



Achieving equitable outcomes for Māori women with cervical cancer in New Zealand: health provider views

Melissa McLeod, Donna Cormack, Ricci Harris, Bridget Robson, Peter Sykes, Sue Crengle

Abstract

Aim This study explored health provider views on changing survival disparities between Māori and non-Māori women, the management of cervical cancer in New Zealand, and achieving equitable outcomes from cervical cancer for Māori women.

Methods This research followed on from a cohort study of cervical cancer treatment and survival in New Zealand. Focus groups were undertaken with three provider groups in different regions working across the range of cervical cancer services. Focus group transcripts were analysed to identify key themes.

Results Providers were encouraged by the reported improvement in survival disparities between Māori and non-Māori women over time. The themes of discussion relating to cervical cancer management included: communication and education; screening; access to treatment; pathways through care; patient factors; and, system standards. Providers also suggested options for further improvements in the management of cervical cancer.

Conclusions The focus groups identified that despite improvements over time in cervical cancer disparities between Māori and non-Māori and in the management of cervical cancer, further effort is required to achieve equitable outcomes for Māori, particularly in the areas of prevention and early detection.

Since the introduction of a National Cervical Screening Programme (NCSP) in the early 1990s, there have been significant reductions in cervical cancer disease incidence and mortality in New Zealand.¹⁻³ However, cervical cancer remains one of the most common cancers for Māori women.

For the 2000–2004 period, cervical cancer was the fourth most commonly occurring cancer and the fifth most common cause of cancer death for Māori females.⁴ There are inequalities in the incidence of, and outcomes from, cervical cancer in New Zealand, with higher mortality rates and lower survival for Māori women compared with non-Māori.⁴⁻⁶

In order to better understand what might be contributing to disparate cervical cancer outcomes, a cohort study (for the period 1996–2006) was undertaken to investigate the potential role of treatment differences in the differential outcomes for cervical cancer for Māori and non-Māori women in New Zealand.

The study found there were substantial improvements in the disparities between Māori and non-Māori women in cervical cancer incidence, mortality and survival, and no differences by ethnicity in treatment at the same stage of disease. However, Māori

women remain at higher risk of cervical cancer and continue to be diagnosed with more advanced disease.

This study concluded that primary prevention and early diagnosis were key components of eliminating the remaining inequalities in cervical cancer between Māori and non-Māori women.³

This article reports the findings of focus groups that were undertaken to explore health service provider views on the cohort study findings (as outlined above) and, more broadly, on the management of cervical cancer in New Zealand and on achieving equitable outcomes between Māori and non-Māori women.

In the domestic context, there has been some qualitative research investigating the experiences of Māori patients and whānau (extended family) with cervical cancer services. These studies involved undertaking key informant interviews with women to explore the reasons for not attending for cervical smears despite being overdue.⁷⁻⁹ One of these studies included views from health professionals.⁷

Lovell et al (2007) interviewed 17 lay women (including four Māori participants) who had presented for an overdue cervical smear in one of three clinics in Manukau City. In addition, this study included views from nine individuals who were screening providers. Within the study many women found screening acceptable, and most of the identified reasons for delaying a smear could have been addressed by structural changes to the healthcare system. Barriers identified included the cost of a smear, concerns over exposing one's body (particularly for Māori and Pacific participants), and gaps in understanding the purpose of screening.⁷

In another study, Buetow et al (2007) undertook indepth interviews with six women (five Māori and one European) who had been overdue for a cervical smear within the preceding six years. The implications for practice from this research included the need to care for and respect the dignity of women having cervical smears, effective communication between the health provider and the woman, offering a regular smear-taker, the option of a female smear taker, and a place for women to wash before the procedure.⁸

Ratima et al (1993) collected screening histories from 46 Māori women with invasive cervical cancer. This study identified issues with access to primary care, referral of women with smear abnormalities and screening programme quality control.⁹

Despite having a critical role in the management of cervical cancer, health providers have rarely been participants in focus groups or subjects of key informant interviews. Providers have important perspectives on cancer care disparities, accompanied by institutional and contextual knowledge that can help in understanding how disparities occur. They also have the potential to identify areas for change or intervention, and act as champions or agents of change themselves.

This study will add to the literature by capturing the views and experiences of a range of health providers who work directly with patients with cervical cancer.

Methods

A qualitative study that investigated health provider views of cervical cancer disparities and management in New Zealand. It followed from a cohort analysis of Māori and non-Māori women with cervical cancer between 1996 and 2006. The cohort study is reported elsewhere.³

Participants—Three focus groups were undertaken in different regions: one with a range of health providers working in a region with a secondary care hospital (Region S); one with Māori health providers (Region M); and the third with health professionals working in a tertiary care hospital (Region T). Additionally, one key informant interview was completed for an individual who was unable to attend the tertiary provider focus group session (K). Participants worked across the range of cervical cancer services (Table 1).

In Region S (the secondary care region), a range of hospital and community health providers who provided care to women with cervical cancer were invited. All Māori providers with women’s health portfolios were invited from Region M. In Region T (the tertiary care region), a range of service providers working at a tertiary care level were invited, based on their availability.

Initial approaches to participants were made by phone, with information sheets subsequently forwarded. Consent forms, including consent to record the session, were completed prior to the commencement of the focus groups. Ethical approval for this study was granted by the Multi-Region Ethics Committee (MEC/05/07/085).

Two Māori researchers attended each focus group: one as presenter, the other as the facilitator. The focus groups began with a brief presentation of the cohort study results.³ Participants were then given an opportunity to ask questions relating to the cohort study. Following this, the focus group proper began. The facilitator gave an outline of the purpose of the focus group, set the ground rules for the session, and introduced the discussion points.

Five discussion points were covered in each focus group. A discussion guide was developed to standardise the wording of the discussion points, and to provide the facilitator with prompting questions should they be required. The questions were:

- Our study shows that survival disparities are decreasing between Māori and non-Māori women. Does this fit with what you see in practice?
- Based on your experience, why are/aren’t survival disparities decreasing?
- What is working well in the management of women with cervical cancer?
- What is not working well in the management of women with cervical cancer?
- How do we get equitable outcomes for Māori women with cervical cancer?

The sessions were recorded and transcribed, and subjected to thematic analysis, by the lead author.¹⁰ A thematic network was used to arrange the category codes into basic themes, organising themes and global themes for analysis.¹¹ A second researcher, who did not attend the focus groups, performed thematic analysis on one of the focus group transcripts. Minor changes to the themes and thematic network were made with consensus decision between the two researchers.

Results

A total of 22 people participated across the three focus groups including both Māori and non-Māori staff working in a range of roles (Table 1).

The focus group participants were generally pleased and encouraged by the improvements demonstrated in the quantitative findings presented. In reflecting on their own experience, most noted that due to the small numbers of women they saw with cervical cancer it was difficult to know whether the pattern of disease had changed in their region since 1996.

Some who had worked in cervical cancer services for many years had noticed a reduction in the number of Māori women presenting, and also had an impression that survival had improved over this time period.

Table 1. Focus group participants

Secondary focus group	Tertiary focus group (T) and	Māori provider group (M)
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Participants (S) N=11	key informant interview (K) N=7	N=4
<i>Non-DHB staff</i> Māori Provider General Practitioner Cancer Society <i>DHB staff</i> Gynaecologist Colposcopy Nurse Gynaecology Outpatients Nurse Oncology & Palliative Care Nurse Specialists (2) Service Manager Community Nursing DHB Māori Health Unit	Gynaecology Oncologist Medical Oncologist Radiation Oncologist Radiation Therapist Gynaecology Ward Nurse Nurse Colposcopist Gynaecologist	Sexual Health Educator Practice Manager (2) Breast & Cervical Educator & Promoter

In relation to the management of cervical cancer in New Zealand, the issues discussed were broad ranging and included factors relating to the providers, the way services are delivered to Māori, and individual patient factors (Table 2).

Table 2. Provider perceptions of factors influencing disparities (positively or negatively) between Māori and non-Māori in cervical cancer

Theme	Topics
Communication and education	National campaigns Health providers
Cervical Screening	Cost Acceptance of screening Patient dislike of smears
Access to treatment	Transport Economic/ financial Cultural Missed appointments Mobile populations
Pathway of care	Provider groups (Māori providers and mainstream) Interlinking of services
Patient factors	Health status Disease factors
Standards	Treatment standards PHOs Ethnicity data

Communication and education

There was consensus in the focus groups that the reduction in disparities between Māori and non-Māori women was in part due to greater awareness of cervical cancer and the cervical cancer screening programme. Multiple modes of communication were identified to have contributed to increased awareness including television advertisements, Māori providers, and improved communication between health providers and patients. The national advertising campaigns were seen as highly successful in raising awareness about cervical cancer.

From the colposcopy clinic perspective there has been a difference in the number of woman presenting as a result of the advertising campaign by cervical screening. And that will eventually impact on earlier diagnosis (T5)

Communication with health providers was identified as having a strong influence on the experiences and outcomes of patients with cervical cancer. Both positive and negative aspects of communication between health providers and patients were identified by the participants. Participants noted that there continue to be situations where patients remained confused after interacting with health providers, for example, because of the language used or explanations given, or because patients may not feel empowered to ask questions.

Some of the women used to have lots of questions when they went to see their GP, and we used to say, well you know, they'd get in there and they'd come out and say I didn't ask any of the questions, I was too embarrassed, I forgot (M3)

There were also situations identified where a negative interaction with a health provider was seen to result in patients disengaging from health services and not attending for appointments. This included situations where patients experienced general rudeness, or were made to feel guilty, e.g. made to feel guilty about being overdue for a smear when attending for one.

Screening

When the focus groups were asked their views on what needed to be done to improve cervical cancer outcomes for Māori women, the health providers generally commented that emphasis needed to be placed on activities at the prevention and early detection end of the cancer continuum.

It's right at the beginning that we've got a lot of work to do. I mean prevention and early diagnosis has to be the way forward. We're very lucky with cervical cancer that we can prevent and diagnose it early and I think we should be putting a lot of effort into doing that (K1)

A dislike of cervical screening procedures was cited as a common reason for not attending for cervical smears or colposcopy for all women. Some felt there had been improved acceptance by Māori women of cervical screening over time.

You know I'm talking about fifteen twenty years we're 'don't go there that's Tapu'. Now that's been brought out in the public, some of them are talking about, you know, you've got to go for your smear (S6)

So where we are today it's really awesome, but I think the thing that is still whakamā for all women, Māori, and Pacific, is the actual procedures of actually going there hopping on the bed (M1)

The cost of screening to the individual was also identified as a barrier.

I think more resources need to go in at a screening level. Because I think those inequalities of, you know, yeah just, income inequalities do count at a screening level (S2)

Access to treatment

Health providers identified a number of access issues relevant to the management of cervical cancer. Transportation was identified as an issue, particularly for women who lived further from a cancer centre. Some felt that although transportation was an issue, it did not necessarily influence a patient's decision to accept or decline treatment and that there was some acceptance of the need to travel for treatment.

My impression is that most patients accept the need to go to other centres which doesn't though take away the fact that that is quite an ordeal (S3)

Others argued that the financial cost of needing to travel long distances for treatment resulted in patients not attending scheduled appointments, or declining treatment altogether. It was also suggested that these financial pressures are likely to be increased in the current economic climate.

I would see as one of the problems in terms of disparities is access to treatment, and certainly with a recession and rising petrol costs and the time it takes and the levels of tiredness and fatigue that our patients feel, they are often barriers to people taking up treatment that probably would be just a matter of standard practice (S4)

Health providers talked about the culture of the health system as a barrier for some women. There was an acknowledgement that some effort had been made to support Māori women within the hospital system, and that this may have contributed to improved access to care.

I think too the support for the woman on the ward has improved over those ten years too as far as allowing their whānau to be there, stay the night, that type of thing. So I think that's where that whole hospital thing is less threatening for them over those years as well (T3)

Pathway of care

In relation to pathways of care, providers discussed the role of both Māori providers and mainstream services, as well as the interlinking of services.

Māori providers—Participants generally agreed that Māori health providers and Māori staff had been successful in helping improve the accessibility of cervical cancer services for Māori women. This success was seen to relate to models of practice that worked to address issues with education and understanding, transportation, location and timing of clinics (such as offering marae-based clinics or late-night clinics), and support to navigate care pathways.

If you have that relationship, and most of us have built that up in our community, we may not have met these women but you know the ones referred to us from the GP if you've rung them up on the telephone, and you booked them into clinics, and you offer transport if they don't have transport, you offer support and if they need you they can make contact with you (M3)

Another success of Māori providers was seen to be the training of Māori health promoters. Focus group participants identified the important role of having the 'right' people involved in the provision of care, including having people who are from or know the community.

Now I think that the decreasing disparities are exactly that, about communication, but having the right person communicating the message to that particular group of people and then just inclusively bringing them in and buddying up with them and through the service (S4)

Mainstream providers—There were a number of examples provided of mainstream services offering a more flexible way of operating to meet their patients' needs including the provision of smoking cessation advice within a colposcopy clinic, provision of Māori colposcopy clinics, and fitting patients in for radiotherapy appointments even if they arrived at the wrong time.

We have two nurses now that do that so that if someone does smoke we've got someone right there rather than give them the card they might never ring up (T4)

The ways in which services worked with each other in the management of cervical cancer was raised. The secondary care focus group identified significant

improvements in the interlinking of cervical cancer services in their region. These improvements were partly possible because of the relatively small population of the region, and the limited number of healthcare professionals working with cervical cancer patients.

It makes life a lot easier and you can refer on and it's a small population. I mean people get in fast to get their treatment and it's much better service for them all the way round really and they can get that personal approach (S5)

However, the increased linking of services and open communication between them also raised concerns by a few participants about potential risks to patient confidentiality.

Missed appointments—A significant concern raised in all of the focus groups was the number of women who become lost within the system, at various points along the pathway of care.

There was concern that women who did not attend (DNA) appointments were not followed up as pro-actively as possible. Māori providers could see the importance of their involvement in assisting both DHB and primary care staff to contact Māori women labelled as DNA for DHB appointments. They gave examples of working with a local medical practice to follow up on DNAs and continuing to invite women for smears after three attempts had been made.

With those DNA's for Māori women, who follows them up, and you know we could, we have the ability to work one on one with those people (M2)

In talking about the challenges of screening and follow-up of mobile populations, health providers identified that part of the solution was to take opportunities to screen this population as they arose, such as basing 'satellite' clinics at convenient locations or providing screening at public events. However, it was recognised that there were challenges in following up with screening results, and getting mobile patients to treatment.

We've taken a clinic closer to the venue and yeah we got the women, but once they left there it's tracking them down to have follow up treatment or, you know, if they need to be, that again presented another problem because you couldn't find them (S6)

Patient factors

Providers identified changes in patient factors over the time period as contributing to improved survival disparities over time, but also as important considerations in the management of cervical cancer and the equity of cervical cancer care. Some expressed the view that an improvement in general health status of Māori may have had some influence on improvements in cervical cancer survival and disparities.

Like foetal mortality rates, it's just an indicator of better general levels of health, better nutrition, better generally raised standards that we're seeing. Maybe it's no specific thing we're doing it's a more generalised improvement (S3)

Changes in the management of co-morbid conditions and in the prevalence of risk factors, such as smoking were raised as positive developments. However, there was concern that smoking continued to play a significant role in the disparities between Māori and non-Māori women influencing both the incidence of cervical cancer and the efficacy of radiotherapy treatment.

I still think we've got a long way to go. And particularly with the smoking thing I don't know how we do that but it's such a pervasive thing because it does increase the chances of cervical cancer but it may affect the treatment too (K1)

Standards

Treatment standards—Although national standards do not exist for treatment services for cervical cancer, participants noted a trend towards improved consistency of practice across the country, as a result of organisation of specialist providers. Some providers expressed the need to set treatment standards, to ensure that practice is consistent both within and across DHBs, and to be able to monitor. One provider noted that any standard that is developed needs to include consultation with Māori and with consumers more generally.

there's a lot more now in terms of meetings and things going on and consistency... there's quite an expectation now that all colposcopists will be attending those meetings and inevitably that creates sort of a homogenous approach...I think that has changed a lot in the last decade so you probably are seeing a greater similarity between the way that individual colposcopists now approach that problem (S3)

PHOs—Participants identified benefits associated with changes to the PHO structure, including improved cervical screening coverage reported in PHO performance indicators, generally improved care resulting from the application of clinical standards, smaller part charges for primary care consultations and greater flexibility in the choice of health professional providing services (e.g. nurse smertakers).

Under our PHO rule they don't have to see the doctor they can just see the nurse you know (M3)

The Māori providers identified challenges in trying to work across PHO boundaries and concerns about the capacity of health promoters within PHOs to respond effectively to the issues faced by such large and diverse groups.

I think having the PHO's has made a difference but I also think having the PHO's has also put some barriers there. Because the women don't necessarily belong to our GP, to our PHO, so therefore do we work with them, don't work with them, are we crossing over into someone else's territory (M4)

Ethnicity data—The need for good quality ethnicity data to monitor Māori health and inequalities, and ongoing problems with its collection and quality were raised by some participants.

Discussion

Cervical cancer incidence, mortality and survival for both Māori and non-Māori women is improving in New Zealand. In addition, the disparities between Māori and non-Māori women in these outcomes are decreasing.

Health providers identified a number of developments in the management of cervical cancer that may have contributed to the improved outcomes for cervical cancer including national social marketing campaigns, standard setting in screening, diagnosis and treatment, and Māori providers contributing to improved access for Māori women.

A number of areas requiring further improvements in order to achieve equitable outcomes for Māori were identified. Additional effort is required to: improve patients' navigation and understanding of the pathway of care; improve access to care; reduce

the cost of cervical smears; and improve communication between patients and whānau, and providers.

Many of the issues identified by health providers for achieving equitable outcomes for Māori and non-Māori women such as communication, cost, information and transport have been identified in other work in relation to cancer care more generally.¹²⁻¹⁴

Focus groups were chosen as the primary method of data collection to capture both the opinions and interactions of different provider groups. This method is susceptible to social desirability bias, where participants refrain from expressing their true opinions in order to conform to the views of other participants. Ground rules were established emphasising respect, sensitivity and confidentiality in order to minimise this occurring.

This research included the views of a range of providers from a number of different DHB regions. There was considerable overlap in the issues identified, which are likely to be applicable across DHBs. There were also region specific issues identified that will vary according to the demographics of the population, geography and service availability within regions.

This research focused on the experiences of health providers, in order to identify areas for improving outcomes for Māori women with cervical cancer. Although outside of the scope of this project, capturing the experiences of Māori patients and whānau is critical to improve the responsiveness of services for this group. While some work has been done in this area,⁷⁻⁹ there remains a real need for more comprehensive work here.

Significant reductions in cervical cancer incidence and mortality have occurred for both Māori and non-Māori women since the introduction of the National Cervical Screening programme in 1991. The introduction of the HPV vaccine into New Zealand schools in 2009 marked another significant development in cervical cancer prevention.

It is imperative that the gains achieved to date are not lost, and we continue to reflect on and improve the National Cervical Cancer Screening programme in order to achieve equitable outcomes for Māori women with cervical cancer. Disparities in cervical screening coverage between Māori and non-Māori are significant and longstanding^{15,16} and are an area where gains can be made.

Engaging health providers is a critical step in working towards the achievement of equitable outcomes for Māori women with cervical cancer. Not only do they offer an important perspective on the systems within which they work, but are also potential drivers of change and improvement in these systems.

Both quantitative and qualitative findings indicate the importance of prevention and early diagnosis as the key areas of focus in order to eliminate the remaining inequalities in cervical cancer between Māori and non-Māori women. The significant gains to date indicate that, with continued effort, this is an achievable goal.

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Author information: Melissa McLeod, Senior Research Fellow; Donna Cormack, Senior Research Fellow; Ricci Harris, Senior Research Fellow; Bridget Robson, Director; Te Rōpū Rangahau Hauora a Eru Pōmare, Department of Public Health, University of Otago, Wellington. Peter Sykes, Associate Professor and Gynecological Oncologist, Dept Obstetrics and Gynaecology, University of Otago, Christchurch and Canterbury District Health Board, Christchurch. Sue Crengle, Senior Lecturer Māori Health, Te Kupenga Hauora Māori, School of Population Health, University of Auckland.

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Correspondence: Dr Melissa McLeod, Te Rōpū Rangahau Hauora a Eru Pōmare, Department of Public Health, University of Otago, PO Box 7343, Wellington, New Zealand. Email: melissa.mcleod@otago.ac.nz

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