



Research Paper

Self-management behavior preferences and influencing factors in Chinese patients with recurrent gout: A qualitative study

Xinyi Hao ^{a, b}, Aiping Wang ^{a, *}, Hao Huang ^a, Yue Sun ^a, Yingying Duan ^a, Shanwen Sun ^a^a Public Service Department, The First Hospital of China Medical University, Shenyang, China^b Nursing Department, Peking Union Medical College Hospital, Beijing China

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ABSTRACT

Objectives: This study aimed to explore the preferences and influencing factors of self-management behaviors in patients with recurrent gout and provide a theoretical basis for developing targeted strategies to improve self-management preferences.

Methods: A total of 10 patients with recurrent gout were recruited from the gout specialist outpatient clinic at a tertiary hospital in Shenyang, Liaoning Province, China. Semi-structured interviews were conducted with these patients, and the Kawakita Jiro (KJ) method was used to analyze the interview data.

Results: After four rounds of screening by five researchers, 35 codes were selected from an initial 132. After three rounds of discussion and induction, the KJ method identified seven domains of self-management behavior preferences in patients with recurrent gout: 1) extensive knowledge of gout, yet difficulty in distinguishing between accurate and inaccurate information; 2) a passive attitude of “no pain, no management”; 3) the challenge of changing entrenched daily habits; 4) the optimistic but unrealistic belief of “self-delusion”; 5) a tendency to seek medical attention late due to hopelessness of cure and familiarity with recurrences; 6) preference for analgesics for gout recurrences while neglecting long-term urate-lowering therapy (ULT); and 7) gout-related stigma.

Conclusion: The results of this study showed that the self-management behavior of patients with recurrent gout could be improved, especially in the aspects of medical seeking behavior, medication compliance, daily management and emotional management. At the same time, we found that gout stigma, difficulty in distinguishing true and false knowledge of gout and negative attitude of “ignoring pain” were significantly associated with self-management behavior.

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What is known?

- Gout patients exhibit poor self-management, primarily characterized by low medication adherence, unhealthy daily eating habits, and inadequate emotional management.
- Self-management in gout patients is influenced by factors such as a lack of gout-related knowledge and low self-efficacy.

What is new?

- Interviews with recurrent gout patients provided insights into their self-management preferences, covering daily

management, emotion regulation, healthcare seeking, and medication adherence, and highlighted the interplay among these aspects.

- Recurrent gout patients may struggle with filtering relevant information and adopt a reactive approach that impedes effective self-management.
- The stigma associated with gout recurrence affects self-management preferences, indicating the need for psychological support within intervention programs for gout patients.

1. Introduction

Gout is a common and treatable disease caused by the deposition of monosodium urate crystals in articular and non-articular structures. It is the most frequent cause of inflammatory arthritis [1], affecting 41 million people worldwide [2]. The prevalence of

* Corresponding author.

E-mail address: jianghaoran88@hotmail.com (A. Wang).

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gout ranges from 0.1% to 6.8% in different countries, with a rate of 1.1% in China [3]. During a gout attack, patients experience swollen, red joints, leading to motor dysfunction and significantly impacting their quality of life. Additionally, studies indicate that the disease burden of gout patients is severe and continues to rise rapidly [4]. Therefore, there is an urgent need for effective care measures to help control symptoms and reduce the recurrence rate of gout.

Self-management, a concept originating in psychological and behavioral therapy and developed by Thomas Creer in the mid-1960s, involves individuals engaging in preventive or therapeutic healthcare activities with the assistance of healthcare professionals [5]. Lorig and Holman defines self-management as a health behavior in which patients actively participate in activities that promote health and continuously monitor and manage their diseases [5]. Effective self-management requires monitoring physical status, maintaining a satisfactory quality of life, and managing behavioral changes and emotional responses [5]. It primarily encompasses three aspects: medical management, daily life management, and emotional management behavior [5]. Compared to traditional nurse-led continuous care, self-management programs are more effective [6]. Since one fundamental cause of recurrent gout is increased blood uric acid concentration [7], closely related to medication adherence, daily living habits, and mood, patients are often most aware of these factors [8]. Therefore, improving self-management behavior in gout patients is essential.

The current status of gout self-management globally remains suboptimal [9]. The effectiveness of gout treatment is primarily attributed to the implementation of uric acid-lowering therapy, which has gained global recognition [10]. However, studies indicate that only a small proportion of gout patients receive definitive uric acid-lowering therapy. Even among those who do, adherence is often poor, with high rates of treatment discontinuation and low follow-up rates [11,12]. Gout patients can significantly reduce their risk by adjusting their diet [13]. Nevertheless, a study involving 1,003 gout patients revealed that 51% consume excessive alcohol [14]. Beyond dietary management, gout patients often perform poorly in daily life management, such as lack of exercise, inadequate sleep, and smoking [15]. Research has demonstrated variability in self-management behaviors among gout patients based on age, gender, economic conditions, disease duration, and complications, although findings are inconsistent [16–20]. For instance, Chinese scholar Liang et al., reported that gout patients with more comorbidities had poorer medication compliance [20], whereas a review by Scheepers et al. indicated that patients with more comorbidities had better medication compliance [16]. Modifiable factors also influence gout patients' self-management behavior in addition to non-modifiable factors. Mastery of disease knowledge is a crucial factor affecting self-management behavior. Higher levels of disease cognition can enhance treatment compliance by fostering an understanding of the disease's long-term hazards and the importance of self-management. In contrast, patients with lower cognitive levels exhibit poorer self-management [21]. Also, good mental health can improve gout patients' self-management and quality of life. However, due to severe pain during gout attacks and concerns about disease progression, patients frequently experience anxiety, fear, and other psychological conditions, with a higher incidence of depression compared to the general population [22].

Despite a better understanding of the factors influencing gout patients' self-management, the recurrence rate remains high. Therefore, this study will conduct semi-structured interviews with patients experiencing gout recurrence to explore the factors influencing their self-management behavior preferences. This study aimed to understand the relationship between these preferences and the factors affecting self-management in patients with

recurrent gout. This will provide a theoretical basis for developing more targeted strategies to improve self-management behavior in the future.

2. Methods

2.1. Study design

A descriptive qualitative study was conducted. Data were collected through individual semi-structured interviews. The initial interview outline was developed based on a literature review and panel discussion. Subsequently, two gout patients were invited to participate in pre-interviews via purposive sampling, leading to revisions and finalization of the interview outline with the following questions: 1) What impact has gout recurrence had on you? 2) What actions do you take daily to mitigate these effects? 3) What difficulties have you encountered in managing these aspects of your life? 4) How do you address these difficulties? 5) Besides these obstacles, are there any factors that assist you in managing them?

2.2. Recruitment and enrolment

Participants were recruited from the gout specialist outpatient clinic at a tertiary hospital in Shenyang City, Liaoning Province, China, between October 2022 and March 2023. This clinic serves patients from across the country.

Maximum variation purposive sampling was used to ensure the richness of information and diversity of participants, thereby enhancing the credibility of the results. Patients were selected based on the following inclusion criteria: 1) diagnosis by the 2015 European League Against Rheumatism (EULAR)/American College of Rheumatology (ACR) guidelines [23]; 2) at least one gout attack in the past year; 3) age ≥ 18 years, disease duration > 1 year; 4) voluntary participation with signed informed consent. Exclusion criteria included inability to complete the entire interview, difficulty in clearly express experiences and feelings, or insufficient Mandarin fluency.

To achieve maximum variation, patients were included with different genders, ages, marital statuses, places of residence, education, disease durations, and clinical stages. In qualitative studies, sample size determination often depends on the richness of the data collected until data saturation is reached, meaning no new information is obtained from participants. Eight participants reached data saturation, and two additional participants were recruited to confirm saturation. Therefore, a total of 10 patients participated in this study.

2.3. Ethical considerations

This study was approved by the Ethics Committee of the First Affiliated Hospital of China Medical University ([2022] No. 458). After obtaining consent from all potential participants, the study objectives and procedures were explained verbally and in writing. Participants were informed of the voluntary nature of their participation and were given the option to decline or withdraw from the study at any time. The interview data were securely stored, and findings were made publicly available. The researchers ensured strict confidentiality of all data and handled it responsibly throughout the study.

2.4. Data collection

The first author, a nursing student trained in structured interview techniques, personally conducted the semi-structured

interviews. Additionally, pre-interviews were conducted with two patients experiencing recurrent gout attacks to enhance interviewing skills and gain practical experience. Interviews were scheduled based on participants' availability and were conducted in a private setting within the hospital (e.g., a multimedia classroom) to ensure confidentiality and prevent eavesdropping. The investigators and participants were not previously acquainted. Before the interviews, the interviewer explained the study's purpose, significance, and duration, obtained consent to record the sessions, and assured participants that recordings and transcripts would be accessible only to the research team. Participants then signed a formal written consent form before the interviews began. Each interview lasted between 40 min and 1 h and was recorded with participants' explicit consent. Recruitment ceased when data saturation was achieved, indicating no new insights emerged. Recordings were transcribed verbatim by the two principal investigators within 24 h, and participants reviewed the written data to ensure authenticity.

2.5. Data analysis

The collected data were analyzed qualitatively using the KJ method, developed by Japanese anthropologist Kawakita Jiro (also known as Affinity Diagram) [24]. This method, named after Kawakita's English initials, was originally used to organize data from a Nepal expedition. It involves summarizing and integrating complex or unclear ideas and facts based on their mutual affinity, clarifying the relationships between these ideas or facts. The interview data were experienced, sorted, coded, analyzed, and recorded on cards. Cards with similar information were classified and analyzed to create KJ maps. Themes and relationships among themes were identified according to card classification and membership. In recent years, the KJ method has been applied in various qualitative studies. For example, Kyoko Nagata used the KJ method to summarize the subjective experiences and perceptions of community patients with schizophrenia when facing difficulties and their coping strategies [25]. Masahiko Inoue employed the KJ method to qualitatively analyze the benefits and challenges of home-based applied behavior analysis (ABA) for parents of young children with autism spectrum disorder (ASD) [26]. The KJ method is well-suited for collecting qualitative information through field surveys and is particularly effective for extracting and organizing social structures and individual behavioral preferences. Thus, we believe the KJ method is highly appropriate for analyzing the self-management behavior preferences of patients with recurrent gout and examining the relationships among various influencing factors.

Our research team reviewed the transcripts multiple times to gain a deep understanding of the data. Initially, we extracted 132 single-meaning vignettes onto cards, then shuffled and randomly assigned to five researchers for grouping based on similarity. Each researcher reviewed the cards individually, consolidating similar ones. Through a multi-stage selection process, we narrowed the cards down to the 35 most relevant ones. We repeated the grouping process, discussed common themes, and color-coded descriptions on blank cards. Themes were further organized into broader categories until a final topic emerged. Isolated cards were designated for separate groups. Finally, we arranged the cards spatially to clarify relationships (Appendix A), resolving disagreements through consensus. All procedures were conducted collaboratively, and participant quotes were presented verbatim with minimal author annotations. Each procedure was jointly carried out by the five researchers. Quotations in this study are transcribed verbatim from participants' responses, with the only modifications being author annotations enclosed in brackets.

2.6. Rigor and trustworthiness

Five researchers, all nursing postgraduates with varying ages, grades, genders, and research focuses, analyzed the data. To ensure the reliability of the analysis, the researchers received training from KJ methodology experts on appropriately combining, compressing, and labeling statements related to gout recurrence according to the KJ method. Additionally, a KJ methodology expert participated in quality control throughout the process, guiding the method without engaging in discussions. The analysis results were validated through discussions with KJ method experts and two researchers who are experienced in qualitative research. The results were translated from Chinese to English by a Chinese translator, and an examiner compared the Chinese and English records to verify the accuracy of the translation.

3. Results

3.1. Participant characteristics

A total of 10 patients with recurrent gout were enrolled, including one female and nine males. Out of the participants, P2 and P4 were from rural areas, while the other eight participants were from urban areas. Ages ranged from 22 to 83 (43.3 ± 19.55) years. The duration of gout ranged from 1 to 30 (7.60 ± 9.50) years. The Body Mass Index (BMI) varied from 22.9 to 32.8 (28.61 ± 3.41) kg/m². Most respondents had medical insurance and a high monthly income for their families. They had no family history of gout, except for participant P3. The number of gout attacks in the past year ranged from 1 to 25 (7.70 ± 6.77). Participant characteristics are detailed in Table 1.

3.2. Theme extraction

After four rounds of screening by five researchers, 35 codes were selected from an initial set of 132. Through three rounds of discussion and induction, the KJ method identified seven domains. The results revealed that the self-management behavior of patients with recurrent gout is generally poor, reflected in four main aspects: daily management (Theme 3), medical-seeking behavior (Theme 5), medication compliance (Theme 6), and emotional management (Theme 4). These aspects can interact with each other. Additionally, poor knowledge (Theme 1) and low belief (Theme 2) in self-management directly negatively impact self-management behavior, and these two factors can also influence each other. Lastly, the stigma associated with recurrent gout patients (Theme 7) can permeate through the other themes over time.

The following sections describe the current state of self-management behavior preferences among patients with recurrent gout, the factors influencing these preferences, and how these factors relate to self-management behavior. Appendix B illustrates the relationships between themes.

3.2.1. Theme 1: knowledge of gout is vast, yet discerning truth from falsehood is challenging

Patients with recurrent gout often lack sufficient understanding of the disease. They typically underestimate the severity of gout, believing it only causes joint pain that can be alleviated with analgesics. They are unaware that gout if not treated with urate-lowering medication and managed with appropriate daily habits, can lead to organ damage and complications such as hypertension and diabetes. Many patients recognize the need for a strict low-purine diet but struggle to control their condition due to a lack of knowledge about the purine content in foods and their daily purine intake. This knowledge gap can lead them to rely on information from other gout

Table 1

Demographic data of the participants

Number	Age (years)	BMI (kg/m ²)	Marital status	Medical Insurance	Degree of education	Employment Information	Monthly household income per capita (Yuan)	Tophi Stages of gout*	Duration of disease (years)	Number of episodes in the past year (times)
P1	48	35.11	Married	Have	Associate degree	Full employment	5,000	Have c	24	20
P2	34	32.82	Married	Have	Junior high school degree	Full employment	2,000	Have b	10	15
P3	22	27.47	Single	Have	Graduate student	Student	1000,000	No b	3	2
P4	83	22.92	Married	Have	Primary school education	Retirement	3,000	Have a	4	15
P5	34	25.95	Divorced	Have	High school degree	Full employment	8,000	No a	10	10
P6	41	28.06	Married	Have	Bachelor's degree	Full employment	6,000	No a	8	5
P7	26	26.87	Single	Have	Graduate student	Student	4,000	No b	4	2
P8	25	29.37	Single	Have	Associate degree	Full employment	5,000	No b	7	3
P9	63	29.30	Married	Have	High school degree	Retirement	5,000	No b	3	2
P10	57	28.05	Married	Have	Junior high school degree	Retirement	4,000	Have c	22	3

Note: * "a" represents the acute attack period; "b" represents the intermittent period; "c" represents the chronic arthritis period.

patients or online sources, often resulting in the use of inappropriate medications or folk remedies without consulting a doctor. The perceived lower cost or convenience of such information sometimes drives this tendency. Additionally, elderly patients' disease management can be influenced by their family's understanding of gout, which is often incorrect. Overall, patients and their families generally have inadequate knowledge of disease management and express a need for more education and support.

The top card of this theme reads: *"Due to the lack of knowledge, my family and I would blindly trust information from others and online channels. Popularization of knowledge can help my family and me manage the disease."* (C-1)

Code 18: *"I feel that my biggest difficulty is the lack of knowledge. I don't know whether I should avoid all meat or if I can eat a little."* (P2)

Code 20: *"When I first got it, I thought it was a sprained foot. At that time, I ate more meat and bone soup and took more nutritious supplements, but it still got worse."* (P10)

Code 34: *"I hope more information can be made available to people like us who lack knowledge about the disease. Ordinary people like me, with low education levels, do not realize how serious this disease is and did not expect that gout could also affect other organs."* (P2)

Code 19: *"I don't know anything about gout myself. My daughter manages my illness, but her knowledge is also limited and often incorrect."* (P2)

Code 35: *"At home, my mother often cooks low-salt and low-oil dishes for me. I think this may help manage my disease, but she is not very clear about the purine content of food."* (P1)

Code 17: *"I didn't go to the hospital before. I got medication information from friends and online and took the medicine myself, which aggravated the disease. Later, when I saw a doctor, I learned that the dosage and method of medication were wrong."* (P2)

Code 30: *"I usually try some folk prescriptions, Chinese medicine, or food therapies that are said to have no side effects and have short treatment courses, generally taking five or six days to finish."* (P8)

Code 31: *"Many people around me have gout. When we dine together, we talk about high-uric-acid foods, so I try to avoid them,*

or we discuss which medicines they have recently used, and I might try those." (P5)

3.2.2. Theme 2: the passive attitude of "no pains, no management."

Patients with recurrent gout demonstrate inadequate self-management beliefs. They often perceive gout as having a minimal impact on their daily lives. Even when joint pain is severe, they tend to rely on painkillers for relief rather than focusing on comprehensive disease management. Additionally, many individuals show strong resistance to external influence or guidance from peers. They are reluctant to incorporate outside perspectives into their disease management approach, even if it means relinquishing some control over self-management. Despite recognizing the importance of effective disease management, they appear unwilling or resistant to changing maladaptive behaviors.

The top card of this theme reads: *"I think taking painkillers is sufficient when gout hurts, and I don't plan to manage it in my daily life. Others don't play much role in disease management; patients are the most important part of managing their disease."* (B-4)

Code 27: *"I feel that managing gout relies mainly on self-discipline; you need to control yourself. Others cannot play much role in managing your disease—the most important factor is yourself."* (P7)

Code 28: *"I don't take gout seriously, even though I often see a lot of related information on my phone and TV, I don't pay attention to it because no matter what diet contraindication gout has, when I crave, I still eat and drink as usual."* (P8)

Code 29: *"Despite doctors advising against drinking, I still drink. I don't insist on taking my medicine regularly. It's like those who don't learn until they hit the wall—like some parents who say things are true, I don't want to listen until I experience it myself. People can be stubborn."* (P6)

Code 7: *"I don't pay much attention to gout. I never look it up online, and it doesn't impact my life significantly. It's not as serious as other diseases. The symptoms are joint pain, which can be treated with some medicine."* (P4)

Code 8: *"Initially, I didn't take gout seriously. I didn't understand the disease well and thought it wasn't serious enough to worry about. I believed that taking painkillers when I had joint pain was sufficient, so I neglected long-term management."* (P2)

Code 26: *"I view this disease similarly to diabetes and hypertension, which are chronic and incurable. Since gout isn't particularly uncomfortable, there's no need for specific management."* (P5)

3.2.3. Theme 3: altering entrenched daily habits is an arduous task

Overall, patients with recurrent gout demonstrated poor daily management behaviors. Regarding diet management, they struggled to change their previous unhealthy eating habits, such as excessive drinking or selecting foods based on mood or preference rather than purine content. Firstly, they argued that consuming their favorite foods is crucial for their quality of life, and they felt their lives would lose meaning if they entirely gave up these foods. Secondly, they noted the numerous temptations in life. When dining out or attending parties, they focused on immediate pleasure rather than dietary considerations. Most importantly, patients with recurrent gout exhibited a certain degree of wishful thinking. When they consumed foods that were contraindicated for gout but not perceived as highly likely to trigger an attack, they considered these foods to be "safe" and chose them to satisfy cravings. Conversely, they completely avoided foods they believed were guaranteed to induce gout attacks.

Regarding water consumption, some patients found it easy to drink adequate amounts due to previous positive experiences with water alleviating gout symptoms. However, others whose gout attacks severely affected their physical function and independence did not drink much water daily. In terms of exercise management, most patients with recurrent gout experienced varying degrees of physical decline. Coupled with their laziness and lack of self-discipline, they failed to adhere to regular exercise routines.

The top card of this theme reads: *"I think it's enough to take painkillers when gout hurts, and I don't plan to manage it in my daily life. Others don't play much role in disease management, and the patients ourselves are the most important part of disease management."* (B-4)

Code 32: *"I don't like to exercise and walk because I'm so lazy that I want to drive to the bathroom."* (P6)

Code 33: *"In the past two years, I have exercised regularly so that gout has not recurred. In the past two years, the gym has been closed because of COVID-19, coupled with people having inertia; I have no exercise, eat more, and feel that the number of gout attacks is also more."* (P5)

Code 4: *"I don't like to drink water myself. Now I am old, and my urination function is not good, so I don't drink too much water. Because of gout, I can't get out of bed and bother others to wait for me to go to the toilet, so I usually drink very little water."* (P2)

Code 5: *"I am not good at exercise now because my legs hurt, I can't exercise normally, and it's hard to go to the toilet. Even if it doesn't hurt, I dare not walk more because sometimes it hurts too much."* (P4)

Code 3: *"My difficulty in managing my disease is that there are too many temptations in my life, and sometimes I can't control them. I don't care about anything when I'm having fun with friends. If I'm in the mood, I just do it first."* (P9)

Code 6: *"I know that gout needs to control diet, but I can't. The key reason is that gout prevents me from eating too many things. If these things are not allowed for me to eat, then what is the point of my life?"* (P3)

Code 9: *"When I was diagnosed 20 years ago, I didn't have any taboos about diet at all. I ate and drank with my colleagues almost every day. Even if the gout attack did not affect my participation in the wine bureau."* (P10)

Code 10: *"After eating barbecue or hot pot, it is not 100% certain that I will have an attack. If I take it ten times, the gout may attack once or twice, and if I take uric acid-lowering drugs in advance, it may not recur. To be honest, I still have a fluke psychology."* (P5)

Code 13: *"I think drinking plenty of water is important. One night, when my feet were not feeling too good, I slowly drank two liters of water. My feet were much better the next morning, so I usually drink plenty of water."* (P5)

Code 15: *"I am not a water person, but I will drink more water after gout because I think this is a very easy thing to do, insist on drinking water rather than other more painful tasks I can do."* (P9)

3.2.4. Theme 4: the optimistic sentiment of "self-delusion"

In the event of a gout attack, patients typically employ various pain-reducing measures, including medication or the application of hot water bags. According to patient reports, enduring recurrent gout attacks over time has led to psychological conditioning that helps them better manage the pain, thereby reducing the prevalence of destructive emotions during these episodes. Nevertheless, some individuals reported difficulties in regulating their feelings during gout-induced pain, leading to frequent disputes with family members and perceiving the pain from gout as more unbearable than death itself.

The top card of this theme reads: *"I have a certain expectation for the situation when gout attacks, so I will take quick measures to control the pain, such as taking painkillers or drinking water, but when the pain cannot be controlled, it is difficult for me to control my emotions."* (B-4)

Code 14: *"After so many years of illness, I have psychological expectations about the situation of a gout attack so that I will accept it, and I will not have negative emotions. I will prepare a hot water bag and take the medicine in advance."* (P5)

Code 24: *"After all, I ate all the food I shouldn't have eaten; it's useless to regret it. When an acute gout attack occurs, just take medicine to control the pain and pay more attention to it in the future. My mentality has always been ok."* (P1)

Code 1: *"Because I know why it happens, I feel that the situation is still within my control, so I don't have too much worry and anxiety; just think about managing it slowly in my daily life."* (P9)

Code 25: *"Attack when what also can't do, want to do can't do in the heart anxious, the mood is very depressed, then I always angry with my wife, in fact not much thing, but I just can't control my emotions, easily angry, the more angry the pain."* (P10)

3.2.5. Theme 5: hopeless of cure and accustomed to recurrences, medical attention is tardily sought

The delayed medical treatment-seeking behavior observed in patients with recurrent gout reflects poor health-seeking habits. Gout is often perceived as a chronic condition that does not typically lead to mortality, and despite seeking medical intervention, there is no definitive cure or targeted medication available. Additionally, individuals often doubt smaller medical facilities while feeling uneasy about larger hospitals they trust due to high patient volumes. Consequently, patients with recurrent gout may need medical attention and monitor their condition, especially if symptoms worsen or the frequency of attacks increases.

The top card of this theme reads: *"I do not trust small hospitals, but it is troublesome to seek medical treatment in large hospitals. I feel gout is an incurable chronic disease and is not very serious, so there is no need to go to the hospital for treatment. At the same*

time, I do not dare to face my real health status, so I do not like to go to the hospital.” (B-4)

Code 11: “Gout attacks once or twice a year; I didn’t take it seriously at all, so I didn’t go to the hospital. This time, the pain is severe, and the recurrence is frequent. I just came to the hospital to see if my condition was aggravated.” (P3)

Code 11: “Gout attacks once or twice a year; I didn’t take it seriously at all, so I didn’t go to the hospital. This time, the pain is severe, and the recurrence is frequent. I just came to the hospital to see if my condition was aggravated.” (P3)

Code 22: “I feel that I don’t dare to face my true health condition at my age. I know I haven’t practiced a healthy lifestyle well, so I don’t dare attend the hospital for a physical examination. If I don’t check, I’m not sick. In fact, I’m escaping.” (P7)

Code 23: “I don’t trust the small hospital nearby, so I’d better not go. If I came to the hospital, I would come to the good hospital I trust. But there are so many people in the good hospital who are suffering and uncomfortable, so I don’t like to.” (P4)

3.2.6. Theme 6: prioritize analgesics for gout recurrences, neglecting long-term urate-lowering therapy

Patients with recurrent gout exhibit suboptimal medication adherence, prioritizing concerns about the side effects of urate-lowering drugs over their potential therapeutic benefits. Additionally, the episodic nature of gout may lead to forgetfulness regarding the need for medication during asymptomatic periods. Patients often administer painkillers only when a gout attack is imminent or underway, aiming to alleviate their symptoms urgently.

The top card of this theme reads: “Only when gout attacks or is about to attack, I can think of taking medicine to control or prevent it. I can’t think of taking medicine when it doesn’t hurt. And I was reluctant to take uric acid-lowering drugs because I was worried about the side effects.” (A-12)

Code 16: “I know this medicine should be taken all the time, but when I took it for about a week and felt that the uric acid had dropped, I stopped taking it. Then, I will control it in my daily life. After all, it also has side effects and kidney damage.” (P1)

Code 2: “When I am in pain, I will remember to take medicine, and when I am not in pain, I will forget to take medicine. Unless you put the medicine in my mouth, I will not have time to take medicine when I am busy.” (P5)

3.2.7. Theme 7: stigma of gout

Stigma may lead to a lack of self-management behaviors in a minority of gout patients.

Code 12: “I taboo that people know I have gout; I prefer it to be private. I feel uncomfortable when people tell me to drink less because I’m a gout patient; I want to be treated like a normal person.” (P9)

4. Discussion

This descriptive qualitative study revealed that patients with recurrent gout displayed poor self-management across several areas, including healthcare-seeking behaviors, medication adherence, daily management, and emotional management. These findings are consistent with Yao et al.’s survey [27]. Many patients with recurrent gout, having experienced the disease for an extended

period, believe they have been “cured for a long time.” Their years of experience lead them to feel a certain degree of certainty about gout attacks, and they may doubt the effectiveness of medical treatments. Consequently, they may not seek hospital care unless symptoms become more severe or frequent, related to poor health literacy [28]. It is also noteworthy that some participants reported avoiding smaller hospitals due to doubts about their authority, although the high patient volume and complexity of treatment in tertiary hospitals can be off-putting.

Overall, patients with recurrent gout demonstrated significant delays in seeking medical care, which may impact their knowledge acquisition and beliefs. Many participants expressed that earlier hospital visits might have prevented the severity of their current condition. The healthcare-seeking behavior of patients with recurrent gout is also linked to medication adherence and daily management [29]. However, this study did not specifically address the relationship between these factors. Therefore, it is suggested that addressing the issue of inadequate medical resources is crucial. Improving the quality of medical services in primary care settings, developing a hierarchical medical system, and ensuring effective patient diversion are essential. Additionally, from a hospital management perspective, adopting advanced information systems and technological means should enhance work efficiency and the quality of medical care.

Painkiller adherence among patients with recurrent gout could have been improved, with few participants adhering to urate-lowering therapy (ULT). Research indicates that satisfaction with medication effectiveness is an independent risk factor for medication non-adherence [21]. In our study, patients tended to use painkillers or urate-lowering drugs only during gout attacks, while their concerns about the side effects of urate-lowering drugs often overshadowed their perceived benefits, leading them to seek ineffective alternatives. These findings are partially consistent with previous studies [30,31]. Additionally, some participants were unclear about the method, dose, and timing of gout medication, resulting in medication errors. This suggests that health education for gout patients should focus on emphasizing the effectiveness and necessity of uric acid-lowering therapy while also providing clear and comprehensive information about potential side effects.

The daily management behaviors of patients with recurrent gout still require improvement. All participants agreed that their condition could be enhanced by modifying their lifestyle; however, they reported difficulties in implementing these changes and often failed to follow through. On the one hand, participants noted the need for comprehensive self-management knowledge. For instance, they were unaware of the specific purine content in foods, the recommended daily water intake, or the optimal timing and amount of exercise. On the other hand, even those who understand management principles found it challenging to adhere to them. They explained that numerous temptations, such as appealing food or wine, made self-control difficult. It is important to note that participants identified alcohol consumption as a significant barrier to self-management. They pointed out that participation in drinking events was sometimes driven not only by personal preference but also by necessity. In China, engaging in alcohol-related social activities serves various social functions, including daily interactions and business transactions. These activities reflect the culturally ingrained moral, emotional, and interpersonal values associated with alcohol consumption. Due to the deep-rooted drinking culture, participants felt helpless in drinking situations, even if they were voluntary. Thus, the entrenched drinking culture in China presents additional challenges for lifestyle modification, which is crucial for effective gout management. This finding suggests a need to promote public awareness of gout to reduce alcohol consumption among patients in a culture with pervasive drinking

habits. Alternatively, healthier social activities could be recommended to patients with recurrent gout, such as tea-drinking with friends or colleagues, hiking, or other forms of recreational exercise.

Regarding exercise, a few participants did not engage in regular physical activity due to simple laziness or the impact of the epidemic. Seeking support is essential for adherence [32], but patients with recurrent gout did not seek additional support in this area, which warrants further investigation in future studies. It is important to acknowledge that patients with recurrent gout experience a significant decline in physical function, directly affecting their ability to adhere to regular exercise or even perform basic tasks such as going to the toilet independently. This decline also contributes to their insufficient water intake. Moreover, most participants reported being in a good mood during interictal periods, attributing their previous indulgences as causes of their condition. Only a few patients described feeling irritable due to recurrent gout attacks, and they struggled to manage this negative emotion, leading to a loss of confidence in managing their condition and causing family disputes. This poor emotional management also negatively impacted other aspects of their self-management. A study indicated that psychological distress in individuals with gout was significantly associated with difficulties in obtaining gout medication from the pharmacy, treating gout flares, and accessing information and education to manage gout effectively [33].

The lack of gout-related knowledge among patients with recurrent gout can directly lead to poor self-management behaviors. It can also indirectly impact self-management by diminishing patients' self-management beliefs. Providing appropriate and comprehensive information about the disease has improved adherence to ULT [34]. Most participants reported having some knowledge of gout, but it was often neither comprehensive nor entirely accurate. This aligns with the findings of Yin et al. [21]. For instance, most participants were unaware that their initial attack was gout; they believed it was joint damage caused by improper exercise, leading them to rest at home or take nutritional supplements instead of seeking timely medical treatment. Upon receiving a gout diagnosis, participants sought information from various sources, including the Internet, television, health professionals, other patients, and family and friends. While they considered health professionals the most reliable source of information, they found them to be the least informative. Conversely, a Korean study indicated 71.9% of patients received gout education during outpatient visits [35]. Consequently, patients experiencing a relapse often resorted to trying online or peer-transmitted information, such as herbal remedies or dietary changes [36], without verifying its effectiveness. Additionally, some participants believed that family support could aid in disease management, but family members' understanding of the disease was often inadequate. Medical institutions could address this gap by assigning specialized nurses to handle education on gout recurrence, explaining the necessity and benefits of ULT to patients, and addressing concerns about potential side effects. Developing educational manuals or creating popular science videos could also enhance patients' understanding of ULT.

Self-management beliefs among patients with recurrent gout serve as a mediating factor between a lack of knowledge and self-management behavior. Participants often perceived gout symptoms as mere hot and red pain in the joints, which they believed could be effectively managed with short-term painkillers and did not significantly impact their daily lives. They were generally unaware of long-term complications of gout, such as tophi, joint damage, and uric acid-containing kidney stones, until they experienced severe manifestations or observed complications in others. Consequently, they did not focus on controlling the disease through

daily management. Participants typically only made slight adjustments to their unhealthy eating habits or took uric acid-lowering drugs during acute gout attacks. Once the acute stage passed, they reverted to their previous neglectful behaviors. This “out of sight, out of mind” attitude made them reluctant to learn more about gout and actively change their behaviors. Although family support was mentioned as potentially helpful, its impact on self-management beliefs was minimal and not substantial.

One participant reported experiencing stigma related to gout, expressing a desire to be perceived as a normal person rather than a gout patient. This stigma, identified as a key aspect in this qualitative study, may subtly influence self-management beliefs, disease management, and knowledge acquisition over time. This finding aligns with a study by a New Zealand researcher [37]. The highlighted experiences emphasize the need for measures to improve self-management behaviors in patients with recurrent gout, considering both the disease's treatability and long-term implications. The factors identified in this study can guide the development of targeted interventions. Furthermore, leveraging technological advancements, such as the Internet and mobile applications, can facilitate the delivery of health education, enhancing patient knowledge and management attitudes toward gout. Addressing the subtle effects of stigma is particularly important in this context.

5. Limitations

This investigation has several limitations. First, the study recruited participants exclusively from a specific medical facility, which may limit the applicability of the results to other contexts. The sample predominantly included individuals with relatively higher economic status, which restricts the generalizability of the findings to those with lower economic status. The results highlight individuals with recurrent gout need to acquire more knowledge and develop positive management attitudes to improve their self-care practices. Future research should consider including participants from lower socioeconomic backgrounds to validate these findings. Additionally, although the male-to-female ratio among the 10 recurrent gout patients interviewed was consistent with the typical gout demographic (more men than women), this imbalance may influence the results. Future studies should aim to include a more balanced representation of female patients. Furthermore, ensuring reproducibility may be challenging, as researchers' interpretations and ethical considerations significantly influence the outcomes.

6. Conclusions

The results of this study indicate that the self-management behaviors of patients with recurrent gout could be improved, particularly in terms of medical treatment behavior, medication compliance, daily management, and emotional management. Among these, poor emotional management can adversely affect the other three aspects, while medical treatment behavior is linked to both medication compliance and daily management. Additionally, we identified that gout stigma, a lack of gout-related knowledge, and insufficient self-management beliefs significantly impact self-management behaviors. A deficiency in knowledge and weak self-management beliefs can result in poor self-care, and these factors can influence each other. Gout stigma can further affect behavior through these interactions.

Data availability statement

The datasets generated during and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Credit authorship contribution statement

Xinyi Hao: Conceptualization, Formal Analysis, Investigation, Methodology, Project administration, Supervision, Validation Visualization, Writing - original draft. **Aiping Wang:** Conceptualization, Project administration, Supervision, Writing - review & editing. **Hao Huang:** Formal Analysis, Project administration. **Yue Sun:** Formal Analysis, Visualization, Methodology. **Yingying Duan:** Formal Analysis, Validation, Writing - original draft. **Shanwen Sun:** Formal Analysis, Data curation.

Declaration of competing interest

The authors have declared no conflict of interest.

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Appendices. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijnss.2024.10.001>.

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