

# 'It's whanaungatanga and all that kind of stuff': Maori cancer patients' experiences of health services

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## ABSTRACT

**INTRODUCTION:** There are unacceptable ethnic differences in cancer survival in Aotearoa/New Zealand. For people with cancer, quality of life and survival are shaped by access to care, but research on Maori access to, and through, cancer care is limited. Internationally, research has shown that primary care plays an important role in providing patient-centred, holistic care and information throughout the cancer care journey. Additionally, Maori health providers provide practical support and facilitate access to all levels of health care. Here we describe the cancer journeys of Maori patients and whanau and identify factors that may facilitate or inhibit access to and through cancer care services.

**METHODS:** Twelve Maori patients affected by cancer and their whanau (family) in the lower North Island took part in face-to-face semi-structured interviews exploring their experiences of cancer screening, diagnosis, treatment, survival and palliative care.

**FINDINGS:** Three key areas were identified that impacted upon the cancer care journey: the experience of support; continuity of care; and the impact of financial and geographic determinants.

**CONCLUSION:** Primary care plays a key role in support and continuity of care across the cancer journey. Alongside interpersonal rapport, a long-term relationship with a primary health provider facilitated a more positive experience of the cancer care journey, suggesting that patients with a 'medical home' are happier with their care and report less problems with coordination between services. Positive, long-standing relationships with general practitioners and Maori health providers assisted patients and whanau with the provision and understanding of information, alongside practical support.

**KEYWORDS:** Cancer; family; health services, indigenous; Maori health; primary health care cancer

## Introduction

There are unacceptable ethnic differences in cancer survival in Aotearoa/New Zealand. It has been documented that Maori have an approximately 19% higher age-sex-standardised incidence rate and a 78% higher age-sex-standardised mortality rate for cancer overall, compared to non-Maori.<sup>1</sup> Stage at diagnosis and presence of comorbidities have not been found to fully explain survival differences between Maori and non-Maori.<sup>1-3</sup>

As well as having significantly higher cancer mortality rates, quality of life differs between Maori and non-Maori at all stages of the cancer

journey.<sup>4</sup> However, few studies have included the voices of Maori with cancer and their whanau in order to pinpoint factors that facilitate or inhibit access to, and through, cancer care services.

A number of studies have highlighted difficulties in access to health care for Maori at all levels of service provision.<sup>5-9</sup> The term 'access' has been defined as the timely use of personal health services to achieve the best possible health outcomes.<sup>10</sup> Access may be conceptualised in terms of whole systems that operate at the structural, clinical/treatment and patient levels.<sup>3,8,11</sup> For people with cancer, quality of life and survival are shaped by the interaction between and across all of these levels that impact on access through, as

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well as to, health care services.<sup>11</sup> Research to date on Maori experiences of access to and through cancer care is, however, limited.<sup>8,12</sup> One such study advocates for improved communication and information, better resourcing for Maori providers and whanau, use of cancer navigators, more coordinated service delivery, changes in mainstream services and cultural competence training for all health workers.<sup>12</sup>

Internationally, research has shown that primary care can play an important role in providing patient-centred, holistic care and information throughout the cancer care journey<sup>13,14</sup> and for those with complex needs.<sup>15</sup> ‘Medical home’ is a concept that encapsulates primary care practices where clinicians are accessible, know patients’ medical history, and help coordinate care.<sup>15</sup> Interpersonal rapport between general practitioners (GPs) and patients has been identified as important in enabling Maori to access health care.<sup>16,17</sup> However, studies have shown that many Maori do not experience good rapport with a primary health care provider,<sup>9,18,19</sup> and further research has highlighted areas where good rapport is also lacking with other practice staff, such as those managing reception.<sup>12,20</sup>

Primary care services delivered by Maori—ranging from Maori-specific services through to advocacy in engagement with mainstream providers—has increased in recent decades.<sup>8</sup> Maori providers have also played an important but unrecognised role in the provision of primary cancer care, through the implementation of health promotion programmes, such as Aukati Kai Paipa and Healthy Eating Healthy Action.<sup>21,22</sup>

Patients who are looked after by Maori health providers report satisfaction with cost, cultural acceptability, convenience of location,<sup>23</sup> and empowerment and comfort, which is enhanced by a setting that prioritises a Maori worldview, alongside practical support.<sup>12</sup> However, most Maori still access mainstream health services,<sup>24</sup> which are much more numerous than Maori provider organisations. Ethnic differences in cancer survival suggest that current approaches to cancer care delivery are not responsive to Maori, although the reasons for this are unclear. This research aims to describe the cancer journeys of

## WHAT GAP THIS FILLS

**What we already know:** As well as having significantly higher cancer mortality rates, quality of life differs between Maori and non-Maori at all stages of the cancer journey. Few studies to date have documented the care experiences of Maori cancer patients and their whanau.

**What this study adds:** Longstanding relationships with primary health care providers are key to continuity of care for cancer patients and their whanau. These relationships, alongside good interpersonal rapport, facilitated positive experiences and informed choices about treatment and other supports throughout the cancer care journey.

Maori patients and whanau and identify factors that may facilitate or inhibit access to, and through, cancer care services.

## Methods

This research explores the experiences of 12 Maori patients and their whanau affected by cancer. A qualitative approach, using face-to-face, semi-structured interviews was considered appropriate for this study, to capture an in-depth understanding of the cancer journey from the point of view of the participants.<sup>25</sup> The method selected does not lend itself to the results being generalisable outside of the geographic areas and the group of participants in this study.

The study team was composed of members from two Maori health provider organisations and researchers from Massey University. The study was approved by the Health and Disability Ethics Committee (MEC/09/11/131). Inclusion criteria were Maori with a cancer diagnosis, from enrolled populations in two Maori provider organisations in the Wellington and Wairarapa regions. Whanau (family) of the person with cancer were also welcome to take part in the interviews. Potential participants were identified by the Maori health providers who recruited participants and gained their written, informed consent. Interviews took place between May and November 2011 and were conducted by two Maori health workers (CD and HT) from one of the Maori health provider organisations, at a time and location chosen by the participant.

Interviews were recorded digitally and transcribed verbatim by one of the researchers. A the-

matic analysis was carried out on the interview transcripts. This involved identifying, coding and categorising the primary patterns in the data.<sup>26</sup> The analyses were undertaken in three parts. Firstly, two researchers independently carried out preliminary coding of the transcripts by hand. Secondly, the researchers compared and discussed the emergent themes with each other and then with one of the participating Maori health providers. Thirdly, qualitative analysis software NVivo (QSR International Pty Ltd, Doncaster, Australia) was used to help organise the thematic codes.

## Findings

Participants were Maori, and ranged in age from mid-30s to mid-70s. All had experienced cancer in the last five years, with the exception of one participant who was a cancer survivor for more than 20 years. Participants had been diagnosed with a range of cancer types, including breast, cervical, prostate, uterine, lung and laryngeal cancers.

Three distinct themes were identified from the interviews as being key areas that enabled or inhibited the cancer care journey for study participants.

These were: experience of support; continuity of care; and wider health determinants, specifically geographical distance and income.

## Experience of support

Participants' needs included emotional support at appointments and at home in the long term, as well as practical support, such as getting to and from appointments, and acquiring and interpreting health information and types of financial assistance available. Support organisations utilised by participants included Maori health providers, GPs, hospitals/district health boards (DHBs), the Cancer Society of New Zealand (CSNZ), Lions Clubs (charity organisation) and hospices.

Whanau support was discussed frequently. Whanau provided personal and emotional support through the journey at all stages. This support came primarily from one family member

who themselves often experienced stress from being in this role. Occasionally time off work was required, impacting on household income.

My husband and I argued. The stress, you know he had to take time off his job to do it. You know when I had breast cancer he actually gave up his job to take me to my treatments. (#5)

Stresses accumulated for whanau in a support role. However, there was no discussion of whanau taking breaks or getting support for themselves, with a few participants referring to 'burnout' of their supportive whanau.

Another whanau role was in helping patients decipher information they received from health workers. Participants who did not have whanau or personal support appeared to be at a disadvantage with regard to both receiving and understanding information about their care. Maori provider organisations often filled this gap, as well as providing help to whanau.

When I was searching for the turbans she [Maori Provider] actually rang up the CSNZ and you know I could have done it but I wasn't even thinking about that. (#7)

Maori providers also acted as facilitators of information for other available support, provided companionship, and assisted with practical and logistical needs, such as attending appointments or finding out where to park cars at the hospital. Maori health providers and whanau were discussed in similar ways by participants. There was trust, comfort and familiarity expressed, as well as knowledge that participants could make contact at any time if needing support—especially when at home.

It is the companionship eh. I mean yeah, you know if it is [a Maori Provider] come on, let's go in there and I will shout you a cup of tea or I go, I say to [Maori Provider] let's go to Petone and look at some fish heads, you know, because there is a fish factory there. (#12)

...all those kind of things that you expect from a Maori service you know and it's whanaungatanga and all that kind of stuff. (#7)

There was substantial discussion of the relationship with GPs, notably where participants had either a long-standing relationship with a family GP, or had never had one, or had 'lost' this relationship. Of the 12 participants, seven had a regular GP. Of these, five described positive relationships, while one participant experienced a long history of unhappiness and distrust in her GP, and another had only visited the family GP once in 20 years. The remaining five participants did not have a regular GP and would see whoever was available at their local clinic, attend after-hours medical centres, or not seek medical care until reaching a crisis point.

I just go to whoever is available when you ring up. (#7)

Participants with a positive, long-term GP relationship tended to highlight the importance of this history.

Same GP, yeah. She has got two files that thick. And she was the one that um, when I first was diagnosed she sent me to a specialist. So there was no shilly shallying. (#12)

The DHBs and hospitals provided a number of services ranging from access to specialists and outpatient care through to district nurses but also petrol vouchers, parking, ambulance/taxi services, and other home help assistance. Interactions with specialists were mostly described positively. These interactions often followed a period of uncertainty for participants, with the specialist providing much anticipated answers or options. It was, however, frequently expressed that appointment times were not long enough, which was also raised in regard to GP visits, and that there was not often the opportunity or 'space' to ask questions that participants might have wanted to ask. It was in these situations where personal support was described as invaluable.

### Continuity of care

A common thread throughout the interviews was the numbers of individuals involved in a person's cancer care. Although participants spoke positively about many of their interactions with health workers, the overall impression was one

of numerous organisations, specialists, doctors, nurses and administrative people involved in the process of care. Difficulties in maintaining relationships with ever-changing staff led to gaps in information and support.

When I was going through some treatments you know you get people coming around you introducing themselves and you are like well hold on, I am not really worried about you right now, I have got to focus on myself so you know come and see me when I am at home, when I am all alone, when there is nobody there to help me. (#1)

Having a positive and long-standing relationship with a GP throughout the cancer care journey was beneficial and facilitated positive experiences of support and follow-up.

Yep, yes, she [GP] is the one that's been putting me on to different people. (#2)

Barriers to accessing information were articulated by participants as an outcome of both inadequate support and a lack of long-term relationships with primary health care providers. Information provided (or not provided) to participants about available support and resources was inconsistent and appeared to be shared in an opportunistic rather than a planned fashion. This included information about the cancer itself (cancer/treatment/follow-up) but also travel/accommodation, support and financial assistance. The availability of information appeared strongly dependent upon the nature of support a patient had at particular moments through the cancer care journey.

And then the chemo came in and I just got lost, absolutely lost. And I just got all these appointments like you have got to be here, you have got to be here, but if it wasn't for [Maori Provider], I wouldn't know where I was going. (#7)

They offered me a tablet. What was that for? Well I couldn't get at, grasp what he was on about, you know? (#11)

### Wider determinants of health

Distance to services and financial constraints, within a wider context of determinants of health,

were the main barriers to care described by participants. Participants' experiences of travel to appointments, even when distances were close, were difficult. With greater geographic distance, this was even more significant. For example, for those living in the Wairarapa (compared to those living in Wellington/Hutt Valley/Porirua) the impact was greater in terms of more time away from home and work and, therefore, in both the ability of whanau to support them and also in losses to income and the other financial costs involved. Dependence upon others for logistic and financial assistance with travel meant that the conditions of travel were less than ideal, with many participants describing having to be away all day, even for a brief appointment, or being in situations that they felt compounded their stress levels.

The financial burdens it puts on you. Because I had to travel from [locality] to [locality] every day... for five weeks for radiotherapy... And the stress, just in that alone. (#1)

The need for financial assistance for this group of participants through the cancer care journey was often critical, but sources of financial support were limited and opportunities for assistance offered in an inconsistent way. For example, little information was freely available about benefit entitlements and mobility cards. Income was also affected through time taken off work by participants or whanau. In general, employers were very supportive and offered time off for appointments, treatment and recovery and also kept positions 'open' or extended leave entitlements. However, the impact on income was still substantial and there was often little support offered to address this.

## Discussion

The main limitation of the study is that it presents the experiences of a small group of participants only and is confined to cancer services within specific geographic areas of Aotearoa/New Zealand. However, few studies to date have documented the experiences of Maori cancer patients and their whanau regarding facilitators and inhibitors to cancer care. The current study emphasises some important and understudied areas within levels of cancer care.

In relation to the theme of experience of support, the results highlight the critical role of information and how the quality of, and response to information is interrelated with the support structures of patients, with Maori provider organisations and GPs being central to this. Support was also relevant for whanau, both during treatment of their family member with cancer but also on discharge home and in terms of adequate follow-up care and services.

The availability of personal support to patients was variable but was considered crucial for making sense of information and advice provided throughout their cancer journey. Whanau and Maori health providers often filled this role and importantly, in some instances, so did relationships with GPs. While the results concur with other literature that 'rapport' is important within face-to-face contacts,<sup>17</sup> in terms of the identified theme of continuity of care they also show that, alongside rapport, a long-term relationship with a GP facilitated a more positive experience. Other work in Aotearoa/New Zealand has also found that having a regular primary care provider is associated with better quality of care,<sup>9,27</sup> and international studies similarly show that patients with a 'medical home' are happier with their care and report fewer problems with coordination between services.<sup>15,28</sup> The concept of 'home' in the context of primary care resonates with the historic family doctor who looked after multiple family generations and was able to treat individuals within the bigger picture of their families and communities. Lasting relationships with primary care providers are particularly relevant to cancer care, with ongoing, personal contact recognised as the foundation of community cancer care.<sup>14</sup> There is little literature on how to develop long-term relationships between primary health care providers and patients in Aotearoa/New Zealand. Lacey et al.'s Hui Process Framework<sup>17</sup> identifies key elements to assist long-term relationship building between health practitioners and Maori, including establishing rapport, active engagement and developing trust.

The current study was developed based on work in the United Kingdom<sup>29</sup> that recognises that primary care is the first level of contact and entry point into the health system, and that nearly all



the priorities for cancer services are affected by actions in primary care—reducing the risk of cancer, early detection, faster access to specialist treatment, and improved support for patients living with cancer. Additionally, focus on the health and wellbeing of the family is the crux of the Whanau Ora policy that was recently introduced in Aotearoa/New Zealand and that emphasises building long-term relationships that enhance whanau capabilities and realise whanau aspirations.<sup>30</sup> Maori have long advocated the value of a Whanau Ora approach to health care, and this approach forms the basis for He Korowai Oranga, the Government's Maori health strategy.<sup>31</sup> Whanau have a critical role in relation to facilitating Maori cancer patient access to cancer care services.<sup>8,32,33</sup> Thus, the Whanau Ora approach will be central to any framework for integrated cancer care for Maori. The Whanau Ora Cancer Care Coordination Project<sup>34</sup> considered the development of culturally responsive models of case management to improve the delivery of cancer control services in the Waitemata area. In their development of a model for reducing cancer inequalities among Maori and Pacific people, the project identified the need for care coordination across health care settings and throughout the personal cancer care journey of the person and their whanau.

The importance of appropriate, timely access and information for patients and whanau in this study is mirrored in other studies and policy initiatives in Aotearoa/New Zealand and internationally.<sup>8,11,12,35</sup> Advocacy and cancer 'navigator' roles have been identified as being key positions required to facilitate and assist people in negotiating the complexity and range of cancer services.<sup>34</sup> Cancer navigators have had success in improving people's cancer journeys overseas,<sup>36,37</sup> with some provisional work done here in Aotearoa/New Zealand regarding their effectiveness suggesting similar results.<sup>12,38</sup> Cancer navigator roles were part of the Community Cancer Support Services Pilot Projects, which were evaluated in 2010 and were found to impact positively on the cancer journeys of patients and whanau, while also aiding health and social service providers.<sup>38</sup> Our study findings suggest that Maori health providers are already providing informal cancer navigation. This begs the question of whether they are

recognised and resourced appropriately to do this important work.

As well as delivering information in a consistent and timely fashion, it is important that the content of the information is meaningful to the receivers. Cormack and colleagues recommend high quality Maori-specific resource material about cancer and cancer service options for individuals, whanau and communities.<sup>8</sup> Our study echoes findings by Walker et al.<sup>12</sup> who advocate for more information and resources for whanau and Maori health providers, alongside changes to mainstream health provision, such as flexible appointment times.

Where wider health determinants impacted on access to, and through cancer services, participants received ongoing support from Maori health providers that went beyond medical care and included emotional support and appropriate practical and logistical support for the whole whanau. Similar findings have been reported in the literature,<sup>8,12,23,39</sup> including one study of a GP population that showed Maori breast screening participation rates rose from 45% to 97%.<sup>40</sup> In that study, barriers to participation were reduced through better information, phoning women to confirm appointments, helping with transport and coordinating appointments for women from the same household. The authors suggest that these strategies can also be used by mainstream organisations to improve screening participation by Maori.<sup>40</sup> Examples of mainstream providers adapting their services to reduce barriers include offering flexible appointment times, providing other types of assistance relating to complex care needs, such as smoking cessation advice at screening clinics,<sup>39</sup> and providing cultural safety training for all staff.<sup>41</sup> Enhancement of mainstream services at all levels of health care delivery to better meet the needs of all those they serve is important if we are to effectively address the unacceptable ethnic differences in cancer survival.

In summary, as well as appropriately supporting and resourcing Maori health providers, these findings suggest there are also lessons for the practice of mainstream GPs, particularly in fostering not only rapport but also prioritising

long-term relationships with patients that build up a history of care. In this way, primary care services are key facilitators for access to, and through, cancer care services. The cancer journeys described in this study highlight the critical role of GPs and Maori health providers in terms of providing consistent information and enabling continuity of care for Maori with cancer.

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### COMPETING INTERESTS

None declared.