

Maori experiences and perceptions of gout and its treatment: a kaupapa Maori qualitative study

Leanne Te Karu MHS; Linda Bryant MCLinPharm, PhD; C Raina Elley MBChB, PhD

Department of General Practice and Primary Health Care, School of Population Health, The University of Auckland, Auckland, New Zealand

ABSTRACT

INTRODUCTION: The prevalence of gout among Maori is one of the highest in the world. This study explores the perceptions, understanding and treatment of gout among Maori.

METHODS: A qualitative general inductive approach was used, guided by kaupapa Maori principles. Participants included 12 Maori aged 48–79 years with gout. Semi-structured interviews were undertaken, taped and transcribed. Themes were identified from transcripts.

FINDINGS: Participants described overwhelming sufferance due to gout, which was sometimes considered inevitable. All participants believed or had been informed that gout is caused by food and/or drink. This led to feelings of self-blame and blame from partners and employers. Whanau (family) were a resource for information and a support when independence was limited. Rongoa (traditional medicine) played a role in the lives of rural but not urban participants. Many reported stoicism, putting up with pain and putting others before themselves, as the 'Maori way'. Medicines used for gout management were predominantly non-steroidal anti-inflammatory drugs, colchicine and prednisone, with allopurinol only playing a role late in the disease. Medications were often poorly understood and consequently improperly used. Relationships with health professionals were important, but cultural, financial and time barriers impaired access and understanding. Gout had a huge, negative impact on the lives of participants.

CONCLUSION: The quality of lives of many people with gout could be improved by better understanding through educational campaigns for health professionals and the community. Culturally sensitive health care systems and a paradigm shift in gout management and early preventive treatment are needed.

KEYWORDS: Drug therapy; ethnic groups; gout; health status disparities; primary health care; qualitative research

Introduction

Gout is common amongst Maori, the indigenous population of New Zealand (NZ). The prevalence of gout is approximately 10% in Maori men, which is one of the highest rates in the world^{1,2} and is associated with significant morbidity in Maori.³ Recent gene mapping suggests Maori may have a genetic predisposition to hyperuricaemia and gout.⁴ Gout requires people to be off work, and stops people undertaking sports and physical activities. Delayed preventive treatment leads to severe physical disability through the development of complications.⁵ In addition, an increased risk of cardiovascular mortality has been demonstrated amongst those with gout.⁶

There is little research into the experience and management of gout in indigenous populations and whether current health care systems are adequately serving them. This study is one of the few that has investigated this topic in a culturally appropriate manner. This study used a 'kaupapa Maori' approach to explore Maori experiences of gout as a disease.

Methods

This qualitative study used general inductive thematic analysis,⁷ where qualitative interviews were conducted with urban and rural Maori participants who had been diagnosed with gout. The intention of this study was to explore perceptions and understanding of gout, its causes, the impact

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CORRESPONDENCE TO:

Leanne Te Karu
Department of General Practice and Primary Health Care, School of Population Health, The University of Auckland, PB 92019, Auckland, New Zealand
ltekaru@mpa.maori.nz

on lifestyle, attitudes towards the condition, and the use of medicines for both symptomatic and preventive treatment.

Kaupapa Maori

The study was guided by the principles of kaupapa Maori. This includes recognition of Te Ao Maori as a paradigm from which matauranga Maori is maintained from generation to generation, through the process of storytelling.⁸ This intergenerational transfer was often undertaken in wananga, or traditional Maori forums of education. The principle researcher acknowledged the importance of this theory in the engagement with participants. Maori terms of relevance to the study are defined in Table 1.

Rangatiratanga and mana motuhake of participants are recognised as kawa and tikanga passed down from tupuna. Similarly, the concepts of whakautuutu, or reciprocity, informed the engagement and korero (discussion) with participants.

As identified by Smith, kaupapa Maori research is a social project: it weaves in and out of Maori cultural beliefs and values, Western ways of knowing, Maori histories and experiences under colonialism, Western forms of education, Maori aspirations and socioeconomic needs, and Western economics and global politics.⁹

Study population

Those who identified as Maori and had a history of gout were eligible to participate. Urban participants were invited from the **Improving Adherence using Combination Therapy (IMPACT)** cardiovascular polypill trial undertaken in Auckland.¹⁰ Rural participants were recruited via a gout clinic in a rural town where the principal researcher worked as a clinical pharmacist. Rolling recruitment continued until saturation of data was reached. Most interviews were conducted at participants' homes, except for three participants who chose to be interviewed at the clinic.

Community consultation

An important consideration was the extensive consultation that was undertaken in the com-

WHAT GAP THIS FILLS

What we already know: Gout and its complications occur disproportionately among Maori, the indigenous people of New Zealand, and yet there appears to be a low rate of gout preventive therapy. The reasons and consequences of both these observations are not well understood.

What this study adds: This study provides an insight into the experiences of gout and its management amongst a group of Maori in New Zealand, and highlights areas where improvements could occur. Additionally, the method used in this study, guided by the principles of kaupapa Maori, introduces a methodology that is culturally appropriate and adds richness and depth to the information obtained.

Table 1. Glossary of terms

Term	Description
Kaupapa Maori	Refers to a Maori subject, rationale and/or process specific for Maori by Maori
Te Ao Maori	All aspects of the 'Maori world', which can include its values, principles and process
Matauranga Maori	Maori knowledge
Rangatiratanga	In a contemporary sense, this refers to chieftainship, power or authority
Mana motuhake	A Maori term for having authority, control and self-determination over one's world
Kawa	This derives from the ancient term ta te kawa or tangata te kawa, which is a pre-dawn ceremony for a new building. In modern Maori, the term kawa is frequently used to refer to rituals or protocols related to, but not limited to, the formal welcome of visitors on the Marae, which is determined by the people of a given area
Tikanga	This derives from the word tika, to be correct to what is accepted as correct customary practice in all Maori contexts, not only the marae. Tikanga is the appropriate behaviour relevant to kawa associated with the ritual, which is determined by the people of the given area
Tupuna	A Maori term for those ancestors from whom they have descended
Whakawhanaungatanga	This represents a korero (discussion) of connection of persons through genealogy and/or kaupapa
Marae-based clinic	A health setting on traditional lands

munity prior to the research. The principal researcher met with local general practitioners, Maori health providers, local Maori leaders and a tribal group (iwi) forum. There was much discussion generated about the proposed research and unanimous support was given.

Table 2. Themes identified during the interviews with selected participant quotes

Overwhelming suffering
I just couldn't move, my legs used to [expletive] pound. The pain was that bad you just wanted to cut your foot off. That's how bad it is. It's real bad and you can't touch it, you can't walk. You lose your appetite. You definitely can't work. It knocks you right, you can't [expletive] eat. It's mean. It just makes you miserable.
Whanau (family)
Well it does impact [on your whanau]. They all stay clear. They know I am grumpy and they know to stay clear. They were like 'oh no, here we go again'. It really impacts on your relationship side.
Rongoa (traditional medicine)
<i>Rongoa rakau (the aspect of rongoa derived from plants)</i> Used by seven of the eight rural participants.
<i>Wairuatanga (spirituality)</i> I look at disease as being spiritual and physical. You do need to understand your spiritual side as well. You need to understand the whole person; that wairua has gone wrong sometimes.
Te Taha Hinengaro (perceptions, beliefs, attitudes, thoughts and experiences)
<i>Stoicism</i> You have to work through it. It's the Maori thing. You just accept it; don't question.
<i>Fatalism/inevitability</i> At the moment my children and my daughter they haven't gotten gout yet but I always talk about it... the youngest one, he's had it. He said '[expletive] mum' and I say yeah but what's some pain and discomfort for your life.
<i>Denial</i> I definitely got two sisters and a brother with the gout now. I see them limping too but they don't admit they have it. Or they say they knocked their toe.
Impact: the ripple effect
I went to work and then I lost my job... Well with gout the boss said 'you didn't get that at work, you got that at home.' I said 'oh well stick your job'... Then I had to go from working outside to working inside in a factory job... I ended up being 17 years in it aye. That gout was always there aye. Sometimes I went to work with no boot aye. Boy if you got caught though aye. I didn't want to miss work though aye cos the shift especially the overtime aye; the Saturdays and Sundays too.
Causality
I thought it was all my fault.
Medicines
I got upset puku (stomach) and diarrhoea and an ulcer too. It was from taking the aspirin and the diclofenac and the Voltaren.
First time I heard there was a pill to prevent gout. I wish I had known before... I'm so proud; pleased to know there is a pill to prevent gout. If I could have saved myself from having gout for all these years! I'm getting old. I'm 64 now. I wish I had known before.
Health professional relationships
These doctors need to have a bash of gout and see what it feels like to them then they would see what it's really like. I think they have no idea.

Informed consent and ethical approval

Written informed consent was gained from all participants. Ethical approval for the interviews was obtained for urban recruitment (NXT Ref. 06/06/072) and by expedited approval for rural recruitment from the NZ Northern X Regional Ethics Committee.

Interview schedule

The principal researcher undertook semi-structured interviews with open-ended questions. Participants were able to respond in both English and Maori, reflective of the participants and kaupapa of the research. As part of the process, whakawhanaungatanga was also essential in building the relationship with the participants.

Thematic analysis

The principal researcher transcribed the interviews. Wherever possible, participants were sent transcripts to check for completeness and representativeness. Thematic analysis of transcripts was undertaken by two of the researchers (LTK and CRE) independently, who then met to discuss their findings and agree on themes. On occasion, a third researcher (LB) was also engaged. Interviews continued until 'saturation of themes' was reached.

Findings

Study population

Twelve participants took part, including four urban-dwelling and eight rural-dwelling participants. The ages ranged from 48 to 79 years and four participants were women.

Themes

The following eight themes were derived as they related to the research kaupapa. A summary can also be found in Table 2.

Overwhelming suffering

All participants could recollect their first episode and the severity of gout.

I just couldn't move, my legs used to [expletive] pound. The pain was that bad you just wanted to cut your foot off. That's how bad it is. It's real bad and you can't touch it, you can't walk. You lose your appetite. You definitely can't work. It knocks you right, you can't [expletive] eat. It's mean. It just makes you miserable. (#9)

Whanau (family)

Whanau were significant in several ways. Firstly, they provided a resource in terms of information.

Information came from... my brother too. He was getting gout a lot and from my Mum too. She had bad gout. (#8)

The burden of disease of gout could also ripple through to whanau, having negative consequences on relationships.

I believe gout can wreck your marriage... Financially it puts a strain too, which just adds to it. Either you are out of work, off work or looking for work. Financially, it can be hard to see a doctor. When you go home you can be a bit too demanding. (#5)

Well it does impact [on your whanau]. They all stay clear. They know I am grumpy and they know to stay clear. They were like 'oh no, here we go again'. It really impacts on your relationship side. (#9)

Rongoa (traditional medicine)

Although rongoa is often perceived as a literal translation for traditional medicine derived from plants, its nature and extent covers almost every aspect of things Maori—physical and spiritual. With respect to gout, rongoa was largely limited to rongoa rakau/wai rakau, the use of traditional plants for healing properties.

Rongoa rakau

None of the urban interviewees used rongoa for the purposes of gout, or in general. In contrast, seven of the eight rural interviewees used rongoa. Four participants described using rongoa specifically for gout in an acute situation, either with poultices/baths or internally, with some easing of symptoms. Three participants used rongoa on

a more regular basis to support overall wellbeing, which they thought would also help their gout.

Wairuatanga (spirituality)

In a traditional sense, wairua is at the centre of rongoa and some participants connected gout with wairua.

I look at disease as being spiritual and physical. You do need to understand your spiritual side as well. You need to understand the whole person; that wairua has gone wrong sometimes. (#5)

Te Taha Hinengaro

Te Taha Hinengaro as a theme for this research refers to perceptions, beliefs, attitudes, thoughts and experiences, as they relate to gout.¹¹

Stoicism was an attitude displayed by all participants in their association with gout and its enduring consequences.

It wasn't too bad... It was always hard to walk. To go to the toilet, you're crawling on the floor to go to the wharepaku [toilet]. (#1)

One possible explanation given was:

You have to work through it. It's the Maori thing. You just accept it; don't question. (#4)

For some participants, there appeared to be an element of fatalism or inevitability that gout would occur.

At the moment my children and my daughter they haven't gotten gout yet but I always talk about it... the youngest one, he's had it. He said '[expletive] mum' and I say yeah but what's some pain and discomfort for your life. You got to go through these things so I talk about these things with my children and with my mokopuna [grandchildren]. (#1)

For others there was a strong sense of denial.

I definitely got two sisters and a brother with the gout now. I see them limping too but they don't admit they have it. Or they say they knocked their toe. (#8)

Participants also spoke about ‘attitude’ being a driver for not seeking optimal understanding or treatment.

Yeah well that is the other thing with our people too is they don’t like asking questions. (#1)

You know I think it was just my attitude. I was bullet proof. Yeah, just my attitude that’s all [when asked why he waited for 14 years before accessing a doctor for support]. (#7)

When asked if they had any thoughts on what would be helpful in terms of treatment, the participants had a number of ideas. One spoke of the need for whanau to not be afraid to ask questions or to learn more. Others had ideas on changing the paradigm of the health care service.

I didn’t like going to clinics at all. If it was a marae-based one, I would go and listen but that’s all maybe. (#7)

Making it easier to access the doctors. We are busy people too and there are long wait times. ... Pharmacist never spoke to me... Be great to have pharmacists involved in informing you what the medicines are that you are taking. Never had that explanation. (#4)

Impact

The research identified the flow-on effect of living with gout that rippled through the lives of those afflicted with this condition. Participant 5 spoke of his belief that gout was a major contributor to the dissolution of his marriage and loss of his job, describing the financial and personal burden.

Employers don’t understand because they have never had it. Never experience it. (#5)

I went to work and then I lost my job... Well with gout the boss said ‘you didn’t get that at work, you got that at home.’ I said ‘oh well stick your job’... Then I had to go from working outside to working inside in a factory job... I ended up being 17 years in it aye. That gout was always there aye. Sometimes I went to work with no boot aye. Boy if you got caught though aye. I didn’t want to miss work

though aye cos the shift especially the overtime aye; the Saturdays and Sundays too. (#11)

Participant 10 spoke of the concern of losing his independence when gout in his fingers made it hard to turn the ignition in his car and to grip the steering wheel. There were many examples of a heavy toll on the person afflicted, both directly with loss of income and loss of function/mobility, but also through potential loss of self-esteem and functionality within whanau and community.

The following two themes—causality and medicines—captured understanding of gout and treatments.

Causality

All interviewees believed or had been informed that gout is caused entirely by food and/or drink.

...kai (food) is what causes gout. (#6)

Due to this underlying belief the participants assumed the onus of their gout development rested with them. For example:

I thought it was all my fault. (#4)

Partners also perceived the participants were responsible for their gout and this impacted negatively.

[Name] (wife) goes [expletive] nuts at me. She looks at me and says ‘[Expletive] here we go again’. (#9)

Most participants stated that they had heard of uric acid and understood there was a connection with crystal formation. One person had heard of serum uric acid levels yet did not know the significance. Two participants felt that joint injury or damage had been a trigger.

Medicines

It was many years before most participants became aware that gout attacks could be prevented through use of allopurinol. The average length of time to be prescribed allopurinol after first onset of gout symptoms was 18.3 years for the total cohort, excluding one participant who was yet to start.

I know lots of doctors don't give it [allopurinol] out. (#1)

Most had spent many years receiving symptomatic relief only.

Yeah well I had the Voltaren, oh [expletive] for maybe 20 odd years. (#3)

But I used to take a lot of colchicine and stuff like that before allopurinol. Colchicine and something else... indomethacin, diclofenac [for 30 years] before allopurinol four months ago. (#2)

Some participants discussed adverse effects from non-steroidal anti-inflammatory medications (NSAIDs).

I got upset puku (stomach) and diarrhoea and an ulcer too. It was from taking the aspirin and the diclofenac and the Voltaren. (#8) [This participant was co-administering Voltaren and diclofenac thinking they were different medicines].

In addition, participants stated their pleasure and at times surprise that there existed a medicine that could prevent attacks.

First time I heard there was a pill to prevent gout. I wish I had known before... I'm so proud; pleased to know there is a pill to prevent gout. If I could have saved myself from having gout for all these years! I'm getting old. I'm 64 now. I wish I had known before. (#8)

One participant had his first gout attack at 23 years of age. He did not see a doctor for gout symptoms until he was 37 and did not commence allopurinol until he was 52 when he was admitted to hospital for gout ulceration requiring skin grafting.

Doses of NSAIDs greater than recommended were sometimes used.

As soon as it starts, I take two of those 100 mg Voltaren. I take two tablets first, then another one so that's three, then another the next day. (#3)

I just sort of have a dozen of those indomethacin. (#2)

Participants discussed the sharing of NSAIDs in an acute situation.

I even shared all these medicines—Naprosyn, Voltaren, many times with whanau, with visitors. (#4)

Three participants who had been prescribed prednisone described it as being very effective.

Those [attacks] were full on but if I took that [prednisone], and then bang it would disappear for another month. (#9)

Another participant described being given a steroid injection in order to continue playing rugby.

Four participants had been prescribed allopurinol for longer than six months and found it very effective. Some participants had previous unsuccessful trials of allopurinol due to a lack of understanding.

I got the allopurinol last year [300 mg] but I just got worse then. I thought I should take double the amount and it only got worse still. (#5)

I had heard from someone... they say 'oh when you take allopurinol boy it gives you the gout' and I was like 'aye, I won't take it.' I did get some years ago and I put them up in the top of the cupboard and I wouldn't take them. (#10)

Health professional relationships

How the health provider and participant engaged had an effect on the understanding and outcome. Cultural congruence helped.

When I got to Auckland hospital there was a Maori anaesthetist... And I said to him, '[Name] do you speak Maori?' 'Ae whaea' And I say 'good'. So I started talking Maori to him. (#1)

Some felt that doctors did not understand what gout was like.

These doctors need to have a bash of gout and see what it feels like to them then they would see what it's really like. I think they have no idea. (#9)

Similarly cost, time and attitudes were factors described as barriers.

Financially it can be hard to see a doctor. (#5)

It's just that I didn't like taking time off work [to go to a doctor]. (#7)

There was little information recalled from doctors about the cause or how to prevent gout.

I don't think they gave you enough. It kind of wasn't even the basics. There were no follow-ups or anything and I was going regularly. There must have been time in there. I didn't know about uric acid levels or what I should aim for. In my mind, I never had it explained. (#9)

One participant overall had a slightly different take on the situation by stating:

I think the doctors do give you some information but maybe it's a lot to take in I think, or not understandable. (#10)

Discussion

The current health care system had not served the participants well. There was little information provided effectively and little understanding of cause or appropriate management of gout for many years. Participants (and whanau) often blamed themselves for the condition. There was no recognition of Maori genetic predisposition,¹² or other possible contributing factors. Uric acid levels can increase in ischaemic heart disease or congestive heart failure, medical conditions that have high prevalence in Maori.^{13,14} High protein diets or excessive use of protein supplements in fit young athletes can also trigger gout.¹⁵ Furthermore, alcohol excess may be overemphasised in gout.¹⁶ The participants interviewed did not appear to be aware of this information, reflecting at times that they were apprehensive they would be prejudged on alcohol intake or that questioning on alcohol intake felt accusatory.

Participants received only acute treatment for their gout for an average of 18.3 years prior to commencing allopurinol. The participants also had little awareness of allopurinol as a preventive agent before being prescribed it. This contributed to a reliance on NSAIDs or prednisone as being the only recognised treatment. Participants also had little understanding of frequency and dosing

of NSAIDs, with very high doses and inappropriate use common.

While the extreme pain and disability had a personal impact, it also extended into many aspects of participants' lives, such as the ability to work, play sport, socialise, interact with whanau and, in some circumstances, maintain independence. The effect of loss of employment, for example, saw whanau unduly stressed and relationships suffer.

All rural participants used rongoa as part of their 'normal' daily regimens or had been raised in a household that used rongoa. None of the urban participants used rongoa. Many considered wairua important in all aspects of health, including the occurrence of gout. Participants dealt with gout in various ways, but most described stoicism and reluctance to trouble others. Relationships with health providers were important, but barriers such as cost, time and cultural mismatch were described, which hindered seeking help. A reluctance to ask questions was evident, but the consultations did not appear to facilitate education in many cases. Whether information had been provided by health professionals or not, it was not deemed understandable, nor did the participants feel understood. The onus of health literacy and cultural competency should sit with the health professional. As such, every interaction must be tapered to meet the needs of the consumer/patient.

Strengths and limitations

This study used a culturally relevant approach to investigate an issue that affects many indigenous and minority populations.^{17,18} The principal researcher is Maori, with experience in working with Maori communities. Community consultation and use of whakawhanaungatanga were key to the study and to participant engagement. A potential limitation of the study was the researcher's passion for addressing inequities in health outcomes for Maori and her role as a health provider. Although the possibility of bias could be perceived, this was worked through with the research team in the construction of the questionnaire, translation of participant interviews and research findings. Triangulation of transcripts with participants and triangulation of

themes between researchers were also strengths of the study.

Comparison with the literature

The findings of this study had some similarities to qualitative research conducted in other countries. Harrold et al.¹⁹ interviewed 26 patients and 15 health care providers in an attempt to understand suboptimal 'urate lowering therapy'. The differences in thinking were marked, with providers believing, in general, that gout is a relatively straightforward condition; that patients know how to manage gout in both the acute and chronic phases; that acute treatment is always effective; that patients understand allopurinol is a long-term effective therapy and are adherent to treatment, and that patients have a clear understanding of the aetiology of gout. Patients, on the other hand, reported ineffective acute management; only a superficial understanding of gout and progression; incomplete understanding of allopurinol and the need for long-term administration; non-adherence with allopurinol and the need to tailor information to the patient.

In a second qualitative study, Lindsay et al.²⁰ explored the experience of living with gout. The emergent themes again identified the need for robust education of both medical practitioners and the wider public.

Whilst there are many case studies providing evidence of pain associated with gout,^{21,22} there is surprisingly little published qualitative research specifically looking at experience of pain.²³ A recent review called for engagement with those experiencing pain directly stating:

The culture of young men today, their value on mateship, mana (self-worth), and manliness [including stoicism in the face of severe pain], and their attitudes to medication and traditional versus pharmaceutical remedies, are areas in need of further research, since the research base is limited.²⁴

With regard to the consequences of pain, there is published research demonstrating a decrease in quality of life and a loss of productivity with employment.^{25,26} Again these studies are limited other than the general and accepted view of pain and

largely follow a survey format in which the 'voice' of those with gout is not specifically captured.

Although much is known about the aetiology, pathology and prevention of gout, it remains a condition that is poorly managed at many levels. In the words of Professor Larry Edwards, speaking at a 2011 NZ Rheumatology Scientific Meeting: 'We have always had the tools to treat gout but we do not do this well.'²⁷ Other researchers describe prescription of allopurinol as being low according to burden of disease.²⁸ The finding that participants generally were not fully aware of the concept of testing for uric acid is also consistent with international findings.²⁹

Implications for research and practice

The suboptimal understanding, management and prevention of gout suggested in this study are worrying. Further investigation is needed into the impact and management of gout among the general population, but particularly among those populations most at risk yet often least well served by the health care system. The burden of gout and other diseases in indigenous or minority populations contributes to health disparities and inequity. Changes to health care systems are needed to ensure effective, culturally appropriate education, appropriate management and timely use of urate-lowering preventive medications. A paradigm shift is needed, along with a substantive education programme for health professionals, those with gout and communities.

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COMPETING INTERESTS

None declared.