

Pre-implementation Qualitative Interviews of Patient/Carers for an Interdisciplinary Gout Clinic

Sacha Bossina^{1,2}, Kate Faasse³ and Ayano Kelly^{1,4}

¹Department of Rheumatology, Liverpool Hospital, NSW 2170, ²Department of Physiotherapy, Liverpool Hospital, NSW 2170, ³School of Psychology, The University of New South Wales, Sydney, NSW 2000, ⁴South Western Clinical Campus, Faculty of Medicine & Health, University of New South Wales, Sydney, NSW 2000.

Background:

Being the most common form of inflammatory arthritis, Gout is a painful and debilitating condition. Despite the availability of safe, cheap and effective medications that reduce morbidity and mortality, many healthcare providers fail to adequately prescribe these medications and adherence can be as low as 50%. Qualitative research can offer rich narrative data to provide in-depth insight into patients' perspectives of their medications in order to understand how we can improve medication adherence.

Results:

26 people contacted, 10 consented to be interviewed, 6 Males, 4 Females, 6 Themes and 18 Subthemes emerged.

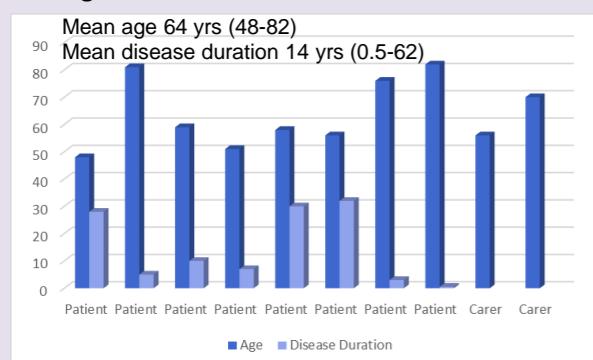


Figure 1. Age and Disease Duration



Asian (1)
European (1)
Indigenous (1)
Samoan (1)
Pacific Islander (1)
Caucasian (4)

Figure 2. Ethnicity

Aim:

We aimed to describe patients' perceptions and experiences of medications to better support adherence to urate-lowering therapies (ULT) in the context of a research study planning the implementation of an interdisciplinary medication adherence program for people with gout.

Methods:

Following a topic guide, we conducted individual semi-structured interviews via phone or video call, with adults with gout or their caregivers in English, recruited purposefully by rheumatologists in an Australian tertiary hospital. Interviews were audiotaped and transcribed verbatim. Using Inductive thematic analysis with investigator triangulation and HyperRESEARCH qualitative software, themes and subthemes were derived until saturation.

Desperate for relief

- Suffering debilitating pain and isolation
- Ready and willing for any treatment
- Avoiding the guilt of dependency

Frustrated with continued Suffering

- Perpetuating cycle of suboptimal care
- Mounting doubts and losing patients
- Constrained by inaccessibility
- Bewildered by the treatment regime

Maintaining a precarious balance

- Avoiding compounding health interactions

Following social expectations & norms

- Culturally honourable to suffer with gout
- Shifting priorities through life

Supported to finally turn the corner

- Security in specialised expertise
- Reassurance from a trusted Health Professional
- Armed with deeper knowledge
- Confidence in consistency and continuity

Self-discovered control and autonomy

- Mastery through self-experimentation
- Gaining the upper hand in a flare
- Taking action with lifestyle changes
- Confidence in established routine

Figure 3. Themes and Subthemes

Theme Patients Quotes

Theme	Patients Quotes
Desperate for relief	<p>"I think having gout is the worst pain ever. I used to curl on my sideI used to be depressed, very sad....I had to take 2-3 weeks off (work)."</p> <p>"Every time a flare came, for me it's like a nightmare. It's terrible, horrible."</p> <p>"Crawling around on your knees with the gout"</p> <p>"As far as I'm concerned, it's one of the worst pains I've ever had. I've had a broken leg, I've had cuts and everything like that and I've never had no pain like that. It's the worst pain you could ever – I wouldn't wish it on my worst enemy. That's how bad it is."</p> <p>- 51 y.o Vietnamese Australian man living with gout for 7 yrs. - 48 yr old Samoan Australian man with gout for 28 yrs. - 59 yr old Aboriginal man living with gout for 10 yrs.</p>
Frustrated with continued suffering	<p>"If I could say to my younger self 30 years ago,you need to take colchicine &Progout in combination & you need to reach your urate levelI would never, ever have suffered and lost so much time in my life."</p> <p>"I was only given preventative medication and just more or less told to go away every time. Even by the rheumatologist, there was no real follow-up. I wasn't told to follow it up or, you know, just take your Progout tablets and then off you go. I didn't have that follow-up."</p> <p>- 58 y.o Caucasian Australian man living with gout for 30 yrs.</p>
Supported to finally turn the corner	<p>"He made you feel so comfortable....He explained himselfHe wrote it down That goes a long way with some people...He's trying to look after your best interests."</p> <p>- 59 y.o Aboriginal man living with gout for 10 yrs.</p> <p>"He explained it all to me in a way that, oh, please, give me that!"</p> <p>"I have a heap of specialists....I wish they would all get in the one room....surely you can have some sort of session all together and think of ways to help me."</p> <p>"If I had any problems, and also the nurse I could speak to if I had any problems with taking it"</p> <p>- 76 y.o Caucasian Australian female living with gout for 3 yrs.</p> <p>"She's the first person in all that time that explained it properly, that I should have a urate target level. Since I've been doing that, it's come down a lot and it's been terrific."</p> <p>"It's funny because you don't feel any benefits physically, but I know in my head and my heart and with the results from my blood test that it's keeping my uric acid levels down, which is great."</p> <p>- 58 y.o Caucasian Australian man living with gout for 30 yrs.</p>
Self-discovered control and autonomy	<p>"Since I've had it so long, I know when it's coming on and when I've got it"</p> <p>"My brother-in-law gets gout pretty bad....He was the one who told me you look for this, you look for that word of mouth. Then I just knew what medication to get, so I told my doctor, this is what I want."</p> <p>- 59 y.o Aboriginal man living with gout for 10 yrs.</p> <p>Every time you see people, they walk and you can say oh, you have gout. We exchange conversation. I ask them, what do they take?"</p> <p>- 51 y.o Vietnamese Australian living with gout for 7 yrs.</p>
Following social expectations and norms	<p>"My friends and family...They had gout as well and didn't bother seeing a GPIt's like a badge of honour"</p> <p>"It was probably age, where I didn't care about how my body... I just wasn't interested, just eating whatever you wanted to eat, having a drink every now and then of alcohol."</p> <p>- 48 y.o Samoan Australian man with gout for 28 yrs.</p>
Maintaining a precarious balance	<p>"I had other health issues, so I probably re-prioritised my health issues instead of gout."</p> <p>"I try to minimise what I take in relation to medication because of the side effects and just trying to let the body handle the pain and just to reduce the side effects and minimise the medication intake."</p> <p>"I've had neuropathy in my legs, so I no longer feel the pain as such, but I do have to eyeball and manage the leg because I may have sores that I can't feel. If I have gout in the joints then the scab may break, so I just have to keep an eye on those things on a daily basis."</p> <p>- 48 y.o Samoan Australian man with gout for 28 yrs.</p>

Future research:

A limitation of our study was that all patients were already engaged with a Rheumatologist. In the future we would like to hear views of younger persons, those that speak other languages, more women, particularly those who are not already engaged with a rheumatologist. Our findings will assist in the design of a Medication Adherence Gout Clinic at Liverpool Hospital and will be used to engage patients in their disease management, ensuring person-centred care.

Discussion:

Interviewees described wanting support from a specialised clinic with early diagnosis, detailed education on gout and options for management, they wanted individualised and specific care plans that addressed all facets of life (including diet and exercise) with clear instruction on medications in a variety of circumstances. Patients encouraged information sharing between health care providers, inclusion of their carers, provision of regular follow up, ULT and serum urate level monitoring, appropriate to their cultural and social situation. These needs may not have been met to date due to inconsistency with gout management guidelines, poor health literacy, health care providers and patients underestimating the complexities of gout, and lack of community awareness surrounding gout.

Suggestions for clinical care:

The patient journey thus far has not been ideal. Creating standardised gout clinical guidelines that promote better care co-ordination, follow up and serum urate feedback, holistic education for patients and caregivers, and provision of individualised and culturally sensitive care plans may enhance medication adherence in gout and thus improve clinical outcomes.

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Sacha Bossina
Department of Rheumatology & Physiotherapy, Liverpool Hospital,
Locked Bag 7103, Liverpool BC, NSW, 1871, Australia
Phone +61 2 8738 4707
Sacha.Bossina@health.nsw.gov.au