



The road we travel: Māori experience of cancer

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Abstract

Aim This research explores Māori experiences of cancer. It does so to shed light on the causes of cancer inequalities for Māori.

Methods The views of 44 Māori affected by cancer—including patients, survivors, and their whānau (extended families)—were gathered in five hui (focus groups) and eight interviews in the Horowhenua, Manawatu, and Tairāwhiti districts of New Zealand. After initial analysis, a feedback hui was held to validate the findings.

Results Māori identified effective providers of cancer services such as Māori health providers. They also identified positive and negative experiences with health professionals. The involvement of whānau in the cancer journey was viewed as highly significant as was a holistic approach to care. Participants had many suggestions for improvements to cancer services such as better resourcing of Māori providers, cultural competence training for all health workers, the use of systems ‘navigators’, and the inclusion of whānau in the cancer control continuum.

Conclusion The research identifies a range of health system, healthcare process, and patient level factors that contribute to inequalities in cancer for Māori. It also explores the role of racism as a root cause of these inequalities and calls for urgent action.

Cancer is a leading cause of death for Māori. It contributes significantly to the difference in life expectancy at birth between Māori and non-Māori. From 1981–2004 Māori cancer mortality rates increased for all cancers combined; whereas non-Māori non-Pacific cancer mortality decreased.¹ Māori are 18% more likely than non-Māori to be diagnosed with cancer and have a 93% higher mortality rate.²

Cancer control has received increased focus in New Zealand since the development of *The New Zealand Cancer Control Strategy*.³ The *Strategy*'s overall purpose is to reduce the incidence and impact of cancer and reduce inequalities with respect to cancer. The first principle of the *Strategy* is to ‘work within the framework of the Treaty of Waitangi to address issues for Māori’.

To address the startling inequalities in cancer for Māori, it is critical that Māori experience of cancer is understood and acted on. However, there is a little written from a Māori view about Māori experience of the cancer journey. There is also limited literature that illuminates the causes of Māori cancer inequalities—but what there is focuses on three key areas (health system, healthcare process, and patient factors) as outlined by Cormack et al.⁴ In taking this approach, Cormack et al. build on the work of Mandelblatt et al..⁵ Cormack et al. note that access to cancer care is ‘complex and multidimensional’. Health system level factors ‘include the focus of the

cancer care system and services, funding and resources, service configuration and location, workforce, availability of information and resources, and expense'.⁴

In the New Zealand context, a nationally representative sample of general practitioners found financial and cultural factors, amongst others, as key barriers to health care for Māori.⁶

Healthcare process factors include 'the way that services operate and work with other services, characteristics of physicians/providers such as training, competence, perceptions and biases, and patient-provider interaction'.⁴

Crengle et al., reporting on the same national study of general practitioners discussed above, noted that general practitioners had lower levels of rapport with Māori than with non-Māori patients. In addition, Māori visited the doctor fewer times per year and their consultations were shorter than those of non-Māori.⁷ Reasons why providers give less and lower quality care to Māori may include lack of a shared cultural or social background and lack of understanding.⁶

Rapport is a key facilitator of access to healthcare, but notions of rapport are culturally bound. Components of rapport include 'the doctor 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'.⁸ Pākehā (New Zealand European) doctors may believe they have established rapport with Māori patients, when in fact they have not.

At a patient level, key factors are 'socioeconomic position (including deprivation, employment conditions, and insurance status), transportation, and patient context'.⁴

Māori carry a much higher burden of deprivation than non-Māori. Deprivation combined with racial discrimination accounts for much of the disparity in health between Māori and non-Māori.⁹ Māori take a holistic approach to health which is inconsistent with a traditional medical approach.¹⁰ Cram et al. note that Māori carry knowledge of previous negative experiences between Māori, and Pākehā health professionals.⁸

While this literature is disparate, nevertheless, a number of studies highlight serious and complex issues in relation to health inequalities for Māori that require urgent attention. They include health system, healthcare process, and patient factors. To tackle inequalities, we must understand their root causes.

Harris et al. discuss the effects of a key root cause—racism—based on data from the 2002/2003 National Health Survey.^{9,11} Data showed 'that self-reported experience of racial discrimination was highest among Māori and that any such experience was strongly associated with negative health effects equally for all ethnic groups'.⁹

This current research aims to explore Māori experiences of cancer in their own words. It does so to shed some light on the causes of cancer inequalities for Māori.

Methods

This research is a qualitative study of the experiences of Māori affected by cancer including patients, survivors, and their whānau. Qualitative methods were chosen because they allow for in-depth exploration of a topic.¹² Including whānau members reflects the collective nature of Māori society. The fieldwork was conducted between late 2004 and mid 2005. Two data collection methods were used:

- Five hui/focus groups: 44 participants in four sites in Horowhenua, Manawatu, and Tairāwhiti.
- Eight kanohi ki te kanohi (face-to-face) interviews with cancer patients and survivors in the same regions.

Participants were recruited by the Māori health providers who were partners in this research and knowledgeable about Māori affected by cancer in their area. All participants were of Māori descent; from their early 20s to mid-70s. While most participants had current experiences of cancer (e.g. in the last 5 years), some had experiences dating back 20 to 30 years.

An interview schedule was developed by the research team for the hui and interviews. The questions were designed to explore with participants their experience and information needs at diagnosis, treatment, prognosis, the availability of services, and their knowledge of the Cancer Society. Participants also focussed on other issues of relevance to them in relation to their cancer journey.

The analysis was done in two stages. A thematic data analysis undertaken by the Wellington-based researchers identified key themes. In addition, the team focussed on identifying specific Māori messages within the data. Then a feedback hui was held at the Cancer Society's Manawatu Centre with research participants, Māori health providers, and Cancer Society staff.

The Wellington researchers presented the results and sought feedback from those present. Hui participants' responses were then used to validate the findings and further analyse the data. Ethical approval for the study was obtained from the Tairāwhiti, Manawatu, and Wellington Ethics Committees.

The research was conducted in the Cancer Society central region. Māori, as a rule, are relativistic and do not claim to speak for all Māori including those living in other regions. Therefore this paper does not claim to be generalisable to other Māori in New Zealand. However, this does not mean that the experiences and lessons learnt from this study do not apply to Māori in other regions.

Results

Māori providers

There was high praise for Māori providers, for their grounding in a Māori/iwi (tribal) worldview, their style of practice, and their support for Māori affected by cancer. Māori providers gave important practical assistance—e.g. transport to the doctor or hospital, collecting and delivering prescriptions, and even having an ambulance alarm connected. They were available to both the cancer patients and their whānau.

'Māori health providers will go that step further' said a participant. Māori providers practised an awahi (supportive) approach, and whakawhānaungatanga (building on relationships). Recognition by Māori providers of their taha Māori (Māori being) was important to participants because it is 'who and what they are', and providers' strong, 'awesome' links with iwi were valued.

The wife of a patient with throat cancer praised a Māori doctor who asked her what she wanted to know. She asked to view her husband's throat, and the doctor organised this with the specialist, giving her reassurance.

Ozanam House

Ozanam House is a residential facility in Palmerston North for cancer patients and whānau from the Central Districts region who are using the Regional Cancer Treatment Service. Participants with experience of Ozanam House had nothing but praise for it as a supportive institution that met their needs very well. Strengths of this 'whānau house' identified by participants included: 'that whānau can stay there', 'there are mattresses in the lounge' [like on a marae], 'you cook your own food', and 'you can talk with others about your experiences'.

Experiences with health professionals

Participants had both positive and negative experiences with their doctors, nurses, and hospice staff. In particular, they valued good communication. One participant felt fully informed about treatment and the duration and effects of medication. Another noted that, during a lengthy surgery, doctors maintained good communication with whānau members.

A further participant noted that good communication between her oncologist and general practitioner, 'made it a lot easier for me and it played a big part in my recovery'. Another participant's doctor, 'told me exactly what was wrong, where it was, and what they were going to do and I thought it was wonderful...all the way through there was this supportiveness'. Some participants' doctors and specialists had given out their phone numbers for day and night contact.

While participants praised good services, they also noted where professionals were not responsive to their needs. One said 'some medical professionals are like WINZ (New Zealand's social security agency), unless you ask the questions you don't get the answers ... and the trouble is if you don't know the question you don't get the answer. How can you ask?'

Another noted that doctors were 'fee driven'. Another participant felt 'there's a judgmental thing with some [doctors] but not all of them'. A further participant reported that a doctor had a 'bad attitude'. A grandmother described the treatment her mokopuna (grandchildren) received as 'unbelievable, like a horror story' and commented that the doctor in question had 'no aroha' (love/compassion).

Another participant had 'to bully the doctor to get a commode and pain relief' for her sister and she had 'to work hard to get them', although 'we didn't want much'. A survivor of cervical cancer was unaware of the impact of having both ovaries removed and would have opted to keep one if she had known it would put her into early menopause.

In each area there was at least one case of misdiagnosis reported. In one case, the correct diagnosis was made when the survivor sought a second opinion. Three survivors described feelings of anger that the misdiagnosis had occurred and were traumatised by the experience.

Participants who worked in the health sector noted that it would be difficult for Māori who were not assertive or proactive to receive the level of care they required. One of these health workers had been unaware of the fact that she could have had a reconstruction at the same time she had a mastectomy operation. She was also unaware of the negative impact of treatment on her sexuality. In one case, a survivor had surmised that his cancer was under control, stating that 'it must be OK' because he had not had a note from the specialist to return for a check.

Nurses were important providers of services, information, and support. One participant spoke of the value of nurses who were caring, understanding, and positive because they provided the reassurance that patients needed. An oncology nurse who visited a participant at home provided a copy of all her notes on request.

By contrast, the information from the hospital on her chemotherapy was one illegible photocopied page. A Māori nurse on her days off helped another participant care for

his dying mother. This was the only support that was offered. Another participant noted that the hospice staff provided a lot of information during home visits.

In health professionals, participants valued competence, compassion, warmth, honesty, respect, and professionals who offered support and took an interest in them, meeting them halfway in terms of cultural needs. One participant said that having a Māori health professional 'made it easier for me' because she was able to 'relate' and felt that the health professional 'related' well to her.

'I just expect a little bit of civility and courtesy and I'm happy'. Participants preferred finding out about their cancer from a person they could trust and feel at ease with, preferably someone with whom they had an established relationship. As one person explained; the 'personal touch made a big difference'. The participants indicated that, for the majority of patients and whānau, the ethnicity of health professionals was less important than the qualities they demonstrated.

The importance of whānau

Whānau involvement in the cancer journey as well as the support whānau gave were seen as highly significant. Whānau fulfilled many roles such as providing support and 'strength' for the person in hospital, nursing care in the home, acting as advocates with health professionals, information-gathering and responsibility for medication. A participant said, 'you won't survive if you don't have the support of your whānau'.

Whānau need knowledge of the entire cancer journey as a participant explained:

... whānau need to know about the illness, what course it can take, what symptoms can appear, about different medications, why they are taking it, how it can help them, and about the side effects. They need to know that there is somebody they can contact if they should have any difficulties.

The responsibility to care for whānau and the cost of this to whānau was also highlighted. One participant cautioned that whānau need to be aware of the extent of their responsibilities when they said 'you [whānau] have to be prepared to go the whole nine yards, totally there for their benefit'. Another participant, while delighted that her children wanted to care for her, was also concerned that they continue their paid employment.

Holistic aspects of health

As well as the medical treatment they received, most participants also sought emotional and spiritual support from within their own culture. Holistic approaches included mirimiri (massage), the application of kawakawa leaves, metallic healing, reiki, and reflexology. 'The hospital deals with your physical problems but they do not deal with your mental and spiritual problems'.

At the feedback hui (meeting), Māori spoke of the need for a mixture of the clinical and the holistic aspects of health that takes into account wairua (spirituality), whakawhānaungatanga (relationships), and whakapapa (genealogy), 'so we [Māori] are all comfortable and we all feel that we are being treated how we feel we should be treated'. Doctors should be trained in these 'important aspects for Māori'.

Making your path a bit easier

Suggested improvements included health system, healthcare process, and patient factors.

- Staff to alert Māori to their entitlements—e.g. transport, benefits, home help, equipment.
- Co-ordinated service delivery, to avoid ‘getting the run-around’ from service to service.
- More frequent specialist clinics for rural participants.
- Flexibility in accommodation arrangements—e.g. ‘an extension of the rapuora concept, namely where people can stay for a number of days’ to get the care rural participants need [given that they often travel for treatment].
- Staff to be ‘aware of what it is to be Māori and where Māori come from...and what we have had to give up. We have our own uniqueness and we are a diverse people’.
- Staff to accommodate tikanga (cultural practices), wairua (spirituality), hinengaro (emotional and mental), tinana (physical), and whānau (Māori family forms).
- Providing a person to help navigate across the cancer control continuum, ‘someone to make your path a bit easier’.
- A care plan at diagnosis would enable whānau to work through and manage the cancer process.
- Māori support groups for cancer patients, survivors and their whānau.
- Counselling and support for whānau.
- Systems in place that provide good information to everyone preferably kanohi te kanohi or face-to-face, with written material providing support.
- An increased Māori workforce including Māori oncology nurses and a liaison person.
- Preventative education.
- Choice for female patients to have women health professionals.
- An explanation of the impact of treatment on patients, e.g. on their sexuality.

Discussion

The present study examined the experience of Māori cancer patients, survivors and their whānau by providing them with opportunities to discuss their cancer journey in their own words. Participants’ discussion can be framed by Cormack et al. and Mandelblatt et al.’s analysis of inequalities in access to cancer services as follows.^{4,5}

In terms of health system factors, participants in this research identified Māori health providers and Ozanam House as examples of services that work for Māori. Māori also identified a number of ways to improve services including co-ordinated service

delivery, informing Māori of their entitlements, an increased Māori workforce, systems in place that provide good information (preferably face-to-face), support and counselling for patients and whānau and more regular provision of services in rural areas.

Māori providers with a Māori worldview, provide practical support to Māori experiencing cancer and are a conduit between the patient and the cancer control system. This research suggests that the work of Māori providers should be extended and further resourced because of its importance in ensuring quality cancer control services for Māori. However, 'since the majority of Māori continue to receive most of their health care from mainstream services, considerable ongoing effort is required to reorient mainstream services, providers, and systems to prioritise Māori health needs'.¹³

Ozanam House provides some clues about how to proceed. It is a mainstream organisation that successfully accommodates the needs of Māori, providing a place where Māori experiencing cancer can be Māori.

At the healthcare process level participants across the four sites reported varying quality. People working in the health system were reported as unable at times to establish rapport, a key issue discussed by Cram et al.⁸ This research demonstrates the need for significantly improved cultural competence training and ongoing assessment of cultural competence of all health professionals, including important gatekeepers such as receptionists and administration staff.

It also shows that an increased Māori health workforce is urgently needed. Indeed, people to assist Māori in navigating the health system will be a valuable addition. Anecdotal evidence from Canterbury District Health Board suggests that the employment of a Māori navigator in the cancer control arena results in improved service delivery for Māori (personal communication, Kaitiaki Oncology, 2006).

At the patient level, the research underscores the importance of whānau involvement in the cancer journey and taking a holistic approach to health. This supports findings by Cram et al.⁸ The research suggests that the concept of the 'cancer control continuum' should include patients and whānau who support and care for the patient. This view implies different priorities, and different ways of working from the concept that sees the continuum in terms of the cancer control workforce.

The health system benefits from the care and support that whānau provide. Whānau need support and adequate resourcing in this role. But their involvement should not replace appropriate support from cancer control services that have an obligation to deliver services fairly to all. This support may need to come from outside the health sector and may require intersectoral action on the part of the health sector in areas such as education, employment and income.

There is an expectation that the New Zealand health service is a level playing field. However, discrepancies in access to quality health services by Māori are beginning to be documented.^{14,15} Too often, participants in this study expressed considerable gratitude for very limited care. This research indicates an urgent need to ensure that Māori receive the same 'gold standard' service to which all New Zealanders are entitled.

This research provides some valuable pointers as to how to achieve this—such as:

- Coordinated service delivery,
- Meaningfully informing Māori of their entitlements,
- Better resourcing of Māori providers,
- Altering mainstream services to support Māori,
- Increasing the Māori workforce,
- Cultural competence training for all health workers,
- The use of systems ‘navigators’, and
- The inclusion of whānau in the cancer control continuum and adequately resourcing them.

Recent work on racism as a root cause of inequalities in health provides a further level of analysis for this research.^{9,11} Reid and Robson state that ‘racism is a major determinant of health and a fundamental driver of inequalities that must be addressed in order to improve Māori health outcomes and reduce inequalities’.¹⁶

Jones has developed a framework for understanding racism on three levels—*institutionalised*, *personally mediated*, and *internalised*—and has applied it to health.¹⁷ She argues that ‘this framework is useful for raising new hypotheses about the basis of race-associated differences in health outcomes, as well as for designing effective interventions to eliminate those differences’.¹⁷

Applying this framework to the current research *institutionalised racism* is where Māori are being structurally excluded from equitable access to health services on the basis of ethnicity; *personally mediated racism* is where health workers make differential assumptions about Māori and treat Māori inadequately; and *internalised racism* is where Māori appear to expect differential lesser treatment (often based on past experiences) personally or within their whānau.

Research on the experiences of Māori across the cancer control continuum and at health systems, healthcare processes, and patient levels is limited as is an analysis of the role of racism in driving health inequalities.

Further research and action is urgently needed as a result if the gap between Māori and non-Māori in relation to cancer is to close. The present research provides valuable information on Māori experience of cancer from a Māori view.

It is critical that these findings are urgently enacted through the Government’s *New Zealand Cancer Control Strategy* if the *Strategy* is to deliver on its purpose and address its principles.

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References:

1. Blakely T, Tobias M, Atkinson J, et al. Tracking Disparity: Trends in Ethnic and Socioeconomic Inequalities in Mortality, 1981-2004. Ministry of Health: Wellington; 2007.
2. Robson B, Purdie G, Cormack D. Unequal Impact: Māori and Non-Māori Cancer Statistics 1996-2001. Ministry of Health: Wellington; 2006.
3. Minister of Health, The New Zealand Cancer Control Strategy. Ministry of Health and the New Zealand Cancer Control Trust: Wellington; 2003.
4. Cormack D, Robson B, Purdie G, et al. Access to Cancer Services for Māori. University of Otago: Wellington; 2005.
5. Mandelblatt J, Yabroff K, Kerner J. Equitable access to cancer services: a review of barriers to quality care. *Cancer*. 1999(86):2378–90.
6. Jansen P, Smith K. Maori experiences of primary health care. *NZFP*. 2006;33(5):298–300.
7. Crengle S, Lay-Yee R, Davis P, Pearson J. A Comparison of Māori and Non-Māori Patient Visits to Doctors: The National Primary Medical Care Survey (NatMedCa): 2001/02. Ministry of Health: Wellington; 2004.
8. Cram F, Smith L, Johnstone W. Mapping the themes of Maori talk about health. *N Z Med J*. 2003;116(1170):1–7.
9. Harris R, Tobias M, Jeffreys M, et al. Effects of self-reported racial discrimination and deprivation on Maori health and inequalities in New Zealand: cross-sectional study. *Lancet*. 2006;367(June 17):2005–9.
10. Durie M. Whaiora Maori Health Development. 2nd ed. Oxford University Press: Auckland; 1998.
11. Harris R, Tobias M, Jeffreys M, et al. Racism and health: of the relationship between experience of racial discrimination and health in New Zealand. *SS & Med*, 2006;63:1428–41.
12. Patton M. Qualitative Research & Evaluation Methods, Sage Publications: London; 2002.
13. King A, Turia T. He Korowai Oranga: Māori health strategy. Ministry of Health: Wellington; 2002.
14. Westbrooke I, Baxter J, Hogan J. Are Maori under-served for cardiac interventions? *N Z Med J*. 2001;114(1143):484–7.
15. Robson B, Harris R. (eds) Hauora: Māori Standards of Health IV: a study of the years 2000 - 2005. Te Rōpū Rangahau Hauora a Eru Pōmare: Wellington; 2007.
16. Reid P, Robson B. Understanding Health Inequities in B Robson & R Harris (eds) Hauora: Māori Standards of Health IV a study of the years 2000 - 2005. Te Rōpū Rangahau Hauora a Eru Pōmare: Wellington; 2007.
17. Jones C. Levels of racism: a theoretic framework and a gardener's tale. *American Journal of Public Health*. 2000;90:1212–5.