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Support needs of gout patients and suitability of eHealth to address these needs

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Abstract

Objectives: To investigate the support needs of patients with gout regarding information, communication, treatment and disease monitoring, and patients' views on and preferences for eHealth applications to address these needs.

Methods: A focus group study using purposive sampling was conducted. Three focus group sessions with a duration of 2 h per group were held with in total of 23 patients using urate-lowering therapy, recruited from primary and secondary care. Audio recordings were transcribed, and data were analysed using thematic analysis.

Results: Eight themes were identified. Five themes addressed support needs of gout patients and suitability of eHealth in addressing those needs: (1) Timely access to healthcare, especially during flares; (2) (personalized) information regarding diagnosis, medication, and diet; (3) insight into uric acid levels and medication side effects through blood monitoring; (4) better coordination across primary and secondary care; and (5) self-management and shared responsibility over care for maintaining health. Three themes addressed eHealth in general: (1) receptive towards eHealth in gout care; (2) the preference for eHealth to have a complementary role (i.e. not replacing face-to-face) contact with healthcare providers; and (3) preferences on eHealth use and functionalities.

Conclusion: Patients expressed various needs regarding their disease management and projected a supporting role for eHealth in (self)management of gout. Addressing the needs and preferences of patients could enhance their understanding of the disease and treatment, self-management, and possibly health outcomes.

Lay Summary

What does this mean for patients?

Gout is a common inflammatory arthritis that, if untreated, can cause severe pain, redness, swelling, and mobility issues. Despite being common, gout care sometimes falls short for patients. Enhancing gout care is crucial to alleviate the burden on people with gout. By understanding the needs of gout patients during treatment, care can become more patient-centered and effective. The use of digital technology to support or improve health and healthcare (eHealth) is a promising way to support gout patients and empower them during treatment. We conducted three group meetings with 23 people with gout using long-term medication to understand their needs for information, communication, and monitoring during treatment. We also explored their views on the suitability of eHealth in gout care. Participants expressed the need for timely access to healthcare, particularly during painful flares. They desired personalized information on diagnosis, medication, and diet, as well as more frequent blood tests to monitor key blood values and medication side effects. They also wanted quicker referrals to specialists and better communication between general practitioners and rheumatologists. Importantly, participants sought more control and shared responsibility in their care. They were open to using eHealth as a complementary tool in gout management. Addressing these needs can improve patient care, support self-management, and potentially enhance health outcomes.

Key messages

- Gout patients have support needs regarding care accessibility, information, disease monitoring and self-management of care.
- We directly linked patients' support needs with views on and preferences for eHealth.
- Participants were receptive to using eHealth when it complemented gout care and includes multiple functionalities.

Introduction

Gout is an inflammatory rheumatic condition, characterized by the deposition of monosodium urate crystals in joints when serum uric acid levels exceed saturation, leading to painful episodes of arthritis. Uncontrolled gout has a considerable impact on healthcare costs, such as hospitalizations and emergency room visits [1, 2]. With nearly 480 000 people affected in the Netherlands in 2017—a number expected to rise by 22% to 580 000 by 2030—the burden on healthcare systems will only increase [3]. Despite the considerable knowledge about the disease and availability of effective medication, management of gout patients remains suboptimal for part of the patient population [4–6]. Causes for this are insufficient patient education, patient–healthcare provider (HCP) communication, and monitoring (i.e. disease status, symptoms and blood values), leading to inadequate use of urate-lowering therapy (ULT) [7–9]. Improving gout care is essential to reduce the burden of gout symptoms on patients, the strain on the healthcare system, the financial impact and loss of work productivity for society.

Adequate use of ULT and thereby improved treatment outcomes may be achieved by supporting patients throughout their care. Research indicates that higher knowledge, perceived support and increased monitoring of blood values can promote adherence to ULT [10–13]. Additionally, patients themselves express a need for support such as information about gout, diet and pharmacological treatment, and disease monitoring by ongoing dialogue with a HCP [8]. Some qualitative research has been performed investigating patient views and preferences on care, as well as needs regarding healthcare and self-management support in various Asian countries [14, 15]. However, studies performed in a European healthcare setting are lacking. Understanding patients' needs during treatment across countries and healthcare settings may contribute to more patient-centered care and better alignment of possible interventions that address support needs, thereby improving management of gout and patient outcomes.

A possible way to support patients and strengthen their role in treatment is the use of eHealth applications. In this study, we define eHealth as the use of information and communication technology to support or improve health and healthcare. Currently, several digital applications have been developed and studied in gout [10, 16–18]. Examples are apps or websites that support adherence to ULT, track the number of gout flares, and provide education [10, 16–18]. It is expected that the use of eHealth applications for supported self-management will become increasingly important given the limited availability of healthcare personnel. This is also stressed by the World Health Organization, and the Points-to-Consider for remote care in musculoskeletal diseases [19, 20]. eHealth in gout may potentially become important as it could be an efficient tool that provides patients with quick access to information and care during a flare-up, and promotes patient engagement through supported self-management of disease and blood values and self-monitoring. These aspects have been shown to positively contribute to improved gout management [10, 12]. Evidence on the effectiveness of eHealth applications in supporting patients with gout and improving outcomes is scarce, and to the best of our knowledge, there are no examples of successful wide-scale use of platforms or applications in gout care. Research suggests that a user-centered approach in eHealth development leads to

better patient outcomes, and simultaneously increases the likeliness of successful implementation in clinical practice [21–24]. Insight into patients' needs and preferences is therefore important to inform patient-centered eHealth applications aiming to empower gout patients.

The current study aimed to investigate the support needs of patients with gout regarding information, communication, treatment and monitoring, and to investigate patient's views on, and preferences for eHealth applications to address these needs.

Methods

Design and setting

A qualitative focus group study was conducted at the Sint Maartenskliniek, Nijmegen, the Netherlands. A topic guide was developed by the study team consisting of three researchers, a clinical pharmacologist and a rheumatologist (Table 1). Subsequently, the topic guide was pilot-tested with a patient research partner, discussing appropriateness and comprehensibility of the questions and any other concerns from the patients' perspective. The COnsolidated criteria for REporting Qualitative research (COREQ) checklist was used to ensure quality and transparency of reporting [25].

Recruitment and participants

The inclusion criteria were: at least 18 years old, having sufficient understanding of the Dutch language, a clinical diagnosis of gout, being able to attend a face-to-face focus group session, using ULT, and having an email address. Participants were recruited via purposive sampling based on age, sex, disease duration, and treated by general practitioner (GP) or rheumatologist to obtain a wide range of views.

Eligible patients were recruited through a list of patients who consented to be contacted for research purposes (primary and secondary care), and rheumatologists at the Sint Maartenskliniek. Patients recruited from primary care were currently under care of a GP (different practices) at the time of the study and patients recruited from secondary care were treated at the outpatient clinic of the Sint Maartenskliniek. Recruitment continued until there were 10 participants for each session, aiming for a preferred number, by one of the moderators, of eight participants to account for a 20% dropout rate.

Procedure and data collection

Three focus group sessions of 2 h were held, as we anticipated that no new information would arise beyond this point [26]. Participants completed a demographic questionnaire and an eHealth QuickScan [27], which is a six-item questionnaire used to gain insight into the patients' digital skills and familiarity with technology. Additional patient information including age, sex, diagnosis, disease duration, medication usage and comorbidities were gathered from patients' health records or from data available from previous research. Each focus group session was led by an experienced moderator (either B.J.F.v.d.B. or J.E.V.). At the time of the study, B.J.F.v.d.B. was head of department research and manager of the hospital pharmacy and J.E.V. was a senior researcher. Additionally, two to three assistant moderators/observers were present at each focus group to assist the moderators with recordings, materials, and non-verbal communication observations. They were not involved in the discussions. No

Table 1. Topic guide for the focus group sessions

Introduction of participants
- Who are you, where are you from and how long have you had gout?

Questions regarding key topics: Part 1

Short introduction about gout. Brief explanation of this study's goals.
- *Main question 1: You have experiences with gout care. Please write down 2 things that went well and 2 things that can be improved on post-it notes (to ensure independent thought processes).*

To facilitate this process, broad categories reflecting the different stages in gout care are presented: diagnosis, selection and start of medication, coping with gout, lifestyle adaptation, monitoring uric acid and side effects, contact with healthcare providers, practical issues/logistics, and other.

The participants will be given 5 min to write down their thoughts, after which the moderator will request each participant to explain their written responses. Afterwards, discussion will be stimulated and in-depth questioning will be done by the moderator. The moderator clusters the answers by affixing the post-it notes to the appropriate categories on the wall.

Sub-questions
- What are/were things that could have been different/better in gout care?
- What do you still need (from healthcare providers)?
- What were you missing in your gout care?
- What problems did you experience in your gout care?
- What support did you have or need when it comes to gout care?
- Do others recognize themselves in this?
- Why is this perceived as tip/top?

Break

During the break, the topics that emerge in the first round of questions will be summarized by the moderator and observers and used to guide part 2.

Questions regarding key topics: Part 2

Short introduction about eHealth. What can eHealth entail in the context of gout care.
- *Main question 2: Which of the previously mentioned and summarized topics do you think digital care is suitable for?*

Sub-questions
- How can digital care help with this tip/top?
- What does digital care need to be able to do to make this happen?
- And which channel? (consider the examples; website, virtual reality, chatbot, serum urate monitoring)
- What are conditions to use digital care for this tip/top?
- Why is digital care appropriate (or not) for this tip/top?
- Why this channel?
- Are there other possible channels?
- What does digital care need to be able to do this to solve the problem and why is this important

End
- Exit questions: Is there anything that you would like to add/discuss/mention?
- Brief evaluation
- Expressions of gratitude and handing out reimbursements and gift cards

prior relationship between the researchers and participants was established. The stepwise process during the focus group sessions consisted of an introduction of participants, key questions of part 1 of the topic guide, a 15-min break, key questions of part 2 of the topic guide, and exit questions and closing remarks (Table 1). Field notes were taken by the observers during the discussions to aid in the interpretation of the findings. Participants were reimbursed for travel and parking expenses and received a 25 euro gift card for their time and effort.

Data analysis

The focus group discussions were recorded, transcribed verbatim, and thematically analysed using an inductive approach by four authors (J.v.d.V., F.A., L.M.V. and B.J.F.v.d. B.) in ATLAS.ti (Version 23), using the approach of Braun and Clark [28]. In the first step, two researchers (J.v.d.V. and F.A.) familiarized themselves with the transcribed data. Next, open codes were generated independently by two researchers (J.v.d.V. and F.A.). The open codes were then compared and discussed until consensus was reached. To ensure reliability, a third researcher (L.M.V.) checked this process. In the third step, subthemes were generated by categorizing the open codes into higher-level potential subthemes. Step 4 involved reviewing and refining the subthemes, with a focus on ensuring distinct differences between subthemes and adequate reflection of the open code content. The subthemes were further categorized to form main themes by four researchers (J.v.d.V., F.A., L.M.V., B.J.F.v.d.B.). The main themes were further defined and renamed by noting down the specific story each theme tells, while also providing clear and precise descriptions for each theme.

Ethical considerations

Patients signed written consent before conducting the focus group sessions. Transcribed data were pseudonymized so that the analysis did not contain identifiable patient information. This study was conducted according to the principles of the Declaration of Helsinki and a waiver from the Medical Research Involving Human Subjects Act (WMO) was obtained from the Medical Research Ethics Committee of Eastern Netherlands (File No.: 2023-16157). Data were handled following the Dutch General Data Protection Regulation.

Results

Out of 279 potential participants, 142 responded to the invitation mail or phone call after 1 week. Ultimately, 30 participants agreed to participate. Reasons for non-participation included lack of time or motivation, holidays, work commitments, travel issues, lack of interest, personal circumstances, frequent hospital visits, not being able to or wanting to engage in group discussions, and feeling healthy. Of the 30 people agreeing to participate, 23 patients (8% of the total approached) joined the focus group sessions with 10, 7, and 6 participants in each session, respectively. Participant characteristics are detailed in Table 2. Seven patients did not participate, citing unspecified personal reasons or providing no explanation. One person went to the wrong location. Using thematic analysis, eight themes were generated. Five of the themes described patients' needs and suitability of eHealth specifically related to those needs (Part I). Additionally, three themes were generated describing patients' general views on the suitability of and preferences eHealth for (self-)management of gout (Part II). Quotes illustrating the themes can be found in Table 3.

Part I: support needs for (self)management of gout
Theme 1: timely access to healthcare, especially during flares

Patients expressed a need for timely access to care and medication, especially when experiencing a flare. Some cited pain and limitations due to a flare as the reason for this need. Additionally, this need was strengthened by the fact that some could only see their GP after the attack had already passed. Participants wanted access to care on weekends, including the possibility to obtain medication. Suggestions to improve access to healthcare included digital contact with HCPs or ordering medication online, also during the weekend. Due to time constraints of GPs and rheumatologists, emergency doctors on stand-by, digital triage tools and chatting or calling with the doctor's assistant may help to improve access to care. Closing and changing of blood test locations influenced the access to care for patients. Finally, patients suggested that stocking of for example prednisone would increase access to medication.

Theme 2: (personalized) information regarding diagnosis, medication, and diet

Patients expressed a need for information on gout diagnosis, its long-term consequences, and diet, enabling them to understand their diagnosis and the necessity of a lifestyle change. In terms of diet, patients wanted to know which types of foods to avoid. Lack of information from HCPs regarding diet resulted in some patients seeking online nutrition information. Regarding medication, there was a need for information on potential drug–drug interactions (long-term) side effects, and the possibilities of discontinuation. Patients needed personalized information for example customized treatment plans rather than general online information. Reliable information was deemed important, bringing patients peace of mind, and information from the hospital considered more reliable than Google or Wikipedia. They also wanted a central, digital platform for gout information, trusting the hospital's expertise over that of GPs, which further emphasized their desire to have this knowledge available digitally and centrally. A need for centrally available and reliable information was expressed, arising from discrepancies between multiple

Table 2. Patient characteristics

Characteristics	Value
Mean age (years), S.D. ($N = 23$)	69 (9.4)
Sex, *n* (%) ($N = 23$)	
Men	22 (96)
Women	1 (4)
Marital status, *n* (%) ($N = 23$)	
Married	20 (87)
Divorced	1 (4)
Widow/widower	2 (9)
Level of education, *n* (%) ($N = 23$)	
Low (up to and including lower vocational training)	2 (9)
Medium (up to and including secondary vocational training)	6 (26)
High (including higher vocational training and university)	15 (65)
Work situation[a], *n* (%) ($N = 22$)	
Retired (early)	17 (77)
Paid work >12 h <20 h per week	1 (5)
Paid work >32 h a week	4 (18)
Current treatment provider[a], *n* (%) ($N = 22$)	
General practitioner	4 (18)
Rheumatologist (or other specialist)	13 (59)
No longer under treatment for gout	5 (23)
Current type of ULT use, *n* (%) ($N = 23$)	
Allopurinol	22 (96)
I don't know	1 (4)
Comorbidities related to gout[b], *n* (%) ($N = 23$)	
Hypertension	7 (32)
Renal dysfunction	4 (18)
Type 2 diabetes mellitus	3 (14)
Atrial fibrillation	1 (5)
Ventricular tachycardia	1 (5)
Cardiomyopathy	1 (5)
Hypercholesterolemia	4 (18)
Hyperlipidemia	1 (5)
None	8 (36)
Number of gout attacks in the past year[a], *n* (%) ($N = 22$)	
0	14 (64)
1–3	5 (23)
4 or more	3 (13)
Median disease duration (years) (IQR) ($N = 23$)	4 (0.8–8)
Digital accessibility and competence	
In possession of a computer, phone or tablet equipped with internet[a], *n* (%) ($N = 22$)	
Yes	22 (100)
No	0 0
Does sometimes search for information on the internet, *n* (%) ($N = 23$)	
Yes	22 (96)
With help from others	0 0
No	1 (4)
Uses email sometimes, *n* (%) ($N = 23$)	
Yes	23 (100)
With help from others	0 0
No	0 0
Uses an app sometimes, *n* (%) ($N = 23$)	
Yes	22 (96)
With help from others	0 0
No	1 (4)
Can download an app, *n* (%) ($N = 23$)	
Yes	20 (87)
With help from others	2 (9)
No	1 (4)
Uses his/her DigiD, *n* (%) ($N = 23$)	
Yes	21 (92)
With help from others	1 (4)
No	1 (4)

[a] Data from one or more participants is missing.
[b] More than one comorbidity possible.

Table 3. Quotes supporting each of the themes

Part I: Support needs for (self)management of Gout

(1) Timely access to healthcare, especially during flares

'I think that if you look at the level of pain of the patient at the time that you have an attack … I think that it is realistic to say that I want to be helped as quickly as possible. Because it [a gout attack] is a serious block. A, you can't do anything at all, and B, you're dying of pain' (FG2, R6).

'Yes, but incidentally had contact with my family physician recently, and this was also online, and that went well for me … For me to go to the doctor is really an issue. If I do have to do it, I don't have that much time for it. Or it is in fact necessary? And a chat function like this is very easy, and then you are phoned by the assistant in the afternoon and you are briefly talked through it. I found it really nice myself' (FG1, R1).

(2) (Personalized) information regarding diagnosis, medication, and diet

'That [the possibility that your gout could get worse] is for me already a reason to feel fear, from now on even worse. I would definitely like to know … well … what should I expect? And when could it [gout] go away' (FG3, R3).

'I find that [information on lifestyle] is really important after all. Even if it is only that they [healthcare workers] tell you where you can find the information. That is actually the most important thing' (FG3, R1).

(3) Insight into uric acid levels and medication side effects through blood monitoring

'I would also like to know. My foot doesn't hurt, but my hands are in constant pain. Then I think about whether this is also gout. Is my uric acid level perhaps higher after all than I think' (FG3, R3).

(4) Better coordination across primary and secondary care

'Up to the point three years ago when I was unable to walk, move or whatever for a week or longer. And then I was given a younger replacement [by the family physician], and they sent me straight here [specialist care]. But if that had happened seven years previously, I would have had a lot less misery' (FG2, R3).

'If the family physician had known, or had received tips from the rheumatologist on how you adjust the allopurinol. If he had had immediate feedback from the rheumatologist, he would himself have perhaps been able to do that simple policy that was implemented. And then I would not have been here at all, and that would have made all the difference, I think' (FG1, R8).

(5) Self-management and shared responsibility over care for maintaining health.

'Because you want, apart from taking medication of course … you also want to know: Can I do something myself? What could my own contribution be to reduce the risk [of a gout attack], and that is with nutrition among other things. And I really looked up a lot for myself, and on the inside of my kitchen cabinet there are tables with foodstuffs where the purine levels are shown, purely to get a bit of an idea myself of what I should simply avoid in foodstuffs, and make a contribution in this way' (FG1, R6).

Part II: Suitability of eHealth in gout care

(1) Receptive towards eHealth in gout care

'I'm completely behind that. Should there be something like that [a digital question-and-answer system] that can provide answers everywhere, that would naturally be fantastic' (FG3, R2).

(2) Complementary role of eHealth in gout care

'If you have face-to-face contact, you will probably see rather more. But I do agree with you. The avatars and that sort of thing will definitely be the future. So, you will have to find a kind of golden mean' (FG1, R1).

(3) Preferences on eHealth use and its functionalities

'If you log in with your number, you get to your platform, and then your physician will have filled in for you the medicines that you have and then possibly also where your pain threshold lies, and what you may take additionally in the event of an emergency' (FG2, R6).

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digital information sources. The use of Artificial Intelligence for asking questions and getting an indication for a diagnosis was discussed as a possibility. Patients suggested eHealth solutions like information sessions, Q&A systems, newsletters, referrals, nutritional advice, and concise medication information.

Theme 3: insight into uric acid levels and medication side effects through blood monitoring

Participants expressed a need for periodic follow-up and more frequent monitoring of sUA levels and values that can indicate side effects. Some perceived the current frequency of monitoring as insufficient or nonexistent, while others were curious about their blood values due to being symptom-free for a long time. In contrast, other patients expressed no need for follow-up or monitoring because they considered it unnecessary due to their symptom-free status. Participants wanted to have insight into blood values that can indicate medication side effects to be able to understand the medication's impact on their organs (i.e. liver and kidneys), and, some questioned the cause of complaints they had and wanted to know if they were a side effect of medication or not.

Theme 4: better coordination across primary and secondary care

Many participants expressed a need for faster referrals from the GP to secondary care. This primarily stemmed from experiencing a lack of knowledge and expertise from the GP, causing late diagnosis and inadequate management of their gout, resulting in flares and disability. Satisfaction with information exchange and communication within the second line of care also contributed to people's need to be referred to the secondary care. Patients mentioned that referral to secondary care might not be needed when a GP would obtain advice regarding gout treatment guidelines from a rheumatologist. When treated in secondary care, patients found it inconvenient that the rheumatologist had limited time, but were satisfied with the rheumatology nurse as a point of contact.

Theme 5: self-management and shared responsibility over care for maintaining health

Participants had varying views on the responsibility of patients and HCPs within gout care. In terms of HCP responsibility, there was a need for a HCP to oversee the medical record, and a need for medication management by a HCP.

However, according to some, responsibility for medication management lied to a significant extent with the patient. Consequently, participants expressed a need for having an active role during treatment, for example by knowing what to do when having a flare, limiting risk of flares by changing diet, taking medication and knowing when to seek a HCP or obtain medication.

In this active role, there was a need to control gout by self-monitoring sUA at home with a digital device to adjust medication and diet independently. While some worried about self-experimentation, they suggested guidance from HCPs, automatic data transmission, and advice on interpreting measurements and medication doses. They also noted the potential risk of missing ULT toxicity monitoring during self-monitoring. Patients suggested routines, pillboxes, and digital reminders on smartphones for managing gout medication as a way to take an active role in medication management.

Part II: suitability of eHealth in gout care
Theme 1: receptive towards eHealth in gout care

Many patients were open and positive towards using eHealth in gout care, valuing the large amount of information and the possibilities for communicating with HCPs it offers. They saw eHealth as inevitable and a realistic future. However, some had concerns regarding quality of care, privacy, digital systems going out of human control, not knowing who is responsible for overseeing a patient's health record, accuracy in diagnosis or answers to questions, and generational differences in digital competence and interpretation of digital information. While digital competence was perceived not to be a problem for younger people, it was stated that it could be for older people. These issues could be mitigated by increasing experience, support, and user-friendly design.

Finally, patients mentioned advantages of eHealth, such as saving time and money due to reduced travel, finding answers more easily and reducing the burden on healthcare. Disadvantages that were mentioned included lack of out-of-the box thinking, inability to afford devices for some patients, feeling unheard when not receiving a reply, mistakes in digital systems and lack of HCP explanation when reading medical jargon in digital lab results.

Theme 2: complementary role of eHealth in gout care

While eHealth may contain more knowledge than HCPs, the latter were considered irreplaceable due to trust in HCPs, sharing emotions, checking sUA blood levels measured at home, and a need for physical presence for some types of care (e.g. joint injections), highlighting eHealth as an addition to gout care, instead of a replacement thereof. Participants emphasized the importance of and need for personal contact in communication with HCPs. Some found eHealth suitable for experiencing personal contact (e.g. through video calls), while others did not. Experiencing personal contact (whether digital or face-to-face) was necessary for more elaborate questions and better for communication in general. There were concerns about missing this inter-personal contact while using eHealth such as digital avatars and video calling.

Theme 3: preferences on eHealth use and its functionalities

Participants made general suggestions for the use of eHealth in gout care, such as reimbursement of digital devices for medical necessity and the use of an app that can be accessed through the hospital. Periodically collecting data through an application can give researchers and doctors more information about gout and its course. Participants discussed the use of a digital gout platform and preferences for functionalities. These included up-to-date, comprehensive, but filterable information, experiences of other patients (moderated by a rheumatologist) and use of digital images to support text, instead of only textual information. The platform should also include a patient's medication information when logging in.

Regarding digital communication, some preferred contact through email, apps and chatting for quick, simple questions and video calling for situations in which non-verbal communication was also needed, such as an appointment discussing the diagnosis. HCP initiated contact through SMS, video calling, emails, referrals to additional information on the patient portal and videos explaining medication side effects were also suggested. A chatbot could help to answer questions and refer to a doctor when needed.

Discussion

This qualitative study identified five themes describing the support needs of gout patients: access to care, information, monitoring, coordination between primary and secondary care, and self-management and shared responsibility over care for maintaining health. Patients were receptive to and positive about the use of eHealth in gout care, albeit complementary to face-to-face contact with HCPs.

Patients encountered challenges in promptly accessing primary care, especially during flare-ups, whereas accessing secondary care was typically more timely. Additionally, patients experienced inadequate diagnosis, treatment and lack of knowledge by their GP, as described by previous research [9]. These factors might have led to a preference for specialized hospital (nurse-led) care in this study, which was also found in previous research [29]. For secondary care, patients were more likely to be taking ULT and had less flares [29]. The challenges and preferences regarding care accessibility underscore the need for improved access to timely and effective primary care. Patients' informational needs are also described in previous studies [6, 14, 30–35], as well as the need for a digital central source of information and education for gout [14, 36]. Patients in our study additionally suggested a role for novel techniques, such as Artificial Intelligence-based chatbots and personalized recommendations based on current diet. Providing good information can increase patient knowledge and thereby contribute to improved adherence [11, 12]. We found a need for unambiguous and reliable information, resulting from experiences with conflicting online information. This issue is important to address, since research in patients with chronic diseases shows a relationship between conflicting information and medication non-adherence [37, 38].

In line with other studies, patients expressed a need for more insight into outcome measures and subsequent feedback from healthcare (professionals) [6, 8]. Our study highlights the need for patients to have more control over their health and care, particularly through home monitoring of serum uric acid (sUA) levels using digital devices. While other research shows positive attitudes towards sUA self-monitoring, it does not specifically address the need for additional control over treatment [13]. A UK pilot Randomized Controlled Trial showed that frequent sUA self-monitoring can improve ULT adherence [10]. Future research should focus on enhancing patient responsibility and control, and

evaluate the (cost-)effectiveness of these interventions across different healthcare systems and settings. During our focus group sessions, participants expressed concern about certain groups being left behind as healthcare becomes more digitalized. Other research also indicates barriers for using eHealth due to gout patients' unfamiliarity with technology [36]. However, in our study, participants were generally receptive towards using eHealth themselves. This contradiction may be explained by the fact that participants in this study were generally digitally competent, interested in the topic, and highly educated, but could also indicate that digital competency of gout patients, and the population in general, is increasing.

Implications

This study informs the development of patient-centered eHealth interventions to address support needs. Patients emphasized the importance of timely healthcare access during flares, advocating for digital care options, including weekend medication ordering. They prefer a centralized digital platform for eHealth that offers personalized information, treatment plans, and peer experiences while ensuring medical accuracy [4]. Additionally, patients should be informed about the medical necessity of additional monitoring, as they often desire increased monitoring even when it may not be needed for maintenance doses of ULT. Increased monitoring, including home sUA measurements, can help keep patients engaged with their treatment. Participants expressed concern about some patients being left behind due to digitalization. To address this, support should be provided for those less familiar with technology, and traditional healthcare options should remain available. The study also highlights the importance of face-to-face interactions with HCPs, which patients do not want to lose with eHealth. This aligns with findings from research on other chronic diseases [39, 40]. Patients prefer eHealth to complement, not replace, traditional care, suggesting a blended-care model for gout management is promising.

Strengths and limitations

A key strength of this study is the use of purposive sampling, which provided diversity in patient characteristics such as disease duration and treatment setting, enhancing the quality by capturing a broad spectrum of perspectives. This is important for aligning with the needs and preferences prevalent in the gout patient population. Two experienced moderators conducted the focus groups, resulting in data richness, increasing the likelihood for high-quality data. The study directly links patients' support needs with eHealth suitability, which may improve technology fit, usage, and implementation, as it aligns with the demand from end-users. However, recruitment efforts faced practical limitations, leading to participants from one demographic area and only one female participant, potentially biasing results. Women often experience higher disease severity, negative illness perceptions and higher impact on daily activities, which may cause more and/ or other needs for support [41, 42]. Selection bias may have further impacted the study, possibly favouring patients with positive attitudes towards technology and higher digital and health literacy [43]. We know that people with an education below high school degree are more likely to have low health literacy. This can result in poorer self-management in chronic diseases and thereby different needs and eHealth preferences, e.g. less perceived necessity for having more monitoring, insight and control [44, 45]. While data saturation could not be assessed iteratively, it is expected that no new themes would emerge beyond the three focus groups, as themes were consistently represented across focus groups.

Conclusion

Gout patients expressed the need for timely access to care, detailed information about their condition and treatments, and active involvement in their healthcare. They are willing to embrace eHealth tools as long as they supplement rather than replace traditional care and face-to-face connections with HCPs are maintained. To enhance the adoption of eHealth among gout patients, applications should be user-friendly, personalized, and should be able to offer communication across different digital communication channels. By addressing these considerations, HCPs and policymakers can better meet the needs and preferences of gout patients, enhancing their understanding of the disease and treatment, self-management, and possibly health outcomes.

Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

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