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

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ABSTRACT

AIM: To investigate the contribution to cancer care and prevention by Māori health provider organisations (MHPs) in Aotearoa/New Zealand.

METHODS: A nationwide postal survey of all MHPs (n=253) was undertaken in 2011. The response rate was 55%.

RESULTS: We found that MHPs are delivering a wide range of programmes including cancer prevention services focussed on health promotion, advocacy, information and support. MHPs identified financial hardship, transport difficulties, and lack of information as the greatest barriers to cancer care. Culturally safe care by mainstream providers would improve cancer service provision overall. The importance of trust and long-term relationships, with a focus on families rather than individual-based care, was highlighted.

CONCLUSION: These findings could lead to substantial improvements in quality of life for Māori cancer patients. This is the first study to show how indigenous health providers contribute to cancer care and prevention in Aotearoa/New Zealand.

There are stark differences in cancer incidence and survival across ethnic groups in Aotearoa/New Zealand (Aotearoa), with Māori carrying a disproportionate cancer burden. Māori have an approximately 20% higher age-standardised incidence rate, and a 72% higher age-standardised mortality rate for cancer overall compared to non-Māori. Additionally, quality of life differs between Māori and non-Māori from diagnosis through treatment, recurrence and survival.

It is well established that there are challenges in accessing health care for Māori at all levels of service provision. Access to care has a substantial impact on cancer outcomes, yet the evidence suggests that mainstream systems of cancer care are substantially less responsive to Māori than non-Māori.

Māori health providers (MHPs) were established in Aotearoa in the 1990s following radical public sector reforms. New funding models enabled MHPs to compete with other providers for health service contracts. MHP values and ways of working were different to mainstream health providers and their services were available to all ethnic groups. One of the most important roles of MHPs was to enable people to access health services. MHPs used Māori models of wellbeing, positive Māori development and Māori philosophical and practical approaches. However, health service contracts focussed on individuals and illness, which was inconsistent with Māori worldviews, emphasising holistic wellbeing and collective approaches to health for the whole whānau (family).

Despite these challenges, the number of MHPs has increased and their main focus is primary health care services relating to prevention and lifestyle issues. Some MHPs offer general practitioner (GP) services and some do not, nonetheless MHPs play a major role in facilitating access for Māori into mainstream health care. This means that even if the MHP does not have its own GP service, regardless, appropriate onward referral (to primary health care
clinics/services in their areas), for those patients requiring this, is a core feature of the work that MHPs were set up to do. This facilitation remains important given that, as a diverse population, not all Māori access MHPs and all secondary care services are within the mainstream health care system.\(^{13}\)

The establishment of MHP services coincided with the development of cultural safety education. Cultural safety programmes were developed in response to growing evidence of disparities in a range of health outcomes between Māori and non-Māori.\(^{14}\) Cultural safety shifted responsibility back on institutions and health workers to address their performance in meeting the health realities of Māori, including access to care.\(^{15}\)

The Medical Council of New Zealand and most District Health Boards (DHBs) have a cultural competency requirement, which is different to cultural safety. Cultural safety makes explicit the role of power in the nurse/midwife relationship with clients. Thus, the definition of ‘good’ care is placed in the hands of those receiving it. Cultural competency is less concerned with power and focuses more on the ability of clinical staff to engage respectfully and reflectively with people from different backgrounds.\(^{16}\)

Primary care plays a key role in facilitating access to services, continuity of care and information that is person-centred throughout the cancer care journey.\(^{17,18}\) As the first point of connection with the health system, primary care influences cancer prevention, early detection, access to specialist treatment and patient support following discharge from hospital.\(^{19}\)

There is some research showing that as primary care providers, MHPs have a distinctive approach to cancer care.\(^{20,25}\) The trust and rapport that MHPs have within their communities enables engagement with mainstream cancer care and support services. Additionally, these relationships enhance MHP driven cancer prevention activities (for example, smoking cessation). There is evidence that MHPs are effective at providing cancer screening\(^{21}\) and support throughout cancer treatment.\(^{22,25}\)

MHPs have been providing primary care services for decades, but information about their services, particularly in relation to cancer, is scarce. There is evidence that MHPs have a wealth of local knowledge from their communities regarding the causes of disparities for Māori including access to and through cancer care.\(^{23}\) This study aims to explore how MHPs facilitate access to cancer screening, diagnosis, treatment, support and palliative care services. Through identifying the services MHPs provide there is potential to build on strengths and help address unacceptable ethnic differences in cancer incidence, mortality and quality of life.

**Methods**

This paper describes a survey of MHPs current role in cancer care. It examines the potential for further services, and explores MHP perspectives on what is impeding or assisting their communities in accessing services along the cancer journey. The study was approved by the Health and Disability Ethics Committee (MEC/09/11/131).

In 2011, we undertook a nationwide postal survey of all MHPs in Aotearoa. As discovered by other researchers,\(^{25}\) there is no publicly available database of MHPs. MHPs can list their organisation on the Ministry of Health website, but this is not comprehensive with 66 MHPs listed at the time this paper was written.\(^{26}\) For this study we therefore used publically available directories and networks in order to identify MHPs. Using this approach, 253 MHPs were identified.

The survey questionnaire was developed based on the Te Huarahi o Nga Tangata Katoa study, which investigated cancer service availability and experiences of patients and providers.\(^{27}\) Our questionnaire explored services MHPs are currently delivering, including core services, types of support for cancer patients and whānau, and also health promotion, screening and other services which help with cancer prevention. Providers were asked to consider barriers to care for people who do not access cancer detection and diagnostic services, and what would help people with cancer and their whānau at all levels of cancer care and support. Finally, MHPs were asked if there were additional cancer care services that they could provide if funded.
The questionnaires were sent to each provider together with a covering letter, information sheet and post-paid reply envelope. The information sheet outlined the aims of the study and explained that completion of the questionnaire implied consent. Non-responders were sent a follow-up survey, and contacted by telephone with a further survey sent on request. Data were entered into a Microsoft Access database. Analyses were undertaken using the statistical software package SAS and involved simple tabulations and percentages. No statistical tests were applied. Microsoft Access was used to group the data in the open text fields.

Results

Of the 253 questionnaires sent out to MHPs, 119 (47%) were completed, 23 (9%) declined (of these, four organisations provided information about the services they provide), 37 (15%) were ineligible (return to sender, organisation no longer exists or is not a MHP). There were 74 (29%) non-responders. These included organisations that were sent the questionnaire and followed up with a telephone call, but did not complete the survey, and organisations that were sent the questionnaire twice but not able to be contacted by telephone. After subtracting the ineligibles, the overall response rate was 55%.

The survey was answered by people from a range of positions within the MHP organisations. Over half of the respondents were Kaiwhakahaere/Chief Executive Officers and managers (15% and 37% respectively), but the survey was also answered by nurses (10%), community health workers (8%), project/programme co-ordinators (8%), GPs (6%) and administrators (2%). Other respondents (9%) included team leaders, group responses, liaison positions and a counsellor. Six respondents did not provide their position within the organisation.

MHPs varied in size, ranging from individuals providing one health service, to large organisations with multiple premises, delivering up to 20 health service contracts. Respondents were asked to show the health services they offered, whether funded or not. Health promotion services were the most commonly provided health service. More than half of the respondents reported providing child/youth health, older people's health, community outreach, social services, infant health, mental health or nursing services. Services that were provided the least were disability support services and rongoā (Māori medicine).

Cancer services

Respondents were asked about the services they provide for people with cancer and their whānau (Figure 1).

Information (64%), advocacy (63%), transport (58%) and health promotion (55%) were the most commonly reported cancer services, while health promotion services related to cancer (such as Aukati Kai)

![Figure 1: Services for people with cancer and their whānau delivered by MHPs.](image-url)
Paipa—a quit smoking programme) were reported by 45% of respondents. Respondents also reported provision of nursing care (36%), GP care (32%), disease state management (26%), and palliative care (24%). Almost 20% of providers reported no cancer service provision and 18% described other support and services including support for whānau, respite care, counselling and psychotherapy, support group programmes, funeral support, celebrations, rongoā (medicine) and accommodation (Figure 1).

In an open question, respondents were asked what services were of most benefit to people with cancer and their whānau. Most often, by Māori for Māori health and support services were described (33%). Specifically, respondents indicated the trust that people have in their MHP, cultural support, holistic healing, access to rongoā and mirimiri (massage), and wrap-around care that is often available after hours.

Advocacy and practical support were also outlined (27%), including transport and support for clinician and other appointments such as welfare agencies and electricity companies. Clinical services were identified (20%) including oncology departments, specialists and community nursing care. Palliative care was also noted (18%), with both palliative care and hospice care specified.

Respondents were asked to choose from a list of reasons why some people might delay accessing a service for early cancer detection or diagnosis. These included screening services and also primary care services such as a GP.

Findings related to delays in accessing cancer screening services indicate that financial barriers and limited information were the main reasons for delay. Half of respondents cited a lack of cultural safety by the screening provider, and provider issues such as not having a regular GP or not being registered with a PHO. Almost half of respondents thought an absence of Māori health workers at the screening provider contributed to delays. Other reasons were also described including: practical issues such as lack of transport and difficulty juggling childcare or time off work; and wider issues such as feeling whakamā (shy or embarrassed), denial and fear of diagnosis (Table 1). Information about accessing screening services due to fears of misdiagnosis, treatment or referral delay was not collected as it was seen as less relevant for asymptomatic people.

Findings with regard to delays in presenting at a primary care provider for

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<th>Screening services</th>
<th>Primary Care presentation with symptoms</th>
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<tr>
<td></td>
<td>(n)</td>
<td>%</td>
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<tr>
<td>Limited information</td>
<td>88</td>
<td>74%</td>
</tr>
<tr>
<td>Financial barriers</td>
<td>98</td>
<td>82%</td>
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<tr>
<td>Provider issues such as no GP or not registered with a Primary Health Organisation (PHO)</td>
<td>57</td>
<td>48%</td>
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<tr>
<td>Lack of cultural safety</td>
<td>59</td>
<td>50%</td>
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<tr>
<td>No Māori health workers</td>
<td>52</td>
<td>44%</td>
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<tr>
<td>Fear of cancer diagnosis</td>
<td>-</td>
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<td>Fear of misdiagnosis</td>
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<td>Fear of treatment</td>
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<td>Reluctance about talking to the doctor about other health issues</td>
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<td>Delay in referral to specialist</td>
<td>-</td>
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<td>Other reasons</td>
<td>48</td>
<td>40%</td>
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cancer detection or diagnosis, suggest that fear of diagnosis, financial barriers and fear of treatment were thought to be key reasons for delay. Additionally, many providers thought that reluctance about talking to the doctor about other health issues, such as diet or smoking, would contribute to delays. Limited information about cancer detection was also considered a factor. Almost half of respondents cited a lack of cultural safety by the primary care provider, while less than half thought that provider issues, such as not having a GP, a delay in referral to a specialist or no Māori health workers at the primary care provider, contributed to delays. Lastly, a fear of misdiagnosis was considered a contributor to delaying access to early cancer detection (Table 1). Just under a quarter of respondents listed other reasons. As with the delay in accessing screening services, these included practical issues, such as taking time off work, childcare and also worrying about the future, such as how to cope financially. Respondents also indicated that people might feel shy about seeing a doctor when they have symptoms, and fear of death, or fear of treatment based on the experiences of others.

In an open text question, providers were asked if they could identify any issues about, or barriers to, services for people with cancer. A quarter of respondents did not have any issues or barriers to identify. One respondent did not know, and data were missing for two respondents. Most respondents (70%) listed issues about, or barriers to services for people with cancer. Answers were similar to those shown for screening and presentation to primary care with symptoms in Table 1. Most commonly cited were transport and access issues. Additionally, a lack of appropriate information for people with cancer was described. This included information about diagnosis and treatment, and also information about support services available.

Financial costs were also reported as barriers to care, with time off work, childcare costs and accommodation adding financial pressure to whānau. Respondents also identified a lack of culturally appropriate services, for example cancer care staff pronouncing names correctly.

Respondents were asked if palliative care was readily available in their communities. Over half of the respondents (63%) thought it was, and 26% thought it was not. Eleven per cent of respondents did not know. Half of the respondents (n=60) identified issues or barriers to palliative care. Of these, location and travel were the main barriers, with many living in rural communities. Related to this were the responses of a smaller number of respondents who specified poor resourcing for community nurses in their area to provide palliative care services for whānau at home. A need for culturally safe palliative care services was described, and suggestions for improvement included acknowledging and improving cultural safety, having more Māori faces within palliative care service delivery, and a need for te reo Māori (Māori language), and karakia (prayer) to be available. A small number of respondents indicated reluctance by Māori to use hospice services due to associating the hospice with death.

Providers were asked if there were additional cancer care services that their organisation could provide, if funded. The question specified services that are currently not easily available or accessed in their communities. Over a quarter (32%) of respondents said there were no cancer care services that their organisation could provide. For many, this was due being a small provider with few contracts and resources. A small number (7%) of respondents did not know if there were cancer services they could provide, and over half (61%) answered positively. Of these, the services listed most were Māori-focussed cancer care services. These included support for whānau, Māori cancer support nurses, Māori focussed psychotherapy and counselling, and culturally appropriate home help. Respondents also listed 24-hour nursing support, mirimiri and rongoā, cancer resources and information specific to Māori.

In addition, the need for dedicated cancer navigator positions was highlighted. Support and advocacy, from diagnosis through to survival or palliative care, were emphasised. Respondents also listed provision of palliative care, appropriate funding for transport services rather than relying on volunteers and mobile nursing teams to access whānau in isolated areas.
Discussion

This study is the first national survey of MHP cancer services. Four key areas were identified in our findings. The first is the largely unacknowledged, wide ranging cancer services that MHPs currently provide and the additional services that they would like to provide if adequately funded. Second, a number of barriers to and through cancer care for Māori were identified, such as financial and transport issues. Third, a continuing need was shown for culturally safe care by all services for Māori with cancer. Finally, the importance of trust and long-term relationships with a focus on families rather than individual-based care was highlighted.

Our list of MHPs was compiled from publicly available directories and networks. It is likely that in addition to our non-respondents, a small number of organisations were not surveyed, although it is impossible to count how many were missed. In 2009, the Ministry of Health estimated that there were approximately 275 MHPs, but only a quarter of these are listed on their website. This raises questions about why MHPs and their work are effectively invisible, with little information available about their contributions, and few evaluations of their work.

A response rate of 55% for this survey is acceptable. It is comparable to the 46% response rate yielded in a recent cross-sectional postal survey of GPs in Aotearoa. Our efforts to increase the response rate included sending out the questionnaire up to three times and following up by telephone. We acknowledge that there may be non-response bias in this study with those organisations not providing cancer services feeling that the survey was not relevant and thus not completing it, however four declines provided information about the services they deliver and these did not differ markedly from the services reported by the respondents. Additionally, there may be some recall bias where MHPs have reflected on the services they offer or barriers experienced by those in their communities.

Results showed that MHPs contribute to cancer prevention, screening and care by delivering a wide range of programmes, including health promotion, advocacy, information and support alongside clinical care. In terms of contributing to cancer prevention, a high proportion of MHPs in our study provided health promotion services to their communities. The context of this work is important as Māori health promotion goes beyond delivering health and lifestyle messages. Ratima describes Māori health promotion as:

>a process of enabling Māori to increase control over the determinants of health and strengthen their identity as Māori, and thereby improve their health and position in society.

In this way, the work that MHPs undertake in health promotion not only plays a central role in cancer prevention, but also contributes to positive Māori development.

Almost half of the MHPs in our study reported providing cancer screening services. Building trust, long-term relationships and practical assistance have been shown to increase cancer screening rates. Our study demonstrated that many MHPs provide practical assistance, such as transport, advocacy and after hours care, but also link families with other services, such as the Cancer Society of New Zealand, hospice or Māori rongoā practitioners.

The coordination of care for Māori has been identified as a major area requiring further work. Literature has shown that cancer navigator roles have succeeded in facilitating improved cancer care in Aotearoa, and internationally—particularly for indigenous populations and those living in poverty. The current study, and our previous work with cancer patients, suggest that MHPs have been delivering informal cancer navigation for some time, but there is evidence that they are inadequately funded to do this work.

Attempts to gather health funding information from Crown funding agencies have proven problematic. Studies asking MHPs directly about their contracts have offered more insight. Lavoie found that MHPs were restricted by narrowly focussed contracts which did not reflect the work carried out. Other studies have found limited scope for MHPs to negotiate with funders, and MHP contracts to be short...
term and audited with a heavy financial focus compared to their mainstream counterparts. Indeed, the available evidence suggests that MHPs are underfunded and over regulated, but their process outcomes are under evaluated. Without these issues being properly addressed by funders, it is difficult to see how the work of MHPs can be acknowledged and supported.

Financial struggles and travel featured consistently in our results as barriers to cancer screening, diagnosis and treatment. Health care reforms, beginning in 1999, aimed to improve primary care access in Aotearoa. By signing up to a PHO, the cost of GP consultations was reduced and some services were free. However, findings from this study suggest that in addition to many Māori not having a regular GP or being signed up to a PHO, other barriers, such as the cost of travelling to appointments, still remain.

A lack of appropriate information was also a barrier to cancer services for the communities served by MHPs. This finding is consistent with work by Walker et al, who encourage more information and resources tailored to whānau and MHPs, and Cormack and colleagues, who recommend Māori-specific resource material about cancer and cancer service options for individuals, whānau and communities.

Our results suggest that fear is a major contributor inhibiting access to primary care services and potentially a cancer diagnosis. Fear of cancer, particularly by indigenous populations, has been documented internationally. Our previous work found that having a trusted community health worker, nurse or GP can help alleviate these fears. Further, persistence by MHPs in contacting and encouraging Māori to attend primary care services has been shown to ease fears about cancer screening, diagnosis and treatment.

Despite 66% of respondents believing that palliative care is available to Māori with cancer, and 24% of the MHPs delivering palliative care services, our results showed that MHPs are not confident their communities can always access the palliative care services they need. For some, this was due to living in remote locations. For those in areas where palliative care services are available, more Māori staff and improved cultural safety in hospices to encourage access was suggested. This aligns with findings from Frey et al, who additionally found a lack of awareness amongst Māori and other groups around palliative care service availability.

MHPs in our study considered that shyness, or reluctance to discuss other health issues, impacted on Māori with cancer symptoms consulting a doctor. This finding suggests a current gap in comfort and rapport with mainstream primary health care providers which has also been described in other studies. There is more work to be done within mainstream health systems and those who work in them to improve cultural safety. Approximately half of the MHPs who took part in this study consistently reported a lack cultural safety as a barrier to all cancer services, from prevention through to screening, primary, and hospital care.

Progress is being made. Our study supported previous findings that whānau play a critical role in relation to facilitating Māori access to cancer care services. Whānau Ora, a new interagency approach to providing health and social services in Aotearoa, may offer better outcomes. The Whānau Ora initiatives encompass a philosophical approach, model of practice and measurable outcomes for health and social services. At the time of this survey, Whānau Ora provider collectives were being established and early reports on Whānau Ora progress are scarce but positive. Boulton et al, for example, have shown how as a Māori-centred framework, Whānau Ora has positively changed ways of working and integration of contracts for a Māori health and social service provider. Although not all MHPs will be part of Whānau Ora collectives (at the time of writing there were 34 Whānau Ora collectives), Whānau Ora represents an opportunity to be appropriately resourced for the wide range of MHP services that overlap across sectors. Thus, the Whānau Ora approach should be considered as central to any framework for an integrated cancer care journey for Māori.
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