

Partners and nurses' knowledge and representations of gout: a qualitative study

Camille Deprouw¹, Maxime Guignot¹, Céline Bougeois-Sarran¹, Constance Bougeois-Sarran¹,
Laurence Coblentz-Baumann², Hang-Korng Ea^{1, 3, 4}

¹Hôpital Lariboisière, service de rhumatologie, pôle locomoteur, APHP, 2 rue Ambroise Paré
75010 Paris, France

² Université Paris Diderot, département de médecine générale, Paris, France

³ Université Paris Diderot, Sorbonne Paris Cité, Paris, France.

⁴ Inserm U1132 Bioscar, Paris 75010, France

Corresponding author: korngea@yahoo.fr

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ABSTRACT

Adherence to gout treatment is poor. Partners of patients and nurses are two major communicators with gouty patients, and their perceptions of illness may affect patient behavior.

Objective: To explore partners' and nurses' knowledge and representations of gout.

Methods: We used a qualitative grounded approach with semi-structured face-to-face individual interviews with a purposive sample of hospital nurses working in rheumatology and internal medicine departments and patient partners. Interviews were audio-recorded and transcribed. All authors met regularly to discuss coding and data interpretation.

Results: Overall, 20 nurses and 12 partners participated in the interviews. Four major themes were evidenced: knowledge gaps (gout cause was unknown, unawareness of urate-lowering therapy and the possibility to cure gout, focus in gout flare and diet); lack of information and education on gout (knowledge acquired by personal experiences, nurses complained to be insufficiently educated, partners highlighted the lack of information and that general practitioners did not have time to educate patients); gout consequences and social impacts (handicapping disease, avoid social activities like dinner with friends); attitudes towards gout flare and patient management (feeling powerless during flare, negative feelings such as being ashamed leading to postpone medical seek or unconcerned about their partner disease). Nurses regretted that they had not enough time to discuss issues with patients.

Conclusion: Partners and nurses' knowledge of gout is based on daily experiences. Participants were eager to learn more about gout. Nurses' education and education programs including partners may improve gout management and patient adherence to treatment.

Key words: gout, education, perception, flare, uric acid

1. Introduction

Gout is often negatively nicknamed and pictured as the disease of kings. Its prevalence increases worldwide reaching 2.5% of UK and Spain adult population, 3.9% of US adults and more than 10% of Taiwanese aboriginal adults (1). Reckoned and described 21 century ago by Hippocrates, its physiopathology is well understood, its cause and predisposing factor crystal-clear identified, its diagnosis easy to ascertain, its target clearly defined, its management supported by several international guidelines and its treatment very efficient permitting to cure when appropriately used (2–6). Thus, the progressive dose adaptation of urate-lowering therapy (ULT) in a treat-to-target (T2T) strategy consistently reduces urate serum level (USL) below the saturation threshold of crystal formation resulting to dissolution of deposited crystals and gout cure (2,7–9). Unfortunately the management of this curable disease encounters numerous barriers that prevent efficient care as recurrently reported (10). For example, less than 40% of patients who need ULT do receive this treatment, and among those who do, many have an insufficient dose to cure (11–13). Subsequently more severe gout with worsened clinical outcomes is observed increasing medical comorbidities and economic burden (14,15). Untreated or ill-treated gout patients continue to suffer from recurrent painful flares and to experience ongoing crystal deposition resulting to clinical detectable tophus, joint destruction and a higher risk of mortality, cardiovascular event, heart attack and stroke (11,16–18).

To improve gout management numerous qualitative studies have been done to understand health provider and patient knowledge, perspectives, beliefs and barriers in gout care (10,19–36). The review of these studies identifies three and four predominant themes among healthcare professionals and patients, respectively (10). Provider barriers include i) lack of knowledge and education in gout management leading to consider gout only as acute condition or to initiate ULT without flare prophylaxis therapy, USL assessment or dose adjustment; ii) misconceptions about patients' knowledge and adherence to ULT (physicians overestimate patients' adherence) and iii) time obstacles (providers complain to have not enough time to offer to patients and to educate patients). Patient barriers involve i) insufficient knowledge in gout leading to misperception on gout severity and chronicity, confusion in gout treatment and misconception in diet; ii) negative interaction with healthcare providers; iii) negative experiences with ULT (unawareness of flares when

initiating ULT) and iv) reluctance of long-term medication (10). These barriers may explain why gouty patients have the lowest adherence rate to treatment among seven chronic diseases including osteoporosis, hypertension and diabetes mellitus (37). Patient adherence to long-term treatment is a complex health behavior involving patient's history and experiences, knowledge, perceptions and beliefs about treatments and disease and patient interactions with healthcare professionals, socio-professional environment and family members (38,39). Some studies suggest that nurse intervention or patients' partner influence patients' adherence in chronic disease condition (9,36,38,40). For instance, Rees et al. report the efficiency of a nurse-led program to improve adherence in gout patients which reaches 91% at the 12-month follow-up visit with 92% of patients having achieved the USL target (2). Moreover, among those who adhere to treatment, more than 90% maintain their ULT 5 years later (7). These results are confirmed recently by a randomized trial comparing nurse-led ULT to usual care led by general practitioners (9). Similarly, in diabetes patients, partners affect patients' eating behavior (food shopping and cooking) (41). It is therefore important to assess nurse and partner perspectives, knowledge and beliefs about gout and its treatment since they are two privileged patient communicators with potential influence. We anticipated that these participants also had gaps of knowledge that needed attention in order to improve their interactions and potential helps to increase patients' adherence. We were interested to characterize the consequences of gout in partners' behavior and their feeling and implication in gout management.

2. Methods

2.1. Study design and participants

2.1.1. Approach

We choose grounded theory approach to investigate knowledge and representations of gout.

2.1.2. Setting

We designed this study to learn about knowledge and beliefs about gout in order to better develop the therapeutic education program on gout at the Lariboisière Hospital in Paris “Parlons goutte” (let’s talk gout”). This study was approved by the national committee Aeres (Evaluation Agency for Research and Higher Education). All participants agreed and gave their written consents. One researcher (CD, rheumatologist resident) saw the rheumatology and internal medicine nurses. Two general practitioners seeing gouty patients recruited and saw their partners (a gout diagnosis was retained if patients fulfilled the Nijmegen criteria (42) and partners were defined as their husband or wife, not necessarily caregiver) (MG, CBS, general practitioner residents)

2.1.3. Sampling

We used a purposive sample in order to cover the widest themes in disease perceptions and beliefs. For nurses: different sex, age, place of exercise, years since graduation and in the department. We interviewed 9 nurses in rheumatology and 11 in internal medicine departments. Partners were 11 women and one man as gout affected mainly men.

2.1.4. Information collection and analysis

2.1.4.1. *Information collection*

Demographic and general data were collected before interviews: sex, age. Data on ethnicity, duration of partner/patient relationship, personal or family gout history, number of gout attacks were collected for partners (table 1). Data on department, year of the degree, and duration of professional experience were collected for nurses (table 2).

Two semi-structured interview guides were designed by 6 investigators (CD, MG, CBS, CBS, LCB, HKE). Face-to-face individual interviews were conducted in a dedicated room in rheumatology and internal medicine departments of Lariboisière hospital for nurses and at home for partners. The interviews were audio-recorded after oral and written consent was obtained from participants. Participants were informed that their individual privacy and identity would be protected and that data would be stored securely and anonymized. We used open questions and let participants describe their knowledge, perceptions, and feelings about gout. Involved themes explored the causes and consequences of gout disease, gout symptoms, impacts on daily life and family, emotional and psychological impacts, gout

treatments, diet, relation with care providers, information and advice received or given. When themes were not mentioned spontaneously, participants were directed with subquestions to explore all covered areas. Interviews were conducted in parallel to the analysis and continued until data saturation (data collection was completed when no new idea/opinion emerged during the last interview).

2.1.4.2. Data analysis

Each interview was transcribed verbatim. Participants agreed to quote the interviews in anonymized form. Using Nvivo 10® software data analysis was performed after each interview. This software stores the qualitative data, allows for coding data and sorting codes, and illustrates data by “word clouds,” for example, whereby the size of the word is proportional to its frequency mentioned during the interview. Data encoding was performed by groups of 2 to 6 investigators, checking that the verbatim interpretation was similar to ensure internal validity. To ensure credibility we had interviewed several participants with prolonged engagement until theme saturation; we made methodological triangulation with in-depth interviews and investigator triangulation with regular meetings to perform coding, analysis and interpretation decision. Wherever necessary, consensus was reached after discussing specific verbatim with or without the help of senior authors (LCB, HKE). The codes were regrouped inductively into different categories based on the grounded theory approach (43,44). Once an interview was performed, the encoded verbatim were compared to previous themes and categories until the theoretical saturation. The constant comparative analysis between encoded data and new interviews permitted to generate themes and models from the data alone. We recoded and relabeled codes, concepts and the core category until a final theory provided the insight.

3. Results

3.1. Participants

We interviewed 20 nurses (18 women; 9 in rheumatology and 11 in internal medicine; median age 37 years [range 22-56]) and 12 partners of gout patients. Nurses worked in

departments since one to 31 years. They were working at traditional, weekly or daily hospitalization. Their professional activity lasted from 1 to 32 years (mean 12.1 years). Three internal-medicine nurses worked in a consultation department (table 2). We interviewed 12 partners (10 women; median age 56 years [range 28-85]). The relationship ranged from 6 to 55 years; the relationship was > 20 years for 8 couples. Patients had between only one (n=1), 2 to 5 (n=8) or more than 5 gout flares (n= 3) (table 1).

3.2. Themes

3.2.1. Knowledge gaps on gout disease and care

Nurses and partners had poor knowledge about the causes, consequences and treatment of gout. Illustrative quotations were summarized in Table 3. For some partners gout was considered as a “spontaneous” disease or secondary to excess walking, increase of urea level or acid level in the body. Other partners and rheumatologic nurses believed that gout was a diet-related disease and incriminated excess intake of meat, delicatessen foods, seafood, sodas, some vegetables (cabbage, cauliflower lentils) or salt. Alcohol was cited but as an afterthought and some nurses pointed out the role of beers and hard alcohols. Only few partners and nurses mentioned the role of genetic, medication or renal factors. Although nurses knew that gout was secondary to hyperuricemia, most of them did not distinguish hyperuricemia from urate crystal deposition. Only few nurses working in the rheumatology department said that gout was related to urate crystal deposition. Similarly, no partner was aware of the relation between gout, hyperuricemia and crystal deposition. Moreover, nurses and partners did not know that crystal deposition continued to accumulate and could lead to irreversible joint destruction. Thus, tophus formation, joint destruction, kidney involvement and cardiovascular risks were barely mentioned. How gout is diagnosed was unknown. Partners and some nurses thought that it could be done by blood analysis, clinical signs or joint fluid aspiration but they did not specify the exact target. Finally, the understanding of gout management was poor and mainly focused on flare treatment and foods to avoid as shown by word cloud (Figure 1). In fact, many partners believed that gout was a chronic and incurable condition with painful and recurrent flares. Most of them reported that gout was neither a severe nor life-threatening disease. A majority was unaware of the existence of

ULT and admitted that they had never heard about these treatments (Figure 2). Partners and nurses who knew about ULT still had misunderstandings and confusion with flare treatments. Some rheumatology nurses knew the purpose of ULT. However, they were not aware of the possibility of gout flare under ULT initiation neither the possibility of severe cutaneous adverse reactions. In contrast to the ignorance of urate crystal burden and efficiency of ULT, nurses and partners all knew the efficacy of flare treatments, especially colchicine, as the role of alcohol and diet to trigger flare (Figure 3).

3.2.2. Lack of information and education on gout

All partners and nurses complained about the lack of education on gout. Nurses reported that gout was not well taught during their scholarship. Their knowledges were mostly acquired during their professional practice and experiences. Partners said that general practitioners did not give necessary information about gout pathophysiology and management and that they did not take sufficient time to educate patient. Most of them had never heard about rheumatologists or the need to have a specialist care. Their knowledges on gout were acquired from internet, TV, radio, family or relationship experiences and, of course, their own history. Thus, some partners said they learned to manage gout flares from the behavior of relatives who had gout. Similarly, they said that after the first flare they learned how to manage the next one. Moreover, some partners knew that flare treatment was more efficient when initiated at the onset of symptoms. All nurses expressed the desire to participate in an education program. They were interested to improve their knowledge on gout symptoms, treatment and management. Partners were interested to learn about gout causes and diet.

3.2.3. Gout consequences and social impacts

Partners and nurses reported that gout flares were responsible of disabilities and had impacts in professional, family and social activities. They assumed that patients had difficulty walking and had to remain in bed during flares. Partners reported that patients were unable to care for, play with and share activities with their children during gout flares. Flares also directly affected their holidays and social relations. The possibility and fear of a gout attack prevented planning holidays or organizing holidays with long travel. Thus, the families did

not move much during vacation. Similarly, they avoided social activities such as having dinner with friends or community gatherings because of the fear of a gout flare, the need to restrict food and alcohol intake and the fear of society jokes.

3.2.4. Attitudes towards gout flare and patient management

Although most partners and nurses admitted that gout flare was responsible of severe and intense pain, some partners felt that patients might exaggerate their pain. Some partners felt sad, powerless to relieve patient pain during flare and subsequently were afraid of the next flare, especially those who thought that gout was incurable and that patients had to bear the recurrent attacks. Emotional and psychological reactions of gout partners were diverse and included indifference, denial, fear, sadness and shame. Some partners reported that they were surprise by the diagnosis of gout since they had a normal diet intake. Most of the partners recognized that the society still conveyed negative images on gout which was considered to be driven by diet and alcohol excess. Partners pointed out that gout was too frequently taken with humor and irony. Thus, they admitted concealing the gout diagnosis to their relatives so as not to feel ridiculous. Consequently, some partners felt ashamed. In contrast, other partners admitted not being affected or concerned by the disease and were interested neither in the management nor in an education program for gout. Moreover, few of them wondered whether gout could be considered a disease. Interestingly, partners' involvements in gout care varied between unconcerned to total control of gout care. In general, partners felt concerned and were implicated in gout management, in particular in diet control and food intake. Some admitted that sometimes patients did not adhere to the diet, especially when eating with friends.

All nurses showed professional behavior and none expressed negative judgments about diet, overweight, alcohol intake or lifestyle. Many nurses felt uncomfortable with gout patients. They reported that some patients did not want to talk or share their thoughts about gout. Some nurses regretted not to have enough time to discuss with and to educate patients. However, other nurses admitted not to have sufficient knowledge to answer patients' requests and questions. All nurses stated that they would be more efficient to manage

patients' concerns if they had a better knowledge on gout disease. They all agreed that patient education and knowledge were the cornerstone of adherence and successful management. Rheumatology-department nurses thought that treatment adherence was poor in gouty patients, whereas internal-medicine nurses thought it was fair.

4. Discussion

This is the first qualitative study in France to examine nurses' and partners' knowledge and beliefs in gout. As identified by previous studies assessing gout patients' and providers' barriers, this study confirmed the unmet need for education programs on gout pathophysiology and management and communication strategies to change the stigma about gout (10,19,21–36). We identified that participants had lack of knowledge about and misconceptions on gout disease, focused on flare treatment and diet management and were unaware of ULT. They felt that gout was an incurable painful condition, with a high impact on family, society and professional activities. They were affected by the negative perceptions of gout in society, which views gout as a self-inflicted disease secondary to an unhealthy lifestyle including eating and drinking too much. These negative images had psychological consequences on partners and patients who felt ashamed and embarrassed, which leads to deleterious behaviors such as concealing the diagnosis and postponing the search for medical care.

Our findings were recurrently reported by previous studies assessing gouty male and female patients, care providers and general practitioners (10,19,21,28,30–36). In our study, we also identified unexplored factors that constituted real barriers to treatment adherence: nurses claimed not to have enough time to inform and discuss the condition with patients; moreover they felt incompetent to give correct information and advice to patients. Some partners admitted not being interested or involved in the management of the disease and many did not consider gout as a disease. In contrast, other partners were willing to help but felt powerless, which could lead to discomfort, psychological stress and fear. Finally, all nurses and partners complained about the lack of information on gout and thought that a better understanding of the disease would help patients comply with treatment. Lack of

information was also a recurrent finding in previous studies, in which care providers and general practitioners admitted giving patients and caregivers little information (10,19). This need could be easily corrected with therapeutic education programs.

Nurses and partners are the two closest communicators with gouty patients, the partners being the primary caregivers. Their influence on disease management depended on multiple factors including coping attitudes, dyadic and couple relation, knowledge, psychological emotion and stress. Their role in treatment monitoring and adherence has been highlighted in many chronic diseases including diabetes, cancers, osteoarthritis, rheumatoid arthritis, hip fracture, and osteoporosis (41,45–49). A positive and compassionate coping attitude favors patient's confidence and adherence to treatment, whereas a negative and stressful attitude might lead to inadequate behaviors. A recent systematic review of 17 qualitative studies involving 1,142 couples showed positive outcomes of couple-based interventions in cancer. Positive outcomes involved improvements in communication, dyadic coping, the quality of life of both patients and partners, psychosocial distress, sexual functioning and marital satisfaction (46). In diabetes, several studies showed that spousal behavior both positively and negatively affected patient dietary adherence (41,45,49).. Similar to these findings, we observed that gout had negative psychological impact on partners, who felt ashamed, embarrassed, powerless, frustrated or fearful of flares. Negative impacts on partners negatively affected the dyad relation, patient behaviors and treatment management. Moreover, some partners felt unconcerned about the disease and were not interested in being involved in a therapeutic education program. This individual behavior might also alter patient concerns and treatment management.

Based on our findings, several propositions can be made to improve gouty patient to treatment adherence: a partner–patient couple intervention strategy could be used as was observed with other chronic illnesses (46); in parallel, education should be given to nurses and partners; online, free-access, short-duration courses on gout should be launched to ameliorate all the negative stereotypic images portrayed by old comic cartoons; defined strategies in order to increase nurse's time to care patients.

This study has several limitations. First, we interviewed nurses of a rheumatologic department specialized in gout care who had taken a course led by a specialist and in which a therapeutic education program on gout had been just set up. However, among interviewed

nurses, very few had attended the course, and only one was involved in the educational program. Still, because nurses worked in the same department and each interview was spread over time in order to encode and analyze data verbatim, nurses might have exchanged information or opinions. Second, because interviews were performed by a rheumatology resident who had previously worked in the department, nurses might be impressed and responses might have not been spontaneous. Nurses might not feel free to give stereotypic answers. Third, most participants were women: only three male nurses and one male partner were interviewed. This situation was related to the “female” profession of nursing and the epidemiologic characteristics of gout. Male partners might have different feelings about gout than women, as was shown with other chronic diseases, cancers or end-of-life of old age (50,51). Our study displayed several strengths including the internal validity and credibility ensured by regular meetings of investigators to code, recode and reread data and interpretation. The involvement of 6 different investigators with different specialties and medical grades permitted in-depth analysis of codes, concepts and core categories.

In conclusion, we have identified a number of feelings in partners and nurses that may affect patient adherence to gout treatment. We confirmed the recurrent findings of lack of knowledge, lack of information given by care providers, misconceptions of gout and the focus on flare treatment. A couple-intervention strategy appears necessary to effect a dyadic partner/ patient relation and the interest of partners in gout disease. A better organization of nurses’ work is needed to give them time to share with and educate patients.

Declarations

Ethic approvals and consent to participate

This study was approved by the national committee Aeres (Evaluation Agency for Research and Higher Education). All participants agreed and gave their written consents.

Consent for publication

Not applicable

Availability of data and material

Interview verbatim is available upon request. Please contact Professor Hang Korng Ea (korngea@yahoo.fr)

Competing interest

None

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Authors' contribution

CD, MG, Céline BS, Constance BS, LCB, HKE elaborated the semi-structured interview guide. CD performed nurse interview, MG performed partner interview. CD, MG, Céline BS, Constance BS performed verbatim transcription and encoding. CD, HKE wrote manuscript.

All authors made substantial contributions to the conception or the design of the work; the acquisition, analysis, interpretation of data.

All authors participated in drafting and revising the manuscript critically for important intellectual content and approved the version to be published

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Figure Legends

Figure 1. **Gout perceptions by nurses and partners.** Nurses' and partners' verbatim were transcribed and represented in this word cloud. Word size was correlated with its frequency retrieved in all interviews

Figure 2. **Gout treatments as reported by nurses and partners.** Gout treatment verbatim was represented. Word size was correlated with its frequency retrieved during all interviews.

Figure 3. **Gout knowledge and gaps.** Gout flare including dietary triggers and efficient treatment such as alcohol intake and colchicine, respectively, was the tip of the iceberg known by nurses and partners whereas the burden of ongoing crystal deposition and the possibility to cure by urate-lowering therapy were unknown face of the iceberg.

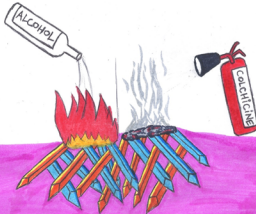
avoid
food
lot
delicatessen
espacially
cabbage
celebrations
drink
excess
always
dairy
red
alcohol
heard
attention
products
especially
offal
fruits
often
dietary
meats
encourage
diet
difficult

A word cloud centered around the topic of colchicine treatment. The words are arranged in a circular pattern, with the most prominent words in the center and smaller words towards the edges. The colors of the words vary, including shades of green, yellow, orange, and red.

colchicine
treatment
inflammatory
gout
allopurinol
patients
benémide
uric
take renal
urates
lowering
attacks
patient
effective
analgesics
disease
zyloric
sometimes
often
fasturtec
seem
give really
moment
diarrhea
attack
colchimax
drug

Dietary triggers

Gout flare cure



Known

Unknown

**Monosodium crystal burden and
urate-lowering therapy**

Age (years)	Gender	Ethnic group	number of patient's crisis	common life (years)
85	woman	Caucasian	2-5	> 20
59	woman	Caucasian	2-5	> 20
43	man	Caucasian	2-5	> 20
41	woman	Asian	2-5	5 à 20
45	woman	Caucasian	> 5	5 à 20
46	woman	Caucasian	2-5	5 à 20
70	woman	Caucasian	1	> 20
65	woman	Caucasian	2-5	> 20
51	woman	Caucasian	2-5	> 20
71	woman	Caucasian	2-5	> 20
28	woman	Caucasian	> 5	5 à 20
68	woman	Caucasian	> 5	> 20

Table 1. Partners' characteristics.

Age (years)	Gender	Year of the degree	Type of activity	Service seniority
Rheumatology nurses				
55	man	1984	WHR,THR	7
31	woman	2004	THR , WHR, DHR	11
39	man	2013	THR, WHR, DHR	2
31	woman	2008	WHR,THR	7
28	woman	2007	THR , WHR, DHR	8
23	man	2014	THR	1
28	woman	2009	WHR, THR	4
54	woman	1986	WHR	13
55	woman	1982	DHR	31
Internal Medicine nurse				
26	woman	2011	THR	4
41	woman	2008	THR	7
26	woman	2012	THR	3
56	woman	2010	Consultation	5
44	woman	1993	Consultation	22
53	woman	1995	Consultation	20
37	woman	2002	THR	13
25	woman	2012	THR	3
27	woman	2011	THR	4
37	woman	2002	THR	13
22	woman	2015	THR	1

Table 2. Nurse characteristics.

THR: Traditional Hospitalization rooms, WHR: Weekly Hospitalization Rooms, DHR: Daily Hospitalization Rooms

Table 3: illustrative quotes from nurses and partners.

Analytical theme/subtheme	Quotations
Knowledge gaps on gout disease and treatment	
<i>Cause of gout</i>	<p><i>"It's salted water which enters in the toe, and bones, joints." (partner 7)</i></p> <p><i>"It's phoric acid overproduced." (nurse 3)</i></p> <p><i>"I told myself: it's too much acid." (partner 4)</i></p>
<i>Diet triggers</i>	<p><i>"Avoid eating too salty, too fat, too acid." (nurse 13)</i></p> <p><i>"Especially not to eat cabbage." (nurse 5)</i></p> <p><i>"Avoid sardines and asparaguses." (partner 5)</i></p> <p><i>"He stops coffee. And I discover that tea is ten times worse than coffee." (partner 5)</i></p>
<i>Treatments</i>	<p><i>"You can't heal from gout. When you get it, it's for all the time and it trigger or not." (partners 2 and 4)</i></p> <p><i>"We can diminish all symptoms and live with it, but I don't think it can be really treated." (nurses 8, 12, 16, 20)</i></p> <p><i>"I know it's always colchicine in first intention, I think. Allopurinol is more depending on gout cause." (nurses 3, 7)</i></p>
Gout consequences and social impacts	
<i>Painful disease</i>	<p><i>"He complained of having pain in his toe as if it was broken, actually." (partner 11)</i></p> <p><i>"It's very painful. They don't tolerate a shoe, they don't tolerate a sock." (partner 11)</i></p> <p><i>"Pain was so unbearable that they became aggressive, concerning behavior." (nurses 7, 12)</i></p>
<i>Disability</i>	<p><i>"He can't put shoes and walk when he gets that." (partner 11)</i></p> <p><i>"Just for opening a bottle it's impossible." (partner 11)</i></p> <p><i>"Patients who use to be autonomous became dependent." (nurses 18, 19)</i></p> <p><i>"It paralyzes hands." (nurse 6)</i></p>
<i>Family</i>	<p><i>"I can't sleep when he is on crisis." (partner 3)</i></p> <p><i>"I must go to toilet with her because she has difficulty to walk." (partner 3)</i></p> <p><i>"He is sad because he cannot go for a walk with her like a normal dad." (partner 11)</i></p>
<i>Hobbies and social network</i>	<p><i>"We did little during the holidays." (partner 1)</i></p> <p><i>"We go there for him, because he wants to play golf, but he never could play." (partner 1)</i></p> <p><i>"I don't know what to say. I don't want to say he had a scooter accident because it's not true. I don't want to lie." (partner 4)</i></p> <p><i>"When we are invited we asked in advance what we will eat." (partner 12)</i></p>

Lack of information and education on gout

- Desire for more knowledge* *"A formation will be interesting. We are more focused on rheumatoid arthritis and spondyloarthritis but concerning gout it's true that there is some degree of lack." (nurses 2, 4, 5, 8)*
"I think this program is a good idea. In term of information because we are ignorant, we don't know anything." (partners 4, 9, 12)
- Incompetency feeling* *"I don't know enough to educate patient." (nurses 3, 18)*

Attitudes towards gout flare and patient management

- Powerless* *"It's a burden to see him suffer and not being able to relieve him." (partner 5)*
"I worked in bank domain, I was unable to do something." (partner 10)
"Patient asked you questions on disease? Oh no! I would be annoyed!" (nurses 3, 6, 8, 13, 17, 18, 20)
- Gout care involvement* *"Well, it's true I supervise his drugs. Before, I buy them, now he goes for. I less look after him, but I steel look after. If we are absent occasionally, I asked him to carry away all his drugs." (partner 1)*
"He must eat less delicatessen. My husband doesn't like chicken. I tell him he is forced to eat that. And I buy vegetables and I cook soup for him. / Beware of sausage! Well, for pleasure takes one slice, but if you feel something tomorrow it's totally ended." (partner 12)
- Partners' feeling* *"When the young lady asks him pain on a 0-10 scale he says 7 of pain. Pain is really subjective, some people handle with it, and some people don't. Me, I should prefer having pain and no take drugs, and pain will stop, that's all. And there is some, when they have little thing it's... Him, it's quiet like that." (Partner 9)*
"For me, like that, I will not use the term of disease. For, me it's like a liver attack. Gastro or something like that." (Partner 9)
"When he took his toe out, we saw it wasn't a whitlow. We laugh a lot!" (Partner 9)
- Limited time* *"We have less time to listen. Patient don't have time to speak, we need to do nursing quickly." (nurse 2)*
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