Exploring Maori health worker perspectives on colorectal screening

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Abstract

Aim To explore Maori health worker perspectives on colorectal screening and identify factors that may influence Maori participation in a colorectal screening programme.

Method Thirty Maori health workers were interviewed to explore their experience with screening programmes, knowledge of colorectal cancer and their perspective on a potential colorectal screening programme. Health workers shared their perspective informed by both their own whanau and whanau they encountered professionally through their health work.

Results Participants were largely positive about potential colorectal screening; however, various access barriers were identified. These included patient-clinician engagement and communication, lack of provision for patient’s privacy during screening and patients feeling discouraged to take part in screening. Factors enabling screening included having an established relationship with their General Practitioner, screening clinicians taking time to build rapport, answer questions and share information, screening practices that were inclusive of Maori cultural norms and possessing high health literacy.

Conclusions Evidence points to growing disparity between the colorectal cancer incidence rates of Maori and non-Maori; disparities in colorectal cancer survival rates are already marked. Participants in the current pilot could provide valuable information to help ensure that the health education, promotion, and clinical practice surrounding a national colorectal screening programme are effective for Maori in reducing disparity and improving health outcomes.

In October 2011 Waitemata District Health Board launched a 4-year pilot colorectal screening programme using 2-yearly immunological faecal occult blood tests (FOBTi) followed by colonoscopy for positive results.

Approximately 2500 New Zealanders develop colorectal cancer and 1100 die from the disease each year, making it one of our most deadly cancers. Historically, Maori have experienced lower incidence rates of colorectal cancer than non-Maori, however, the recent CancerTrends report shows rates for Maori are increasing, whilst those for non-Maori are trending downwards. Recent research has also broken down the ‘survival gap’ between Maori and non-Maori diagnosed with colorectal cancer.

Although Maori have been less likely to be diagnosed with colorectal cancer than non-Maori, Maori are significantly more likely to die from colon cancer than non-
Maori. This ‘survival gap’ has usually been explained away to later stage of diagnosis, but a recent study by Hill et al has shown patient comorbidity and markers of health-care access and quality to be each responsible for around one third of this ‘survival gap’.

Maori access to screening programmes remains a concern, with significantly lower participation rates in breast and cervical screening than non-Maori as well as the national participation targets. For national screening programmes to succeed, participation must be clearly linked to improved health outcomes. However, for Maori the screening programme must prove itself not only beneficial, but also appropriate and accessible.

Despite inequitable participation rates in the national breast and cervical cancer screening programmes, there has been little research specifically focussed on identifying participation barriers for Maori. Two qualitative studies have identified issues of inappropriate exposure as contributing to lower cervical screening rates for Maori. In a similar vein, a recent study of cervical cancer health provider views [8] found that despite improvements in Maori cervical cancer outcomes, a dislike and lower level of acceptability of screening procedures were still influential deterrents to participation.

Crengle et al reported on a successful drive by a local health provider to improve breast-screening uptake amongst Maori women. Increasing the local providers’ personal involvement in enrolling women, assistance with transport and increased community engagement with the screening programme dramatically improved screening coverage.

In a study of anxiety before, during and after mammography, Brunton et al found that Maori (and Pacific) women experienced significantly more anxiety about being diagnosed with breast cancer; a factor that may or may not affect screening participation.

This research provides a starting point for further research and discussion into factors both discouraging and enabling Maori participation in a potential national colorectal screening programme.

This qualitative study sought to explore Maori health worker perspectives on current screening programmes and identify factors that may affect access to colorectal screening.

**Method**

This study is part of a wider study (‘Modeling of Disease and Cancer Outcomes in New Zealand’) funded by the Health Research Council of New Zealand and approved by the Multi-regional Ethics Committee. This study focused on a solely Maori cohort, and their perspectives concerning screening, whereas a recently published arm of the wider study reported on a solely European-origin cohort of New Zealanders.

Following consultation with Maori health providers the research team decided to utilise a snowballing technique to recruit employees of Maori health providers as participants. The community identified that Maori health workers could offer a broad commentary on both the screening pathway and the various barriers to participating in screening. Participants were asked to share their experience of screening programmes so far and to offer their thoughts about a potential colorectal screening programme. Participants were encouraged to discuss their own experiences as well as that of other Maori they had encountered in their role as health worker.
The interview process was inclusive of Kaupapa Maori research methodologies by seeking to validate Maori experiences, beliefs and values. This process included the use of a Maori interviewer, appropriate cultural protocols of engagement, use of the Maori language and asking affirming Maori-centric questions (i.e. from a non-deficit perspective).

A semi-structured interview schedule (the same was used with the Maori and non-Maori cohorts) guided interviews and covered: participants’ perceptions of current screening programmes, their knowledge of colorectal cancer, their knowledge and opinions concerning colorectal screening processes, ideas around population screening and potential barriers to participating in colorectal screening.

All interviews were conducted face-to-face by a Maori researcher. Interviews were audio-taped and transcribed verbatim in their entirety. Interview duration was 30-60 minutes. Participants received a petrol voucher in recognition of their contribution. All participants gave their informed consent to participate. Qualitative data from the transcripts was analysed using content analysis. This involved multiple readings of transcripts in order to identify and code emergent themes.

Results

Thirty participants were recruited from Auckland, Wellington, Christchurch and New Plymouth. Twenty-four participants were female and six were male. The age range was 40–66 years (which was reflective of the health worker cohort). All participants self-identified as Maori. None of the participants had been diagnosed with colorectal cancer although 9 had whanau who had been.

The analysis identified three core themes:

- **Lessons learnt from other screening programmes**, 
- **Experiences of colorectal screening**, and 
- **The importance of cultural appropriateness along the colorectal screening pathway**.

Lessons learnt from other screening programmes

Participants shared both their own screening experiences as well as those of their own whanau and whanau encountered professionally.

These experiences can be dichotomised into (1) barriers to participating in screening and/or to a positive screening experience and (2) factors increasing the likelihood of participating in screening and/or screening being a more positive experience.

The four key barriers are described below.

- **The importance of an appropriate level of engagement between clinician and patient:** Participants discussed the need for screening clinicians to develop a meaningful relationship with the patient before engaging in the screening protocols. This included understanding the person’s journey through the health system (including negative experiences), their fears about the outcome of the screening and providing the person with relevant information about themselves (including their qualifications and experience within the screening service).

- **The impact of quality communication within the consultation:** Whanau had raised concerns with Maori health workers about being rushed during screening consultations which led to feeling disempowered and not fully
informed about screening protocols and result dissemination. The screening environment also became negative if clinical staff used the time to lecture the patient on other health matters.

“…and a lot of our Maori are frightened to ask questions…so they sit and they hear all these flash words and it can be quite intimidating…they fear that if they ask a question it will be considered a dumb question…So a lot of our people do sit there in a real whakama state [withdrawn] about even, you know, asking simple questions.”

(P29, male, age 48)

- Failure to preserve modesty and respond to patient discomfort within the screening environment: Participants commented that in the Maori communities they serviced patients were concerned about the expectation that they should feel comfortable naked (or partially) without adequate discussion or provision for some measure of modesty.

“…they’re quite invasive…it’s kind of like delivering a baby to a certain extent …your modesty goes out the window. You’re kind of all exposed…there’s that amount of vulnerability around screening.”

(P2, female, age 43)

- Barriers to accessing a referral: Whanau also discussed with Maori health workers incidences where they had known they qualified for a screening programme, but were discouraged by a health professional from accessing it. This had led them to feel they were denied access to services on the basis of their ethnicity. This comment from a participant with a strong family history of cancer, including colorectal cancer, requested screening illustrates this barrier:

“…he checked the records and checked what it says about screening, and said, “Oh, I don’t think that you would actually qualify for this.”

(P12, female, age 69)

Key factors in ensuring screening access included the following:

- An established relationship with their primary care clinician (doctor, nurse or other clinician): Overwhelmingly the stories/experiences of participants and the wider Maori community included that if they trusted and had a positive relationship with their general practitioner, and they asked them to be part of a screening programme that they would participate. Participant comments revealed that general practitioners, as the trusted health advocate of their patient, had the ability to reduce patient anxiety. When asked whether they would participate in colorectal screening if asked by their GP, the following comment is illustrative of the importance of a positive relationship:

“…the GP that I used to have, no, I’d say no straight out, but this GP that I have now, she’s excellent ‘cause I feel she cares.”

(P3, female, age 41)

- The importance of including cultural norms within the screening environment: Participants noted that many patients (and their whanau) were impressed when they attended a screening clinic to find Maori beliefs and values were intrinsic to service delivery; they were treated with respect. Maori staff were present, a blanket or sheet (for covering themselves) was offered and that staff appeared
relaxed and not in a hurry. These experiences occurred in mainstream and Maori-specific services.

“…they’d offer a Maori cloak for women that are whakama [withdrawn]… so that when I go and have my mammogram screening that just makes me feel a little bit more comfortable.”

(P18, female, age 54)

One participant discussed attending the same Maori health provider for screening as her whanau and friends and the reasons that they feel satisfied with this provider, and return there for regular screening:

“I suppose it’s private, you know, you’re in the room, as Maori, as we do, we talk over a cup of tea, coffee, kai, you know…It’s just the whole accommodating as us, how we’re used to, how we are laid-back, relaxed, that kind of environment…So no, it’s really good, and getting to know the people who work there, and also it’s after hours.”

(P27, female, age 42)

• Empowerment of client encouraged: Experiences where clinicians had built an appropriate rapport with the patient, explained the procedure (without jargon) and sought a discussion with the patient made patients feel that there was an equal power sharing opportunity. In this environment Maori patients felt more confident to ask questions that were of concern to them in regards to both the procedure and the next steps in the process.

“I have found that with the support of our GP the process [breast screening] has been very, very good…with the cervical screening, it’s something that my GP’s nurse actually does and she does it very well. She makes me feel comfortable and so I have no qualms about going back…”

(P10, female, age 54)

• Health literacy skills: Maori health workers discussed that because they were familiar with the health system it allowed them navigate a health consultation, and in turn use skills to support their clients/whanau through health services. In the quotation below, a participant talks about the important role that health workers can play in supporting Maori in unfamiliar health situations:

“…and whanau’s great [to provide support], but sometimes it needs to be someone that’s actually a bit clinical or…a health person…so that they can awhi [support] the person, but then talk to the clinical if required.”

(P11, female, age 46)

However, there was concern from participants that in their absence, many patients (and their whanau) who may not have yet developed these skills would not feel comfortable advocating for themselves. They perceived health literacy as not just having the right information, but the ability to use that information to advocate for health services.

“…when you go to them…the doctor, specialist or something, a lot of it has to do with the ability to actually interact with them before you go, and have the ability to ask the right questions…that you get the right answers and the right information.”

(P17, male, age 58)
Participants’ experiences along the colorectal screening pathway

Nine participants had experiences of their whanau members being diagnosed with colorectal cancer and two others had experience of the colonoscopy procedure. The participant group also noted that some of their former patients had undergone colorectal screening or had been diagnosed with colorectal cancer.

Stories of feeling disempowered through the immodesty of the procedure (and its lack of reorganisation to be patient-centred), disappointment that medical jargon reinforced unequal power relationships and inability to access screening when initially requested were again echoed by participants (on behalf of themselves, their patients and their whanau). These feelings seem to mirror those experienced within other screening programmes.

“They’re not going to talk to you in a language that you understand. Like up on the wards…and the doctors say, “Well, you’ve got blah blah blah,” double speak medical jargon, blah blah blah. And I’ve watched the Maori patients and their families, they’re, “Oh yeah, cool, yeah, that’s good.” As soon as they’ve gone, I’ll go back and I’ll say, “Did you understand that?” “No.”

(P18, female, age 54)

Maori health workers expressed feeling frustrated at the lack of available health promotion/education material on colorectal cancer, its symptoms, epidemiology and incident rates among Maori. They reported having to resort to seeking information via internet search engines at times. They noted that if they were to advocate for colorectal screening they would need appropriate health literature so they could support whanau to understand not only the screening process but also the potential outcomes (including the requirement for further clinical investigations) and prognosis.

“I kick around in the Maori health area a lot and I haven’t actually seen anything…like any pamphlets or any information at…it’s not there in your face like other stuff…”

(P14, male, age 60)

Whanau experiences presented a range of concerns for participants, because some whanau were unaware that their presenting symptoms were related to colorectal cancer, whilst others had no apparent symptoms but were later diagnosed with colorectal cancer. Participants advocated for the differing pathways to both detection and treatment of colorectal cancer to be clarified through health education and promotion. Participants noted that a being presented with a range of patient experiences with colorectal cancer might better help the Maori community understand its varying presentations and impacts.

There was concern amongst the participants that they would also need to develop a specific Maori male approach to assist this cohort, who has had less exposure to screening programmes. The lack of familiarity and positive experiences of other screening programmes was seen as potential barrier for Maori males in addition to reluctance to engage with health services.

“My wife…talks about health issues. She talks about the wellbeing of our mokopuna [grandchildren]. It’s just easy, whereas men, we just don’t, that’s not part of our conversation that we have.”

(P29, male, age 55)
The need for a culturally appropriate approach

Participants identified that often within their own, their whanau and their patients’ interactions with the health system it was difficult at times to differentiate between barriers of cultural difference and communication (and those situations in which both barriers existed).

Participants were unequivocal that there was a need for screening clinicians to develop cultural competence specific to working with Maori. This could involve learning culturally appropriate engagement protocols, understanding how to use Maori concepts (tapu/noa) and language within a consultation, as well as learning how to create an environment that reduces power inequalities and in doing so fosters more meaningful interaction between patients and clinicians in a setting where patients are able to feel more at ease. Participants felt that developing this competence would result in higher levels of satisfaction between the Maori community and screening clinicians.

“Getting them back for repeats [screening] might be quite difficult…it will depend on how well the service provider makes people feel comfortable and understands what they’re doing and looks after them well, and they come out of there thinking, “Well I just had a really horrible thing done, but I’m okay and I feel good about it.”

(P9, female, age 45)

Specifically when the procedures involved in colorectal screening were explained, including the need for a patient to collect their own faeces sample for a FOBT, participants anticipated that Maori would feel generally comfortable with the process. They expected that because this screening procedure could take place in one’s own home, it would reduce the number of access barriers for Maori.

“Simple to do it yourself, I like that...you know, just being Maori, we seem to focus on that, if we can do it ourselves, we’l1 do it. I’d rather that than let somebody else do it.”

(P23, female, age 49)

Discussion

This research highlights four specific points that may be usefully applied to the Waitemata District Heath Board’s colorectal screening pilot and national screening programme that may follow.

Firstly, the role of primary health care providers is pivotal in engaging Maori in the colorectal screening programme. Two key factors will influence programme uptake:

- Primary care clinicians need to have a positive relationship with their Maori patients (which seemed to be defined by participants as when they demonstrated competence in working with Maori ), and
- Primary care clinicians see value in the screening programme (given that clinicians had deterred some participants and people known to participants from engaging in other diagnostic procedures/screening programmes).

Secondly, training should be undertaken with screening staff to increase their competencies in working alongside Maori.
The findings also identify the need for screening clinics to ensure:

- Appropriate time is allocated to each patient to reduce anxieties,
- Patients are provided opportunities for further discussion, and
- Patients are supported and feel valued within the screening environment.

It is interesting to note that participants were clear about what improvements needed to be made to current screening programmes; improvements which could be usefully applied to colorectal screening. This would include culturally appropriate engagement strategies,\textsuperscript{16} use of te reo,\textsuperscript{17} ability to deconstruct power relationships and the inclusion of a sheet/blanket during screening.

Thirdly, the dearth of colorectal cancer health promotion and health education information is a barrier to both the Maori health providers and clients/whanau in engaging in a colorectal screening programme. This finding is consistent with other research which has explored barriers to screening uptake.\textsuperscript{18}

The participants’ commentaries about their lack of knowledge about colorectal cancer and screening are particularly noteworthy given that these participants worked in health settings. It would seem a targeted health education and promotion campaign would be required to put colorectal cancer on the Maori health map. Attempts to implement screening prior to successful awareness raising may lead to false conclusions that the Maori community isn’t interested in colorectal screening, where perhaps the reality will be that it has not yet been established as a health priority for Maori.

Lastly, there is already a role within the Maori community for Maori health workers as screening advocates. Their experience with other screening programmes could be used in developing health education and promotion materials for the colorectal screening programme. The support role that Maori health workers could play for Maori taking part in colorectal screening could benefit people directly by making them more comfortable in the screening environment, but could also be an avenue for generating feedback to further improve screening accessibility generally.

This research has two main limitations. Firstly, the cohort were actively engaged in the health system, and therefore although they offered a broader narrative than their own experiences, further concerns may have been raised by those who do not access current health services and/or screening programmes. However, the ability of the participants to draw on collective experiences from their community is also a strength in this study, as it allowed for a more in depth discussion of the range of opinions within the wider Maori community based on their experiences as whanau members and then as health workers.

Secondly, no one within this participant cohort had experienced colorectal cancer themselves (although nine had whanau who had been affected). Therefore there is an opportunity for the Waitemata pilot screening programme to explore from a qualitative perspective the experiences of Maori (and non-Maori) who participate in the screening programme to determine whether their experiences of this programme match the perceptions of this participant cohort.
Conclusion

Recent evidence\(^5\) identifies that any future colorectal screening programme needs to ensure equitable access to screening and follow-up treatment for Maori. This research suggests that with specific targeted engagement by general practitioners, and with increased clarity on how screening clinicians can work with Maori participants to promote a positive screening environment it is likely that Maori communities will benefit from colorectal screening. However, it is important that the pilot programme takes the opportunity to test materials with and explore the perspectives of Maori who take part in the pilot.

The valuable feedback of Maori participants may help to further refine the screening programme before it is rolled out nationally. There is a significant risk that failure to tailor screening promotion, processes and materials will negatively impact Maori access to screening and in doing so negatively impact on health outcomes and whanau ora.

Competing interests: None declared.

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References: