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A qualitative study to explore health professionals' experience of treating gout: understanding perceived barriers to effective gout management

Chloe Humphrey BBiomedSci;¹ Richard Hulme MBChB, FRNZCGP;² Nicola Dalbeth MBChB, MD, FRACP;^{3,4} Peter Gow MBChB, FRACP;⁵ Bruce Arroll MBChB, FRNZCGP;⁶ Karen Lindsay MBChB, FRACP^{4,7}

ABSTRACT

INTRODUCTION: The management of gout is challenging and mainly occurs in primary care. This study aims to explore the experience of treating gout among primary care clinicians and understand the perceived barriers to effective therapy.

METHODS: Fourteen health professionals from primary care practices in South Auckland were recruited. Each participated in a semi-structured interview exploring their experience of treating and managing gout patients were analysed thematically.

FINDINGS: Participants described the large burden of gout in their communities and the importance of the clinician–patient relationship in gout management. Four themes summarise the perceived barriers to effective urate lowering therapy (ULT); unique gout factors, eg its intermittent nature and potential for stigmatisation; systemic barriers to optimal treatment, or barriers that emerge from working within a certain organisation; uncertainty about ownership, or who should carry responsibility for overcoming barriers to optimal treatment; and cultural barriers to optimal treatment.

CONCLUSION: Clinicians in primary practice perceive gout management to be mainly acute rather than preventive care. Patients may be stigmatised and management difficult particularly when diet is emphasised over ULT. Practice nurses are a group potentially available and willing to assist in educating patients. These findings may be helpful in planning for and improving healthcare in gout.

KEYWORDS: Gout; general practice; uric acid; primary health care; allopurinol; primary prevention

¹ Medical student, University of Auckland

² East Tamaki Healthcare

³ Department of Medicine, University of Auckland

⁴ Department of Rheumatology, Auckland District Health Board

⁵ Department of Rheumatology, Counties Manukau District Health Board

⁶ Department of General Practice and Primary Health Care, University of Auckland

⁷ Department of Immunology, Auckland District Health Board, NZ

Introduction

Gout is a common form of inflammatory arthritis, and management is frequently suboptimal. In New Zealand (NZ), many Māori and Pacific Island men have a genetic predisposition to gout and experience more severe and debilitating disease.^{1–3} The most recent epidemiological data show that gout prevalence in Māori and Pacific Island males aged 65 years is more than 30%.⁴

Acute gout attacks are self-limiting and can be treated with non-steroidal anti-inflammatories (NSAIDs) colchicine or prednisone.⁵ Gout management also includes lifestyle modification advice, especially dietary exclusion of alcohol, high purine and fructose foods.⁵ However, unless urate lowering therapy (ULT) is started and continued long-term to reduce the serum urate below saturation concentrations, patients can develop progressive disease, with recurrent

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CORRESPONDENCE TO:
Karen Lindsay
Department of Rheumatology,
Auckland District Health
Board, Auckland, NZ
klindsay@adhb.govt.nz

WHAT GAP THIS FILLS

What we already know: Gout treatment in NZ and overseas is frequently suboptimal, with statistics showing that treatment outcomes for Māori and Pacific Island men are particularly poor. Although the barriers to optimal gout management have been examined from the patient perspective, a health professionals' perspective has not been examined in NZ.

What this study adds: This study identifies important perceived barriers impacting on the clinician–patient relationship that may contribute to a poor outcome in gout management. Clinicians may benefit from putting less emphasis on dietary modifications over ULT. Practice nurses are a group potentially available and willing to assist in educating patients.

attacks, gouty tophi, joint damage, and limitation of quality of life.^{6,7}

There are low national rates of continuous allopurinol prescription and serum urate monitoring in NZ.⁸ To date no qualitative data exist on the perspective of NZ health professionals as to why gout treatment remains suboptimal.

Qualitative research can help provide insights into 'real world' experiences of patients and clinicians⁹

and suggest ways to make health care more sensitive to the needs of the patients.¹⁰ The aim of this study was to explore South Auckland primary care clinicians' experience of treating gout and their perception of the barriers to effective ULT in gout patients.

Methods

Participants were recruited from a Primary Health Organisation (PHO) in South Auckland in 2012. The PHO had 106,310 patients (14% Māori and 45% Pasifika).¹¹ In 2012, 2452 patients presented to this PHO 682 times with acute gout attacks. Of these patients, 18% had serum urate levels at therapeutic target (<0.36 mmol/L).¹¹

Participants were recruited by interviewer CH, a medical student (six general practitioners (GPs), four nurses, and one pharmacist). Interviews were conducted and themes were derived inductively from the data.¹² Validation interviews using the same questions were held with one GP and two practice nurses recruited from general practices from another PHO in South Auckland (total number of participants = 14). Clinicians who had regular interactions with patients with gout participated. All participants provided written informed consent, and the Northern Y Regional Ethics committee reviewed and approved the study protocol (NTY/06/12/136).

A single interviewer (CH) conducted semi-structured, one-on-one interviews with all study participants using questions compiled by KL (Table 1). Health professionals were asked to discuss potential barriers to effective gout treatment, patients posing particular problems, memorable gout patients, and ways changes in their practice in the community and nationally could improve the quality of gout management. Further questions were asked if clarification was required. Interviews were conducted in a private setting convenient to each participant and interview duration varied from 20–60 min. To form an idea of organisation-wide perceived barriers to optimal gout treatment, clinicians were included who affect gout management through prescribing urate lowering therapy (ULT) or who provide allied healthcare or support such as practice nurses

Table 1. Guideline for questions to ask during interviews

Initial guideline and starting point for the interviews:

- What are the barriers to effective gout treatment? The themes and questions to be focused in this qualitative study may change over time.

The interview may be completely open to allow ideas to originate from the patient, focus group or healthcare worker.

In the event of a lack of spontaneous rapport the following questions may be used to facilitate the patient or group in volunteering information.

- What experience do you have of treating gout or seeing patients with gout? (Please give examples of memorable or typical patients you have seen.)
- Which patients pose particular problems?
- What do you feel are the barriers to effective gout therapy?
- What factors in your practise need to be changed in order to improve the success of gout treatment.
- What changes could be made at a community level to reduce the burden of gout?
- What could be done at a national level to improve gout treatment/reduce the burden of gout arthritis?

and pharmacists. Two GPs also had a management role in their organisations.

Confidentiality was ensured by allocating each participant a numeric code, to store data anonymously. Each interview was recorded and transcribed, and the transcripts were analysed and coded using the NVivo software tool (QSR international QSR International Property Ltd, version 9).

Weekly meetings were held between CH and KL to clarify and define emergent themes. Group meetings were then used to validate themes in discussions with clinicians from the PHO, members of the Māori Gout Action Group, and at Continuing Medical Education meetings with PHO GPs, some of whom had taken part in interviews.

Results

Six main themes emerged in health professionals' experience of treating gout, including four barriers to effective ULT. First, participants acknowledged and described the large burden of gout pain and disability in their South Auckland community. Central to their ability to treat gout effectively were clinician–patient relationships, and their enabling effect in educating patients and managing gout. Perceived barriers to effective ULT included gout factors, systemic barriers, ownership and cultural barriers.

Clinician–patient relationships

Participants tended to frame their understanding of potential barriers to effective therapy by looking at both sides of the clinician–patient relationship.

Participant 1 (GP): *I think gout is very difficult to treat at times. It is a two way approach, from doctors and patients.*

Therapeutic relationships, however temporary, required engagement and communication between two people, with the expressed purpose of helping patients to change their behaviour around diet, alcohol consumption and long-term use of ULT.

Participant 11 (GP): *That's the role of the clinician, to motivate them to change, you know, how do you motivate them to do that? How do you empower them? How do you make them aware of complications of an illness, and how they can be prevented?*

Types of behaviours needing to change were eating seafood, drinking beer, drinking sugary drinks, and taking prescribed ULT. For some dietary modification was the dominant behaviour discussed. Non-adherence to diet and lifestyle factors were considered the biggest barriers to effective gout therapy, and they also generated frustration, suggesting clinicians also perceived that patients get repeated attacks because they do not observe the recommended dietary restrictions. Others focused on starting ULT, developing a relationship and incentivising patients to take ULT to reach target serum uric acid measures.

Perceived barriers to effective gout management

Gout factors as a barrier to effective management

The natural history of gout (beginning infrequently, presenting acutely, insidiously progressing, and the development of comorbid conditions) was a barrier to effective management. It was treated acutely rather than chronic, preventive treatment.

Participant 1 (GP): *I think active management is important, rather than being reactive. And that's something that probably most GPs are not really doing that well.*

The perception of acute gout as being triggered by diet was felt to negatively affect effective gout treatment. Combinations of comorbidities and treatment side effects meant that gout therapy for individuals was complex. This created uncertainty as to the best management of acute and chronic gout.

Participant 2 (Pharmacist): *Well, it's about the complexity of the condition, the co-existing morbidities, so like for example renal function, and the fact that allopurinol as a preventer, and I know it's not the only preventer, but needs to be managed carefully.*

In addition, interviewees felt that patients did not take allopurinol as instructed and re-presented only with acute gout attacks. Clinicians described feeling that they had little control over both aspects of patient behaviour. This led to frustration and despair on the health professionals' part, who perceived patients as not taking responsibility over their own health (ownership) and contributed to a perception of futility around gout management.

Participant 10 (GP): *At the end of the day, he didn't do anything to help himself either, and it was really frustrating treating the person.*

Conversely, some clinicians focused on arranging for follow up when acute attacks abated, starting ULT along with anti-inflammatory medication, monitoring serum urate to achieve target levels, and using blister packs to reduce confusion, in particular as doses were escalated. They described cases of observed clinical improvement. Often patients who lost momentum, forgot to fill out prescriptions, and did not attend follow up appointments, had a greater burden of disease and associated medical comorbidities which made it challenging to continue ULT.

Systemic barriers

The second group of barriers impacting patient-clinician relationships were organisational. They included factors such as time constraints and using a business model rather than best practice for each patient. For example, some clinicians perceived that their practice's focus was on shorter waiting times, with limited access to follow-up appointments with the same doctor.

Participant 11 (GP): *Practices who offer drop-in systems can have large volumes of patients in their waiting room, and if there are limited numbers of staff, doctors in particular, working, then there's some time pressure on doctors to see patients relatively quickly*

Interviewees felt there were insufficient resources to treat patients with gout and that the problem needed more central government funding. Lack of time, the systemic barrier most commonly

referred to, was perceived as a barrier to delivering effective healthcare because it limited the time available to talk to patients, explore their willingness to adopt behavioural change, and provide gout education.

Participant 3 (GP): *It's another thing, too, the time issue. Cause if you're really, really busy, you don't spend time to talk to the patient, you don't have time, if we're busy.*

Clinicians also identified areas where they would like to improve their own practice, such as spending more time with patients, but were restricted by systemic constraints.

Participant 9 (GP): *Of course, also it's the health professionals, you know, I blame also ourselves that we don't spend enough time to educate people about gout.*

Ownership barriers

The third theme was ownership of the gout problem, the barriers to preventing gout, and who in the relationship should try to overcome them. Some had the sense that patients lacked ownership over their own health.

Participant 10 (GP): *At the end of the day, you can only do so much with medication. What do they say, you can take a horse to the water, you can't make him drink it.*

A sense of who should take ownership became externalised beyond patient-clinician relationships as some participants also identified potential solutions in the community or nationally, through media campaigns to educate the wider public about gout and gout management. Clinicians who felt that gout could be effectively managed displayed a stronger sense of ownership over outcomes of gout management, and gave different examples of how to incentivise a patient with gout to take ULT. These interviewees also identified scope for improvements in their own practice.

In the PHO, nursing staff triaged patients. They spoke about the importance of relationships in educating patients and understanding barriers

to gout management. They described a desire to help in managing gout, but felt that it was not part of their job description or an expectation of their role.

Participant 6 (Nurse): *We actually don't do much with the patient, we just take blood pressure and weigh, and then they go to the doctors... while they're here, we do talk to them about the foods and taking medications regularly and alcohol limits and all that. But not really into it, one-to-one, you know? And yeah, so if we do something like that, more education on it, one-to-one, then we'll feel that we do something about it.*

One nurse interviewed had been involved in gout management and felt able to improve patient engagement and gout management through education, in research studies, and as part of practice development.

Cultural barriers

Participants recognised cultural differences between clinicians and patients as a further barrier to best gout management, as it affected many aspects of the patient-clinician relationship. Language differences formed a barrier to communicating the mechanisms of gout attacks and its treatment and made it difficult to persuade patients to adhere to recommended behaviours and ULT. This challenge was compounded by limited time to explain and educate.

Participant 2 (Pharmacist): *You can never perceive the level of comprehension. It's very hard, you know, people will go to them 'do you understand?' and they'll go [nods head] and mean 'no'.*

Clinicians felt that talking about food and alcohol was necessary to prevent gout attacks, but was also a cultural issue that was difficult to confront. If they were not from the same culture participants at times were reticent about bringing up the subject of food and alcohol. Perceptions of the patients and their apparent lack of concern for having gout were felt to be culturally based issues.

Discussion

Recent results from the Aotearoa NZ Health Tracker showed a higher prevalence of gout

among Māori and Pacific people, leading to a large burden of gout in the community of South Auckland.¹³ This qualitative study has explored the experience of a range of primary care clinicians in the South Auckland community and the barriers they perceive to effective ULT in patients with gout. Clinicians are aware of the suffering of gout and of the need to provide effective education about lifestyle and medications.¹⁴⁻¹⁶ We found interviewees were frustrated that gout was treated mainly as an acute condition rather than addressing the barriers to initiating preventive action and treating gout as a chronic disease. They felt there was inadequate time for patient education. Where treatment was suboptimal or where poor gout outcomes existed, there was a sense of frustration and despair among clinicians and a feeling of futility in their attempts to tackle gout in primary care: a wider education campaign was needed.

These results are consistent with research conducted locally and internationally. They mirror many of the findings from research into the experience of men living with gout in NZ, in particular the experiences of Māori men with gout who feel they do not have enough good information about the condition.¹⁶ A review conducted in the United Kingdom found that only a small proportion of gout patients receive adequate education, advice and treatment for their condition and that doctors focus on treating attacks acutely rather than managing gout chronically. Additionally, ULT was often under-prescribed and under-dosed.¹⁷ Similarly, a qualitative study involving 18 health professionals in the UK found there were discrepancies in knowledge and understanding of best practice around gout treatment, that it was treated acutely rather than chronically, and that there were few incentives to provide optimal treatment.¹⁸ Lipworth et al. suggest that clinicians may under-prescribe ULTs for several reasons, such as a long-held but unsubstantiated fear of allopurinol hypersensitivity, lack of time and resources, and possibly due to a confusing message regarding which ULT to use, at which dose and in which patients.¹⁹ To address the issue of time poverty in primary care, a 'seven-minute protocol' has been developed in Counties Manukau District Health Board to enable patients to receive treatment for acute attacks simultaneously be started on preventive medication.²⁰

Of importance, patients often feel that there is a stigma attached to gout and they harbour a sense of shame because of its relationship with food and alcohol intake.^{14,21} Some clinicians placed a high priority on the role of food and alcohol intake in gout management, and saw it as an important barrier to optimal gout care, thus potentially perpetuating the stigma and unwittingly creating an environment where reticence about seeking help for gout management could occur.²¹ A recent study also found that gout educational resources similarly over-emphasised diet and alcohol as recommended lifestyle changes to help prevent attacks, rather than improving patients' knowledge around the efficacy and mechanisms of ULT or being aware of target serum urate levels.²² Newer, more appropriate gout resources developed in response to this emphasise that even sustained lifestyle and dietary changes can reduce serum uric acid only by 10%.²³

Due to genetic factors, Māori and Pacific Island patients have a predisposition towards poor excretion of uric acid, and knowledge of this may help destigmatise gout in this group.¹ Genetic risk was not mentioned by our interviewees as a barrier to optimal gout treatment, highlighting the importance of improving and supporting cultural competence among clinicians to overcome perceived cultural barriers. Through this lens, clinicians are responsible for knowing their own culture, and differences between their culture and their patients'. Understanding these differences might impact on health inequalities for Māori and other Pacific people who suffer the greatest burden of gout.²⁴ In clinics and organisations with a high proportion of Māori and Pasifika patients, on-going further training in cultural safety of clinicians may be a way forward in addressing the perceptions health professionals hold of lack of patient ownership of responsibility in achieving effective gout treatment.²⁴⁻²⁷ In a step towards addressing this, the NZ Ministry of Health has commissioned a review of the available gout patient and clinician educational material available to primary care doctors with a focus on the health literacy skills of doctors.^{23,28}

One clinician felt that behaviour among patients with gout reflected familial, culture-wide lack

of ownership or responsibility. They described observing patients laughing about gout and perceived them as not taking it seriously or not wanting to do anything about their condition. This perception is mirrored by a qualitative study finding men often use humour as a way of dealing with gout they perceive as embarrassing, and untreatable.¹⁴ Te Karu et al. highlighted the experience of Māori men with gout, who described using stoicism and accepting the suffering of gout, its perceived inevitability, as a response to the poor information they felt they had received about gout prevention.¹⁶

A higher level of teamwork between GPs and nurses may improve satisfaction of both patients and the general practice workforce, improve outcomes, and engender innovative solutions to community health problems in chronic disease.²⁸ This and other initiatives that include nurses in gout management have been shown to be highly effective in improving effective gout management.²⁹ Because of limited GP time to educate patients, nurses could do this using the currently available resources on gout.²³ Counties Manukau District Health Board has an At Risk Individuals programme, a connected care programme that uses electronic health records shared across community and hospital settings, where nurses are part of multi-disciplinary teams with an ongoing co-ordination role that is patient and whanau centred rather than focused on episodic reactive care. This would be suited to patients with poorly managed gout (R. Hulme, personal communication). Nurses in this study recognised the potential for their role development in the primary care management of gout that was currently limited.

Strengths and limitations

To our knowledge, this is the first qualitative study of the experience of treating gout among clinicians. It is likely that bias of perspective and interpretation was introduced by the two researchers interpreting the data, and that important issues were not elicited by the interviewer. However, initiatives to improve gout management, both locally in South Auckland and nationally, reflect the themes that emerged.

Validation of the relevance and importance of themes was sought from participants and groups within and beyond the practices involved, including the members of the Māori Gout Action Group. Data were analysed in depth. Themes were generated from the data and attempts to validate findings were made throughout the research both within and beyond participating practices. However, not all participants who were originally interviewed could be involved in the analysis and formation of themes as they had to attend Continuing Medical Education meetings or research meetings about the findings. Further qualitative studies of gout treatment in other areas of NZ could further explore clinicians' experiences.

The present study suggests clinicians tend to treat gout in South Auckland acutely and on demand rather than preventatively. The clinician–patient relationship was felt to be central for good outcomes, engagement and adherence to lifestyle changes and adherence with ULT. We suggest that over-emphasis on dietary change (which is rarely effective) may be a barrier to effective ULT. Practice nurses appear willing to assist with the education and monitoring of patients with gout. This research and other studies have highlighted that there is much to be done to support GPs treating patients with gout, especially in areas where there is a large burden of disease. We found a need for better guidelines around gout management in order to provide clarity and consistency of gout treatment messages, and a need for emphasis on treating to target with ULT rather than expecting patients to change their lifestyles.

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CONFLICT OF INTEREST STATEMENT

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