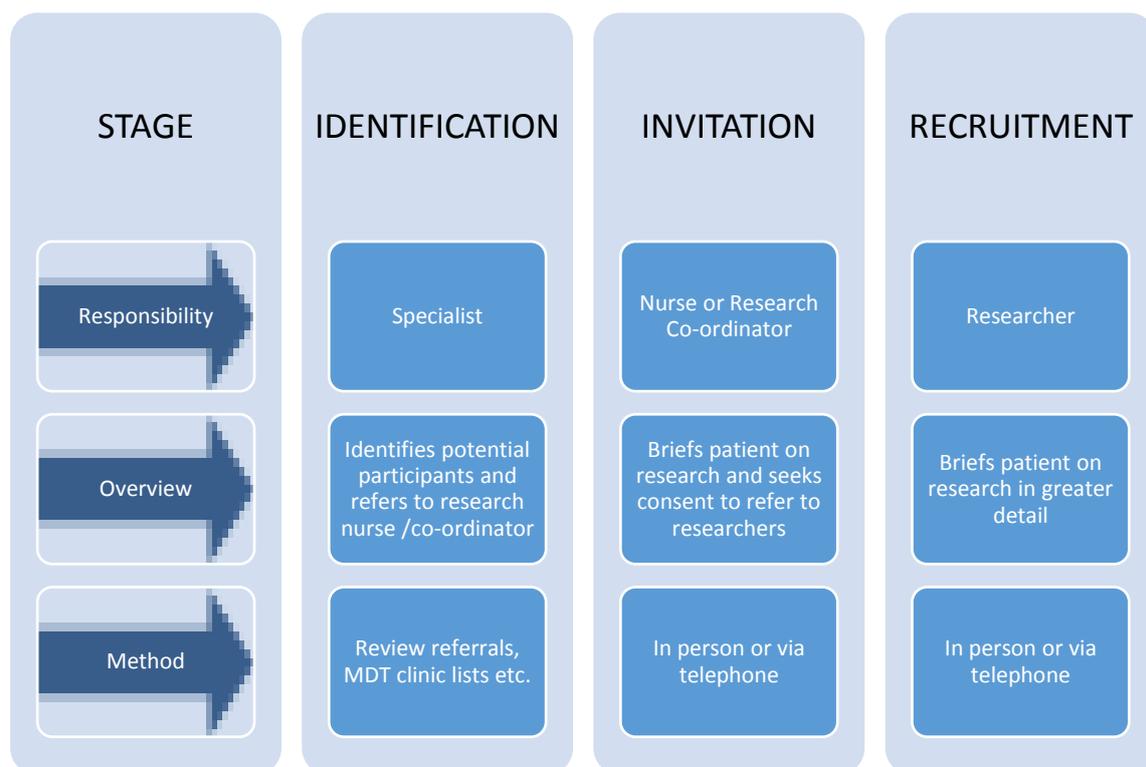
Participating specialists also used their discretion to determine if patients were sufficiently well to participate in the study.

In preparation for patient contact a researcher's recruitment script was prepared to guide telephone contact with patients and ensure consistency in the information shared with each participant (Appendix D).

Once a patient had been identified as eligible for the study by the specialist, s/he informed the nurse or hospital co-ordinator. The patient was then contacted directly to ascertain their interest in participating in the study. A referral was then made to the researchers for those patients who gave verbal consent for their contact details to be shared (Appendix E). A record was kept of all referrals received. Time available from receipt of a referral to contact and recruitment of

patients was limited. Often there were four days (including two weekend days). Within this timeframe the necessary research activities were undertaken including: a) inform the potential research participant about the study before their scheduled consultation and b) organise logistical issues associated with the research process. See figure 4 for an overview of the patient identification, invitation and recruitment process, responsibilities and methods.

Figure 4: Patient identification, invitation and recruitment responsibilities, overview and method by stage.



On receipt of referrals, the researchers contacted each patient by phone, provided further information about the research (guided by the script) and answered questions and concerns. Attempts to contact patients were made the same day a referral was received to ensure patients had as much time as possible to consider the information and seek advice to enable informed consent. A record was kept of attempts made to contact patients. All five participants were happy to be contacted by phone.

When a patient indicated interest to the researchers in participating in the study their verbal consent was initially sought. Further details about processes and logistics were then discussed in relation to that particular patient, e.g. meeting researchers, appointment time, parking etc. The specialist and referrer were informed by the researcher when a patient had agreed to participate in the study so they could prepare for and undertake their roles and responsibilities in the research process.

Patients were asked by the researchers if they were likely to have whānau with them on the day of their appointment. If they had invited whānau, they were asked if they would like them present during their interview post-consultation. The patient was asked to inform their whānau of their intent to participate in the research and what would occur prior to the consultation, e.g. recording the consultation and interview. Patients were also informed that the researcher was available to discuss the research with whānau if requested. Written information sheets were then sent to the patient, using one of three methods (email, post or courier) with email and post being the most often preferred. Sending out information provided participants with an opportunity to review and consider their participation in the study and discuss this with others if they so desired. Additional copies of the information were included for whānau/support people when appropriate.

On the day of the patient's appointment, prior to their consultation, the lead researcher met and welcomed the patient/whānau, re-affirmed they were willing to participate in the study, answered any questions and obtained their written consent for participation in the study. Post-consultation, before the interview commenced, patients were asked to provide demographic information and formally indicate if they wanted a copy (audio-recording and/or typed transcript) of their interview. Whakawhānaungatanga (to establish relationships) and rapport building activities occurred during activities as indicated by patient cues.

Patient and whānau characteristics

In total, 23 people were referred to the C3 Qual study. Of those, 18 patients agreed to participate, three did not. For one non-participant, reasons related to their illness, for another work (one Māori participant). For a third participant, family commitments prevented their participation. One participant was not interviewed as the researchers were uncertain if they [the researchers] had been exposed to an infectious disease and did not want to risk the well-being of the patient. One person referred did not meet the research criteria. Of the 18 participants, 13 identified as NZ Europeans and five as NZ Māori. The five NZ Māori participants are the focus of this research.

Of the five Māori participants, three were female and two were male. Ages ranged from 32 to 74 years. Participants experienced a range of cancers including lung (unconfirmed), stomach, prostate, and breast. Four participants also live with at least one other disease or health condition in addition to the cancer they were attending the consultation to discuss. One participant, the youngest, did not have any other health concerns. Participant health conditions and comorbidities included: pre-diabetes (suspected), anaemia, cardiovascular disease, gout, chronic obstructive pulmonary disease and arthritis. Participants attended different types of consultations, two were seen in medical oncology and three in radiation oncology. Four participants were supported by whānau to their consultation and the fifth was supported by a Māori nurse from their primary health care service. All consultations occurred in hospitals in the North Island, four in cancer centres and one in a regional hospital.

Four whānau were informed about the study by the patient. Participating whānau consisted of a partner, sisters, a daughter and a grand-daughter and in one instance, a nurse from Māori Health Provider (MHP). The MHP nurse and two of four whānau stayed for the interview, two chose not to.

Instruments and data collection

Consultations

Recording (using a small digital voice recorder) consultations where treatment decision-making was to occur was selected as one of the methods to gather data. This method enabled the consultation to proceed as 'normal', within its usual environmental context, a hospital consultation room, and with minimal interruption and influence as a result of the research process. Specialists were provided with the digital audio recorder prior to the consultation and were responsible for undertaking the recording. Recorders were kept in a secure place by specialists when not in use. The researcher was not present in consultations.

Recording consultations may have meant people (specialist and patient/whānau) did not behave as usual. However, evidence suggests that both the patient and doctor quickly forget the consultation is being recorded, particularly when the situation in which it occurs remains 'routine' (K. Dew, personal communication, 2014). This enables discussion to occur in a reasonably similar way to that which would have been the case in a 'normal' consultation situation. A number of participants reported this was the case in this study.

Interviews

Patients/whānau were interviewed as soon as possible after their consultation occurred. Interviewing is *"...valuable for exploring research topics when there is little known about them or the issues are complex"* (Liamputtong, 2013). Interviewing allowed the examination of participants' perceptions and shared power and control of the research process with the participants who were potentially vulnerable. Interviewing participants soon after the consultation also increased the likelihood that information would be 'fresh' in participants' minds. The timing of interviews was also considered to ensure participation in the research was as convenient for participants as possible. As the interview was recorded using a digital audio recorder, the interviewer could focus on the participants and questions, rather than taking notes. Brief notes were taken by a second researcher when present.

Based on literature and expert advice a semi-structured questionnaire was developed in consultation with C3 Qual team members and piloted. Questions were designed to explore themes related to the research questions, gather rich data and expand on ideas raised during the interview by the patient/whānau (Appendix f). Broad theme areas explored included communication, whānau participation and treatment (decision-making and status). Semi-structured questions were used which enabled the researcher to tailor questions to participants and their context as well as providing an opportunity to develop rapport with patients/whānau. For example, while the questions were ordered, how they were asked by the researcher did not always occur in a linear fashion, as participant talk sometimes pre-empted topics contained further down the interview schedule or returned to a topic discussed earlier.

The patient/whānau interview questions (Appendix F), patient information form (Appendix G), consent (Appendix H), and demographic forms (Appendix I) developed for this study were first drafted by a few members of the C3 Qual research team (led by thesis author). They were then circulated to the wider research team for review and finalised.

Conscious that researcher related factors may also influence the process when undertaking semi-structured interviews (Dew, 2007), researchers undertook interview training to ensure consistency across interviews and maintain patient safety. Additionally interviews were undertaken jointly with an experienced interviewer until all individuals were deemed competent by the principal investigator (primary supervisor) to interview alone. Research interviewers debriefed post-patient/whānau interviews with each other (when two were present), and with the principal investigator (primary supervisor).

Patient/whānau interviews took place in a variety of hospital and University settings. A change in venue, from the room in which the consultation was undertaken, provided an opportunity for patients/whānau to take a mini-break and partake in refreshments prior to commencing their interview for the study. The change of space also provided further opportunity for the researcher to

whakawhānaungatanga, continue building rapport, and check patient well-being and willingness to proceed with an interview.

Specialists' debriefs

Specialists' debriefs capture their valuable perception as a participant in the consultation and as a cancer care and treatment provider. Recognising that cancer specialists often work in a highly stressful area with large workloads, it was important to make participation in the research easy, with minimal impact on daily practice. Specialists were asked to record themselves answering 12 key questions (open and closed) from a prompt sheet using a digital audio recorder (Appendix J). This approach kept the requirements of specialists suitably brief and also meant they could undertake the self-debrief at a time and in a venue convenient to them.

The specialist debrief interview questions were drafted by members of the research team (co-led by thesis author), and were based on the research questions and a review of the literature undertaken for this thesis. They were then circulated to the wider research team for consideration and modifications were made based on the feedback received. Questions asked specialists to consider factors such as: what they had told the patient, overall views of the consultation, the impact of comorbidity on decisions discussed, and personal characteristics of the patient that impacted on the consultation.

Field notes

Field notes were made pre and post-consultation and post-interview, capturing the thoughts and observations of the researcher about the participants and processes (Patton, 2002). According to Patton (2002) field notes *“enable the capture of information from formal, informal and unplanned interactions that might assist deepen observations”* (p. 286).

Recording and transcribing the data

Data was gathered using digital audio recordings. Recordings made by specialists (consultation and debrief) were collected along with the interview recording (held by the researchers) then downloaded from the recording device onto a secure and

virus protected computer that was regularly backed up. These files were labelled and the initial few minutes of each recording were checked to ensure that each of the three files belonged to the correct patient and had been labelled accordingly. Audio-files were transcribed verbatim by an expert medical transcriptionist. Participants were allocated unique codes to maintain anonymity. The recording device was kept in a locked cabinet when not in use. On receipt of the typed transcription file (password protected), original audio files were then deleted from the recording device.

Hard copies of transcribed files were printed and checked for accuracy by one of the interviewers against the audio files. Hard copies of the transcripts were also kept in a locked filing cabinet. Audio-files and typed transcript files held by the transcriber were destroyed once advised that the researcher had received them. Finally, electronic copies of the transcript files were up-loaded to Dedoose a qualitative software management system (SocioCultural Research Consultants, 2015).

Data analysis

A case strategy of inquiry includes a detailed description of the setting or individuals along-side generic analysis (Stake, 1995). Thematic analysis involves the process of encoding qualitative data (Boyatzis, 1998). Three types of case analysis strategies were utilised in this study. Firstly, individual case descriptions which looked to identify themes from codes within cases. Secondly, themes across cases were identified. Thirdly, consideration was given to codes of interest which did not recur (salient analysis) yet seemed important to decision-making).

Data were coded for the established variable of interest, comorbidity and other factors in an open and inductive manner, which appeared to influence treatment decision-making by listening to the audio-recordings and reading through of text. Texts were re-read several times. An inductive approach was taken when coding based on the content of the data. Codes were examined for themes. Dedoose, a software programme was used to assist with data organization and analysis.

According to Yin (2003, p. 116) for case study analysis, pattern matching is “*one of the most desirable techniques*” and appropriate for a descriptive case study when specific variables have been established prior to data collection. In this research, pattern matching focused on one variable, comorbidity, and themes that emerged within and across the cases. A cross-case synthesis is a common analytic technique employed when there are multiple cases and it potentially strengthens findings (Yin, 2003). Initial conclusions were then drawn within and across cases.

Themes which emerged from the data were discussed with supervisors on the research team. Given more themes emerged than able to be considered for a Masters thesis, selected themes were chosen to focus on. The themes selected occurred frequently within and across most cases. Comorbidity and selected themes were then analysed further giving consideration to a Māori world view informed by Durie’s Te Whare Tapa Whā model.

Saliency analysis is associated with thematic analysis where codes that do not recur yet may be important to the study are identified (Buetow, 2010). In this research, saliency analysis was employed when a finding of interest appeared important to a participant (patient/whānau, specialist), or the researcher, but did not emerge from pattern matching or thematic analysis.

Final results were reviewed by supervisors and other key team members.

Ethics

Ethics approval for the C3 Qual study was initially applied for from the Multi-Region Ethics Committee, as the research was to be undertaken in two localities situated in two different hospitals in NZ. The standard ethics application appeared to have been tailored for ‘intervention’ or ‘trial’ type research involving medical devices and drugs with the potential for patients to receive differing treatment as a result. It did not lend itself well to qualitative research designed to occur in a hospital setting such as this research.

The application was heard by the Central Region Ethics Committee, delegated from the Multi-Region Ethics Committee at a time when the national ethics process in NZ was undergoing a period of change. Two researchers (Co-PI/supervisor and thesis author) attended the session where the application was considered and provided clarifications as needed.

The major issue of concern raised by the ethics committee pertained to the role of the treating specialists. Their role in the study was further clarified to confirm that the specialist who was potentially providing treatment to the potential participant was not the one who would inform, invite or recruit patients into the study. Other minor amendments were also made. The Central Region Ethics Committee approved this study CEN/12/06/026 (Appendix K).

Locality approval was also sought as a requirement of ethics and to ensure the research was appropriately organised. Localities are the areas where the research would be undertaken. Locality assessment approval was provided by the participating hospitals and endorsed by their respective Māori advisory groups.

Additionally, consultation and approval was sought from the University of Otago Ngāi Tahu Research Consultation Committee (Appendix L). This committee is appointed by Ngāi Tahu and was established under a Memorandum of Understanding between Te Runanga O Ngāi Tahu and the University of Otago (the University). The University, in honouring its commitment to Te Tiriti o Waitangi and in recognition of a special relationship with Ngāi Tahu (tangata whenua of the South Island), requires all research undertaken by the University, which may be of interest to Māori, to have appropriate consultation take place with Māori in the development phase of the study.

Summary

In summary, this research has drawn on and been guided by a Māori Centred Research approach. This involved a case study approach and qualitative methods. Participants recruited to participate in this study included patients/whānau and specialists from three NZ hospitals. Data was recorded and coded from three key

points, the consultation, patient/whānau interviews and specialist debriefs. Themes emerged by triangulating codes from the three data sources. Themes occurred both within and across cases and a detailed description established for each.

Chapter 4: Results

Introduction

This chapter presents the study results, bringing together cancer treatment decision-making information from the four data sources used in the research. The first data source was transcripts of consultations where cancer treatment decisions were discussed between Māori cancer patients, whānau and specialists. The second was the specialists who recorded their answers to a set of questions post-consultation, referred to as the doctor debrief (DD). The third source of data was gathered from semi-structured interviews (IV) with Māori patients and whānau post-consultation. The researcher field notes are the fourth data source used in this study, which were gathered pre and post the consultation and interview.

The results are presented as a narrative of each of the five individual case studies. Each case study is presented in three parts. Part one provides an overview of the case, part two presents themes which appear to influence the patients and specialist's decision-making and part three presents communication and decision-making findings in the consultation, and concludes with an overall summary.

There are three types of participants in this study, patients, whānau and specialists. To assist with clarity of who is being referred to in this chapter they have been grouped as follows:

Each patient participant is referred to as whetū (star). They have been assigned pseudonyms (inspired by Matariki, a star constellation signalling a Māori New Year) to protect their identity when being referred to directly or when being quoted. The case names are: Waitī, Waitā, Waipuna-ā-Rangi, Tupu-ā-Nuku and Tupu-ā-Rangi.

Whānau participants present in the consultation and interview are referred to as either whānau or by the relationship position they hold relative to the whetū.

Specialist is a term used to group medical doctors. Radiation oncologists are medical specialists trained to treat cancer patients with radiation therapy. Radiation therapy is one treatment option able to be used in the care and management of some cancers. Medical oncologists are medical specialists trained to treat cancer patients using medicines or drugs. Other cancer treatment options include surgical oncology, haematology and palliative care. In each of the five cases the specialist's area of expertise is noted. To protect the identity of specialists participating in this study they are referred to as MS1, MS2, MS3, or specialist.

Where relevant in the text, the particular source of data will also be identified. For example, consultation (Con), Dr Debrief (DD) and interview (IV). Each quote will also identify which participant the quote belongs to if it is not previously indicated in the relevant paragraph. If the quote is from a specialist then the patient they are referring to will also be added, for example "the patient chose radiation" (MS1, Wai, DD), referring to Specialist 1, Waipuna-ā-Rangi (Wai) as the patient, and the data source being a doctor debrief.

All consultations were undertaken in a hospital setting, three in regional blood and cancer centres and one in a regional hospital. Interviews were undertaken in a hospital whānau care room or in another private space. Details about participants and length of consultations and interview are listed in Table 1.

Table 1: Summary of participants in the consultation and interviews and recordings lengths

Case	Participants in consultation	Type and length of consultation	Participants in interview	Length of interview
Waitī	Waitī, the Māori health provider nurse (MHP nurse) and specialist (MS1)	Radiation oncology. 30 minutes	Waitī, the MHP nurse, and two interviewers (thesis author and one NZE interviewer)	20 minutes
Waitā	Waitā, his granddaughter and the specialist (MS1)	Radiation oncology. 34 minutes	Waitā, his granddaughter and one interviewer (thesis author)	35 minutes
Waipuna-ā-Rangi (Wai)	Waipuna-ā-Rangi (Wai), two sisters (S1 and S2) and the specialist (MS2)	Medical oncology. 1 hour and 3 minutes	Wai, her two sisters and two interviewers (1 NZM and 1 NZE)	43 minutes
Tupu-ā-Nuku (Nuku)	Tupu-ā-Nuku (Nuku), her partner (P1), the specialist (MS3) and a cancer nurse specialist	Medical oncology. 1 hour and 11 minutes	Nuku and one interviewer (thesis author)	56 minutes
Tupu-ā-Rangi (Rangi)	Tupu-ā-Rangi (Rangi), his sister and the specialist (MS1)	Radiation oncology. 28 minutes	Rangi and one interviewer (thesis author)	29 minutes

Note: Data for the five cases included in this thesis was collected during the period August 2013 to April 2014.

Narrative case summary one: Waitī

Overview

Waitī is a woman, mother and daughter. She is 62 years of age and lives with and cares for, with assistance, her 90 year old unwell mother. Waitī was early for her consultation and was assisted by a Māori Health Provider (MHP) nurse who drove her to the appointment and pushed her wheelchair. Her daughters were unable to attend the consultation, as one lives in Australia and one was working.

Waitī has severe Chronic Obstructive Pulmonary Disease (COPD) and is under the care of a respiratory physician. She reported that she has lost about 70 percent of her lung function and had quit smoking about a year ago. Other than a 'normal' cough and chest infections which she associated with her COPD, she did not appear to have any symptoms. Waitī had recently been advised by her respiratory physician that recent test results suggest she likely has lung cancer, and he referred her to see a radiation oncologist. The severity of her COPD however, means a definitive cancer diagnosis cannot be made.

The specialist is a radiation oncologist. He is a male and has been practicing medicine in NZ for the past 16 years.

Themes influencing Waitī's treatment decision-making

This section begins by presenting how whānau, the specialist, patient and medical factors appeared to influence Waitī's treatment decision-making. It ends by describing how the specialist's treatment decision-making appeared to have been affected by medical, specialist and healthcare system factors.

Whānau

In Waitī's case, whānau appear to influence her decision-making in two ways. Firstly, and possibly most importantly, she identified in both the consultation and interview that her two daughters would be involved and that she would not make a decision until she had talked with them. Waitī is awaiting the return of one daughter from Australia. On her return they would discuss her situation before returning to see the specialist with her answer. Waitī also appeared to have been influenced by her daughters' expectations that she have treatment. She reported that one daughter had offered to go on the alternative treatment journey with her, a journey she started pre-consultation and the other wanted to know why she was "*not doing anything*", seemingly referring to treatment.

Secondly, Waitī appears to have considered her mother in her decision-making. Particularly as it could compromise her ongoing ability to undertake her carer role if she accepted treatment. Although Waitī rejected this idea in her interview, it was apparent in her answer that she had previously given thought to the future care options for her mother, stating "*I won't put my mother in a rest home*".

Specialist

The specialist appeared to influence Waitī's decision-making by determining who would be responsible. Firstly, he did not make a clear treatment recommendation, which appeared to be due to uncertainty associated with her diagnosis, prognosis and impact the treatment may have on her quality of life. Secondly, when expressing his uncertainty he clearly indicated his view that decision-making was Waitī's, "*I guess that's why you're here, because we just don't know*".

Patient

Waitī's hinengaro (mental well-being) appeared to influence her decision-making. Going into the consultation it was apparent that living with a severe comorbidity had taken an emotional toll. At times, Waitī appeared sad and expressed hopelessness when talking about her quality of life with the specialist. For example, she described how she had "*Absolutely nil. Absolutely none*", referring to her quality of life. She also went on to describe how although she tried to do as much housework and moving about as possible she was often unable to complete tasks: "*I try and do as much as I can [housework, moving around], but then I've just got to give up.*" Further on she expressed the thought that there was "...nothing good going for me at the moment".

Having an uncertain diagnosis in itself was a cause of distress. Several times throughout the consultation Waitī made comments indicating her distress at her situation stating:

"I'm asking for a miracle"

"A lot of different things going through my mind"

"Oh God, I don't know"

(Waiti, Con)

Given her circumstances, it was unsurprising then that Waitī described her mind as "*going in a whirl*".

Medical: comorbidity, disease and treatment

As stated earlier, Waitī has a severe comorbidity, COPD. This appeared to be a significant aspect which influenced many factors including her decision-making. COPD in her case reduced both her diagnostic and treatment options, surgery was ruled out for instance. In the consultation, the specialist explained to Waitī that he and 'others' were unsure if she had cancer, advising her it was "*important for you to know*" about the uncertainty as they

were “not a hundred per cent. Eighty... depending on who you talk to... ninety percent sure”. Furthermore, the specialist described the impact he thought the treatment might have on her existing poor lung capacity as: “It might go from thirty per cent to twenty-seven per cent.”

While side-effects, such as increased tiredness were of concern for Waitī, there was a consensus between her and the MHP nurse that the treatment side-effects affecting her lung were of greatest concern, as noted here by Waitī and the MHP nurse:

“Which would leave me what percentage... say I've got thirty per cent.... How much more am I going to lose?...That's why I ask the question. If they take away even two per cent...It's huge. (Waitī, Con)

Will that mean that Waitī ..., if you take away that two to three per cent, would she be confined to like basically resting most of the day...” (MHP nurse, Waitī, Con)

Concerns about the side-effects of treatment, particularly further reductions in lung capacity were reiterated by Waitī and the MHP nurse throughout the interview.

Prognostic information and treatment effectiveness also appeared to be important to the MHP nurse which was evident in questions she raised with the specialist. The specialist indicated in the consultation the prognosis for people with a lung cancer diagnosis is usually poor: “So most people, even with these smaller cancers, they say ninety per cent don't last three years. If this is a cancer.... And if we leave it without any treatment, most people are gone within three years”.

How Waitī could be supported to live with further shortness of breath resulting from the proposed treatment appeared to be an important factor raised by the MHP nurse and echoed by Waitī in the consultation. The question of how oxygen therapy might help to relieve Waitī's shortness of breath post-radiation treatment was raised with the specialist by the MHP nurse. Although the specialist indicated oxygen would help relieve

symptoms he was unable to provide any detailed information about how that might work on a daily basis. Instead the specialist suggested Waitī and the MHP nurse “talk to Dr P [her respiratory specialist] about that”.

While a large proportion of the consultation was focused on radiation therapy, the use of alternative treatments was raised by Waitī and talked about again in her interview. Waitī attended the consultation while already using an alternative treatment regimen, which she linked to being Māori. This was illustrated when she informed the specialist: “don't know if you know much about the Māori ethnicity ofwe try other things. Alternatives as well”. The specialist's response to alternative therapy was generally positive however he reiterated his belief in radiation treatment; the specialist stating: “You're welcome to try them, of course. But I feel confident that it [radiation treatment] will work”.

Speaking in detail about alternative treatment appeared to lighten her mood, and injected humour into the consultation. A possible reason for this could be a move to talk about something seemingly positive or less gloomy than the negative side-effects of radiation treatment. Waitī described what she was taking to the specialist as:

Waitī: *“...apricot kernels, seeds.*

MS1: *Raw? ((chuckles))*

MHP nurse: *Kind of.*

Waitī: *Not pleasant, I can tell you.*

MS1: *((laughs))*

Waitī: *...and vitamins and all that sort of thing,...
try and keep it... on an even keel. But you're
allowed a smoothie. So ((laughs))*

MHP nurse: *((laughs))*

MS1: *((laughs)) Alright.*

Waitī: *And the thrill of the day: have a smoothie.
((laughs))*

MS1: *((laughs)) Alright.”*

(Waitī, Con)

Themes influencing the specialist's treatment decision-making

Medical: comorbidity, disease and treatment

Waiti's age, fitness for treatment, COPD, disease and treatment factors all appeared to influence the specialist's decision-making. He assessed Waiti's fitness and ability to participate in radiation treatment during the consultation by assessing her ability to walk (unaided) for a distance of about 20 metres. In determining if Waiti was 'fit for treatment' the specialist also sought information from Waiti about the impact COPD has on her activities of daily living including mobility asking if she could "*get up a flight of stairs, or not*" for instance. Although Waiti's COPD was severe, negatively affected her (and meant she was unable to walk up a flight of stairs), the 'cut-off point' identified by the specialist, the offer of radiation treatment was not withdrawn nor did it appear to be altered.

The severity of Waiti's COPD had resulted in surgery being ruled out as a possible treatment mode prior to this consultation. Additionally, the specialist was also concerned about the speed at which lung cancer can progress. This appeared to underpin his preference for early treatment, as he explained to Waiti, "*If it is a cancer, some cancers grow slowly, but lung cancer generally doesn't. Tends to grow relatively quickly, and spread to other places. So it's always easier to treat early if we can*".

Specialist

Not unexpectedly, the specialist appears to have drawn on his experience of treating other cancer patients in determining the likely effectiveness of the proposed treatment for Waiti. After questioning from the MHP nurse about the chances of eradicating Waiti's lung cancer the specialist explained, that "*based on what we've done here before, [there is] about seventy per cent chance*

of getting rid of that [cancer]". There was no mention at that time of the specialist considering treatment guidelines in Waitī's case.

Healthcare system

Health system mechanisms and processes appear to have influenced the specialist's treatment decision-making in Waitī's case. There was mention of the specialist talking with Waitī's respiratory specialist beforehand which introduced the possibility that either one or both together could have made the decision about which treatments would be offered to her. It is also possible that her case may have been presented at a multidisciplinary team meeting where such decisions are increasingly being made.

Communication

This section begins by presenting an overview of communication related factors that occurred with the potential to influence treatment decision-making in the consultation. Treatment decision-making options, processes and status are also reported. The section closes by summarising factors appearing to influence treatment decision-making in the consultation.

The specialist gave Waitī information about the proposed treatment, disease status and prognosis which reflect elements of supportive practice that seeks to empower and enhance patient autonomy. The specialist used different methods to communicate information (e.g. visual and verbal) and used little medical jargon. Lay language was used to convey information at times but not others. For example, when the specialist showed an x-ray in the consultation he explained, *"so the black stuff's the lungs. And I'm just going to change the view. (It's very light).... you've got severe damage in your lungs".* Other information such as lung function and risk of treatment side-effects and prognosis were conveyed using percentages. This approach appeared to be effective as neither Waitī nor the MHP nurse reported having problems understanding the specialist in their interview.

The specialists 'style' was also evident at different times throughout the consultation and may have influenced decision-making. In her interview, Waitī reported that the specialist was *"Very straight up....you can't mistake what he's telling you"* which may indicate his 'style' was clear and straightforward for her to understand. Rapport was evidenced by the sharing of information, discussion, and laughter several times towards the end of the consultation. The specialist's manner was also evident in his complementary response towards Waitī's efforts to give up smoking. After the consultation, both the specialist and Waitī reported positive perceptions of each other:

"He's a very nice man, and very open. Straight up. Love it....very informative." (Waitī, IV)

"...calm and collected and a very thoughtful type of person." (MS1, Waitī, DD)

Finally, the presence of a third party, the MHP nurse, also influenced the communication dynamic. The MHP nurse potentially influenced decision-making by asking pertinent questions and providing information about Waitī's well-being. She also contributed to discussions in a positive and helpful way. For example, she asked about options such as oxygen therapy post-treatment to improve symptoms like shortness of breath so Waitī's quality of life could be enhanced.

Decision-making

Four treatment options were discussed in Waitī's consultation. The options of declining treatment and complementary and alternative treatment were raised by Waitī, and radical and palliative radiotherapy were raised by the specialist. Considering the risks of adverse impacts and side-effects of the proposed radiotherapy treatment from a starting point of 30% lung capacity appeared to be a major factor influencing treatment decision-making by both Waitī and the specialist. Although the specialist expressed confidence in the treatment, he was unwilling to make a treatment recommendation and

clearly placed responsibility for decision-making with Waitī stating *“we felt that you needed to hear this, to think about it yourself, and just be happy in your decision”*.

Perhaps trying to ascertain all her options, Waitī enquired about the consequences of declining treatment. The specialist acknowledged this options and assured her she would continue to be monitored and as the disease progressed palliative treatment could be considered to manage symptoms in the future if she wished.

In the closing phase of the consultation Waitī shared with the specialist her view that she would continue with the alternative treatment she was taking as it was not *“going to do any harm to try, anyway”*. She also informed him she would talk with her daughters and complete a course of the alternative treatment prior to returning for her follow-up appointment in a month’s time when they could *“see where we are”*.

If Waitī were to make the decision to treat, the specialist indicated she would be required to undergo a ‘PET’ scan to assess whether the cancer had spread to other parts of the body. The results of the scan could further alter the treatment options made available to Waitī.

Summary

In Waitī’s consultation several factors emerged which appeared to influence her decision-making. Her whānau (daughters) and being in the position of having no clear treatment pathway due to the severity of her COPD, seemed the most important of these. Additionally, the impact of the proposed treatment on her quality of life, if she chose that option, was of concern to both her and the MHP nurse.

It was not completely clear which factors were most prominent to the specialist and his decision-making in Waitī’s case, except that radiation treatment appeared to be the only option offered. Additionally, it was noted

there was an apparent lack of a clear treatment protocol for the specialist to draw on to determine the best course of treatment for Waiti.

Information was shared and communication between all participants appeared to occur in a positive manner. The MHP nurse provided valuable information for the specialist, and advocacy and support for Waiti.

Treatment decision-making also appeared to be, in part influenced by activities which occurred prior to the consultation, surgical treatment for instance was ruled out. In the consultation, two treatment options were raised by the specialist, radiation treatment and palliative radiation treatment at a later stage. Waiti raised alternative treatments and the option of 'doing nothing'. The specialist appeared to put decision-making into Waiti's hands, evidenced by the provision of options and expert knowledge but no actual treatment recommendation. Waiti's decision was to delay treatment decision-making for one month, during which time she would continue taking the alternative medicine and talk over her situation and options with her daughters. Should Waiti accept treatment further medical tests are required and will further influence what treatment options would be indicated.

Narrative case summary two: Waitā

Overview

Waitā is a father, husband and grandfather. He is 74 years of age and lives with his wife who was unable to attend the consultation and interview due to work commitments. Waitā's granddaughter (adult age) provided transport and supported him in his consultation and interview. He walked slowly with a slight shuffle, head still and in a curved downward position. Waitā worked with heavy machinery up until two years ago when a significant cardiovascular event resulted in his retirement. At that time he also ceased smoking and drinking. As a result of multiple and serious health issues, Waitā has had numerous interactions with health providers. He has also become eligible for assistance from the 'system' which despite being uncertain about, he has had some success in navigating.

Waitā lives with a number of health issues including a heart condition, severe gout, pre-diabetes, arthritis (under the care of a physiotherapist) and has previously had a heart attack and strokes. Furthermore, he has a cardiac defibrillator in place. Waitā also talked about having a range of other health related issues including: memory decline, hearing loss, tiredness, and appeared to have some shortness of breath. He takes a number of different medications for his conditions and reports taking "*a lot of pain killers*" and having an inhaler. Waitā indicated his belief that aspirin, which he was on, had "*eaten the lining*" of his stomach and more recently he had been taken off warfarin (a blood thinning drug often prescribed for those with cardiovascular disease).

Waitā reported he was initially treated with antacids by his GP for stomach pains thought to be indigestion. The pain became acute resulting in a collapse at home, ambulance assistance and a week-long stay in hospital. He also had bleeding from the bowel. Waitā recently attended a consultation, supported by his wife and sons, where he was informed he had stomach cancer.

The specialist in this consultation was the same as for the previous case.

Themes influencing Waitā's treatment decision-making

This section begins by presenting how whānau, the specialist, patient, medical factors and healthcare system factors appeared to influence Waitā's treatment decision-making. It ends by describing how the specialist's treatment decision-making appeared to have been affected by Waitā, medical and healthcare system factors.

Whānau

In Waitā's case it appears his whānau were a motivating factor to have treatment. Waitā expressed concern about his cancer and the risks for his whānau, and was particularly concerned for his mokopuna (grandchildren) and worried that the cancer might be "*catching*". Waitā's granddaughter also appeared particularly important to him describing her as his 'caregiver' and as someone who 'knew all about him'. It appeared important to him that his granddaughter was able to maintain his privacy, however how involved she has been or will be in his treatment decision-making was not obvious in the consultation or interview.

Specialist

The specialist's ability to provide treatment safely appeared to be of concern to Waitā. For example, he appeared apprehensive about the specialist's uncertainty regarding where to aim the radiation treatment and asked him to confirm that "*in other words, when you give me radiation, you're only guessing where it is*". He later reiterated his concern about the specialist 'guessing' where his cancer was in his interview although he also appeared to understand that delivering the treatment might be, as the specialist said, "*a tricky thing*". The specialist wishing "*it was more straight forward*" and suggesting that he and his colleagues were "*good at guessing*" did not appear to alleviate Waitā's concerns.

Patient

A range of emotions were expressed by Waitā in his consultation and interview, however it was difficult to determine what impact they had on his decision-

making. These included disappointment at being refused surgery, confusion and apprehension. Additionally the specialist noted in his debrief that Waitā seemed overwhelmed. In both the consultation and interview Waitā talked several times about the pain he experienced, though it was difficult to ascertain the impact this was having on his emotions if any.

Waitā also attended the consultation with a history of being motivated to seek treatment. For example, he informed the specialist he had cycled twice daily (using a stationary indoor bike) to improve his fitness so he could have surgery. In addition, he appears to have a simple straightforward view of treatment and cancer, as he explained in his interview *“if it's going to help me, well go ahead and do it....I know that I've got cancer, and well... that's it. Get some treatment”*.

The specialist also noted in his debrief that Waitā's personality did not lend itself to making treatment decisions and having to do so evoked an emotional response stating, *“He's not really the kind of person that wants to make decisions regarding his healthcare. Seemed a little bit unhappy about having to make those sorts of decisions, or even discussing them”*.

Medical: comorbidity, disease and treatment

Although Waitā's quality of life is adversely affected by the different comorbidities he has, it appears that this factor may have positively influenced his decision-making. His response to dealing with his comorbidities and associated symptoms has been to seek out help to manage them from healthcare providers. Seeking out help from specialists for cancer therefore follows in this vein.

Potential side-effects from treatment (e.g. nausea, vomiting and diarrhoea) did not appear to overly concern Waitā. A possible reason for this could be because he is accustomed to side-effects from some of his other medications, such as *“those water tablets”*, which make him go to the toilet *“every half hour”*. The specialist also provided assurances that side-effects could generally be managed with medications.

Healthcare system

As mentioned previously, other specialists were involved earlier in Waitā's case and it appears as if his expectation of radiation treatment was in part due to treatment suggestions made by them prior to the consultation. Waitā explained "*... they reckon my next move is to have radiation*". This was also evident in his interview when he explained what he thought the purpose of the consultation was for: "*...they were going to check me up. I thought they were going to ... get ready for radiation..., that's what I thought I was coming in for*". Having multiple health conditions, combined with being declined for surgery and having an uncertain outcome from his recent chemotherapy consultation may in part explain why Waitā attended the consultation confused and under the impression he was going to commence preparations for radiation therapy.

Themes influencing the specialist's treatment decision-making

Patient

Waitā's quality of life, which could potentially be improved by treatment, was a factor which appeared to influence the specialist's decision-making.

Medical: comorbidity, disease and treatment

Determining Waitā's fitness for treatment appeared to influence the specialist's decision-making. To assess Waitā's fitness the specialist asked him several questions about his ability to lie flat for instance, "*If you lie down....Flat on your back? No pillows, or anything like that? Do you think you can do that for twenty or thirty minutes? Lying like that?..You have to lie pretty still for the radiotherapy*". It seemed Waitā's assurances that he could do as requested was sufficient to satisfy the specialist.

Waitā's cardiovascular comorbidity was identified as a key factor in the specialists' rationale to offer treatment. According to the specialist, Waitā's chances of recommencing prophylactic medication (warfarin), designed to reduce the risk of

further cardiovascular events, would be improved if the cancerous ulcer was “sealed” by radiation treatment. The importance of this aspect was identified by both Waitā and the specialist. In the consultation the specialist explained, “*if we were to give you the radiation, it would be because we want you to go on to Warfarin*”. At another point he also stated:

“It [radiation] won't get rid of the cancer, but it might heal the ulcer temporarily, and let you go back on the Warfarin for some time....right now, the only reason to give you radiation is to... so that you could go back on the Warfarin if you wanted to.”
(Waitā, Con)

Symptoms were also identified by the specialist in the consultation as a factor which would influence his treatment decision-making. In particular, he urged Waitā to report symptom recurrence while awaiting treatment. Symptom recurrence would motivate the administration of treatment regardless of associated uncertainty, as the specialist explained to Waitā, “*I'll tell you what, if you definitely notice any bleeding then we'll do it for sure*”.

The prognosis for Waitā, even though his stomach cancer was small, was of concern to the specialist because of the potential for the cancer to grow and spread. Even with the radiation treatment offered, Waitā's prognosis remained poor. The specialist explained to Waitā, “*Even with the radiation therapy, the ulcer will come back at some stage....So you're still kind of stuck. It just gives you a little bit of a window.*”

The ability to deliver treatment safely appeared to be a key concern for the specialist, however it would not stop ‘them’ trying. He considered targeting the cancer with radiation “*a little bit tricky*” as there was uncertainty about the cancer's exact location and furthermore it was situated on a moving organ (stomach). The specialist also reported that he was not “*absolutely sure*” that treatment could be given safely but he and his colleagues were “*going to try*”.

Healthcare system

Other healthcare professionals determined which treatment options were available in Waitā's case prior to the consultation, with surgery ruled out and

medical and radiation oncology appointments scheduled. The specialist also used the word 'we' several times when talking about treatment and developing radiation treatment plans for example, indicating that other health professionals had been and would be involved in the future.

Communication

This section begins by presenting an overview of communication related factors that occurred with the potential to influence treatment decision-making in the consultation. Treatment decision-making options, processes and status are also reported. The section closes by summarising factors appearing to influence treatment decision-making in the consultation.

It appears that communication in the consultation was satisfactory for the participants as both Waitā and the specialist spoke favourably about each other. The specialist reported the consult was "*easy*" and that there were "*no communication difficulties*" while Waitā reported in his interview, that he understood what the specialist had said. The presence and contribution of his granddaughter, who recalled and clarified information may also have contributed to Waitā feeling positive about the consultation.

Waitā's general health status had declined in some areas which may have influenced communication. For instance, in his consultation he reported having difficulty remembering things and spoke of having hearing loss in his interview. Despite this Waitā was able to recall fairly accurately in his interview what was spoken about in his consultation.

Information load was noted of concern in Waitā's consultation by the specialist. Narrative in both the consultation and interview indicated he had been 'pre-loaded' with treatment information from other hospital services. In addition, he received a significant amount of information from the specialist in the consultation, possibly putting him at risk of information overload, which was noted by the specialist in his debrief.

It was questionable whether Waitā understood all of what he had been informed about or even consented to, to date. For example, he was unclear as to why he had been *"cut open"* prior to the consultation until advised by the specialist. While the specialist reported he believed Waitā generally understood most things related to his treatment, he was less sure if Waitā fully *"understood his treatment options"*. The specialist attributed his concern to Waitā's ability to cope with the large amount of information given. Despite the specialist's misgivings, Waitā credited him for improving his understanding of a number of issues relevant to his situation. For example, Waitā explained to the specialist *"You know, I've only been with you what, how long, and I've learnt a lot about myself. You see it was never explained to me, you know I know what to do, what to expect, what to look for"*.

A range of strategies were utilised to convey information, for example, the specialist explained in his debrief how after sensing Waitā had become *"...a little bit overwhelmed with the amount of information"* he then constrained the amount of detail given so as to take the *"technical level of the discussion down to Waitā's level"*. The specialist also appeared to take a 'bilingual' approach at times, using medical language first then explaining things in lay terms. In his debrief the specialist explained how he was conscious he *"needed to be aware about jargon, and sort of try and clarify some of the jargon there that we normally use"*. Perhaps due to these strategies Waitā felt sufficiently comfortable with the specialist to ask questions when he did not understand something, for example, asking the specialist *"well what does irritate mean?"*. It also appeared that such strategies were effective as Waitā indicated his knowledge about symptoms had increased and now he knew what to "look out" for.

The use of a range of communication strategies and Waitā's feedback to the specialist may also have resulted in the specialist forming the perception that Waitā's understanding of treatment details was satisfactory. The specialist stated in his debrief that he was *"fairly certain that he [Waitā] understood the rationale and the potential toxicities and the actual challenges of delivering the treatment, as well as most of the treatment process"*.

Decision-making

As noted previously communication about treatment options commenced between Waitā and other medical professionals prior to the consultation. The fact that he had attended the consultation thinking he was going to be ‘measured up’ for treatment suggests that Waitā may have decided to accept treatment prior to attending the consultation.

Waitā’s appreciation of the seriousness of his situation appeared to grow as a result of talking with the specialist. Midway through the consultation, for example, Waitā informed the specialist he understood *“it’s a serious thing...it sounds very bad”*. However, a poor prognosis did not appear to negatively influence Waitā’s decision to seek treatment.

Traditional Māori healing methods (traditional healing) had played a part in Waitā’s previous treatment choices. He shared with the specialist his past history of having stopped ‘Western medicine, replacing it with traditional healing, and expressed his faith and belief that *“It worked”*. The specialist’s response appeared somewhat short, as he informed Waitā *“I don’t know anything about that”*, closely followed by a return to the conversation about radiation treatment. The primary healer Waitā once saw had died and it did not appear as if Waitā had contacted any others, therefore it seems unlikely that traditional healing will play a part in the future treatment plans for this cancer.

The specialist recommended radiation treatment, however who would make the actual ‘decision’ about this appeared to cause some tension between he and Waitā. Waitā’s preference was clearly for the specialist to make the decision as he considered him the ‘expert’, which he articulated to the specialist. In his interview he also signalled this view when he stated *“Like they’re [the specialist’s] the experts”*. Ultimately Waitā appeared to consider himself to be *“...in his [the specialists] hands”*. However, in contrast to this view, Waitā also talked in a manner in his consultation which suggested he saw decision-making in a partnership way. For example, his response to the specialist when he was unable to indicate how much ‘time’ he might have, was to ask *“well what’s our next*

move?". While the specialist acknowledged Waitā's position, it appeared he believed Waitā should participate in decision-making.

Summary

Several factors emerged in the consultation which appeared to influence Waitā's decision-making. Two central factors appeared to be his desire for treatment and the specialist's treatment recommendation.

Three key factors appeared to influence the specialist's decision-making, the presence (or absence) of symptoms, Waitā's quality of life, and treatment benefit for his cardiovascular comorbidity.

Communication appeared to occur with ease in this consultation despite differences of opinion at times between the specialist and Waitā. Information was shared between all participants including Waitā's granddaughter, a regular carer for him. Waitā had been given a lot of treatment information prior to the consultation and his understanding of his situation appeared limited. The specialist recognised that, at times Waitā seemed overwhelmed by the information detail and volume.

Treatment decision-making was in part influenced by activities which occurred prior to the consultation. In the consultation, one treatment option was raised by the specialist. Waitā voiced his preference several times that the specialist make the decision, which the specialist did. Waitā accepted the treatment offered however the specialist appeared less certain at the end of the consultation, perhaps because of the potential challenges it posed.

Narrative case summary three: Waipuna-ā-Rangi

Overview

Waipuna-ā-Rangi (Wai) is a 32 year old woman, daughter, sister, aunty and niece. She lives with whānau, two sisters and a nephew. Wai is currently single, in full-time paid employment and has no known comorbidities. About three weeks prior to her consultation she sought help from her GP for persistent breast pain, outside that which she normally associated with menstruation. Her GP referred her to radiology for further investigation.

Wai attended a radiology appointment where she underwent three procedures (mammogram, ultrasound and core biopsy). She was advised at that appointment her results would be discussed at a multidisciplinary team meeting. Prior to visiting her GP to receive her results (which were not available when she did) Wai was contacted by a breast care nurse to organise an appointment with a medical oncologist. During this period, Wai and her sisters talked with another woman who had experienced similar procedures and they began to suspect a cancer diagnosis. Wai was supported to the consultation and interview by her two sisters (S1 and S2).

The specialist was a female medical oncologist with twelve year's work experience. Ten of those years were spent overseas practicing medicine, hereafter she is referred to as the specialist or MS2.

Themes influencing Wai's treatment decision-making

This section begins by presenting how whānau, the specialist, patient, medical and healthcare system factors appeared to influence Wai's treatment decision-making. It ends by describing how the specialist's treatment decision-making appeared to have been affected by medical and healthcare system factors.

Whānau

Wai was supported to the consultation and interview by the two sisters she lives with and whose support and encouragement appeared to influence her decision-making. One sister played a larger role verbally, both in the consultation and interview than the other, and also supported Wai to her assessment. The sisters generally participated in the consultation through asking questions, repeating information, providing information and sharing laughter on several occasions. Although one sister noted in the interview that she had gone to the consultation prepared to ask questions, most were either asked by Wai or addressed by the specialist. Some questions asked by the sisters may have assisted Wai with her understanding of what was being said by the specialist and also addressed questions Wai may have had but was uncomfortable asking. For example, when the specialist was talking about the type of surgery that may be undertaken to remove the cancer S1 asked her *“Will they leave her lop-sided? ... does she just put a fillet in there”*.

The impact of the support of her sisters was also noted and commented on by the specialist in her debrief and by Wai. In her interview Wai expressed her view of support as *“I do think for Māori, it is really important to have a support system in place”*. The type of support that the sisters offered to provide was emotional but also included assistance with transport and treatment administration in their home if needed.

Specialist

Characteristics of the specialist appeared too positively influence Wai’s decision-making in the consultation. Both Wai and her sisters were complimentary about the specialist’s ‘style’ in their interview. Wai’s initial somewhat negative expectations of how the specialist might present were not met as she explained in her interview,

“She was really good. Like I thought it was going to be quite cold, but she was actually really lovely. And she talked to me. Like she was talking to me. Like sometimes when you go to the doctor it’s not like they’re talking to you.” (Wai, IV)

The specialist's treatment recommendation, *"that we start with chemotherapy then go on to surgical resection, and then radiation, and then hormone therapy"* appeared to be an important influencing factor on Wai's treatment decision-making. Wai and S1's responses, when asked in the interview if a treatment decision had been made or communicated to the specialist, indicated that they would do what the specialist recommended.

Wai: "Pretty much this is... yeah, this is what we're doing. Whenever you [the specialist] want."

S1: Yeah. Whatever you [the specialist] say is the best option, we're going with treatment."

(Wai, IV)

Patient

Prior to attending the consultation Wai had begun to prepare for receiving a cancer diagnosis. She sought information about breast abnormalities from 'Dr Google' and, via her sister had talked to someone who had experienced breast cancer.

"If ((FIRST NAME-S1))'s boss hadn't had breast cancer... I would be ill-prepared to hear the news. I would guess not really prepared, but you know, because she had already had experience, and then she'd helped, like by talking ((FIRST NAME-S1)) through her own experience of it, you know I would still probably... I'd arrive here today and be like, "Pardon?". (Wai, IV)

Wai also consciously prepared herself emotionally for the consultation, driven by concern that her emotions could make her journey tougher. In her interview she explained, *"before I came to the meeting, I decided to... you just have to push that little bit of that emotional thing aside, so that you can actually hear what she's saying. Because it's my body. It's happening to me"*

Additionally Wai's personality, described by the specialist as "introverted", along with Wai's own plan to put her emotions aside during the consultation may also have accounted for her managing her response to her diagnosis during the consultation. Wai described in her interview how letting her emotions out might adversely affect her journey; *"if I don't keep myself in check over that, you know, my*

emotions, then there'd probably be quite a difficult journey for me". Her decision to manage her emotions prior, combined with the impact of also receiving her diagnosis in the consultation may possibly account, in part, for the limited emotional expression evident in the consultation. Much of Wai's dialogue consisted of 'yes', 'no', 'okay' and 'yeah' answers.

About ten minutes into the consultation the specialist became aware that Wai had not 'officially' been told her diagnosis. After apologising she informed Wai that she had *"right sided breast cancer, with lymph node involvement"*. Whether receiving her diagnosis in the consultation impacted on her treatment decision-making was difficult to ascertain. However, it is possible that responses such as shock and anxiety may have occurred. Despite this Wai and her sisters were able to chuckle, joke and laugh in the consultation. Possible reasons for the use of humour may include the nature of Wai and her whānau and their general approach to life, or a coping mechanism used in difficult situations (or both).

Wai expressed in her interview the view that hospital staff focused on the physical body whereas her view as a Māori was more holistic, stating *"... for Māori, you know, because we're mind, body, and soul"*. A possible reason for this perception may be due to the large proportion of the care up until the consultation being focused on establishing a diagnosis, and then the care focused on the disease and treatment factors. There was evidence however that the specialist did attend to emotional and coping factors to some extent in the consultation. For example, the specialist advised Wai that cancer could be *"emotionally difficult"* and could *"take you to a very dark place because that sitting at home thinking about having cancer, and thinking about chemotherapy for weeks on end, does not put people in a good mental health space"*.

Wai's ability to remain working while receiving treatment was raised as a concern by her and her sisters in the consultation and was also mentioned in her interview. The specialist's response indicated her preference for *"my ladies to continue to work if they can"* however she also acknowledged that *"lots of women aren't able to continue to work on this treatment"*. In the consultation it transpired Wai had

already informed her workplace of her situation. She reported that their response was positive as they had recent experiences with staff who had cancer.

The specialist, in her debrief, identified that Wai was “*pretty young*”, which made her “*amenable to treatment*”, although Wai herself did not identify this as a factor.

When asked in her interview about consideration of alternative medicines or treatments Wai’s response indicated she had not heard of any nor did she seem interested in seeking any out.

Medical: treatment

Concerns were raised by Wai and her sister about the side-effects of the proposed chemotherapy treatment. In particular, hair loss and fertility which had the potential to influence treatment decision-making. The specialist raised hair loss as a likely side-effect of the chemotherapy drugs, “*You will lose your hair. You will get a wig. That is fully funded*”. Wai was sufficiently concerned about her fertility and asked the specialist “*will I be able to have children?*”. The specialist assured her that the treatment should have no long term effects on her fertility nor should it stop her from being sexually active.

Healthcare system

Healthcare system factors appeared to influence Wai’s treatment decision-making, in particular the speed of diagnosis and support available. The speed at which events occurred leading up to Wai’s diagnosis was noted by her in her interview where she stated “*I went there Monday last week. It's Wednesday. That's like... nine days later? Nine days later you've got cancer, girl. And I was like, ah yeah.*” Wai also indicated that making sense of everything that had occurred was a challenge.

“It's like having a puzzle, but not having the front cover to see what the puzzle looks like.... you're getting these pieces, and... they just look like puzzle pieces. But you can't see the picture....for me, it would have been better if I had some cohesiveness in the process....Like it just feels quite separate.”
(Wai, IV)

During the consultation the specialist talked about ways to manage treatment administration, mindful of Wai's employment circumstances. The specialist indicated she could organise for her treatment to be given towards the end of a week so she had some recovery time over the weekend which could improve her chances of being able to return to work the following week.

The specialist also offered support by way of facilitated access to nurses, social workers and the hospital Māori support services, which were accepted by Wai.

Themes influencing the specialist's treatment decision-making

Medical: comorbidity, disease and treatment

A range of medical factors including comorbidity, disease characteristics, treatment protocols, effectiveness and side-effects all appeared to influence the specialist's treatment decision-making in Wai's case. At the beginning of the consultation, the specialist asked Wai a range of questions about her health and found she did not have any comorbidities to consider in treatment decision-making.

Treatment protocols appeared to inform the specialist's decision-making, as she stated in her debrief, *"It was reviewed that the standard protocol would be a more classic protocol would be surgical resection, but because of the size of the tumour, neo-adjuvant therapy is recommended"* in Wai's case. The characteristics of the cancer and treatment goals were discussed and linked to the chances of removing the cancer. The specialist for example, informed Wai about the rationale for chemotherapy treatment in relation to surgery being due to characteristics of her cancer *"the size of the lump in your breast, the size of the tumour"* which underpinned the rationale for offering neo-adjuvant chemotherapy *"up front, before doing surgery"*. The rationale given indicated the proposed treatment could improve her prognosis as they would *"try and shrink down your cancer, to try and get it as small as possible, to try to improve the chances of fixing it"*.

Other disease characteristics (positive oestrogen and progesterone receptors) were also mentioned as conducive to forming treatment options. For example, the specialist explained that positive results meant the tumour was “*less aggressive*” and open to hormone therapy as a viable treatment modality later on, while a third receptor test with an inconclusive result, required further testing to inform treatment planning.

The specialist also expressed concern about Wai’s ability to tolerate treatment, side-effects and her tumour’s response to treatment. For example, an additional heart scan was ordered to monitor the effects of one of the proposed chemotherapy drugs.

Healthcare system

In Wai’s consultation, the healthcare system in the form of a breast multidisciplinary meeting was identified by the specialist as a place where Wai’s case would be presented, the afternoon of her consultation. This introduced the potential for the breast multidisciplinary meeting to influence treatment decisions already made in Wai’s consultation.

Communication

This section begins by presenting an overview of communication related factors that occurred with the potential to influence treatment decision-making in the consultation. Treatment decision-making options, processes and status are also reported. The section closes by summarising factors appearing to influence treatment decision-making in the consultation.

All parties in the consultation reported having a positive experience with each other. The specialist reported in her debrief that there was “*an adequate amount of time*” in the consultation and that she was impressed by the questions asked by both Wai and her sisters. The specialist also reported that Wai was “*delightful*” and that she did not have any communication difficulties. Humour resulting in shared laughter was also evident several times in the consultation.

However there were several communication elements identified with the potential to influence rapport in the consultation. For example as mentioned previously, ten minutes into the consultation the specialist became aware that Wai had not been given her diagnosis due to a communication error, seemingly between her GP and radiology. This interrupted the flow of the consultation with the specialist deciding to go “*back to the beginning*” and apologising several times.

Much of the conversation in the consultation was dominated by the specialist, seeking out and giving vast amounts of information. Topics covered included disease characteristics, treatment (long and short term modalities, length and frequency), treatment side-effects and their management and social issues such as employment. In the first five minutes of the consultation the specialist asked Wai approximately 35 questions and later gave about 36 different pieces of information in an eight to nine minute period about potential side-effects and ways they could be managed. Wai appeared to cope with this by asking one sister to write things down for her so she could ‘listen’. The specialist was conscious of the amount of information given, and commented that she was glad Wai had “*three sets of ears paying attention*”.

Wai’s sisters’ presence and participation in the consultation also appeared to influence communication and potentially decision-making. With support from her sisters, Wai was able to reiterate fairly accurately information the specialist had provided in the interview. However, they all struggled at times to recall information, particularly detailed medical information, such as the name of specific chemotherapy drugs for instance.

In addition to a high information load, a vast amount of medical jargon and complex instructions were given, as evident from the following excerpts:

“...invasive ductile carcinoma.... There are a few features that make them think that it's a particular subtype called metaplastic.

There's a test called the oestrogen receptor, a test called the progesterone receptor, and a test called HER2. Cancers will only make the oestrogen and progesterone receptor if they feed off of

the female hormones.... therapy targeted at that oestrogen receptor, called endocrine therapy, or hormonal therapy.

You can see here that your tumour is oestrogen receptor 3+ positive, and progesterone receptor 2+ positive....Now your tumour has been tested for HER2, but the test came back indeterminate- which is code for 'unknown'.... So we're doing a special second test, called a FISH test. And when that result comes back, we'll make a determination on whether or not you need Herceptin.

The three drugs are 5FU, Epirubicin, and Cyclophosphamide.... They're given... in the vein, they're given every three weeks, and they're given for three cycles. Okay, so that's nine weeks of treatment....At the end of that, we then transition to a medicine called Docetaxel. It's given either by itself, or if your tumour shows that there is HER2 positivity, I would add on Herceptin with the Docetaxel....The Docetaxel would be given every three weeks for three cycles. So it's a total of 18 weeks, or four and a half months, of chemotherapy.

(MS2, Wai, Con)

The specialist appeared to try, at times, to translate jargon into lay language, for example “*improve surgical clearance*” was translated to mean “*try and make sure we get everything out of the breast*”. Several other communication strategies were also employed by the specialist including repetition of information, pausing to take questions, and offers of written information to take away.

Terms used by Wai and her sisters to describe medical information such as “*the clouds ... and the blobs*” for mammogram results and Wai’s statement in her interview “*Oh God. Never heard those words before*”, suggest they were unfamiliar with medical terms generally and found it challenging as many people are in this situation. The challenge of developing an understanding of the language used when talking about cancer and how that might enable information to be processed was expressed by Wai in her interview:

.....like so cancer has its own language, I don't know anything about that language. But if I did, it'd probably be a lot different. Like you know, like a double mastectomy. What does that mean? If I don't know that it means that both your breasts have been removed. Like do you know what I mean? Like if there's an understanding of the language, or any language, for that, it

makes things easier to process, I guess. So if the language becomes more common, and we begin to understand what that language means. (Wai, IV)

Perhaps reflecting on her own position and generation Wai shared in her interview how that morning she had thought “*probably if it's a little overwhelming, they should just make a YouTube video about it*”.

Decision-making

An overarching treatment plan involving four different modalities was presented by the specialist and discussed. The primary focus of the consultation was on neo-adjuvant chemotherapy and Wai was provided with details on drug regimens, side-effects, ways to manage side-effects and treatment cycles. The specialist also informed Wai of treatment benefits and indicated she would be required to undertake three further tests. The specialist sought an indication from Wai that she wanted to proceed with treatment by asking her if it was ‘okay’ to begin organising scan dates while she was preparing herself for the physical examination. Towards the end of the consultation Wai was given an appointment, for her first chemotherapy treatment. The option of no treatment or alternative treatments were not raised by any party during the consultation.

Whānau were identified by Wai in her interview as participants in decision-making as “*everything's a whānau decision*”. That statement was made despite the fact that Wai’s wider whānau had not yet been informed that she might have cancer. It seems possible her sisters, will likely influence her treatment decision-making going forward given their involvement to date.

All treatment options were subject to a caveat placed by the specialist on the results of the three further tests, two of which would check whether the cancer had spread before treatment would start. The specialist indicated that she undertook the consultation based on the premise the results to the three additional tests would be negative.

Summary

Wai received her breast cancer diagnosis in the consultation. Unfortunately the consultation had commenced before the specialist became aware of this. She revised her approach accordingly.

Two factors which appeared to be major influences on Wai's decision-making were the specialist's treatment recommendation and whānau support. Priority was also given to determining *which* treatment was to be given, rather than deciding 'if' Wai wanted any treatment.

There were three key factors which influenced the specialist's decision-making. Firstly, preparing the patient to improve the chance of a positive surgical outcome and secondly, reducing the risk of growth and spread. Third were, treatment protocols and review, which recommend this approach to treatment when a patient presents with the disease factors Wai had.

Communication appeared to occur with ease despite the initial challenge regarding Wai receiving her diagnosis someway into the consultation. Information was shared between all participants including Wai's sisters who provided information to the specialist. They also provided advocacy and support for Wai. Suspecting she had breast cancer meant Wai attended the consultation with some treatment information (not all of medical origin) and was given a significant amount more by the specialist. The amount of information given by the specialist was likely influenced by Wai not having had her diagnosis communicated to her prior to the consultation. Much of the consultation contained medical jargon which was challenging at times for Wai to understand.

In the consultation, medically appropriate treatment options were raised by the specialist, non-medical alternative treatment options did not feature. Decision-making in this consultation appeared to be based on the specialist giving and gathering information (including Wai's values), then making a recommendation in a non-coercive manner. Wai accepted the treatment offered to her in the consultation.

Narrative case summary four: Tupu-ā-Nuku

Overview

Tupu-ā-Nuku (Nuku) is a woman, mother of two, grandmother and until recently, a mātua whāngai (adoptive parent). She is a widower, aged 52 years, who works part-time at an after-hours medical centre (nursing) and helps out on the family sheep and beef farm some 60km from town. Nuku was supported to the consultation by her partner (P1), who chose not to participate in the interview.

Nuku has a range of minor health conditions including lower back ache, menopausal symptoms and occasional gout. Nuku intermittently uses an inhaler, takes an iron supplement monthly for anaemia and recently had gynaecological surgery. She has also just completed a course of antibiotics for a respiratory type infection/irritation which has not fully resolved.

While showering, Nuku discovered a lump in her armpit and went to the after-hours service that same evening. Nuku reported she and the after-hours GP focused on the lump being a possible lipoma and she was referred to a surgeon for further tests as a precaution. She attended the surgeon's appointment alone thinking this was the likely scenario and was overwhelmed when told she had breast cancer. She also commented on the fast speed at which her tests and diagnosis had happened, however noted her appreciation for that on reflection. She was referred to medical oncology by the surgeon who performed her single mastectomy. Nuku reported her case had been to a 'multi-meeting' and that there was initial uncertainty about the origin of her cancer which had delayed her breast surgery (mastectomy). The wound from the surgery was still healing when she attended the oncology consultation in this study.

The specialist was a female medical oncologist (MS3). This specialist did not provide her age or the number of years she has been practicing. A cancer nurse specialist was also present in this consultation who had a long established relationship with Nuku.

Themes influencing Nuku's treatment decision-making

This section begins by presenting how whānau, the specialist, patient, medical factors and healthcare system factors appeared to influence Nuku's treatment decision-making. It ends by describing how the specialist's treatment decision-making appeared to have been affected by Nuku, medical and healthcare system factors.

Whānau

Whānau had the potential to influence Nuku's treatment decision-making in two different ways. Firstly, treatment timing, and secondly, by introducing the possibility of her cancer having genetic links.

Nuku's immediate supporters included her daughter who lives over 500km away, a son who lives in town, and her partner. Her daughter plans to support her regularly during treatment. Nuku, wanting her daughter's support and conscious of the travel, childcare and employment logistics involved, asked the specialist to consider that in the timing of her treatment, *"And I just need to let you know now that you know, she wants to be involved, I want her to be involved, so we need to involve her so she can get time off work and come home"*.

The specialist suggested, and Nuku accepted, a referral to a geneticist. The specialist indicated that given her age and breast cancer diagnosis, combined with a family history of heart disease, it could be useful to inform how her children's healthcare in the future could be managed. Particularly for her

daughter, who could be advised about when to commence regular screening. This factor possibly provided a platform for Nuku to consider her cancer diagnosis in relation to the well-being of her whānau.

Specialist

The specialist commenced the consultation by establishing what was important for Nuku and further into the consultation, employed a number of strategies to manage treatment expectations and give support and encouragement. For example, the specialist managed patient expectations by giving *“the worst case scenario”* so her patients felt as if treatment *“wasn't as bad”* as they thought it was going to be.

The specialist shared with Nuku her understanding about how best to cope with treatment indicating it was her team's job to *“get you through this, to keep some normality and normal life going on”*. The specialist also conveyed to Nuku, her belief she would cope well with the proposed treatment.

The opinion of the specialist potentially influenced Nuku's treatment decision-making in the consultation. The specialist clearly recommended chemotherapy treatment twice in the consultation and provided information to accompany her recommendations.

“So if you say to me what would my recommendation be, it would definitely be to try the chemotherapy, up to six cycles plus a year of Herceptin. In an ideal world, that's what we would like to give you”. (MS3, Nuku, Con)

In her interview Nuku indicated that the specialist had told her *“exactly what the plan was”* and she had said *“yes, okay”* to the treatment offered.

Patient

Leading into the consultation it appeared Nuku was struggling to cope with her emotions which may have influenced her decision-making. Several times throughout the consultation Nuku shared information which gave some insight into her emotional well-being. For example, she informed the specialist *“There’s too much time to think”* and several times throughout the consultation described herself as having *“lost the plot”* in relation to her surgery, firstly because surgery had been cancelled and then because it was rescheduled. There were also instances where Nuku expressed uncertainty about treatment and was tearful. Nuku also expressed some anxiety about waiting for treatment to commence, wishing it was *“tomorrow, and then we’re on the road”*. Nuku also noted that she and her partner *“are probably focused on all the negative stuff first. And we’re not hearing the good bits. Like she gave me oh, three pages of Herceptin, and I thought, “Oh, here we go”*.

Nuku’s well-being and possibly treatment decision-making may have been affected by three whānau related issues including: coping with the recent return of a whāngai (foster child) back to their family, her late husband’s cancer related death, and her whānau response and expectations related to her diagnosis. She reported having had nightmares about her late husband and the impact of his loss was identified by Nuku in her interview as something that could be *“compromising”* her and creating treatment uncertainty. Receiving care from the same doctors and nurses as her late husband seemed to contribute to her feelings regarding treatment.

The burden of coping with other people’s emotions at this time was also identified as a concern by Nuku in her interview, *“because everybody else around me seems miserable. And that’s what I don’t want. I don’t want to be like them. And yet I don’t know how to fix them. Because they’re worried about me”*. Her response was to *“ignore them”* and decline their requests to visit *“because they*

don't look after themselves" and she didn't want to have to "look after them" given her need to focus on her own well-being at this time.

The impact of treatment on Nuku's ability to return to nursing work was raised as a concern as she has not worked since having her mastectomy and was currently experiencing health insurance problems. Work options were discussed in relation to the proposed chemotherapy treatment, in particular likely effects and health risks associated with Nuku's place of employment. Nuku expressed concern that her immune system would be compromised as a result of chemotherapy and working in a place where she would be regularly exposed to *"people coming in with bugs and things like that"* would put her at greater risk of infection. The specialist indicated that her experience with other cancer patients had shown that there were a range of possibilities with some continuing to work full-time or part-time with some job modifications. Her experience with nursing staff particularly was that some could not continue to work during treatment due to the nature of their job.

Towards the very end of the consultation the issue with Nuku's insurance provider was discussed. Although she left mentioning this until the end of the consultation, Nuku indicated in her interview that her *"main focus for her [the specialist] today was...could you sort of put something on paper so that my insurance gets paid, and then my living gets paid"*.

Medical: comorbidity, disease and treatment

A range of disease and treatment related side-effects appeared to influence Nuku's decision-making. Disease details given by the specialist including tumour size (2cm), grade (III), rate of growth (quick and aggressive), growth factor (HER2 positive), with lymph node involvement indicated clearly that that the cancer had spread outside the breast and was serious. As Nuku is a nurse it

seems possible that she would have a greater appreciation of the seriousness of her disease than a patient without a medical background.

Given her family history of heart disease, Nuku attended the consultation particularly concerned about heart side-effects associated with the Herceptin drug, which she had anticipated she would be offered. She raised this within the first few minutes of the consultation stating, *“Herceptin.... I'm concerned about that. Well probably the side-effects with the heart muscle and things. Because we've got a family full of dicky hearts”*. The specialist acknowledged her concerns and provided assurance that this could be monitored and managed with regular testing using a *“standard protocol”*.

Other side-effects commonly associated with chemotherapy such as hair loss were also of concern to Nuku. In anticipation, Nuku informed the specialist she had already *“got me wig....Picked me hat”* and had cut her hair to aid the transition.

Nuku reported using alternative medicines including *“wheat grass shots”* once she received her diagnosis, hoping to boost her immune system in anticipation of chemotherapy. The specialist expressed interest in hearing about the alternative medicines. The specialist indicated that ‘they’ did not know enough about the *“interaction of antioxidants”* with chemotherapy and that some doctors were looking into the role of selenium. Later, in her interview, Nuku indicated she was concerned about taking alternative medicine while receiving chemotherapy fearing *“they'd [the doctors] probably give me a higher dose of chemo, which I wouldn't want”*.

Healthcare system

Access to support services and advocacy from health professionals to get the system to work for the patient could possibly have influenced Nuku's treatment

decision-making. For instance, the specialist offered access to a social worker to assist with resolving her health insurance issues, and a psychologist to help her work through issues related to her late husband. Nuku gratefully accepted referrals and explained in her interview how the referrals provided her some relief because she worries about *“everybody else worrying about me”* and it would also provide her whānau with *“people to talk to as well”*. Additionally, working the treatment booking system to Nuku’s advantage so her daughter was able to support her was something encouraged by the specialist. The nurse indicated this was something she did regularly.

Themes influencing the specialist’s treatment decision-making

Patient

In addition to clinical factors, Nuku’s age and fitness appeared to influence the specialist’s treatment decision-making. For example the specialist stated *“as soon as I see a fit young lady with lymph nodes involved, I’m already thinking about chemotherapy”*. Additionally the specialist commented in her debrief that Nuku was a *“very well informed nurse”*, who was keen to progress treatment and was well supported by her partner.

Medical: comorbidity, disease and treatment

The specialist gathered information from Nuku about her health and well-being including comorbidities, and became aware that Nuku had a strong family history of cardiovascular disease, often occurring at young ages. This information combined with a recent heart scan result (with less than optimal results) and known cardiovascular side-effects from one of the drugs she was offering, appeared to influence her decision to plan additional heart monitoring activities.

Although the specialist voiced her position that Nuku had already received the most critical mode of treatment (surgery), for her breast cancer, she offered chemotherapy treatment due to the potential of disease recurrence and spread given her disease characteristics. For example, she informed Nuku that lymph node involvement results in *“worry about the chances of cancer coming back in the future”*. Chemotherapy and Herceptin treatment were identified by the specialist as *“the only thing we’ve got then to reduce the chance of the cancer coming back”* and Nuku’s circumstances warranted an *“aggressive approach”* to treatment.

Healthcare system

Often treatment plans are formulated at multidisciplinary meetings, and in Nuku’s case it appears the specialist had attended a *“big meeting”* where her case had been discussed and the *“best course of treatment”* determined.

Communication

This section begins by presenting an overview of communication related factors that occurred with the potential to influence treatment decision-making in the consultation. Treatment decision-making options, processes and status are also reported. The section closes by summarising factors appearing to influence treatment decision-making in the consultation.

Information about Nuku had been communicated to the specialist by the cancer nurse specialist prior to the consultation, particularly about her emotional state, her deceased husband and the amount of information she had been given prior. Similarly, Nuku had gathered information about the specialist from colleagues and attended the consultation feeling *“happy”* with who she was about to discuss her treatment options with, based on the information she had received. Nuku shared information about herself freely with the specialist and the cancer nurse

specialist including her emotions, concerns and her whānau, indicative that she felt a level of trust. The specialist also commented on the benefit of the cancer nurse specialist being present in the consultation as *“she’d already got a good rapport and established relationship with the patient”*.

Prior to the consultation Nuku had been given information by her surgeon and other hospital staff. She had also sought out information from colleagues, a neighbour and the internet. Communication in the consultation was largely dominated by the specialist who, conscious of the large quantity of information she was going to provide warned her accordingly *“I am going to give you quite a lot of information”*. This included information pertaining to the disease treatment, side-effects and coping strategies. Nuku indicated she would *“have a good look at it [treatment information]” at home and take some time to “think about it”*.

The specialist utilised a range of approaches to convey information including: scenarios, repetition, written information, prioritising information to remember, and by regularly asking if Nuku had questions. She also ascertained Nuku’s preferred method for receiving information about risks and benefits by asking *“do you like to see facts and figures, or do you rather just talk in general terms?”*. Several times throughout the consultation the specialist indicated there would be other opportunities to *“recap”* and *“revisit”* with both her and the cancer nurse specialist. It was evident in Nuku’s interview that the specialist strategy of prioritising what was important to remember was effective as Nuku reported: *“I know the one thing that I have to take notice of is my temperature”*.

Rarely did it appear as if the specialist attempted to ascertain Nuku’s level of understanding of the information that had been given to her. In her interview Nuku struggled to recall specific details such as medication. For instance she reported in her interview that *“with regard to the medication. I have no idea what she was going on about”*. Yet, she was fairly accurately able to recall

information about treatment cycles and side-effects. Nuku appeared unconcerned about her inability to recall specific details at this stage saying that *“by the end of the treatment I’ll know exactly what they are. So I can wait”*.

Nuku described the consultation as going *“generally quite well”* and her perception of the specialist’s communication style as *“very good”* and *“very slow...very quietly”* noting her belief this style was *“very good for P1 as well”*. Similarly the specialist indicated she had no communication difficulties and described Nuku’s preparation of questions prior to the consultation as helpful so she could ascertain what was important for her.

Decision-making

The specialist primarily discussed chemotherapy treatment details and also advised that chemotherapy treatment plans could be altered if needed. Additionally, the cancer nurse specialist raised radiotherapy in the consultation as a possible treatment as part of the treatment pathway given her age, but warned she was *“on the cusp”* for eligibility. The cancer nurse specialist had delayed the radiation consultation until after Nuku’s medical oncology consultation.

The specialist reported in her debrief that Nuku had accepted the recommended chemotherapy treatment perhaps informed by her responses such as *“...I’m going to do what it takes to do everything, and I’m not going to say no...”*. Nuku however, reported in her interview, the need for time to decide, despite saying yes to treatment. When asked if she had decided what treatment, if any, she wanted, her replies were somewhat jumbled. For example at one stage she replied *“not really. I know that I’m going to take everything that’s on offer”*, and then later stating *“But I don’t know. I’m not going to say no though.... And I just said yes”*.

Summary

The major factors which appeared to influence Nuku's decision-making were her whānau and her own medical situation. Additionally her emotional state appeared to influence her decision-making going into the consultation, and although by the end she seemed somewhat relieved, Nuku still expressed a need for time to consider her circumstances.

Factors which appeared to shape the specialist's decision-making were the multidisciplinary meeting treatment review and treatment protocols indicating chemotherapy as the best option for reducing the chance of disease recurrence or spread.

Communication seemed straightforward and appeared to flow in this consultation, perhaps as both Nuku and the specialist had gathered information about each other prior. Information was shared between the participants, with the specialist dominating a large portion of the talk throughout. Ascertaining from Nuku her preferred method for receiving medical statistics was noted as a desirable communication tactic undertaken by the specialist. Nuku appeared to struggle to remember all the information that was provided, but was able to focus on what was important to her during the consultation and interview.

Treatment decision-making appeared to be in part influenced by factors which occurred leading up to the consultation, including Nuku changing her mind several times about choosing chemotherapy. In the consultation one medical treatment option was raised by the specialist while Nuku also shared her use of alternative treatments. Decision-making was guided by the specialist who ascertained from Nuku what was important to her and made a treatment recommendation in a seemingly non-coercive manner. Nuku's concerns about side-effects seemed to be sufficiently addressed and she verbally indicated her desire to undergo treatment. Despite this, later in her interview she indicated

she needed more time to consider the information before definitively confirming that she would go ahead with chemotherapy.

Narrative case summary five: Tupu-ā-Rangi

Overview

Tupu-ā-Rangi (Rangi) is a father and grandfather who is employed full-time in the scrap metal industry. He is 74 years old and lives alone. Rangi has two sets of children, some older in their 50's and some younger, who reside in the Wellington and Auckland regions. Rangi's sister supported him to the consultation, although was unaware of Rangi's appointment until he rang her that morning asking her to attend. She appeared anxious about leaving her sick husband at home, and that combined with the clinic running late meant she was unable to stay for the interview which was then rescheduled. On the day of the interview Rangi was in the process of purchasing a house (settlement day) with one of his children.

Rangi reported taking medication daily for prostate cancer, an iron deficiency, cholesterol, and a combined tablet for his heart and kidney. He has had prostate cancer for about 10-12 years, which was detected when he was asymptomatic at an opportunistic community screening event. Rangi was referred by his GP, in liaison with his urologist, as recent test results indicated his cancer was growing. Rangi has been under the care of a urologist for approximately six years and had previously received treatment for his prostate cancer.

The specialist in this consultation was the same as for Waiti and Waita.

Themes influencing Rangi's treatment decision-making

This section begins by presenting how whānau, the specialist, patient and medical factors appeared to influence Rangi's treatment decision-making. It ends by describing how the specialist's treatment decision-making appeared to have been affected by Rangi and medical factors.

Whānau

Two sources of whānau support were apparent in Rangi's interview, although it was difficult to detect if this influenced his decision-making. Firstly, support was available from his whakapapa whānau (genetic relatives) including his sister who supported him to the consultation, and his children. Secondly, he indicated support was available from his workplace whānau (workplace colleagues considered family). He described his workplace as being "*quite a family sort of affair*". In his interview Rangi described how his perceived need for support changed during the consultation. He went from thinking he needed support going into the consultation, to thinking while in the consultation that he would be able to 'draw' on himself. Rangi indicated he would only need support "*...maybe if I was pretty weak*". Should he need support in the future Rangi described how he could get this from his children who know about his cancer and treatment although not how "*serious*" it is.

Specialist

The specialist made a clear treatment recommendation in the consultation saying "*I think it [radiotherapy] would be quite useful for you*" which appeared to influence Rangi's treatment decision-making. Rangi's response "*And when will that start?*" possibly signalled a pre-existing intent to continue accepting cancer treatment. Another possible reason for this may be that Rangi perceived the specialist as an authority on cancer and treatment. When the specialist informed Rangi how treatment could be "stretched out over two weeks" to make it more tolerable, Rangi appeared to defer to his expertise by his "*Hey, you're the man*" response.

Patient

A range of patient specific factors such as philosophical outlook and work retention appeared to influence Rangi's treatment decision-making. Rangi's optimism featured in his consultation and interview. For example, his optimism was highlighted towards the middle of the consultation in a response to the specialist, *"Because like I say, if it's going to help me, all good. That's the way I look at it"*. He also appeared unconcerned about side-effects: *"Well hey, there's side-effects for from anything.... like I say, we'll have to go through it before we can find the effects"*. And then his will to live and easy going attitude showed later in his interview when he indicated he was aware that his time on Earth was limited and if treatment was going to *"give me more living the life, yeah, hey why not?"*.

The ability to keep working while receiving treatment also appeared to be important to Rangi. In his consultation for example, he appeared relieved to hear from the specialist he would be able to go to work after each treatment appointment. The importance of retaining his employment was also shared by Rangi in his interview when he explained how, after his treatment, if he was *"okay"* then he could drive himself *"straight to work"*. It seems possible that despite being of pension age, Rangi may require additional income from paid employment to service his pending mortgage.

In addition to the radiotherapy treatment discussed in the consultation Rangi talked of complementary and alternative medicine in his interview. He described how a friend had encouraged him to use lemon tea as it was *"apparently more stronger than chemo"*. While appearing open to trying it, he also seemed to have a low expectation of it working saying he did not expect to be *"cured overnight"* from it. It did not appear as if this would influence his decision to accept radiotherapy treatment.

Healthcare system

The specialist's ability to work the system so that Rangi's treatment appointments could be booked at a suitable time appeared to be important to Rangi's decision-making. Early morning appointments, for example, worked well for Rangi as they maximised the potential of him being able to go straight to work afterwards, which he appreciated.

Medical: comorbidity, disease and treatment

Comorbidity and treatment factors, while talked about in the consultation, did not appear to influence Rangi's decision-making, however disease factors did. For example, Rangi was interested in knowing the results of his most recent tests to which the specialist informed him there was a change in his disease status due to "*a growth in the prostate*" which had spread by sending "*seeds into the bones*". It appears that the change in disease status in particular may have influenced Rangi's treatment decision-making.

Full details about what would be involved with undertaking radiotherapy were discussed including length, frequency, procedures, treatment goal and benefits. And, although the specialist warned Rangi that treatment benefits could be unnoticeable because he was "*actually really well*" this did not appear to deter his decision to accept radiation treatment.

Themes influencing the specialist's treatment decision-making

Patient

The specialist described Rangi as someone who did not appear to be interested in waiting for "*more severe symptoms*" to develop, which possibly indicates the specialist may have viewed him as a patient motivated towards treatment.

Medical: comorbidity, disease and treatment

Patient symptoms and disease factors appeared to influence the specialist's treatment decision-making, while patient comorbidities did not. In Rangi's case the specialist ascertained information about symptoms by asking "*Any problems?*" and although Rangi replied "*No*" the specialist probed further. Rangi revealed he had recently experienced back spasms and swelling in his leg. Symptom management seemed significant to the specialist as he later explained to Rangi his rationale for treatment was designed to "*prevent it from getting worse*". In his debrief, the specialist also indicated as Rangi had symptoms, radiotherapy treatment was indicated.

In addition to symptoms, new information about Rangi's disease from prostate antigen and other test results indicated "*quite a big bulk*", and spread of the cancer. These factors appeared to be important to the specialist in determining treatment. The need for the specialist to have this information stood out as he halted the consultation until he was able to access it (it was not available in Rangi's file and he had to leave the room to view films). The specialist also reported that when a patient, such as Rangi, had "*progressed through first-line hormone treatment for his metastatic prostate cancer*" the "*next treatment is radiotherapy for symptomatic areas*". This suggested that a treatment protocol may have guided the approach being taken by the specialist to his treatment. At the end of the consultation the specialist also indicated a further "*special*" radiotherapy scan was required to aid the development of Rangi's treatment plan.

Communication

This section begins by presenting an overview of communication related factors that occurred with the potential to influence treatment decision-making in the consultation. Treatment decision-making options, processes and status are also

reported. The section closes by summarising factors appearing to influence treatment decision-making in the consultation.

The parties in this consultation, except Rangi's sister who did not appear to speak, seemed satisfied with each other and their exchanges. Communication in the consultation appeared to be largely controlled by the specialist with the majority of talk originating from him focused on giving and collecting information. The specialist confirmed with Rangi information he had received about him regarding his history, and gathered information on a range of topics including: symptoms, well-being, living situation/family, smoking and alcohol use. The specialist gave Rangi explicit information about his cancer and the proposed treatment including goal, benefits, side-effects and limitations. Rangi was provided with the opportunity to ask questions. Once Rangi had verbally agreed to treatment the specialist provided more detailed information about treatment provision.

Rangi appeared slightly confused about past and present medication and cancer treatment in his consultation and interview. Rangi expressed his expectation that the doctors have that information and that they should share that with each other.

Neither the specialist nor Rangi talked explicitly about prognosis at any time during the consultation, rather the specialist indicated to him that the goal of radiotherapy treatment would not be to cure the cancer, but to "*shrink it down for some time*". One interpretation of this portion of the transcript could be to suggest the specialist was implying to Rangi, that the cancer cannot be cured. Rangi's general responses to information about treatment and side-effects suggested he had some awareness of his prognosis.

The specialist used a mixture of medical and lay terms to communicate information, for example he explained how Rangī's cancer may have spread using lay terms:

So prostate cancer is when cancer grows inside the prostate. So it can grow up yeah, and start affecting the bladder. It can grow back and start affecting the bowel. But it can also send little seeds along further to other places in your body, and they grow (like that). (MS1, Rangī, Con)

Despite the missing scan results, the specialist reported that there were no communication difficulties in the consultation. He reported that Rangī had plenty of opportunities to ask questions and there was sufficient time for the consultation as Rangī was the last patient in that day's clinic. The specialist described Rangī as *"very easy to talk to, quite relaxed"*. The specialist also reported in his debrief that he thought Rangī had understood the treatment options but not necessarily in any depth suggesting *"perhaps [Rangī] didn't want to understand a great level"*. The specialist believed that Rangī had made a *"reasonable decision"*.

In his interview Rangī described the consultation positively and reported that he understood what the specialist had said to him. Possibly in relation to the specialist having to leave the consultation to review results and not having been provided information about medication (e.g. from his urologist and GP), Rangī noted that he was *"quite an efficient doctor. But he seems to have too many things going at once, he wasn't quite prepared"*. Despite this, Rangī reported that the specialist was *"great"*.

Decision-making

Early in the consultation Rangī indicated he wanted the radiation treatment offered however, the specialist indicated his desire to provide more information about the proposed treatment first. Towards the end of the consultation the

specialist explicitly ascertained Rangi's treatment decision by asking him outright "*sounds like you want to have radiotherapy?*". To which Rangi's informal "*Yeah*" reply indicated he had decided to have the treatment discussed. The specialist also sought Rangi's written consent in the consultation. No other treatment options, such as no treatment, were raised by either of the participants.

Summary

Several factors emerged which appeared to influence Rangi's decision-making including being prepared to continue treatment and his optimistic outlook on life. Being able to undergo treatment and keep working was also appeared important to Rangi.

Two key factors appeared to have an important influence on the specialist's decision-making. Firstly, Rangi's motivation for treatment, and second, disease treatment protocols indicating that radiotherapy is indicated when a patient with Rangi's disease characteristics is no longer responding to first-line treatment.

Although communication in the consultation was interrupted by missing information, Rangi and the specialist both reflected positively on the consultation. Rangi appeared to have a limited desire to develop any in-depth understanding about his disease and treatment and this was noted by, and of some concern to the specialist, who responded by persisting with information provision.

Treatment decision-making appeared to be influenced in part by Rangi's history of seeking treatment and the healthcare system (GP and Urologist) which referred him to the specialist. It was unclear if his case had been reviewed in a Multidisciplinary Team Meeting, or if other treatment options, such as surgery,

had been considered. In the consultation, one medical treatment option, radiation therapy, was presented. While an alternative treatment option was mentioned in his interview other options such as watchful waiting were not. The specialist appeared to ascertain in part, Rangi's values, determined the best treatment, and formally sought his consent. Rangi agreed to undergo treatment.

Across Case Summary

Five narrative case summaries identifying factors appearing to influence treatment decision-making in consultations with Māori patients with cancer, their whānau and specialists were presented. Particular attention was paid to comorbidities as they had previously been identified as a cause of cancer treatment inequities, and Māori have a higher incidence of comorbidities compared to non-Māori. The findings were ascertained using the four data sources and qualitative methods referred to in the methodology chapter. The use of Te Whare Tapa Whā and Mead et al.'s (2013) model were helpful when considering factors influencing patients' decision-making.

Of the five cases presented comorbidity appeared to have clearly influenced treatment decision-making in two. The patients in these two cases appeared to have severe comorbidities (cardiovascular and respiratory), however their comorbidities did not appear to negatively influence the treatment they were offered in the radiation consultations studied. The specialists did however inform them that other treatment options such as surgery had been ruled out earlier in the treatment decision-making pathway. It appeared that risks to patients' lives associated with surgery were deemed unacceptable and the risks appeared to be exacerbated by their comorbidities.

Themes relating to whānau, specialists (particularly their treatment recommendation), patients and medical factors (including, comorbidity, disease

and treatment) appeared to influence patients' decision-making in different ways within cases. Healthcare system factors appeared to influence some. Medical (including, comorbidity, disease and treatment) factors seemed to be the primary influence on specialists' treatment decision-making. Healthcare system factors also appeared to influence specialists' decision-making in four of the five cases.

Patients/whānau and specialists in all five cases generally talked in a complimentary and positive way about each other. Also notable, was the significant amount of medical information given to patients by specialists knowing that it was a lot for most to take in. All specialists utilised strategies at times to aid patient and whānau understanding of medical jargon.

Specialists attended consultations having prepared a treatment option (relative to their specialty) based on known clinical (particularly, medical history and disease) factors. Other treatment options unfolded in some cases during the consultation. Specialists' treatment recommendations appeared to be very important to patients, and whānau were particularly important in the one case where no treatment recommendation was made. A treatment decision was made by all five patients in their consultations. Four appeared to accept the treatment option offered by the specialists and one decided to delay decision-making due to complications caused by her comorbidity. The themes identified above which appeared to influence treatment decision-making will be discussed in the next chapter.

Chapter five – Discussion

This thesis has explored factors influencing treatment decision-making in cancer consultations with Māori patients/whānau. Particular attention was paid to comorbidity given the higher burden amongst Māori with cancer (Hill, Sarfati, Blakely, Robson, Purdie, Dennett, et al., 2010; Sarfati et al., 2016; Sarfati et al., 2011). This Māori centred research study utilised case study methodology and qualitative methods to collect and analyse data and to help ‘make sense’ of the complex phenomena of factors influencing treatment decision-making in cancer consultations.

This chapter provides a discussion of the key findings and makes recommendations about factors influencing cancer treatment decision-making in the context of consultations with Māori patients/whānau. Similarly to previous chapters, discussion of key findings has been organised to reflect factors influencing both the patients’/whānau and specialists’ decision-making separately. A conceptual model draws together these factors. The chapter ends with an examination of the strengths and limitations of this study, a conclusion and summary of recommendations.

To my knowledge this is the first ever study which has explored factors influencing treatment decision-making in cancer consultations with Māori patients/whānau. Factors which appeared to influence patients’ decision-making included: whānau; specialist factors particularly treatment recommendations; emotional wellbeing; medical factors such as comorbidity (particularly when severe), disease and treatment and; the health care system factors. Factors which appeared to influence specialists’ decision-making included: medical factors like comorbidity, disease factors like symptoms and treatment; health care system factors such as multidisciplinary team recommendations; patient factors like fitness for treatment and; specialist

factors such as previous experience. Decision-making processes and communication factors also appeared to influence participants' decision-making in the consultation.

Factors influencing patients' decision-making

A number of the factors found in this study to influence patients' decision-making are consistent with past research involving Māori, although not specific to cancer. These are whānau (Dew, Signal, et al., 2015; Durie, 1994; Glover et al., 2007; Nikora et al., 2012; T. Walker et al., 2008), patient factors and information (H. Tupara, 2009). Other factors that were identified in this study but were not in found in the literature relating to Māori include the specialists' treatment recommendations, comorbidity, and the health care-system. This is most likely a reflection of the paucity of research and published literature on Māori treatment decision-making.

There is a scarcity of literature relating to how comorbidities influence treatment decision-making in cancer consultations and none specific to Māori, nor other indigenous people and racial and ethnic minority groups. This occurs despite these groups commonly having higher rates of comorbidity and poorer cancer outcomes than their majority population counterparts. In NZ, Māori with cancer tend to experience higher rates of comorbidity than non-Māori (Hill, Sarfati, Blakely, Robson, Purdie, Chen, et al., 2010; Stevens et al., 2008). In this study, four of five Māori patient participants had comorbidities requiring medication. The impact of comorbidities on patients' lives varied and appeared to be affected by the type, severity and/or number of comorbidities they had and how well they were managing.

In this study the lives of patients with major comorbidities were significantly affected by their comorbidities. They did not work and needed additional support. This finding is consistent with research by Fortin et al. (2006) which

found comorbidity adversely affected health related quality of life in adult patients (Fortin et al., 2006). In contrast, the lives of patients with less severe comorbidities in our study seemed minimally affected, except perhaps for taking daily medication. Patients' views of comorbidities also varied including what patient's considered to be a comorbidity and the perceived importance of this in relation to their cancer. Some patients expected that doctors would 'know' and determine if their comorbidities were important to decision-making or not.

The attitude of patients to decision-making has been noted to have an influence on treatment decisions (Shelton et al., 2013). This was seen in the current study where patients with comorbidities had established regular treatment seeking patterns over time and signalled early in their consultations their intent to take-up the treatment offered. There appears to be a lack of literature that studies the attitudes of indigenous patients to cancer and treatment, with or without comorbidities.

Patients who have received a cancer diagnosis are often offered some form of treatment with the intent being curative or palliative and at times, may involve more than one treatment modality (National Bowel Cancer Tumour Standards Working Group, 2013; National Breast Cancer Tumour Standards Working Group, 2013). Additionally, the treatment may be neo-adjuvant (lead in to main treatment), primary, adjuvant (in addition to primary treatment) or second line (treatment offered when primary treatment is no longer working or contraindicated). The results of this study are consistent with the Sarfati et al.'s (2016) review, which reported that some patients with comorbidities are less likely to receive curative treatment than patients without. This was particularly so for the two patients with severe comorbidities who had surgery, considered primary first line treatment (treatment considered optimal), ruled out because of their comorbidities.

For patients, disease progression and prognosis appeared important. In this study the risk of adverse side effects was greater for one patient with a major comorbidity which appeared to contribute to patient distress, increased patient treatment information seeking and influenced the decision-making process. Treatment side-effects were also important to patients who wanted to know what to expect and what could be done to manage side-effects. Previous research has identified that disease related factors influence patients' decision-making and treatment decision-making, including the impact of side-effects (E. L. Mead et al., 2013). Specialists should be mindful that cancer patients with major comorbidities may have greater psychological and information needs.

This study also supports previous research into cancer treatment and complementary and alternative medicine (CAM) use by cancer patients (Chrystal, Allan, Forgeson, & Isaacs, 2003; Horneber et al., 2012). CAM may be considered and used by cancer patients as part of their cancer treatment regimen either in combination with or as a complete alternative to Western medicine. In this study, four Māori patients with comorbidities talked about using alternative healing medicines and methods. Specialists' responses were generally accepting and may also relate to the patient's prognosis. Lack of knowledge about CAM has been identified in NZ as a possible barrier to communication between the patient and specialist (Bocock, Reeder, Perez, & Trevena, 2011). Increasing specialists' knowledge and communication skills when talking about CAM in cancer consultations where treatment decisions are made may be an area for improvement.

Waiti's use of CAM was the most prominent of the four cases studied. CAM use by patients has been linked to hope (Richardson, Sanders, Palmer, Greisinger, & Singletary, 2000) which may be the case for Waiti given the risk of adverse treatment effects and her poor prognosis. This research also found similarities with literature reporting patient desires for holistic care involving CAM and

traditional Māori healing methods (T. Walker et al., 2008; Walton, Reeve, Brown, & Farquhar, 2010).

Patient attitudes about their cancer, treatment and decision-making varied in this study. Some patients wanted the doctor as the 'specialist' to decide the best treatment while others expressed their 'autonomy' to varying degrees in information seeking and decision-making. Some patients appeared to have an optimistic outlook towards life and their treatment while others were gravely concerned about both. These findings are in agreement with Mead et al.'s (2013) literature review which found patient attitudes and concerns may influence treatment decision-making.

Another important finding was how negative past experiences of cancer within whānau can influence participants emotional responses to their diagnosis and potentially their decision-making. While family, friends and important others experiences of cancer have been found to influence patients' treatment decision-making, patient experiences of coping with cancer within the whānau were not (E. L. Mead et al., 2013). Emotional responses in this circumstance are not wholly surprising given the emotional toll a cancer diagnosis can have on a person. Concern about the psychological status of one patient was attended to by the specialist in the form of a referral for the patient and whānau to support services. It seems plausible that the emotional burden cancer patients experience may be amplified in such a scenario. These types of experiences, involving whānau dying after receiving a cancer diagnosis and/or treatment, may also increase the risk of Māori, experiencing spiritual issues. In Tranberg et al.'s paper spiritual issues with Aboriginal people were linked to fatalism (treatment is 'pointless' and death as the outcome cannot be altered). . Evidence of Māori fatalistic thinking however was absent from the data and literature reviewed in this study.

One unanticipated finding was the employment of humour by patients and whānau in some consultations. In one consultation the patient's predicament was fairly dire yet humorous talk emerged about private body parts. In cases where humour was present it appeared to lighten the mood of the consultation, similar to findings by Dew et al. (2015). Humour, when used at the right time with Māori has also been identified in the literature as something which can aid rapport building and put patients at ease (Cram, 2014b).

Prior studies have noted the impact of a cancer diagnosis on patient employment and household income (Bennett et al., 2008). In some cases, maintaining employment was identified as an important issue and workplaces were reported by participants as being supportive. Rangi even attributed 'whānau type' qualities to his workplace. Maintaining employment has been linked to empowering the patient to help understand and manage their cancer experience (Egan et al., 2016).

The prevalence of mental disorders such as depression and anxiety is high for cancer patients (Mitchell et al., 2011). Additionally the risk of mental disorders is higher for cancer patients than the general population (Hinz et al., 2010) and the prevalence is higher in patients with comorbid disease such as COPD (Rapsey et al., 2015). In this study, some patients' mental states appeared to be affected differently by their comorbidities, which in turn may have influenced their decision-making. In Waiti's case her vulnerable mental state was evident however her mental wellbeing did not appear to be well attended to by the specialist. Lockett et al.'s (2011) study found some ethnic minority cancer patients report significantly worse distress and depression than majority populations (Lockett et al., 2011). This study however did not attempt to compare Māori with NZ Europeans (the majority population in NZ).

Prior studies have also noted the importance of whānau in the patient's cancer experience (Dew, Signal, et al., 2015; Slater et al., 2013; T. Walker et al., 2008).

This study showed that patients considered and involved whānau in treatment decision-making in various ways. All participants were supported to their consultations, four of five participants by whānau members. Whānau support to consultations is unsurprising given that Māori culture is based on collectivist principles (Patterson, 1992) and in line with work by Durie which suggests that Māori health and decision-making is aligned to interdependent approaches (Durie, 1994).

In this study, whānau were considered by some participants to have a right to be involved in treatment decision-making. Whānau played many roles across and within the different cases such as provider of normality, information gatherer/stimulator/provider, aid to carrying the 'load', protector and advocate. Participants also considered the impact of their treatment choices on whānau. These findings were not unexpected, as whānau have been identified as important in decision-making in traditional and contemporary contexts (Durie, 1994; Nikora et al., 2012; Hope Tupara, 2012). There are also similarities between these findings and those related to whānau in New Zealand cancer literature by Walker et al. (2008), Slater et al. (2013) and Egan et al. (2015). This result also loosely matches the findings of Mead et al.'s 2013 review with regard to the influence of minority racial and ethnic groups family on decision-making.

It is interesting to note however, that not all participants involved whānau in decision-making directly. No evidence was found to explain why Māori patients may not involve the wider whānau in decision-making at the consultation. This result may simply be a reflection of differing participant preferences or may be for more complex reasons relating to whānau dynamics and changing realities for Māori, ultimately as a result of colonisation. Additionally, many Māori living in modern day Aotearoa have integrated Western/NZ European cultural practices into their lives.. Durie (1994) argues that Western culture in NZ values

self-sufficiency and independence which could explain a preference by some participants for a more individualistic decision-making approach. Many Māori have also become isolated from their home lands and other whānau members due to living large distances from both, therefore involving whānau in decision-making may be more challenging. This isolation may be further exacerbated as many whānau now live overseas. Over 100,000 Māori live in Australia for instance (Statistics New Zealand, 2015). Another possible reason for not involving whānau could be to protect them or to enable the patient to choose an appropriate time to share their situation and reduce anxiety.

The role of whānau influence in patients' treatment decision-making seen in this study is consistent with Lawrenson et al.'s (2010) study of rural general practitioners' perceptions of Māori palliative care requirements where whānau were identified as key in patient management (Lawrenson, Smyth, Kara, & Thomson, 2010). This research appears to be the first to attend to specialist's perceptions of the influence whānau may have on Māori cancer patients' treatment decision-making in the outpatient secondary cancer care setting. A possible explanation for the role of whānau emerging as an influence may be in part due to improvements made to doctors' training in New Zealand. For example, the University of Otago medical school trains new doctors using models like Waikare o Te Waka o Meihana in which whānau are recognised (Pitama et al., 2014).

These results may help us to understand one element, how whānau influence treatment decision-making, in the complex array of factors which influence Māori patients' decision-making in cancer consultations.

In NZ, the health care system (the system) has been found to influence access to treatment for cancer patients and Māori in particular (Cormack et al., 2005). The system largely sets policy, processes and procedures which guide how consultations are undertaken. In this study, patients were referred for

treatment and consultations largely followed conventional processes whereby the patient (including whānau/support) met with a specialist (and a breast care nurse specialist in one consultation) in a private room, and shared and discussed information. None of the participants had met prior. Most consultations also involved a physical examination. Consultation appointment lengths generally aligned to the times scheduled, with radiation oncology appointments lasting about 30 minutes and medical oncology about 60 minutes.

Access to system support services such as psychologists and social workers was offered in some consultations along with offers to 'work' the system so treatment could be delivered in a patient responsive manner in others. While specialists appeared to try and not pressure patients to make a decision, at the same time there appeared to be an expectation that the patient either make a decision or at least give an indication as to what they might choose to do. It appeared the reason for this was to set in motion treatment related appointments which would enable further tests and treatment administration to commence in a timely way given system constraints. While there are system issues to be overcome, it is also important to note that there are many good aspects to the NZ health care system and in particular the fact it is publicly funded increasing accessibility for NZ citizens.

Factors influencing specialists' decision-making

Many of the factors found to influence specialists' treatment decision-making in this study are consistent with past research. Comorbidity, disease and treatment related factors for instance were identified in this study as influencing specialists' decision-making as were a range of disease factors including symptoms, tumour growth, spread and progression. This finding supports previous research into factors influencing specialist decision-making which

identified comorbidity and disease related factors (Grunfeld et al., 2001; Tariman et al., 2012)

In this study severe comorbidity made treatment decision-making difficult in two cases. This finding is similar to those of Shepherd et al.'s (2008) who found 95% of the 605 cancer specialists surveyed identified other patient health problems caused difficulties in treatment decision-making (Shepherd et al., 2008). In Waitā's case a unique situation occurred. His comorbidity was identified by the specialist as a key factor prompting his decision to offer cancer treatment. Radiation treatment in Waitā's case would enable him to recommence prophylactic treatment for cardiovascular disease for a period of time. It appears the Waitā's risk of another cardiovascular event was more concerning to the specialist than his stomach cancer.

The lack of high quality evidence to inform treatment decision-making for cancer patients with comorbidity make it difficult for patients and specialists to weigh up treatment benefits and harms. Often cancer patients with comorbidity are excluded from gold standard studies such as randomised control trials because of their comorbidities alongside other factors such as age (Lewis et al., 2003). This creates a conundrum for the specialist in that treatment guidelines are often based on studies which have excluded patients with comorbidity even though such patients form a significant proportion of the cancer patient population (Sogaard et al., 2013). Additionally these studies often have few, if any, indigenous participants who often have higher levels of comorbidity and poorer survival (Sarfati, Gurney, Stanley, & Koea, 2014; Sarfati et al., 2016). Future cancer studies and treatment guideline should therefore be inclusive of indigenous and comorbid populations.

Specialists in this study gathered information about comorbidities in the consultation. Comorbidities influenced patients' fitness for treatment differently. Additionally, patients' medication use had to be considered for

contraindications and their ability to cope with treatment procedures assessed. Despite concerns about patient fitness in the two cases where there were major comorbidities, the specialist did not appear to alter the treatment option offered. Therefore comorbidity did not appear to be a reason for radiation treatment withdrawal in the cases studied.

While treatment details such as number of medications and treatment frequency were attended to, side-effects appeared to feature more so for specialists, particularly during the treatment administration phase. Specialists wanted to give this information and one could speculate that this was to insure that patients could be informed in their choice. These findings are consistent with other studies into treatment decision-making which identified the influence treatment factors, including side-effects, have (Sundaresan, King, Stockler, Costa, & Milross, 2015).

Another important finding was that patients' Whānau and their medical history in particular was found to influence which tests specialists order to inform treatment decision-making and monitoring. Gathering a medical history is standard procedure in many circumstances. Given the higher incidence of comorbidities among the Māori population and minority groups (Centers for Disease Control and Prevention, 2013) ensuring this is comprehensive and inclusive of family history may be particularly important.

One unanticipated finding, seemingly related to the system, occurred when a patient's consultation proceeded with missing information despite it being relevant to the treatment offered. This raises concerns about how a patient could truly make an informed choice and give consent and how the specialist determines best patient centred treatment when vital pieces of information are missing. Ideally specialists would have all results in advance of the consultation to maximise resources and minimise patient distress.

Other factors influencing specialist decision-making matching other studies included patient factors like willingness for treatment (Cavalli-Björkman et al., 2012), and system influences like multidisciplinary teams (Mendick et al., 2010).

Communication

Specialists, patients and whānau were complimentary of each other and good communication was established, which was critical to ensure that important information was shared between them.

Prior studies have noted the importance of communication in the cancer treatment decision-making process (Hack et al., 2012; M. Johnson, 2012; Laidsaar-Powell et al., 2013; T. Walker et al., 2008). Some of the communication findings in this study were consistent with this literature. For example, whānau aided communication by providing information, some specialists established what was important for the patient and rapport building activities were undertaken (Hack et al., 2012; M. Johnson, 2012; Laidsaar-Powell et al., 2013; T. Walker et al., 2008).

Information giving is complex and providing all information can be impossible (Mendick et al., 2011). Deciding what the 'right' amount of the 'right' information is, to tell a patient, so they may make an informed treatment choice and give informed consent, is no doubt challenging for specialists to achieve in 30 to 60 minute consultations. Additionally, the results of this study show the information load patients had to process often began accumulating prior to the consultation. Disease and treatment related information was given or sought from other health professionals, family and other sources such as the internet. Information loads also appeared to be greater and more complex in medical oncology consultations compared to the radiation oncology consultations. Information complexity was further compounded when patient comorbidity was considered.

Support options and coping strategies were also discussed more in medical oncology compared with radiation oncology consultations. Ensuring a patient can make an informed decision when giving consent may inadvertently be an underlying cause of information over-load. One flaw or risk of giving ‘all information’ is completely overwhelming the patient. Therefore it is important to ascertain from the patient what information they would like and tailor information provided in the consultation accordingly, in line with cancer communication guidelines (Rodin et al., 2009).

In NZ, one description of health literacy is *“the ability to obtain, process, and understand basic health information and services to make appropriate health decisions”* (Ministry of Health, 2010b). Avoiding medical jargon has also been found to aid effective patient provider communication (Shahid, Durey, Bessarab, Aoun, & Thompson, 2013). Of the communication related activities observed in this study specialists tried to manage information loads, used a variety of information giving methods and tried to tailor information to the patient. It was also interesting to note that although medical jargon was often evident, some specialists mentioned or were observed to translate medical jargon using lay terms in consultations. Effective strategies used by specialists to enhance Māori patient health literacy in cancer consultations are important.

Prior studies have noted the importance of patients trusting and having confidence in specialists (Henman, Butow, Brown, Boyle, & Tattersall, 2002). An interesting finding in this study was the case where both the patient and specialist had gathered information about each other prior to the consultation. This activity may be possible in smaller cities where hospitals serve a smaller population. In this study, Nuku had gathered information from community contacts about the specialist and the breast nurse specialist had provided the specialist information about Nuku. A possible explanation for Nuku’s information gathering might be related to Nuku’s prior negative whānau

experience with cancer services. Establishing trust in the specialist she would accept treatment from was therefore important. A possible explanation for the specialist undertaking this activity could be linked to the breast nurse specialist having a long established relationship with Nuku. She was able to inform the specialist about the patient's concerns and anxiety which enabled the specialist to prepare for the consultation accordingly.

Nuku's consultation was also the only one where the specialist opened by asking the patient directly what her key priorities were prior to discussing treatment which was also found to be important by Henman et al. (2002). As this specialist only participated in one of the cases studied it is difficult to determine if opening this way was unusual for her. Nevertheless, determining patient priorities can help the specialist tailor information to what is important to the patient's decision-making.

Comorbidities have been found to negatively influence prognosis (Hong et al., 2015; Sarfati et al., 2009; Stevens et al., 2008) and survival, with Māori patients experiencing poorer outcomes compared to non-Māori (Hill, Sarfati, Blakely, Robson, Purdie, Chen, et al., 2010). Yet, within the consultations studied little conversation between participants attended to prognosis in any detail. This finding supports previous research which suggests that specialists struggle to discuss prognosis and there is little to guide them on the best way to do this (Hagerty, Butow, Ellis, Dimitry, et al., 2005). It is also likely that the prognosis of patients with comorbidity or multimorbidity is more difficult to determine.

In two of the cases studied, it appears that the majority of information on patients' comorbidity was obtained by specialists after questioning patients rather than through referrals. Additionally more comorbidity information was generally given by patients to the researchers in interviews than to specialists in consultations. Why comorbidity and medication information was lacking from patients' referrals is unknown. A possible explanation is that referrers simply

include information they think is relevant, not necessarily all information. The lack of time pressure in the interview may also explain why some patients gave the interviewers more comorbidity and medication information than to specialists. Additionally the cultural concept known as whakama (shyness, embarrassment) may provide another possible explanation for patients withholding comorbidity information from specialists, particularly if rapport had not been well established and/or the consultation was time pressured.

If patients were whakama with specialists, the sharing of more detailed information with research interviewers suggests they were not whakama with them. This may be explained by the researchers being Māori and having time to whakawhānaungatanga with patients/whānau prior to and post the consultation. A different power dynamic and less stressful circumstances could also explain this. Another plausible reason for poor communication relates to the difference in backgrounds between the specialist and patients who are from different ethnic groups (Boffa, 2008). Some NZ health workers have reportedly found it more difficult to communicate with people not of a similar background (Crengle, Lay-Yee, Davis, & Pearson, 2005). In such circumstances Hill et al. (2013) report specialists may be *“more likely to rely on stereotypes and less likely to seek clarification from the patient or their family”*(pg. 38).

Decision-making

It is important for specialists in consultations to determine patient priorities, concerns and needs when working up treatment options and making decisions.

The second question in this research was to identify factors (other than comorbidity) which influenced treatment decision-making in the consultation. A strong relationship between specialists' recommendations and patients' decision-making has been reported in the literature and is not restricted to indigenous or racial/ethnic minority populations (Davidson et al., 2013; E. L.

Mead et al., 2013; Puts et al., 2015). The specialists' recommendations were an important factor which appeared to influence patients' decision-making in this study.

Some studies have found that patients associate treatment recommendations made by specialists with optimal treatment (Henman et al., 2002). Furthermore, Henmen et al.'s 2002 study suggests that there is, in fact, no decision to be made because having treatment is a given, meaning that the consultation is merely to discuss the details that need attending to. Similarly, patients in the current study chose to attend a medical or radiation oncology consultation to discuss treatment options. Attending the consultation could be interpreted as the patient expressing intent to undergoing some form of cancer treatment. The vast majority of people choose (for whatever their own reasons may be) to seek help and care from those who are experts. Māori, like anyone else, want and should have the 'best' care. In the realm of cancer care, specialists are the experts and the fact that people will follow their recommendations is generally to be expected.

Taking a more passive role in decision-making is linked to patients of an older age (Davidson et al., 2013; Obeidat et al., 2013). In this study the age of the participants who appeared to base their decision on specialists' recommendations varied. Patients in two of the cases were aged in their 70s, and one was younger in her 30's. While it seems logical to follow treatment recommendations made by cancer experts, there are however personal circumstances and risks which must also be considered. On reflection, the patient who defers treatment decision-making to the specialist risks feeling the treatment decision was not actually theirs. They may go on to experience regret and it may influence their sense of satisfaction with the decision made (E. L. Mead et al., 2013; Obeidat et al., 2013). It is therefore important that specialists invite patients to participate in decision-making and signal to them the value of

their participation. After all, patients have a right to participate in decision-making and specialists have ethical obligations to share decision-making with patients (Salzburg Global Seminar, 2011).

Some studies have noted the potential for patients with comorbidities to experience more opportunistic screening leading to early diagnosis as a result of being in regular contact with health services. Others have shown the opposite, where a patient's comorbidity has distracted the patient and health professionals leading to a delayed diagnosis (Corkum et al., 2012; Fleming, Simmons, Leakehe, & Voyle, 1995; Sarfati et al., 2016; Terret, Castel-Kremer, Albrand, & Droz, 2009). Both outcomes were observed in this study. It was apparent in two cases that the patients' diagnosis (or suspected diagnosis) occurred as a result of being under the care of a specialist. In a third case, it appeared as if the initial investigation of the patient's cancer symptoms in the primary care setting were distracted by the patient's major comorbidity. These findings are important as they demonstrate how comorbidities can potentially affect the extent of disease at diagnosis and patient prognosis.

Comorbidities have been found to influence the ability of specialists to definitively make a cancer diagnosis and develop treatment options (Vansteenkiste et al., 2013). In this study there was one instance where a definitive diagnosis could not be made due to the patient's comorbidity, which added significant complexity to her case and may have resulted in her wish for further consultation with whānau. Mead et al. (2013) suggests there is reduced treatment uptake by patients when specialists do not make a recommendation (E. L. Mead et al., 2013). It would be interesting to examine cases where treatment recommendations had not been made to ascertain if there is an association with treatment decline. Decision-making by patients with major comorbidities with a high risk of adverse outcomes may be more inclined to delay or consider the option of declining treatment.

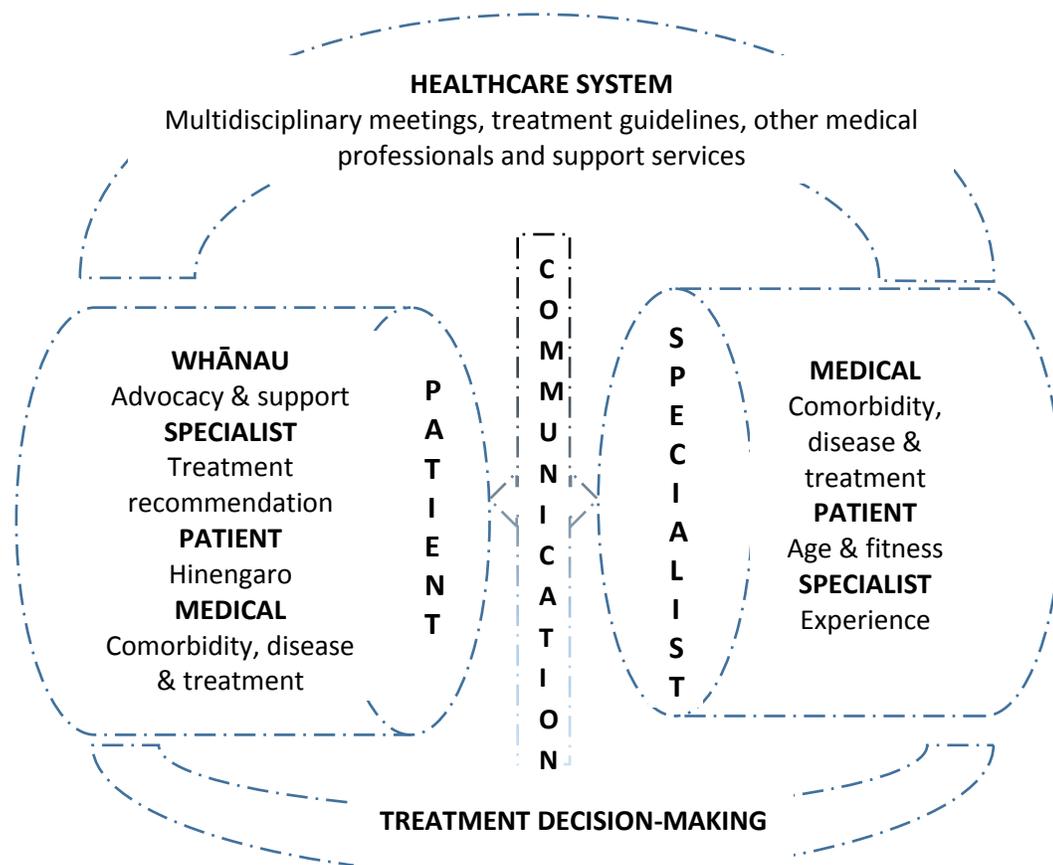
In these cases decisions about which treatment options would be made available to these patients were often determined ‘up-stream’, some by a multidisciplinary team, prior to the consultations studied. This is of concern as a recent review by Stairmand et al. (2014) found comorbidity was not well considered by multidisciplinary teams and members were likely to be unaware of the extent to which comorbidity is ignored (Stairmand et al., 2015). Stairmand et al. (2014) argue that multidisciplinary teams should systematically consider patient comorbidity in treatment decision-making as it may contribute to improved patient outcomes.

Several decision-making models involve the specialist making a treatment recommendation to the patient (Charles, Whelan, & Gafni, 1999; Kon, 2010; Makoul & Clayman, 2006). In this study specialists made treatment recommendations in four of the consultations. This finding is in line with Frongillo et al. (2013) who found that the majority of cancer patients receive a treatment recommendation (Frongillo, Feibelman, Belkora, Lee, & Sepucha, 2013). In Waiti’s case, where a treatment recommendation was not made by the specialist he clearly stated that the decision was for Waiti to make. Patient led decision-making aligns with informed models of decision-making.

Conceptual model of decision-making

The key factors found in this study to influence patient/Whānau and specialists decision-making have been used to create a conceptual model of decision-making (Figure 5). This model identifies the different levels of treatment decision-making determinants for Māori patients/whānau and specialists, which include factors at the healthcare system, patient, specialist and communication levels all of which influence decision-making processes in consultations.

Figure 5: Conceptual model of factors influencing treatment decision-making in cancer consultations with Māori patients/whānau and specialists.



Strengths and limitations

This qualitative study of factors influencing decision-making in cancer consultations with Māori has a number of strengths and limitations. First, and possibly most importantly, the major strength of this study is that it appears it is unique in Aotearoa/NZ in focusing on the indigenous people, Māori. Given that both Māori patients'/whānau and specialists' perspectives were required, the selection of a Māori centred research paradigm and a case study research strategy was appropriate. The nature of the research questions and the

environment in which the phenomena occurred was also suited to the use of qualitative methods.

A Māori centred research approach ensured that Māori were the focus of the study and a Māori world view considered by the involvement of Māori at all levels of the research. Qualitative methods used in this study enabled a broad focus on comorbidities and consideration of real life contextual factors likely to influence the phenomena of decision-making not obtainable from quantitative studies. Developing a deeper understanding of issues faced by Māori and specialists in decision-making is important in the New Zealand context. Such understanding will ensure that quantitative studies which cover the range of related factors do not fall into the trap of over simplifying a complex process.

The quality of information was enhanced by the decision to draw data from multiple sources for the different participants. Looking for coinciding patterns amongst the data and data triangulation strengthened the internal validity and rigor of the study. The researcher acknowledges that information may have been shared between patients/whānau and specialists prior to and post the recorded consultation. The use of audio-recordings also meant that only verbal exchanges were captured. Videoing may have provided a richer data set and should be considered for future studies of this nature. The literature review was also limited in that this is not a well indexed field meaning articles may have been missed and additionally only English language literature was included. The literature review findings were also limited by the apparent lack of studies regarding indigenous peoples in this field. Field notes enabled the researcher to record behaviours and activities observed during data collection.

In this study, research activities aligned with notions of reciprocity and tika (the right thing to do). For instance, participants were offered copies of information captured and shared with the researchers should they want it. To ensure good quality research occurred, development of the research protocol, questions, and

analysis involved my supervisors and at different points in the process, other senior members of the C3 Qual research team.

Ensuring that this research was undertaken ethically was highly important as it was recognised that the participants were in a 'vulnerable' state. Attention was paid to ensure people could give 'informed consent' regarding their participation in the study and approaches to potential participants were made by a third party not affected by the outcome. When people were approached to participate in the study they were informed clearly that it was completely voluntary, that their treatment would not be affected in any way and that everything they said, if used, would be anonymised, to maintain their privacy.

The research protocol required eligible participants to have received their cancer diagnosis prior to the consultation, however in one case the researchers did not become aware that this had not occurred until they were in the patient/whānau interview. This particular issue was discussed with a supervisor and it was agreed that the case would stay in despite the deviation from protocol on the condition that the issue was acknowledged when the case study was written up. It is possible that this patient may have behaved differently during the consultation as a result of having just had their diagnosis confirmed compared to the other patients who had days or weeks to process the diagnosis prior to the consultation.

Limitations of this study include a possible change to behavior by those participating in the consultation knowing that it was being recorded and response bias by the interviewees. Despite these risks, consultations and interviews seemed to flow easily and no comments were made by any participants which suggested they were affected by the audio-recorder at any time. This finding is in line with work by Henry et al. (2015) (Henry et al., 2015). Additionally the transcripts were reviewed by two senior clinicians (one a practicing oncologist) from the C3Qual study who did not note any variance

from what might be considered 'normal' practice in cancer consultations. Future research could explicitly ask patients and specialists about how it feels to be recorded and whether they thought it changed their behaviour.

Despite being a small study of five Māori patients, their whānau and three oncologists from two differing specialties, this study shows that research taking a Māori centred approach, with these different groups can be successfully undertaken. Furthermore, this can be done in Western based hospital settings and a rich and comprehensive body of information can be obtained.

Originally this study aimed to recruit 15 Māori participants from the C3 Qual study. However this was impossible for two reasons. Firstly, there were difficulties recruiting a large hospital and associated specialists into the C3 Qual study, primarily due to hospital staffing issues. Secondly, there was an over-estimation of the number of Māori participants that would be eligible for the study from participating hospitals. Additionally, one specialist participated in three of the consultations studied which may mean some findings are related to his/her practice. It is likely such difficulties could be overcome if the study was undertaken over a longer time period and more patients and specialists were recruited.

A larger sample and access to patient medical records would also enable verification and comparison of findings. If a similar study was to be repeated I would recommend the specialist debrief be expanded to a brief interview and that the questions asked be amended to include greater detail about how and who participated in the development of treatment options. I would also recommend that follow-up be undertaken to ascertain the patient's decision and treatment status 4-6 weeks post initial treatment consultation. This could be done via a patient notes review and follow-up telephone interview.

It is important to take a cautious approach in generalising these results to all Māori cancer patients/whānau and oncologists. However, this study does provide valuable understanding and insights in a field deficient of knowledge.

Summary

This study examined factors influencing treatment decision-making in cancer consultations between Māori patients/whānau and specialists with a view to identifying clues into the causes of Māori cancer treatment disparities. Consultations were recorded and participants were provided with an opportunity to discuss factors in their own words. Themes influencing patient decision-making identified in the literature were organised based on Te Whare Tapa Whā and Mead et al's (2013) conceptual model of shared decision-making.

A number of particularly important factors were found to influence patients' decision-making including medical factors (e.g. comorbidity, disease and treatment), patient (e.g. emotional wellbeing) and the healthcare system. Of particular note was the influence of the whānau and specialists' recommendations on patient decision-making. Specialists' decision-making was influenced by patient (e.g. fitness for treatment) and specialist (e.g. experience) factors. Medical factors (e.g. comorbidities, disease and treatment) and healthcare system factors (e.g. multidisciplinary team recommendations) appeared to be particularly important factors influencing specialists decision-making.

Treatment options in these consultations were prepared in advance by specialists in consultation with other medical professionals. This meant that a large portion of consultations were controlled by specialists informing patients of the medical treatment options available along with details such as side-effect and administration. Other options, both medical and alternative, were only

discussed when raised by patients. This suggests that an informed type model of decision-making occurred in the consultations studied.

To ensure patient participation and a patient centred approach is taken it is important to establish the patient's agenda in the consultation. Additionally it is important that specialists translate medical jargon, and recognise that comorbidity may add additional load to communication. Similarly to other studies the development of Māori specific resources may be helpful in improving patient/Whānau health literacy (Cormack et al., 2005; Slater et al., 2013; T. Walker et al., 2008). In respect to treatment decision-making, treatment aids and support may also be beneficial to patients' decision-making (Furber, Murtagh, Bonas, Bankart, & Thomas, 2014; Stacey et al., 2014).

However, no one major thing appeared to stand out as a possible cause of Māori cancer treatment disparities. Similarly, Hill et al.'s (2010) qualitative study of colon cancer management differences between Māori NZ and non-Māori New Zealanders found no dramatic difference between groups at any one management step. Rather, they identified small differences which accumulated along the management pathway including diagnosis, waiting times, quality of care and interventions (Hill, Sarfati, Blakely, Robson, Purdie, Dennett, et al., 2010).

I was unable to determine from the findings in this study if potential causes of Māori cancer treatment disparities occurred in the consultations studied. As this was a small case study of five patients, a larger study may better answer the research questions. A comparative analysis between Māori and NZ Europeans consultations may also be helpful. Additionally, treatment options were largely determined prior to the consultation by the specialists, multidisciplinary teams and other colleagues. I suggest that further research is warranted 'up stream' from the consultation. This might include further exploration of treatment processes like the referral pathway and complex case management involving

multiple specialties and providers. More clues into the drivers of Māori cancer treatment disparities may lie there.

Based on the findings of this study the following recommendations are suggested:

Policy, service and practice

- Acknowledge diversity amongst patients of Māori ethnicity in the delivery of patient centred care
- Recognise that Māori patients are more likely to carry a greater burden of cancer and other diseases coming into the consultation which may require a suite of responses (e.g. psychology support services, genetic testing, modification of standard procedures and taking a comprehensive medical history);
- Cultural safety training for staff (including specialists)
- Provide additional opportunities and support to enable informed shared decision-making involving when there are a number of participants involved and the case is complex (e.g. no clear treatment pathway).
- Provide additional space and support for whānau supporting patients

Research

- Undertake ethnic inequalities focused research earlier in the treatment decision-making pathway.
- Undertake a comparative analysis of factors influencing treatment decision-making between Māori and NZ Europeans (planned as part of C3 Qual).

Appendices

Appendix A: C3 Qual – Clinician information sheet

Appendix B: C3 Qual – Clinician consent form

Appendix C: C3 Qual – Clinician Demographic Information Form

Appendix D: C3 Qual – Patient Interview/invitation checklist

Appendix E: C3 Qual – Referral form

Appendix F: C3 Qual - Patient/Whānau Interview Schedule

Appendix G: C3 Qual – Patient/Whānau Information Sheet

Appendix H: C3 Qual – Patient/Whānau Consent Form

Appendix I: C3 Qual – Participant Demographic Information Form

Appendix J: C3 Qual - Clinician Prompt Sheet

Appendix K: Ethics approval letter

Appendix L: Ngāi Tahu Research Consultation Committee letter



C3 – Cancer Care Journeys and Clinical Decision-making

Patient and Clinician Responses to the Consultation

CLINICIAN INFORMATION SHEET

Thank you for showing an interest in this research. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.

Who is doing this study?

This study is being led by researchers at the University of Otago Wellington, Massey and Victoria Universities and is funded by the Health Research Council.

What are the aims of the study?

There are significant inequalities in cancer survival between Māori and non-Māori, and evidence that comorbidity and service access play important roles. This research aims to understand the independent and interacting influences of ethnicity and comorbidity on cancer survival and to develop interventions that will strengthen health service delivery. In the first phase of the research we studied decision-making in multidisciplinary team (MDT) meetings. This second phase aims to assess:

1) the impact of ethnicity and/or comorbidity in specialist cancer treatment consultations

2) understand the perceptions of clinicians and patients/whānau of the impact of ethnicity and/or comorbidity on cancer treatment consultations

3) identify interventions specific to cancer treatment consultations that would reduce disparities in cancer survival due to ethnicity and/or comorbidity.

In so doing, it is hoped to better understand the decision-making process in consultations and the ways that clinician-patient communication can be enhanced. It is hoped to identify effective approaches already in use that can be promoted and to explore ways to improve less effective approaches through piloted interventions. Further details are outlined below.

What does this study involve?

This research is being undertaken with clinicians interested in reducing cancer disparities potentially due to comorbidity and/or ethnicity and patients who have received a cancer diagnosis. Thirty consultations where clinicians discuss cancer treatment options with patients will be recorded (audio) and analysed.

Potential participants will be identified by clinicians and following MDT meetings. A clinician, nurse, administrator or researcher will advise potential participants there is a study they are eligible for. The researcher will provide information and consent those choosing to participate.

If you agree to participate in this research project you will be asked to:

Identify potential patients eligible for this research.

Record some of your consultations (about 5). The researcher will provide you with a digital recorder and the names of patients and appointment times of those who have agreed to participate,

Record your responses to each of the consultations on a digital recorder (clinician debrief) shortly after the consult using a prompt sheet of questions (please see below). We estimate it will take about 3-5 minutes to complete per consultation.

Provide some demographic information about yourself to enable us to broadly describe the range of clinicians participating in the study (please see below).

Patients and their whānau will also be asked to participate in a semi-structured interview post-consultation to record their responses to the consultation. In each case, consent from all participants (clinicians, patients and whānau) is required. If this is not possible, that consultation will not be studied.

The recordings and transcripts will be anonymised by the researcher before other members of the research team hear/see the data. This process of anonymisation will include removing all clinician and patient/whānau names and the anonymised linking of patient ethnicity and comorbidity status by using data provided by the clinician from the clinician's debrief. Once data has been analysed the research team will present the findings to the participating clinicians to seek feedback on the findings and advice about potential interventions and a paper will be drafted. These findings will inform the development of questions for further stages of the research.

You may withdraw from participating in this project at any time without any disadvantage to yourself of any kind. If you withdraw, the consultation/s and clinical debriefs you participated in will not be used in the research.

If you agree to participate the consultation and debrief data will be used in publications but you will not be named and every effort will be made to ensure that you are not identified in any reported data. You will be provided a copy of the results should you wish. Transcripts and audio recordings will be kept on password protected computers and in locked filing cabinets for ten years, at which time they will be destroyed by Associate Professor Signal.

Ethical issues

This study has received ethical approval from the Central Region Ethics Committee (REF: CEN/12/06/026). If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact your professional organisation.

Timeframe

It is hoped to collect data during 2013 and early 2014. Data will be analysed and findings reported back to participating clinicians by early 2014. A paper will then be completed for publication. It is planned to pilot at least one intervention identified from Phase 2. This would likely occur in late 2014.

If you have any questions about the research please contact:

Associate Professor Louise Signal, Ph (04) 918-6477, Mobile 021 0324 720 University of Otago, Wellington, email louise.signal@otago.ac.nz

or Professor Chris Cunningham, Ph (06) 380 0627 Massey University, Wellington, email c.w.cunningham@massey.ac.nz



Te Whare Wānanga o Otago

C3 – Cancer Care Journeys and Clinical Decision-making

Patient and Clinician Responses to the Consultation

CLINICIAN CONSENT FORM

I have read and understood the information sheet explaining this research.

I have had the opportunity to talk about the research and ask questions. I am satisfied with the answers I have been given.

I understand that my participation is voluntary and that I can withdraw from this research at any time.

I understand that I will not be named and that every effort will be made to ensure that I am not identified in any reported data.

I know whom to contact if I have any questions about this research.

I agree to take part in this research. Please circle the option that applies to you.

YES

NO

I agree to allow consultations I attend and my debrief be recorded. Please circle the option that applies to you.

YES

NO

I _____ **hereby consent to take part in this study**

(First Name/Surname)

Signature: _____ **Date:** _____

- I would like a copy of the findings of the research to be sent to me after the research is completed. Please circle the option that applies to you.

YES

NO

If yes would you like this sent hard copy or electronically ?

In order to send you a copy of the transcripts and research findings could you please record your details below.

Name: _____

Address: _____

Email: _____

Signature: _____ **Date:** _____

*Please turn over the page and complete demographic information.

This research is being led by researchers from the University of Otago Wellington and Victoria and Massey Universities.

If you have any questions about the research please contact:

Associate Professor Louise Signal, Ph (04) 918-6477 University of Otago, Wellington, email louise.signal@otago.ac.nz or

Professor Chris Cunningham, Ph (06) 380 0627 Massey University, Wellington, email c.w.cunningham@massey.ac.nz



C3 – Cancer Care Journeys and Clinical Decision-making

Patient and Clinician Responses to the Consultation

CLINICIAN DEMOGRAPHIC INFORMATION

We would like to collect a few details for statistical purposes. This information will assist us describe the group of clinicians who took part. No individual names will be used in any reports.

Name: _____ Position: _____

(First Name)

(Surname)

1. Are you: ↑Female Male

2. When were you born? ____/____/____

dd/mm/yy ↑ ↑

3. Which ethnic group/s do you belong to? (tick the box or boxes that apply to you)

New Zealand European

Māori

Samoan

Cook Island Māori

Tongan

Niuean

Chinese

Indian

Other (such as Dutch, Japanese, Tokelauan)

Please state if 'Other': _____

How long have you been practicing medicine?

Overseas

In New Zealand

What area/s of medicine do you specialise in?

Thank you for your participation in this study.

Appendix D

C3 PHASE 2 PATIENT INTERVIEWS INVITATION CHECKLIST

1	<p>Introduce self: xxx, Researcher, University of Otago – Wellington,</p> <p>You have been referred by ..., XX</p> <p>as someone who may be interested in participating in our research?</p> <p>Is that correct? And are you still interested? Is now an OK time to talk?</p>	
2	<p>You are under no obligation to participate,</p> <p>and that it will in no way will your decision affect their treatment or how the Doctors/nurses will treat you</p>	
3	<p>Why? The journey of a person with cancer can be</p> <p>complex and</p> <p>people may receive care from multiple doctors and nurses</p> <p>in different settings</p>	

	<p>often away from home.</p> <p>People must make critical decision about many things including which treatment to have.</p> <p>These decisions are often made in or soon after consultation with a doctor.</p> <p>This study explores the things that people and their doctors consider when making treatment decisions.</p>	
4	<p>What's involved? 3 things.</p> <p>1) Your informed consent is required to participate.</p> <p>2) The doctor will record your next consultation as normal (researcher not present)and</p> <p>3) you will be asked to participate in a private interview after your consultation (about 30mins, cupa tea)</p>	
5	<p>What then? The researchers will analyse all the information they collect and see if they can find some clues/answers.</p>	Optional
6	<p>Who's doing this? Our doctors and doctors from (xx and xx Hospitals) and researchers who come from the University of Otago-Wellington, Victoria & Massey Universities)s are working with the doctors from XX and XX Hospital</p>	

7	Any questions?	
7	<p>Three Likely responses.</p> <p>1) Yes interested and would like to find out more</p> <p>2) May be unsure/maybe (would like some time to consider)</p> <p>3) No, not interested</p>	
8	<p>Patient response Yes interested:</p> <p>Seek verbal consent to participate YES/NO</p> <p>OK method to send info/consent forms etc. email/post/hard copy prior to appointment</p> <p>confirm appointment details date _____/time_____/venue (check referral)</p> <p>Check if bringing whānau support YES/NO how many? _____</p> <p>Check if they want the support person/whānau to be in the interview with us YES/NO</p> <p>How best to advise the support person/whānau about the research _____</p>	

	<p>Parking arrangements (Cancer Soc, xx)</p> <p>Meet briefly prior (see bottom section of referral form). We'll need about 5-10 mins prior to appointment to discuss research and get written consent.</p> <p>Patient response Unsure/Maybe:</p> <p>ask if they would like time to think and then be contacted again at a later time? Today/Tomorrow?</p> <p>Patient response No:</p> <p>Thank-you for listening and giving it consideration</p>	
9	<p>In closing for patient who wants to proceed</p> <p>Remind patient that they are under no obligation to participate,</p> <p>that it will in no way will their decision affect their treatment</p> <p>or how the Doctors/nurses will treat them</p> <p>and they may withdraw from the research if they change their mind.</p> <p>Look forward to meeting you on xxx and thank you again.</p>	

Appendix E

REFERRAL FORM:

Patient Name: Ms/Miss/Mr/Mrs _____

First Name Surname

Contact Details: Home phone: _____

Work phone: _____ Cell phone: _____

Email: _____

Preferred method of contact: _____

Special considerations e.g. disabilities

Eligible for study:

- Has received cancer diagnosis NZ European
- Will be discussing treatment options in next consult NZ Māori
- 18yrs+ old

Verbally consented to be contacted by researchers Date: _____

Entered on patient file:

Name of person completing referral _____ **Date:** _____



Date Referral Received: _____

Record of contact made with patient

Date	Time	Method	Outcome

Additional Information provided by patient:

Will bring whānau/support person/s: No Yes If yes, their consent required if going to participate in interview

Address/s to send information to:

Appointment date: _____ Time: _____

Venue: _____

Preferred parking: XXXX Car park # _____ XX Petty cash required

Interview room booked: Location: _____ Time: _____

Advised patient consented and consult to record: Doctor Nurse



C3 – Cancer Care Journeys and Clinical Decision-making Qualitative Research-Consultations

PATIENT/WHĀNAU INTERVIEW SCHEDULE

1. INTERVIEWER INTRODUCTIONS

Mihimihi as appropriate to the patient/whānau.

Ascertain if patient/Whānau is well enough to participate at this time and that other 'practical issues' e.g. parking in hand, missing rush hour traffic.

Check amount of time patient is able to be available for interview.

Reminder: Can take a break, just ask

2. INTERVIEWER TO REVISE WITH PATIENT/WHĀNAU THE STUDY

This study is by researchers at Otago - Wellington, Massey and Victoria Universities

The study aims

We know that the journey of a person with cancer is complex, and often people receive care from many doctors and nurses in different places far away from home. Deciding what treatments to have is an important part of the cancer journey. In our study we are interested in exploring the things that people and their doctors think about when they are making treatment decisions.

3 INTERVIEWER TO RECORD (turn on recorder & check numbers moving)

- Date and venue
- Name of researcher/s
- Name of patient
- Names of others present and relationship to the patient
- Clinician that this patient saw

QUESTIONS FOR THE PATIENT/WHĀNAU

1. Can you tell me what brought you here to meet with Dr _____ today?

Explore: initial symptoms and decision/influences to access health care (GP/acute?); Investigation's and experiences with other services/clinician's; background leading up to the consultation e.g. What happened...what was that like for you?; Preparation for visit

(information seeking, friends/family etc.); what were the patient's expectations of the consultation?

2. How did your meeting with Dr ____ go today?
 - How do you feel about that meeting?
 - Did you understand everything that the doctor told you?
 - Were there any things said that you did not understand?
 - Why not?
 - Did you say everything you wanted to?
 - Why/why not?
 - If Whānau present, did you all get the chance to join in the discussion (if you wanted to)
3. What did Dr ____ say to you about how your cancer might be treated?
 - Have you made a decision about which treatments to have?
 - If yes: what have you decided,
 - Why?
 - If maybe: what will help you make that decision?
 - Is there a timeline for making that decision?
 - If no: What are the reasons why you haven't made a decision yet?
 - Do you think you might try different treatments/make a different decision in the future?
 - If Whānau present, how have you been involved in the treatment decisions?
4. Do you have any other health issues you think might affect your treatment or what treatments you choose?
 - Could you please tell me about them?
5. Do you have any other issues you think might affect your treatment or what treatments you choose?
 - Could you please tell me about them?
6. Is there anything else you would like to tell me about the meeting today or your treatment?
7. Do you have any questions for me?
8. Has this interview raised questions or concerns you that you would like to talk with somebody about? (If so, provide information about where to seek advice).

Mihi whakamutunga: explain the process from here, offer koha (get signature acknowledging receipt) final thank you and close the interview. Escort out and organise to pay parking if necessary

C3 – Cancer Care Journeys and Clinical Decision-making

Consultations

PATIENT/WHĀNAU INFORMATION SHEET

Thank you for showing an interest in this research. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you of any kind and we thank you for considering our request.

Who is doing this study?

This study is being led by researchers at the University of Otago-Wellington and Massey and Victoria Universities. This research is funded by the Health Research Council.

What are the aims of the study?

The journey of a person with cancer can be complex. Typically people receive care from multiple doctors and nurses in many different settings, often remote from their home. Throughout the journey people must make critical decisions on many things including which treatment to have. These decisions are often made in, or soon after, a consultation with a doctor. This study explores the things that people and their doctors consider when making treatment decisions.

What does this study involve?

This research is being undertaken in Auckland and Wellington. Thirty consultations where cancer treatment options are discussed with patients will be recorded (audio) and analysed. If you decide to take part in this research you will be asked if one of your consultations can be recorded. If any whānau/support people attend their consent will also be sought. All participants (doctors, patients and

whānau/support people) in the consultation will need to consent for that consultation to be recorded and used in the research. If this is not possible, that consultation will not be studied. If you and your whānau/support people consent, the researcher will meet with you just prior to your scheduled appointment and answer any questions you may have and collect written consent. The consultation will occur as per usual and the time will be determined by standard hospital systems used to book appointments. The doctor will record the consultation and the researcher will wait for you in the waiting room.

Soon after your consultation is finished, you will be asked to participate in an interview with a researcher which will be recorded. You will be asked if you want your whānau/support people to participate in this. You do not have to answer all the questions, and you may stop the interview at any time. We would also like to collect information on you including: your age, gender, ethnicity and health status. The name/s of everyone participating in the consultation and interview will be anonymised and names will not be linked to any comments in reports of the research. In recognition of the additional parking costs you may incur by participating in the interview our researcher will organise with you to pay your parking costs.

Participation in this study is voluntary (your choice). You may withdraw from participation in this project at any time. This will have no affect on your future health care. If you withdraw, the information on you, your consultation and the interview you participated in will not be used in the research.

If you do participate the results of the project may be published but you will not be named and every effort will be made to ensure that you are not identified in any reported data. Information about your age, gender, ethnicity and health status will be used to describe the people who participated in the research. It will be used collectively and will in no way identify you as an individual. Transcripts and audio recordings will be kept on password protected computers and in locked filing cabinets for five years, at which time they will be destroyed by Associate Professor Signal. You are most welcome to request a copy of the results of the project should you wish.

Ethics Approval

This study has received ethical approval from the Central Region Ethics Committee

(REF: CEN/12/06/026).

If you have any questions about the research please contact:

Associate Professor Louise Signal, Ph (04) 918-6477, Mobile 021 0324 720 University of Otago, Wellington, email louise.signal@otago.ac.nz

or Professor Chris Cunningham, Ph (06) 380 0627 Massey University, Wellington, email c.w.cunningham@massey.ac.nz



C3 – Cancer Care Journeys and Clinical Decision-making

Consultations

PATIENT/WHĀNAU CONSENT FORM

I have read and understood the information sheet explaining this research.

I have had the opportunity to talk about the research and ask questions. I am satisfied with the answers I have been given.

I understand that my participation is voluntary and that I can withdraw from this research at any time.

I understand that I will not be named and that every effort will be made to ensure that I am not identified in any reported data.

I know whom to contact if I have any questions about this research.

Please circle the option that applies to you

I agree to take part in this research.

YES NO

I agree for my GP to be advised I am a participant in the study

YES NO Name: Practice:

I agree to allow the consultation I attend to be recorded.

YES NO

I agree to be interviewed soon after my consultation.

YES

NO

Please circle the option that applies to you

I agree for my interview to be recorded.

YES

NO

I agree for my whānau/support person/s to be present during my interview.

YES

NO

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

If you have any questions about the research please contact:

Associate Professor Louise Signal, Ph (04) 918-6477 University of Otago, Wellington, email louise.signal@otago.ac.nz or

Professor Chris Cunningham, Ph (06) 380 0627 Massey University, Wellington, email c.w.cunningham@massey.ac.nz

I _____ hereby consent to take part in this study

(First Name/Surname)

Signature: _____ Date: _____

Project explained by: _____ Signature: _____

Project role: _____ Date: _____

Note: Copies of consent forms will be given to you and placed on your medical file.



C3 – Cancer Care Journeys and Clinical Decision-making

Consultations

PARTICIPANT DEMOGRAPHIC INFORMATION

We would like to collect a few details for statistical purposes. This information will assist us describe the group of people who took part. No individual names will be used in any reports.

Name: _____

(First Name) (Surname)

1. Are you:

Male Female

2. When were you born?

Day: _____ Month: _____ Year you were born: 19 _____

↑ ↑ ↑

3. Which ethnic group do you belong to? (tick the box or boxes that apply to you)

New Zealand European

Māori

Samoan

Cook Island Māori

Tongan

Niuean

Chinese

Indian

Other (such as Dutch, Japanese, Tokelauan)

Please state if 'Other': _____

Thank you

This research is being led by researchers from the University of Otago-Wellington, Massey and Victoria Universities.

C3 – Cancer Care Journeys and Clinical Decision-making Qualitative Research-Consultations

CLINICIAN PROMPT SHEET

Clinician Prompt Questions

- 1) Please record the date and your name.
- 2) Please state the name of the patient.
- 3) Please describe the outcome of the consultation.
- 4) Please describe briefly the treatment option/s discussed with the patient.
- 5) Please describe any factors that influenced the treatment option/s developed for this patient.
- 6) Does the patient have any comorbidities that impacted on treatment options?
Yes/No
 - 4.1 If yes: Please describe the impact they had.
 - 4.2 If no: go to question 5.
- 7) Please describe how the consultation went and why?
- 8) Did you have enough time to spend with the patient today discussing their treatment options?
- 9) Are there any personal characteristics of the patient that impacted on the consultation and if so what were they and why did they impact?
- 10) Do you think the patient understood their treatment options? What makes you think this?
- 11) Were there any difficulties communicating with the patient for any reason?
- 12) Is there anything else you would like to say?

Thank you for your participation in this study.



Health and Disability Ethics Committees

1 the Terrace
PO Box 5013
Wellington
0800 4 ETHICS
hdec@mh.govt.nz

11 September 2012

Associate Professor Louise Signal
University of Otago
PO Box 7343
Wellington South
Wellington

Dear Associate Professor Signal

Re:	Ethics ref:	CEN/12/06/026
	Study title:	C3 - Cancer, Comorbidity and Care: Cancer Care Journeys and Clinical Decision-Making - Patient and Clinician Responses to Consultation (HRC REF: 11/202)

I am pleased to advise that this application has been approved by the Central Health and Disability Ethics Committee. This decision was made through the full review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at any locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at a given locality in New Zealand, it must be authorised by that locality, and this authorisation recorded as soon as possible in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

After HDEC review

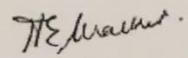
Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Participant access to ACC

The Central Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,



Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE

TE KOMITI RAKAHAU KI KĀI TAHU

21/08/2012 - 48
Tuesday, 21 August 2012

Associate Professor Signal
Public Health
Wellington

Tēnā koe Associate Professor Signal

Title: C3-Cancer, Comorbidity and Care: Cancer care journeys and clinical decision-making - Patient & Clinician responses to consultation.

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 21 August 2012 to discuss your research proposition.

By way of introduction, this response from the Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum, it states "Ngāi Tahu acknowledges that the consultation process outlined in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology; they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the 2006 census.

The Committee notes and commends the establishment and inclusion of a Māori oversight group as part of this project.

The Ministry of Health website <http://www.health.govt.nz/publications> contains a list of Māori health publications. The Committee recommends you review the Māori health

The Ngai Tahu Research Consultation Committee has membership from:

*Te Rūnanga o Ōiākou Incorporated
Kāi Huirapa Rūnaka ki Puketeraki
Te Rūnanga o Moeraki*

NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
TE KOMITI RAKAHAU KI KĀI TAHU

publications on this website, eg. Unequal Impact II: Māori and Non-Māori Cancer Statistics by Deprivation and Rural-Urban Status 2002-2006 and Tatau Kahukura: Māori Health Chart Book 2010. Another Publication, Hauora: Māori Standards of Health IV (2000-2005), has its own website, <http://www.hauora.maori.nz/>. These publications provide information on a range of Māori health issues and will assist in ensuring your research has an appropriate Māori health focus.

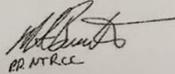
The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

We wish you every success in your research and the Committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 21 August 2012 to 21 February 2014.

The recommendations and suggestions above are provided on your proposal submitted through the consultation website process. These recommendations and suggestions do not necessarily relate to ethical issues with the research, including methodology. Other committees may also provide feedback in these areas.

Nāhaku noa, nā



MR Brunton

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