

Are we just dishing out pills constantly to mask their pain? Kaiāwhina Māori health workers' perspectives on pain management for Māori

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ABSTRACT

AIM: To explore kaiāwhina (Māori community health workers) perspectives on supporting whānau Māori with chronic pain, and to understand their views on the use of online resources for pain management.

METHOD: A Māori-centred, qualitative design using focus groups as the primary data collection method. Analysis using the general inductive approach.

RESULTS: Thirteen kaiāwhina working in the Greater Wellington region took part in the focus groups. Four key themes were identified: (1) treatment of chronic pain in primary health relies exclusively on medication, (2) health literacy approaches to pain management are urgently required, (3) Māori have significant unmet need for culturally responsive pain management, and (4) the availability of, and referral practices to, specialist pain services are inadequate for Māori communities.

CONCLUSION: Current chronic pain management was predominantly biomedical, and educational strategies lack health literacy approaches. Primary health services exclude traditional Māori methods of treating chronic pain and do not focus on whānau wellbeing. The lack of referral for Māori to specialist services highlights the existing health inequities for Māori. Developing new initiatives (both in-person and online) to address chronic pain management for Māori must be Māori-led and co-designed with whānau to result in holistic solutions for Māori.

Chronic non-cancer pain is the leading cause of disability worldwide^{1,2} and disproportionately affects Māori and their whānau, as Māori adults are 1.4 times more likely than non-Māori adults to self-report chronic pain.² Despite the disproportionate burden, Māori are less likely to visit their general practitioner for pain management.³ Māori report a sense of stigma and stoicism towards expressing their pain and are therefore less likely to report their symptoms and seek primary healthcare for pain management.⁴

In addition to access issues in primary healthcare, Māori experience barriers accessing specialist pain services in

Aotearoa New Zealand.⁵ Previous experiences of racism in the healthcare setting and a lack of culturally responsive services, along with barriers such as sparse community-based support for accessing pain services and the high costs of transportation, have been posited to contribute to health disparities.⁴ To address these inequities, culturally appropriate primary care and specialist pain management services are needed.⁴

Online health resources (eg, apps, websites and social media) have the potential to provide cost-effective health information and foster healthy behaviours in people with long-term health condi-

tions,⁶ such as chronic pain.⁷ Despite the promise of online health resources, endorsement of these resources by healthcare providers is crucial for uptake and use by end-users. A 2019 survey with New Zealand health providers showed only 53% (111/210) recommended online resources (eg, websites and apps) for pain management.⁸ Some also expressed concerns around safety and lack of specificity of online information resulting in not addressing individual health needs.⁸ Lack of culturally tailored information was also seen as a barrier to recommending online pain management resources.⁹ Evaluations of international online pain management resources (apps and websites) showed none of the available apps provided culturally tailored information¹⁰ and only one of the 27 evaluated websites was culturally appropriate for Australian Aboriginal people.¹¹ This highlights that existing online pain management resources do not meet the needs of Māori with chronic pain.

Internet connectivity in New Zealand is high (90%).¹² However, internet access remains comparatively low for some population groups, such as Māori, Pasifika, people living in rural areas, people with disability and older adults (age >75 years).¹³ Thus, to mitigate this digital divide, co-designing digital solutions with end-users from marginalised communities is recommended for increased uptake and achieve digital inclusion.¹⁴ Some online resources, specifically those co-developed and tailored to Māori communities, have shown promise in improving maternal health¹⁵ and obesity.⁶ For example, OL@-OR@, an app-based personalised intervention, co-designed using Kaupapa Māori Research processes, aimed to foster healthy eating and physical activity for Māori and Pasifika communities.⁶ Although there was no significant improvement in initial adherence to behavioural guidelines between the groups at 12 weeks,¹⁶ the co-design process and significant community engagement led to increased uptake of the intervention after trial completion.¹⁷ Thus, online resources co-developed with Māori living with persistent pain have the potential to improve access to specialised services and may help address inequities in pain management.

The New Zealand Māori Health Strategy: He Korowai Oranga is the guiding document for the health and disability sector to improve health outcomes for Māori.¹⁸ The overarching aim is to foster Pae Ora (Healthy Futures), with Whānau Ora (Healthy Families) as a foundation and Mauri Ora (Healthy Individuals) and Wai Ora (Healthy Environments) as key elements.¹⁸ The Whānau Ora programme, implemented by district health boards (DHBs) in collaboration with community-based Māori health providers, places whānau at the centre of service delivery.¹⁹ Community-based health services delivering Whānau Ora programmes often contract kaiāwhina (Māori community health workers) to deliver services. The kaiāwhina play complex roles to meet the aspirations of the whānau by working closely with whānau supporting them with information related to health, education and social services in the community.²⁰ They are viewed as an integral part of the New Zealand health system workforce by linking the health sector and Māori communities.²⁰ Kaiāwhina often accompany whānau during clinical consultations to assist whānau to communicate their healthcare needs. After the consultation, they also ensure whānau have a full understanding of the clinical information discussed with the healthcare providers.²⁰

Understanding the perspectives of kaiāwhina on how they currently support whānau to access healthcare for chronic pain management may be an important step in addressing health inequities in chronic pain. The initial aim of the study was to focus on kaiāwhina attitudes toward online resources for pain management. In partnership with the kaiāwhina from Kokiri Marae and Tu Kotahi Māori Asthma and Research Trust (Tu Kotahi), a secondary aim was included to explore the challenges kaiāwhina faced when supporting whānau to access health services for pain management.

Methods

Study design

We used a qualitative study design underpinned by Kaupapa Māori Research principles,²¹ recognising Māori values and customs, following tikanga processes throughout the research project and meeting the aspirations of participants.²¹ This was a

Māori-centred research project, as defined by the Te Ara Tika Guidelines for Māori Research Ethics.²² Senior Māori researchers from our team (BJ and TI) with expertise in Kaupapa Māori Research,²³ together with our Māori community partner (CD) from Tu Kotahi, were involved collaboratively with non-Māori researchers (HD, MP, RG, LH) throughout all phases of the research project. The focus group was chosen by our Māori community partner (CD) as the preferred method of data collection because it facilitates interactive discussion. The Consolidated Reporting of Qualitative Studies (COREQ) checklist was used to guide reporting of this study.²⁴

Ethical approval and cultural consultation

Before study commencement, we consulted with Ngāi Tahu (a Māori iwi (tribe) with an existing mana whenua relationship with the University of Otago). We also consulted Tu Kotahi, who are a respected Māori provider in the local community. Our senior Māori researchers (BJ and TI) and Māori community partner (CD) guided the study design and informed the interview guide, data collection procedures, data interpretation and dissemination of study results. The University of Otago Human Ethics Committee – Health (H18/028) approved the study protocol.

Participants and sampling

The inclusion criteria consisted of kaiāwhina from the Greater Wellington region who self-identified as Māori and were currently working for any health service within Takiri Mai Te Ata Whānau Ora Collective. Participants meeting these criteria were invited to take part in the study by our Māori community partner (CD), who also led the kaupapa Māori (ie, by, for and with Māori) approach throughout the entire research process. Purposive sampling was chosen to maximise the range of viewpoints from kaiāwhina with a variety of health backgrounds and experience (novice to expert).

Cultural considerations and procedures

A kanohi ki-te-kanohi (face-to-face) focus group was held in a marae based in Lower Hutt, Wellington. The focus group started with a mihi whakatau (formal introduction

by our Māori community partner, CD) and a mihimihi, with both researchers and participants formally introducing their whakapapa (identity and heritage). CD has worked in this community for over 25 years and is a well-respected and trusted member of the community. Semi-structured interview questions were used to encourage participants to talk through their experiences. The opening question asked how kaiāwhina assist and support whānau with chronic pain and what their views were towards online resources for pain management. During the focus group, the Māori section of the national depression website (<https://depression.org.nz/maori/>) was presented to guide the conversation on online resources. Our Māori community partner (CD) led the focus group with the senior Māori researcher (BJ) and HD took field notes. To ensure accuracy of interpretations, key messages were presented back to participants for clarification and endorsement. The focus group discussion was audio-recorded and transcribed verbatim by a professional transcription service fluent in te reo (Māori language).

Data analysis

The general inductive approach was used to analyse the qualitative data, as our study aims were exploratory. We used a constant comparative framework that systematically categorised and compares qualitative data for analysis purposes.²⁵ This approach was chosen as it allows for a greater understanding of similarities and differences between participant perspectives.²⁵ Transcription of the digitally recorded focus groups was completed by professional transcribers who were fluent in te reo Māori. HD initially coded the transcriptions and presented the initial summary to Māori researcher BJ and community partner CD, who led the focus group. BJ and CD verified the initial summary with the transcript to provide a te ao Māori worldview that ensured the cultural sensitivity of the data interpretation. HD, BJ and CD had a meeting to discuss and agree on the initial sub-themes and draft interpretations. In keeping with the inductive approach, the agreed draft sub-themes and interpretations were then circulated to other research team members (MP, TI, LH and RG). Following iterative discussion, the final themes and

interpretations were agreed upon under the guidance of senior Māori researchers (BJ and TI) and our Māori community partner (CD). A draft summary of results was presented to all focus group participants in a subsequent hui for feedback and endorsement.

Results

Thirteen kaiāwhina working in the Lower Hutt region took part in the focus group at Kokiri Marae. All the kaiāwhina were women (aged between 23 and 65 years) from different professional backgrounds, such as nursing and social work. Some of the kaiāwhina also had lived experience of chronic pain and/or were supporting someone with pain in their whānau. Although the interview guide was mainly focused on the primary aim of the study, which was to understand kaiāwhina perspectives of online resources to support pain management, the participants focused more on the secondary aims, highlighting the challenges they experienced while supporting whānau to manage their chronic pain. None of the participants had experience or knowledge of online pain management resources. All participants have agreed with our summary findings requesting no further changes.

Four main themes emerged from the focus groups:

- Treatment of chronic pain in primary health relied exclusively on medication.
- Health literacy approaches to pain management are urgently required.
- Māori have significant unmet need for culturally responsive pain management.
- The availability of, and referral practices to, specialist pain management services are limited for Māori communities.

Treatment of chronic pain in primary health relied exclusively on medication

Kaiāwhina held the view that whānau were predominantly managed with pain medications at the primary healthcare level and expressed a lack of holistic understanding about the causes of pain.

“They [whānau] do not even understand their own pain, and where it’s coming from; they are just given, dished out pills constantly to mask their pain, and they don’t even know where it’s coming from.”

Some whānau diligently took the medications as advised by primary healthcare providers and consequently developed side effects because of that treatment (eg, depression).

“I found with my sister, so she’s been in chronic pain for years, for years, and it actually went from chronic pain to depression. She ended up on tramadol, and now they’ve upped that, and now she’s depressed. Because, she’s tries to explain to them how she’s feeling to the doctor, the pain she’s experiencing, and then he [doctor] just gives her; treat the cause not the symptom. Now she’s on happy pills to help her to get by.”

One of the kaiāwhina reported that she had referred someone with chronic pain to their primary healthcare provider, and that they were treated solely with long-term pain medications despite its limited effectiveness.

“It worries me, it’s gone too long, and it’s gone too far, and now she’s [the whānau] psychologically... religiously taking these medications, and I think she’s getting really sick even more.”

Some participants discussed the adverse effects whānau experienced from prescribed long-term pain medication. As an alternative to seeking primary health services, some whānau were self-medicating with substances such as marijuana, as a more effective way of managing pain and sleep.

“And so, I have come across a couple of clients, probably during the last two years, that their whānau were buying them marijuana, and I’m like, ‘Oh no, that’s no good for your breathing.’ But it helps with the back pain every now and again; they can sleep. I mean, it’s not ideal, but it works for them now and again, and their breathing is already compromised anyway, quite severely.”

Health literacy approaches to pain management are urgently required

Some participants felt the need for healthcare providers to use effective educational approaches when discussing chronic pain with whānau. One kaiāwhina explained how she used her health literacy skills for managing someone with asthma-related chest pain to help improve her self-management.

“She’s on Spiriva and Breo and the doctor said, ‘You should be fine with that, but then just use your blue inhaler if you need it.’ Well, she hadn’t been; she said, ‘I didn’t think I could. I didn’t think I needed to really...’ I said, ‘If you’re hurt on your chest, you might have a chest infection, or your asthma’s just not controlled. So, how about using your reliever, and to start with just use four puffs every four hours, and I’ll come and check you in a couple of days.’ Well, she had the best sleep she’d had in a long time.”

Kaiāwhina also talked about whānau not being listened to by their healthcare provider, which acted as a barrier to building good health literacy. As one kaiāwhina explained, it was vital to spend the time needed and listen to whānau to get a complete understanding of their health situation.

“With one of our whānau, it ended up to be a lack of sleep, really, in the end, and that was just by us looking at it—you know the whānau—and so, a lot of lack of sleep with the breathing, with the asthma, and you get worse, and, ‘Have you slept?’ ‘We get about two hours a night.’ So, once you get down to the kōrero, but that could take a long time.”

Kaiāwhina valued the need for educating whānau suffering from disabling pain and distress. They felt culturally tailored online resources (eg, a website like depression.org.nz) could help facilitate the kōrero on chronic pain with whānau. They recommended having waiata and karakia and using short videos with less jargon of whānau stories of living with pain. However, participants acknowledged that kaumātua might not be familiar with

technology and gadgets and suggested smartphone-based resources (eg, apps and text) may be more helpful. Kaiāwhina valued having other whānau stories about managing pain as part of the online resource because it can be a useful educational tool for the whole whānau. As a kaiāwhina stated after looking at the depression.org.nz website:

“What a great thing for the whole family though, like for example my sister’s children; they don’t understand what their mother’s going through. They’re like, ‘Oh gosh, it’s just that again auntie complaining, blah-blah-blah.’ If they see other people, like my mum and how their family are dealing with it. ‘Oh, he’s like mum.’ Yeah, ‘like my mum,’ and how their family are dealing with it, because we all deal with it somehow; it’s a great way for them to learn too.”

Māori have significant unmet need for culturally responsive pain management

The kaiāwhina explained that although whānau might use traditional Māori methods of healing (rongoā) for pain management, they did not usually share this information with their healthcare providers.

“Often they’ll say, ‘I don’t really want to tell the doctor; I’ll just live with it.’ ‘I just grin and bear with it,’ and of course the doctor will just give more Panadol or tramadol, or more prednisone, and they don’t want any more medication. So they kind of make their own remedies; might use some rongoā; that’s quite useful for bringing inflammation down in your body, and they kind of ease the pain that way.”

Other traditional healing methods, such as mirimiri (massage), were highly valued by some whānau for pain management, because they not only improved physical (tinana) health but also spiritual (wairua) and psychological (hinengaro) wellbeing.

“My sister [with chronic pain] had huge benefits from [mirimiri]; so, you know how we have healers out at Orongomai, and when we have them over at Wainuiomata, and she’d go

there for mirimiri, and honestly she felt awesome, because it didn't just mirimiri her tinana, but her wairua as well, and hinengaro. She just felt really, really good. Those things have been great in our community for whānau with chronic pain."

The availability of, and referral practices to, specialist pain management services are limited for Māori communities

The kaiāwhina unanimously reported that to their knowledge primary healthcare providers were not referring whānau Māori to pain management services. None of the kaiāwhina were aware of whānau that were referred to a specialised pain service and were thus unaware of what services pain clinics offer. As kaiāwhina could only refer whānau with pain to their primary healthcare providers, they were interested to know about the criteria for referring whānau to specialised pain services from primary healthcare.

When asked whether they were aware of any pain management service, the responses were:

"No, I've never heard of it before. How long has it been around; why didn't they say something?"

"So, although we don't know about the service, first I've heard of the service; are GPs aware of this service?"

"I've never heard that anybody who had some success because I don't know anybody that [was] referred."

Discussion

The primary aim of this investigation was to explore the clinical perspectives of kaiāwhina with respect to the accessibility and effectiveness of online resources for chronic pain management for Māori whānau in the Greater Wellington region. However, the findings highlighted the secondary aim, that is, the challenges witnessed by kaiāwhina supporting whānau experiencing chronic pain within the current health system. These challenges included that chronic pain management appeared predominantly biomedical at the primary care level, and educational

strategies were observed to lack health literacy approaches for supporting whānau with chronic pain. Kaiāwhina participants considered that health services exclude traditional Māori methods of treating chronic pain to maintain hauora (wellbeing).

The kaiāwhina in our study observed that whānau living with chronic pain were predominantly managed through pharmacological treatments, even though the current best practice for pain management for all of the chronic non-cancer pain conditions is through non-pharmacological management strategies.²⁶ Recommended non-pharmacological strategies include pain education, self-management, encouraging meaningful physical activity, cognitive behavioural therapy and distraction techniques. For Māori, this could also include mirimiri and therapeutic massage, as hands-on treatment was perceived to be an effective, holistic approach to pain management.²⁷ Pharmacological management strategies are recommended only for specific pain conditions such as chronic neuropathic pain and cancer-related pain.²⁸ That we found a primary reliance on pharmacological management strategies is discordant with the recommendations of the Ministry of Health equity framework,²⁹ whereby healthcare professionals should be committed providing evidence-based and culturally safe care to address health inequities for Māori.

As poor health literacy is highly prevalent among the New Zealand population, including Māori,³⁰ whānau with chronic pain require effective educational strategies on chronic pain mechanisms and management. Health literacy is the ability of an individual to understand, interpret and make informed decisions about their health condition and associated symptoms.³¹ Although evidence for the association between health literacy and pain self-management is inconsistent,³¹ health literacy interventions specifically designed for Māori, targeting patients with low health literacy and training healthcare professionals are effective in improving patient knowledge of long-term condition management (eg, cardiovascular diseases).³² Healthcare providers and health systems thus may have a key role in building the health literacy skills of Māori and thereby improving equity.³² More routine use of

health literacy strategies that include adult learning principles, teach-back and reinforcement may be encouraged. Such health literacy approaches could be used to help Māori with chronic pain better understand their condition and make more informed choices on pharmacological and non-pharmacological pain management strategies. This strategy would require the health systems and healthcare workforce to be trained in the use of health literacy approaches for management of long-term conditions, including chronic pain.

The exclusion of traditional Māori methods for pain management indicates an unmet need for culturally responsive care for Māori. A previous study that explored the lived experience of Māori adults living with chronic pain (n=10) identified the use of rongoā Māori by many of the participants.⁴ The use of rongoā was believed to treat the *person as a whole*—physically, psychologically, emotionally and spiritually. The use of Māori traditional methods, such as rongoā, is in line with incorporating Māori models of health, such as Te Whare Tapa Whā,⁴ into routine clinical practice. A recent meta-synthesis of qualitative studies exploring Māori consumer experiences in Aotearoa healthcare services also suggests the need for upskilling clinicians to provide culturally responsive care to address inequities.³³

Our finding of limited specialist referrals for whānau with chronic pain is similar to a previous study that reported lower referral rates for Māori compared to non-Māori by primary healthcare providers.³⁴ Some patients with chronic pain need a referral from a primary healthcare provider to be assessed and/or managed by a tertiary pain service, or other relevant specialist services. Existing tertiary pain services consider the biopsychosocial influences underpinning chronic pain, but they are largely individually focused and lack a holistic Māori-centred approach.⁴ A recent audit of patients attending tertiary pain services in New Zealand reported Māori, Pasifika and Asians were underrepresented compared to New Zealand Europeans.³⁵ Lack of focus on the role of spirituality in health and the absence of whānau-centred care were suggested as contributing to existing inequities for Māori with chronic

pain.^{5,35} Incorporating tikanga Māori into health services, along with whānau-centred care, would help to improve the healthcare experiences of Māori and help to provide culturally responsive care in healthcare settings.³³

This study provides important clinical recommendations for pain management. To mitigate some of the challenges, the kaiāwhina suggested the potential for collaborative care pathways with primary care and pain specialists in training and upskilling them in chronic pain assessment and management. Kaiāwhina-led pain educator services could then provide whānau with educational resources and facilitate communication with their primary care providers for referrals to specialist services.

In an increasingly digitally connected world, online public health initiatives offer the potential to enhance the access to, and cultural relevance of, chronic pain management approaches.³⁶ Broadly, relevant examples such as depression.org.nz could provide scalable, culturally tailored pain education resources for improving health literacy around pain mechanisms and management strategies.¹¹

This is the first investigation exploring the perspectives of kaiāwhina supporting whānau with chronic pain. One of the strengths of this study was the process of reflexivity, whereby participants were verbally presented with a summary of the key messages for sense-checking at the end of the focus group, and in a subsequent hui they were asked to contribute to, edit or endorse the accuracy of the draft results. The study has some limitations. As the kaiāwhina were recruited from the Lower Hutt region of Greater Wellington, they may not reflect the perspectives of kaiāwhina working in other regions in New Zealand, where access to pain management services may differ. However, the limited representation of the Māori workforce, lack of specialist referrals for Māori and the absence of specialist pain services suggest that the perspectives from the Lower Hutt region are likely to be similar across New Zealand. This study was limited to kaiāwhina only, and further research is needed to incorporate the perspectives of other primary care providers (eg, general

practitioners, physiotherapists, psychologists and occupational therapists) working in pain management. We also acknowledge that our findings reflect kaiāwhina views on supporting whānau with chronic pain, and we recommend future research directly exploring whānau views on accessing pain services, barriers to pain management and the use of digital solutions to pain management.

This qualitative study has identified potential gaps in healthcare pathways and culturally responsive care for Māori living with pain, which invariably contribute to inequities of outcomes for this population. Digital solutions have the potential to

address some of the existing inequities due to the lack of access to in-person services. However, developing new initiatives (both in-person and online) that are culturally unsafe can result in the unintended consequence of perpetuating existing inequities. To mitigate this risk, any digital pain management resources developed in New Zealand need to be co-designed with Māori and community focused. The clinical care pathways for Māori with pain and their whānau should be examined in future research to identify access issues and gaps at the community, primary and tertiary levels of the health system, to address inequities and to provide Māori with holistic, integrated and coordinated care.

Competing interests:

Nil.

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