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## Original Article

### Living with gout. Experiences, impact and challenges of the disease. Qualitative study through focus groups



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#### ABSTRACT

**Objective:** To delve into the experiences of people living with gout regarding its causes and triggers, recommended treatments and therapeutic measures, and the impact of living with this problem.

**Subjects and methods:** Descriptive qualitative study. Opinion sampling, looking for discursive variability according to sex, age, socioeconomic position and treatments. Three focus groups were made with 11, 6 and 7 people, following a pre-established script of topics. Analysis following thematic content analysis procedures.

**Results:** Participants were 19 men and 5 women, of different ages, socioeconomic status and treatments. Frequent comorbidities: hypertension and hypercholesterolemia. Genetics and the lack of renal elimination of urate were mentioned as causes of gout. They reported little knowledge of the causes and need more explanations about them. As triggers of the attack they identified: excess food and/or alcohol, trauma, stress or not following the treatment. Various drug treatment and expressed concern about their possible adverse effects were listed. Difficulties in adherence to the recommendations were also described. Non-pharmacological measures: rest, cold, proper footwear, walking, drinking water, and diet were also described. Chronic gout has an important impact on the daily life of patients and their families. Pain invalidates and leads to difficulties in performing daily activities. Irritations and mood swings were reported, which affect their family relationships.

**Conclusions:** These findings provide proposals to improve the care of people with gout. Information on its causes, the triggers of the crisis, dietary recommendations and exercise should be improved. The variability of treatments and recommendations on lifestyle should be analysed in depth.

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### Vivir con gota. Experiencias, impacto y retos de la enfermedad. Estudio cualitativo mediante grupos focales

#### RESUMEN

**Objetivo:** Comprender las experiencias de personas con gota sobre sus causas y desencadenantes, tratamientos y medidas terapéuticas recomendadas e impacto de vivir con este problema.

**Sujetos y métodos:** Estudio cualitativo descriptivo. Muestreo opinático, buscando variabilidad discursiva según género, edad, posición socioeconómica y tratamientos. Se hicieron 3 grupos focales con 11, 6 y 7 personas, siguiendo un guion de temas preestablecido. Análisis siguiendo procedimientos del análisis de contenido temático.

##### Palabras clave:

Gota  
Experiencias de los pacientes  
Investigación cualitativa  
Grupos focales

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**Resultados:** Participaron 19 varones y 5 mujeres de diferentes edades, posición socioeconómica y tratamientos. Comorbilidades frecuentes: hipertensión e hipercolesterolemia. Como causas de gota mencionaron la genética y la falta de eliminación renal del urato. Refirieron escaso conocimiento de las causas, y necesitar más explicaciones sobre las mismas. Como desencadenantes del ataque identificaron: excesos alimentarios y/o enólicos, traumatismos, estrés o no seguir el tratamiento. Enumeraron diversos tratamientos farmacológicos y expresaron preocupación por sus posibles efectos adversos. Destacaron dificultades de adherencia a las recomendaciones. También describieron medidas no farmacológicas: descanso, frío, calzado adecuado, andar, beber agua y dieta. La gota crónica tiene un impacto importante en la vida diaria de pacientes y familiares. El dolor invalida y comporta dificultades para realizar actividades cotidianas. Refirieron sentirse irritables y con cambios de humor, que repercuten en sus relaciones familiares.

**Conclusiones:** Estos hallazgos aportan propuestas para mejorar la atención de las personas con gota. Se recomienda mejorar la información sobre sus causas, los desencadenantes de la crisis, las recomendaciones alimentarias y el ejercicio. Las causas tras la variabilidad de recomendaciones sobre tratamientos y hábitos de vida deberían analizarse en profundidad.

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## Introduction

Gout is a disease caused by the deposition of monosodium urate crystals, due to a sustained excess of uric acid (UA) in the blood. Its clinical manifestations are secondary to the inflammatory response to these crystals. Its prevalence and incidence are increasing due to increased life expectancy and changes in diet and other habits<sup>1</sup>.

Gout and its associated comorbidity have a major individual, family and psychosocial impact. It causes pain, significant disability, increased use of health services and poorer quality of life<sup>2,3</sup>. Despite the existence of effective treatment, its management is suboptimal<sup>4</sup>. Some professionals perceive it as a minor health problem, with good adherence and response to treatment, while others report under-diagnosis and insufficient doses of anti-hypertensive drugs. Some patients report limited knowledge of the disease, challenges in changing lifestyle and lack of effectiveness and adherence to long-term treatment<sup>5–8</sup>.

To improve the approach to musculoskeletal problems, Outcome Measures in Rheumatology Clinical Trial (OMERACT), an international initiative of health professionals, was created to promote the incorporation of patients' perceptions and experiences and their active participation in rheumatology research decisions. Its OMERACT 2.0 programme aims to ensure that outcome measures from clinical trials and observational studies identify patient-relevant aspects<sup>9</sup>.

Qualitative research can improve understanding of the experience of people with gout. However, although studies have been conducted in different contexts<sup>10–12</sup> we have not identified any in our setting. This information is essential for understanding patients' beliefs about their disease, improving the effectiveness of interventions, deciding on relevant findings for future studies and framing research priorities in this field<sup>13</sup>.

This paper aims to understand the experiences of people with gout about its causes and triggers, recommended treatments and therapeutic measures, the impact and challenges of living with gout, as well as the information received from professionals.

## Subjects and methods

### Design

Descriptive qualitative study

### Participants

We included people diagnosed with gout, registered in the electronic medical record, attended by the public health system in

rheumatology or primary care (PC) services. Sampling was deliberate, reasoned and opinionated, following pragmatic criteria such as accessibility, ease of contact and discursive variability according to gender, age, socioeconomic status and treatment. Participants were selected by their PC or rheumatology referral professionals, who requested participation and informed patients of the study objectives. Three health centres participated in the study. [Table 1](#) shows the characteristics of the participants.

### Techniques for obtaining information

Between February 2017 and March 2019, 3 focus groups were conducted with 11, 6 and 7 participants. The groups took place in 3 health centres, and were moderated by an interviewer (PHS), an expert in qualitative research. The guide of topics to be explored (perception of cause and triggers of gout, diagnosis; symptoms; effects on daily life; treatment; social perceptions; information from professionals and identification of areas for improvement in care) was drawn up by the whole research team, based on the literature review and the clinical experience of the research team ([Table 2](#)). The groups lasted between 90 and 150 min. After written informed consent, they were audio- and video-recorded, transcribed verbatim and anonymised.

### Data analysis

The research team was composed of public health specialists (PHS), primary care physicians (PCP) and rheumatology specialists (CDT, BRD). In the pre-analysis phase of the first group, the provisional analysis plan was established with the participation of the entire research team. Subsequently, the analyst (PHS) applied the procedures of thematic content analysis, supported by Atlas.ti: familiarisation with the discourses (careful reading of transcripts and formulation of pre-analytical intuitions); coding of texts and design of the initial analysis plan; elaboration of categories of analysis and assignment of codes to the categories; analysis of each category, and elaboration of a new text with the main results. The coding and establishment of categories was based on the focus group guide, the categories emerging from the groups and the consensus of the research team.

### Ethical aspects

The study was approved by the Ethics Committee of the Ethics Committee of the Hospital de la Santa Creu i Sant Pau (2017; P12/073). Participants signed informed consent prior to the groups

**Table 1**  
Characteristics of the people participating in the focus groups.

Focus group	No. of people	Gender	Age	Social class base don occupation <sup>a</sup>	Years since gout diagnosis	Uricemia lowering treatment	Comorbidity
Group 1 Barcelona	11	3 women 8 men	2 < 50 years 5 de 50–70 years 4 > 70 years	3 Class I 2 Class II 6 Class III	4 ≤ 10 years 6 > 10 years	5 Alopurinol 4 Febuxostat	5 Hypertension 5 Dyslipaemia
District 7. Horta-Guinardó Medea index 79,2 (2016)					Uno not stated	2 No treatment	2 Depression-anxiety 1 Heart transplant
Group 2 Barcelona	6	One woman 5 men	1 < 50 years 5 de 50–70 years 0 > 70 years	1 Class I 4 Class II 1 Class III	2 ≤ 10 years 3 > 10 years	2 Alopurinol 3 Febuxostat	4 Hypertension 3 Dyslipaemia
District 9. San Andrés Medea index 74,5 (2016)					One not stated	One no treatment	1 Diabetes
Group 3 District 22. Badalona. La Salut Medea index 72,3	7	One woman 6 men	0 < 50 years 1 de 50–70 years 6 > 70 years	0 Class I 3 Class II 4 Class III	4 ≤ 10 years 3 > 10 years	2 Alopurinol 1 Febuxostat	6 Hypertension 3 Dyslipaemia
Totals	24	5 women 19 men	3 < 50 years 10 de 50–70 years 11 > 70 years	4 Class I 9 Class II 11 Class III	10 ≤ 10 years 12 > 10 years	9 Alopurinol 8 Febuxostat	15 Hypertension 11 Dyslipaemia
					2 Not stated	7 No treatment	5 Diabetes 2 S 2 Depression-anxiety 1 Heart transplant

S: stroke.

Class I: directors and managers and university professionals; Class II: intermediate status occupations and self-employed; Class III: manual workers.

<sup>a</sup> Domingo-Salvany et al.<sup>31</sup>.

**Table 2**  
Script of themes explored in the Focus Groups with people diagnosed with gout.

Topics	Examples of questions
1. Knowledge of gout. Perception of causes and triggers. Experience with diagnosis	What is gout?
2. Experiences with clinical manifestations	Why do you think you get gout? What do you think causes it?
3. Effects on daily life. Relationship to other diseases	What do you think triggers the attack? Who told you that you had gout? Were you asked for diagnostic tests? Can you recognise when a gout attack is about to start? What happens to you when you have gout? How long does it last? Over time, do you feel that you have got worse? How does gout affect your daily life (physical, emotional, personal, family, work and social)? Do you think gout affects or is related to other diseases?
4. Experiences with drug treatment and non-pharmacological measures	What medicines do you take to treat gout?
5. Relationship with professionals. Questions from patients and proposals for improvement in approach to gout	Do you take your treatment regularly? When you have no symptoms, do you stop taking the treatment or continue to take it? What other things do you do to treat your gout? Who is your gout professional of reference? Do you think they understand you? What was explained to you about gout and did you feel well informed? Were you given written information or other materials? Apart from what the doctors and nurses explained to you, did you seek further information about gout? What could be improved in the approach to gout?
6. Social view of gout	What does society think about gout and people with gout?

and anonymity and confidentiality of personal data was guaranteed by coding.

**Rigour and quality**

To ensure rigour and quality, Calderón’s criteria (relevance, methodological-theoretical adequacy, validity and reflexivity)<sup>14</sup> were followed. Sufficient data were collected to answer the

research questions, and we affirmed the accuracy, transparency and honesty of the results.

**Results**

Twenty-four people (5 women), 3 under 50 years of age, from different age groups, social class and years of diagnosis, 8 treated with febuxostat, 9 with allopurinol and 7 without pharmacolog-

ical treatment participated in the groups (Table 1). The results are presented according to the following categories of analysis: 1) knowledge of gout (perception of causes, triggers and experiences with the diagnosis); 2) experiences in relation to clinical manifestations; 3) effects on daily life, relationship with other diseases; 4) experiences with pharmacological treatment and non-pharmacological measures; 5) relationship with professionals. Information received about the disease; and 6) social view of gout.

The quotations illustrating and justifying the results are presented in Tables 3–5 and in Appendix Tables 1–3. In Appendix Table 6 and Supplementary Table 4, the proposals for improvement of the participating patients are presented.

#### *Patients' knowledge about the disease: causes, triggers and experience with the diagnosis*

##### *Causes of gout*

Most participants reported a family history of gout, and considered themselves predisposed to gout. They all mentioned excess UA, due to overproduction or lack of elimination. Also, crystal formation and deposition. Eating behaviours were widely emphasised as causes. The boundaries between causes and triggers were blurred.

##### *Triggers of attacks*

As triggers of the attack, they mostly emphasised over eating and/or excessive alcohol consumption. They listed foods associated with attacks: vegetables (cabbage, asparagus, spinach, cauliflower, tomato) and mushrooms; red meat or pork; sausages; offal; oily fish and seafood; and alcohol consumption. However, some questioned food as a trigger, describing their diet as healthy and moderate. As other triggers, some participants reported attacks following trauma, sport, stressful situations and one mentioned treatment withdrawal. Triggers varied from person to person and some were unknown.

##### *Patients' experience with the diagnosis*

According to the participating patients, the diagnosis was mostly made on the basis of clinical impression and hyperuricaemia. The setting was PC, emergency departments or community pharmacies. Two cases reported difficulties in diagnosis, when the arthritis did not affect typical locations

##### *Symptoms and signs. Duration of the attack*

Most reported *severe joint pain* in the first toe, although some had involvement of the ankle, heel, knee or multiple involvement. They also listed symptoms such as stinging, burning, tingling, prickling, tightness, heaviness, stiffness and a feeling of having something solid inside. They highlighted inflammatory signs such as warmth, redness, swelling, stiffness and significant limitation of mobility and/or lameness. Some participants mentioned tophi.

They described variability in the frequency of attacks (one participant had had many attacks and others between 2 and 4). In general, their duration ranged from three to seven days, although with years of evolution, the tendency was towards longer duration. They related duration and severity (the greater the severity, the longer the duration). One person had an attack that forced him to be in a wheelchair for 45 days and some reported a duration of 20 and 30 days. The quotes are presented in Table 3.

##### *Effect of the gout attack on daily life*

The diagnosis of gout led to lifestyle changes and effects on physical, psychological, family, social and occupational levels.

With regard to *lifestyle changes*, a number of people highlighted the difficulty of following dietary or alcohol recommendations, especially if they were very restrictive, and of maintaining them in the long term. While some acknowledged their active role in avoiding attacks due to diet, others posed the dilemma of abstaining from what they liked best or accepting the consequences.

On a *physical level*, pain, sometimes very severe, limited or hindered mobility. Carrying out activities of daily living became hazardous. Some people did not move from their home and others sought alternative ways of walking to avoid the pain. In addition to pain, inflammatory symptoms were reported.

On a *psychological level*, gout has a negative impact on mood, especially as it is a chronic condition, to be managed in the long term, seeking coping strategies. They reported anger, irritability, stress and mood swings.

On a *social and occupational level*, the gout attack makes it difficult to get out of the house, walk, play sports, participate in plans with friends or go on holiday. Occupationally, several participants admitted that because of the gout attack they were unable to work, although some, especially the self-employed or people with non-physically demanding jobs, took their drug treatment and limped to work. One woman had to change jobs because of gout.

Reactions to a gout attack varied. Participants reported that adaptation and coping are individual, and depend on the severity of the attack, the character and context of each person.

##### *Gout and comorbidity*

Several participants had gout and other cardiovascular risk factors (hypertension and/or hypercholesterolaemia), although only some were aware of their relationship. In the groups, they commented that gout was associated with kidney impairment (lack of UA elimination). Some reported having diabetes and one participant stated that gout could aggravate cardiovascular problems. The quotes relating to these categories can be seen in Table 4.

#### *Experiences with pharmacological and non-pharmacological treatment*

##### *Drugs for treatment of the attacks*

Participants listed various anti-inflammatory drugs, were familiar with their trade names and highlighted the efficacy of some of them and reported that, with appropriate and early treatment, attacks were of much shorter duration.

As *uricemia lowering treatment* (ULT) most cited Allopurinol and Febuxostat. They were aware that they lower uricemia and prevent attacks. Some people commented that when they stopped treatment their UA levels increased again. They also talked about the importance of finding the right dosage and drug regimen and the need for balance between medication and health-dietary measures.

##### *Perceived benefits of treatment and preferences*

For most of them, the pharmacological treatment significantly improved their quality of life, as the attacks disappeared and they were able to carry out daily life activities, without feeling ill and without so many restrictions on food and alcohol. Some cases observed these improvements after dose adjustment and/or change of treatment.

Some commented that they would rather take a pill than a strict diet, which is difficult to adhere to in the long term. One person preferred not to take pills.

##### *Concerns about adverse effects of drug treatment*

A number of participants had not experienced problems with medication and were not concerned about possible adverse effects. One person had a liver disorder, which he considered a serious problem, and some asked about adverse effects, especially regard-

**Table 3**  
Patients' knowledge of gout, symptoms, signs and duration of the attack.

Categories	Subcategories	Quotes
1. Knowledge of gout. Experiences with diagnosis.	1.1 Causes of gout	"I think there are a lot of genetic causes. I haven't drunk alcohol for many years and I'm up to the back teeth with so much chicken. . . , and it doesn't work. We have something passed down from our ancestors. My paternal grandparents had gout as well". (P10, M, 57 years, GF1)
	1.2 Triggers of the attack	"I understand that we all have uric acid, but we have too much of it". (P3, M, 55 years, GF1) "I had a congenital heart disease and had a transplant. I got gout, because I was taking a diuretic. Eating and drinking was not the problem". (P11, M, 37 years, GF1) "There was a time when it was automatic, if I became nervous I could see it coming. Two of three days later I got it". (P6, M, 60 years, GF1)
	1.3 Experience with the diagnosis	"Basically it's a problem associated with eating and drinking". (P2, M, 59 years, GF2) "I was diagnosed in primary care. The symptoms were obvious. The analyses results were always sky high". (P2, M, 59 years, GF2) "Since my big toe did not hurt, which is what they always say happens with gout, and it was the first time I had it, we were in doubt as to whether it was gout or not". (P6, M, 60 years, GF2)
2. Symptoms and signs. Duration of the attack	2.1 Symptoms and signs	"At the beginning you feel heat and discomfort, going from less to more. . . gradually increasing. More heat, more heat, until the foot begins to be inflamed. It's the big toe, then the ankle sometimes, everywhere.. hands, knees. . .". (P6, M, 83 years, GF3)
	2.2 Duration of the attack	"In my case, at the beginning I had minor attacks which lasted 3 days. I associated it with sport. The testing lasted almost 6 months. During the 6 months, I had an attack practically every month. One day it was the ankle, the next the knee". (P3, M, 44 years GF2)

**Table 4**  
Patients' experiences of the effects of gout on daily life. Gout and comorbidity.

Categories	Subcategories	Quotes
3. Effects on daily life. Relationship to other diseases.	3.1 Changes in lifestyle	"If they were very specific things it would be easy, but when it's been so many years and it is not only you who is paying for it but your family as well, there comes a time when you can easily do the most basic things but things that are not so basic you do them sometimes well, sometimes not, because if not. . .". (P10, M, 57 years, GF1)
	3.2 On a physical level	"A horrendous pain. During the first attack I was in a wheelchair for a month and a half without being able to go a single step. I was in tremendous pain". (P4, W, 52 years, GF2) "Getting up in the morning and going to have a shower becomes a tough chore. It's not comfortable to stand up. You try to make the least possible effort. I get up and in the meantime try to do everything, get this, put this down, the telephone, go to the bathroom, then I sit down and don't want anyone to disturb me". (P11, M, 37 years, GF1)
	3.3 On a psychological level	"Your mood shifts. It's not that you want your family to suffer but unconsciously you pay for the pain by being in a bad mood with those around you. . . Maybe someone knocks you a bit in the foot or something and you go through the roof". (P5, M, 67 years, GF1)
	3.4 On a social and occupational level	"On a professional level, someone who has to constantly go off sick may be affected, depending on the company". (P10, M, 57 years, GF1) "It does affect me at work. I had to stop doing it because I was on my feet for 12 hours a day". (P4, W, 52 years, GF2)
	3.5 Interpersonal variability	". . . It depends on your character and predisposition to decide between – I prefer to abstain and not suffer from it or I don't care and I will get through it –. In the end it is really a question of how each person is able to manage their limitations, whether these be imposed or self inflicted". (P11, M, 37 years, GF1)
	3.5 Gout and other diseases	"I have always had quite over the top parameters. Cholesterol, sugar. My uric acid level was high too, but the doctor did not attach any importance to it. I had never had what you could think was a gout attack, an attack of pain . . .". (P1, M, 58 years, GF2)

ing the kidneys, and mentioned that anti-inflammatory drugs could damage the kidneys.

#### Treatment adherence

Seven patients were not taking ULT. The rest mostly stated that they had been taking their basic medication regularly for years. They considered it a preventive treatment which, together with proper nutrition, improved their quality of life. Some had stopped and had to resume it when UA increased again.

#### Non-pharmacological therapeutic measures

Here, some listed lifestyle modifications with reduction or avoidance of the consumption of foods that increase the risk of stroke or alcohol. They commented on the beneficial effects of drinking plenty of water and walking and exercise, except during a crisis. Others found chronic lifestyle modifications difficult to maintain and preferred to take medication.

They also mentioned *physical measures* such as cold, hot/cold contrast, rest and putting their feet up. *Regarding complementary*

*therapies*, one participant had tried homeopathy, without positive results, and others had used phytotherapy. In addition, one participant emphasised the importance of wearing the *right shoes and* another mentioned *serenity*.

*Interaction with the professionals: information provided on the disease and its treatment. Patient's questions regarding gout. Proposals for improvement suggested by the patients*

#### Information on the disease and its pharmacological treatment received by professionals

The results show some polarisation in patients' opinions, consistent with variability in interpersonal information needs. For some, the information was sufficient, and further information could be counterproductive and cause nervousness. For most, the information received focused on advice on food, drink and long lists of forbidden foods. They stressed that they had little information on the causes of the disease, medication during the attack and for prevention, prognosis and the relationship between gout and other



**Table 5**  
Patients' experiences with drug treatment and non-pharmacological measures. Social view of gout.

Categories	Subcategories	Quotes
4. Experiences with drug treatment and non-pharmacological measures	4.1 Drugs for the treatment of attacks	"I have to find a balance between eating, drinking and medication. I have found the solution with the doctor's guidelines, with finding the medication. In addition, I also have hypertension and hyperglycaemia. Finding a balance with medication has been essential" (P2, M, 59 years, GF2)
	4.2 Perceived benefits of treatment and preferences	"Medication has developed and we are more or less following the guidelines and managing. We can lead a relatively normal life. Ten years ago perhaps I was a bit less strict, which I am not now, although I do still eat". (P1, M, 58 years, GF2)
	4.3 Concerns about adverse effects of drug treatment	"It is necessary. You get used to it. Maybe I have problems in other places, but as it is necessary, to continue with the life you have, I take it and there is no problem". (P1, M, 58 years, GF2): —"What will Adenuric® destroy? That is what worries me." (P10, M, 57 years, GF1) —"The side effects are always a worry. . . I wouldn't choose to take it but I have to". (P4, M, 56 years, GF1)
	4.4 Treatment adherence	"I've never been a pill popper. I realise that you prescribe them for a reason and you assess the possible negative effects. In the end it is an improvement. That's why I never don't take 4 or 5 or 6, I don't know how many I take per day". (P1, M, 58 years, GF2) "With regards to taking medication, it is essential to trust the doctor you are with". (P4, W, 52 years, GF2)
	4.5 Non-pharmacological measures	"I try to drink water even though I don't really want it. I take a lot of drugs and this makes me drink water. I don't only do it for the gout. Everyone is advised to drink 2 l of water per day, I'm incapable of it". (P5, M, >70 years, GF3) "Hot and cold showers. The contrasts unblock". (P2, H, 59 years, GF2) "They gave me a diet to follow, not to eat rabbit, fats and to walk". (P8, W, 72 years, GF1) "I was giving a three-fold leaflet which indicated that red meat, alcohol; oily fish and seafood were forbidden". (P10, M, 57 years, GF1) "Every individual is told something different. One person is told that asparagus is forbidden and others that they cannot eat red meat". (P12, M, 83 years, GF1)
5. Information received from professionals	"People think that you are greedy. That you stuff yourself silly with food". (P3, M, 68 years, GF3) "It is not terrible disease for other people. It's a shame that it hurts you but you yourself have to do something too". (P1, M, 84 years, GF3) "It depends on the companies or on the people. It always depends on people. If the person in front of you has had some type of problem or knows what it is, then they understand". (P10, M, 57 years, GF1) "I was really well looked after. It depends on familiarity, on how used to being in contact with it they are. It is all relative, if they know you and you have persisted in having to stick to a diet, then they are more on your side". (P11, H, 37 years, GF1)	
6. Social view regarding gout according to the patients	6.1 Lack of empathy	
	6.2 Comprehension and support	

diseases. Some were concerned about the variability and contradictions in professional recommendations. Few had received written information and commented that leaflets explaining the disease, especially at the beginning of the disease, would be beneficial.

Several people had searched for information on the internet, mainly about non-recommended foods and beverages. They had doubts about their quality, and had identified contradictions and conflicts of interest.

#### Topics on which patients asked for information

During the focus groups, several patients raised questions about issues explored during the groups, or other concerns. Although this aspect was not planned for in the research protocol, the research team considered it an opportunity and a means of getting the participants to answer these questions after the focus groups were over.

Patients requested information on: the causes of gout and triggers of the attack; food and drink (e.g. tomato or coffee); relationship between hyperuricaemia and renal function; drug treatment of gout (Febuxostat or Allopurinol, which is better for the kidney?); clarifications on the treatment of attacks and preventive treatment; asked whether tophi can disappear; they enquired about the relationship between gout and other diseases, in particular whether it can affect eyesight; they asked for precise recommendations regarding exercise; they asked about the variability in the prevalence of gout; where to find quality information on the internet and about the current state of research on gout; where is research being done and why?

#### Proposals for improvement suggested by the patients

Proposals for improvement in the management of gout emerged from patients' statements during the groups. We have divided them according to whom they are addressed: the health system, professionals or the community (Table 6).

#### Social view on gout

Many participants commented that, on a societal level, there is an unempathetic, blaming and even derogatory view of people with gout. It is attributed to excessive eating and drinking, taking non-recommended foods and lack of self-care. Family members often react angrily or show weariness of the limitations of gout, considering it a problem that can be avoided by maintaining a proper diet. Moreover, it is thought to be a minor health problem, which is not severe, has been known since antiquity and is a transient disease of wealthy people.

Other participants reported feeling understood and supported by family and friends and related this attitude to a greater knowledge of the disease and of the person with the problem. In addition, they highlighted the suffering of the family in the face of pain and mobility limitations, lameness and the difficulty of sticking to the diet and maintaining it in the long term. Table 5 presents some quotes that justify this category.

#### Discussion

We present the results of a qualitative focus group study, conducted in our context, which probes into the experiences of living

**Table 6**

Suggestions for improvement in the management of gout for the health system, professionals and community.

Healthcare system	Improve human resources to facilitate accessibility and avoid changes of professionals in order to maintain continuity of care. Improve training in gout management for professionals in all care settings (emergency, primary care and rheumatology). Reduce the stigma of gout.
Professionals	Improve <i>training</i> on the diagnosis and approach to gout. <i>Lifestyle recommendations. Health education:</i> Make individualised and well-informed recommendations on eating and drinking. Some do not work. Avoid variability in recommendations and contradictions between professionals. Clarify and emphasise the foods and drinks that can be eaten. Do not focus only on prohibitions. Recommend non-pharmacological therapeutic measures, e.g. appropriate exercise. <i>On diagnosis:</i> Avoid delays and errors in diagnosis in all care settings (emergency, primary care and rheumatology). <i>On treatment:</i> Inform about the therapeutic goals, effects and consequences of pharmacological treatment during crises or as crisis prevention. Ask if there are concerns about possible adverse effects of uricosuric treatment and interactions with treatments for other comorbidities (hypertension, DM2, hypercholesterolemia... ). Discuss non-pharmacological measures and complementary treatments. <i>Information to patients:</i> It is essential to establish and maintain a relationship of trust between professionals and people with gout. Explain in detail the causes and triggers of gout and its relation to other diseases. Emphasise the possibility of cure with appropriate treatment. Provide and hand out clear, readable and understandable information sheets. Recommend reliable sources of information on the Internet.
Community	Reduce the stigma of gout. Improve public knowledge about gout and understanding of people with gout. To reduce the stigma of gout.

with gout and provides information to professionals on opportunities to improve their approach.

This study offers a global approach to the different spheres in which gout, in its acute and intercritical forms, can affect the sufferer. Participants addressed the causes and triggers of the disease; how they were diagnosed; comorbidities; interference in daily life to pharmacological treatment, and non-pharmacological measures. In addition, as users of the public health system, they proposed ways to improve the approach to gout addressed to various stakeholders.

Several qualitative studies with gout patients from different countries and populations have been published in the past. Information is mainly available from English speaking countries such as the USA, Canada, New Zealand and England<sup>2,5,10,11</sup>. There are also data from the Netherlands<sup>3</sup> or from specific ethnic groups such as the Maoris<sup>15</sup> and various meta-analyses and meta-syntheses have even been published on different aspects of the disease and its management<sup>10,11,16</sup>. However, until now there were no data available for the Spanish population. Our results are concordant with these studies in most of the domains explored: causes of the disease and triggers of the attack<sup>5,7,11</sup>, diagnosis<sup>10,17</sup>, involvement in daily life<sup>3,10,18–20</sup>, comorbidities<sup>11</sup>, treatments and adherence<sup>5,6,11,16,21</sup> and perception of the disease by society<sup>18,22,23</sup>.

For the patients in our study, pain is the main domain in the experience of having gout as in the meta-synthesis of Stewart et al.<sup>10</sup> Pain, in addition to being an unpleasant experience, interferes with family, social and professional life, causes feelings of helplessness and dependency, and can often lead to symptoms of anxiety and depression<sup>20</sup>. In addition, participants perceive rejection and lack of empathy from society, also described in other studies<sup>18,23</sup>.

Diet and lifestyle were also a main and recurrent aspect in the patients' discourses, as a cause of the disease or as a trigger for attacks. This point is repeated in most of the studies, although they analyse different lifestyles and eating habits<sup>10,11,15</sup>. In the populations studied and in our own, changing these habits, although difficult and costly, is perceived as a possible treatment for gout.

Despite being a disease with a known pathogenesis and effective treatment, there is evidence that it is underdiagnosed and undertreated. Multiple patient and professional barriers have been described that impede the correct management of gout<sup>4</sup>. In our

study, patients listed, in addition to poor knowledge of the causes and consequences of the disease; the lifestyle imposed by work or social and family relationships, a key element in our context; difficulties in maintaining, in the long term, behavioural changes in diet or alcohol consumption; lack of adherence to pharmacological treatment and negative stereotypes about the disease at a social level. To overcome these barriers, various measures have been proposed, such as strict monitoring by nurses<sup>24</sup> or the incorporation of tools for shared decision-making, both conventional and electronic<sup>25,26</sup>.

According to our results, healthcare professionals should be more accessible and improve information to patients. Patients suggested reinforcing information on diet and lifestyle, and short- and long-term effects of uracaemia-lowering treatment. As in other studies, they emphasised the importance of continued follow-up after diagnosis and initiation of treatment, to review goals, doubts and concerns regarding treatment<sup>5</sup>, considering that professionals are in a privileged position to promote adherence to treatment as a key aspect of gout care<sup>27</sup>. They also insisted on the need to avoid stigmatisation of the disease, an aspect that involves patients, families, professionals, health systems and society in general.

Patients would benefit from more information and dialogue on causes, treatment goals and consequences of gout, co-morbidity, longer visits, and recommendations of natural remedies by practitioners<sup>5,27,28</sup>. Clear, consistent written information with key messages on lifestyle, nutrition and ULT may be helpful for better self-management<sup>29</sup> of the disease.

In the present study, it is notable that there were more patients without pharmacological treatment among those with lower social status. This could be attributed, in part, to a greater lack of knowledge and self-care and poorer adherence to treatment in this population, which is consistent with previous studies in gout and other diseases, which have found poorer adherence in populations with lower health literacy<sup>30</sup>.

In conclusion, the study participants considered pain to be a major element of the experience of living with gout. The presence of pain determines interference in many areas of daily life, physically, psychologically, in the family, socially and at work. As in other countries, sufferers demanded better management of the disease, optimised explanations of the disease and its consequences

by health professionals, and complained about society's negative view of people with gout.

### Study strengths and limitations

This study was conducted with a transdisciplinary team, in public PC and hospital services in Catalonia. The sampling of volunteers and the small sample size, although similar to other qualitative studies, limit the transferability of the results to other contexts and populations. Nevertheless, both men and women were included, from different age groups, socioeconomic status, years of evolution and type of treatment, so that the discursive variability of patients' experiences is wide. The discourses have been subjected to a rigorous and reflexive qualitative analysis.

During the groups, participants shared experiences, knowledge, ideas, behaviours and novel and useful information about living with this problem. In addition, although it was an emergent aspect, and unplanned in the methodology, patients were able to ask the rheumatology and PC specialists questions at the end of the groups, which was considered very positive and could be useful in other studies.

### Implications for practice and future research

Our study indicates the need to improve communication, information and patient knowledge about lifestyle, self-care, disease consequences and to address questions about ULT and its curative capacity, which could improve adherence.

Gout is related to determinants such as age, gender, socioeconomic, cultural and ethnic aspects. These aspects need to be further investigated, from the patients' point of view, in other contexts, to understand their experience and improve the approach to gout. It is also suggested that there is a need to investigate further the impact of gout on sexual relationships and sleep, aspects that did not emerge in our study.

### Ethical responsibilities

Following data protection law, participants were coded to ensure anonymity. The study was approved by the Research Ethics Committee of the Hospital de la Santa Creu i Sant Pau (2017; P12/073). The Participant Information Sheet and Informed Consent Form are presented in Appendix B Annex 1.

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### Conflict of interests

The authors have no conflict of interests to declare.

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### Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.reumae.2022.03.002>.

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