

# “Gout was like the boss”. A qualitative study exploring the impact of gout on employment.

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## Introduction

People with gout report that the disease influences many dimensions of their daily functioning, including mobility, work, social relationships, and engagement in recreation and leisure activities. When asked to identify and rank areas of life affected, patients reported four aspects to be the most important: pain, loss of joint motion, work loss, and joint inflammation.

The impact of disease on employment has been studied in other types of inflammatory arthritis. Some people with gout experience shame, embarrassment, and social stigma due to cultural narratives that gout is a self-inflicted disease of dietary excess. These characteristics may cause people with gout to have unique experiences and challenges within the workplace.

## Methods

All participants had gout and at least one flare during their employment. Semi-structured interviews were conducted by a rheumatologist and a general practitioner.

Purposive sampling was used to ensure a broad and diverse representation of demographic (age, ethnicity, gender), work (sedentary and physical jobs, self-employed or working for another), and gout characteristics (disease duration, presence of tophi andflare frequency). During the interview, participants were asked to share their experience with gout and its impact on employment. An interview schedule containing open-ended questions and probes was used.

Demographic information, work, and clinical data were reported by participants before the interview. Each interview was audio recorded, transcribed verbatim, and anonymized to ensure confidentiality.

Data collection and analysis occurred simultaneously, and initial data informed successive sampling as themes were generated. Interviews continued until no new themes were generated from the data and purposive sampling was completed. Data was analyzed using a reflexive thematic approach. Transcripts from the interviews were read and re-read to immerse the researchers in the data. The themes identified from the transcripts were initially coded and categorized by a single researcher using NVivo software, version 14 (QSR International Property). Initial codes and concepts were reviewed by two further researchers, and final codes were grouped into potential themes and subthemes. The researchers met regularly to discuss the data throughout the analysis stage, and the final themes were defined, named, and agreed upon by all authors.

Table 1. Demographic, clinic and employment characteristics of the participants.

Participant	Sex	Age (years)	Gout duration (years)	Tophi	Work Roles	Time off wor due to gout i the last year
1	M	62	41	Yes	Wharf worker/Hospitality /Retail	No
2	M	41	8	No	Manager	No
3	M	56	12	No	Architect	No
4	M	54	2	No	Computer programmer	No
5	M	74	14	Yes	Factory maintenance	Retired
6	M	57	3	Yes	Chemist engineer	No
7	M	48	8	No	University teacher	No
8	M	53	9	No	Storeman	Yes
9	M	60	30	Yes	Government officer	Yes
10	M	59	12	No	Engineer/Hospitality	Yes
11	M	49	9	No	Engineer	No
12	M	36	1	No	Project supervisor	Yes
13	F	36	18	Yes	Senior Administrator	Yes
14	F	33	10	No	Service Consultant	Yes
15	M	29	13	Yes	Storeman/Psychologist	Yes
16	M	42	8	No	Teacher	No
17	M	66	37	No	Factory worker/Commercial	Retired
18	M	67	7	No	Teacher	Retired

Figure 1: Thematic map describing the main themes and their relationship with work experiences for people with gout.

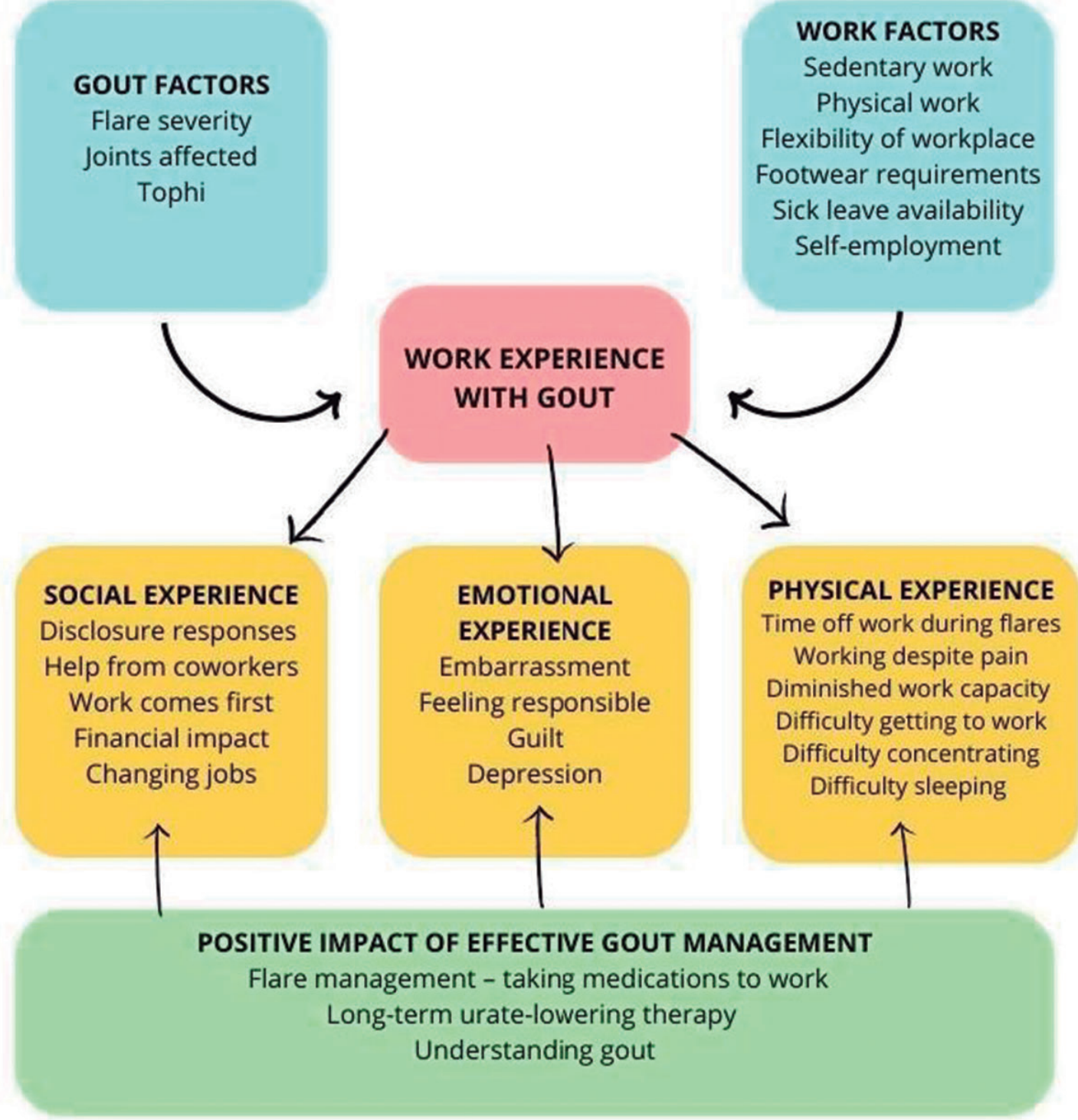


Table 3. Work factors influencing the experience of working with gout.

WORK FACTORS	Quotes
Physical work	"... a lot of jobs required physical labour...so those jobs they would be affected by gout. If I had gout, I wouldn't, I wouldn't be able to turn up." (12)
Footwear requirements	"Well, the worst thing was, because I normally wear jandals, so gout was alright. But when I had to go to work, I had to put on the big boots and that was the hardest thing to get your foot into a boot." (5)
Sedentary work	"Because it's office work, there is not a high demand for walking. But if it required walking, you know, there was no way in hell with the flare, even with all of the flares, pretty much, you were near bed-bound." (11)
Flexibility of workplace	"I work in the office, so I don't need to be out or physically active. But when I do see clients, I would revert to virtual calls if I couldn't get out." (2)
Sick leave availability	"When I run out of sick leave and if I don't go to work, I don't get paid." (8)
Self-employment	"I might have had the odd day off if I was in paid employment, but because you are self-employed you know you are not going to get paid, so you just carry on." (3)

Table 4. Physical, emotional and social experiences of employment for people with gout.

PHYSICA EXPERIENCES	Quotes
Time off work during gout flares	"If we looked at it as an annual average, I would say approximately on month a year, during this time I was affected by gout disrupting my employment." (9)
Working despite pain	"You just went with your pain and did what you could." (15) "I have to plan my day, I have to manage my day around my pain." (2)
Diminished work capacity	"... I still had pain so during the day you weren't really giving 100%. You were pretty much just attending, trying to do your best and probably running at about 60%." (11)
Difficulty getting to work	"... it became difficult if I had to walk a long way. Like if I was having a bad gout attack, it became very difficult to walk from the car park to my desk at work." (4)
Difficulty concentrating	"And then when I'm sitting at my desk at work, it becomes very difficult to concentrate on my work because I've got such a sore foot basically." (4)
Difficulty sleeping due to pain	"To be honest, I probably should not have gone to work. Not 100% because I'm not resting... So when I go to work, still tired, still have a little pain, and I just couldn't do my job properly." (8)

Table 2. Gout factors influencing the experience of work.

GOUT FACTORS	Quotes
Pain intensity at the time of gout flares	"If it wasn't above 6 or 7 I could actually do most of the work I needed to do, just by the compartmentalising the pain, but in the first flare when it was up at 9 or 10, there was no way you could actually remove the pain from about it to do your day-to-day work." (11) "Gout dictated a lot of that. Gout was like the boss. He says: you have gout, if it is a little gout, you go to work. If it's a big gout, well, you can't, even no matter how bad you want to go, you sometimes can't." (9)
Tophi	"And then tophi appeared. And my hands were like claws..., so I started struggling, climbing, climbing the ladder, because my hands were like claws..." (1)
Joints affected	"Put it this way. Some days you could work with gout. Some days, you can't. You know if I have gout in my elbow. For instance, I can still use my fingers. So, depending where I had the gout was depending on what I could actually do. Like if it is affecting my knee, you can't walk around." (1)

## Results

Eighteen participants were interviewed. Participants were between 29 and 74 years (mean age 53 years) and were mostly male (89%). Twelve interviews were in person and six remotely. There was diversity across age, gender, ethnicity, BMI, employment characteristics, and clinical features of gout (Table 1).

Six main themes were identified from the interviews. A thematic map describing the themes and their relationships is shown in Figure 1. Gout factors: Pain intensity, presence of tophi, and the joints affected by the flare were gout factors that influenced the experience of work. Illustrative quotes are shown in Table 2. Participants reported that severe flares made work virtually impossible, whereas mild flares were considered to be inconvenient. The location of the joint affected by a gout flare also determined limitation in work. Work factors. Physical requirements of the work, flexibility of the workplace and sick leave availability were key work factors. Illustrative quotes are shown in Table 3. The physical requirements (such as walking, lifting, or climbing) impacted employment experiences; having a sedentary job was different from a physical one.

Flexibility in the workplace also determined whether employees with gout could work. The possibility of working remotely reduced the impact of gout on their job.

Physical experiences: Participants reported a variety of experiences with how gout had a physical impact on their employment (Table 4) This ranged from the complete inability to work to working despite pain. Gout flares also caused difficulty getting to the workplace. Pain affected the ability to concentrate at work. If the flare was intense, participants simply could not concentrate and only focused on the pain.

Emotional experiences: emotional responses included feeling responsible, embarrassed, guilty, or depressed (Table 4). Feeling responsible for missing work, being less efficient, or needing help were common. Some participants (particularly women and younger participants) felt embarrassed and tried to hide their disease.

Participants also described feeling guilty. Participants who considered the disease self-inflicted blamed themselves for causing their flares and not being able to go to work.

Social experiences: social impacts included experiences within the workplace and in other aspects of the person's life outside the workplace. Illustrative quotes are shown in Table 4. Some participants were afraid of disclosing their gout diagnosis in the work environment, to avoid judgmental comments about their age, diet, or lifestyle. However, many experienced empathetic support and help from co-workers. The consequences of gout had a personal financial impact. Some participants had changed their job because of gout or had to look for jobs that were 'gout friendly.'

The positive impact of effective gout management: effective gout management improved experiences with employment. Understanding their disease was important, knowing how to control gout flares with anti-inflammatory medications and the impact of committing to long-term urate-lowering therapy (Table 5).

Table 5. Positive impact of effective gout management.

	Quotes
Flare management – taking medications to work	"When I started with more pain I could work because I very quickly was able to control the pain with colchicine, so It didn't stop me." (18) "... it caused discomfort which required me to change my work pattern, but it didn't stop me working and I would deal the occasional flares by taking anti-inflammatories or some painkiller." (6)
Long-term urate-lowering therapy	"... being on regular medication now, I don't have as many flares. Work is a little bit easier now because I'm feeling a little bit healthier." (1)
Understanding gout	"So that was kind of the uneducated version of taking drugs for the sake of pain killing, but not understanding the root problem of gout...that pain and discomfort that I had from gout was inhibiting. I couldn't do anything. I couldn't physically walk. So, it made me realise that something needed to change. And so that was the main point that made me decide to seek treatment and knowledge on gout." (2)

## Conclusions

Both gout and work characteristics influence the employment experience for people with gout. Effective management of gout led to improved work experiences in all its domains.

