

Improving gout education from patients' perspectives: a focus group study of Māori and Pākehā people with gout

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ABSTRACT

INTRODUCTION: Gout is a common form of arthritis that is typically managed in primary care. Gout management guidelines emphasise patient education for successful treatment outcomes, but there is limited literature about the educational experiences of people living with gout in New Zealand, particularly for Māori, who have higher gout prevalence and worse gout outcomes than Pākehā.

AIM: To explore gout patient education in primary care from the perspectives of Māori and Pākehā people with gout.

METHODS: In total, 69 people with gout were recruited through primary care providers in three locations across New Zealand. Nine semi-structured focus groups were run with Māori and Pākehā participants in separate groups.

RESULTS: Thematic analysis yielded two themes in relation to gout education: (i) 'Multiple sources of gout education'; and (ii) 'Gaps in gout knowledge'. Participants received education from general practitioners, educational resources, family and friends, and their own experiences. Māori participants preferred information to be kanohi-ki-te-kanohi (face-to-face) and with significant others present where necessary. Participants disclosed gaps in gout's epidemiology and management. Pākehā and Māori participants reported limited understanding of the genetic basis of gout or the biological underpinnings of the condition and its treatments, but learned treatment adherence through experience.

DISCUSSION: Despite improved gout patient education, knowledge gaps remain and may contribute to poor medication adherence. Gout patient education interventions need to be tailored to culture and incorporate suitable methods of disseminating information about gout management.

KEYWORDS: gout; health-care education; communication; Māori health services; qualitative trials

Introduction

Gout is a debilitating form of arthritis initially characterised by intermittent attacks of painful, swollen joints.¹ In New Zealand, gout prevalence is 3.9%, with higher rates among Māori (7.7%).² Māori have earlier onset of gout with more

severe disease than New Zealand Europeans (Pākehā).³ Successful gout management requires long-term daily treatment with urate-lowering therapies such as allopurinol to reduce blood uric acid levels.¹ According to dispensing records of adults prescribed allopurinol for gout, 67% of

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Māori and 71% of Pākehā regularly collect their prescriptions.⁴ Non-adherence to medications that can control gout is therefore of concern.⁵ The ability of health-care providers to communicate consistent, clear information repeatedly to gout patients is crucial to improve medication adherence.⁶

Despite the development of clinical guidelines,^{7–10} gout management remains suboptimal.^{11–13} Patient education is crucial for optimal gout management.^{14,15} Successful patient education relies on educational resources that fit the health literacy of the population.¹⁶ Gout patient education is commonly provided in primary health care by oral communication from general practitioners (GPs) or nurses and written resources.¹⁷ Gout education and the resources provided may vary across professionals and may not meet the preferences of patients. Māori may face additional barriers to optimal treatment outcomes when educational resources or health-care systems are not culturally appropriate.¹⁸

Findings from this overall study previously revealed commonalities in Māori and Pākehā gout patients' desire for information about diet and medication, but also showed differences in preferred communication channels, with Māori being less likely to prioritise information about gout from a doctor and preferring spoken over written information about gout.¹⁹ In our previous paper, we documented quantitative ranking data on gout educational preferences made during a focus group ranking exercise.¹⁹ The present paper describes data from the discussions arising during the focus group study reported in the previous paper.¹⁹ The aim of the present analysis was to explore experiences of gout education in primary health care from the perspectives of Māori and Pākehā people with gout.

Methods

Design

Focus group methodology accommodated the exploratory nature of the study and allowed group discussions when researching disease education.¹⁹ Focus groups are considered culturally appropriate as a method for exploring

WHAT GAP THIS FILLS

What is already known: Māori have a higher prevalence of gout and are more likely to have suboptimal gout treatment outcomes. There is limited understanding of Māori patients' gout education experiences and whether these differ from the experiences of Pākehā patients. Previous research has revealed some differences in gout education preferences between Māori and Pākehā patients, but research to date has not fully explored these differences.

What this study adds: Māori and Pākehā patients derived their gout education from multiple sources – health professionals, educational resources, family and friends, and their own experiences. Māori with gout preferred face-to-face communication of information over written material. Patients from both ethnicity groups had significant gaps in their knowledge about gout that require further education.

views expressed by Māori participants.¹⁸ We incorporated a Nominal Groups Technique^{20,21} in the focus group meetings to obtain quantitative ranking data, which has been reported elsewhere.¹⁹ The focus groups involved 5–11 participants who engaged in semi-structured discussions around diet, medication and ways of communicating information about gout. We ran separate focus groups for Māori and Pākehā participants according to their primary ethnic identity. For the Māori focus groups, at least one Māori researcher was present to facilitate tikanga Māori (appropriate cultural practices). Participants in all focus groups were provided with the Stop Gout pamphlet²² at the start of the focus groups as an example of national best practice gout patient education and to assist with generation of ideas. Focus group meetings ranged from 70 to 125 min and were audio-recorded and transcribed.

Participant recruitment, inclusion and exclusion criteria

We recruited participants from one urban and two rural locations. Participants were not included if they were receiving secondary care for gout, as gout is mostly managed in primary care and we wished to identify areas for improvement in primary care. Additional exclusion criteria included primary ethnic identity other than Māori

or Pākehā. Participants' GPs invited them to participate. A research assistant then called each participant by telephone to confirm their willingness to attend a focus group. Willing participants were posted an information sheet, consent form and brief health questionnaire to complete before attending the focus groups. GPs completed a questionnaire confirming gout diagnosis and medications of participants consenting to engage in the study. Sample size was determined by the requirements of the larger study. Nine focus groups were sufficiently rich and demographically varied to address the aims of this qualitative analysis. The study was granted ethics approval by the New Zealand Health and Disability Ethics Committee (15/STH/9). All participants provided written informed consent before the focus groups.

Data analysis

Focus group transcripts were analysed by the first author (C.J. Rolston) using an inductive form of thematic analysis with a realist epistemology, in accordance with steps outlined by Braun and Clarke.²³ This involved an iterative process of coding extracts of the transcribed discussions, grouping codes to develop themes, and then checking to ensure that codes and themes were informative and representative of the entire dataset.²⁴ C.J. Rolston consulted with three other researchers (T.S. Conner, L.K. Stamp, G.J. Trehane) to refine codes and finalise themes. Two Māori co-authors (T. Neha, S. Pitama) reviewed a full draft of the themes but were not directly involved in conducting the analysis.

Results

Sample

The sample consisted of 69 participants (49 men, 20 women) aged 28–87 years, with a mean age of 66 years (standard deviation (s.d.) = 11.9). Mean duration of gout was 17.6 years (s.d. = 15.6). Participants reported a mean of 1.92 (s.d. = 2.31) gout flares in the year preceding study enrolment. Participants either identified as Māori (39%) or Pākehā and not Māori (61%). Table 1 presents the demographic characteristics of participants by location and ethnicity.

Themes

Two themes were identified in the thematic analysis: (i) multiple sources of gout education; and (ii) gaps in gout knowledge. Within each theme, there were differences in health education experiences between Māori and Pākehā participants that we articulate in the following sections.

Multiple sources of gout education

Participants obtained education about gout epidemiology and management from four main sources: health professionals; educational resources; family and friends; and their own experiences. Māori participants described more information gathered from friends and family than Pākehā participants.

Health professionals

Participants described how they had derived gout knowledge from interactions with GPs

Table 1. Demographic characteristics of participants overall and according to location and ethnicity

	Focus group location				Ethnicity	
	Overall	1 (Urban)	2 (Rural)	3 (Rural)	Māori	Pākehā
Focus groups held, <i>n</i>	9	3	2	4	4	5
Participants, <i>n</i> (%)	69 (100.0)	24 (35.0)	16 (23.0)	29 (42.0)	27 (39.0)	42 (61.0)
Male, <i>n</i> (%)	49 (71.0)	19 (79.0)	13 (81.0)	17 (59.0)	17 (63.0)	32 (76.0)
Disease duration in years, <i>mean</i> (s.d.)	17.6 (15.6)	19.9 (17.2)	23.2 (18.2)	17.6 (12.2)	20 (11.1)	19.7 (17.6)
Years in formal education, <i>mean</i> (s.d.)	10.7 (4.5)	11.8 (5.3)	11.2 (3.1)	9.4 (4.1)	10.3 (3.8)	11.0 (5.1)
Taking urate lowering therapy, <i>n</i> (%)	54 (78.3)	16 (67.0)	15 (94.0)	23 (79.0)	21 (78.0)	33 (79.0)

Note: Not all participants fully completed demographic information questions. Statistics provided in this table have been calculated with the exclusion of non-responses. s.d. (standard deviation); *n* (number of participants).

and nurses. Some participants described their health professional as a source of detailed, useful information, while others described receiving little to no gout education from health professionals or contradicting information. In particular, participants reported medication information in the pamphlet provided during focus groups contradicting their recollection of GP recommendations:

'I just see here it says if you have gout [ie a gout attack] don't stop taking the allopurinol which is the dead opposite to what the doctor told me so that's a bit of a contradiction.' [Pākehā]

Educational resources

Participants discussed a variety of educational resources including pamphlets, TV advertisements, and websites. Access to resources was an issue, with some Māori and Pākehā participants commenting they had not received written resources before attending the focus group:

'I've never seen a gout pamphlet before.' [Māori]

'Then when I saw my own GP, it was more of a verbal thing than take something home to read so, maybe I needed something printed.' [Pākehā]

Some Māori participants expressed views about the necessity of information to be comprehensible and communicated across various mediums:

'The use of plain language and communications to the people who get gout.. and perhaps the use of various mediums of communication, by text, by phone, by korero kanohi-ki-te-kanohi [speaking face-to-face].. letters, anything, so long as it's understandable.. and transparent.' [Māori]

Overall, Pākehā participants appeared more satisfied with written education resources than Māori participants:

'No, I've never seen it [Stop Gout pamphlet] it's quite good, very good, best one I've seen!' [Pākehā]

Some Māori participants preferred more pictorial information to be included in pamphlets:

'Pictures done in stories you know rather than blah, blah, blah.' [Māori]

Participants who accessed gout information online reported being overwhelmed with the amount of information available. They were unsure about the accuracy of information provided online and described how websites contradicted one another:

'I did what [name of another participant] did, jumped on the internet too but there was a lot of information and some of it was like sort of contradicting each other.' [Māori]

Family and friends

Interactions with family members or friends who had gout assisted both Pākehā and Māori participants in recognising their gout symptoms:

'I never knew what gout was.. I'd been away for years and I said to my sister-in-law I've got very sore toes.. she looked at me and said oh sis you've got gout and I said what's gout?' [Māori]

Māori participants described more information gathered from friends and family than Pākehā participants.

'I used to ask my old man, he used to, you know he used to get gout.. and then I've started getting it and oh jeez.. and I just couldn't understand it, you know because I don't drink either.' [Māori]

However, information sharing between participants and their family members was more likely to be anecdotal rather than evidence-based for both Pākehā and Māori participants:

'Yeah it wasn't in my toes or anything like that and coz my brother gets it in his toes, same as my father and so I was thinking oh well it can't be gout coz they, they get it in the toe.' [Māori]

Own experiences

Participants relied on their own experiences to understand their individual gout symptoms and treatment needs. In the absence of comprehensive management plans, participants opted to

experiment with diet, lifestyle and medication(s) for gout management. This included the use of dietary supplements as natural alternatives to prescription medication. Some Māori participants described the use of Rongoā (traditional Māori medicine) for gout:

'I find I have tried kawakawa on where it is sore and that's amazing.' [Māori]

Experimentation with lifestyle management helped both Māori and Pākehā participants identify foods that triggered flares and medication dosages that provided effective management:

'It is a learning experience: mussels and beans were the main two that set mine off.' [Māori]

'I've halved it, I was on four a day, those big fat probenidic pills and I thought that's a bit tough so I whittle it down to two a day and if I start, my fingers start to swell up, which is the first indication it's gonna hit me, I'll have three and then I'll do that for a couple or three days and then go back to two when it's all, when the things have gone down or if my knee stops aching but if I can control it by that quite easy.' [Pākehā]

Gaps in gout knowledge

While most participants reported some knowledge about gout and available treatment options, gaps in participant knowledge were evident across all focus groups.

Gaps in knowledge of gout epidemiology

Before their own diagnosis, most participants reported that they did not know that gout existed or of their risk of developing gout. Both Māori and Pākehā participants were aware of higher gout prevalence in Māori:

'I think Māori are more prone to having gout than Pākehā.' [Māori]

Participants demonstrated limited knowledge of a genetic basis for gout and did not report comprehensive understanding of the biological processes causing gout symptoms to occur:

'Yeah, either eat so many foods and they'd test you and then probably find out then, but every individual's different and I think it's got something to do with the, what's inside you.' [Māori]

Gaps in knowledge of gout treatments

Participants' knowledge regarding medication risks, modes of action and available treatments was limited. Both Māori and Pākehā participants expressed concern over unknown risks of long-term medication use and this influenced medication adherence:

'I've had painkillers to take while I've been overseas, my pain is still there, I think no this is enough and then I start worrying about the effects that certain tablets have on me so I'll just stop [the painkillers] and bear the pain.' [Māori]

'I don't know whether they [medication] are good for the system though. I know it's not bad if you only have a few of them but I think if you're taking them every day, it might become dangerous for the kidneys which always seem to be the thing that suffers for whatever treatment you have.' [Pākehā]

The awareness that adherence to urate-lowering therapy is vital to managing their gout resulted from experiences of gout flares due to non-adherence rather than from an understanding about long-term uric acid reduction:

'I suffered for years and years but, and I know I get onto allopurinol and I cured myself in about four or five years and I stopped taking it and boy, did I get a thrashing after that!' [Pākehā]

'I think the most important bit of information you should know about allopurinol is you should take it all the time... because, because when you take it cold, it'll cause gout or if you increase it dramatically when you have gout, it'll worsen the gout.' [Māori]

Participants across all focus groups described successful gout management with urate-lowering therapy, highlighting benefits such as absence of gout flares and being able to eat food that would trigger gout flares without urate-lowering therapy:

'Since then I've been on allopurinol, I've had no attacks or anything like that with it when I take the medication, I still drink beer, if I feel like it or alcohol, eat seafood and everything like that and since I've been on the allopurinol, I haven't had any problems at all.' [Pākehā]

Discussion

This study found both commonalities and differences in gout education experiences and knowledge among Māori and Pākehā participants. Commonalities included not knowing about gout before diagnosis, deriving their gout education through multiple channels, needing more consistent information from health professionals, needing better access to educational resources such as the 'Stop Gout' pamphlet and educating themselves about gout triggers through trial and error. Differences were mainly that Māori participants described prioritising learning about gout from friends or family and were less satisfied with written educational materials than Pākehā participants.

The findings support the following improvements to gout education. Primary health-care providers should provide clear, consistent messages about gout management. This includes wider dissemination of pamphlets with information in easily understandable language. Many of the currently available resources provide conflicting messages and are written in complex language.²⁵ Furthermore, gout education resources and pamphlets need to account for individual differences in patient preferences. There have been attempts to improve cultural relevance of educational resources by translating some gout pamphlets into Te Reo Māori; however, translation alone may not ensure people with gout embrace key messages. Other studies have also found that Māori participants report benefits from face-to-face communication, which incorporates their whānau.²⁶ This medium of health education may reduce misinformation about gout.

Improving education for people with gout should result in better treatment outcomes, which may reduce the effect of the disease on both individuals (in terms of pain and disability) and society

(with decreased health-care costs). In particular, patient knowledge that continual use of urate-lowering therapy maintains urate levels within a normal range, rather than cures gout, appears important to medication adherence. Both the American College of Rheumatology and European League Against Rheumatism guidelines identify education about gout as a key component of successful gout management.⁷⁻⁹ Improving patient education and dissemination of gout management strategies promoted by these guidelines should result in fewer cases of gout progressing to chronic gouty arthritis and decreased associated economic burden.

Limitations and implications for further research

The study is limited by its sampling from only three locations. We ran separate focus groups for Māori and Pākehā participants primarily to ensure inclusion of Māori. Having focus groups that included people with a range of ethnicities together may have led to more agreement about apparent distinctions by ethnicity in preferences for gout education. Our study did not include people of Pacific Island ethnicities who are also over-represented in gout prevalence rates in New Zealand (8.6%).^{2,27} The cultural practices of Pacific Island people with gout and how these relate to gout education needs may not be the same as for Māori or Pākehā. Future research on gout education would benefit by recruiting participants from a wider diversity of ethnicities and using a range of methods to determine ideal forms of gout patient education.

The educational preferences of Māori participants for kanohi-ki-te-kanohi (face-to-face) information were consistent with the quantitative findings from this project.¹⁹ However, the qualitative methodology and analysis allowed more flexibility in exploration of these differences. This provided a richer understanding of differences in the way Māori and Pākehā patients obtain gout knowledge and how they apply this knowledge to day-to-day gout management. Incorporating how face-to-face gout education could be better facilitated may provide clinicians with appropriate health literacy tools to support Māori patients with gout.²⁸

Conclusion

People with gout obtain education from a range of sources, but gaps in knowledge of gout epidemiology and management remain evident in both Māori and Pākehā patients with gout. These gaps suggest that gout education in New Zealand requires further refinement, including clear, consistent presentation of key gout epidemiology and management concepts while acknowledging Māori and Pākehā patient preferences in educational needs that consider the multiple sources of information about gout.

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COMPETING INTERESTS

None.