

Exploring Barriers to Medication Adherence in Patients with Inflammatory Bowel Disease: A qualitative Study

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Abstract

Background: Medication adherence is critical to achieving optimal treatment outcomes in patients with chronic inflammatory bowel disease (IBD). However, non-adherence remains a common challenge, potentially leading to disease relapses, increased hospitalization rates, and decreased quality of life. Understanding the barriers to medication adherence from the patient's perspective is essential for developing effective patient-centered interventions.

Objective: This study aimed to explore the barriers faced by patients with inflammatory bowel disease in adhering to their medication.

Method: A qualitative descriptive design was adopted, with semi-structured interviews conducted with a purposively selected group of adult patients with Crohn's disease or ulcerative colitis until data saturation was reached. Data was analyzed using thematic analysis to extract key themes related to patients experiences and beliefs about medication adherence. Studying starts from January 15th, 2025, to March 10th, 2025.

Results: The study results revealed several major sub themes barriers affecting patient's adherence to medications, including Discontinue Due to Side Effects, stop medication upon symptom improvement, unavailability of prescribed therapy, discontinuation due to high cost, and forgetting to take medication. Analyses showed that these factors overlapped between individual, economic, and systemic factors.

Conclusion: This study confirms that adherence to medication in patients with chronic inflammatory bowel disease is affected by a variety of barriers. This calls for comprehensive interventions that include health education, improved medication availability, financial support, and the introduction of support tools that enhance medication reminders. These interventions aim to improve treatment outcomes and enhance quality of life.

Keywords: *Inflammatory Bowel Disease, Medication adherence, Barriers.*

Introduction

Inflammatory bowel disease (IBD), which includes Crohn's disease and ulcerative colitis, is a chronic inflammatory disease of the gastrointestinal tract characterized by recurrent episodes of activity and remission. IBD represents a growing global health burden, with the number of people affected rising to more than 6.8 million according to 2017 estimates, reflecting a continued rise in its global prevalence (Alatab et al., 2020; Al karaawi & Kadhim 2024). The disease requires ongoing treatment and close medical monitoring, as it has significant impacts on patients' quality of life, including pain, fatigue, anxiety, and social isolation (Kaplan et al., 2021; Alnaffakh et al., 2024). In this context, medication adherence is a crucial aspect of IBD management, as treatments, such as aminosalicylates, immunosuppressants, and biologics, help reduce inflammation, control symptoms, and prevent complications. Good treatment adherence leads to better clinical outcomes, with lower rates of relapse and hospitalization (Haar et al., 2021). However, despite the availability of effective treatment options, several studies indicate that a significant proportion of patients do not adhere to their prescribed treatment plans (Lamb et al., 2019). Treatment adherence is a complex behavior influenced by multiple interconnected factors, including psychological factors, personal beliefs, and anticipated side effects, as well as the difficulty of integrating treatment into patients daily routines. Lack of knowledge about the disease or fear of prolonged medication dependence also contribute to poor adherence (Ghadir et al., 2016). Furthermore, socioeconomic status, education level, and the availability of family and medical support influence patients adherence to treatment (Kanazaki et al., 2022; Al-hussein, 2018).

Despite the presence of numerous quantitative studies and its determinants, understanding the deeper contexts of patients' experiences and beliefs can only be achieved through qualitative research. Qualitative approaches allow participants to express their personal thoughts and experiences related to treatment in a more comprehensive and authentic manner (Pyo et al., 2023). Researchers have recommended exploring patients perspectives to understand the motivations and barriers that influence their treatment behavior (Hill et al., 2022).

Moreover, cultural and environmental factors play an important role in shaping patients perceptions of treatment adherence. In some contexts, social stigma and traditional beliefs may negatively impact patients acceptance of treatment. Limited time during medical consultations and poor communication between patient and physician also contribute to a clear gap between treatment recommendations and actual patient behavior (McQuaid & Landier 2018; Al-Ashour et al., 2024).

Given the multiplicity and complexity of factors affecting treatment adherence in IBD patients, there is a need for a qualitative study that explores barriers from the patients' perspective. This study aims to light on the psychological, behavioral, social, and systemic challenges that may hinder patients' adherence to their treatment. The findings constitute a necessary step toward developing personalized and contextualized treatment interventions that help improve patient outcomes and promote continuity of care. To achieve this, the study adopted a qualitative approach based on semi-structured interviews with a group of patients to explore their perceptions and barriers to treatment adherence in depth and comprehensively.

Methodology:

This study adopted a descriptive qualitative design to explore the barriers faced by patients with chronic inflammatory bowel disease in self-care management. The study was conducted at specialized hospital for gastroenterology and hepatology at Al-Najaf city, from January 15th, 2025 to March 10th, 2025. Participants were interviewed in this hospital during their period of receiving biological therapy.

The interviews are semi-structured interviews were used as the primary data collection tool with open ended questions, lasted between 15 and 20 minutes, conducted face-to-face in a calm environment that ensured participants' privacy and psychological comfort while sharing their personal experiences, through interview there are interactive between the researcher interviewer and participants interviewees to provide daily experiences details about the study topic.

Participants were selected using a purposive sampling method, including patients of both sexes and different ages groups, diagnosed with either type of IBD: Crohn's disease or ulcerative colitis, Participants were required to be able to clarify their experiences clearly, have rich and in-depth experience dealing with the disease, and voluntarily consent to be interviewed and audio-recorded. Only participants who demonstrated a readiness to share meaningful obstacles and could respond thoughtfully and reflectively to the interview questions were included. Data collection continues until thematic saturation point was achieved, which reached after 16 participants (nine females and seven males) were interviewed at which point no new codes or themes were emerging from the data.

Data collection and analysis

Data were collected through semi-structured interviews. Initially, basic demographic information was documented for each participant, including age, gender, education level, and disease type (Crohn's disease or ulcerative colitis). The interviews were conducted face-to-face with written consent from the participants and were audio-recorded, ensuring complete confidentiality. No names or identifying information were collected. After completing all interviews, the recordings were transcribed verbatim in Arabic and then accurately translated into English, preserving the original meaning of the participants' experiences. Data were analyzed using reflective thematic analysis, following the six stages outlined by Braun and Clarke, which include in-depth data familiarization, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and finally writing the analytical report. This approach helped uncover recurring and meaningful patterns and experiences that reflect the barriers to self-care for patients with chronic inflammatory bowel disease (Braun & Clarke, 2006).

To ensure the trustworthiness and credibility of the findings, a range of strategies were implemented, including peer debriefing, continuous review of data throughout the analysis process, and careful and systematic documentation of all research procedures. The researcher also maintained contextual awareness and self-reflexivity throughout the study by continually reflecting on the role and influence on data collection and analysis. Ethical principles were strictly adhered to, including voluntary consent, confidentiality, and participants' right to withdraw at any time without consequences.

Ethical consideration

This study was approved from Ethical Committee of the College of Medicine, University of Kufa, prior to data collection. The study objectives were clearly and understandably explained to participants, and they were assured that their participation was entirely voluntary and that they had the right to withdraw at any time without consequences. Written informed consent was obtained from all participants prior to interviews. Participants' names and any personal information that might identify them were not disclosed to ensure complete confidentiality and privacy. Participants did not receive any financial rewards for their participation in the study.

Results

Qualitative results: The interviews were manually analyzed, and explore six subthemes related to the barriers faced patients with IBD and prevent them from treatment adherence. these themes provide a comprehensive understanding of the barriers patients encounter (1).

Table (1.): Thematic Analysis Findings of Qualitative Data

Theme	Sub-theme	N (Participants)
Medication adherence barriers	Discontinue Due to Side Effects	9
	Discontinuation Due to Perceived Ineffectiveness	7
	Stopping Medication when Symptom Improve	8
	Unavailability of Prescribed Therapy	9
	Medication Discontinuation Due to High Cost	11
	Forgetting to take medication	6

Medication adherence barriers: was one of the most prominent challenges identified by most study participants. Several recurring barriers to continuing to take prescribed medications emerged. Discontinue due to side effects: nine of participants indicated that they discontinued certain medications due to experiencing bothersome side effects such as nausea or joint pain, which led them to avoid the medication for fear of worsening these symptoms:

“ Some drugs when I take made me feel nauseous and sometimes increased my joint pain so I stop this drug I fear from side effects it causes me...”.

This quote indicates the impact of a patient's experience with side effects on their decision to discontinue medication. Concern about worsening symptoms plays a pivotal role in their treatment behavior, requiring the provision of appropriate treatment alternatives and patient education on managing these side effects.

Discontinuation due to perceived ineffectiveness: seven of participants reported that they stopped taking their medication because they felt it was ineffective, reflecting frustration and despair at continuing to use a treatment that did not achieve tangible improvement:

“ I neglected the medication because of my mental state. I got bored with it because it didn't seem to help. Some days I take the medication, and other days I don't. I'm tired of the medication not benefiting me...”.

This quote reflects the relationship between the psychological perception of treatment effectiveness and personal motivation to adhere to it, calling for psychological and communication interventions from caregivers to explain the mechanism of the medication's long-term effect.

Stopping medication when symptom improve: Eight of participants explained that they stop taking their medication when they feel temporarily better, due to the mistaken belief that their symptoms have completely disappeared:

“ When I feel better, I stop the doctor's treatment for a while, but I return to the treatment after I feel my health deteriorating...”.

This behavior demonstrates a lack of awareness of the chronic nature of the disease and the need for ongoing treatment even in the absence of symptoms, highlighting the importance of ongoing therapeutic education.

Unavailability of prescribed therapy: Nine of participants stated that medication shortages at hospital or in their city posed a significant obstacle to their adherence to the treatment plan:

“ During the previous period, the biological treatment was not available more than four times, and it was not present. My health was affected, and I cannot buy it because it is expensive. It was also not available in my city...”.

This illustrates the impact of limited healthcare infrastructure in some areas, calling for improved distribution mechanisms and ensuring the continued availability of essential medicines.

Medication discontinuation due to high cost: Eleven of participants suffered from the financial burden associated with treatment, leading them to stop taking it due to their inability to afford its ongoing costs:

“ The cost of treatment was very expensive. I push myself to continue working to cover the financial need. One strip cost 13,000IDQ, I need this strip every day...”.

This quote highlights the direct impact of the economic situation on treatment behavior, which necessitates government interventions to provide treatments at subsidized or free prices for those with chronic diseases.

Forgetting to take medication: six of participants reported that daily busyness or work pressures lead them to forget or postpone taking their medications, negatively impacting treatment effectiveness:

“ Sometimes, I delay taking my medication on time because I'm busy with work; I take it at night or the next day or sometimes I don't take it...”.

This statement highlights the role of organizational and personal factors in medication adherence, calling for the adoption of reminder strategies such as phone apps or family support to improve compliance.

Discussion:

The results of the current study revealed several barriers preventing patients with inflammatory bowel disease in Iraq from adhering to their prescribed medications. These barriers included discontinuation of medication due to side effects, discontinuation due to perceived ineffectiveness, discontinuation when symptoms improve, unavailability of treatment, high medication costs, and forgetfulness. These barriers reflect the complex interplay of behavioral, psychological, economic, and structural factors that influence medication adherence.

The study's findings are consistent with those of Xu et al., in China, who identified seven key themes that influence adherence: refusal of treatment due to unacceptability of the disease, lack of knowledge about the disease, beliefs about treatment, perceived effectiveness of treatment, side effects, cost, and psychological factors (Xu et al., 2024). However, the impact of these barriers in Iraq is exacerbated by specific local conditions, such as irregular availability of medications, limited access to biologics, and patients' financial burdens due to poor health insurance, which increase the rate of discontinuation. Discontinuation of medication when symptoms improve reflects a lack of awareness of the chronic nature of the disease and the importance of continuing treatment. This is linked to a lack of health education and regular medical follow-up, which plagues the Iraqi healthcare system due to limited resources and a shortage of gastroenterologists.

Furthermore, the results of Hommel et al., study indicate that forgetfulness was the most common barrier to treatment non-adherence, followed by interference with daily activities such as work or school, difficulty swallowing pills, and being away from home, which leads to patients' lack of regular medication intake (Hommel & Baldassano, 2010). In Iraq, it is attributed to the complexities of daily life, such as work and school, and is exacerbated by the lack of structured reminder systems or support programs for medication adherence. A review by King et al., (2025) also highlighted the importance of modifiable factors such as patients' poor understanding of treatment, difficulty accessing medications, and lack of personal organization as key factors contributing to poor

adherence (King et al., 2025). These barriers are exacerbated in Iraq by challenges navigating the healthcare system, poor awareness, and the absence of individualized treatment plans.

Based on the above, barriers to medication adherence in Iraq arise from a complex mix of psychological, practical, and financial issues, exacerbated by limited healthcare resources and infrastructure. Hence, there is an urgent need to develop interventions that take into account the specificity of the Iraqi context, such as enhancing health education, improving communication between patients and caregivers, ensuring the availability of medications at affordable prices, and providing ongoing psychosocial support to enhance adherence and improve health outcomes for IBD patients in Iraq.

Conclusion

The results of this qualitative study revealed that adherence to medication among patients with IBD faces multiple, interconnected barriers, ranging from personal, psychological, economic, and systemic factors. The most prominent reasons patients discontinued their medication included bothersome side effects, a feeling of ineffectiveness, and some discontinued adherence as soon as symptoms improved. This reflects a partial understanding of the nature of the chronic disease, which requires long-term treatment, even during periods of remission. Participants also cited external barriers, such as the lack of consistent medication availability, the high cost of medications, and forgetfulness, a common reason for discontinuation. These findings highlight the challenges patients face on a daily basis and emphasize the importance of adopting holistic approaches that go beyond providing treatment, but also include psychological, educational, and social support to help patients understand and cope effectively with their condition. The study highlights those challenges related to the health system (such as drug shortages and costs) are no less important than internal challenges, requiring a multi-level response from healthcare providers and health policies.

Limitations:

This study faces several limitations that should be considered when interpreting the results. First, the limited sample size may affect the ability to generalize the results to all IBD patients in Iraq, as it

may not fully reflect the diversity of experiences and different health conditions. Second, the study was conducted within a single or specific healthcare setting, which may limit the representativeness of the results to other regions or healthcare facilities with different capabilities and population distribution. Third, there is a potential for response bias, as participants may tend to provide answers in line with what they perceive as socially desirable, or they may have difficulty remembering precise details related to medication-taking behaviors. Finally, given the cross-sectional design of the study, causal relationships between the barriers identified and treatment adherence cannot be inferred. This calls for future studies with broader, longer-term approaches to better understand these relationships. These limitations reinforce the importance of caution when generalizing the results and point to the need for extensive research to support and extend these findings in the Iraqi context.

Recommendation:

1. Promote patient education about the nature of chronic inflammatory bowel disease, the importance of medication adherence even during periods of symptom improvement, and explain potential side effects and how to manage them.
2. Ensure regular availability of essential medicines in public health facilities and facilitate access to them, especially in remote or underserved areas.
3. Adopt simple technology interventions, such as medication reminders via phone apps or text messages, especially for patients who experience frequent forgetfulness.
4. Conduct more qualitative studies in different settings to understand the contextual characteristics of barriers and engage patients in developing strategies to improve medication adherence.:

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Conflicts of Interest

The authors declare that there are no conflicts of interest related to this work.

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