Indigenous inequalities in cancer: what role for health care?

Citation for published version:

Digital Object Identifier (DOI):
10.1111/ans.12041

Link:
Link to publication record in Edinburgh Research Explorer

Document Version:
Early version, also known as pre-print

Published In:
ANZ Journal of Surgery

General rights
Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy
The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.
Indigenous inequalities in cancer: what role for health care?

Sarah Hill,* Diana Sarfati,† Bridget Robson† and Tony Blakely†
*Global Public Health Unit, University of Edinburgh, Edinburgh, UK and
†Department of Public Health, University of Otago Wellington, Wellington, New Zealand

Key words
cancer survival, cancer treatment, ethnic inequality, Indigenous, Māori.

Abstract

Introduction: Poorer cancer survival in Indigenous populations contributes to health inequalities in both New Zealand and Australia.

Methods: We reviewed recent evidence of cancer treatment and outcomes among Māori and non-Māori New Zealanders and examined the range of factors that may contribute to poorer survival in Māori.

Results: There is clear evidence that Māori have poorer cancer survival compared with other ethnic groups, particularly European New Zealanders. Two recent studies show that Māori patients receive poorer quality treatment for cancers of the lung and colon, even after adjusting for patient factors. These findings suggest the need to consider how the health-care system as a whole may disadvantage Indigenous patients.

Discussion: We present a framework for considering how inequalities may arise in the delivery of cancer care, taking account of the health system as a whole – including the structure and organization of cancer services – as well as treatment processes and patient factors. A key feature of this framework is that it directs attention towards system-level factors affecting cancer care, including the location, resourcing and cultural focus of services. Our analysis suggests a need to look beyond individual patient factors in order to improve the quality and equity of cancer services and to optimize cancer survival in Indigenous populations.

Introduction

The differential health status of Indigenous and non-Indigenous people is an ongoing challenge for the health sector in both Australia and New Zealand.¹,² Cancer is an important and growing contributor to these health inequalities³,⁴ and provides a salient case study for considering how health services may either reduce or exacerbate shortfalls in Indigenous health. This article focuses on the experience of Māori cancer patients, but such discussion has relevance for other diseases and for Indigenous populations in Australia (and Canada) in whom similar patterns have been observed, particularly in relation to cancer treatment and survival.⁵,⁷

Methods

We reviewed recent evidence on cancer treatment and outcomes among Māori and non-Māori New Zealanders and explored possible factors contributing to poorer survival in Māori. In doing so, we sought to look beyond patient-level factors to take account of the health system as a whole. Our intention is that this analysis will direct attention to some important areas to address in strengthening cancer services and ensuring Indigenous and non-Indigenous populations benefit equally from the health sector’s commitment to cancer control.

Results

Inequalities in cancer outcomes

While the last 10 years have seen an encouraging reduction in cancer mortality in New Zealand, inequalities in cancer remain and in some cases are increasing.³ Total cancer incidence is around 20% higher in Māori compared with non-Māori New Zealanders while mortality is almost twice as high.⁹ This disproportionate burden of mortality occurs because Māori are not only more likely to develop cancer (particularly the less treatable types), but also more likely to die from cancer following diagnosis.⁶,¹⁻¹⁴

There is clear evidence that Māori have poorer survival than other ethnic groups for most types of cancer.⁶,¹⁻¹⁴ (Pacific patients have poorer cancer survival compared with European patients, although their outcomes are somewhat better than those of Māori.¹⁰). Māori experience a significant survival disadvantage for almost all the most common cancer sites (including lung, breast...
Indigenous inequalities in cancer care

Why do Māori patients do worse? From a clinical perspective, differences in both disease and patient characteristics are often seen as likely contributors to differential outcomes. There is no doubt that these factors play a role in survival differences between Māori and non-Māori patients – particularly at stage at diagnosis, an important predictor of survival. But do they fully account for the survival gap between Māori and non-Māori, and (even if they do) does this mean health services are irrelevant to cancer inequalities?

Compared with non-Māori, Māori patients are more likely to be diagnosed with late-stage disease for cancers of the lung, breast, prostate, colorectum and cervix, and for melanoma. As well as being diagnosed at a later stage, Māori are also less likely to have stage at diagnosis recorded. While differential stage accounts for some of the survival difference between Māori and non-Māori patients – particularly for cancers of the breast and prostate – it is important to note that significant survival differences persist even after adjustment for stage at diagnosis.

Differences in co-morbidity may also contribute to poorer cancer outcomes in Māori patients. Māori New Zealanders have higher prevalence of diabetes, cardiovascular and respiratory disease, all of which may limit treatment choices and reduce survival. Reasons for higher co-morbidity in Indigenous peoples are complex and include greater socio-economic deprivation, poorer access to favourable determinants of health and (ultimately) historical disadvantage through the processes of colonization.

So do differences in stage at diagnosis and patient co-morbidity fully explain why Māori cancer patients have poorer survival? Research from both New Zealand and Australia suggests not, with poorer survival in Indigenous patients persisting even after adjustment for both stage and co-morbidity. Moreover, it is important to consider why Māori patients are more likely than non-Māori to have co-morbid conditions and less likely to be diagnosed at an early stage of cancer progression as both factors are potentially responsive to health care.

Inequalities in cancer treatment

Emerging evidence suggests that Māori experience particular barriers to accessing diagnostic cancer services. New Zealand’s cancer screening programmes have lower coverage for Māori and Pacific women compared with Europeans. In addition, Māori are more likely to experience unmet need for primary health care (the usual route to diagnosis for cancers not detected by screening). Within primary care, Māori experience shorter consultation times and are less likely to be referred for specialist review compared with other ethnic groups. Difficulties in access to and through the health system are likely to contribute to delayed cancer diagnosis in Māori patients.

There is also growing evidence that Māori patients face barriers to effective care even after a cancer diagnosis is made. Audit data from New Zealand’s national breast screening programme suggest Māori women wait longer to receive treatment following a diagnosis of breast cancer. Two recent studies show Māori are less likely than European patients to receive curative treatment for cancer of the lung and colon.

Stevens et al. reviewed management of lung cancer in a cohort of patients diagnosed and treated in Auckland and Northland in 2004. They found Māori patients were significantly less likely than Europeans to receive potentially curative treatment (received by 12% of Māori compared with 22% of European patients). This disparity was not accounted for by differences in disease factors or patient co-morbidity: after adjustment for age, sex, tumour type and stage, co-morbidity and small area deprivation, Māori patients remained only a third as likely to receive curative treatment (Māori/European odds ratio = 0.30, 95% confidence interval (CI) 0.10–0.80). While Māori and European patients were equally likely to receive diagnostic and staging investigations, European patients had significantly shorter waiting times from diagnosis to treatment compared with Māori.

Similarly, Hill et al. found significant ethnic differences in treatment of patients with colon cancer. Māori and non-Māori patients received similar rates of surgical resection, but Māori were around a third less likely to receive adjuvant chemotherapy (Māori/non-Māori ratio = 0.69, 95% CI 0.53–0.91 among patients with stage III disease). As with lung cancer, there were also significant differences in the timeliness of treatment: among those receiving adjuvant chemotherapy over half of all Māori patients waited 8 weeks or more to start treatment, compared with a quarter of non-Māori patients.

Taken together, these findings suggest the health service as a whole may deliver a lower quality of cancer care to Māori compared with non-Māori patients. This does not mean that individual health workers or service providers treat their Māori and non-Māori patients any differently (indeed, no New Zealand studies have explicitly examined this possibility). But at a population level, Māori appear to be receiving less curative cancer treatment compared with non-Māori (particularly European) patients. Inevitably, these differences in treatment will contribute to poorer cancer outcomes in Māori.

Discussion

Factors contributing to inequalities in cancer treatment and outcomes

Inequalities in treatment of Māori and non-Māori patients may arise at three levels: differences in individual patient factors, differences in health-care processes and differences in the function of the health system as a whole in relation to Māori and non-Māori populations (Table 1).

Clinicians are likely to be most familiar with those factors that operate at the level of individual patients, as these are the factors most visible in the clinical encounter. Less apparent but equally important are factors operating at the level of health-care processes (such as referral systems and presentation of treatment options) and the health system itself (including the location, resourcing and cultural ‘norms’ of services). In practice, these three levels interact, and some factors may fit under more than one level depending on the perspective taken. For example, capacity to meet the costs associated with receiving care may be considered either a system- or a patient-
level factor, depending on whether one focuses on the provision and funding of services or the capacity of individual patients to meet treatment-related costs.

**Patient factors**

Māori New Zealanders have higher co-morbidity compared with other ethnic groups,15,21 which may affect their treatment options.26 Yet both recent studies of cancer treatment found Māori patients received lower rates of curative intervention even after adjustment for co-morbidity.25,26 Co-morbidity is not necessarily a contraindication to treatment such as chemotherapy, which confers significant survival advantage even in the presence of pre-existing medical conditions.32,33 Withholding potentially curative treatment in the presence of co-morbidity will disproportionately disadvantage groups with higher levels of coexisting disease. Patient co-morbidity may interact with other factors – including communication difficulties and cultural differences between patients and health-care providers – to decrease the likelihood of Māori patients being offered treatment.

Ethnic differences in treatment are often attributed to patient choice, yet neither study found evidence that this contributed to differences in interventions between Māori and non-Māori cancer patients.25,26 While Māori patients were reported as slightly more likely to refuse treatment for lung cancer (13% of Māori compared with 9% of all patients), this did not explain their lower rate of curative treatment.25 No ethnic differences in treatment preference were found among patients with colon cancer.36

Some researchers have suggested that ethnic minorities are more likely to use alternative therapies and therefore reject mainstream treatment, but there is little evidence to support this in the New Zealand context.34,35 and care should be taken to avoid patient stereotyping.36,37 Recent qualitative research shows many Māori are comfortable combining clinical treatment with more traditional forms of healing, seeing these as complementary rather than mutually exclusive.38 Patients of all ethnicities are less likely to accept health care if they perceive the disadvantages as outweighing the advantages.34 Where health services experience recurrent difficulty in engaging with patients from a particular ethnic group, questions must be raised about the cultural safety of those services,39 the context in which patients are making health-care decisions, and past interactions between service providers and the population group in question.40

### Table 1 Factors affecting equity of cancer treatment for different ethnic groups

<table>
<thead>
<tr>
<th>Domain</th>
<th>Specific factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structural and system-level factors</td>
<td>Location and resourcing of health services, Health service funding, Cultural focus of health providers</td>
</tr>
<tr>
<td>Health-care processes</td>
<td>Complex, multi-stepped processes, Health worker reliance on stereotypes, Communication</td>
</tr>
<tr>
<td>Patient factors</td>
<td>Co-morbidity, stage at diagnosis, Socio-economic status, Patient preferences</td>
</tr>
</tbody>
</table>

As in Australia, New Zealand’s Indigenous population experiences significant socio-economic disadvantage relative to other ethnic groups (particularly Europeans).15 Deprivation is associated with later stage diagnosis and poorer access to cancer treatment.41 As noted earlier, socio-economic disparities in care may be considered both a patient- and a system-level factor as cost-related barriers reflect an interaction between patient circumstances and the funding and delivery of services.

### Treatment processes

Cancer care is complex, often involving multiple specialities, referral pathways and service providers. This complexity poses challenges for all patients, but Māori appear particularly disadvantaged. Hill et al. found Māori with stage III colon cancer were 30% less likely to receive adjuvant chemotherapy compared with non-Māori patients, even after adjustment for co-morbidity.26 There was no single step in the treatment process at which Māori received dramatically less care than non-Māori (Fig. 1); rather, the picture is one of subtle but accumulating disadvantage, ultimately producing a substantial treatment disparity with chemotherapy offered to only 50% of Māori patients (compared with 64% of non-Māori), and Māori twice as likely to wait 8 weeks or more to start chemotherapy.

Māori may be disadvantaged by unconscious stereotyping on the part of health workers. Evidence from the USA suggests stereotyping on the part of health professionals makes an important contribution to ethnic inequalities in treatment.42 The influence of stereotyping may be particularly pronounced in the presence of uncertainty and time pressure43,44 – features that characterize many clinical encounters, particularly in cancer care.45 To date, no New Zealand studies have explicitly examined the role of discrimination in clinical decision-making, although there is evidence that some health-care workers have negative stereotypes concerning Māori patients,15,37 and Māori are more likely than Europeans to experience discrimination by a health professional because of their ethnicity;46 this is associated with lower odds of breast or cervical screening, and negative health-care experiences.

Communication issues are a recurrent theme in qualitative studies of health-care experiences among Māori.35,38 Effective communication is important for patients from all social groups, but health workers often find this more difficult with patients from backgrounds different to their own.24 Such difficulties may prevent doctors from eliciting complete information from their patients, making them more likely to rely on stereotypes and less likely to seek clarification from the patient or their family.47

### Health system factors

Service location, funding and the cultural focus of providers may all contribute to inequalities in treatment. These factors reflect the entire health system rather than decisions or actions of individual health workers. Such ‘institutional’ characteristics influence all levels of the health system and can have a profound effect on the equity of care offered to different population groups.

A review of cancer services in New Zealand identified a number of system-level factors that may contribute to lower quality care for Māori patients.40 These include the location of cancer services, the expense of care, the composition of the cancer care workforce and a
tendency for cancer services to focus on the total population without addressing the needs of some ethnic groups.

Patient access is influenced by the location of services—particularly cancer centres—which are concentrated in New Zealand’s main population centres. Centralization may increase the overall quality of care, yet may also exacerbate inequalities in access for some population groups. Māori are more likely to live in rural areas at greater distance from New Zealand’s six cancer centres.

The effect of centralization on inequalities will partly reflect what support is provided to patients and families obliged to travel away from home to receive care. The absence of ethnic inequalities in survival from childhood cancer suggests it is possible to address the access barriers faced by Māori. Paediatric cancer services in Aotearoa are highly centralized, with most patients and whānau remaining at specialist cancer centres throughout the acute phase of treatment (N. Douglas, pers. comm., 2008). The special status of childhood cancer may attract higher levels of systemic support for patients and their families, while relatively small patient numbers may reduce potential for ‘slippage’ in referral and support systems.

Decreased funding for cancer services is likely to impact on waiting times and service quality, and may differentially reduce the accessibility of care for those in less affluent groups. While public hospitals provide the majority of cancer treatment in New Zealand, a quarter of patients with colon cancer use the private system for some aspect of their care. Private care may offer advantages in terms of shorter waiting times and possibly better outcomes compared with secondary public services. Māori/non-Māori differences in private cancer care are greater than the ethnic gap in insurance coverage (26% among Māori and 43% among Pākehā in the 2002–2003 New Zealand health survey), suggesting that in the absence of insurance, non-Māori may be more likely to pay for private care. This suggests non-Māori may be better able to ‘buy out’ of geographical disadvantage in cancer care—for example, by paying for private investigation and diagnosis rather than depending on non-specialist public services.

Cancer treatment also involves substantial indirect costs. A third of families with children undergoing cancer treatment have to borrow money to meet financial commitments associated with care. For adults, cancer treatment often requires time off work. These factors will disproportionately impact on Māori, who have fewer financial resources and are more likely to be in insecure or in casual employment compared with other New Zealanders.

Specialist cancer treatment in New Zealand is delivered through mainstream providers, who also provide the majority of cancer support services. The previously mentioned review found that most services focus on the total population and reflect European cultural norms—perhaps unsurprisingly, given the dominance of Europeans and under-representation of other ethnic groups within the health workforce. This mainstream focus in health-care provision may inadvertently neglect the needs of Indigenous and ethnic minority groups.

**Conclusions**

Questioning the fairness of our health system is an uncomfortable undertaking. The principle of care based on need is a core value for most health professionals, particularly in the context of a life-threatening disease. None of us wants to believe that our health system—or those of us working in it—might discriminate on the basis of ethnicity. Yet an honest look at the evidence makes it difficult to avoid this assessment.

An important and potentially illuminating feature of the framework presented here is that it looks beyond individual patients and health workers to consider the role of the health system as a whole. We have no evidence that individual health professionals provide differential care to Māori and non-Māori patients; yet the evidence shows the system as a whole is delivering unequal care. This leads us to examine features of the health system itself to consider whether these might result in a kind of organizational discrimination—also known as institutional racism.
The organization, location, funding and staffing of cancer services may all contribute to inequalities in the care of Māori and non-Māori patients. Many of these features reflect the historical development of New Zealand’s health system, and are less a product of contemporary decision-making than a failure to recognize and reverse the long-standing effects of past decisions. Yet we have the opportunity to address these institutional factors by considering and changing the way in which care is offered in the future. To ignore this opportunity is to accept a health system that provides poorer treatment to those patients with greatest need.

While health service structures underpin the delivery of cancer care, provider–patient interactions and clinical decision-making are also important for equity of care. Each of us may benefit from examining our practice and asking whether the care we provide (or the decisions we make, or the research we undertake) meets the needs of all patient groups, and not just the most visible. For example, it is important to ensure patients are offered all appropriate cancer treatment and that chemotherapy is not withheld unnecessarily in those with pre-existing medical conditions.

There are success stories in the treatment and care of Māori patients, offering potentially important lessons and reminding us that inequalities are not inevitable. As noted earlier, New Zealand’s paediatric cancer services deliver high-quality care to all population groups, with Māori children enjoying the same outcomes as non-Māori. Since the introduction of a national screening programme, Māori/non-Māori inequalities in the incidence of cervical cancer have diminished. And while breast screening coverage remains unequal, some regions have successfully increased their coverage among Māori women. It is to be hoped that early detection of other cancers will also improve following advances in access to primary health care.

In order to recognize the strengths and address the weakness of cancer services, we need information on health system performance – including data disaggregated by ethnicity. BreastScreen Aotearoa (the national breast cancer screening programme) is an example of good practice in this area, with independent reporting on coverage by ethnicity. Inclusion of such data in all routine cancer service monitoring would be a positive step. Quality improvement systems also offer a potential tool for improving equity across population groups, providing information is communicated back to staff in a timely and effective way. Finally, increased attention to workforce planning and support for Māori participation will help build a health system more responsive to the needs of Māori communities.

There is much to celebrate in New Zealand’s cancer services. Many doctors, nurses, allied health professionals and volunteers work hard to provide high-quality, compassionate care to patients and families living with cancer, often in a context of limited time and resources. While recognizing the strengths of our health system – and particularly its staff – it is also important for us to recognize that this system does not always provide equal care to Māori and non-Māori, and that these inequalities contribute to poorer survival for Māori with cancer. Inequalities in cancer treatment and survival can be addressed, but only if we are prepared to ask some difficult questions.

### References
