Patients' perceptions, attitudes, and experiences about the management of mild-to-moderate ulcerative colitis

Francesc Casellas a,⁎, Daniel Ginard Vicens b, Sabino Riestra Menéndez c, Noelia Alfaro Oliver d

a Crohn-Colitis Care Unit, Hospital Universitario Vall d’Hebron, Ciberehd, Paseo Vall d’Hebron 119, 08035, Barcelona, Spain
b Gastroenterology Department, Hospital Universitario Son Espases, Carretera de Valldemossa, 79, 07120 Palma de Mallorca, Islas Baleares, Spain
c Gastroenterology Department, Hospital Universitario Central de Asturias, C/Celestino Villamil, s/n, 33006 Oviedo, Asturias, Spain
d Advanced Research Techniques in Health Services (TAISS), C/Cambrils 49, 28034 Madrid, Spain

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Abstract

Objective: To establish the perceptions, attitudes, experiences, and satisfaction with clinical management of ulcerative colitis (UC) patients, particularly in aspects related to treatment.

Methods: A qualitative, descriptive, exploratory study. A discussion group was performed in patients who were in remission according to the criteria of the Mayo index, who had never taken biologics or corticosteroids in the past year. They were selected by: course (mild/moderate), time since onset (under 5 years/5 to 9 years/10 years or more), follow-up area (primary care [PC]-hospital/PC-specialist care/hospital), treatment (yes/no), UC care unit (yes/no), belongs to patient associations (yes/no) and sex. A descriptive–interpretative content analysis was performed to detect emerging categories, providing them with an explanatory framework.

Results: Diagnostic delay was detected due to lack of clinical suspicion from PC and delayed diagnostic tests. For follow-up, patients prefer care on demand, channeled through remote care, which helps to resolve questions, problems with treatment, or when a relapse occurs, minimizing visits to the hospital. They demand more information, both about UC and treatment. The expectations about treatments are limited, so they mainly requested efficacy and safety.

Conclusion: The results suggest the importance of developing strategies to facilitate care on demand and remote care, and to investigate on effective and safe treatments to minimize the detriment to quality of life of patients. These strategies should guarantee fast care and, together with safe and effective treatments, optimize the management of UC patients.

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⁎ Corresponding author at: Paseo Vall d’Hebron 119, 08035, Barcelona. Tel.: +34 93 274 61 56; fax: +34 93 489 44 56.
E-mail addresses: fcasellas@vhebron.net (F. Casellas), daniel.ginard@gmail.com (D.G. Vicens), sriestram7@hotmail.com (S.R. Menéndez), nalfaro@taiss.com (N.A. Oliver).
1. Introduction

The importance of ulcerative colitis (UC) is progressively increasing in the health systems of developed countries.\(^1\)\(^-\)\(^3\) UC is a chronic condition affecting mainly young adults in their reproductive or training years, and has a substantial impact at the clinical level, on their quality of life, and on the resources used. Despite the great impact of UC on patients’ quality of life, little is known about their satisfaction with clinical management of the disease, or with associated drug treatment.\(^4\)\(^-\)\(^8\) Since UC manifests primarily as relapses, which require immediate care, the main recommendations are care on demand and remote care.\(^9\) A multidisciplinary approach is also recommended, where particularly physicians and nursing staff interact. Aware of the multidisciplinary approach, some hospitals have comprehensive care units (CCU) for UC, including health education in UC, a responsibility generally assumed by nursing, in addition to other similar strategies, such as a nurses’ office specialized in UC or also a UC specific clinic.\(^5\)\(^-\)\(^9\)\(^-\)\(^12\) Regarding drug treatment, the main expectation of patients is to achieve control of the symptoms of their disease. However, many patients perceive poor control of symptoms, a concern that is added to the occurrence of short and long-term side effects as their disease progresses. This feeling of helplessness leads them to think that they will not recover the quality of life they had before diagnosis.\(^8\) Given this situation, it may be thought that knowing the perception and satisfaction that patients with UC have about their clinical management and treatment is very relevant, because it will allow for designing strategies aimed at improving their quality of life and promoting adherence and treatment efficacy. To know patients’ perception and satisfaction, a qualitative methodology is the procedure that is most commonly used because it is suitable for addressing topics in an exploratory manner when it is desired to know the perspective of the concerned parties, their priorities of interests and needs. It also allows, from a phenomenological vision, to incorporate different perspectives and the diversity of their points of view.\(^13\)\(^-\)\(^14\)

Given the wide severity spectrum of UC, from very mild to very severe, it would be very ambitious to try to address the management of all types of UC.\(^15\) Thus, this research will be focused on determining the perceptions, attitudes, experiences, and satisfaction about clinical management of patients with mild-to-moderate ulcerative colitis, particularly in aspects related to treatment.

2. Methods

A qualitative research study was designed, which was conducted in a discussion group (DG) of patients with mild–moderate UC. The speech of the DG, in addition to collecting the individual experience of perceptions, attitudes, experiences, and satisfaction about clinical management of UC patients, particularly in aspects related to treatment, obtains a collective vision of patients since it recovers their social and cultural context.\(^15\) No questions were asked to the discussion group. The moderator explained at the beginning of the meeting that the interventions were free and are focused in any aspect that for the patients is relevant. Spontaneously, the participants were talking about their worries, feelings, and perceptions, and the moderator was checking the aspects of the discussion map that were covered spontaneously. If close to the end of the meeting, an aspect of the discussion map was not approached spontaneously by the participants, the moderator, in a gentle way, introduced that aspect for an open discussion by the group.

UC patients were selected using a theoretical sampling method for qualitative studies, that is for assuring structural representativeness (every type of patient is represented) rather than statistical representativeness (every type of patient is represented in a number proportional to its prevalence) a usual sampling method in qualitative studies.\(^13\)\(^-\)\(^14\) The inclusion criteria for an UC patient were: age over 18 years and UC duration of at least 1 year, in clinical remission according to Mayo index criteria\(^16\) (with no increased stools above their usual frequency, no blood in stools, and is normal according to the physician’s judgment), with a disease course pattern of mild-to-moderate disease according to the physician’s judgment, with a maximum of a one yearly relapse, and who had never taken biologic antiTNFα agents, or corticosteroids in the past year. The heterogeneity was ensured by selecting different UC profiles using the mentioned variables, considering the representation of the distribution of variables such as diagnosis, disease duration, treatment, follow-up area, and care in UC specific unit, if the patient belongs to any association and sex. Patients were selected from different hospitals in Madrid. The DG was attended by 8 UC patients (Table 1), meeting in January 2013 with an approximate duration of 1 h and a half. At the DG meeting, the meeting moderator controlled that every topic of the discussion map was covered. The topics included in the discussion map were key aspects in satisfaction with management of their UC and the factors on which it depends, particularly those related to treatment. The most relevant aspects about management were characteristics of the site where patients are treated and resources it has (equipment, human resources such as specialized nursing, care on demand, remote care); diagnostic and follow-up procedures (continuity of patient follow-up by the professionals, patient–professional communication, professional competences, time of visits, aspects of diagnosis, follow-up of diagnosis, protocols and clinical practice guidelines, patient education and training); in addition to treatment (aspects about the treatments administered or those to be administered, first-line treatments such as salazopyrins and mesalazines, treatment expectations, impact of treatment on their daily life associated with administration routes, symptom reduction, performance of blood and urine tests, aspects associated with quality of life, maintaining control over disease), influence of treatment on quality of life and treatment adherence.

The speech of the DG was recorded and transcribed literally, assuring the confidentiality and anonymity of the participants. The transcription was analyzed using the NVivo 8.0 program, coding the speech in order to detect emerging dimensions. Coding of the texts and definition of the categories were compared between two investigators, who in turn discussed the explanatory framework. Subsequently, a notoriety analysis was performed, taking into account the number of times the dimensions appeared in the text. After
coding, an analysis of descriptive–interpretative content was performed to provide an explanatory framework of the categories and subcategories of each emerging dimension. Finally, participants were classified by severity, by sex, disease duration, follow-up area, if they are receiving treatment for UC, if they are managed in a CCU for UC, and if they belong to a patient association to establish associations between participant profiles and their speech.

In parallel to the data collection and analysis process, a process of triangulation, discussion, and comparison of results was carried out. This allowed the reliability of the study to be increased and to ensure that saturation of the speech was reached with the DG conducted. The results were compared with the available literature to verify the validity and consistency of the results.

3. Results

3.1. Mentions of emerging aspects in the speech

The most noteworthy findings after coding of the speech are shown in Table 2. The most frequent mentions are related to treatment, follow-up of UC, and the diagnostic process. In the mentions related to treatment, they devoted more time particularly to safety and effectiveness, relating effectiveness with the perception of control of the symptoms of UC. Within follow-up of the disease itself, the greatest number of mentions deal with diet and stress control, though as shown in subsequent content analysis they are relevant aspects, but not as much as care on demand, which is associated with other mentions such as care of relapses and remote care. The participants dedicated a good part of the speech related to the diagnostic process describing the information gaps and problems of diagnostic delay they encountered.

3.2. Content analysis

Content analysis describes how management of UC is perceived in the different stages of the diagnostic process, the information on UC, its follow-up, and its treatment. As an illustration of this analysis, selected verbatim (literal transcription) are shown in Table 3.

3.2.1. Diagnostic procedures

As reflected in the speech, the standard diagnostic process begins when the patient with symptoms goes to the family physician and from primary care (PC) is referred to the gastroenterology department (Table 3, verbatim 1). When symptoms start, patients mentioned two kinds of problems associated with diagnostic delay due to: 1) lack of diagnostic suspicion by the family physician of patient's symptoms. This fact had been already described in previous studies.17,18 This may even lead to a change in physician (Table 3, verbatim 2); and, 2) delayed performance of diagnostic tests (Table 3, verbatim 3).

3.2.2. Information needs

In general, participants of the DG reveal the lack of information at the time of onset of UC. The lack of information is associated with three aspects: 1) UC itself, where patients may even be unaware that it is a chronic disease. They state that they learn more about their disease as it progresses. In general, they do not know the impact of UC on their health and daily life (Table 3, verbatim 4). 2) Relapses and strategies to reduce their impact: since relapses occur unexpectedly and have large social impact, patients report that they should be informed about strategies to deal with them. Relaxation tools or dietary guidelines would help them to reduce the uncertainty they feel about the possibility of a relapse (Table 3, verbatim 5); and 3) the treatments administered: when a treatment is prescribed, patients are not informed about its efficacy or side effects (Table 3, verbatim 6). The main reasons for the lack of information according to patients are the lack of time and the physician’s attitude, who does not offer information spontaneously (Table 3, verbatim 7). Patients feel the need to constantly demand information. However, it can be seen how patients with moderate versus mild diagnosis are more aware of the need for information due to the impact of their UC. This active search for information sometimes leads them to change specialist, or they are informed by attending talks organized in hospitals by patient associations.

3.2.3. Follow-up

Regarding the aspects related to follow-up of UC, it was observed that patients with mild severity report that regularly scheduled checkups to monitor their UC are conducted by a specialist, either from the hospital or from their reference specialist center. However, their daily follow-up is performed...
by the PC physician. The PC physician is responsible for the management of their treatment and their symptoms (Table 3, verbatim 9). On the other hand, for follow-up of a moderate diagnosis, both regularly scheduled checkups of UC and symptoms that can occur in daily life are performed from the PC physician. The PC physician is responsible for the management of their treatment and their symptoms (Table 3, verbatim 10). Thus, the area of specialist care, or from the gastroenterology department, or the CCU for UC (Table 3, verbatim 11). In general, participants to the DG declared that both care on demand, remote care, and interconsultation are three aspects offered by the CCU for UC, they are only accessible to patients who rarely suffer relapses and are managed from primary care, or from the gastroenterology department, or the CCU for UC (Table 3, verbatim 14). When forced to go to the emergency room, they are quite dissatisfied with the management due to the delay in providing a clinical solution, mainly because of inadequate knowledge of UC management (Table 3, verbatim 15). When patients experience a relapse, they demand immediate care by a specialist. Patients prefer to avoid administrative steps, because they think it is more effective if they are treated at the time of the relapse. They find a quicker solution and money is saved by the system because fewer resources are used. Patients with experience in the management of a relapse in the emergency room, think it should be avoided. They report that patients with a relapse are managed like any other patient, sometimes performing unnecessary laboratory tests, which greatly delay an adequate clinical response (Table 3, verbatim 16). To avoid going to the emergency room, patients suggest the possibility of receiving care on demand from a specialist in UC, either in the gastroenterology department or the CCU for UC.

### Table 2 Frequency and proportion of mentions of emerging aspects in speech.

<table>
<thead>
<tr>
<th>Area</th>
<th>Number of mentions</th>
<th>% of total mentions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnostic process</td>
<td>16</td>
<td>11.0</td>
</tr>
<tr>
<td>Information</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Disease</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Social aspect</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Delay in diagnostic tests</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Delay in primary care</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Follow-up of ulcerative colitis</td>
<td>62</td>
<td>42.5</td>
</tr>
<tr>
<td>Diet</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Stress control</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Care on demand</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Relapse care</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Emergency room</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>UC comprehensive care unit</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Primary care</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Variability in criteria</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Second opinion</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Trust in professional</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Remote care</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Frequency of checkups</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Consultation time</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Interconsultation</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Hospitalization</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Treatment</td>
<td>68</td>
<td>46.6</td>
</tr>
<tr>
<td>Safety—side effects</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Treatment expectation</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Effectiveness—perception of control</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Adherence</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Strategies to increase adherence</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Time of ingestion</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Information about treatment</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Assessments</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Cost</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

#### 3.2.4. Relapse management

Regarding the management of relapses, patients’ opinion and level of satisfaction with care of a relapse are determined by disease stage, in short, by the frequency and severity of relapses. As with routine follow-up, patients with mild UC who rarely suffer relapses are managed from primary care, follow the usual steps of the health system and are forced to go to the emergency room for the treatment of a relapse, while those with moderate diagnosis are treated by specialists or the CCU for UC (Table 3, verbatim 14). When forced to go to the emergency room, they are quite dissatisfied with the management due to the delay in providing a clinical solution, mainly because of inadequate knowledge of UC management (Table 3, verbatim 15). When patients experience a relapse, they demand immediate care by a specialist. Patients prefer to avoid administrative steps, because they think it is more effective if they are treated at the time of the relapse. They find a quicker solution and money is saved by the system because fewer resources are used. Patients with experience in the management of a relapse in the emergency room, think it should be avoided. They report that patients with a relapse are managed like any other patient, sometimes performing unnecessary laboratory tests, which greatly delay an adequate clinical response (Table 3, verbatim 16). To avoid going to the emergency room, patients suggest the possibility of receiving care on demand from a specialist in UC, either in the gastroenterology department or the CCU for UC.

#### 3.2.5. Care on demand

With care on demand, patients perceive that they obtain a more agile and immediate response, improving the management of the disease and the course of the disease, which has repercussions on greater satisfaction. However, participants are aware that care on demand should be properly managed, which requires prior remote care. This allows visits on demand to be processed with routine ones, avoiding unnecessary waiting. They also add the need for educating the patient about the course of their disease and how it should be managed.

The patients declare that because of the characteristics of UC and its manifestation by relapses, the most important request, particularly in patients who have moderate UC, is care on demand, because it ensures immediate care. They note the need for immediate care when a relapse occurs or when its symptoms are triggered, to prevent its worsening (Table 3, verbatim 17). On the other hand, the chronicity of their disease requires them to go frequently to the health system, an aspect they would like to avoid, because it interferes with their daily life due to losses of school and/or working days. Thus, they rate the possibility of remote care as a very positive option. Its main advantages are: resolving questions about symptoms, resolving questions about treatment, information on routine diagnostic tests with normal results, management of routine appointments on demand (Table 3, verbatim 18). Third, they stress the need for more comprehensive care, where conditions derived from their UC should activate care mechanisms such as interconsultation. Through these processes, patients believe that their care is more continuous and controlled (Table 3, verbatim 19). Although participants declare that both care on demand, remote care, and interconsultation are three aspects offered by the CCU for UC, they are only accessible to patients...
Table 3  Samples of verbatim (literal transcription) of the perceptions, attitudes and experiences and satisfaction with clinical management of patients with ulcerative colitis.

<table>
<thead>
<tr>
<th>Diagnostic procedure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>1. Mila: In my case specifically when I noticed symptoms my family doctor was the one who initially referred me to the specialist, [...] tests were done. A colonoscopy, they also performed a gastroscopy to see well the diagnosis. In the end, they told me an ulcerative colitis and for me follow-up is done by my specialist.</td>
</tr>
<tr>
<td>Lack of diagnostic suspicion</td>
<td>2. Jesús: I had to change my family doctor because at first the one I had did not pay much attention to me or did not know how to identify what I had, and when I changed family doctor he diagnosed me with what I had, he ordered a number of laboratory tests and so forth for me and he referred me [...] to have a colonoscopy done.</td>
</tr>
<tr>
<td>Delay in diagnostic tests</td>
<td>3. Pablo: I initially had to have my disease detected by having a colonoscopy done through private medicine, because it [public health] would take several months and I was suffering a strong relapse. It couldn't wait and so I had to pay for it, then I made a claim for it [...]</td>
</tr>
</tbody>
</table>

Information about diagnosis

| Aspects of UC itself | 4. Izaskun: Yes I agree a bit with what he says, I, 16 years ago [...], well, when they ask me "how did you take knowing you had a chronic disease", well, I didn't know it, I simply felt bad and a person came and gave me a diagnosis, and I said, well, if he knows what I have, well then, that's it, he'll tell me what I have to take, and then later after some time goes by, you say, "well then, this is not over?" |
| Information about relapses | 5. Joaquín: And you don't always have a mode and a manner to be able to solve it, do you? Then, it works well for me, but these are things that I have picked up a bit based on my own experience, right? Related topics, for example, to relaxation, meditation, yoga, for me this in general, living a quiet life (quiet relaxed) and then diet. I think each one of us is our own best doctor, and then it should be adequately balanced, you should eat a little of everything without overdoing it by eating spicy foods, sausages and such, but in general a little like this, right? |
| Treatments administered | 6. Izaskun: Of course, I had migraines but it was suddenly four a month and maybe I had three every two months. Well there, when you begin to blame some things, well, then it's harder to take it. [...]. And often what you need is for them to explain it to you properly, if what you imagine is true or not true, and I don't know. What we talked about before that sometimes there is time for an explanation and other times there is no time, and other times, if you don't see trust you don't even ask. |
| Lack of information | 7. Gael: For me, my experience, is that initially they informed me rather little, rather little, later...when at first I changed physician two or three times also because it was the same, they didn't pay attention to me, and also I'm very inquisitive, I ask questions all day long. And in the end I found a doctor who answered my questions, well I stayed (logically) with her, and she's the one with whom I have more or less such trust, so it's even a bit difficult for me to leave her. [...] And that is a problem that exists in medicine and now doctors are changing a bit, which is psychological contact with the patient. That they lacked it before, you went to the doctor and sat down and they gave you a talk and you said to them 400 mg (...) "take this" and they didn't even explain why they gave you medicine and now they do explain, they sit ... (Yes, yes) (Same as verbatim 23). |
| Information by talks | 8. Izaskun: [...] the problem is that there isn't enough time in a specialist's office [...] I have received a lot of information, through talks given in the association or sometimes at hospitals, since there you always have an hour or two and you have a doctor who is as telling you things calmly and has prepared them well, and who then lets you to ask questions at the end. So, that is where I found more information, because there is very limited time in the offices. Petra: Totally. I've never heard of what you are talking about. That there are or talks or the other stuff, in what hospital? Izaskun: Well, for example, at La Paz every year they have .... Mila:...at La Paz!! Gael: I have seen it practically everywhere, Eh? |
| Follow-up of ulcerative colitis | 9. Petra: It's the tests, taking the results to the specialist and then transferring them to my family doctor. It hasn't been very repetitive, it was once, and then six or seven months a bit of a hint and until then fine ... I haven't needed... With my regular checkups, there is no problem every two years. |

(continued on next page)
Diagnostic procedure

Follow-up area: Specialist care

Joaquín: My experience is very positive, because I take for granted that they are people habituated to it. It is not the same to find yourself with a general specialist physician, who in principle, may or may not have a deep knowledge of the disease. But in this case, the fact that it is a subject, well, a bit delicate. You deal specifically with people who know the subject, I have seen very humane treatment, and the truth is that it has been very positive.

Follow-up according to patient severity

Mila: If the relapses are very frequent, they already (they refer you) consider they must send you to a unit, that you should be taken directly. But if you actually have relapses that are widely spaced, then that is not necessary. Well, I trusted them. If I don't have trust in the doctor who is handling my case...

Lacks in PC physicians

Gael: And my experience is that in a matter of family doctor and all that, ... well, up to a point, because when things become a bit complicated, the physician's lacks can be seen, because, of course, not .... (Blanca: There is no knowledge). They don't reach there. I prefer to go directly to specialist [...]. Things they could have, that they could have caught in time, even just a relapse, and [...] your specialist knows what to prescribe and it ends sooner.

Mila: That is because they prescribe you something else, for another condition. Petra: That is what you should always tell your family physician. Gael: I tell my doctor, but he still prescribes it anyway.

Management of relapse

Gael: If you go to the unit, you should go even without an appointment. You go there and tell them you feel ill and maybe they let you go last so as not to jump ahead of everybody else, but they let you be attended and that's it. (Same as verbatim 17).

Gael: Everything's very slow, in the emergency room you are there hours and hours for a blood test. The experiences I have had were bad.

Gael: ... you waste time there. Because later you are going to feel even worse, because until your doctor arrives, a precious time passes; so the best thing is to go to your specialist who tells you to go at the latest time, so you go and maybe it's something that the specialist can solve in a moment by changing your medication or the like, because the people in the emergency room don't know what you take.

Overall care

Gael: If you go to the unit, you should go even without an appointment. I go there and tell them you feel ill, and they let you see the specialist. (Same as verbatim 14).

Blanca: You have to follow the steps, which is the family doctor and then ... and I think if more than six months or something like that passes, you have to go back to the family doctor with your referral slip because it's no longer valid. "I came for a checkup", no. You can't go for a checkup now, you have to have a referral slip...

Remote care

Izaskun: Well actually now everything is already by phone all (In your case,) in my case, well, it's fine. But previously it wasn't by phone for me it was a bit stressing, because as I was at the university it meant losing the morning so [...].

Interconsultation

Izaskun: And then, what I also believe is important [...] eh, ... interconsultation requests [...] I have [...] problems with my eyes, or ... I have osteopenia, so, the specialist himself is the one who prepares the referral slip and it's much faster than if you have to start over again.

Care on demand

Petra: Of course, I think that there is a certain filter, depending on what severity you are. If they can stop you in the family doctor, they won't take you to the unit.

Checkups and performance of follow-up tests

José: You get used to them.

Mila: Colonoscopy is unpleasant.

Joaquin: Man, you spend couple of days a little...

Mila: You gradually prepare your mind about it. You have to keep a diet before.

Petra: the sachets

Pablo: the sachets are the worst for me.

Mila: Not these one if you are working.
Follow-up of ulcerative colitis

Management criterion

22. Gael: Yes, aside from that, I think that at first, I don't know, those of us who have had it for longer, at first, well, it's a little according to the fashion. This time it's a different drug, at first they said you had to eat certain foods, now they say you can eat everything, I mean, every time it's changing.

Information on UC and treatments

23. Gael: For me, my experience is that at first they informed me rather little, rather little, later... when at first I changed physician two or three times also because it was the same, they didn't pay attention to me... And that is a problem that exists in medicine and now physicians are changing a little, which is psychological contact with the patient. That they lacked it before, you went to the doctor and sat down and they gave you a talk and you said to them 400 mg (...) "take this" and they didn't even explain why they gave you medicine and now they do explain, they sit ... (Yes, yes) (Same as verbatim 7).

Trusting relationship

24. Petra: I, in contrast, have trust in the family doctor and my condition is mild, and for me it is like a resource for even the smallest ailment, I turn to her before going to the specialist. And it is more convenient for me, it's near my house and closer, I don't know... there is trust, for me, I consider her, I don't know, she is a doctor, I consider her a friend, and any little thing that maybe I relate it to this, which maybe is not related, I go and tell her about it, for me, the family doctor is solution, sincerely.

Accessibility

25. Gael: You see the first thing in my experience is that you call by phone, where if they can solve it, they solve it there. If they can't, they tell you come by here, you go tomorrow late or early. I go, I go there.

Second opinion

26. Pablo: I was receiving care at the Ramón y Cajal and one of the reasons why I left was because they told me there to speak directly with a surgeon. And I said "no", before I'm going to see the opinion of another doctor before, and I went to Puerta de Hierro, that was ten years ago. And they have not operated on me.

Stress control and nutrition

27. Mila: But in practice, in theory, I think that they all are going to say the same thing: "No stress, a healthy diet, avoid raw vegetables, avoid irritating products, other..." (Joaquín: spicy foods.) That's right. That is in theory, in practice, each one of us is our own doctors, a bit. Because I know what is good for me and what is not, and this mister and the other and the other. And is it so... eh?

28. Joaquín: That's why I said before that it was very important to make sure that the diet is as balanced as possible. Because obviously due to colitis itself you are going to lose a large part of nutrients, right? Then you have to reinforce that somehow.

Treatment Information

29. Petra: No, in fact, no one says it, take this and that's all and they don't tell what it will do to you. They didn't explain anything to me. That is also true, they don't explain it to, you're absolutely right.

30. Gael: And then in that subject they do... And sometimes they explain very little the side effects, things that can happen to you. Of course, in order not to frighten you, it's clear, I don't know a minimum amount, or how this drug works in your body, what is going to do to, why they prescribed you it.

31. Blanca: What's more, they write the prescription and you don't even know what they are writing, tablets or whatever it is.

Jesús: And many times you don't even know what it's for, because maybe they have prescribed two or three things and they begin to prescribe and your don't know whether one thing is for one thing or another.

32. Izaskun: I myself need them to explain it to me. It's no good me if just tell me to take it. Because if I have to make an effort to take it, it is causing me discomfort, well, at least I need to know why I have to take it and what benefits it is going to provide me.

Adherence

33. Pablo: Man, sometime you feel lazy, but know you have to take it and (you know it beforehand) and you have take it. You either take or take it, you can't go about...

34. Izaskun: And then I also have had other problems, for instance, one day you vomit, and you say, now what do I do, I take it again, I don't take it again (of course, the doubt, the doubt). Yes. The true is that TRADE NAME, if I take more it strictly, but the rest I forget more.
considered appropriate by their disease stage (Table 3, verbatim 20).

3.2.6. Clinical practice variations

Regarding the need for checkups and follow-up assessments such as blood tests or different diagnostic tests, despite the inconveniences involved, patients express their resignations because they perceive them as necessary (Table 3, verbatim 21). Where they express some bewilderment, and even dissatisfaction, it is about the variability in criteria. Patients perceive that throughout the course of their disease, treatment criteria have been modified, but it is not necessarily reflected in its efficacy. They report that there is a great variety of criteria in the management of the disease, possibly because of the lack of knowledge of its etiopathogenesis. This lack of common criteria is clearly reflected in dietary advice (Table 3, verbatim 22).

3.2.7. Patient–physician relationship

Regarding the best rated qualities of professionals who manage their disease, there are four: a) the information provided to the patient about their UC and its treatments (Table 3, verbatim 23), b) establishing a relationship of trust (Table 3, verbatim 24), c) accessibility (Table 3, verbatim 25), and d) possibility to ask for a second opinion in case of complex therapeutic decisions (Table 3, verbatim 26).

3.2.8. Treatment

Patients emphasize, in addition to drug treatments, aspects such as nutrition and control of stress. They see a certain lack
of tools to cope with stress, which in turn is perceived as related to their UC. Physicians simply mention it, without going into further detail (Table 3, verbatim 27). Although patients know that a prior diet has no impact on occurrence of the relapse, they still consider it necessary, both at times of relapse when they state that they require a more controlled diet, and to facilitate nutrient absorption during remission (Table 3, verbatim 28).

As regards the treatment, patients focus on the information they receive, adherence and their expectations. Patients generally agree that information on treatments is limited. Furthermore, few physicians inform patients spontaneously, they only offer information on demand. They often focus only on the dosing regimen and pay less importance to information about its efficacy and safety (Table 3, verbatim 29). Even though it is true that patients agree that they should have complete information about their treatments, they question whether it is advisable to inform in great detail about side effects, to prevent patients from being frightened or influenced (Table 3, verbatim 30). However, patients are often in a situation where they have been prescribed several drugs simultaneously for different diseases and do not know which one is indicated for each condition, because it was not explained to them (Table 3, verbatim 31). Despite the points of disagreement, patients prefer to receive information about the treatments including their efficacy, safety, and how they act and are administered. With regard to adherence, patients report taking the medication without problems, although they mention that they sometimes feel lazy, because they have to be very persevering (Table 3, verbatim 33). The main problems of adherence are sporadic forgotten doses and vomiting after ingestion. Vomiting after ingestion raises the question of whether to take the medication again or not (Table 3, verbatim 34). In order to improve adherence and prevent forgotten doses, patients themselves develop strategies such as: a) prepare doses in advance (Table 3, verbatim 35), b) use a pillbox (Table 3, verbatim 36), c) mark doses somehow after having taken them (Table 3, verbatim 37) and d) associate the time of ingestion with meals (Table 3, verbatim 38). Expectations about improvement of treatments are limited given the requirement of such frequent and invasive controls and follow-ups such as colonoscopy and blood tests, either for the disease or for the treatments. Regarding taking the medication, they show a resigned attitude, declaring that it does not require any effort from them (Table 3, verbatim 39). In addition, despite being adherent to the treatments, they sometimes have little perception of control over their UC. The lack of efficacy of the treatments is noted more by patients with moderate diagnosis, because they do not achieve remission and continue to suffer relapses (Table 3, verbatim 40). Given this starting point, what they expect first from treatment is for it to be effective, eliminating their symptoms, since there is no treatment to cure UC. Second, treatment should be safe, minimizing short and long-term side effects. Patients with UC are aware that their treatments entail serious side effects (Table 3, verbatim 41). During the DG, it was pointed out that when assessing treatment expectations, a determining factor is the patient's disease stage. If the patient is in remission, it is expected that treatments will not have side effects, if the patient has suffered a relapse, the priority is effectiveness, for symptoms to subside (Table 3, verbatim 42). With regard to characteristics of the treatments they would like to see improved, they mention a reduction in the number of doses, number of tablets, and an increased number of tablets in certain containers. Nevertheless, they consider it of little importance, since they admit that they have become used to the medication. However, they still do not have a treatment through which they perceive control over their disease, because they suffer relapses (Table 3, verbatim 43). In summary, the main expectations of patients about treatment are to have effective and safe treatments that help them perceive control over their disease.

4. Discussion

The main findings obtained during the DG in mild-to-moderate UC patients are, according to the patients' opinion, the delay in diagnosis due to the lack of clinical suspicion by PC and the delay in the performance of diagnostic tests. The lack of information of patients about aspects of the disease, relapses, and treatments is also noted. Given the need for information, patients are obliged to change physicians or seek it by other means such as talks organized by patient associations. The factors most highly valued by patients with moderate diagnosis are care on demand and remote care, because both ensure an immediate treatment and prevent worsening. Regarding the treatments, they requested efficacy and safety at least to achieve control over the symptoms of the disease. The expectation about treatment differs according to disease activity, prioritizing symptomatic efficacy when they are in relapse and safety when they are in remission.

The main needs of patients with UC related to clinical management of the disease are care on demand and remote care. These demands are in line with the course of UC itself.6,19,20 Of course, it is not only a patient who requires regular checkups, who should be guaranteed, but also a patient who requires immediate care of relapses. Since UC is an unpredictable disease requiring most of the resources in emergency medical care and that if it is not treated worsens impairing patient's quality of life and increasing consumption of resources, mechanisms should be established to offer such patient-centered care on demand, which is provided at the CCU for UC.9,20–24 Some studies have already suggested that both care on demand and remote care are managed by nursing, because having a more direct contact with the patient will make them channeled more efficiently.24 On the other hand, patients whose follow-up is performed from PC, except for their regular checkups, lack immediate management to resolve questions or when a relapse occurs, which is consistent with the findings from other studies.17 For this, a system of direct communication between PC and specialist care should be established to provide the quickest possible response.

UC has a great social impact on patients, particularly from moderate diagnosis, since it causes a substantial change in the patient's life, decreasing their quality of life due to uncontrolled symptoms.8 Once diagnosed with UC, patients experience a great emotional overload due to poor control of symptoms. Patients come to think that their symptoms are not going to improve during the rest of their life and that they are never going to have control over their
life again as before.7,8 The perception of lack of control of symptoms is increased when they see the paucity of effective treatments to achieve rapid relief of symptoms or remission, as well as the lack of safe treatments, since most entail serious adverse effects.5,6,25,26 This situation of helplessness in view of the poor control of symptoms and reduction of quality of life causes patients to take significant risks with the prescribed medication.8,24 Therefore, their expectations about treatment are mainly associated with efficacy and safety of the treatments, rather than with characteristics such as number of doses or number of tablets.20 Nevertheless, any improvement in this line is also considered positive, but not a priority.

The limitations of this study are those intrinsic to a qualitative study. The results have no statistical representation, but constitute a phenomenological explanation that helps to understand the experiences, perceptions and attitudes of the patients. As a strength, it can be highlighted that the qualitative findings are consistent with the results obtained in other studies in which it is observed that there is a need for care on demand, remote care, and drug therapies that are effective and safe.

In summary, the UC patients want care on demand to prevent symptoms from worsening and leading to greater work problems, social isolation, and emotional overload. The results suggest the importance of developing strategies to facilitate care on demand and remote care, and to investigate effective and safe treatments to minimize the detriment to quality of life of patients. These strategies should ensure immediate care for patients with UC and, together with effective and safe treatments, minimize the occurrence of relapses and achieve remission.

Conflict of interest

The authors declare that they have no conflict of interest with respect to the execution of this work.

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