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"I JUST KIND OF WANTED TO CLOSE MYSELF OFF AND DIE"

The long shadow of inequity for Māori with gout

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Abstract

Gout is a health condition that can be managed to prevent morbidity and premature mortality. Māori have a higher prevalence of gout yet are less likely to receive appropriate care than non-Māori. There is scant literature presenting the patient/whānau voice relating to the health system response to gout. The study reported in this article aimed to highlight barriers and enablers in achieving best practice management of gout as defined by patients in order to inform the development of appropriate pathways and services. Using a Kaupapa Māori approach, interviews were undertaken with 23 participants as part of a multi-layered intervention to improve the management of gout for Māori. Two domains emerged from the analysis of the interview data, the first relating to biomedical practice and the second relating to Kaupapa Māori. Both domains were overarched by the theme of te ara pai—creating interwoven solutions to shift power. Reframing the health system to enable rangatiratanga for Māori would address inequity for Māori with gout and is likely to benefit other health conditions.

Keywords

health inequity, gout, primary care

Background

With discussion increasing on reframing the health system to produce equitable health outcomes for residents of Aotearoa New Zealand, this article highlights some of the gaps where attention is needed for this to be realised. It brings to the fore

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issues that are pertinent to processes such as the Health and Disability System Review (2019) and the Waitangi Tribunal (2019) health claims. These processes are looking to address inequity and improve models of care, especially for Māori, who are most disadvantaged within the current system.

Māori have the highest rate of mortality across both genders and all ethnicities in New Zealand (Ministry of Health, 2015). There is overwhelming evidence of inequity in multiple health outcomes for Māori (Robson & Harris, 2007), including cardiovascular disease, diabetes and gout (Stokes et al., 2018). Gout is associated with significant morbidity and premature mortality (Clarson et al., 2015; Dalbeth et al., 2012; Fisher et al., 2017); it is present in an estimated 38% of Māori men aged 65 years and over (Jackson et al., 2012). Recent developments in the understanding of gout indicate that it is best considered as a disease of urate transport, with the occurrence of gout principally due to genetic variation. The earlier understanding of gout was that it is a disease of purine metabolism with occurrence primarily due to intake of alcohol and specific foods (Dalbeth et al., 2019). The former lends itself to an informed discussion about preventing gout; the latter lends itself to blaming patients for poor lifestyle choices. In New Zealand, there is an inverse relationship between those regularly receiving gout prevention medicines and those experiencing gout (Dalbeth et al., 2016). For Māori, this inequitable management of gout is described as not only unjust and unfair but also contravening both versions of New Zealand's founding document, the Treaty of Waitangi, and the United Nations Declaration on the Rights of Indigenous People (2007; Dalbeth et al., 2018).

Gout is readily diagnosed and treated with inexpensive and relatively safe medicines to prevent acute attacks (Doherty et al., 2012). Allopurinol, taken regularly and long-term, is the preferred medicine to manage the cause of gout. Prevention becomes increasingly important with disease progression and in the presence of reduced kidney function (Richette et al., 2017). Best practice clinical management of gout consists of lowering serum rate to a target depending on whether tophi—hardened lumps of monosodium urate crystals under the skin—are present (Dalbeth et al., 2019). Gout is predominantly managed in primary care.

Studies have investigated gout perception, beliefs and understanding from both patient and clinician perspectives nationally (Humphrey et al., 2016; Martini et al., 2012) and internationally (Harrold et al., 2013; Harrold et al., 2012). We are unaware, however, of gout studies that explore systems issues; nor have we found any such studies undertaken in an Indigenous research framework—in this case a Kaupapa Māori approach (Curtis, 2016). Such a research approach intends to be conscientising and transformative, with Māori at the centre. It also seeks to be guided by principles that enable self-determination by Māori and to undertake a critical analysis that unpacks and exposes the current system (Smith, 1997).

The work reported here is part of a larger project that seeks to understand and address the barriers preventing optimal gout management for Māori, in the context of historical and current inequity in health services and outcomes for Māori. This study sought stakeholder experiences of a gout programme at a marae clinic with a focus on the key factors in the ecosystem for Māori. It aimed to describe these factors and their relationships within the ecosystem, in addition to the impact of the programme on the system.

Methods

The study was sited in a single general practice (a marae clinic) in Auckland, Aotearoa New Zealand. The practice serves an enrolled population of more

TABLE 1 Outline of problem and response

The problem	Stakeholder engagement	Multi-layered initiatives
Before programme implementation, only 14% of those enrolled at the practice achieved clinical best practice management of gout.	Community members Practice clinicians Kaimahi Rheumatologist	Community design and hui Decision support tool All-of-practice staff education Nurse standing orders Point-of-care urate testing Health literacy resource Evening clinic

than 3,000 people and sits under the umbrella of a Māori primary health organisation. The enrolled population is predominantly of Māori ethnicity (~80%), with the remainder Pacific (~12%), New Zealand European (~6%) and Asian (2%), and other ethnicities accounting for the remaining 2%. Most people (98%) enrolled at this clinic live in neighbourhoods categorised in the lowest deprivation quintile as measured by NZDep2013 Index of Deprivation (Crampton et al., 2020).

From June 2017, a multi-layered gout programme evolved in response to the evident and urgent problem of uncontrolled gout in the practice patients (see Table 1). The approach looked to improve both clinician response, based on current best clinical practice, and community engagement, to empower whānau to support self-management. Evaluation of the programme commenced in 2019 and included interviews with stakeholders and an audit.

Participants

Māori enrolled at the practice were eligible to participate in an interview if they had experienced any component of the multi-layered intervention. People were purposively selected for invitation to be interviewed, seeking to include people from one or more of the following categories:

- those who had taken part in community hui, both males and females with a range of ages
- those who had interaction in the clinic only, both males and females with a range of ages
- those who have achieved target serum urate levels
- those who have not achieved target serum urate levels

Participants were initially approached at the marae where the practice is situated by a kaimahi who had a very trusted relationship with whānau. This was followed by one or more meetings with the lead investigator to explain the study, answer questions and obtain written consent. Interview meetings were scheduled individually and took place either in the patient's home or at the marae. Interviews were conducted by the lead investigator, generally lasted about 60 minutes, and were audio recorded and transcribed verbatim, also by the lead investigator. Participants were offered a $20 grocery voucher as koha at the end of the interview but were unaware of this during recruitment. Whānau were encouraged to attend alongside participants. Given the lead investigator/interviewer had a part-time role in the practice, the possibility of a perceived conflict of interest was managed by being explicit with participants that they would remain anonymous. Further, it was essential to receive all types of feedback, both negative and positive.

The interviews were semi-structured, with open-ended questions used flexibly to allow the conversation to flow. As part of the process, whakawhanaungatanga was essential in building the relationship with the participants. Engagement with the participants was guided by the seven Kaupapa Māori practices intended to guide Māori researchers, as shown in Table 2 (Te Awekotuku, 1991).

Analysis

From listening to the interviews during the transcription process and through the iterative reading of the transcripts, phrases and sentences recognised as recurrent themes were categorised using the qualitative research software NVivo. Braun and Clarke's (2006) six-step phased approach was used as a general inductive method of analysis, with consistent and pertinent kōrero allowing themes to emerge (Thomas, 2006). Reviewing, defining and naming themes was conducted several times. Reflexivity was a core component of the process in that the research was emancipatory, being underpinned by the social responsibility to change an inequitable situation (Baker et al., 2004).

TABLE 2 Kaupapa Māori practices

Aroha ki te tangata	A respect for people
Kanohi kitea	The seen face (i.e., presenting yourself to people face to face)
Titiro, whakarongo, korero	Look, listen, speak
Manaaki ki te tangata	Share with and host people, be generous
Kia tupato	Be cautious
Kaua e takahia te mana o te tangata	Do not trample over the mana of the people
Kaua e mahaki	Do not flaunt your knowledge

A process of triangulation and consensus was undertaken with all authors, using this general inductive method of analysis to obtain agreement on themes. Participants were invited to a hui at the marae, at which initial themes were presented. Their collective feedback confirmed the validity of the provisional themes presented. Ethics approval was granted by the Northern B Health and Disability Ethics Committee (ref. 18/NTB/213).

Results

From a list of 192 potentially eligible persons, 23 were invited to be interviewed and all accepted. Some were more recent enrollees, and some were long-time patients at the practice. Whakawhanaungatanga revealed all participants had a strong connection to their Māori heritage. Sixteen were male (average age 55 years, range 24–82 years) and seven were female (average age 62 years, range 47–85 years). Twelve participants had achieved the target serum urate level of < 0.36 mmol/L. Eleven participants had attended educational hui sessions.

Participants often responded in a mix of English and te reo Māori, reflective of the participants and Kaupapa Māori nature of the research. This process provided participants with an opportunity to respond using their own terms. Communicating bilingually was an important practice for participants and reflected their worldviews.

Five core themes emerged which were unanimously endorsed by participants. The themes have been situated into two domains representing two contrasting perspectives: Western biomedical practice and Kaupapa Māori understandings of health and wellbeing (see Table 3).

There is an inherent crossover between the themes, and te ara pai overarches the first four. They are separated to support analysis for systematic change. The first domain is Western in the sense that it represents the health system and medicines. While medicines sit within the system, they were a specific element that was discussed beyond the system itself. The second domain is Indigenous, specifically Māori, and highlights participants' perspectives on their lives and experiences.

Domain A

Western health system

The Aotearoa New Zealand health system provided the most significant overarching theme raised by every participant. In presenting this theme, the points of discussion will include access and health professionals.

Access. The single most common theme expressed by interviewees was access to the health system. Access was represented in two streams of commentary. The first was physical access. Participants referenced the ability or lack thereof to get into the clinic. For those in employment, this was especially problematic. Some had to take the whole day off work to be able to attend a consultation. This was due to the logistics of the hours and place of employment. If, for example, one participant worked on a roading crew, and the collective transport left at 6:30 a.m. and returned after 5 p.m., there was no way they could "pop in" for a consult. Hours of employment were often outside the clinic hours, and places of work were sometimes a long commute from the clinic and participants' residences.

For some, a lack of transport was integral. One man discussed not having access to a vehicle, and with public transport unavailable, he simply could not get to the clinic. For acute conditions like a gout flare, exacerbation of heart failure or pulmonary disease, walking was not an option.

Despite the acknowledgement of clinic staff working to capacity, another point of discussion was the inability to acquire an appointment promptly. For acute conditions, the delay was considered too long. Waiting times, once appointments were made, could be stressful. Employment absence was especially challenging to manage and at times led to participants leaving before being seen:

TABLE 3 Themes

Domain A: Biomedical practice	Domain B: Kaupapa Māori
Western health system—access and health professionals	Hauora—holistic health and wellbeing
Medicines—prevention vs treating symptoms	Mātauranga—embedded knowledge and knowing
Te ara pai—creating interwoven solutions to shift power	

> [I] find it hard to say to my boss, "Hang on, boss, I might be another hour because I can't get into my appointment yet." I mean I still got to get the medicines and maybe even get to the lab if the nurses are too busy to take my bloods. (male, 46–60 years)

The second aspect of access is framed as financial or economic. Cost was a significant barrier that prevented participants from accessing services, including making initial contact by phone. This was a barrier if participants did not have credit on their phones. Further to transport issues already mentioned, there was an added concern over the cost of transport. The direct costs of "the system" were, however, proffered more often as a significant barrier. The cost to see a general practitioner (GP), including losing income when taking time off work alongside medicines co-payments, was most often talked about. For participants who owed money, this situation was compounded:

> I think it's like 15 or 17 bucks a visit, and because they might have already had three other visits that haven't been paid, it'll stop them from coming in. And yeah, most of them are just too whakamā to come in and sort it. (male, 24–45 years; referring to whānau members)

Participants lived on such a fine line in terms of finances that several discussed going without GP consults or medicines if an unplanned expenditure occurred. One man talked of inadvertently losing his medications when moving house and simply not having the money to get another prescription to replace them. Another man discussed starting a job working in the freezer department at a food factory. This required him to buy warm clothes, which became the priority over medical access. As disease progression occurred, participants in more physical work roles were unable to continue their jobs:

> I was quite a physical man back then. I used to work on the rubbish trucks and then a lot of real physical work. Then I went into roading—because it was less [physical] so that sort of caught up with me as well, so I had to chuck them all in. (male, 46–60 years)

> I was working as a fork hoist driver and was in the warehouse doing a lot of lifting [and had to leave]. (male, 24–45 years)

Ironically, when participants lost employment due to gout, this improved their access in terms of being able to attend appointments during the day—but money became tighter, creating a different barrier: "And it's so disabling—I went onto the sickness benefit for [gout] because it kept coming that continuously" (male, 24–45 years). This man had been employed as an underwater engineer and eventually lost the ability to hold a welding torch due to joint damage of tophi. He went from earning a "good wage" to being on a benefit and struggling to pay for clinic appointments.

Health professionals. These were often the first point of diagnosis for participants, and, as such, the first to provide information about gout. Doctors at both primary and secondary levels were explicitly mentioned, as were primary care nurses and community pharmacists. Participants discussed the continuum of care and the ability of health professionals to influence and assist with health outcomes. Comments centred on variable engagement and the provision of information that participants found later to be incomplete or inaccurate. This was particularly so for those who had a long history of inadequately managed gout. One man discussed his first experience of gout some 20 years ago; it had been diagnosed by his family GP. Management, he recalled, was the advice to cease consumption of seafood and tomatoes alongside daily colchicine administration, which he estimated he followed for 14 years. He understood now that this was not best practice management for gout prevention.

The most common message participants heard from all the different health professionals mentioned above was that gout is caused by certain foods and alcohol. The advice given therefore directed them to avoid these. Even if participants did not consume such items, the focus remained the same:

> But he asked me, I don't know how many times, did I drink. And I said no. He couldn't understand why my uric acid level was so high. And I just couldn't understand either. I said no, I don't drink a drop. (female, 40–59 years)

Without exception, the belief that certain foods and alcohol were the sole cause of gout had either been long held or was still held by participants. This belief had either been initiated or perpetuated by health professionals. Participants also identified a lack of information provided by health professionals relating to how gout flares can be prevented with urate-lowering therapy. Therefore, it was common for participants to believe the management of gout comprised only pain relief rather than prevention with urate-lowering therapy. Many used the term "gout pills" when discussing medicines for symptomatic relief, referring most often to diclofenac (sold under the brand name Voltaren). This is raised under the umbrella of health professionals as it reflects the competency of the health professional in following evidenced guidelines, engaging further with people and imparting understandable information. This issue will also be discussed under "Medicines" below.

One person discussed feeling let down by a series of different health professionals (doctors, community pharmacists, nurses) and feeling the need to find an alternate path themselves:

> I thought, you're not making me better, you're just prolonging my [illness], you're just keeping it at bay so it won't hurt no more and telling me to come back next week and get some more gout pills, and that's the way I was thinking, "Crikey, I'm sure there's a better way of getting rid of this." (male 61–82 years)

It was common for participants to report feeling that practitioners' communication was ineffective. Some agreed that perhaps they might have been told about the management of gout, but because they were unable to understand the conversation, they were unable to recall it. Further, they found that health professionals in general and doctors in particular were quick to give instructions without engaging: "And that's what [it] is, aye—doctors talk on top of you. They keep saying you gotta do this, you gotta do that, you shouldn't do this, you should do that" (male, 24–45 years).

This type of commentary ranged from clinical competencies to discussing the realm of cultural safety. Participants spoke at length about the provider being the key to access and understanding: "The barrier for me is having people that connect with me. Health professionals need to think, aye. They need to think like normal people. They need to come back down to earth" (male, 24–45 years).

Participants discussed feeling judged by health professionals, and this prevented them from sharing information or receiving it. "They feel like they'll be judged," commented one. "That happens, that's what it is. . . . Ask me that, I've been there done that. I've been to lots of doctors" (male, 24–45 years).

One man felt his "mana had been trampled", while another talked about the propensity of health professionals to approach the interaction from a deficit model:

> Oh yeah and they mostly say all the negative stuff—that's how I think of it—because you are dragging the person down. Why don't they get on and give them what they really need—a bit of love—bring their spirits back up again—aye, that can go a long way. (male, 24–45 years)

One participant had become convinced that it worked in health professionals' favour to provide only symptomatic treatment as this would ensure revenue: "Yeah, all they wanted was their fee, prescription, and then see you later, come back, and here's a month's supply. And that was it, and that's how I believe they made their money" (male, 6–82 years).

Another thread presenting itself under the umbrella of cultural safety with regard to health professionals surfaced when participants discussed being advised not to consume kaimoana. It was clear that some participants saw kaimoana as more than just a food group. Participants discussed collecting kaimoana as a cultural rite and a right, as a connection to their upbringing and their whenua. The elimination of this food is, therefore, often incomprehensible as it is part of participants' identity. As one expressed, "I mean to say, it is our kai" (male 61–82 years). Another commented, "Kaimoana. It's our cultural thing, isn't it (male, 24–45 years).

Medicines

The class of medicines most often discussed were non-steroidal anti-inflammatory drugs (NSAIDs). Whilst this class of medicines can be helpful in acute circumstances, they have the potential to cause significant side effects, including kidney damage, and should not be used frequently (Richette et al., 2017). The most talked about and valued NSAID was Voltaren, which was generally referred to as "gout pills", as noted above. Only one person proffered the generic name of diclofenac. This medicine was prized as being effective for most:

> I was buying them for 12, 13 years, maybe 14 years or even longer. When I first got the gout my mate said "You got the gout", and he gave me the pill and that same afternoon from the morning the pain was gone. (male, 61–82 years)

The above commentary was from a man who stated he bought Voltaren from the same pharmacy for all those years without being questioned or redirected. He admitted there had been a cost to purchasing the tablets. Still, this cost he had calculated was significantly less than having to take time off work to see a doctor and pay the associated costs.

It was common that participants would acquire Voltaren through multiple mechanisms. Buying it was one method. The most common method, however, was "borrowing" or "sharing". One man talked about his workmates having a "pool" of Voltaren that they could all access to prevent absenteeism. Another participant also discussed using food to barter for Voltaren, paying people in eggs or bread for some of their supply. Every participant knew of Voltaren. Some participants knew it as the "pink triangle gout pill" but most knew the brand name. Many were confused as to its role, with one participant commenting: "We only know them as gout pills" (male, 24–45 years).

As participants often took NSAIDs before enjoying food triggers, they misattributed Voltaren and NSAIDs as being preventative medication: "Prevent it from coming on, isn't that what Voltarens do?" (male, 24–45 years). Participants had no concern over the dose of the medicine they were administering, instead prioritising pain resolution. One man discussed his regular approach of administering 450 mg diclofenac in a 6–8-hour time frame, this being three times the maximum dose in a 24-hour period. Two participants reflected on buying ibuprofen (sold under the brand name Nurofen) when diclofenac was unavailable. Nurofen was viewed as being more readily accessible through supermarkets, at a much-reduced cost. Two participants spoke about purchasing packs of Nurofen Zavance (sodium ibuprofen) tablets during an attack and using the entire pack to get relief. Participants sometimes volunteered that they were aware medicines could have unwanted side effects, but this knowledge was incomplete and inconsistent.

In contrast, participants who had been administering allopurinol were clear that its purpose is gout prevention and said that it had changed their lives. There were many adjectives used in praise of allopurinol, including "wonderful" and "amazing". Participants stated they did not mind taking medication every day if it meant the pain of gout would be prevented: "All I know is that it's [allopurinol] got magic in it. It is magic. If you don't take it, you're gonna be in pain" (male, 24–45 years). One man discussed a 50-year history of gout flares and how he didn't realise life could be flare-free until he was prescribed allopurinol:

> I think the priority of not having the gout is good for me and it is good for my family. You know I can spend a longer time with my mokos [i.e., mokopuna], and you know I look back on the past and how I used to struggle with gout and it's not that good and it's awesome how I take the pills now. (male, 61–82 years)

When asked hypothetically whether they would have administered allopurinol regularly if they had been prescribed it after the first couple of attacks, participants were adamant that they would have, with one answering: "Yeah, oh yes, wholeheartedly, I would have signed on the dotted line too myself" (male, 46–60 years). Six participants felt it was helpful to get the allopurinol in blister packs to keep track of whether the medicine had been taken for the day or not.

Domain B

This domain's themes relate to Māori concepts and participants' perspectives on them in relation to their experiences with gout. It should be stated, however, that there is difficulty in isolating single themes in the commentary due to the concepts behind the words being complex in their interconnectedness.

Hauora

The Waitangi Tribunal (2019) defines hauora as "holistic health and wellbeing" (p. xxi). For Māori, this means to be well and in balance with the physical, spiritual and environmental community in which people live. It is reflected in the concept of whānau and is interconnected to the environment and mauri of a person. In considering the vital essence, or wellness, of a person, the key point made by participants was the high level of pain they suffered. Without exception they spoke of how significant, disabling and demoralising it was, such that they "wouldn't wish it on their worst enemy".

It was common for participants to be unable to weight-bear on affected joints, and therefore they struggled to walk. This made it challenging for them to function at the most basic level. Participants talked of the different sites where the pain could occur, often describing initial attacks occurring in the feet with extension upwards: "Yeah, and it was just my foot, then knee, elbow, shoulders, fingers, toes—[it] just moves everywhere on the body. Man and it's so sore and disabling" (male 24–45, years). Participants talked about feeling like the pain of gout was happening without any breaks: "I was getting gout after gout after gout (male, 61–82 years).

For some participants, this could also mean an extension to urate kidney stones, and they talked of admission to hospital with the sequelae of this.

The barriers in access to timely, appropriate, safe healthcare led to disease progression and many years of painful suffering for participants. For some participants, the repeated cycle of gout flares had led to permanent damage to joints. This had broader implications apart from their employment, as discussed above. Participants talked about losing the functional ability to carry out activities that had been part of their lives, including being able to play sport, undertaking cultural activities like kapa haka, or even just being active.

Hauora reflection and engagement for participants ultimately revealed what became an erosion of their spirit or wairua. It often began insidiously, with employment changes as gout progressed: "I went to Security after the farm but prior to that I was always an outside doors person. I like being outside. I don't like being stuck inside" (male, 24–45 years).

For others, the loss of functional ability to carry out a treasured activity also meant a disconnect from a wider whānau subset (e.g., kapa haka and sporting whānau):

> That's the most hurtingest [*sic*] thing, like I see my mates now and heaps of them are in good [rugby] teams like Auckland Blues and some of them fly over to Australia for their games, and they're always telling me, "Bro, you're better than all of us." And I always think, "Oh man, I can't even play rugby anymore." (male, 24–45 years)

Participants for whom the pain of gout was a regular occurrence and for whom the downwards trajectory of losing employment, losing functional ability and losing confidence led to them feeling worthless and questioning life.

> Yeah, like being that disabled when you can't do anything, it does drop your self-esteem, your motivation, everything goes out the window. Like when I had it real bad, eh, I didn't want to do anything. I didn't want to talk to anyone, I just kind of wanted to close myself off and die. (male, 24–45 years)

Whānau. This subtheme is included under the theme of hauora because health is not an individual endeavour to Māori: whānau are intertwined with wellbeing and flourishing. The concept of whānau is a collective representation of generations who share genealogical descent. It also includes non-biological relationships that are important to the individual. Whānau are often connected to a physical place by whakapapa that descends from Māori creation stories. The literal translation of family from a Western perspective differs from the extensive interconnectedness of physical, spiritual and geographical identity, that inform whānau.

Whānau featured prominently as a component of participants' wellbeing and a reality in thinking about health outcomes. Participants had lots of experience of watching other whānau members with gout: "Dad had the gout for as long as I can remember" (male 46–60 years). Participants recognised the possibility of genetic predisposition to gout. One reported that "gout runs in the whānau". Another identified that gout was prevalent not only in his whānau but in Māori generally:

> We were eating the same kind of kai, me and my Pākehā mates, we go to school at the same time. You know, we're partying the same time, aye, you know. Next minute I'm walking around with a big fat toe and they aren't. (male 61–82 years)

There was an association between the experience of their loved ones and the pathway that the participants followed themselves. Those whānau members that had "managed" with only symptomatic treatment of pain over many years often provided medicines for symptomatic treatment to participants. This was the main model of treatment the participants discussed.

Conversely, if a whānau member's gout was well controlled on allopurinol, then the outcome was different:

> Yes, I thought it was an older person's sickness, and never thought that I could get it as young as I did. But, Dad became a good friend to talk with as well—got advice from him and he kept drilling into me, take your pills every day. (male, 24–45 years)

Not only were whānau sometimes the diagnosticians and a repository of knowledge and suppliers of medicines for pain, they were also the greatest sources of support:

> I've been stuck like this and couldn't stand up, and my partner's had to shower me and stuff like that. It's been that bad, and I'm surprised she's stuck by my side this long, but she's helped me a lot and I'm getting my health back on track. (male, 24–45 years)

As a corollary, the ripples of gout strongly affected whānau. Participants were unable to partake in whānau activities, they required extra support, there were fiscal implications at several layers, and whānau became emotionally upset at watching their loved ones suffer repeatedly:

> You're crying too, and it's so sore and you look up and see everybody who cares about you trying to help you. But you know they can't really do anything, and you go to the ambulance and the hospital. And it's happened a few times too, so I'm used to it now, I'm in and out of hospital too many times. (male, 24–45 years)

Participants also spoke about how they viewed their roles as a resource for the next generation of whānau. Those that were no longer suffering painful attacks, wanted to ensure the transmission of correct knowledge to avert unnecessary suffering. They were already taking the opportunity to share their knowledge and experiences where appropriate.

Mātauranga

For the purposes of this research, mātauranga is the realm in which knowledge is transferred from generation to generation. Its genesis is the creation story of the world today and is inclusive of new knowledge and new development. It provides a framework for societal lore and engagement physically, environmentally and spiritually. To possess knowledge is to enable empowerment. Concerning knowledge of gout, participants discussed the gaps they had come to recognise: "You know, there was nobody out there that educated me on how you get gout" (male, 61–82 years).

Many discussed inaccurate information or knowledge with negative connotations. The common threads for this tied back to believing gout was caused entirely by poor lifestyle, especially consuming certain foods and alcohol, and that it was associated with old age. This inaccurate knowledge had consequences of its own. Participants talked about the denial that they saw or experienced:

> Maybe it's bravado. I don't want to be seen as the person stuck with a label: "he's got gout" or "he's sick". Possibly because of some of the reasons that, the associated causes like alcohol. I used to think, 'cos I didn't drink, I used to hate saying that I've got gout 'cos people just associate gout with alcohol. And some that did know me through church, and I didn't want that stigma. (male, 24–45 years)

One person went so far as to say that people were afraid of the word "gout" because of this misinformation, while others discussed being whakamā about admitting they had gout.

These emotions were predicated on perceptions that were not wholly accurate. The most common myth that had become entrenched was the need to avoid certain foods. Participants discussed spending an extraordinary amount of time thinking about what they could do to solve this issue. The concept that food was the sole cause of gout was reinforced by participants' experience of linking pain with eating "trigger food". Some participants, however, realised there must be more to the aetiology of gout by observing that food avoidance did not necessarily lead to gout prevention:

> I stopped the kaimoana for a couple of years, and it was still coming back, so I thought, "Man, it must be the way I'm eating." You know, so I tried to change the eating, but it still comes back, and I'm thinking, "What is it?" (male, 24–45 years)

Participants presented overwhelming kōrero that they should be provided with tailored logical understanding to integrate their thinking and approach to gout. They referenced wanting education and communication to move away from the focus on food and alcohol:

> Yeah, not food and alcohol and all of that. It's the acid within, where it is, how it's produced, why it's produced. All those little things that we're never told about. . . . When people do understand it then they get [it], they recognise what's going on. (female, 40–59 years)

Participants talked about the need to understand the condition and the medicines for it:

> I think everybody should have education right across gout. Everybody should know what causes gout. Everybody should know how to manage it. I didn't know those things before I got on the allopurinol. Education, everybody should have it. (male, 61–82 years)

Education was thus identified as the key to empowerment, with a proviso being that knowledge needed to be provided under the umbrella of cultural safety to enable self-management.

Te ara pai

"Te ara pai" can be loosely translated as "the right path", and this theme—creating interwoven solutions to shift power—overarches the other four themes. It considers what has worked well for participants and what advice they have. Te ara pai is a platform for transformational change to enable the flourishing of health outcomes.

While most of the commentary stressed failures of professionals, policy and process in the health sector, there were also reflections on how the system can respond, highlighting the elements of success. These represent insight and opportunity for systemic change. The participants also provided specific recommendations on what is required to bring about change.

Perhaps unsurprisingly, the recommendations centred on mitigating barriers. It was recommended that access be available outside of the current clinic hours:

> You've got nothing between, say, 4 and 10 at night when they can access. They need that kind of treatment and there's no funding for Māori after hours. . . . That would be good for all those ones working, 'cos they're not getting a lot of money. (female, 60–85 years)

This participant also promoted the idea that Hauora—clinics designed explicitly by and for Māori—needed increased resources. She discussed the benefits of a marae-based clinic, where cultural safety was a key component appealing to whānau. But it was at times inaccessible due to limitations of Western health system constructs. Others also advocated a marae setting for the delivery of health services, with appropriately skilled staff. Participants' own experiences informed their recommendation of this model of health delivery.

> Well, my whakaaro is that everything would be nice if we had it at the marae. . . . I think the staff makes such a difference towards anybody doesn't matter who it is. Now what I mean by that is staff can make you feel like it is okay to come in. (male, 61–82 years)

Three participants recommended the marae clinic studied receive resourcing to increase the size of the clinic. Another participant discussed the increasing of Hauora funding for this to occur: "So that would be helpful if they had a Hauora, you know. . . . Maybe they need more for the Hauora, maybe funding's going the wrong way, the wrong places" (female, 60–85 years). Another recommendation was that in an ideal model, healthcare could sometimes be provided in people's homes.

There were examples of some health professionals' behaviour being held as a model for other health professionals to follow. Participants talked of doctors at the marae clinic who were not dissimilar to them—just "normal people" who understood their lives and were able to tailor the consultation to them. Some participants spoke of the community pharmacist who knew more than just their names and engaged with them at a level to provide understandable information.

Commentary about the approach of health professionals also extended to a rheumatologist, who had been very active in the area of gout over many years. He had attended hui with participants, and they evidenced the transmission of knowledge by him in a culturally safe environment. Others provided positive commentary on the nurses: "You know [nurse X] and [nurse Y], they don't run you down. They're always there to help you. . . . You can feel the aroha" (male, 24–45 years).

There was much commentary about the role of kaimahi and how important it is to have people who have had life experiences that whānau have also had. The non-regulated healthcare workers at the practice were recognised as more like kaitiaki in terms of helping to provide guardianship of participants' health journeys. There was recognition of the programmes that kaimahi delivered at the practice. A male kaimahi was singled out as being necessary for other men to connect with and as a source of support and aroha for many. There was a recognition that all went above and beyond to assist with all manner of things.

That the practice offered transport to and from appointments was also acknowledged as being valuable and integral to receiving healthcare. Without this service, some people stated they simply would not be able to come in. There was also commentary about the gratitude people felt towards the kaimahi who transported them and the level of assistance she provided.

In terms of specific education and empowerment around the condition of gout, people provided an overarching directive that the situation needed to change to create a culture where people felt able to discuss and communicate about gout. People also needed to receive the correct information, tailored to meet their needs.

Participants advocated that knowledge dissemination should be consistent and multi-levelled, from an individual perspective to community engagement and national campaigns.

Many participants suggested dedicated media and health campaigns. A common suggestion was the development of television commercials made in conjunction with whānau, so that they resonated. Role models like rugby and rugby league players leading media campaigns was also advocated: "I think they need to advertise more, aye. 'Cos you see on the TV breast cancer awareness. You see suicide awareness. You see everything else, but nothing about gout" (female, 60–85 years).

The younger participants recommended social media campaigns to ensure younger people received appropriate messages. Some of the senior participants discussed their preference for paper resources and suggested pamphlet drops. Participants also recommended campaigns be developed so that Māori felt connected and could better receive messages—that the imagery and faces needed to be reflective of Māori. Some people discussed a previously co-designed gout resource booklet as an excellent example of enticing Māori to learn: "Look, yeah, this [booklet] is exactly what I'm talking about, gout—there, look. Living without pain, okay, this is it, this is what you should put out."

A final, unsolicited, point concerned the research itself. Participants stated that the pathway of kaimahi contact and subsequent engagement by a Māori researcher premised on whakawhanaungatanga worked well.

Discussion

This research, albeit focused on gout, evidences how health inequity is its own ecosystem for Māori. From the consideration of the physical environment in which health services are delivered, when they are delivered, and by whom they are delivered, to the ability to access whether by phone or physically and the associated costs—all these factors are crucial. Māori suffer disproportionately from a debilitating condition yet are forced to engage in a system that is often hard to access, does not always provide best practice clinical treatment, and does not always provide a safe environment in which understanding and understandable messages are communicated. Healthcare providers have a responsibility to manage the complexity of health literacy demands on patients but often approach it from a deficit framework, where the onus is on the patient to understand (Reid, 2020).

That Māori are more likely to be employed in labouring roles and more likely to be socially disadvantaged is not new. This is the effect of the country's colonial history, which is shared with most other Indigenous populations globally. A disadvantaged position is a challenging place to thrive from. What was clear was that for some participants, it was nigh on impossible to access regular gout prevention therapy without significant impact on employment security.

The significant pain of gout, the length of suffering, the overuse of inappropriate NSAIDs and difficult relationships with health providers have been previously described (Te Karu et al., 2013). This research delves deeper into understanding health system issues and presents recommendations from those who have been directly affected. It also presents the breadth of health professionals' contribution to poor care and inaccurate information which further stigmatises gout and the people suffering with it. Additionally, it highlights the desperation of people such that they feel the only option is to seek medicines for symptomatic relief from various sources, including presentation to emergency departments, and supermarkets and pharmacies.

The authors are unaware of previously published research on the consideration of advice to cease eating kaimoana as a breach of cultural rights. This consideration is underpinned by the traditional connection of wellbeing to resources over which rangatira exercised authority. Article II of the Treaty of Waitangi specifically classifies fisheries as a taonga for continued access and authority. This raises the prospect of a breach of the Treaty if people are unnecessarily advised by healthcare workers to avoid kaimoana.

Racism within the New Zealand health system has been well documented (Harris, et al., 2012; Huria et al., 2014; Jansen et al., 2008), with a recent meta-analysis of New Zealand studies consistently demonstrating that racism is an important health determinant contributing to inequities (Harris et al., 2018). We have previously reported barriers on the road to optimisation of medicines, a process that has often not included patient voices (Te Karu et al., 2018). In this study, we heard the consequences of people feeling judged and being the recipients of culturally unsafe care. To add insult to this situation, there are associated costs with this system, which does not always respond well.

Strengths and limitations

Selecting Kaupapa Māori as the framework within which this research was conducted and ensuring that participants felt safe and empowered to pass over their whakaaro was a strength of this research. Participatory research conducted in this way can inform system- and policy-based changes to address inequity. That the participants unanimously endorsed the themes at the follow-up hui was further validation.

A collaborative approach was adopted to explore participant experiences of gout and gout management, with some forays to extend these learnings to broader Māori contexts. This, we argue, was necessary to honour our approach to Kaupapa Māori and means that, while there may be ideas of value to diverse groups, there is no claim of generalisability. The intention was to contribute to positive change for participants and whānau as well as provide learnings for the health sector and systems.

Conclusion

This study conducted with a Kaupapa Māori approach is the first to describe Māori experience of having to negotiate the complexity of gout, in the context of not having been afforded the societal privileges of non-Māori. The most significant finding articulated by the participants was the failure of the health system's response to their condition. The nature and extent of this has been years in the making, with the health system systemically failing to provide a solution to a condition that is manageable. Individual context compounds the disease for patients but, overwhelmingly, it is the practitioners and system that have failed. To continue not to act in the face of this demonstrated need is, by definition, institutional racism.

A secondary theme within this overarching failure is clinical practitioners' focus on certain foods and associated triggers, not the prevention of the disease through urate-lowering therapy. Whānau also articulated the connection to food, raising the question of whether this is experiential or learned from health professionals. A national information campaign for both clinicians and whānau is evidentially required.

Patients grappled with the conflict of self-determination within the context of hauora and the power within Western health models. While both the patient and the clinician pursue wellbeing, their engagement is dominated by Western policy and process.

Māori perspectives are often overlooked within health structures imposed by colonial underpinnings of superiority, restricting practices of hauora, whānau and honouring mātauranga. The long shadow of inequity is the reality of this failure and a missed opportunity to engineer health systems so all benefit. The barriers creating the shadows of inequity must be removed to support transformation in health aspiration for whānau.

> *Mehemea ka moemoeā tātou, ka taea e tatou.*
> *If we dream together, we achieve together.*
> —Princess Te Puea Herangi

Glossary

aroha	love, compassion, empathy
hauora	health
hui	meeting
kai	food
kaimahi	worker
kaimoana	seafood, shellfish
kapa haka	Māori cultural performing group
kaitiaki	guardian
Kaupapa Māori	research by Māori, with Māori, for Māori; a term used to describe traditional Māori ways of doing, being and thinking, encapsulated in a Māori worldview
koha	gift
kōrero	conversation, talking, discussion
mana	prestige, status, authority, influence, integrity; honour, respect
Māori	Indigenous people of Aotearoa New Zealand
marae	complex of buildings around a sacred open meeting area
mātauranga	knowledge, tradition, epistemology
mauri	life force, vital essence
mokopuna	grandchildren
Pākehā	New Zealander of European descent
rangatira	leaders, chiefs
rangatiratanga	authority, self-determination
taonga	prized possession, property, treasure
te reo	the Māori language
wairua	spirit, soul
whakaaro	thoughts, opinion
whakamā	shy
whakapapa	genealogy, ancestry, familial relationships
whakawhanaungatanga	connection of persons through genealogical ties; topic, purpose, theme
whānau	family, extended family
whenua	land, homeland

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