



Compounding inequity: a qualitative study of gout management in an urban marae clinic in Auckland

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ABSTRACT

INTRODUCTION: Gout remains a health equity issue; Māori and Pacific peoples are disproportionately afflicted, with increased burden and loss of quality of life, yet are less likely to receive appropriate management, which mainly occurs in primary care.

AIM: This study aims to understand the perspectives of the mainly Māori and Pacific clinicians and staff at an urban marae practice about barriers and challenges to delivering effective care to a Māori and Pacific community with high burden of gout.

METHODS: Semi-structured interviews were conducted with 10 staff members delivering health care to a mostly Indigenous community. Interviews sought to ascertain staff views of enablers and barriers to optimal gout management and analyse them thematically.

RESULTS: Three themes were identified: community disadvantage; demands unique to Indigenous providers; and challenges and opportunities for optimising gout management. High prevalence and heavy impact of gout on wellbeing in the community was intertwined with socioeconomic disadvantage, precariousness of employment and entrenched inaccurate (yet pliable) patient views on gout, to the detriment of focused, effective care. Structural and funding demands on providers inhibited staff focus on the clear community need. Providers saw the culturally safe and competent approach necessary for improvement as requiring community empowerment with appropriate clinical tools and adequate resourcing.

DISCUSSION: Despite provider intent to deliver culturally appropriate and safe care and equitable health outcomes for patients suffering from gout, general practice initiatives without aligned resourcing or incentives are inhibited when inequity is pervasive. Simply asking Māori providers to do more for the same amount of resource may not be effective.

KEYWORDS: General practice; uric acid; health equity; Indigenous; primary health care, Māori.

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Introduction

Historically known as the ‘disease of kings’ due to its prevalence among the wealthy and privileged,¹ the contemporary reality of gout in Aotearoa (New Zealand) is one of socioeconomic and ethnic

inequity in both prevalence and management in primary care.² Compared to non-Māori, gout is more prevalent among Māori, occurs at an earlier age and has worse outcomes.³ People of Pasifika ethnicity also experience increased prevalence and poor outcomes.²

WHAT GAP THIS FILLS

What is already known: Gout presents a heavier burden on Māori and Pacific wellbeing than on other ethnicities, with treatment also worse for Māori and Pacific peoples. Barriers to optimal gout management have been examined from the perspective of patients, community, and health professionals in general practice, but the perspective of Indigenous providers faced with high need has not been examined in Aotearoa New Zealand.

What this study adds: Māori health-care providers report structural limitations that are barriers to the provision of tailored gout prevention to people who are most in need. Initiatives are structurally inhibited and likely to be ineffective if they do not encompass whānau, workplaces, and communities, without appropriate resourcing or alongside conflicting incentives embedded in the system.

Gout may best be understood as a genetically determined deficiency of urate transport.⁴ Urate-lowering pharmacotherapy, primarily with allopurinol, is an effective and inexpensive first-line treatment to reduce serum urate levels below saturation concentrations, preventing gout flares, tophi development, joint damage and loss of quality of life.^{5,6} However, health professionals, particularly in primary care, continue to prioritise lifestyle advice such as avoidance of specific foods and alcohol over current best practice guidelines, which favour preventive medication.⁷

Models of care to improve gout management have attempted to integrate two key stakeholders – health professionals and people living with gout.^{8,9} Multidisciplinary approaches that address prescribing and monitoring of urate-lowering medicines have shown benefit,^{10,11} as have patient-focused programmes encompassing patient education and health literacy.¹² However, these approaches often ignore critical players in gout and its management, including whānau (extended families), workplaces, and communities. These approaches are also blind to the unintended effects of structures and barriers created by the health system itself, including prioritisation and funding for gout care, particularly in practices serving high numbers of Māori and Pacific patients suffering from gout. Therefore, gout and its treatment remain a critical issue of inequity.

The Indigenous community perspective of barriers and enablers in achieving best practice management of gout has previously been reported,¹³ as have the wider perspectives of clinicians in primary practice across south Auckland.⁷ The current research, using kaupapa Māori methodology, aimed to explore the mainly Māori and Pacific staff perspectives at an urban marae of the enablers and barriers to medicines optimisation for gout; acceptability of an intervention including a decision support tool; and staff experience of the multidisciplinary collaborative team approach. We also sought their views on possible improvements that might eliminate the burden of gout for the mainly Māori and Pacific patients of this Very Low Cost Access (VLCA) practice. We present the qualitative analysis of these staff views, collected 12 months after implementation of the intervention.

Methods

A kaupapa Māori approach underpinned the interview process and overall methodology, appropriate to the participants and the community they serve. This approach emphasises self-determination by Māori, and kaupapa Māori principles of respect, generosity, caution, and humility, with the aim of enabling fruitful and emancipatory kōrero, and deconstruction and transformation of methodological approaches to the advancement of Māori, in line with the principles of ownership and empowerment of Māori set out in the articles of te Tiriti o Waitangi.^{14–16} Protecting and incorporating the knowledge, skills, attitudes, and values of Māori society were further demonstrated by engaging Kaumatua to assist the development of the multi-layered initiative and by seeking Marae leadership opinion and approval for representation of data.

Study setting

The general practice is situated within the grounds of an urban marae complex offering clinical and multiple social services. The practice serves an enrolled population of more than 3,000 people who are mainly of Māori ethnicity (~80%), with the remainder Pacific (~12%), New Zealand European (~6%), Asian (2%), and other ethnicities (2%). Most people (98%) enrolled at this clinic live in neighbourhoods categorised in the most deprived quintile, as measured by NZDep2013 Index of

Deprivation.¹⁷ It is a VLCA practice, where most of the enrolled population are deemed 'high needs' and the patient co-payment is capped.

Participants

All staff employed at the clinic were eligible to participate in the study and were invited by LTK to an interview. Ten staff participated; nine were of Māori and Pacific ethnicity (overall, 92% of clinic staff are Māori and Pacific, mirroring the enrolled patient population). Roles included one locum and three long-term general practitioners, all mid-career; three nurses, all senior; two community health workers; and one practice administrator-manager. One community health worker declined an interview stating they had no direct dealings with the intervention. To help de-identify participants, given the low numbers involved, quote attribution is presented here only as either clinical staff (doctors and nurses) or non-clinical staff.

Participants were interviewed individually, audio recorded, and interviews were transcribed verbatim by author, LTK. Interviews varied in length from 17 to 48 min. Participants were offered a chance to edit their transcripts.

Participants were informed both verbally and in writing that being interviewed was their choice, there would be no consequences if they declined to be interviewed, and they could withdraw their interview within 1 month after it had taken place.

Semi-structured interviews were conducted with mostly open-ended questions using an interview guide to provide a framework for discussion (Box 1).

The intervention

From June 2017, a multi-layered initiative was progressively implemented in the study general practice. The intervention (summarised in Box 2) aimed to improve clinician management of gout for Māori in line with current evidence. At the same time, community engagement sought to empower whānau to promote self-management and improve community understanding of gout risk factors and appropriate pharmacotherapy.

Box 1. Guide for interviews

Interviews sought feedback on the following questions:

- What was your experience with the gout initiative?
- What worked well in terms of the gout initiative? What were the enablers?
- Did you use the Decision Support Tool? (Clinicians – for prescribing? Non-clinicians – as a prompt? Any recommendations?)
- What could be improved on in the implemented project? What barriers did you encounter?
- What would enable optimal management of gout for the enrolled population?
- Any comments?

Box 2. Components of the multi-layered initiative to improve gout care

- Community design and community 'champions'
- Community hui
- Decision support tool
- Practice staff education
- Point-of-care urate testing
- Nurse standing orders
- Gout health literacy resource
- Direct communication to a rheumatologist
- Evening clinic

A key component of the intervention, a tapered decision support tool, aimed to prompt and guide delivery of best-practice management of gout in consistent and sustainable ways. The tool appeared as a traffic light system on the front or dashboard of the practice management system (PMS; computer software). It prompted and guided clinicians to prescribe urate-lowering therapy, including its 'cover' and titration, to achieve a target serum urate concentration below saturation. The dashboard system was open to all users of the PMS.

Analysis

Thematic analysis of interviews was supported by NVivo software (QSR International) following an iterative reading of each transcript. Cyclical reviewing and refining coded excerpts of transcripts occurred using categorisation, and analytic reflection until themes were identified.¹⁸ The themes were agreed upon by consensus with author BA, then with the other authors.

Ethics approval for the research was given by the Northern B Health and Disability Ethics Committee (18/NTB/213).

Results

The analysis identified three themes relating to enablers and barriers to optimal management of gout for Māori at this urban marae practice in south Auckland: community disadvantage; Indigenous health provider demands; and achieving gout optimisation.

Themes

Community disadvantage

Gout was identified as being highly prevalent in this community, impacting heavily on people's lives, and that it was intertwined with the effects of socioeconomic disadvantage to the detriment of optimal care.

'There are a lot of people with gout – so many of them – every second person.' [Non-clinical staff]

Disadvantage was a substantial issue that affected many facets of care, both directly and indirectly. The prioritisation of addressing socioeconomic marginalisation competed with optimising gout management. Staff were spending time addressing broader social issues, including food and housing insecurity, assistance with clothing, finance, and transport, which consumed consultation time. All participants consistently raised the reality of socio-economical marginalisation in the community.

'The environment we are working in, the whānau we are working with, the desperation that is there, the co-morbidities, the social issues and all those sorts of things, are wrapped up in a patient that has gout.' [Non-clinical staff]

Employment impacted access to care. Patients were often employed in blue-collar roles, unable to easily leave work to access health care and where job security could be an issue.

'The thing is the majority of people with gout are men and they are working so they have to take time off work and it's job security. It is very tricky for men. It is inequitable.' [Clinical staff]

Staff felt people had not always received appropriate education from previous providers, nor a dedicated campaign to empower them. The importance of empowerment was discussed, and that through lack of empowerment inaccurate information had become entrenched in people's minds. For example, it was common for members of the community to deny they had gout – 'feeling whakamā', or shame. This denial was tied back to misconceptions leading to behavioural blame:

'They all think it is the food side – that that's why they get gout... a lot is that they need education.' [Non-clinical staff]

However, participants also observed that no patients refused urate level testing when offered. It was felt that this reflected underlying deeper concerns despite a tendency to minimise or deny the effects of gout.

Indigenous provider demands

The second theme related to conflicts in priorities created by structural and funding demands on providers. All participants discussed the breadth and depth of community need and how this flows on to health provider demands. Addressing wider determinants of health was layered upon a constant need to protect practice income, such as achieving funded, nationally set health targets. This competition redirected activity.

'...you have limited resource, and you have to spread it where you can. Resources are being put into areas where the money is coming from. So that's the competitive environment that it needs to work in.' [Clinical staff]

A key issue raised by all staff was health targets as a pay-for-performance mechanism and how they influence clinical practice. Staff were cognisant that these targets drove behaviours and that this was not the ideal situation, but the reality of a practice in a struggling community.

'Targets are what matters. If conditions are not a target, the wider staff are not paying attention to it. I think it is not on our radar... You know if gout was sitting in the health targets it would be done!' [Clinical staff]

For this reason, there was suggestion that health targets should have more flexibility for

practices managing the health needs of specific populations.

‘It would be great if the Ministry [Ministry of Health] would give us some money and allow us to do with it what we deem to be important. ... It’s one of those things that you don’t want the money to drive how we perform, but also too we have to have systems in place so that we can focus on certain things and do those things.’ [Non-clinical staff]

Interwoven with health targets was the concept of a ‘practice champion.’ As funding is attached to health targets, ‘champions’ focused on ensuring revenue was maximised.

‘If you don’t have someone who is a champion for it in the practice, then these things have not got such attention. Having champions is really important.’ [Clinical staff]

Again, the ability for champions to function optimally was linked back to payment and health targets.

‘I think the funding is key – you still have to have a champion, but the funding is key. The champion is less powerful without the funding. I find that if there is funding attached to it, there is a drive to meet that health target – it will happen.’ [Clinical staff]

Similarly, gout not being a health target to promote activity meant in an overworked environment, standing orders for nursing staff were not used optimally.

‘I didn’t use the standing orders sorry ... it came down to being time poor for us. It’s a busy clinic – we have so much going on.’ [Clinical staff]

Hours of access were an issue to the community, and participants discussed the challenges and wanting to be able to respond but lacking resource to do so.

‘There is definitely a demand for longer clinic hours – I get that all the time.’ [Non-clinical staff]

Equally, access to laboratory services was recognised as conflicting with patients’ work commitments and a problem rippling through to providers to solve. Patients generally use or

exceed their time off work to be seen in the practice and accessing a community laboratory adds to that pressure. Locations of laboratories may mean further prohibitive travel across town. Although it is possible for a nurse to collect blood in the clinic for later delivery to the laboratory, this was seen as another competing task for overloaded nurses.

‘Bloods are really important – some [patients] haven’t had bloods for 2-3 years.... Our nurses will take labs here if they have time – it is so full in town at the lab.’ [Non-clinical staff]

Further, staff noted that the practice accepts patients who other clinics have rejected, implying that the enrolled practice population may become progressively more medically and socially complex over time.

‘There’s a lot of clinics that don’t accept them (patients) – they even tell them [to] come to ours. We get heaps of them – we get a lot of ‘rejects’ – people get told they are full. Practices can pick and choose.’ [Non-clinical staff]

Staff commented that ageing facilities did not always meet the needs of staff and patients, such as recurrent issues with internet technology and phone access. Therefore, we deemed infrastructure a barrier to optimising use of the decision support tool.

‘I thought it [decision support tool] was actually very good because it kept it in everyone’s face but the thing was that the internal server would crash and the password protection would lock people out – the whole system locks down and locks you out.’ [Clinical staff]

This was disappointing as some clinicians also reported the value of the tool:

‘The form is conveniently presenting all the information I need to get to make a decision in one spot, and I’ve got the dashboard running, and it takes me one click to do it – I am in.’ [Clinical staff]

One clinician discussed being upskilled simply by using the tool.

‘It was helpful for me in prompting me to do a couple of things I otherwise wouldn’t have. Make sure that I have colchicine cover was a big

part of it and it helped me think about how long I am doing cover for ... that was a big thing for me.’ [Clinical staff]

Most, however, either did not use the platform on which the dashboard sits or they took no notice of it because of the lack of associated funding (as discussed above).

‘It never prompted me even if read because my focus is not gout because it is not a health target. I am just being honest.’ [Clinical staff]

Achieving gout optimisation

The third theme related to how to optimise gout care for the clinic’s population. Despite the barriers identified, all participants emphasised the importance of the project, and that the initiative was helpful and essential to providing a focus.

‘...project itself has been blimmin useful – if nothing else it has brought more focus to this practice to consider this significant condition.’ [Clinical staff]

In discussing the burden of gout, all participants also stated their intent to continue to do better with achieving optimal management and that they had learnt through the process. This re-messaging to improve adherence to urate-lowering therapy required understanding across the spectrum, at all levels and therefore community empowerment was necessary:

‘I think the approach that you take with the community is really really important.’ [Clinical staff]

The importance of community empowerment was emphasised as needing to be under the umbrella of a culturally safe and competent approach.

‘We approached it from a Te Ao Māori aspect [or] perspective, which was important and helpful. We provided expertise when it was needed and I think the messages were repeated reasonably consistently.’ [Clinical staff]

There were instances where community education had a powerful effect on assisting clinician management. There was value placed on patients being ‘activated’ so they understood aims of treatment and associated pathways and drove their consultations.

‘I did not have all the ins and outs of specifically what that programme was, but certainly, the patients reported about the programme. So there seemed to be a good awareness ... they knew there was a plan to get their urate levels to a certain target and to the normal range so yeah there were patients with established gout who knew what they were aiming for. That was good.’ [Locum GP]

As an incentive to do better or to drive response, some staff thought a stronger emphasis on monitoring would have been helpful.

‘I would have added more strength into monitoring to target and how that was done. Even to the point a monthly report of how many of those people came in and had a visit – how many had a spot urate done or a blood test and was medicine uptitrated.’ [Clinical staff]

All participants discussed resourcing as a key to future success.

‘Thinking it through, you know, if we had two full-time people here driving it, it would be all done and dusted by next Christmas – well, in the real world, what can be done? Can we throw money at it – like can we get five bucks every time we do something – no. Well, that’s probably not going to happen either.’ [Clinical staff]

‘Trouble is that nobody in the clinic has time for that follow-up and that’s where we are. If we had that dedicated person and that time, it would run well I think. It would be awesome if we did have that, but the reality is different.’ [Non-clinical staff]

‘Resourcing dedicated appointment times for using that tool. Book the pallet just for gout because if the patient is coming and we are just taking the opportunistic time for gout, obviously we are limitedThat is the competing type of environment that we are in.’ [Clinical staff]

In terms of the decision support tool, paradoxically, clinicians who had not used it discussed the merits of its intent and function:

‘I think it would be really useful if gout was a classification on the patient’s file that would be a prompt as you open it to say what is the gout management – this is where you do it. That sort of thing that would be quite helpful. You do need

to hand us some tools to help us work through that. And I do believe pathways and dynamic tools are really really helpful.' [Clinical staff]

Although fiscal and human resourcing were seen as key issues, the importance of having the 'right' resource was also highlighted. Human resourcing was discussed as needing to be underpinned by a philosophical approach where whānau-centred health is the driver.

'We are all in it together. One thing I have learned about since working here is we don't need to convince our team that it is about whānau. They all know that and that is a blessing in itself. Sometimes you have to convince people that it is about family first. We don't need to do that here. It is embedded in everybody and they know exactly why they are here, that is why they work here. They could be somewhere else but it is the how, how we achieve it.' [Non-clinical staff]

Discussion

Gout remains an equity issue. Māori are disproportionately afflicted, with significant burden. Despite higher prevalence in Māori, at least in part due to genetic variability, Māori are less likely to receive recommended treatment.² This qualitative study reporting interviews with 10 health workers at a Māori primary care clinic in a neighbourhood of high deprivation identified three themes. The participants were aware that the community they serve was disproportionately affected by gout and yet received insufficient funding to improve their outcomes. They felt that as an Indigenous provider, they experienced further, unique demands, including having to address wider determinants of health, being overworked, and infrastructural problems. All participants discussed the benefit of the intervention but lack of support to realise its potential, including clinical champions, specific targets and funding. Staff consistently highlighted the overarching systemic issues of funding and prioritisation that affected their ability to respond to their already disadvantaged patient population.

This research highlights that disadvantage can be compounded by a health-care response when the system is not proactively addressing inequity. The Health Quality and Safety Commission has identified that 'historical acts of taking land, resources

and culture, compounded by the monocultural nature of today's health system and service delivery' leads to accumulated intergenerational disadvantage for Māori.¹⁹ This research suggests that societal disadvantage can ripple through to the service deliverer if people have significant and complex health needs, and the system does not fully recognise this and compensate accordingly.

Pay-for-performance health care has met with criticism, both nationally and internationally.^{20,21} Various iterations of pay-for-performance initiatives have been implemented in Aotearoa, but the appropriate balance to achieve quality, equity, and efficiency has yet to be struck.²² The broader distortionary effects of targets, particularly targets with financial incentives attached, on health service behaviours internationally and in New Zealand are now well described.^{23,24} The granular effects on decision-making and allocation of resources and attention, and indeed the anti-equity effects of services forced to ignore the apparent needs of Indigenous people to hit targets and maintain revenues, were demonstrated in this research.

The Crown's obligation to provide primary health care for the Indigenous people in this country is currently the subject of legal investigation, with alternative models being sought.²⁵ Additionally, previous research has concluded there is institutional racism in contracting practices between government-funded accountability processes for Māori-led public health providers compared with providers whose services are designed for the overall population.²⁶

Previous research has identified a lack of concordance in physician and patient views on gout management.^{27,28} This Auckland research, however, demonstrated alignment between what Indigenous providers of health care saw as barriers and what the community had previously reported.¹³ The site for this intervention was purposively chosen because it is a practice with a stated aim of delivering a culturally safe environment for whānau, guided by principles of tikanga Māori. This removal of a major identified barrier allows a focus on understanding potentially unknown or less well-identified barriers, such as pressure to deliver on health targets driving clinician behaviour to maintain funding levels for critical service delivery.

Evidence demonstrating efficacy for computerised decision support exists, although it is variable.^{29,30} Eccles *et al.*, for instance, found that full technological support for asthma and angina care did not provide the complete answer for busy clinicians managing care for patients with complex, multiple conditions.³¹ Similarly, the impact of the decision support tool in this study proved to be moderate when structural barriers remained, whereas the empowerment of community was a powerful tool to change clinician behaviour. Participants discussed wanting to respond in more accessible and responsive ways as needed by their community, but felt constrained by the construct of a health system primarily funded on 15-min appointments occurring every 3 months.

Humphrey *et al.* claimed to provide the first qualitative study to report clinician experience of treating gout.⁷ They identified the need for primary care to respond and manage gout appropriately, and also identified the business model of health care as a barrier to optimum management. This research aimed to build on that study and to understand how optimal management could occur to benefit Māori, who are disproportionately disadvantaged.

Strengths and limitations

This research advances understanding of Indigenous health providers' perspective of barriers to optimal gout management in Aotearoa and raises new ideas on ways to achieve optimal management with equity as the driver. That the research occurred at a site where cultural safety and equity are already drivers of health delivery enabled analysis of potential wider issues.

However, the number of participants was relatively low due to the size of the practice. The lead author led the development of interventions, so there was potential for bias in finding favour with the overall project. This was mitigated by critical reflection and triangulation with co-authors in thematic analysis and discussion.

Conclusion

Despite provider intent to deliver culturally appropriate, culturally safe care and equitable health outcomes for patients suffering from gout,

initiatives without aligned resourcing or incentives are not sufficient when inequity is pervasive. This research highlights the importance of transformative and holistic thinking. For these health-care workers in a predominantly Māori setting in a colonised, inequitable society, the challenge of providing people with optimal gout management requires the mitigation of multiple barriers far beyond providing safe, culturally appropriate care. Enablers include: addressing historic socio-economic injustice, addressing ingrained inaccurate beliefs about gout and better and more context-specific practice resourcing. Gout affects relatively more Māori than others and optimising treatment by, for and with Māori requires more than simply asking Māori providers to do more with the same amount of resource.

Competing interests

LTK has a small part-time role working at the clinic. She has no-one reporting to her and is not involved in any management decisions. She was involved in the development of the initiative. MH also has a part-time role at the clinic as a general practitioner. She was not interviewed.

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