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Obstacles to Medication Adherence for Patients with Inflammatory Bowel Disease: A Qualitative Study in East China

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Purpose: To identify the factors impacting medication non-adherence in patients with inflammatory bowel disease (IBD) in China, and to provide a reference for effective interventions.

Patients and Methods: Individual semi-structured interviews were conducted between December 2020 and July 2021 in four tertiary hospitals in East China. A conventional content analysis method was used in data analysis to extract themes and sub-themes in IBD Patients with poor medication adherence.

Results: The 10 participants included were those who were diagnosed with IBD at least 1 year and could provide rich information and express strong desire. Seven themes emerged after data analysis: (a) non-acceptance of disease; (b) Lack of cognition of disease; (c) medication beliefs; (d) perceived efficacy; (e) Forgetting and delays; (f) costs of medication; (g) personality and psychological factors.

Conclusion: Our data confirmed that in addition to comprehensive disease education and effective communication, medical staff should also pay attention to individualized factors, and develop effective response strategies for medication management support to reduce recurrence and control the disease.

Keywords: Crohn's disease, inflammatory bowel disease, medication adherence, ulcerative colitis, qualitative study

Introduction

Inflammatory bowel disease (IBD) is a chronic idiopathic inflammatory disease with intestinal and extraintestinal features characterized by relapses and periods of remission, which includes ulcerative colitis (UC) and Crohn's disease (CD).[1] The incidence of IBD has increased rapidly in China in the past two decades, which now has the highest prevalence of IBD of any country in Asia (3.64 per 100,000 people).[2] Due to its chronic and relapsing characteristics, patients with IBD often require long-term medication.[3,4] However, many patients lose confidence during the treatment process and experience a decrease in medication adherence. The overall rate of nonadherence of patients with IBD in Iran was 33.3% (27.6% intentional nonadherence and 5.7% unintentional nonadherence),[5] and An Australian study showed a 24% non-adherence rate,[6] 72.7% (218/302) of IBD patients in Bahia-Brazil were non-adherent to medication.[7] It revealed that 31.4% (33/105) of IBD patients had low medication adherence in China.[8]

There is limited qualitative research on IBD medication adherence. A qualitative study from New Zealand showed that medication adherence was negatively impacted by side effects and regimen factors, including (high) number of pills/dose frequency, and that refilling medications was perceived as challenging. In contrast, healthcare professionals were

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seen as the main drivers of medication adherence, and family, friends and colleagues, as well as targeted health system factors, such as medication subsidies, were seen as supporting factors.[9]

Poor adherence has been associated with exacerbation of the disease, increased health care costs, and may be a primary cause of treatment failure.[10,11] Several studies evaluated the influencing factors of nonadherence to IBD treatment, and indicated that medication nonadherence may be associated with gender, age, medication cost, disease activity, disease duration, drug type, and other factors.[8,12–14] Another study has also highlighted the importance of beliefs about medication and doctor-patient relationships.[6] Although most of the studies use quantitative methods, qualitative studies, which focus on the patients' real feelings in a specific situation, have proven to be an efficient and effective method of determining medication adherence.[15,16] Nevertheless, such qualitative studies in IBD patients are lacking in China.

Therefore, the aim of this study was to further understand the patient experience with medication adherence and investigate potential factors using qualitative methods, and hope to target interventions to these factors in the future. This study highlights the interplay between disease acceptance, medication adherence, and treatment persistence in inflammatory bowel disease (IBD), underscoring their role in influencing patient engagement and long-term outcomes. Cultural factors, especially in regions such as China where traditional Chinese medicine is favored, add to the complexity of adherence behavior, highlighting the need for tailored, culturally sensitive interventions to optimize IBD care.

Methods

Study Design and Participants

A descriptive qualitative study was conducted to address the following research question: "What factors affect the medication adherence of IBD patients?" We generated semi-structured individual interviews at a time convenient for the participants. We used the Consolidated Criteria for Reporting Qualitative Research guideline (COREQ) to report the method used and the findings obtained.[17]

The participants were recruited using a purposeful sampling method combined with the maximum variation strategy (for different hospitals, disease types, gender, age, duration of illness, medication types, and education level) in four tertiary hospitals from December 2020 to March 2022. These were participants who were diagnosed with IBD at least 1 year and could provide rich information and express strong desire. Patients were excluded if they met the following criteria: a) age < 18 years; b) good medication adherence; c) Patients with psychiatric disorders, serious concomitant physical diseases, or cancer. Before starting our study, they received a consent form and a study information sheet, including the objectives and procedures of the study.

Adherence Measures

Adherence was judged by comparing the theoretical medication times with the actual medication times in the recent 1 year. Referring to the definition of modified medication occupancy rate (mMPR),[18] patients with a treatment plan compliance rate of more than 90% were considered to have high adherence, and those who adhered at less than 90% were considered low adherence.[19] In this study, patients who voluntarily stopped medication, changed medication, advanced or delayed medication time by more than 1 week were considered as low adherence.

Data Collection

All participants were interviewed privately via telephone and the duration of the interview was 45–60 minutes each. Open-ended follow-up questions were posed in an unbiased manner to obtain detailed descriptions and avoid inducing questions. The main questions were as follows. (a) What's your opinion about IBD? What is your treatment plan? (b) Which medication you are currently taking? How are these medications generally used? (c) Do you have any opinion about long-term medication use? (d) Where do you usually get your information or guidance on medication? How about your communication with the healthcare professionals you see? (e) What are your feelings or experiences during medication use? (f) If you did not stick to it, what were the reasons? (g) What do you think are the difficulties in using medication at present? What is the biggest difficulty? (h) What concerns do you have about future treatment?

Data Analysis

Data collection and data analysis was conducted concurrently. We performed a conventional content analysis of the qualitative data. In this approach, researchers immerse themselves fully in the data to enable new insights to emerge that provide a richer understanding of the experience and avoid using preconceived categories.[20] Two coders (FX and YXZ) each independently performed the reading, coding, and analysis. Codes, themes and sub-themes were discussed in the team in regular and ongoing conversations via a cyclical analytical process to avoid redundancy and guarantee accuracy. The original transcriptions, initial coding and codes were in Chinese and subsequently translated into English for further comparison by a peer reviewer.

Rigor

Rigor was maintained via several recognized techniques in this study. The credibility was established through peer debriefing and member checking. The researchers consulted with one another to resolve any disagreements or ambiguities in methodology or data analysis. No major changes to the analysis arose from this debriefing. The themes and sub-themes extracted from the data were returned to the participants to ensure the findings were comprehensible and conveyed their intention. Participants consented to the proposed contents. In addition, the interviewer is a nurse in charge of the Department of Gastroenterology and a volunteer of the China Crohn's & Colitis Foundation (CCCF, a non-public charity foundation). Prior to the interview, she established a trusting relationship with the patient and conducted four pre-interviews before the formal interview to become proficient in interview techniques and adjust the interview outline.

Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki, ensuring that all ethical principles were adhered to throughout the research process. Research ethics board approval was obtained from the ethics committee of Hangzhou Third Hospital (number 20201231Y029). All participants were provided with information about the study's purpose, procedures, and potential risks prior to their participation. Confidentiality of participants was ensured, and written informed consent was obtained from each participant. Participants were explicitly informed that their anonymized responses and direct quotes may be used in publications resulting from this research. To ensure anonymity, we removed identifying information from the transcripts and used numbers (N1, N2, etc.) instead of names. All audio recordings and transcripts were saved on a password-protected computer, which was only known to the researcher.

Results

A total of 10 participants were interviewed in the study, including 3 CD patients and 7 UC patients. Table 1 shows the characteristics of the participants. Their average age was 38.2 years, and their disease duration was ranging from 1–14

Table 1 Characteristics of Participants

No.	Gender	Age, Years	Type of Disease	Disease History, Years	Current Severity	Education	Occupation	Residence	Current Medications
N1	Male	33	UC	9	Remission	Bachelor	Engineer	Urban	Mesalazine
N2	Male	26	CD	14	Mild activity	Master	Student	Urban	Methotrexate, mesalazine
N3	Male	32	UC	9	Mild activity	Bachelor	Engineer	Rural	Infliximab, methylprednisolone
N4	Female	35	CD	3	Moderate activity	Bachelor	Designer	Urban	Mesalazine, infliximab
N5	Female	34	CD	5	Moderate activity	Bachelor	Clerk	Urban	Mesalazine, infliximab
N6	Male	49	UC	1	Moderate activity	Junior high school	Unemployed	Rural	Infliximab, methylprednisolone
N7	Male	61	UC	5	Severe activity	Primary school	Retired worker	Urban	Mesalazine
N8	Female	57	UC	3	Severe activity	Junior high school	Unemployed	Rural	Mesalazin, methylprednisolone, infliximab
N9	Male	30	UC	9	Remission	Senior high school	Unemployed	Rural	Mesalazine
N10	Male	25	UC	1	Mild activity	Master	Student	Urban	Mesalazine

Notes: Current severity: 1) Each subject serves as a self-control to evaluate the abnormality of bowel movement frequency; the daily bleeding score represents the most severe bleeding in 1 day; 2) UC patients use the modified Mayo score:[50] The subject's review of abdominal discomfort, overall well-being and other manifestations, such as physical examination findings and subject performance status, score ≤2 points and no single sub-item score >1 point for clinical remission, 3–5 points for mild activity, 6–10 points for moderate activity, 11–12 points for severe activity; 3) CD patients use Harvey-Bradshow's simplified CDAI calculation method:[51] ≤4 points for remission, 5–7 points for mild activity, 8–16 points for moderate activity, >16 points for severe activity.
Abbreviations: UC, Ulcerative colitis; CD, Crohn's disease.

years. Data analysis identified seven major themes: (a) Non-acceptance of disease; (b) Lack of cognition of disease; (c) Medication beliefs; (d) Perceived efficacy; (e) Forgetting and delays; (f) Costs of medication; (g) Personality and psychological factors.

Non-Acceptance of Disease

Acceptance of disease is mainly reflected in two aspects, one is that patients were usually reluctant to accept when they were diagnosed; the other is that the stigmatization of IBD by the public makes patients feel that their illness was not accepted by others, leading to a mentality of concealment. Six interviewees showed non-adherence behavior as a result.

Rejection of Medication Due to Non-Acceptance of Disease

Three study subjects were completely resistant to accepting the disease immediately when they were informed of the disease and had the rejection of medication.

> I couldn't accept it at first, and I didn't want to go to standard treatment until there were very serious complications. Because at that time I was only a young girl, I didn't want to take the medication, so the mesalazine was not taken in a very standardized manner. (N5)

> At first, I couldn't accept the fact that I was sick, and (I thought) I could take less medicine if I could. (N8)

Inconvenience of Medication Due to Concealing the Disease

The main symptoms of IBD are "blood in the stool" and "diarrhea", which brings physical and psychological distress, and causes the patients to feel a sense of stigma. "The mesalazine was in a small packet, and it was embarrassing when you took out a small packet after the meal and others just looked at it." (N1)

> When I was first diagnosed, I was about to go to high school and participate in military training, and I didn't want anyone to know about it. I stopped for about half a month during military training. (N2)

> If it were unfamiliar people together, I wouldn't take out the medicine in front of them. (N3)

Lack of Cognition of Disease

Disease cognition usually refers to the patient's understanding and awareness of the disease and treatment. Nine participants in this interview reported discontinuing medications due to a lack of cognition of the disease.

Ignoring Treatment Due to a Lack of Understanding of the Disease

The phenomenon of neglecting treatment due to a lack of awareness of the disease is common in this interview. Many participants believe that IBD is not a major issue, resulting in medication non-adherence. One young CD patient regretfully said,

> I stopped taking medication. (Because) I didn't know about the condition at first, I didn't know it would suddenly become so severe, and I thought it was just like a cold.

Meanwhile, her experience made her think that IBD could be controlled without medication,

> I had asthma as a child, but I didn't take medication, I got better later through exercise and never had a relapse. Therefore, I thought it was also a chronic disease at that time. It doesn't matter if I don't continue taking medication after treatment. (N4)

Some participants believe that medication can be discontinued if symptoms improve or there are no complications.

> Over the past two years, I have adopted a light diet and had no particular complications, so I have not standardized my medication. (N5)

> Because after being diagnosed, the disease was quickly brought under control. I thought it was just like a cold, and I would be cured after controlling it. Then I didn't continue taking medication. I thought I recovered, but I didn't expect it to happen later. I didn't ask the doctor, and I didn't understand this disease at that time. (N8)

> After discharge, I took medication irregularly. because I had no bellyache anymore and I had a colonoscopy at the time, my intestines healed. so I felt even more relaxed and didn't take the initiative to take medication. (N10)

Unclear and Insufficient Doctor-Patient Communication

The first step in patients' understanding of the disease and medication treatment is often informed and educated by doctors. The doctor did not make it seem too serious, so unclear and insufficient doctor-patient communication often affects patients' correct understanding of the disease and their medication adherence.

> The doctor just advised me to take the biological agents on time, but there is no clear advice on how to take mesalazine, which made me not take medication seriously. (N3)

> I have seen so many doctors, but none of them said that my disease was very troublesome and requires persistent medication. No one has told me that. In high-level hospitals, there are all critically ill patients, and my illness seems to be a very mild one. The doctor didn't take it seem too seriously, alas, it has led me to take many detours. (N8)

> Another reason why I stopped taking medication was that the colonoscopy report showed chronic colitis. I was wondering if it was ulcerative colitis, and I guessed that the doctor had made a mistake. (N10)

Medication Beliefs

Medication belief refers to the patient's attitude and subjective perception towards medication, and the medication belief of IBD patients can affect their medication adherence. Ten participants in this interview mentioned medication non-adherence due to medication beliefs.

Medication Does Not Work

Some participants stated that the medications prescribed by the doctor did not help much with their diseases. And they believe that auxiliary medications do not need to be taken.

> I think hormones have some effect, but other drugs have little effect, so I don't take them. (N6)

Long-Term Medication Can Affect Health

Seven participants hold the belief that "long-term medication is not beneficial". Some of them believed that long-term medication was harmful to the body, some were concerned that long-term medication would lead to drug resistance, and some were concerned about the side effects of the drug. These concepts lead to non-adherence with medication.

> I am afraid that this will develop resistance. I think if any medication is taken continuously, it is initially effective, but if resistance develops later, it will have no effect. If the drug level continues to rise, I am afraid there will be no medication to take later. (N10)

> My family has a misconception that long-term medication has too many side effects. They tell me to reduce my medication dosage when I feel better. My family always imposes this mindset on me, and then I reduce my dosage. (N3)

> I heard from others that long-term use of hormones has significant side effects, so I want to try if there would be any reaction if I don't eat them. (N6)

Trouble with Long-Term Medication-Taking

IBD is a chronic disease that requires long-term medication, which brings trouble to their daily life and work. A total of 4 participants expressed this information.

> The injected medicine is definitely better, taking it orally every day is troublesome. I can't do it by taking it orally every day. (N6)

> The difficulty with long-term medication. means that you can't live like everyone else……and it is not convenient to take an enema if you go out. (N9)

Long-term repeated medication actions, even if the medication is nearby, can occasionally cause some patients to engage in lazy behavior.

> Taking medicine like this for a long time, sometimes I don't want to reach out for the medicine and pour water… I may be lazy. In fact, it's not a very troublesome thing, but if I persist, I will sometimes overlook it. (N10)

Perceived Efficacy

Perceived efficacy is usually a patient's perception of the treatment effect, which is more about the patient's subjective feelings, but also to a certain extent affects their medication adherence. A total of 8 participants mentioned this theme.

Poor Effect After Medication

Some patients felt that the effect of the medication was not obvious after taking the medication, leading to doubts or giving up. Five participants felt that the medication had no effect, and then they reduced their dosage or felt that it did not matter if they missed taking it.

> I sometimes miss taking mesalazine, because it is not as effective on CDs and its functions are relatively weak. (N2)

> I thought the enema worked better, so I stopped the mesalazine tablets. (N8)

> Actually, the medication was effective within the first six months, and the inflammation indicators were still under control. But in the second half of the year, there were perianal lesions, and the medication became uncontrollable. And then I gradually stopped taking the medicine. (N5)

Reduce Medication Without Discomfort

Five interviewees reported no discomfort after reducing, delaying, or omitting medication, which usually leads to a decrease in their adherence to medication.

> In fact, the reaction of this disease is relatively slow. If I forget one or two pills, it usually takes two to three days before it gradually becomes uncomfortable To be honest, for someone like me who has had this disease for a long time, I have become accustomed to occasional belly pain or discomfort… It's normal for me to feel such pain.So it always makes me less alert. (N3)

> I want to try if there will be more diarrhea if I don't take hormone medication, and it's okay if I don't take it! Then I won't eat it. (N6)

> I don't feel any change after stopping taking the medicine for a day or two. Basically, except for the spicy food, I'm eating all the normal food. Nothing is wrong. (N10)

Suffering from Drug Side Effects

Immune agents or hormones, when used in long-term or high-dose, may cause side effects such as rash, itchy skin, full moon face, buffalo back, and limb wasting in patients, and may also induce or worsen gastrointestinal ulcers.[21,22] The side effects of drugs can cause physical discomfort for some participants, leading to resistance to medication.

> Because I am prone to nausea when taking methotrexate, I feel very uncomfortable after using it. Perhaps there are also psychological factors, and I am a bit resistant to this drug. (N2)

> After using hormones my body and face also developed acne, and pain all over my body. Then my face turned red, which was very scary, and my body became swollen. During that time, I was very depressed. (N3)

Forgetting and Delays

Forgetting and event delay are usually unintentional non-adherence behaviors of patients compared to other reasons. Seven participants mentioned non-adherence with medication due to forgetting or delayed events, mainly reflected in forgetting to bring or take medication, unplanned itinerary, busy state, and the impact of daily routines.

Forgetting to Bring or Take Medication

Forgetting medication is a common occurrence for participants, and some may take small measures to prevent forgetting.

> I sometimes forget to take mesalazine. To avoid forgetting, I divide my medication that was originally taken three times a day into morning and evening, as it is easy to forget and miss it at noon. (N2)

> The most commonly used is mesalazine. Occasionally, I forget to bring my medication or the medicine I'm carrying is just finished, so I need to keep it in the office drawer. (N3)

> The main thing is that I have too many diseases, I take too many drugs, such as hypertension and diabetes. So many drugs make me easy to forget to take.(N7)

Event Delay

Some participants did not forget to take medication, but were delayed in taking medication on time due to other events, such as unplanned schedules, busy with work or study.

> Sometimes, due to some circumstances, the itinerary may be temporarily changed, and the medication may not be sufficient. (N3)

> Because there are many things to do after the start of school. I don't have enough awareness, and then I started stopping my medication. Because there are big and small matters in daily life, I can't guarantee that I can take medication on time every time. (N10)

> Sometimes when I eat late, I may miss taking medication. (N3)

> I didn't have this habit of taking medication for a long time before. Sometimes, for example, when I'm busy doing experiments, I may have a lie-in on weekends, skip breakfast, and also skip taking medication in the morning. It is also difficult to develop the habit of taking medication consistently. (N10)

Costs of Medication

IBD patients require long-term medication, some of which are expensive or cannot be reimbursed by medical insurance, which brings an economic burden to many patients and some extent affects their medication adherence. Four participants refused to follow the doctor's treatment recommendations due to drug cost issues, resulting in reduced or discontinued medication.

Unable to Afford the High Medication Costs

> The doctor suggested that I use infliximab for treatment, but I didn't follow his advice. I had just graduated and started working. So the income is still limited, and I can't afford such expensive drugs. (N5)

> I currently have medical insurance at school and can reimburse 70%. But if I graduate from school in the future without medical insurance, a box of medicine costs over 50 yuan and can only be taken for two to three days, which is quite expensive. (N10)

Reducing or Stopping the Medication Because of the Pain of Paying

Some participants reduced or stopped their medication because of the pain of paying.

> One of the reasons why I stopped taking medication is because I am worried about money. Imported mesalazine is quite expensive. I have spent 150,000 to 160,000 yuan and borrowed a lot of money. (N8)

In previous years, a box of medicine cost 200 to 300 yuan, which was particularly expensive, all at one's own expense. I still love money. It takes a lot of money to keep taking this medicine. (N9)

Personality and Psychological Factors

In addition to the various reasons mentioned above, the influence of personality and psychological factors on patients with non-adherence to medication cannot be ignored. These factors usually vary from person to person and are not easily detected in the short term. Five participants mentioned these factors.

Blind Optimism

Some patients are blindly optimistic about the disease due to their previous physical health, believing that they will recover, so they do not take long-term medication.

I don't believe I will be knocked down by the disease. When I was young, my health was very good. (N7)

I didn't believe it at the time. I've always been in good health, and I think I can recover without medication. (N8)

Feeling Depressed and Unwilling to Take Medication

The course of IBD is long and the condition may recur during treatment. Diseases bring physical discomfort, dietary restrictions, and even social and work disruptions. Combined with concerns about the future, many patients may occasionally experience depression or even "self-abandonment", which may affect their treatment adherence. Two participants self-reported skipping medication due to depression.

Sometimes when my psychological state is particularly bad, I seem to have no interest in anything, including food, and occasionally I don't take medicine. (N5)

Because I have been at home since I got sick. I cannot work and socialize normally like other young people, and sometimes I may miss taking medication when I am in a bad mood. (N9)

Discussion

The main purpose of this qualitative study was to explore the factors influencing medication non-adherence in patients with IBD. This was also one of the purposes for which we initially planned to conduct the study, hoping that it would explain and complement the results of the current quantitative studies on medication adherence in IBD patients, which would help us propose more targeted interventions. The results of this study provide a deeper understanding of the complex reasons behind nonadherence, which include personal beliefs and systemic challenges. In the following discussion, we will analyze these factors in detail and explore their implications for improving medication adherence in clinical practice.

Acceptance, Adherence, and Persistence in the Management of Inflammatory Bowel Disease (IBD)

Acceptance of illness, adherence to medication, and persistence emerged as key themes in this study, highlighting their interplay in influencing patient engagement and long-term outcomes in inflammatory bowel disease (IBD) management.

Acceptance, defined as the patient's willingness to acknowledge the disease and integrate management into daily life, provides the foundation for adherence to medications, and especially in chronic conditions, acceptance predicts adherence to medications.[23] Increased acceptance is associated with improved psychological well-being and agreement with treatment goals.[24] Medication adherence, the act of following a prescribed treatment regimen, is critical for disease control. However, it alone does not capture the sustained commitment required for lifelong treatment. This study found that while initial adherence may be high, maintaining long-term adherence is often hampered by factors such as side effects, treatment fatigue, and perceived ineffectiveness. Medication adherence, defined as "the length of time from initiation of treatment to discontinuation of treatment", represents the behavior of continuing treatment regardless of

symptom status and is complementary to medication adherence, but it represents a distinct behavior.[25] For example, persistence supports adherence because patients experience treatment benefits, which strengthens their commitment. Notably, limited attention has been paid to adherence and persistence in IBD research. Studies such as a Canadian survey of patients with ulcerative colitis (UC) reported lower adherence (40.9%) and persistence (71.9%), with different predictors for each behavior.[26]

In addition, there are sociocultural influences, including preferences for alternative medicine, that further complicate these constructs, particularly in regions such as China, where preferences for traditional medicine may influence acceptance and adherence to Western treatments. Traditional Chinese medicine (TCM) emphasizes a holistic approach based on the principle of "Unity of Heaven and Man (Tian-ren-he-yi)", integrating factors like diet, lifestyle, labor, social context, and the natural environment. It views the human body as interconnected within itself and with the surrounding ecosystem, focusing on restoring the balance of yin and yang to promote health. Many Chinese IBD patients favor TCM for its perceived safety and efficacy, valuing its comprehensive approach to managing disease while addressing the dynamic interaction between the body and its environment.[27]

Understanding the dynamic interplay between acceptance, adherence, and persistence provides a comprehensive framework for optimizing IBD care. Tailored interventions targeting cultural, psychological, and behavioral barriers are essential. Future research should integrate these dimensions to enhance treatment evaluation and design interventions for better outcomes.

Pay Attention to the Patient's Psychological State at the Time of Diagnosis and Assist Them in Transitioning to a State of Acceptance of the Disease

Lack of cognition of the disease is a factor reflected in this study, which is consistent with another Korean study.[10] Most IBD patients are unaware of the disease at the time of diagnosis, and once they understand that it is a chronic disease that requires long-term treatment, they are often unable to accept it. In addition, a cross-sectional survey from the USA found that 84% of patients with IBD reported perceived stigma.[28] American scholars have previously found that concealing the disease and skipping medication may be related to the social stigma of IBD,[11] which has a negative impact on medication adherence. In this study, some participants said they did not accept their illness because of stigma, which led them to avoid taking medication in public in order to hide their illness. This is consistent with other studies.[29,30] In clinical work, healthcare professionals should pay attention to IBD patients' acceptance of their disease, and classify patients who feel stigma as a high-risk group of medication non-adherence. Healthcare professionals need to strengthen psychological counseling and health education for patients to help them successfully overcome the denial period and accept the disease.

Establish an IBD Specialist Team, Strengthen Disease Education, and Focus on Doctor-Patient Communication

Doctor-patient relationship and communication are important factors affecting medication compliance, the same finding was reported in other studies in South Korea and Australia.[10,31] The discordant doctor-patient relationship or low trust in the physician may trigger non-adherence.[32,33] In our interview, we found that several participants also stated these factors. The one-way communication mode is commonly used in clinical practice in China; however, it cannot meet patients' understanding of the disease and medication, especially for the elderly. The communication mode that enables patients to participate in the self-management of diseases, such as the teach-back method, can improve the doctor-patient relationship, which can also promote their sense of self-worth and improve their cognition of diseases and medication adherence. With the popularity of smartphones, health applications (apps) targeting IBD patients, such as "Crohn's Diary", "GI Monitor", "Changzhidao", have also played a positive role for children and adolescents in promoting self-management of IBD.[34,35] These apps can also intuitively promote and improve the efficiency of education through various channels such as graphics, video, and animation.

It should be noted that there is no official IBD specialist nurse in China. Compared to the Internet, patients preferred to receive information, including education on medications, "what to expect in future", living with IBD and diet, from specialist doctors or nurses.[36] A study found that the incorporation of a specialized nurse in an IBD unit had major

healthcare, economic and research benefits.[37] IBD specialist nurses solve patients' actual problems through remote consultation and telephone consultation, and provide patients with knowledge about IBD treatment (dosage, administration mode, drug interaction and side effects), diet, pregnancy, travel, vaccinations, and prevention. It is important to strengthen the specialist training of medical staff and establish a professional IBD team to avoid blindness, randomness, and ineffectiveness of health education. Therefore, strengthening specialized training for medical staff can solve the problem of not being able to provide homogeneous education to patients, thereby improving doctor-patient communication and avoiding the inefficiency of health education.

Emphasize the Evaluation of Patients' Medication Beliefs and Promote Their Awareness of Proactive Treatment

Our study found that medication belief is an important factor leading to patients' medication non-adherence. Many participants believe that "drugs have little effect", and "long-term medication is harmful", which is pessimistic about medication treatment. Canadian scholars Ediger et al demonstrated that 12%-13% of patients stopped or reduced their medication due to fear of side effects and uncertainties about the effectiveness of their medication.[38] Horne et al, the UK scholars also found that patients' beliefs about medication are positively correlated with their adherence.[39] For first-time diagnosed patients, the "IBD Patient Medication Belief Questionnaire"[40] with good reliability and validity can be used to evaluate their medication beliefs. In our study, two interviewees chose to stop taking medication due to their family's belief that "long-term medication is not good". Therefore, in addition to establishing correct medication beliefs for the patient themselves, it is also necessary to provide communication guidance to their close caregivers.

Pay Attention to Patients' Perception of Efficacy and Conduct Regular Follow-Up

The association between taking medication and how quickly symptom relief would influence the patients' perceived benefit of continuously taking medication. Hommel et al from the United States also found a relationship between the immediacy of medication effects and patients' medication adherence.[41] This is generally consistent with the theme drawn from this study.

Patients mainly take medication at home, and their medication experience is a commonly overlooked issue. Some participants experienced recurrence and even complications due to medication withdrawal or reduction behavior. In recent years, China has attached increasing importance to continuing care. Chen et al constructed a remote medication management model, which includes conducting motivational interviews, WeChat group messages, and telephone calls to provide personalized and continuous follow-up for IBD patients, and the study has shown that it can improve patient medication adherence.[40] Therefore, clinical nurses should follow up and track patients' medication efficacy, pay attention to their treatment experience, educate them on the possible side effects and the possible relapse caused by non-adherence, and use negative cases to prompt patients to understand the importance of medication adherence in order to promote their long-term adherence behavior.

Recognize the Unintentional Non-Adherence Caused by Forgetting or Event Delay, and Use Multiple Reminders to Intervene

It was found that 49% of patients had intentional non-adherence and 28% had unintentional non-adherence in a survey of patients with IBD in the UK.[39] Forgetting and delaying events can appear to occur in multiple contexts, including school, activities such as sleepovers, and a temporary schedule change,[41] which are often unintentional behaviors. Current studies in the USA and China have also proposed various intervention measures for forgetting or event delay, such as visual reminders (stick notes, pill boxes in a conspicuous location) or auditory reminders (automated text messages, alarms), and special reminder applet.[41,42] In addition to the above methods, one participant in our study felt that forgetting was prone to occur at noon on weekdays, so he/she adopted the method of combining mesalazine with taking it in the morning and evening. Indeed, one study has shown that there is no significant difference in the therapeutic effect between once-daily mesalazine and three times daily dosing.[43] Hence, developing effective reminder methods, simplifying medication plans, and utilizing technological means based on individual characteristics may have a certain effect on unintentional non-adherence caused by forgetting or event delays.

Focus on Family and Social Support for IBD Patients and Improve Health Insurance Policies

In this study, 5 interviewees indicated that their family's support was of great help to them. An Australian study showed that patients who joined an IBD patient organization had better medication adherence.[44] Therefore, an effective social support system can help patients acquire knowledge, enhance confidence, and motivate them to take their medications as prescribed.

We found that medication adherence in our interviews with IBD patients in eastern China was influenced by factors such as treatment costs and access to healthcare, which is consistent with the findings of similar studies conducted in Western countries.[32] This is consistent with a study by Horne et al[45] that found medication costs to be a major barrier to adherence in European countries. A previous study from Canada had shown that IBD patients would stop the medication when the disease was relieved due to economic difficulties.[38] However, unlike Western populations, where insurance coverage can generally alleviate some of the financial burden, many patients in China still face significant out-of-pocket costs for biologic therapies, which may explain the relatively low adherence rates observed in our study. Our study also found that 3 participants stopped or reduced their medication due to economic factors. The prices of some drugs are indeed high; however, it was found that patients who were persistent with their medications incurred a 49.8% reduction in overall medical costs compared to patients who did not adhere.[46] In China, the national insurance system partially covers physician consultations and prescription drugs, but coverage varies depending on the type of insurance the patient has (eg, urban insurance vs rural insurance) and the specific drugs involved. When communicating with patients, healthcare professionals can analyze the pros and cons of them, indicating that non-adherence with medication may incur more costs in the future. When making medical decisions, doctors also need to consider their financial ability when selecting drugs for patients, and it also calls on the government to introduce powerful health insurance policies for IBD patients.

Emphasize Psychological Support and Adopt Personalized Management for Patients with Different Personalities

Canadian Scholars Byrne et al found that the rates of depression and anxiety were found to be 25.8% and 21.2% in IBD patients, and disease activity was significantly associated with depression and/or anxiety.[47] Another study from the UK also demonstrated that depression was the only independent predictor of complete non-adherence with maintenance mesalazine therapy.[48] In our study, 5 participants experienced anxiety or depression due to disease activity and recurrence, with two of them taking anti-anxiety/depression drugs. Anxiety and depression Scales can be used to screen patients, and patients with anxiety or depression status should be included in high-risk management groups, and provide psychological treatment.

Chronic Disease Medication Compliance Tools Need to Be Improved and Developed

Most adherence scales primarily assess whether patients take medications as directed, but they often overlook the initial decision or willingness to start taking a prescribed treatment. In chronic conditions such as IBD, acceptance can be influenced by patients' understanding of the disease, the necessity of medications, concerns about side effects, and trust in healthcare providers.[49] The absence of this component in adherence scales means that barriers in the early stages of treatment initiation may be underrecognized. Similarly, persistence is an important but often overlooked aspect of adherence. Persistence refers to a patient's ability to continue to follow a prescribed regimen over time, which is critical for managing chronic conditions such as IBD. Factors that influence persistence are often different from those that influence initial acceptance, including long-term side effects, treatment fatigue, financial constraints, and evolving personal health beliefs. The lack of persistence items in adherence scales may result in an incomplete understanding of why patients discontinue treatment over time, even when initial acceptance is high. Thus, by not capturing these components, existing adherence scales may miss key insights into the different stages of medication adherence, especially in chronic conditions that require long-term commitment. Future adherence tools for IBD could be improved by integrating measures of acceptance and persistence, providing

a more comprehensive assessment that could inform targeted interventions at different stages of adherence behavior.

Limitations

Some limitations remain to be discussed. First, this study was conducted during the COVID-19 epidemic, and the medication used by the enrolled patients was mostly injection or oral, lacking sufficient long-term rectal administration cases. Second, our study was conducted in East China, with a fair economic situation, which may cause some bias. Third, the interviewees were all adults, and further research has not been conducted on adolescents, children, and the elderly population.

Conclusion

Through qualitative interviews with 10 respondents, it was found that patients' resistance to diseases, lack of understanding of diseases, low beliefs in drugs, perception of drug efficacy, and a series of factors such as cost and psychology all affect non-adherence. Considering the characteristics of China's healthcare system, given the high prices of IBD drugs (especially biologics), expanding public insurance coverage or launching subsidy programs specifically for IBD treatments would make it easier for patients who currently face high out-of-pocket costs to adhere to medications in the long term. In addition, regular training of healthcare providers, especially those in public hospitals, could improve understanding of IBD-specific challenges and enhance communication between patients and providers, thereby increasing patient trust and adherence to prescribed therapies.

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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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