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Patients' and gastroenterologists' preferences regarding outcomes and medication attributes in ulcerative colitis

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Abstract

Background Patients' and gastroenterologists' views on the relative importance of treatment outcomes and medication attributes for ulcerative colitis (UC) may differ. We aimed to explore which treatment outcomes and medication attributes are considered important by both for therapeutic decisions.

Methods Eight gastroenterologists and 23 patients with UC in Greece participated in semi-structured interviews and focus groups, respectively. The focus groups and interviews were audio-recorded, transcribed and coded, utilizing thematic analysis until data saturation was achieved.

Results Themes that were discussed included the impact of UC on daily life, UC-related outcomes, drug-related attributes and the patient–doctor relationship. Within these themes, disparities between the perspectives of gastroenterologists and patients were evident on 2 main issues. Gastroenterologists prioritized clinical remission and emphasized long-term objectives, such as mucosal healing, while patients focused on shorter-term outcomes, such as the early and sustained relief of symptoms. Regarding medication attributes, important factors for patients were primarily those that impacted their daily life, such as route of administration, dosage and the need for hospital visits. In contrast, gastroenterologists were more concerned about potential adverse events and non-responsiveness to treatment. There was a consensus regarding the importance of shared decision-making for UC management, emphasized by both patients and clinicians.

Conclusions Gastroenterologists mostly prioritize objective measures of remission, while patients mainly focus on factors related to their quality of life and overall well-being. Enhancing communication regarding different goals and expectations may strengthen the physician–patient relationship, ultimately resulting in better shared therapeutic decision-making.

Keywords Ulcerative colitis, qualitative research, patient-centered approach

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Introduction

Ulcerative colitis (UC) is a relapsing–remitting, chronic, idiopathic inflammatory disease that leads to progressive bowel damage and requires lifelong management [1-3]. The management of moderate-to-severe UC has become increasingly complex, given the growing number of available biologics and small molecules with various efficacy, safety, and administration characteristics such as dose and frequency [4-6]. As the therapeutic options with unique features expand, there is a growing acknowledgment that therapy selection should be adapted to suit the preferences and requirements of patients [7].

Patient-centered care has gained significant interest, especially for chronic conditions like UC, where patients manage long-term disease burdens. Understanding patients' perspectives on medical options is crucial for recognizing their daily challenges.

Integrating their preferences, needs, values and considerations into clinical practice encourages active participation in therapeutic decision-making [8,9]. A patient-centered approach can enhance compliance and satisfaction, leading to better therapeutic outcomes and stronger relationships between patients and healthcare providers [10]. Therefore, understanding the factors important to UC patients is essential [11]. Multiple studies have highlighted gaps in perceptions between healthcare providers and UC patients regarding optimal disease management and the disease's impact on health-related quality of life [12,13]. However, there is also a need to understand healthcare providers' perspectives on treatments in order to fully grasp the patient–provider relationship in long-term follow-ups. Limited research has explored patients' perspectives on UC treatment priorities [14-16], and a few studies have compared clinicians' preferences to those of patients, despite potential differences in views on treatment outcomes and medication characteristics [17,18]. Using a qualitative approach, this study aimed to explore both Greek gastroenterologists' and patients' preferences in the decision-making process regarding UC treatments.

Materials and methods

Study overview

We used a qualitative descriptive design, incorporating focus groups with patients and interviews with gastroenterologists. This approach allows for an in-depth examination and systematic analysis of semi-structured data to provide valid insights into subjective experiences [19,20]. The design was deemed most appropriate for gathering comprehensive insights from participants. The study protocol was reviewed and approved by the Local Ethics Research Committee, Aristotle University of Thessaloniki. Our study is reported according to the consolidated criteria for reporting qualitative research (COREQ), a checklist of 32 items specifically designed for reporting interviews and focus groups [21].

Focus Groups

We conducted focus groups to gain insight into patients' care experiences and explore the impact of their illness on their lives [22,23]. Focus groups were preferred over individual interviews to capture the dynamic exchange of viewpoints and concepts in a group environment, generating insights through interaction. Engaging participants in collective dialogue allowed us to capture how individual opinions were influenced by group dynamics, providing valuable context to the data collected. Potential participants were identified through 2 tertiary clinical sites specializing in the treatment of inflammatory bowel disease (IBD) and the online community of the Hellenic Society of Crohn's Disease and Ulcerative Colitis Patients. To be included in the study, patients had to be older than 18 years, have a confirmed diagnosis of UC, be able to give informed consent, and understand and speak Greek fluently. We aimed to recruit both biologic-experienced patients and biologic-naïve patients to capture a diverse range of viewpoints. Each focus group was planned to include 6-10 participants. Upon contacting potential participants, a researcher (AK) provided a detailed explanation of the group's objectives, emphasized the voluntary nature of participation and assured confidentiality. Informed consent was obtained from all participants before the focus group sessions.

The focus groups were conducted in a semi-structured format led by an experienced psychologist (MT), who introduced topics, posed questions, moderated the discussion and ensured all participants had the opportunity to contribute. A second researcher (AK) observed the sessions, recorded audio, assisted the facilitator with time management and took field notes to aid transcription. Discussions followed a semi-structured topic guide (Appendix 1) developed by consensus among 4 researchers (AK, MT, PP and AT). The guide included open-ended questions exploring patients' experiences and perspectives on living with UC, its management, and available treatments. Each session began with an introduction by the moderator, explaining the rules to encourage active involvement. Participants were encouraged to speak freely, interact and discuss their experiences, with confidentiality emphasized. Audio data were transcribed verbatim before the main analysis, and a preliminary qualitative data analysis occurred simultaneously to achieve data saturation [24].

Interviews

Semi-structured interviews with gastroenterologists were conducted to explore each physician's unique perspectives through 1-on-1 interactions. Individual interviews allowed for a flexible and personalized approach, enabling physicians to express their thoughts openly without group influence. Eligible participants were gastroenterologists specializing in IBD, identified from the Hellenic Group for the Study of IBD, and selected based on their experience and patient volume. Written informed consent was obtained from participants before the interviews.

All interviews took place in quiet, private settings. A single researcher (AK) conducted face-to-face interviews, prompting participants to discuss topics related to the research question using open-ended questions. Interviews followed a semi-structured topic guide (Appendix 2) developed by consensus

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among 4 researchers (AK, MT, PP and AT). The guide included questions aimed at exploring the general approach and experiences of gastroenterologists in treating UC patients. Interviews lasted 15-30 min, were audio-recorded, securely stored, and transcribed verbatim.

Data analysis

We conducted a thematic analysis [25-27] using the general principles of grounded theory [28] to analyze the transcriptions of focus group sessions and interviews. The analysis followed these steps:

(1) Familiarization with the data: Researchers carefully read and re-read the data to gain a deep understanding of the content. This step involved actively engaging with the data to become familiar with the depth and breadth of the material, including noting initial ideas and observations.
(2) Generating initial codes: After multiple readings of the transcripts, significant words or phrases were identified and highlighted. Marginal notes were taken, and an initial set of codes was created to categorize various data segments.
(3) Searching for themes: Researchers identified relationships among different codes, grouping similar concepts together to form themes and subthemes.
(4) Reviewing themes: Themes were reviewed in 2 stages. First, the researchers examined each theme within the coded data to ensure its relevance. Next, they reviewed the themes across the entire data set. This process involved comparing the themes with the original data to confirm their accuracy and refining the thematic structure to better align with the research objectives.
(5) Defining and naming themes: In this step, the researchers defined each theme clearly, ensuring they reflected the core idea or concept within the data. Each theme was given a concise and meaningful name that captured its essence, allowing for a clearer interpretation of the themes.
(6) Writing the report: Finally, the researchers produced a detailed report, weaving together the themes with supporting data excerpts. This step involved writing a comprehensive narrative that linked the themes to the research questions and provided a clear interpretation of the findings.

To enhance credibility, these steps were independently carried out by 2 researchers (AK and PP). Through regular meetings, codes and recognized themes underwent review and discussion until consensus was reached, with feedback from the entire research team. A complete list of themes, reflecting the experiences of focus group participants and the perspectives of gastroenterologists, was developed. Transcripts were initially coded in the original language, with Greek quotations translated into English for presentation. After completing the inductive analysis, we identified codes more representative of patients and gastroenterologists, allowing us to discern similarities and differences between the 2 groups. Data collection continued until theoretical saturation was reached, defined as the point when no new themes or concepts were identified.

Results

Study participants

Initially, 26 patients were identified from 2 IBD clinics and volunteered for the focus group study. Three patients could not be reached or did not attend their scheduled sessions. The remaining 23 patients participated in 3 focus groups, each lasting 60-90 min. One group included 7 patients treated with biologic therapy, another had 10 patients not treated with biologic therapy, and the third group was mixed, with 6 patients. The first 2 sessions were face-to-face, while the third was conducted online via laptop, mobile or tablet. Participants included 12 females, and their ages ranged from 22-54 years (median 35.5 years). Thirteen patients had lived with the disease for more than 10 years, 7 for 5-9 years, and 3 for less than 5 years. Positive group dynamics were noted, with all participants contributing equally to the conversations.

For the interview study, 8 gastroenterologists were recruited. Of these, 8 worked in public hospitals, 5 of which were also university hospitals. Additionally, 5 gastroenterologists also had a private practice. Most participants were male (n=6), with ages ranging from 45-62 years (median 56 years). Seven had been practicing gastroenterology for over 20 years, and 1 for 15-20 years. All reported treating more than 70 UC patients per month. All participants were members of the European Crohn's and Colitis Organisation (ECCO). The interview sessions lasted between 20 and 30 min. The characteristics of the participants, including both patients and physicians, are presented in Table 1.

Table 1 Participants' characteristics

Demographic and clinical characteristics of focus group participants (Patients, n=23)	
Age, median	35.5 years
Sex, n (%)	
Female	12 (52.2)
Male	11 (47.8)
Biologic therapy, n (%)	
Yes	12 (52.2)
No	11 (47.8)
Disease duration, n (%)	
≥10 years	13 (56.5)
5-9 yearsw	7 (30.4)
<5 years	3 (13.1)
Demographic characteristics of interviews participants (Gastroenterologists, n=8)	
Age, median	56 years
Sex, n (%)	
Female	2 (25.0)
Male	6 (75.0)
Practicing gastroenterology, n (%)	
≥20 years	7 (87.5)
15-19 years	1 (12.5)

Patients' perspectives

In focus groups, 5 main themes were discussed: the impact of UC on daily life, UC-related outcomes, drug-related attributes, dealing with UC, and the patient–doctor relationship. We identified a total of 15 subthemes derived from these main themes. Indicative quotes supporting these themes and subthemes from patients are presented in Appendix 3. The themes discussed in the focus groups are summarized as follows:

Impact of UC on daily life

UC patients shared their experiences with the condition, highlighting its profound psychological impact. Many described the diagnosis as a shock, leading to denial and significant emotional strain. Phrases like "shock" and "denial" underscored the psychological toll. Participants vividly described how UC imposes constraints on various aspects of their lives, including professional, social, and personal domains, leading to a challenging and restricted lifestyle. Participants recounted periods of withdrawal and isolation, feeling they had made sacrifices without receiving expected benefits. Emotional and psychological burdens were recognized as prominent subthemes. A primary concern was the unpredictability of symptoms and the necessity of always being aware of restroom locations.

Fear of future complications, such as cancer, and managing flare-ups during crucial life moments contributed to insecurity and disrupted normalcy. Additionally, some participants experienced anxiety or guilt regarding the hereditary nature of UC, fearing the possibility of passing the illness to their offspring. Women of reproductive age expressed concerns about family planning, including fertility, pregnancy, and the risks of flare-ups associated with it.

Outcomes related to UC

Regarding UC-related outcomes, almost all participants prioritized their symptomatic response. They strongly desired the disappearance of symptoms, highlighting the significance of being free from bleeding, pain and urgency, to regain a sense of normalcy. The ability to function without worrying about restroom locations and living a symptom-free life was strongly emphasized.

Secondary priorities included achieving a broader sense of normalcy in daily life and an improved quality of life, encompassing emotional well-being, social interactions, and the ability to pursue professional and personal goals.

Drug-related attributes

Patients focused primarily on the impact of medications on daily life, considering factors like the route of administration, dosage requirements and the necessity of frequent hospital visits. There was a shared preference for medication with fewer doses, long intervals between administrations, and minimal invasiveness. Less frequent hospital visits and treatments contributed to a feeling of normalcy and momentarily forgetting about the illness.

Some patients envisioned an "ideal" medication: a single dose or 1-time treatment offering a lasting solution. A minority reported that drug characteristics were less concerning as long as the medication was effective. Various modes of treatment administration, such as injections and pills, were discussed, with participants expressing willingness to use any form that would lead to symptomatic relief. Concerns about the long-term use of certain medications, particularly those with potential side effects, were also expressed.

Dealing with UC

Participants acknowledged the crucial role of medications in controlling UC, emphasizing the importance of adhering to prescribed treatment regimens for successful management. Coping strategies included seeking psychological support, actively managing stress, and making lifestyle changes. Avoiding stressful activities and relying on supportive individuals were essential. Understanding and accepting the condition were crucial for achieving a balanced and fulfilling life.

Patient–doctor relationship and shared decision-making

Trust in healthcare professionals was identified as a crucial theme. Participants emphasized the importance of relying on their doctors for accurate information and personalized treatment plans. They shared experiences of changing doctors until finding one who matched their psychological needs. A positive change was noted when transitioning to a supportive doctor who offered reassurance and clear explanations. Establishing a strong relationship with the physician during the early stages after diagnosis was crucial for long-term condition management. The significance of having a doctor who addresses not only physical symptoms but also provides emotional support was highlighted.

Information and communication with healthcare providers were considered essential for shared decision-making regarding treatment. Participants advocated for active involvement in treatment decisions, including choosing medication and its method of administration. They expressed a preference for having more control over their healthcare and the ability to tailor treatments to their preferences.

Gastroenterologists' perspectives

The interviews with gastroenterologists touched upon 4 main themes: shared decision-making in treatment, UC-related outcomes, drug-related attributes, and patient support. Fourteen subthemes were identified from these main themes.

Indicative quotes supporting these themes and subthemes are detailed in Appendix 4. The themes discussed in the gastroenterologists' interviews are summarized as follows:

Views on shared decision-making

Shared decision-making was identified as a key theme, with physicians emphasizing the importance of personalizing treatment based on the patient's desires and requirements. However, time constraints and the lack of decision aids were identified as barriers to achieving a truly collaborative approach. Clinical practice often relies on informational materials like brochures and presentations to inform patients about their condition and treatment alternatives.

Physicians noted that patients' preferences for involvement in decision-making vary widely. Some desire an active role, forming opinions about their treatment, while others prefer to delegate decision-making to avoid the stress associated with making choices. Generational differences also impact the extent to which patients want to be involved, with younger patients tending to be more assertive, while older patients may be more receptive to the doctor's recommendations.

Outcomes related to the UC

Clinical remission was identified as the primary focus and goal of treatment. This refers to the absence or significant reduction of disease activity and inflammation in the colon. Achieving and maintaining clinical remission was seen as crucial for the patient's overall well-being and health. Physicians emphasized the importance of long-term outcomes, particularly over a 5-year period, when considering treatment goals. Mucosal healing, defined by endoscopic improvement and histologic remission, was emphasized as a secondary outcome essential for long-term disease management and prevention of disease progression.

Drug-related attributes

The absence of significant side effects and serious toxicity was identified as the most important factor for treatment selection. Physicians emphasized the significance of minimizing risks associated with treatment to ensure patient safety and avoid undesirable consequences. The most worrisome adverse reactions mentioned included malignancies, severe infections, and alterations to immune pathways.

Effectiveness was also considered vital, with a focus on bringing about rapid and sustained improvement. Physicians stressed the importance of selecting medications that remain effective over a long period. Confidence in the medication's ability to manage the condition for many years was deemed crucial. They also highlighted the importance of treatment methods that fit each patient's daily routines and their capacity to adhere to prescribed regimens.

Patient support

Dedicating sufficient time for discussions with patients was emphasized by the participants. Adequate time was considered essential for ensuring patients fully comprehend and perceive the information provided. Recognizing the importance of understanding patients' perspectives, including their fears, concerns, and life circumstances, was seen as facilitating agreement on treatment strategies. Moreover, the necessity for psychological support was acknowledged. Physicians suggested incorporating a psychologist into the healthcare team to address the unique challenges and mental health aspects of UC patients.

Discussion

This study explored the concordance between patients' and gastroenterologists' preferences regarding therapeutic decision-making for UC using qualitative methods. Focus groups and interviews provided insights into the challenges, priorities, and preferences related to managing UC.

Patients highlighted the profound impact of UC on their physical, emotional, and social well-being, expressing a strong desire for symptomatic relief and improved quality of life as their primary treatment goals. In line with our findings, a 2020 systematic review of 11 qualitative studies highlighted physical symptoms as the greatest challenge for patients [29]. Similarly, findings from a recent Greek study [30] revealed that 78% of UC patients reported their condition to be mentally exhausting, underscoring the substantial emotional toll UC takes on patients. This emphasizes the importance of addressing not only physical symptoms, but also the psychological and emotional aspects of the disease. Such an approach is consistent with the principles of patient-centered care, where managing the emotional and psychological impact of UC is crucial, as confirmed by various studies on health-related quality of life in UC patients [31].

Regarding specific drug attributes, patients preferred medications with minimal invasiveness and fewer doses to maintain normalcy and minimize disruptions. These priorities are consistent with findings from the discrete choice experiment (DCE) study where patients with UC ranked oral administration and minimizing risks of adverse events as highly important [32]. Moreover, a qualitative study found that patients prioritize pill-based dosing schedules over injections or infusions, which aligns with the findings of our study [15].

Additionally, patients expressed a strong desire for shared decision-making, emphasizing the importance of trust, effective communication and active participation in treatment planning. They valued transparent discussions about treatment options, outcomes and potential risks. Similar to our results, previous research has also shown that patients with UC express a growing preference for active involvement in the decision-making process regarding their treatment options [33-35]. Moreover, this aligns with findings from the CARES study [36], which also identified significant gaps in understanding between patients and physicians, and from the DCE study [32], which emphasized that patients valued personalized care and preferred active involvement in treatment decisions. Similarly, the study by Viazis *et al* [30] emphasized that patient satisfaction during interactions with healthcare providers is significantly influenced by effective communication and trust.

Conversely, gastroenterologists prioritized objective and scientific metrics of remission, focusing on long-term outcomes such as mucosal healing, defined by endoscopic improvement and histologic remission. This perspective aligns with previous research, which showed that physicians value long-term remission and endoscopic outcomes as key treatment goals [15,32]. For drug attributes, gastroenterologists emphasized patient safety and the long-term efficacy of medications, focusing on minimizing side effects and optimizing treatment outcomes. Gastroenterologists expressed agreement on the importance of shared decision-making, recognizing its potential to enhance patient satisfaction and adherence. However, they identified significant barriers to its implementation, such as time constraints and the lack of decision aids, which hinder truly collaborative care.

This discrepancy in perspectives highlights the differing priorities between patients, who seek immediate relief and improved quality of life, and physicians, who focus on sustained clinical outcomes. While both groups agree on the importance of long-term symptom control, patients place greater emphasis on addressing the immediate physical and emotional toll of UC. Addressing these obstacles is essential for fostering a patient-centered approach and aligning treatment decisions with patients' values and priorities.

Our results highlight the importance of enhancing provider–patient relationships to promote shared decision-making in UC management. As therapeutic options for UC continue to expand with varying efficacy, safety, and administration profiles, understanding both patients' and clinicians' preferences becomes even more essential. Bridging the gap between patients' immediate goals—such as symptom relief and quality of life—and clinicians' focus on long-term clinical outcomes is key to developing a truly patient-centered approach to treatment.

One of the novel contributions of our study is the emphasis on the integration of patients' values and preferences into the decision-making process, recognizing the significant emotional burdens that often accompany chronic conditions like UC. This approach to decision-making is consistent with the growing body of literature advocating for patient-centered care in chronic disease management [37-39]. By facilitating better alignment of treatment options with the individual needs of patients, we can enhance satisfaction and improve therapeutic outcomes. Our findings underscore the critical role of shared decision-making in aligning these perspectives and suggest that decision aids can play a pivotal role in this process. These tools, which provide evidence-based information in an easily understandable format, can support active patient participation, reduce uncertainty and promote informed decision-making. The recent Cochrane review supports the utility of decision aids in enhancing patient understanding and decision-making in chronic conditions, highlighting their potential application in UC management [40].

From a research perspective, our study opens new avenues for exploring which treatment outcomes and medication attributes are most important to both clinicians and patients with UC. Through rigorous examination in a larger sample, we can ascertain which factors hold the utmost importance to patients, thereby refining our understanding of patient-centered care in UC management. Of particular importance is the potential utility of these patient-important outcomes as endpoints in future clinical trials. By aligning trial endpoints with the outcomes that matter most to patients, we can enhance the applicability of research findings, ultimately aiming for more efficient and personalized treatment strategies in UC management.

The main strength of this study is the significant interaction observed among focus group participants, enriching the data collected and enhancing understanding. This interaction not only enriched the breadth of data collected but also enhanced the depth of understanding as participants challenged, corroborated and expanded upon one another's viewpoints. Including patients with different treatment experiences and disease durations provided a comprehensive insight into their experiences [23]. The use of a qualitative exploratory design allowed the acquisition of non-formalized responses, and hence an in-depth understanding of their preferences and concerns. To ensure the internal validity of our conclusions we adhered to relevant guidelines for the conduct and reporting of qualitative studies [20,21].

Despite its strengths, the study has several limitations that need to be addressed. The small sample size could be considered a limitation; nevertheless, discussions recorded both during focus groups and during interviews allowed us to claim we met theoretical saturation. Furthermore, the inclusion of solely Greek participants with UC could limit the generalizability of our findings. The economic crisis and the COVID-19 pandemic have significantly impacted the Greek healthcare system, potentially influencing the experiences of UC patients in ways that may not be representative of other contexts. Therefore, while our study provides valuable insights, the unique circumstances in Greece may limit the extrapolation of findings to other regions.

In conclusion, while patients and gastroenterologists share common goals of improving treatment outcomes and enhancing quality of life for individuals with UC, there are differences in their perspectives and priorities. This study underscores the need for shared decision-making between them to improve clinical practice. Incorporating patients' preferences into decision-making at every stage of care is crucial for healthcare providers to offer personalized care and decide on optimal therapeutic plans for UC patients.

Summary Box

What is already known:

- Ulcerative colitis (UC) significantly impacts patients' physical, emotional, and social well-being, influencing their quality of life
- Patient-centered care is crucial in UC management, encouraging active patient participation in treatment decision-making to improve outcomes
- Limited research has explored and compared both patients' and clinicians' treatment priorities in UC, especially in specific populations such as Greek patients and gastroenterologists

What the new findings are:

- UC patients prioritize immediate symptomatic relief and improving daily life, emphasizing the importance of minimal treatment invasiveness and fewer medication doses
- Gastroenterologists focus on long-term outcomes, emphasizing clinical remission, mucosal healing and minimizing side effects, reflecting a safety-driven approach to therapy
- Patients value shared decision-making, advocating for more involvement in their treatment decisions and highlighting the importance of trust and communication with healthcare providers

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Supplementary material

Appendix 1 Semi-structured topic guide for the patients' focus groups

Impact of ulcerative colitis on daily life
What does living with ulcerative colitis mean to you? Do you think ulcerative colitis affects your daily activities or your quality of life in general? In what way? What worries or scares you most about ulcerative colitis? Why?
Management of ulcerative colitis
What does remission of ulcerative colitis mean to you? Which of the treatment outcomes do you consider to be the most important? How about secondary outcomes? How do you think remission of the disease can be achieved? What do you think are the main barriers in achieving remission of the disease?
Medication
How satisfied are you with your current medication for ulcerative colitis? Are there any medication side-effects that worry you or scare you? What characteristics would you like an ideal medicine for ulcerative colitis to have? Which of these do you consider most important?
Closing question
If a friend of yours was diagnosed with ulcerative colitis, what advice would you give them?

Appendix 2 Semi-structured topic guide for gastroenterologists' interviews

General questions
How do you define "shared decision making" and how familiar are you with this process? In what ways, if any, does shared decision making differ from informed decision making? What do you think are the barriers to integrating shared decision making into everyday life? Do you currently use any tools or decision aids in daily clinical practice?
Management of ulcerative colitis
Which treatment outcome is the most important when choosing among available medications for patients with ulcerative colitis? How about secondary outcomes? How does ulcerative colitis affect patients' quality of life?
Medication
What characteristics would you like an ideal medicine for ulcerative colitis to have? Which of these do you consider most important? What are your biggest concerns about the treatments patients are receiving? Are there any medication side-effects that worry you?
Closing question
What is your advice for treating and supporting patients with ulcerative colitis?

Appendix 3 Identified themes and subthemes with example quotations from the focus groups

Theme 1: Impact of ulcerative colitis on daily life
Subtheme 1: Impact on Freedom and Quality of Life “There was no response to the treatment, so the symptoms were intense. I was shocked. I couldn’t eat what most people were eating, so that was difficult. I had to stay indoors because there was insecurity.” “I try as much as I can to plan my day so that I am near a toilet every few hours, ideally every 2-3 hours. However, this is not always possible, which makes me anxious. Daily life has become difficult. As for food, I don’t even discuss it—the constant restrictions create frustration.” “My life revolved around a toilet. I mean, I would go to a place, and the first thing on my mind would be if there is a toilet. I would enter a store or a shop, first looking for the restroom and then checking if there is a table. “ “My job involves constant movement with a schedule of 1-2 h, and I’ve identified locations where I can find a restroom quickly if needed.” “During flare-ups, it was hell, no question about it, from every perspective. There were numerous urgent bathroom visits, mucus, and bloating.”
Subtheme 2: Emotional and Psychological Impact, Challenges in Social Interactions “Tremendous insecurity in my personal, family, professional, and social life.” “I made the ‘sacrifices’ that the illness demanded, yet it still didn’t provide the necessary reward. I would say that I’m doing all these things, and I would blame myself, wondering if I’m not doing it right, if I shouldn’t have done that particular thing, and ultimately, even if you did it, it’s your fault.” “I would wake up, and my biggest anxiety, being a teacher, was how I would get through my day. Even worse, how I would manage to go on a field trip with the bus and accompany the children with dignity while supporting my profession. That is tragic, it creates panic.” “I also had to take leave from work many times because I needed to be constantly near the bathroom. When I had to go out or visit a friend’s house, I always made sure to know where the bathroom was and to have easy and quick access.” “I didn’t have the stamina to cope. Of course, not even for a coffee; I had to plan everything just to go out for a coffee, making sure there was a bathroom available.” “Simply put, I just wish, like everyone else, to be independent, functional, and not have the need to undergo surgery or constantly experience flare-ups, always worrying about where the nearest toilet is. It’s a desire for normalcy. These are my concerns. Now, having recently become a father, I worry about my child having to go through the same issues, hoping it’s not something hereditary. Such thoughts come to mind.” “It affected every aspect of life, from the morning when I started work or went to school until the evening when I lay in bed unable to sleep. Psychological, physical, decision-making—whether to go out or not, to resolve a relationship with a certain person or not, to work at that school or not; everything. Travel. Many dilemmas, in the end dominated by the word “no.” No, you won’t eat; no, you won’t go out; no, you won’t have fun; no to everything, just to be okay.” “I didn’t go out as much as I wanted to, meaning when my friends wanted to go somewhere, I wouldn’t go, or if I did, I would be anxious about what might happen. It also affected my professional life because I had to take time off work for about a year until the situation stabilized.”
Subtheme 3: Fear of Relapse “I worry only about whether I will be able to rely on medication at some point. In other words, if something goes wrong with my body, if it starts functioning differently and no longer responds to the medications.” “Let’s say if I stop responding to this medication, what else can I try? Because I’ve already tried pills and other intravenous medications.” “In the first year after I went back into remission, there was the fear that now this will come back, now this will create a problem. You never know.” “I am concerned about the treatments we undergo and how they will affect our health. If our average lifetime is affected. Furthermore, if I reach a point where I need to undergo surgery to remove the intestine, meaning if I experience a flare-up again and reach this point, how do I proceed afterward.”
Subtheme 4: Long-Term Outlook “What scares me more than ulcerative colitis is the possibility that it might be hereditary and could be passed on to my child.” “How long will this continue, and if at some point I have a severe relapse, will I need to undergo surgery? “ “And what quality of life will I have in old age? Because, for me, it’s the opposite. As I age, the situation worsens, and I don’t know what quality of life I will have as I grow older.” “I generally have some fear about how things will be in the future, whether they will always be this good or if I decide to have children, how pregnancies will be, and such. I think about it a little and wonder how things will go.” “I am aware that there is an increased likelihood of developing comorbidities with cancer, especially considering the family history. I am also concerned that symptoms may worsen in the future if there are potential flare-ups.” “Now, my concern revolves around the possibility of a potential worsening that might require surgery, extensive resection of the colon, or the risk of progression to cancer. This worry is heightened by the fact that both my mother and her sister passed away from colorectal cancer.” “I feel unwell, and of course, it often crosses my mind how much more likely I am than someone else to develop colorectal cancer.” “It’s understandable that I would fear a form of cancer as well. Because generally, everyone fears it, I don’t have any specific issue with that. Given that we are surrounded by a disease, I fear it evolving into something like that.”

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Appendix 3 (*Continued*)

Theme 2: Outcomes related to the ulcerative colitis

Subtheme 1: Primary treatment outcome - Symptomatic Response

"I want to stop being married with the toilet. To stop being afraid, being unable to eat properly, unable to go out, unable to drink."

"I want to be without diarrhea, to be without fear, to be without anxiety in my daily life. To be able to share things with both my family and my partner."

"Not to have this constant pain, let's say, because at least I don't know how it is; I haven't discussed it with other people. I understand which contractions are normal and which ones are related to colitis."

"I hope that the treatment I receive will minimize or completely stop the bleeding, and that my bowel movements will become normal, eliminating the frequent urgency to use the restroom. I also wish to be free from pain during this process."

"I want to be pain-free. Pain management is crucial for me."

"The disappearance of symptoms is my goal. I want to live a fully normal life without mucus, bleeding, frequent urgency, so that I can engage in a complete and normal social life with family, friends, and work."

"Not seeing any bleeding is important to me because it negatively affects my psychological wellbeing. Additionally, it can lead to iron deficiency, causing symptoms like fatigue, lack of energy, and lethargy. So, being free from bleeding helps me feel more energetic and active in life."

"Essentially, it's the disappearance of symptoms, being able to eat whatever I want, and socialize without the fear of needing to find a restroom."

"During a crisis period, where I don't care about the form of the medication, I want the symptoms to be reduced. Whether it's injectables, suppositories, or anything else, I don't mind."

"The most important thing for me is to have no symptoms at all."

"To live without symptoms, to have a normal daily life without the presence of the disease, is the most significant for me. The fact that I need to have scheduled check-ups every 3 months doesn't bother or worry me. From a treatment, what I expect is precisely that—to have no symptoms at all."

"To have no symptoms at all. To be at least functional. If I have any, to be able not to burden either those around me or myself, obviously, to be able to do everything on my own. That's it."

Subtheme 2: Secondary priorities - Normalcy and Quality of Life

"The most important result of a treatment is being able to maintain balance in my everyday life."

"Remission for me means the ability to choose for myself what I will do during my day, how I will move, and whether I will be able to see people or not. That, for me, is what remission means."

"I want to be able to continue my sports activities, maintain my social connections without any cost to me, and pursue my academic career or any other endeavors."

"To be able to live normally without depriving myself of things in everyday life. Without losing my energy."

"To not constantly think about my intestines, what will happen, when to take the pills, just to have a sense of normalcy, a routine, to take my medications as advised, go for my check-ups as recommended, and not have it on my mind at all."

"At least to have fewer issues, fewer problems. If it's not 100%, at least to be a significant percentage."

Theme 3: Drug-related attributes

Subtheme 1: Most important characteristic - Reflections on Frequency and Administration

"I can say that I wouldn't like to come to the hospital once a month for these 2- to 3-h sessions. That. I wouldn't like to do that. I would prefer to use injections, for example, but I'm afraid to change."

"I would prefer it not to be intravenous because I'm afraid. So, it would be like an orange-flavored pill, and what else? I would like it to have no side-effects. That's it. Those are the things I would like."

"Fewer doses as much as possible. Because it gives you more options. You could go abroad, you can travel, you can feel free."

"So, to have long intervals. Can you do it once a year? This creates the psychological sense that you are not in contact with the hospital, so you might forget about the illness. This, along with the ideal medication having no side-effects, if indeed that exists."

"I could use it daily. It would be ideal for me if it were in a form like a pill, for example, it's easier to use daily."

"I would prefer infrequent and sparse doses. I don't care if it's intravenous or an injection, etc., it would be fine if it were a pill, but not daily for me. If it was just a spray, I would take it every day and it wouldn't bother me."

"If it were every month, I wouldn't mind, as long as it was a pill. It just needs not to be intravenous or subcutaneous for me. I struggle with that, and it should have flavors."

"I would like, if a medication becomes available, not to have to take it every day. Ideally, taking it once a week or even once a month, to avoid the daily routine. Of course, this is in ideal situations."

"I would prefer it to be once a month and manage it that way."

"It's not very crucial in the end compared to the results, so I could say that having a lower frequency, either once a week or every few days, would be preferable. That's it. "

"I would prefer not to have maintenance drugs, but rather a medication that acts directly during a flare-up, providing immediate results within 24-48 h. I wouldn't want to undergo maintenance therapy throughout the year."

"I would like to be able to stop the treatment, not have it continuous, not have to take medication constantly for the rest of my life. That's what I would like if it were possible."

"Currently, I believe what I'm doing is the appropriate treatment. It's in pill form, which is convenient for me. It's not like treatments involving hospital visits for infusions and injections. The most ideal scenario for me is having it in pill form and not experiencing any symptoms. So, it covers me in that respect."

"I think what I'm currently taking is an injectable in the form of a pen, which is very easy to use. I use it once a month, and it's scheduled, so I know when I'll be doing it. What particularly impressed me is that the first time we did it, all the symptoms immediately stopped. It was like magic."

"I would prefer longer intervals between taking the medication, and as I mentioned before, not having to change the regimen during flare-ups."

"I think a pill would be ideal, so I wouldn't have the commitment of the treatment every 2 months, and of course, with longer intervals."

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Appendix 3 (*Continued*)

Subtheme 2: Secondary priorities - Impact on Daily Life

“So, for example with intravenous therapy, you have to be admitted to the hospital for so many hours; it wasn’t a good medication for me.”

“Less frequent visits to the hospital if possible. And as much coverage as possible between visits and a shorter stay time here. After that, the possibility of having therapy from anywhere else, to be able to do it even in the afternoon somewhere else in a private clinic.”

“The only thing that limits your life is that you can’t leave from here. You can’t go abroad.”

“Currently, I undergo infusions at the hospital, going once every 2 months. I would like, for example, to do it once every 6 months or ideally once a year. Ideally, I would like to take at least one pill that covers everything and be done with it.”

Subtheme 3: Secondary priorities - Drug-related adverse events

“I had significant hair loss, and there I struggled a bit.”

“Indeed, my fear of the side-effect of triggering another autoimmune condition is quite serious, and I’ve heard similar concerns before, especially regarding multiple sclerosis.”

“Cancer, I think, is the worst, and beyond that, there are a thousand others to think of.”

“Mainly in the future, I’m concerned about the issue of pregnancy. Now, in the present, I’m worried about the fact that the medication makes me feel sleepy, and I have a constant rhinitis, for example, and this is very annoying in my daily life. I mean, my nose constantly bleeds, and it worries me on a daily basis; it’s just absurd.”

“I’m hoping in the long run not to have any issues, either with the kidneys, or I don’t know where else a side-effect might strike.”

“What concerns me most regarding the use of treatment and medication is the possibility of developing cancer. That’s the most significant worry on my mind.”

Subtheme 4: Secondary priorities - Non-response

“I worry only about whether I will be able to rely on medication at some point, i.e., if something goes wrong with my body, it functions differently, and it no longer responds to the medications.”

“I am worried about whether I will stop responding to this medication and what else I can try, because I have already tried pills and other intravenous medications.”

“Later, if the treatment doesn’t work for me, if there is no other medication.”

“Another, and perhaps the most significant concern, is if a certain treatment doesn’t work for me. If I have to change medications and struggle to find a solution to my problem, going through a period of uncertainty. In the past, it was challenging for me to understand what was happening and what was affecting me until I figured it out. I fear it happening again, not knowing what’s going on and struggling to find a solution.”

Theme 4: Dealing with ulcerative colitis

Subtheme 1: Adherence to Treatment and Lifestyle Changes

“Technically, medications played a significant role in management, along with a general focus on diet. There were specific foods I stopped eating, and I’m fine with that if it means avoiding not only flare-ups but also making life easier.”

“Taking care of ourselves and avoiding unnecessary stress is crucial. We should refrain from engaging in activities that stress us out further. Surrounding ourselves with supportive people who help and encourage us is important.”

“Psychology is my top priority. Diet is also crucial for me. When I’m in a flare-up, I can hardly eat anything. So I had a bit of difficulty finding the right foods. I had to meticulously record my symptoms in relation to what I ate. Avoiding the foods that bothered me helped a lot, and practicing yoga has been very beneficial for me.”

“A proper diet, coping strategies, and I believe psychology play a significant role in managing this condition when I follow the treatment correctly.”

Subtheme 2: Psychological Support

“If you change your mindset, you can usually correct many things, and one of them is colitis.”

“So, during that phase, I went to a mental health center and requested psychological support because I believed that I couldn’t handle it on my own. It had helped me a lot, especially during the period when I was taking a high dose of cortisone, and my nerves were on edge.”

“It’s essential to pay close attention to your mental well-being. If you find it challenging to manage on your own, seeking the help of a psychologist is important, as you have more to lose compared to a healthy individual.”

Subtheme 3: Adaptation and Coping Strategies

“I’ve read enough, engaged with the topic sufficiently, and had many discussions. I believe I have a comprehensive understanding and knowledge of the disease and the current situation. Of course, if new information comes my way, I will take the time to read it, or if something new arises, I’ll address it. However, I won’t actively seek out additional information.”

“Recognizing the problem and accepting it are crucial steps. Knowing that we have this issue, accepting it, and allowing our lives to continue with the present condition, meaning that we will live with it.”

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Appendix 3 (*Continued*)

Theme 5: Patient-doctor relationship
Subtheme 1: Communication Challenges with Healthcare Providers “Treatment and information from the doctor is important. Having some kind of discussion, feeling that you’re heard, not being afraid to ask questions. Because at first, I thought I was annoying people and the doctors by reaching out to them.” “Physician training, simply personalize each patient. While books may describe the symptoms, clinical presentation, and treatment, each patient is a unique entity. Address each patient individually.” “In 2002 or 2003, there was a gastroenterology conference, where a roundtable discussion was organized. In this roundtable, I, as one of the patients, a psychologist discussing the psychological support possibly needed by patients, a nutritionist, and others spoke. It would have been logical for the doctors to listen to, this to comprehensively understand the issue for the patients. However, the room was empty; all the doctors had disappeared. As soon as our roundtable started, our doctors had disappeared.” “I am researching on my own, unfortunately, I can’t have extensive discussions with my doctor as he has his own tasks and patients. However, I would like to have a conversation when he has some free time, something like that.” “I also have a very bad experience. My complaint from the first diagnosis I had was how badly, how terribly, my doctor informed me about what I have.”
Subtheme 2: Trust in Healthcare Providers “You need to have a doctor you can trust; it’s a crucial aspect, especially in such an illness.” “Unfortunately, I also had a doctor who didn’t handle it well at all. I went from bad to worse in the beginning, and I ended up on the verge of collapse. I had lost a lot of weight, my hematocrit was severely low due to bleeding, and I was in a miserable condition.” “Personally, I believe it’s crucial to have a doctor you can trust and who understands your situation.” “Yes, a doctor may have graduated thirty years ago and, if they choose not to progress, they may opt not to do so.” “I have also changed doctors and dismissed some, not because they were bad physicians, but simply because they didn’t fit with my personality. It’s a matter of finding the right person to connect with, not necessarily implying that the other is a bad scientist, and I certainly respect everyone’s perspective. “ “Having a doctor who inspires confidence is crucial. Every patient is unique, and a doctor clearly knows the right course, medication, or any other approach that needs to be followed.”

Appendix 4 Identified themes and subthemes with example quotations from the interviews

Theme 1: Shared Decision-Making in Treatment
Subtheme 1: Patient Involvement in Therapeutic Decision-Making “I agree that they should participate, but not on an equal footing. In other words, the indication of the treatment and which treatment should be prioritized, I believe, should be decided by the doctor. However, beyond that, this treatment should be personalized for each individual. It should be tailored not only based on all the other factors they know, but also according to what the patient wants. Therefore, we suggest one or more treatments, but I believe the patient should be involved in the final decision because they are the ones who will undergo it, and they need to cooperate. “ “The doctor should neither delegate the responsibility of decision-making to the patient and ask the patient to choose, nor impose their personal preferences when there are various options.” “I consider it a crucial aspect in daily practice to always involve the patient in decisions that are going to be made, regardless of the nature of those decisions. Whether they are related to diagnosis or treatment, because ultimately the issue primarily concerns the patient themselves.” “The joint decision-making process involves presenting the basic choices based on the data I have, regarding both the disease phenotype and the characteristics of the patient. I express my opinion on each option, and then the patient tells me which of the choices aligns more with their specific needs.” “I imagine that the doctor provides them with scientific data in a simple and understandable way and offers them alternative solutions that can be adapted to their lifestyle and beliefs. Not everyone has the same lifestyle or beliefs. You try to address their questions in case they exist, and usually they do.”
Subtheme 2: Decision-Making Tools in Clinical Practice “We don’t have decision-making tools in clinical practice, the standard approach for patients before the initiation of treatment is to provide them with informational material, given to all patients, describing the disease and their therapeutic options. This includes documents and PowerPoint presentations, tailored as much as possible to their language. For selected patients who have the ability to understand English and access specific sources of information, such as the American Association of Crohn’s and Colitis, this serves as additional information.” “Unfortunately, a decision-making tool doesn’t exist. I don’t know if it exists; I haven’t looked into it, but we don’t do that. What I do is try to explain to them the pros and cons of each option, the pros and cons of each option that is suitable for them if there are 2 or 3, to persuade them. So it’s a personal conversation with me, and I provide them with the information. I don’t have a tool for that.” “The presentation from my side would include the medical data, the disadvantages and advantages of each decision, the cost, and the benefits that each decision may have for the specific case of the particular patient. Beyond the purely verbal communication, in the form of an interview, so to speak, as we are doing now, depending on the case, this can be enriched with the use of questionnaires that the patient completes. These questionnaires can indicate how satisfied the patient is and whether they agree or disagree with some of these decisions.” “Only with words. I am trying to explain to them the official medical standpoint. The viewpoint that studies have shown this, that the effectiveness of the medication is that. That this viewpoint is based on specific clinical studies, conducted in this manner, showing these results. They have been published, subjected to specific scrutiny and observation.” “We provide them with brochures, questionnaires, and share our clinic’s email for them to communicate about anything at any time. Additionally, we collaborate with a psychologist, so we also receive feedback from that perspective.” “I inform him about the data we have, updating him on the available information and statistics regarding the effectiveness of each treatment,

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Appendix 4 *(Continued)*

as well as potential issues that may arise during the course. Furthermore, I present both the advantages and disadvantages of each option, considering their impact on his daily life." "I think that, except for rare occasions when we use some scale optically, if they want to mark from 0 to 10 for their condition or if we want to note the degree of success/danger, we are not accustomed to it. We rely only on our experience."
Subtheme 3: Patient Attitudes Towards Shared Decision-Making "There are people who generally want to have a say and an opinion, and there are people who, by choice—not because they lack the ability or cannot understand—prefer to delegate the therapeutic decision to others. They don't want the anxiety of making the choice themselves. What do you suggest? This. These personalities also exist." "Patients, in any case, read, extensively use the internet, learn, and have questions. Therefore, most of them want to participate, yes, and I think that's where it's heading. As the older generation of patients fades away and the younger ones, who are more familiar with social media and the like, come in, I believe it will move in that direction." "In the way I approach and the relationship I have developed with patients, I observe that when I give them the floor and allow them to express their opinions, ask the questions they want, and share their concerns and considerations about the decisions we are about to make, an interactive discussion begins. I see that they are very enthusiastic, and it is something they really enjoy and appreciate—participating in the decision-making process." "So, there are patients who come and say, 'Look, I have researched it, and I believe that the specific treatment suits me better.' In other words, they have knowledge now. Therefore, younger ages can definitely participate 'equally' in this game of shared decision-making. They have sufficient knowledge about the matter."
Subtheme 4: Barriers to Shared Decision-Making "We do have natural obstacles. Regarding the public healthcare system, the main obstacle is the lack of organized structures and the shortage of time, resulting in all these things being done hastily and without much depth. Moreover, we don't have decision-making tools in clinical practice." "Time. In public hospitals, at least, it's time because this process takes time. That is, to discuss and explain to the patient exactly what you are thinking, why you believe that each of the following treatments, for example, may or may not suit them, to answer their questions, and all of this, to arrive at a joint decision, takes time. It requires an hour, which is often challenging when trying to see 20, 25 or 30 people in a day."
Theme 2: Outcomes related to the ulcerative colitis
Subtheme 1: Primary treatment outcome – Clinical remission "The first thing of interest is clinical remission. Obviously, I set other goals as well, but the primary focus is on clinical remission." "The ability of the therapeutic intervention provided by the doctor to deliver a long-term positive outcome for the patient. In other words, the treatment should have a duration, and the positive results should be sustained over time." "Clinical remission, for the patient to be well." "The primary endpoint is effectiveness, meaning to make the person well, clinical remission. That is the primary goal. Since inflammatory bowel disease is a persistent problem that significantly impacts the quality of life, the primary concern in a new treatment is the relatively quick relief from the distressing symptoms, mainly the persistent bleeding and the urgent need for bowel movements, commonly referred to as urgency, and the presence of blood."
Subtheme 2: Secondary priorities - Endoscopic healing, histological healing "I will also consider endoscopic remission. Not as a primary goal, but it is important to me as clinical remission." "To potentially achieve a good image when performing an endoscopy on the patient." "Endoscopic healing. To have no mucosal alterations in the endoscopy." "Primary is endoscopic healing, and of course histological healing if the pathologist can participate." "Mucosal healing is the most important, and endoscopic improvement. It is clear that we are interested in the patients' quality of life, but perhaps because we have the data, we must look ahead, at least 5 years ahead. That's why I believe that most of us do not settle only for the quality of life and are trying for mucosal healing." "If possible, endoscopic and, let's say, histological healing are the conclusive points that interest the treating physician."
Subtheme 3: Secondary priorities - Health-related quality of life "And, of course, the more emphasis we place, the more we familiarize ourselves with the patients' quality of life, which is very important, and we should take that into consideration." "A good quality of life involves the ability to carry out and perform all activities without feeling any sense of limitation. This includes the disease being in remission, or in a clinical state where it doesn't hinder the individual in any of the mentioned activities." "The overall quality of life and the liberation of individuals from ulcerative colitis are crucial. Ulcerative colitis tends to dominate patients' lives and daily routines."
Theme 3: Drug-related attributes
Subtheme 1: Most important characteristic - Avoiding Serious Side-effects "The issue of the absence of side-effects is crucial. In other words, we should ensure that the patient does not experience any unwanted reactions during the efforts we make to achieve the goals mentioned earlier. This should always be in our minds."

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Appendix 4 *(Continued)*

“The most important factor is that it doesn’t have significant side-effects, and it lacks serious toxicity. It should be easily accepted by the patient without causing concerns of this nature. Side-effects that may result in irreversible consequences, such as malignancies, severe infections, or damage to sensitive organs of the human body. I believe this is also very important and should be taken into consideration.” “To have no side-effects is the most important factor. The development of malignancy primarily.” “The first thing that concerns me is to avoid anything that would force me to discontinue the medication. If a very serious side-effect occurs, such as the development of cancer, I will obviously stop the medication. I believe that in everyday life, the security issues are the ones that trouble us.” “What is most important to me in a treatment I will provide to my patient is safety. The issue of infections, especially in older ages, and the issue of malignancies.”
Subtheme 2: Secondary priorities - Long-Term Effectiveness “Maintaining results. In most cases, effectiveness is the most important aspect both in the short term and in the long term. “ “To be highly effective; in other words, I would like a medication with an efficacy of 90% and above. Despite having numerous pharmaceutical options and the emergence of new ones, none of them promises that level of effectiveness, which is a considerable gap.” A medication that can be effective for a long period, without the worry of losing its efficacy. The patient should be confident that they can take it for many years, maintaining a good condition of their disease.” “The ideal drug is the one that could quickly induce remission of the disease and maintain long-term remission.”
Subtheme 3: Secondary priorities - Improving patients’ quality of life “So anything that makes their life difficult, whether it’s a simple dermatitis or anything else.” “To avoid partial response because it keeps the patient in a constant state of alert. Going from 8 bowel movements with blood to 3 with blood is clearly an improvement of over 50%, but in practical terms for the patient it may not have such a significant impact, because the patient is still tied to the uncertainty of whether there will be a restroom, if they will make it, if they will run into issues.”
Subtheme 4: Secondary priorities - Patient-Friendly Administration “The medication should be as easy as possible for the patient to take. This means having a simple pharmaceutical form, such as a very small pill or a tasty syrup, if we were to consider different forms. “ “It is a method of administration that is convenient and ensures compliance with the treatment. That’s why the new daily dosage packaging has an advantage over others. Now, as for injectable medications, in my personal opinion, the administration route is not clear-cut. There are patients who prefer intravenous, and there are patients who prefer subcutaneous. It’s not clear-cut.”

Theme 4: Patient Support
Subtheme 1: Challenges in Communication: “As treating physicians of patients with chronic diseases, we must realize that we need to dedicate the necessary time that the patient desires to make all this information understandable and perceptible to them. We should explain things in a clear and concise manner that is easy for the patient to comprehend. “ “As for the rest, their personal problems, it is true that the hospital, at least, is something burdensome. It is not easy to keep up with the worries of daily life. That is, this is another problem. The presence of a psychologist could help, you know.”
Subtheme 2: Patient Heterogeneity - Personalization of Treatment Plans “The individualization of the therapeutic plan based on the patient, considering all possible parameters. Fears, concerns, whether they want to start a family, employment status—factors beyond endoscopic images or CRP levels.” “These goals relate to specific situations, such as achieving a good outcome, always in consideration of the age group to which each patient belongs. The needs of patients are not the same across all age groups. We should consider specific situations, such as when we have a pregnant woman or a young woman who wants to become pregnant. These are specific issues that need attention, and we should set them as goals in the discussion with the patient. Topics may also involve aspects of sexual life and fertility. These are issues that may not be directly related to the main disease but are still crucial aspects to address.”
Subtheme 3: Trust in Healthcare Providers “Doctors should consider themselves allies of their patients. It’s not just about giving advice; we must invest time. If we don’t invest time, we will lose the patient, and we might not lose them as a ‘customer’, but we will lose them in terms of compliance. Also, I believe that we must give great importance to these patients’ quality of life.” “I think the patient initially wants to enter a system where they feel safe themselves. That is, it should be evident that the team, in the end, and their doctor are listening to them. They understand his concerns. And many times, it is known that our concerns and their concerns do not align.”