

# Barriers to Care in Gout: From Prescriber to Patient

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**ABSTRACT. Objective.** To explore the understanding of gout and its management by patients and general practitioners (GP), and to identify barriers to optimal gout care.

**Methods.** Semistructured interviews were conducted with 15 GP and 22 patients in Sydney, Australia. Discussions were focused on medication adherence, experiences with gout, and education and perceptions around interventions for gout. Interviews were audio recorded, transcribed verbatim, and analyzed for themes using an analytical framework.

**Results.** Adherence to urate-lowering medications was identified as problematic by GP, but less so by patients with gout. However, patients had little appreciation of the risk of acute attacks related to variable adherence. Patients felt stigmatized that their gout diagnosis was predominantly related to perceptions that alcohol and dietary excess were causal. Patients felt they did not have enough education about gout and how to manage it. A manifestation of this was that uric acid concentrations were infrequently measured. GP were concerned that they did not know enough about managing gout and most were not familiar with current guidelines for management. For example and importantly, the strategies for reducing the risk of acute attacks when commencing urate-lowering therapy (ULT) were not well appreciated by GP or patients.

**Conclusion.** Patients and GP wished to know more about gout and its management. Greater success in establishing and maintaining ULT will require further and better education to substantially benefit patients. Also, given the prevalence, and personal and societal significance of gout, innovative approaches to transforming the management of this eminently treatable disease are needed. (First Release November 15 2015; J Rheumatol 2016;43:144–9; doi:10.3899/jrheum.150607)

*Key Indexing Terms:*

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Gout is a painful, inflammatory arthritis caused by excessive uric acid (UA) in the joints<sup>1</sup>. Its incidence and prevalence is increasing, attributed to a Western lifestyle and longevity<sup>2,3,4</sup>. Despite the availability of effective medications, studies reveal poor success with few people achieving sustained remission of their gout<sup>3</sup>. As in most countries, in Australia the majority of patients with gout are treated by their general practitioner (GP). International research has identified barriers to individuals achieving optimal control of their gout, but there has been limited qualitative research to provide deeper understanding of these factors.

Management guidelines are available<sup>5,6,7,8</sup>, but few practitioners are familiar with their existence<sup>9,10</sup>. However, some studies have shown that practitioners express high levels of confidence in managing gout<sup>11</sup>. Over one-quarter of patients with gout report 4 or more comorbidities, making management of their gout more complex<sup>12</sup>. A substantial proportion of patients delay seeking treatment, and low rates of medication adherence for gout have been identified<sup>13</sup>. These behaviors could be related to perceptions of stigma and shame identified by patients in the United Kingdom<sup>9</sup> and New Zealand<sup>14</sup> associated with a diagnosis of gout.

Globally, it is apparent that inadequate numbers of patients

receive appropriate and timely care for their gout. This problem requires more than simply educating patients and GP, although this approach is important and can improve outcomes<sup>15</sup>. Understanding the reasons for the failure to achieve effective, longterm control of this debilitating condition is needed to prevent not only tophi, bone erosions, and permanent disability<sup>16</sup>, but also pain, disruption of quality of life, and economic disadvantage<sup>3,17</sup>. We undertook this study to better understand the barriers to effective gout management. Through semistructured interviews with a sample of Sydney-based GP and patients with gout, we (1) investigated the understanding and management of gout by patients and prescribers, and (2) explored the barriers to optimal management of gout in this primary care setting.

## MATERIALS AND METHODS

**Recruitment.** Using a snowball recruitment strategy, GP known to the research team were invited to participate. Each GP interviewed was asked to identify 1–3 patients with gout and invite them to participate. Additional patients were contacted by a member of the research team (RD, rheumatologist). Demographic information (age, sex, cultural background, height, weight, and comorbidities) was also collected from each patient prior to the interview.

**Interviews.** Consenting GP and patients were interviewed by 1 researcher (SV) either in person or by telephone. Interviews were focused on exploring participants' experiences with gout, medications prescribed, lifestyle interventions, and education received (Table 1), and were designed to evoke discussion. Semistructured interview guides for both patients and prescribers have been provided as supplementary data (available from the authors on request). Participants were reimbursed for their time. Each interview was recorded and transcribed verbatim.

**Analysis.** A process of inductive thematic analysis was used. Each transcript was read independently by 2 reviewers (SV and DK) and separate themes were identified for GP and patient transcripts. After analyzing half of the transcripts, the reviewers met to discuss emergent themes and developed a framework for analysis of the remaining transcripts. Once analysis was complete, the reviewers met again to compare themes. Interviews were stopped when thematic saturation had occurred; that is, when no new themes were identified compared with those in preceding interviews.

*Table 1.* General discussion topics for general practitioners and patients participating in gout interviews.

### General Practitioners

- Obstacles to gout management
- Associations with other diseases/risk factors
- Acute attack management
- Chronic/longterm management
- Allopurinol usage
- Education
- Need for more resources/services/guidelines
- Referrals: rheumatologist, dietitian, etc.

### Patients with Gout

- Management of acute attacks
- Longterm gout management
- Knowledge of gout and medications
- Personal triggers
- Medication risks, adherence, and complementary therapies
- Research undertaken and the need for more education
- Broader effect of gout: work/social life/stigma

**Ethical considerations.** Our study was approved by the University of New South Wales Human Research Ethics Advisory (reference number 2014-7-10) and the University of Western Sydney Human Research Ethics Committee (reference number H10689). All participants supplied written informed consent in accordance with the Declaration of Helsinki.

## RESULTS

### General Practitioners

Interviews were conducted with 15 GP (9 women and 6 men) practicing in Sydney. To promote discussion, each GP was asked to identify barriers to achieving optimal outcomes.

### Understanding and Management of Gout by GP

**Current approach to gout.** For an acute attack of gout, almost all GP stated that nonsteroidal antiinflammatory drugs (NSAID) would be their first-line medication. The majority also reported they would use colchicine, whereas steroids were reserved for more serious cases. One doctor explained, "It's either going to be Colgout [colchicine] or it's going to be an antiinflammatory" (GP #050). Allopurinol was reported to be the first-line urate-lowering therapy (ULT) by all GP. The number or severity of gout attacks was the main factor influencing GP to initiate therapy with allopurinol. For example: "I'd be wanting to put them on [allopurinol] if they're having attacks every month or so" (#056). When asked if they would complement an initial allopurinol prescription with anything else, fewer than half the doctors stated they administered prophylaxis against an acute attack, for example with colchicine, when initiating ULT. Treatment goals for allopurinol were often multifaceted, such as "to have a biochemical low level of uric acid, and to have them without gout" (#035). All GP stated that they gave their patients some verbal education about gout, and about half the doctors reported that they gave their patients written material. However, some doctors suggested that patients were not given enough information. For example, 1 doctor stated, "I should give them handouts probably, so they've got more education" (#041). To further assist patients, most GP said that they were happy to refer complex cases to a rheumatologist, and some doctors recommended that patients see a dietitian.

**Approach to prescribing allopurinol.** Most doctors said that they started patients with 100 mg or less of allopurinol daily, and about half of the GP reported that they up-titrated the dose of allopurinol. Many doctors stated that they had a standardized dosing regimen, which at times depended on other factors, for instance: "Usually I'd start them on 300 [mg], unless they're tiny, tiny little people, then I might start then on 100 [mg]" (#041). All doctors stated that they tested patients' UA concentrations, with the majority also testing renal function. Most doctors were aware of some potential adverse effects of allopurinol, such as "nausea or gastro" (#047).

### Barriers to Care by GP

**Awareness of guidelines.** Fewer than half the GP interviewed were aware of management guidelines for gout. For instance

1 GP stated, “I’m sure they exist... I haven’t actually personally, ah, looked at anything that’s called gout guidelines” (#059). Other GP stated that they used web-based guidelines such as Medscape (emedscape.com/article/329958-overview).

**Knowledge of risk factors.** While most doctors noted that “[there was] always the issue of alcohol and diet” (#044) as risk factors for gout, other risk factors such as genetic associations, renal function, or concomitant use of medications such as diuretics were rarely identified. Most doctors commented on links between gout and other lifestyle-associated disorders, with 1 doctor explaining that patients often had “multiple clinical problems such as diabetes or high cholesterol” (#074).

**Education.** Many GP felt that they did not receive sufficient education on gout management, which led to some GP expressing a lack of confidence in treating patients. One doctor explained, “There’s definitely more that I can learn to make me more confident” (#047). Further, some GP believed that more community awareness of gout was needed. One doctor said, “I don’t think there is any awareness in the community, or significant awareness of gout” (#038). About half of the doctors suggested that more GP resources, such as flow charts, and patient educational material, including “a website” (#056) or “some groovy YouTube video” (#068) could be helpful.

**Patient factors.** Some GP mentioned that patient factors such as comorbidities could complicate gout diagnoses and treatment. The majority of GP noted that low medication adherence was a major barrier to successful treatment: “They’re not always compliant because you have to convince them that this [allopurinol] is prevention” (#059). Several GP stated that cultural and language barriers complicated patient education and resulted in different understandings about gout. For instance: “I’ve got a fair number of Pacific Islanders and Maori folk who consider, you know, gout’s just part of the normal picture of life” (#068). Some GP also felt that there were stereotypes surrounding gout. One doctor explained, “It sort of has this Hogarthian view of, you know, that people, very fat English people drinking port with their legs up” (#071).

### Patients with Gout

In total, 22 patients were interviewed (3 women and 19 men). Ages ranged from 38 to 93 years (median 59 yrs) and the average body mass index was 29.7 kg/m<sup>2</sup> (Table 2). Their understanding of, and approach to, managing gout was explored.

### Understanding and Management of Gout by Patients

**Short-term management.** Fewer than half of the patients reported using NSAID during an attack, whereas many patients stated that they used colchicine. For example, 1 patient said, “I go and see the doctor and get, ah, Colgout

Table 2. Demographic characteristics of 22 patients with gout.

Characteristic	n (%)*
Age, yrs	
< 40	2 (9.1)
40–49	5 (22.7)
50–59	4 (18.2)
60–69	7 (31.8)
> 70	4 (18.2)
Sex	
Male	19 (86.4)
Female	3 (13.6)
Ethnicity	
Australian European	9 (40.9)
Italian	3 (13.6)
Fijian	2 (9.1)
Other	8 (36.4)
Body mass index, kg/m <sup>2</sup>	
18.5–25, healthy	3 (13.6)
25–30, overweight	12 (54.5)
> 30, obese	7 (31.8)
Patient-reported comorbidities**	
Hypertension	5 (13.2)
Diabetes	3 (7.9)
Renal	5 (13.2)
Respiratory	5 (13.2)
Cardiac	8 (21.1)
Other	12 (31.6)

\* Some percentages may not add up to 100% because of rounding. \*\* A total of 38 comorbidities were reported by patients and this was the denominator used to calculate the percentage comorbidities column.

tablets” (Patient #180). Steroids had been used by some patients, for instance: “He [the GP] tried injecting steroids straight into the joint” (#177). A few patients stated that they had resorted to using opioids to curb their pain, for example: “When I had my really bad attack...I had to take 2 Endone... It was excruciating” (#156).

**Longterm management.** The majority of patients with chronic gout reported that they were taking daily allopurinol, with about half stating that their dosage had been modified over time, including patients altering their own dosages. For example, 1 patient said, “I just made the decision to put myself on 200 mg, which I did, and so far since then it’s been okay” (#186). A small number of patients stated that they were taking longterm colchicine, either as prophylaxis with allopurinol or as a standalone preventative, for instance: “[My rheumatologist] just said to take it [colchicine] for a couple of months” (#174). When directly asked, fewer than half the patients stated that their UA concentrations had been tested in the previous year. One patient commented, “No, I think the only time I ever did that, um, the first time the gout came on heavily” (#180). Several patients explained that they had tried complementary therapies, such as “drinking apple cider vinegar” (#171). About one-quarter of the patients commented that increased hydration was beneficial because it “[helped] flush the system out” (#195).

*Level of care.* All patients stated that they had sought GP advice for gout. About half of the patients had been referred to a rheumatologist, with visit frequency varying widely, from “I’ve only been to the rheumatologist’s once” (#135) to multiple appointments each year. A few patients mentioned that they had accessed other health professionals, such as a dietitian. Complementary practitioners were also consulted, as 1 patient commented, “We went to a naturopath and she made up the herbal medicines” (#144). Some patients explained that they had undergone procedures (3/22) or been hospitalized (4/22) because of their gout, for instance: “They did an operation where they stuck a needle into the joint” (#180).

*Quality of life.* Almost every patient emphasized the negative effect gout had on their lives. The majority of patients stated that gout prevented them from working or affected their social lives. One patient said, “I’d just take a week off work, because I just can’t put a shoe on, let alone work” (#141). In addition, most patients commented on the severity of the pain associated with a gout attack, including 1 patient who stated, “I couldn’t even put the sheet on my toe because it was that painful” (#168).

### **Barriers to Optimal Gout Management in Patients**

*Understanding of gout.* Most patients had a basic knowledge of gout, for instance: “It’s uric acid in the blood” (#144). A few patients were unsure whether or not they actually had gout. One patient stated, “It’s a just constant sort of a pain, it’s as if it was more arthritic than gout-ish” (#138). Just over half of the patients interviewed mentioned personal triggers for acute attacks. For example, 1 patient said, “But the main contributor — and I never deny it — um, to me, would have to be the beer” (#180). Most patients were aware that diet and alcohol intake could increase the risk of a gout attack. Comments such as “you’ve got to stop drinking red wine [and] beer” (#150) were common. Despite this, only a small number of patients cited other associations, such as “it’s an old man’s disease” (#159) or “it was a hereditary issue” (#186).

*Understanding of gout management.* Overall, knowledge of gout medications was poor. Fewer than half of the patients taking allopurinol were aware of its mechanism of action. Very few patients understood the function of colchicine, despite its common usage. Fewer than half of the patients interviewed could identify the earliest manifestations of an acute attack, limiting the opportunity for prevention, for example with colchicine. One patient explained, “I think I was probably unaware and doing other things, and suddenly it was painful in the joint” (#147).

*Medication-related barriers.* About one-third of patients reported that they had experienced adverse effects from gout medications, ranging from “nausea and...drowsiness” (#132) to a severe allergic reaction (to febuxostat) requiring hospitalization. No patients were aware of allopurinol hypersensi-

tivity syndrome. Some patients explained that they had experienced medication problems because of comorbidities or drug interactions, for instance: “Because of the heart pills, I can’t take antiinflammatories” (#168). The majority of patients reported that they took their medication regularly, out of habit. For example, 1 patient “made it part of [their] morning routine” (#174). However, a few patients said they only took medication as required, and some appeared to have a negative attitude toward taking medications in general. One patient commented, “It was against all of my personal philosophies to spend the rest of my life taking a pill” (#171). A few patients said that they had run out of medication and were not able to obtain replacements, such as “[they] just couldn’t afford it” (#162). Several patients said they wished they had been more aware of medication options, for instance: “It probably would have been nice to have been told about it [allopurinol] a bit earlier” (#174).

*Stigma.* More than half of the patients interviewed felt that there was stigma surrounding gout, particularly regarding alcohol consumption. For instance, 1 patient said, “Everyone just says, ‘Oh, you’re a pisspot!’ That’s, that’s the way it’s equated in the community” (#177). Another patient explained, “I don’t tell anyone outside the family... I am really conscious of the negative, ah, comments about gout. And all the jokes that people make about gout” (#192).

*Education about gout and its management.* Fewer than half of the patients recalled receiving written or verbal information about gout from their GP. Examples of educational material received included “brochures” (#144), “a card about gout” (#195), and “[the GP] told [them] what not to drink, or not to eat” (#162). The majority of patients explained that they had researched gout themselves, including reading their medication product information, purchasing books, and browsing the Internet. A common response was: “When they said I had it [gout], I went and Googled it” (#189). Many patients expressed an interest in learning more about gout or having more informative resources, for instance: “If there’s some reading to do or, I’d like to read it, yeah” (#138). Often, patients had particular questions they wanted answered, such as: “I wonder what, ah, what triggers it in some people and not in others” (#147).

### **DISCUSSION**

This is the first qualitative study investigating the understanding and management of gout by patients and GP undertaken in Australia. Our work adds to qualitative investigations in the United Kingdom<sup>9</sup> and New Zealand<sup>14</sup> regarding perceived barriers to better outcomes in patients with gout. Our study confirms that more and improved education about gout and its treatment is needed because a lack of education was identified as a barrier to care by both patients and GP. It is known that education can alter knowledge and behavior<sup>18</sup>, and it is also evident that attitudes must change if progress is to be made.

We found that few GP or patients appreciated the risk for acute attacks with commencement of ULT. Contrary to guidelines<sup>6,7</sup>, most GP did not volunteer that they would administer prophylactic medication against an acute attack, a comment that was reinforced by patients both in our study and internationally<sup>3,19</sup>. An acute gout attack following the commencement of allopurinol can lead to patient disengagement from treatment, so care must be taken to prevent, or at least explain, this phenomenon.

UA concentrations were perceived to be monitored irregularly. Half the patients (11/22) stated that they had not had their UA concentration tested in the past year. This is congruent with a British study which found that only 34% of patients taking allopurinol had had their UA concentrations tested in the previous year<sup>20</sup>. However, this information conflicts with reports by the GP in our study, who stated that they usually tested UA concentrations. It may be that there is a lack of understanding by patients about what was being tested or why. Regular UA monitoring is indicated, especially early in ULT, to allow appropriate titration of allopurinol dosing to ensure an optimal dose for each patient. Studies from Europe<sup>21</sup> and New Zealand<sup>22</sup> have reported that most patients with gout need higher-than-prescribed doses of allopurinol, hence it is evident that education about the importance of monitoring UA concentrations for patients and GP is essential.

Likewise, there were conflicting responses about prescribed allopurinol dosages. While most GP interviewed stated that they started patients on a dose of allopurinol  $\leq$  100 mg/day, in accordance with guidelines<sup>6,7,8</sup>, this does not agree with the literature, which shows much higher dosages of allopurinol are prescribed — commonly 300 mg/day in the Australian context<sup>23</sup>. To enhance the effect of further GP education, a focus on creating awareness about current guidelines on dosing and monitoring requirements for allopurinol is needed.

GP were aware that they lacked sufficient training on gout, and many GP noted a lack of information about gout in the general practice literature. Patients also felt that they needed more information, and their overall understanding of gout and their medications was inadequate. This lack of knowledge about gout is likely to have contributed to the stigma patients felt about their diagnosis, especially the connotations regarding alcohol and dietary excess, perceptions at times perpetuated by GP, friends, and family. Stigma was a major barrier to care for some patients and provision of simple, informative educational resources for patients, doctors, and the community is a key strategy likely to improve gout management.

There were some limitations of our study. Not all patients interviewed were treated by the GP in the study cohort. There may have been a selection bias toward participants who were interested in procuring information about gout. Our study was conducted in Sydney, Australia, with participants recruited

across a range of urban settings, but did not include rural or remote settings. However, the results are congruent with data from studies in the United Kingdom<sup>9</sup>, New Zealand<sup>14,24</sup>, and the United States<sup>10,25</sup>, suggesting a wider generalizability. Future studies should evaluate the effectiveness of increased and better education for patients, GP, and the community on gout and its management, and particularly the effects on medication adherence, monitoring UA concentrations, knowledge of risk factors, and community perceptions of gout. It is a reasonable hypothesis that better understanding will lead to improved outcomes for patients with gout, and the effectiveness of future educational interventions will need to be evaluated.

Our study explored GP and patient perceptions and attitudes to gout and its management. Our findings identified that false perceptions about gout and its treatment, and behaviors of both patients and GP, served as barriers to effective management. These factors are recommended as key targets for GP, patient, and community education to substantially improve the management of this prevalent and troublesome condition.

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