What factors contribute to uncontrolled gout and hospital admission? A qualitative study of inpatients and their primary care practitioners

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INTRODUCTION

Worldwide prevalence of gout ranges between 0.1% and 10%, with a 0.8% prevalence in Australia in 2014–2015.1 2 Patients with uncontrolled gout have a poorer quality of life, higher risk of depression and functional disability, and higher work absenteeism.3–5 Suboptimal prescribing and treatment monitoring, failure to achieve recommended target serum urate levels, lack of education on lifestyle modifications, and poor medication adherence have all been reported as barriers in studies from around the world.3 6–22

Chronic conditions have the following features: multiple, complex causes; usually of gradual onset; occur across the life cycle; compromises quality of life; persists leading to deterioration of health and loss of independence; and can lead to premature mortality.23 Despite fulfilling these criteria, gout is not named as a chronic condition by the WHO,24 or the Australian Institute of Health and Welfare.25 The natural history and severity of complications qualify gout as a chronic condition requiring similar management to any other chronic illness.

The chronic care model pioneered by Wagner et al provides a framework to improve outcomes in patients with chronic illness. It involves reorganising health systems to be more appropriate to patient needs, providing patient support and education, supporting expert care and having supportive information systems.25 This includes a variety of...
components such as healthcare team building exercises; regular health provider meetings and feedback sessions; maintaining good electronic records or registries which are readily accessible; educating health providers; developing and distributing guidelines or protocols; setting up electronic alerts or reminders to physicians and patients with regard to follow-up visits, scheduled appointments or meetings; educating patients and formulating self-management or care plans; and involving specialists or experts and community clinicians in patient care. This framework has been applied widely in primary care for patients with a variety of chronic illnesses such as chronic obstructive pulmonary disease, diabetes mellitus and cardiovascular disease. This has resulted in improvements in patient-level health outcomes and also improvements in professional-level outcomes such as prescribing of medications and adherence to guidelines.26–28

Despite the availability of effective treatments, patients continue to have flares of gout that cannot be managed in the outpatient setting. Our study focused on hospital inpatients who are likely to have more severe and uncontrolled disease. We conducted a semi-structured interview study in a tertiary Australian hospital to provide deeper insight into why patients ended up admitted to hospital with gout and discover potential targets for better disease control.

**METHODS**

**Patient involvement**

Patients were not invited to comment on the study design and were not consulted to develop patient relevant outcomes or interpret the results. Patients were not invited to contribute to the writing or editing of this document for readability or accuracy.

**Recruitment and data collection**

**Patient**

We recruited inpatients who met the eligibility criteria (box 1) admitted to the Canberra Hospital in the Australian Capital Territory (ACT). The Rheumatology service provided the patient samples based on the eligibility criteria (box 1) where they were either directly involved in managing these patients or were consulted by other specialist departments. We chose convenience sampling to obtain detailed insight into patients who are likely to have the most sub-optimally treated gout in our community. Informed written consent was obtained from all patients.

We conducted face-to-face individual semi-structured interviews based on the protocol from a similar study in primary care29 and covered treatment, impact on daily life, patient understanding, difficulties faced in managing gout and opinions about the current level of gout control (see Appendix 1 of online supplementary appendix 1). The original protocol was kindly provided by the authors of the study which was then modified to fit this study. Hospital records were accessed to determine whether patients were on chronic urate-lowering therapy (ULT) prior to admission.

**Health practitioner**

Written consent was obtained from patients to contact their general practitioner (GP). A semi-structured phone interview was conducted after obtaining verbal consent from the GPs focusing on their diagnostic approach, goals of management, difficulties faced in managing gout, patient risk factors and comorbidities, factors preventing optimal treatment, and medication prescribed (see Appendix 2 of online supplementary appendix 2). Neither patients nor GPs were reimbursed for their participation.

**Data analysis**

All interviews were audio-recorded, de-identified and transcribed verbatim using a professional transcription service. We used thematic analysis to examine the data for common concepts or repeated patterns and then grouped these into categories for discussion.30 DCHK and EAS coded the interviews using an inductive process and discussed the data on three occasions. Once we had completed the inductive coding process, we saw the similarities between our themes and the chronic care model, particularly the different levels of the healthcare system that were influencing patient care. We developed a coding matrix to organise themes into the following influencing factors: patient, health practitioner, patient-health practitioner, health system, community. The themes and concepts were presented to AKDR and KF for comment. The interviews ceased when no new themes...
were generated from further patient interviews and a strong thematic understanding had developed.

**RESULTS**

A total of eleven patients were interviewed. Their characteristics are described in table 1. Only three GPs agreed to be interviewed. Two GPs declined participation as they were no longer the respective patients’ regular GP and the other GPs declined without providing a specific reason.

| Table 1 Characteristics of recruited patients |
|---------------------------------------------|
| Age Years                                    |
| Range                                       |
| 29–90                                       |
| Mean                                        |
| 67                                          |
| Number of patients (% of cohort)             |
| Sex                                         |
| Male                                        |
| 9 (82)                                      |
| Female                                      |
| 2 (18)                                      |
| Primary reason for admission                |
| Acute gout                                  |
| 9 (82)                                      |
| Acute myocardial infarction                 |
| 1 (9)                                       |
| Infected joint prosthesis                   |
| 1 (9)                                       |
| On chronic urate-lowering therapy prior to hospital presentation? |
| Yes                                         |
| 4 (36)                                      |
| No                                          |
| 7 (64)                                      |
| Presence of documented comorbidities (other than chronic gout) |
| Yes                                         |
| 10 (91)                                     |
| No                                          |
| 1 (9)                                       |
| Common documented comorbidities (other than chronic gout) |
| Diabetes mellitus                           |
| 7 (64)                                      |
| Hypertension                                |
| 10 (91)                                     |
| Chronic kidney disease                      |
| 4 (36)                                      |
| Vascular disease (including ischaemic heart disease, peripheral vascular disease and cerebrovascular accident) |
| 5 (45)                                      |
| Hypercholesterolaemia                       |
| 4 (36)                                      |
| Chronic obstructive pulmonary disease        |
| 2 (18)                                      |
| Atrial fibrillation                         |
| 3 (27)                                      |
| Osteoarthritis                              |
| 2 (18)                                      |
| Miscellaneous                               |
| 6 (55)                                      |
| Number of comorbidities Per patient         |
| Range                                       |
| 0–8                                         |
| Mean                                        |
| 4                                           |

Severe pain and functional disability

**Patient factors**

Most patients reported significant pain and disability due to gout, with some patients forced to use mobility aids to move between places.

Well, basically it’s quite painful. It limits you for what you could do, especially within my foot. I couldn’t weight bear, so I had to have a set of crutches (PT3)

For some patients, the severe nature of an acute gout attack has led to fear, anxiety and anticipation, of having another excruciating attack.

And you know it’s like living in a little box that you’re just waiting when is the hurricane coming (PT6)

The same patient (PT6) also felt that the hospital was the best place for treatment due to the severity of pain. One patient implied that suffering through so much pain had also affected their mental health.

I can’t bear going through this again. My mental state’s pretty good considering I’ve been in so much pain (PT7)

Gout not considered important and stigmatisation of gout

**Community factors**

Most patients reported that people have said that gout was due to consuming too much alcohol or ‘rich’ food and having a ‘rich’ lifestyle.

There’s widespread, well widespread belief that it’s alcohol related, and it’s certainly not, or it doesn’t have to be (PT1)

A couple of times when I have had a gout attack people have said, “Oh, you’ve been living the good life, too much alcohol (PT3)

These beliefs mostly originated from the general community.

**Patient factors**

Patients’ own perception of the disease itself also reinforced these beliefs. In one case, the patient thought that gout only occurred in old people.

When I first went to the doctors they said, “Oh, you’ve got gout,” just by the way I was walking. And I said, “Can’t be. Gout’s only for old people (PT3)

Another patient was in disbelief that despite avoiding ‘rich’ foods and having minimal alcohol intake, he was still having recurrent gout attacks.

Our food intake is very simple. It’s not rich food in any way and not prepared in a rich manner. My alcohol intake would not keep a micro-brewer alive (PT4)

Some patients felt that gout was an unimportant disease compared with other health issues.
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It was just one of those minor health problems (PT1).
It’s not a life and death disease, or illness, or whatever it is (PT3).

For one patient, having gout as an additional disease was not too concerning as he already had a collection of many other health issues.

I’ve got so many other things going on (health issues) …at the moment it, what’s one more little (gout), yeah, nothing to worry about (PT11)

The GP for PT11 reported that a diagnosis of gout was a relief and had less immediate, severe outcomes for the patient.

Main concern was that he (patient) was going to lose a toe basically, rather than it being gout, so he’s actually if anything relieved that it was gout as a diagnosis (GP1)

Health practitioner factors

The source of stigmatisation also appears to originate from health practitioners including hospital practitioners and GPs.

He (senior doctor) said “What gives gout?”. The young fella (junior doctor) said “Oh, too much rich living, too much rich food (PT2)

I’m only young, I’m not that old and that’s what the surgeon said, at your age you shouldn’t have this disease (PT7)

One of the GPs assumed that the patient was consuming large amounts of alcohol in the context of recurrent acute gout attacks.

I’m sure she (patient) must be taking a lot of alcohol too: I’ve never asked her that (GP3)

Poor continuity of care and lack of confidence in general practitioners

Patient-health practitioner factors

Some patients did not see a regular GP for their healthcare.

Not really (seeing a regular GP). I mean I’ve seen a few doctors. Like if I have a gout attack, I’ll generally go back and see that doctor during that attack type thing (PT3)

Two GPs who declined to be interviewed reported that they were no longer the patients’ regular GP, suggesting a loss of continuity of care. For one other GP, his patient was reported as being a frequent interstate traveller and consulting different GPs for various health issues which has caused a significant lack of continuity of care.

Patient factors

In one case, the patient frequently presented to the hospital for an acute gout flare instead of their GP. This seemed to be due to low confidence in their GP’s ability to manage acute gout.

GP doesn’t really know because I don’t run to him all the time because he cannot do much like when you come to the hospital (PT6)

From some of the patients’ perspectives, there was doubt as to whether their GP had the ability to manage gout.

I don’t know how much knowledge he (GP) had about gout because he knew of my uric acid levels and never prescribed anything for it so I’m not sure if he didn’t have an understanding or he knew and just thought oh I can’t put you on the medication because once you’re on the medication you’re on it for life (PT7)

One patient bypassed their GP during recurrent acute gout attacks and would present to hospital instead as she felt that hospitals can provide better treatment. The same patient was also having her gout cared for by another doctor, presumably a specialist, rather than their own regular GP.

I don’t call my GP or anything because he cannot help me, I need to come to the hospital (PT6)

Suboptimal management

Health practitioner factors

Delayed administration of chronic ULT and inappropriate prescribing were apparent. Six of the recruited patients, prior to the current admission to hospital, were only on acute therapy (paracetamol, colchicine and non-steroidal anti-inflammatory drugs) for recurrent acute gout attacks. One patient reported taking colchicine daily, using this drug as a form of ‘chronic’ therapy. In another case, the patient stated that their GP initially repeatedly prescribed steroids for acute gout attacks prior to being commenced on chronic ULT much later.

At first I don’t think it was gout because I didn’t know at that stage but unfortunately my GP knew from my blood test that he’d done but didn’t prescribe any medication. So to treat it at the time I would just take painkillers (PT7)

If the joint was too swollen, I’d go and see the doctor who would say oh it’s muscular and he might prescribe some steroids (PT7)

There was a great variation in patients’ reports of being given information on the risks of taking anti-gout medications, lifestyle and dietary advice, or written information on gout. Most patients did not remember having received information from their GPs, and even if they did, they felt that the advice provided was inadequate. Some patients received information from pharmacists or by referring to the medication information sheets that were packaged with their prescriptions.
In one case, the patient reported that she had also never received any written information from the hospital medical practitioners.

Ever since I came here (hospital) I never heard any doctor tell me what food is not good for me or, but print out some paper from the computer to tell me what’s not good for gout so I can follow that up (PT6)

As far as all the patients were aware, uric acid levels were also infrequently checked, usually once, and at most twice a year by their GPs.

Health system factors
For one patient, living in a non-urban area was reported as a barrier to having uric acid levels checked due to lack of pathology services.

Cause I live in Yass (a town in New South Wales), we don’t actually have any way to do blood work there, it would be something that she (GP) has to ask me to come back to Canberra to get that done (PT9)

Poor understanding and misconceptions of gout
Patient factors
Most patients appreciated the fact that gout was due to an increase in uric acid of some description.

“I’ve tried to cut down on all my acidic acid foods and not just that just anything contributing. Unfortunately I believe that living in Canberra is the main contributor, is probably 70 percent of the contributing factor” …“I think it could be like, yeah due to the climate because Canberra’s very cold and I have, maybe and also it could be the build-up of more acidic acid in my body of late” (PT9)

Some patients believed that gout was caused by uric acid accumulating in an injured area (both previous and current), by some form of opening or cavity that allowed escape of uric acid into the joint, acidic foods, weather changes and ageing.

Some patients suggested that gout was caused by an inability to metabolise/excrete uric acid in the liver/kidneys. Beyond that, most patients could not confidently explain how gout occurs or how a flare is triggered and held misconceptions of the disease.

My understanding of what gout is it’s pretty much crystallisation in the joint going across, so just how it gets inflamed from there. I understand it’s from the uric acid level in my body, from my liver not being able to pass it through enough to actually go through my urine to, it’s just getting built up inside of me (PT9)

Patients also had various levels of understanding and knowledge of prescribed treatment. For example, some believed that colchicine was building up resistance to ‘acids’ in the body or breaking down uric acid. However, some patients did not know anything at all about how treatment works. In one case, the patient analogised colchicine to ‘magic’ tablets. Patients were not too concerned about how prescribed medication(s) worked if they improved them symptomatically.

Well pretty much all I know is from how the tablets work, I’m not 100 percent sure, and it almost feels like they’re just magic tablets (PT9)

Treatment, I wouldn’t have a clue (PT10)

Many patients had poor knowledge of the side effects of both acute and chronic ULT, with most stating that there was an effect on the liver or kidneys but being unable to elaborate in much further detail. Some patients had experienced side effects from treatment, one of them presumably from the lack of prophylaxis when being commenced on allopurinol which cause acute flares. They were unaware whether these were expected side effects of treatment. A few patients had misconceptions that using non-pharmacological methods such as drinking a plentiful amount of water, applying high-pressure water jets (on affected areas), avoiding running or wearing inappropriate footwear can assist with recovery of an acute gout attack.

Health practitioner factors
For one GP, atypical symptomology in a patient with multimorbidity and complex health issues presented a challenge in making a diagnosis of gout. The diagnosis of gout was first made in a tertiary setting after multiple presentations of acute gout attacks.

The main challenge was differentiating it between, gout and osteomyelitis, given his history, so, um, the, um yeah, I guess the way it presented was a little atypical, in there was no pain there, there was just redness and swelling of the metatarsal-phalangeal joint, so I guess diagnostically it was atypical, and the primary concern for him was, more an osteomyelitis kind of event, rather than the gout, so they were the main challenges (GP1)

From the patients’ perspective, health practitioners also seemed to have an inaccurate understanding of the causes of gout, such as (mental) stress and physical injury, and the presentation of gout, specifically the joints it may affect. One patient reported that his GP was more concerned about the development of kidney stones from gout rather than the effect on joints, suggesting a misprioritisation of the disease’s symptomatology.

He said (senior doctor) “Yeah, but one of the biggest things is stress. Stress will give you gout quicker than anything (PT2)
They (GPs) said basically it comes back from a previous injury (PT3)

Another GP held the presumption that gout was not common in females and so failed to recognise the disease early, resulting in delayed treatment. In this scenario, gout was also first diagnosed in a tertiary setting.

We never diagnosed gout before because we didn’t think of gout as what could be the cause of the symptoms, being a lady, it’s not very common in ladies so you don’t think about it (GP3)

For one GP, the patient was said to be misdiagnosed with cellulitis instead of an acute gout attack in hospital, leading to inappropriate treatment and hence delayed diagnosis. Another GP held the perception that patient behaviour change happens when you give education and advice, which unfortunately does not hold true in theory or practice.

Community factors
More than half of patients had gained their understanding and knowledge of the disease from alternative sources of information such as the general community, printed or digital articles, and relatives, rather than their GPs or other medical professionals.

Widespread in the community. People believe there is a specific trigger for their gout. Their gout is from oranges, or their gout is from bananas, and so it goes on (PT1)

DISCUSSION
This study of hospital inpatients revealed patients’ experience of shame and how they regarded gout as being not particularly important, despite the significant pain and disability that accompanied acute flares. These findings were associated with poor continuity of care, lack of patient confidence in their GPs, suboptimal management in both community and hospital settings, poor understanding and disease misconceptions held by both patients and physicians.

Noteworthy in our study was that two GPs who declined an interview reported that they were no longer the respective recruited patients’ regular primary physician. In addition, several patients were seeing different GPs to manage their gout, and one appeared to be dependent on hospital-based treatment for managing acute gout flares. This is concerning as continuity of care for patients is associated with fewer hospital admissions in patients with chronic conditions such as asthma. Continuity of care builds better interpersonal relationships between patients and GPs, enabling a better understanding of patient needs, greater adherence to treatment and more appropriate care. If patients with gout were treated in line with best care for chronic conditions, it is possible that hospital admissions could be prevented, and disease activity could be better controlled and followed-up.

Our study focused on admitted patients with gout—a potentially preventable admission—and how we might improve care in the community. It could be considered that these patients represent the ‘tip of the iceberg’ and are the most complex and difficult to treat. We do not intend to imply that gout is poorly managed throughout primary care, and in most cases of gout, they are managed well in the community. However, our attention to these complex patients reveals learnings that can be applied more generally to gout management and most importantly that the condition should be taught and thought of as a chronic disease instead of an acute condition.

Gout has long been misperceived as a disease caused by self-destructive habits and lifestyles. In our study, sources of stigmatisation predominantly came from the community, but some patients reported health professionals contributing to the stigma. Widespread propagation of these misconstrued beliefs further reinforces patient denial of the disease and avoidance of seeking treatment. This has been shown in other qualitative studies where patient misconceptions and knowledge of stereotypes associated with gout such as consuming too much alcohol and certain foods, and the fact of being labelled with a chronic disease hindered enthusiasm towards taking chronic ULT. Patients avoid treatment and trivialise their condition when they perceive that health providers consider gout to be self-inflicted. Our study confirms that shame, guilt and embarrassment are affecting the way patients with gout seek and adhere to treatment.

The misunderstandings of the pathophysiology of gout have led to the disease being ignored as a chronic condition requiring long-term management. It is not viewed seriously as a form of inflammatory arthritis. Consequently, gout is considered a minor health condition and is being inappropriately treated as only an acute episodic condition rather than one requiring chronic ongoing treatment. These themes were also shown in our study when patients considered gout to be unremarkable compared with their other health conditions.

Previous literature has shown that suboptimal treatment by health providers both in primary and tertiary settings can be due to insufficient training, education and knowledge to provide adequate care; paucity of time spent to properly educate patients about the disease; and lack of appropriate follow-up. In our study, patients felt that there was lack of appropriate advice about lifestyle changes and explanation of side effects of medications, leading to doubts about the ability of their health providers in managing gout, with one patient repeatedly presenting to hospital instead of seeking treatment from her GP. However, this could also reflect the difficulties faced by primary care health practitioners in managing gout in complex multimorbid patients, such as a majority of those seen in our study, rather than primary care mismanagement or failure. It may be that hospitalisation
with appropriate specialist services may be an optimal setting to manage such patients.

Gout is a chronic condition that can be managed successfully with the appropriate pharmacological and supportive care. There are currently effective treatments available that precludes need for in-hospital management.37–41 Our study focused on inpatients with gout as they represent a disconnect between the health system and care of patients with a chronic condition. The severe pain associated with an acute gout flare was a consistent part of our data and it was unsurprising that this was the most prominent feature from the patients’ and health practitioners’ perspective. The chronic care model25–28 42 has been used to develop and implement successful management strategies for patients living with other chronic conditions. The model provides a systematic approach to improve the care of complex multimorbid patients. We envisage that the management of gout, especially for complex patients, would be greatly improved if a similar framework was applied rather than an overemphasis on acute flares.

More recently, a chronic care management programme in New Zealand targeting patients from high-needs socio-economic backgrounds with gout showed better patient outcomes compared with the national average.43 The programme involved a collaborative effort between community pharmacists, GPs, specialist physicians, nurse practitioners and gout educators, with roles including prescribing and dispensing medications; maintaining regular contact with patients; advising patients to have blood tests and then monitoring the results on a shared information system; providing patient support and improving health literacy; and acting as a liaison between patients and healthcare teams. The programme demonstrated a framework which is characteristic of the chronic care model where an empowered patient with inter-provider collaboration and support improved patient outcomes.

The chronic care model25–28 42 highlights the need for an activated patient who is involved in the management of their own health conditions, health practitioners that are prepared and appropriately responsive, and a health system that supports continuity of care in both community and hospital settings. Our study demonstrates multiple areas of breakdown in the health system—patient relationship due to patient distrust of the health system and stigmatisation, lack of continuity of care, and poor understanding and misconceptions of gout. By shifting the focus of gout management into the domain of chronic care, it becomes clear that there are multiple levels within the health system that needs improvement to ensure patients with gout receive quality care.

This study provides a critical new approach to optimising management of gout in the community. The next step would be to examine how gout management is currently implemented in order to identify key areas for improvement and align it with a chronic care framework.25–28 42 This may include patient self-management support and behavioural change programme, addressing community-level stigma, shifting the focus of health practitioner training of gout as an acute disease to a chronic condition and improving the health system to promote continuity of care. These strategies should be implemented in partnership with patients and health practitioners across the healthcare continuum to ensure that a chronic care approach to gout is feasible and acceptable to all involved.44

Strengths and limitations
This study has several important strengths. A semi-structured interview approach offered the advantage of pursuing more detailed interrogation and clarification of noteworthy comments from participants that emerged during lines of questioning. As this study focused on patients with gout in an inpatient setting, it has provided us with different patient perspectives on the status and management of their gout and deeper insight into why they needed to have inpatient treatment specifically instead of just being managed as outpatients. Interviewing both the patients and their respective GPs’, at least for those who fully participated and those that provided reasons for not participating, permitted further comprehension of the factors leading to uncontrolled gout. Finally, our use of the chronic care model theory to explain our findings and make recommendations for improving care was a strength of the study.

In terms of limitations, there could have been a potential mismatch of illness perceptions between patients and their respective GPs and we were limited by our inability to recruit all the GPs. Because this was an interview-based study, it is possible that participants may be subjected to recall bias about medical management received or provided which may lead to incorrect assumptions about the reasons for uncontrolled gout. Some patients were admitted primarily for reason(s) other than gout and there may have been differences in these patients’ experience of gout that were not uncovered. As this study was performed in a tertiary care setting, there could be other factors related to gout management in the primary care or community setting that we were unable to identify and make conclusions on.

Conclusion
In conclusion, patients’ lack of continuity of care with their GPs, the stigma, and perceiving gout as insignificant in their overall health have produced a complex effect which has led to a cycle of treatment avoidance behaviours and recurrent hospitalisations for severe acute gout flares. This situation is further exacerbated by suboptimal management from health practitioners, lack of patient confidence in their GPs and significant deficits in knowledge and understanding of gout in both patients and health practitioners. To address these barriers, we need a multipronged approach that could be well-informed by the chronic care model to prevent complications and improve health outcomes in patients with chronic gout.
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