Patient Preference and Adherence

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ORIGINAL RESEARCH

# Experiences of Chinese Rheumatoid Arthritis Patients Who Chose Western Medicine, Traditional Chinese Medicine, and a Combination of Treatments: A Study Based on Interviews and Thematic Analysis

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**Background:** This qualitative study, part of a prospective mixed-methods research, aimed to gain insights into the medical experiences and disease perceptions of Chinese patients living with rheumatoid arthritis (RA). Specifically, the study examined how RA patients' perceptions of their disease were influenced by the diagnosis and treatment they receive.

**Methods:** RA patients undergoing treatment were invited to participate in this qualitative study. Face-to-face semi-structured interviews were conducted among 18 patients, and the collected data were analyzed using thematic analysis.

**Results:** The 18 participants in this study had a mean (SD) age of 58, a median disease duration of 6.5 years, and a predominance of female subjects (17 out of 18). The qualitative analysis identified two themes with six sub-themes: 1. Patients' experiences of treatment: discovery of the disease, misdiagnosis and mistreatment, and patients' treatment choices; 2. Feelings about the disease: psychological impact, reflections on the disease, and expectations of treatment.

**Conclusion:** This study provides valuable perspectives and data to enhance the understanding of the relationship between patients' illness perceptions and their healthcare choices.

**Keywords:** rheumatoid arthritis, qualitative study, illness perception, patient choice

## Introduction

Rheumatoid arthritis (RA) is a chronic autoimmune disease characterized by progressive joint damage, loss of joint function, and the occurrence of various complications.[1] The 2021 American College of Rheumatology Guideline for the Treatment of Rheumatoid Arthritis emphasized the need for early evaluation, diagnosis, and management of RA.[2] However, the low disease awareness and poor patient compliance in China have resulted in low rates of early diagnosis and hindered the implementation of the "treat to target" approach, led to non-standardized treatment practices, and contributed to a high disability rate among RA patients.[3] Recognizing the critical role of patients' disease perception in the treatment and prognosis of RA, the 2020 Practice Guidelines for Patients with Rheumatoid Arthritis published in China stressed the necessity for patients to understand the disease, follow expert diagnosis and treatment guidelines, and cooperate with doctors in diagnosis and treatment.[4] Unfortunately, most RA patients in China currently lack systematic and standardized health education, resulting in challenges related to medication adherence, lifestyle modifications, psychological support and consultations, and follow-up care. Additionally, there is a notable lack of research on disease perception among RA patients in China.

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People's perceptions of disease are inherently shaped by social and cultural backgrounds. In China, the medical landscape has long been featured by the significant role of Traditional Chinese Medicine (TCM), which differs from the Western conception of complementary and alternative medicine. Professionals practicing TCM in China are subject to the regulation by the National Health Institutions of China, and are required to undergo examinations to obtain certification as licensed practicing physicians, commonly referred to as doctors. Notably, certain therapies derived from TCM have been proven to be effective in RA treatment.[5,6] The accessibility of Chinese medicine hospitals and outpatient clinics, coupled with the medical insurance coverage for TCM treatment costs, provides Chinese patients with the convenience of choosing TCM therapy for RA. Therefore, patients in China can choose anti-rheumatic therapy, TCM, or a combination of both approaches for RA treatment based on their individual needs.

In mainland China, patients can go directly to the hospital and choose the department they want to consult without first going through primary care or being referred by a general practitioner. In general, patients visit the hospital outpatient center independently, select a specialty for medical services at the registration desk, usually based on their personal judgment of symptoms. Therefore, the patient's choice of department is crucial, which directly affect their subsequent treatment. Moreover, in mainland China, when doctors determine that patients with chronic diseases are in a mild condition, they will ask them to come to the hospital regularly for follow-up and prescription of medication. Only when doctors determine that the patient's condition is serious will they recommend hospitalization. After treatment, once the patient's condition is stabilized, the patient will be discharged from the hospital to continue regular outpatient follow-up treatment.

The purpose of this study is to gain an in-depth understanding of the experiences and perceptions of Chinese RA patients, from disease onset, to seeking medical care, confirming the diagnosis, selecting a physician, and undergoing treatment. RA patients are the ones who experience the pain, and the results of this study endeavor to offer a patient-centric insight into the RA experience. This perspective can be invaluable in aiding helps physicians to understand their patients better and develop greater empathy.

## Methods

This qualitative study is one component of a prospective mixed-Methods study designed to assess the impact of the outpatient visit process on RA patients' perceptions of their illness. Specifically, this study explores how patients' perceptions of their illnesses are affected by the diagnoses and treatments they receive. To gain insights into the experiences of RA patients regarding diagnosis and treatment, one-to-one semi-structured interviews were conducted.

The study complies with the Declaration of Helsinki. Ethical approval was obtained from the Ethics Committee of Beijing University of Chinese Medicine and Peking University Third Hospital. And before participation, patients signed written informed consent that included consent for the publication of anonymized data.

### Participants

Patients were recruited from the rheumatology outpatient clinics and Chinese medicine outpatient clinics of Peking University Third Hospital and the rheumatology specialist outpatient clinics of a Chinese medicine hospital in Beijing.

Eligibility criteria for participation included: (1) diagnosed with RA in accordance with the American College of Rheumatology (ACR) and EULAR criteria; (2) age above 18 years; (3) voluntary provision of informed consent.

Exclusion criteria were: (1) co-morbidity with other rheumatic immune diseases; (2) tumors or other conditions that seriously affected disease perceptions or mental disorders; (3) pregnancy.

All patients participated voluntarily.

The sample consisted of males and females, as well as those treated by rheumatologists, those receiving alternative therapies (TCM treatments) and those receiving combination therapies. Purposive sampling was conducted to gain a broader understanding of patients' experiences and perceptions. The recruitment process adhered to the principle of maximum differentiation, inviting patients with varying lengths of time since diagnosis, different ages, and diverse treatment approaches to be interviewed. Patient recruitment was conducted by the researcher in the outpatient clinic, and continued until theoretical saturation was achieved.

## Data Collection

All interviews were conducted by the same researcher and took place in the outpatient clinics of the two hospitals. Each interview lasted approximately 30 minutes.

The semi-structured interviews covered the following key areas:

(1) the experience of the disease discovery, the diagnosis process, and the subsequent treatment journey; (2) the physical and psychological experience following illness; (3) the patients' expectations for the future; (4) other unsolicited topics.

Each interview commenced with an open-ended question, inquiring how the patients initially learned about their RA diagnosis. Subsequent questions were framed according to the interview outline, with the sequence adjusted based on the actual patients' responses. All interviews were recorded. Interview questions are provided in Appendix.

## Analysis

The data Analysis for this study was carried out using inductive thematic analysis,[7] and the NVIVO 12 was employed for data coding and thematic extraction.

The analysis proceeded through several steps:

Transcript creation: Transcripts were generated from the audio recording of the whole interview, incorporating detailed accounts of the interviews as recalled by the interviewers;

Familiarization: Two researchers, one of whom was the interviewer, listened to the audio recordings and read the interview transcripts repeatedly to familiarize themselves with the data.

Coding: After familiarization, the transcripts were coded back-to-back by two researchers, using an inductive approach, where codes were generated based on patterns that emerged from the data.[8]

Theme development: After completing the coding process, two researchers worked together to review and categorize the coding into potential themes. These themes were then reviewed, named, and identified as the experiences and feelings of people with RA.

The research interviews were held in Beijing, with both the interviews and subsequent data analysis conducted in Chinese. Upon completing the data analysis, the researcher collaborated with professional English translator to render the content into English. To ensure precision and authenticity, independent individuals without a research affiliation reviewed the translated English text and confirmed its representation of the original Chinese content.

# Results

## Descriptives

A total of 18 patients participated in the interviews. Of these 18 patients, seven were undergoing treatment with disease-modifying antirheumatic drugs (DMARDs) in the Rheumatology Department, six had transitioned to TCM therapies after discontinuing treatment in the Rheumatology Department, and five were concurrently receiving both DMARDs and TCM treatment. The interviewed patients had a mean age of 58.0 years (SD=14.5 years), and the time since their first definitive diagnosis ranged from 0 to 47 years, with a median duration of 6.5 years. The participant group consisted of 17 females and one male. A summary of the characteristics of the interviewed patients is provided in Table 1.

## Themes

The qualitative analysis identified two major Themes with six sub-themes: 1. Patients' experiences of treatment: discovery of the disease, incorrect diagnosis and treatment, patients' treatment choices; 2. Feelings about the disease: psychological impact of the disease, reflections on the disease, and expectations of treatment.

# Patients' Experiences of Treatment

## Discovery of the Disease

As outlined in the recent Chinese guideline for RA diagnosis and treatment, the early detection of RA is crucial for effective treatment and improved prognosis. Diagnosing the disease requires an evaluation of a patient's clinical symptoms, alongside laboratory and imaging assessments.[9] Most of the patients interviewed sought medical help due

**Table 1** Patient Characteristics

| ID | Age(y) | Gender | Time since the First Definitive Diagnosis(y) | Current treatment |
|---|---|---|---|---|
| 1 | 73 | F | 40 | TCM |
| 2 | 59 | M | 4 | TCM |
| 3 | 33 | F | 0.1 | TCM |
| 4 | 76 | F | 0.5 | ITCWM |
| 5 | 35 | F | 5 | TCM |
| 6 | 81 | F | 47 | ITCWM |
| 7 | 38 | F | 2.5 | ITCWM |
| 8 | 74 | F | 26 | ITCWM |
| 9 | 50 | F | 13 | ITCWM |
| 10 | 52 | F | 0.1 | DMARDs |
| 11 | 68 | F | 2 | DMARDs |
| 12 | 60 | F | 19 | DMARDs |
| 13 | 74 | F | 8 | DMARDs |
| 14 | 51 | F | 1.5 | DMARDs |
| 15 | 46 | F | 12 | DMARDs |
| 16 | 60 | F | 18 | DMARDs |
| 17 | 54 | F | 20 | TCM |
| 18 | 60 | F | 3 | TCM |

**Abbreviations**: F, female; M, male; y, year; TCM, traditional Chinese medicine; DMARDs, disease-modifying anti-rheumatic drugs; ITCWM, integrated traditional Chinese and Western medicine.

to joint pain. Contrary to textbook descriptions that primarily associate initial pain with small joints, patients reported that pain could occur in any mobile joint from head to toe.

Patient 2: The earliest symptom was a sudden pain in my wrist, and it felt like I thought I had gout.

Other patients described their first symptoms as predominantly red and swollen joints.

Patient 6: I thought I had frostbite, (the joints) were red and, oh so red and painful.

The early recognition of symptoms can directly influence a patient's subsequent choice of medical care.

Patient 9: I could not lift my shoulder and it hurt. The pain in my shoulders was intermittent and alternated and I just assumed at the time that it was a bone disease, and, yes, I went to the orthopedics department to seek treatment.

## Incorrect Diagnosis and Treatment

Public awareness of RA remains low in China, with a 2017 survey revealing that nearly 90% of the population was unaware of the appropriate consultation department for RA. Patients' medical choices are influenced by their symptom perceptions, prior medical knowledge, and past healthcare experience. Only a small portion of the interviewed patients, three in total, selected the Rheumatology Department on their first visit and received prompt and accurate diagnosis, with the others suffering from varying degrees of delayed diagnosis. Among the interviewed patients, a notable number initially sought medical attention from the Orthopedics Department.

Patient 9: I just assumed at the time that it was a bone disease, yeah, so I just went to the Orthopedics Department for treatment, received injections and fluids, and it just got worse and worse.

This choice reflects the cultural and medical traditions in China. TCM has a long-standing history of research in orthopedics, while rheumatology and immunology have been developed more recently. Consequently, those experiencing

joint pain in China often attribute their symptoms to bone-related issues. As a result, when faced with discomfort in bones, joints or periarticular soft tissue, many patients initially seek consultation with orthopedic specialists.

Patients with predominantly hand and wrist pain are frequently misdiagnosed with tenosynovitis in the Orthopedics Department and treated with Diclofenac diethylamine cream. Those with primary complaints of knee pain and activity limitation are often misdiagnosed with osteoarthritis or joint strain and often treated with Sodium Hyaluronate Injection. Some patients are not provided with a definitive diagnosis and only receive symptomatic treatment.

However, two interviewed patients reported being relatively fortunate. They were treated in the orthopedics department for only a short period before the doctors, recognizing the ineffectiveness of the treatment during follow-up appointments, evaluated the patients' rheumatological and immunological indices and referred them to the Rheumatology Department.

> Patient 14: I initially only experienced bone pain, therefore I went to the Orthopedics Department rather than the Rheumatology Department. I took an X-ray and then he (the orthopedic doctor) advised me to come to the Rheumatology Department to confirm the diagnosis.

Another department often chosen by patients is sports medicine, where sports medicine physicians rendered diagnoses such as fasciitis or synovial hyperplasia depending on the patient's initial symptoms. Two interviewed patients said they had such experiences, with one undergoing a synovectomy.

> Patient 10: I had foot pain at first. I went to sports medicine. He (the doctor) said it was just fasciitis.

> Patient 12: I went to sports medicine at first and had the synovium removed, as he (the doctor) said it was synovial hyperplasia. But it did not get better after that.

## Patients' Treatment Choices

The Rheumatology Department has a relatively recent establishment history in China, and there is a disparity in medical resources and quality of care across different regions, alongside variations in the expertise of doctors.[10] TCM has long been favored by local patients for the treatment of RA. Therefore, patients face multidimensional choices in terms of the model of care, the care location, the hospital, the doctor, and others.

> Patient 9: We tried to grasp at any straw. Anyway, I heard that there is a doctor in Shandong Province who specializes in treating RA, so I went to Shandong. Then I heard that there is a doctor in the city of Suzhou who specializes in treating RA, so I went to Suzhou. But the authority (experts) is still in Beijing.

Many interviewed patients mentioned their experiences to various hospitals and locations in pursuit of the most suitable care. The statements of the interviewed patients revealed that the perception of the disease significantly influenced the patients' decisions regarding whether to seek care in the TCM department or the Rheumatology Department. Most of the patients who chose the TCM Department mentioned the word "Tiaoli".

> Patient 7: I think this disease is systemic, and it's only when you get your whole body toned up that you can fight it. And then Western medicine, I have been trying before. Western medicine is, how to say, I feel that it's just more targeting, but it's not good at regulating the whole body.

"Tiaoli" in the Chinese health concept refers to restoring the balance of various substances and internal organs within the body, enabling it to regain its healthy function. In TCM, the body is viewed as a holistic entity, where any disease affecting a specific part of the body is believed to be the result of imbalances in the body's overall system. Accordingly, treatment should also be considered holistically, coordinating qi and blood, yin and yang of the body to maintain balance and promote overall health. Patients who seek care at TCM outpatient clinic for treatment are devotees of this concept and believe that taking Chinese medications can help them improve their health from within.

The interviewed patients were more inclined to visit the TCM Department if they perceived their symptoms to be related to TCM's understanding of the illness cause, such as "cold" and "dampness".

> Patient 5: This disease is the result of being young and not keeping warm, and freezing.

Patients attributing their disease to an "immune deficiency" are more likely to consult a rheumatologist. Although RA is indeed the result of an immune disorder, patients often hold a firm belief that it stems from immunocompromised.

> Patient 16: Rheumatoid arthritis is immunocompromised.

The therapeutic and negative effects are also important factors influencing the choice of medical treatment. Patients weigh these effects to determine whether to continue their current treatment or explore alternatives. TCM, as a complementary and alternative medicine, offers more options for patients when they have received poor treatment outcomes or serious negative effects from one medical modality.

> Patient 5: I had difficulty with Western medicine due to its pronounced side effects. While others may have no reaction after taking the medicine, I often struggled with diarrhea. The worst incident involved inadvertently pooping on the bed. Moreover, the treatment effects consistently fell short in comparison to the side effect. The treatment (test index) values even fall by 0.01 each time, and the decrease was minimal. Then the doctor suggested that I should see a TCM practitioner.

Regarding regional options, a patient's choice of whether to receive treatment locally or in a different location, such as Beijing, can be directly influenced by differences in medical quality and cost. Patients thoroughly evaluate their options when choosing hospitals and doctors based on factors such as the reputation of the hospitals and doctors, the location, the treatment effectiveness, the treatment cost, the registration convenience, and admission procedures of the hospital.

> Patient 1: I initially took the medication prescribed by the doctor I had previously attended, but it was difficult to get an appointment with him. Then I signed up to go to his students for treatment. Regardless, I chose my doctor for convenience. Then I moved to a community near this hospital, so I started consulting with a doctor who practiced there.

# Feelings About the Disease

## Psychology of the Disease

Some interviewed patients admitted initially struggling to accept their illness, while others said they had come to accept it. Most patients who found it hard to accept their condition often showed resistance and a pessimistic outlook, believing that RA is "costly and painful for the rest of their lives". They were reluctant to learn about RA and had thoughts of quitting therapy or even contemplating suicide.

> Patient 18: I think the less I know (about the disease) the better. I cannot accept I have this disease, mainly because I do not think it can be cured.

In contrast, patients who accepted their condition tended to have a more positive and open mindset, believing that RA is a chronic disease and that a good attitude can positively influence their treatment. These patients reported that they initially considered rejecting their diagnosis or even ending their lives, but ultimately chose to face it with calmness.

> Patient 9: I just begged my child's father to give me some medicine (poison) to end my suffering. That kind of torture was not like making a gash with a knife. It was the kind of torture that only someone who has the disease might experience, the kind of torture that keeps you awake day and night. After having the disease for so many years, maybe I am gradually accepting it.

Throughout this mental transformation process, the patients' mindset, family support and guidance, and the doctor's explanation of treatment all play a significant role.

> Patient 6: Now I am in a better frame of mind after I learned Zhouyi, the ancient Chinese text that offers insights into philosophy and life. I used to wonder, why is my condition so severe compared to others? Some people got better with treatment, but I was still suffering. Then I realized that everyone's experience with the disease is different. RA is not a hereditary disease in my family but I got it anyway. I do not want to be a burden to anyone. I only have this one daughter, who loves me so much and treats me so well. She said she had to come with me for fear that I might accidentally fall. I have come to understand this world better, and I want to live. I think that by staying alive, I can bring some peace to my daughter that her old mum is still there.

## Reflections on the Disease

After being diagnosed with RA, most patients inevitably question "Why me" and "Why do I get sick" and try to search for the cause of their illness. We can roughly divide the patients' self-reported causes of RA into three categories based on their own statements: internal physical causes, external environmental factors, and psycho-emotional triggers.

Internal physical causes: Among the intrinsic physical factors, patients first considered genetic factors, examining their family history of the disease for clues.

> Patient 8: I am genetically predisposed, and my mother was like that (swollen and painful deformed joints).

Additionally, they often revisited their personal medical histories.Three patients interviewed explicitly linked their condition to thyroid disease, a connection supported by existing literature. Some studies have shown that thyroid abnormalities may precede or follow the appearance of rheumatic manifestations in patients affected with connective tissue diseases or RA.[11] Besides, RA has been identified as an independent factor associated with thyroid dysfunction.[12]

> Patient 12: Originally, I was an exceptionally healthy person, with no prior ailments. However, my RA began after I underwent a surgery to remove an enlarged thyroid gland. I started the leg pain (RA) half a month after I stopped (thyroid hormone medications).

> Patient 7: At the time, my thyroid function was not optimal, and I suspected I might have had Hashimoto (thyroiditis). But I did not treat it. Additionally, with the home renovation and work pressure, I was just stressed and was not in a good mood.

Two patients speculated that anemia might be a factor contributing to their RA.

> Patient 1: My struggle with anemia was particularly severe, persisting from pregnancy-related anemia and only subsiding after I reached menopause.

The current study found that anemia is a common extra-articular manifestation in RA, with hemoglobin level fluctuations associated with changes in disease activity.[13] Anemia in patients could be an early symptom of RA, while the correlation may lead to misinterpretations about causation from the patient's perspective.

External Environmental Factors: Patients frequently mentioned cold and humidity as external factors they suspected might have played a role in their illness.

> Patient 15: I used to use cool water, especially in winter.

Psycho-Emotional Triggers: The most frequently cited psycho-emotional issue was stress. Even seemingly minimal and unobtrusive stressors can potentially provoke prolonged pro-inflammatory cytokine production in individuals predisposed to RA.[14]

> Patient 18: How did I get this disease? I think one cause is physical exertion, and the other is exposure to water and dampness, particularly during activities like washing.

## Expectations of Treatment

Patient 10's words, "I just want to be normal!", resonated with all patients interviewed. Almost every patient mentioned the word "normal" when discussing their expectations for the future, implying that they viewed themselves as "abnormal".

> Patient 2: It affects my normal life, sometimes I cannot even cook or hold a cup.

The grip of RA subjected patients to a perpetual state of dysfunctional distress, especially during the active phase of the disease.

> Patient 9: Any trivial task for a healthy person can be a nightmare for a patient with active RA.

> Patient 13: It's just a single napkin, ah, I just cannot tear it, even though it's so thin. I do not have the strength.

The pain and limited joint mobility make it impossible for patients to perform daily tasks, especially those requiring fine motor skills, significantly affecting their psychological well-being.

Patient 13: The simplest thing, such as wearing the underwear or buttoning it up, become impossible.

These accumulating difficulties lead patients to perceive themselves as "abnormal" and adopt the role of the patient. Thus, patients aspire to return to normal, and this belief encourages them as they persevere in their treatment. For these patients, controlling symptoms is the bare minimum requirement, while their main goal is to restore normal joint function.

Patient 4: I hope it does not hurt anymore, and I want to live freely as I did before, but I know I am still sick.

The restoration of normal test indicators is a strong desire for some patients.

Patient 11: The minimum goal (is) the absence of pain and swelling. The higher goal is for all test indicators to be normal. If there is no pain but the indicators are not normal, it feels like a latent bomb ready to explode.

Ultimately, the most sincere hope of every patient is to become a "normal person" who can independently care for themselves and no longer be a burden to others.

Patient 6: I just want to be able to live on my own; I do not want to cause trouble to anyone else.

# Discussion and Conclusion

## Discussion

Research on illness cognition began in the 1950s. Influential models in this field include the explanatory model of illness proposed by Kleinman, a renowned medical anthropologist, and the common-sense model of self-regulation proposed by Leventhal et al.

According to Kleinman's explanatory model, a layperson's understanding of illness includes the following questions:

1. What do you think caused your problem?
2. Why do you think it started when it did?
3. How do you think your illness affects you and how does it work?
4. How serious is your illness and is it short or long lasting?
5. What kind of treatment do you think you should receive?
6. What is the most important outcome you would like to get from this treatment?
7. What are the main problems your disease causes you?
8. What do you fear most about your illness?

When experiencing physical changes, patients draw upon the knowledge from their cultural or social environment to understand the disease in terms of these questions.

Leventhal's common-sense model of self-regulation suggests that patients understand the disease through five main attributes:[15]

1. Identity: the disease label and its symptom indicator;
2. Timeline: whether the threat is acute, cyclic, or chronic;
3. Cause: antecedent causes, such as injury, infection, genetic weaknesses;
4. Control ability: potential for cure and/or control;
5. Consequences: physical, social, and economic consequences.

Using the above two theories as a reference, we developed an interview outline for this study. From the qualitative analysis, we identified two themes and six sub-themes in total.

Theme 1, first highlight how patients' initial symptom recognition and their past disease experience combine to shape their understanding of the disease. For instance, patient 2 initially identified his disease as gout and this early assumption significantly influenced his choice of care. Currently, the awareness of RA is limited in China. When patients experience symptoms of joint discomfort, they often go to orthopedics or other departments that they believe can address their symptoms. Therefore, healthcare authorities should intensify the efforts to raise RA awareness in the broader society to help patients recognize their condition accurately, thereby reducing the chances of misdirected treatment. Also, doctors in orthopedics, sports medicine, and other departments frequently consulted by RA patients should be trained to avoid misdiagnosis and refer patients to the Rheumatology Department promptly, to facilitate early diagnosis and treatment. Then explores the choice of treatment. In China, the healthcare system is a complex mix of modern medicine and TCM, along with various ethnic minority medical practices. In addition, China has a relatively comprehensive universal medical insurance system. Patients have many options for medical treatment, but most lack professional medical knowledge, making them vulnerable to information overload. Thus, patients often resort to any available treatment options, resulting in a lack of timely, correct, and standardized care.

Theme 2 addresses the patient's perception of the causes of their illness. This reflection is often a straightforward explanation formed by a combination of personal experience and information acquired from empirical observation, media reports, internet sources, and other places. It often reflects common-sense reasoning, which may contain both accurate and inaccurate elements. And shed light on the emotional impact experienced by patients after being diagnosed with the disease. Physicians and society should increase their empathy for RA patients by demonstrating understanding, compassion and a willingness to listen to their real needs. Furthermore, support from family, community, and doctors plays a pivotal role in helping RA patients cope with their condition. Also, the mental health of patients should be a central consideration and efforts should be made to assist patients in developing a positive perception of their disease to prevent them from giving up treatment or even committing suicide. In the treatment of RA, it is incumbent on physicians not only to provide DMARDs but also to offer symptomatic therapy that can comprehensively enhance the patients' life quality. This approach can help patients to mitigate false beliefs and misconceptions, thereby promoting better adherence to treatment.

In 2017, Chinese researchers conducted a study on the healthcare behaviors and illness perceptions of Chinese RA patients through literature analysis, pointing out that Chinese RA patients have low illness perceptions, which affects their healthcare behaviors and medication adherence.[16] Following this, researchers used a common-sense model of self-regulation (CSM)-based questionnaire to investigate the impact of illness perceptions on the health-related quality of life of Chinese RA patients, indicating that the way Chinese RA patients perceive their illness affects their health-related quality of life.[17] Currently, Chinese researchers are gradually paying more attention to the impact of RA patients' illness perceptions on their healthcare behaviors, self-management, medication adherence, and quality of life. However, the current body of research is still in its infancy, with a limited number of studies and research teams. The research method is mainly based on literature analysis and questionnaires, using the illness perceptions questionnaire to collect data, and drawing conclusions through statistical analysis, failing to carry out further in-depth investigation. Patients' illness perceptions are crucial as they provide important information about disease experiences and evaluation of treatment effects. While questionnaires can quickly gather illness perceptions scores from a large number of RA patients, this method is limited, and may miss more detailed and deeper information. Therefore, this study chose to use interviews to gain a deeper understanding of patients' experiences and feelings.

China's healthcare environment is unique, with TCM being an integral part of the healthcare system. Chinese RA patients can choose to receive purely Western antirheumatic therapy, TCM therapy or a combination of both, depending on their needs. Patients' perceptions of RA and their health-seeking behaviors may be influenced by traditional Chinese culture and multiculturalism. Surveys of illness perceptions among patients treated with TCM or a combination of TCM and Western medicine are still in their early stages. A survey conducted in Singapore demonstrated significant differences in illness perceptions between patients who received only Western medicine and those who received both Chinese and Western medicine.[18] Therefore, in this study, we chose to co-interview patients who received Chinese medicine, Western antirheumatic therapy, and a combination of both.

Previous studies have shown that medication adherence among RA patients is generally low, and non-adherence to medication can lead to higher rates of disability, mortality, and higher healthcare expenditures.[19] Therefore, during the interview, the researcher conducted detailed inquiries about the patients' medication use, and found that some patients

privately reduced or stopped their medication. Noncompliance of medication-taking behavior was often related to concerns about adverse drug reactions.

> Patient 16: They [other patients] all say that rheumatoid cannot kill you, so what if you end up taking methotrexate tablets and die? Methotrexate started to raise my aminotransferases as soon as I took six tablets.

Interviewed patients said they are concerned that liver damage from methotrexate would cause more serious harm than RA, which they view as, merely joint pain, while liver damage could affect life expectancy. These patients believed that oral medications are metabolized by the liver or kidneys, and that long-term medication will impair liver and renal function, so they prefer to take less medication if possible. Out of concern for the benefits of treatment, patients weigh the therapeutic effects against the side effects, balancing whether to continue current treatment or try a new treatment.

A portion of patients' noncompliance with medications is related to symptoms. RA patient often suffer from anxiety or depression, and rheumatologists often recommend that patients seek help from a psychiatrist when experiencing emotional distress. However, not all patients are willing to visit the psychiatry department. In the Chinese cultural and social context, mental illness is often stigmatized.[20] According to TCM theory, a bad mood can be both a cause and a symptom of disease, and the scope of Chinese medicine treatment includes both disease and illness. TCM/alternative medicine provides patients with more choices when one form of medical treatment is ineffective or has serious negative effects.

## Conclusion

Through in-depth interviews with patients, we gained insights into the experience of Chinese RA patients in: (1) the discovery of the disease, the diagnosis process, and the subsequent treatment journey; (2) the physical and psychological experiences after illness; (3) the patients' expectations for the future; (4) other relevant topics.

These perspectives from the patients provide valuable data to understand the formation and evolution of patients' disease cognition. They also highlight the need for medical staff and relevant government departments to improve medical services and alleviate patient suffering, considering patient's choices and purposes.

### Practice Implications

The findings of this study provide insights into the patient's experience of RA, offering a deeper understanding of the challenges faced by RA patients. This fosters greater doctor-patient empathy, and guides physicians to make more targeted efforts to improve patients' quality of life.

## Study Limitations

Since the study was conducted in an outpatient clinic, it primarily included patients with potentially milder or less severe levels of the condition. Patients who did not seek outpatient care or refused to participate in the study were not included in the interviews. Therefore, the generalizability of the Results to a broader population should be approached with caution. Data saturation was achieved across the entire group of Participants interviewed. However, different Conclusions may be drawn when examining different subjects of the population or including those with more severe conditions, which is a potential avenue for further research.

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## Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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