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Medical consultation in ulcerative colitis: Key elements for improvement

Yago González-Lama, Elena Ricart, Ana Cábenez, Pilar Fortes, Susana Gómez, Francesc Casellas

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Abstract

Ulcerative colitis (UC) is a chronic inflammatory disease with a high impact. In order to improve patient outcomes, the clinician-patient relationship in daily practice is critical. Clinical guidelines provide a framework for UC diagnosis and treatment. However, standard procedures and the medical content focused upon medical consultations in UC patients has not yet been defined. Moreover, UC is a complex disease, given that patient characteristics and patient needs have been proven to vary during clinical consultation since establishing the diagnosis and upon the course of the disease. In this article, we have discussed the key elements and specific objectives to consider in medical consultation, such as diagnosis, first visits, follow-up visits, active disease patients, patients on topical therapies, new treatment initiation, refractory patients, extra-intestinal manifestations, as well as challenging situations. The key elements have been mentioned to comprise effective communication techniques, motivational interviewing (MI), as well as information and educational aspects, or organizational issues. The key elements to be implemented in daily practice were reported to comprise several general principles like duly prepared consultations, in addition to honesty and empathy with patients, as well as effective communication techniques, MI, information and

educational points, or organizational issues. The role of other healthcare professionals such as specialized nurses, psychologists, or the use of checklists was also discussed and commented on.

Key Words: Ulcerative colitis; Patient experience; Shared decision making; Medical consultation; Motivational interviewing; Patient education

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Core Tip: Nowadays, patient-centered medical care has become accepted as a preferred care model, especially concerning chronic and heterogeneous diseases like ulcerative colitis. Clearly, medical consultations can substantially be improved by defining objectives along with the patients and adapting decisions and actions to this specific context. This comprises disease clinical features and stage, such as diagnosis, flare, and others, disease impact and patient's needs, as well as patient's opinions and preferences. Moreover, improvement can be obtained if we put into practice different resources that have demonstrated their efficacy in improving patient care such as effective communication techniques, motivational interviewing, or the use of checklists.

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INTRODUCTION

Ulcerative colitis (UC) is a chronic inflammatory disease that affects approximately 250 people out of 100000[1,2]. Different studies have reported the great impact of UC on patients, health systems, and society[3-6].

Currently, patient-centered medical care is synonymous with good-quality care, and it has become accepted as a preferred care model[7]. Effective clinician-patient communication is one of the cornerstones of patient-centered care, with proven impact on treatment adherence[8] and patient outcomes[9]. Key factors of effective communication have been shown to include patient understanding, trust, and respecting patients' preferences, in addition to shared decision-making. These factors are instrumental in influencing health outcomes like increased treatment adherence or better self-care skills[10].

On the other hand, UC characteristics and needs have been shown to greatly vary since the time the diagnosis has been made and during the disease course. Indeed, a recent publication demonstrated that patient preferences with respect to the disease management, disease information, as well as other items, differs depending on the context[11]. As a consequence, clinician-patient communication and decisions should similarly be adapted in daily practice.

Taking into account all of this information, we sought to define particular clinical scenarios and key elements to be considered upon medical consultation. For this purpose, we conducted a literature review and gathered expert's opinions. Although this work is focused on UC, most of the results can be applied to patients with other types of inflammatory bowel disease (IBD).

OVERARCHING PRINCIPLES IN A MEDICAL CONSULTATION FOR UC

Along with a set of overarching principles (Table 1), we have proposed eight particular clinical scenarios for which key elements and specific attitudes should be accounted for (Table 2).

Shared decision-making is increasingly advocated as an ideal model of therapeutic decision-making. In this model, the physician has the responsibility to inform the patients and provide them advice, whereas the actual decisions on how to act on this information are being made in a collaborative work environment between the patient and physician[12].

Among overarching principles during clinical consultation (Table 1), apart from an appropriate environment and preparation to the consultation, honesty and empathy with patients are essential, as is the adaptation of the physician's language and terms to the patients' understanding by avoiding technical terms that may not be fully understood. These features should always be considered as being dynamic when providing care to UC patients.

Taking into account UC's complexity, impact, and related treatments, in addition to considering non-adherence rates, it is essential to include behavioral interventions that likely improve patient outcomes

Table 1 Overarching principles for the clinical consultation in patients with ulcerative colitis

No.	Overarching principles
1	Appropriate environment where the clinical consultation takes place (tidy, clean, a chair for accompanying person, <i>etc.</i>)
2	Motivational interviewing
3	Use of appropriate verbal and non-verbal language
4	Good manners (salutation, face to face interaction, <i>etc.</i>) and empathy
5	Be honest about what we know, what we do not know and describe actions regarding what to do/what to avoid
6	Ideally prepare and organize the clinical consultation before seeing the patient (medical history, check labs, imaging tests, <i>etc.</i>)
7	Establish the objectives of the clinical consultation: Adapted to each clinical scenario Adapted (including the message) to each patient's features Taking into account patient's opinion and preferences

[8,13,14]. One such intervention is motivational interviewing (MI)[15]. MI is a directive patient-centered style of counselling, designed to help people further explore and resolve ambivalence about behavior changes. MI involves providers communicating in supportive, caring, and empathic ways to resolve a patient's ambivalence in view of health behavior change[16]. Specifically, providers ask, listen, and inform their patients when attempting to elicit motivation towards changes[16]. A systematic literature review involving patients with IBD has suggested that MI can be effective in improving outcomes for individuals suffering from IBD, given that patients displayed improved adherence rates and greater advice-seeking behavior, perceiving providers as having more empathy and better communication skills [15].

CLINICAL SCENARIOS AND KEY ELEMENTS DURING CLINICAL CONSULTATION FOR THE DIAGNOSIS/FIRST VISITS

The first scenario pertains to diagnosis/first visit(s) (Table 2). The emotional impact that is conveyed to any patient and environment when being confronted with the UC diagnosis is usually huge[3,17]. In addition to the initial anxiety and uncertainty, numerous patients report experiencing depressive symptoms and mental blocks after having become aware of their diagnosis[17,18]. Therefore, it is crucial to calm down the patients and help them cope with their new situation[19]. Given this context, effective clinician-patient communication has been shown to overcome barriers, while assisting patients in the decision-making about their care[9]. Communication between clinicians and patients is an interactive process upon which clinicians should listen, be open, receptive, and non-judgmental with patients[9]. Effective communication will contribute to build confidence.

In this scenario, it is also crucial to provide a minimum of information about the disease, its extra-intestinal manifestations and treatments, which should be adapted to the patient characteristics/needs and conducted in a constructive way, while also collecting data about the patients' support, especially concerning their family. On the other hand, a reasonable selection of the information to be provided is similarly advisable, thereby giving the patient the opportunity to adequately assume each issue and learn more about it[8,11]. Similarly, the same should be done with respect to the therapeutic plan by sharing treatment decisions and providing positive messages, such as: "Currently, there are several treatment options for this disease, and our objective is to improve your situation". The concept of "chronicity" should also be introduced by using expressions like: "while this is a long-term process, we can control the disease activity and avoid disease progression and symptoms", *etc.* Regarding health education, general information about diet, hygiene, healthy lifestyle, and other features should be provided[20].

An IBD specialized nurse working in a dedicated unit is likely able to improve all the information that we provide to the patient, resolve fears and doubts, and ameliorate adherence to treatments, care, and healthy habits[21]. Often, patients leave the doctor's office with large amounts of information and they feel overloaded. Therefore, changing the environment and providing a nursing summary can be very useful[19,22]. For communication to be optimal, we should try to additionally give the information in writing, at least with respect to what is essential. Reliable sources on the Internet should also be offered. In this context, many patients seek information on the disease from the internet. However, many times this information is inaccurate and even false, which might produce a negative impact on patients[23].

Table 2 Adapting the consultation to the different clinical scenarios when managing patients with ulcerative colitis

No.	Clinical scenario	Objectives	Key elements
1	Diagnosis/first visits	To engage patients in the management of their disease (treatments, visits, labs, image techniques, contact data, <i>etc.</i>); To inform wisely patients; To collect relevant data about the disease, patients and their environment	Use open questions rather than direct questions; Practice empathy: a climate of trust will make the patient feel comfortable and more information will come out naturally; When informing patients go as far as the patient needs or wants, <i>e.g.</i> , "What do you know about UC?"; Explore people's understanding, reactions and opinions about UC information; Explain the therapeutic plan (treatment objectives and goals, available therapies including surgery, response evaluation, <i>etc.</i>); Prepare the consultation: check labs, imaging tests or other available data before seeing the patient and prepare specific attitude, procedures or messages
2	Follow-up visits	To evaluate response to treatment (induction/maintenance), safety and adherence; In the induction phase, to ensure that the patient has achieved the pre-defined objective/goal; In the maintenance phase, to assure that the patient is really in remission and adherent; To explain test results	Use open questions; Solution-focused approach; Let the patients express themselves about their life (family, partner, work/studies, social life, traveling, diet, <i>etc.</i>): <i>e.g.</i> , "How are you doing? Are you doing everything you would like to do?"; Be open to patients asking questions; Detail the therapeutic and follow-up plan (<i>e.g.</i> , colonoscopy for colon cancer surveillance as indicated); Assess sexuality and fertility issues; Assess pregnancy desire: <i>e.g.</i> , when informing about drugs; Practice empathy; Prepare the consultation (see point 1)
3	Patients with active disease	To assess carefully the impact of UC on the patient's life (family, partner, work/academic, social life, traveling, diet, <i>etc.</i>); To adapt the treatment and patient's environment	Explain the therapeutic plan in detail but mainly explain and agree on what the objectives are, treatment goals and options, including surgery (informed shared decision making); Practice empathy; Prepare the consultation (see point 1)
4	Patients on topical therapies	To look for treatment acceptance and adherence	Explain in detail and clearly that topical therapies can be very effective with few adverse events (very good risk/benefit balance); Solution-focused approach; Discuss about the costs, explain their mechanism of action and options to improve comfort; Evaluate the patient's opinion and preferences; Practice empathy
5	Start of a new treatment	To assess carefully the impact of UC on the patient's life (family, partner, work/studies, social life, traveling, diet, <i>etc.</i>); To adapt the treatment and patient's environment; To fully understand the implications of starting a new treatment (changes in daily life, <i>etc.</i>)	Explain in detail and clearly the therapeutic plan but especially safety issues and new adaptations in patient's life; Solution-focused approach; Practice empathy; Prepare the consultation (see point 1)
6	Refractory patients	To assess carefully the impact of UC on the patient's life (family, partner, work/studies, social life, traveling, diet, <i>etc.</i>); To adapt the treatment and patient's environment	Explain the therapeutic plan in detail but mainly explain and agree on how far we are going to go, which are the treatment goals and options, including surgery (shared decision making); Solution-focused approach; Be especially cautious as non-standard treatments/strategies might be considered (<i>e.g.</i> , off-label uses, clinical trials, <i>etc.</i>); Spread positivity, make the patients feel accompanied; Screen for depression/dysthymia; Practice empathy; Prepare the consultation (see point 1)
7	Extra-intestinal manifestations	To inform patients about other symptoms or diseases	Explain the therapeutic plan in detail but mainly explain and agree on how far we are going to go, which are the treatment goals and options, including surgery (shared decision making); Solution-focused approach; Introduce the concept of multidisciplinary and coordinated care; Practice empathy; Prepare the consultation (see point 1)
8	Patients with negative feelings or mistrust	To win the patient over; To be patient but solid	Consider referring the patient to a psychologist; Explore fears, insecurities, frustrations; Do not confront the patient; Practice empathy; Explain the therapeutic plan in detail but mainly explain and agree on how far we are going to go, which are the treatment goals and options, including surgery (shared decision making)

For all sections, we start from the fundamentals of shared decision-making. UC: Ulcerative colitis.

There are several phases and common emotional reactions to the diagnosis, including denial, frustration, anger, and guilt; it is therefore essential to be attentive to the patient's emotional response [24]. In addition, it must be kept in mind that the patient faces significant losses, such as loss of health, of previous lifestyle, of quality of life, *etc.*

At the first visit, the patient should be offered the possibility to access the consultation, telephone, nurse, e-mail, or walk-in visits, as this has been shown to improve the patient's confidence in the care team [25].

Finally, physicians should keep in mind patient's opinions and preferences [11]. Therefore, it could be very useful to explore their beliefs, needs, and expectations. Moreover, it is advisable to leave some time for the patients, enabling them to ask questions during the consultation and encouraging them to "make a list of questions" if necessary for the next consultations [11].

CLINICAL SCENARIOS AND KEY ELEMENTS DURING CLINICAL CONSULTATION IN FOLLOW-UP VISITS

Physicians should continue addressing UC's impact on patients during the entire course of the disease. Indeed, during follow-up visits, patients may already be more aware of the disease's impact; they may thus be more comfortable to express it[22]. Apart from negative emotions, other problems may arise, such as those related to sexuality, sleep, work, or social life. In this context, it is vital to address, in male and female patient's sexuality issues and conception wishes, in order to optimize pre-conceptional, pregnancy and post pregnancy counselling, including the monitoring and therapeutic management of these patients[26]. Assessment of emotional aspects on the other hand should be an integral part of follow-up visits.

The objectives of pharmacological UC treatments are usually focused on controlling or at least reducing physical symptoms. Nevertheless, like in any other type of chronic disease, other psychological and social factors may influence the course of the disease[27]; they thus deserve appropriate attention. A central issue at this point is the assessment of treatment response upon induction and maintenance, in addition to evaluating safety and treatment adherence. While it is crucial to ensure that the patient has achieved the treatment goal, the treatment's impact on safety must likewise be assessed. In addition, considering the high rate of poor adherence in UC[28], health professionals should clearly address this issue, while actively involving the patients in implementing effective and individualized interventions to improve adherence[8].

Similarly to the first visits, information and education are vital in daily consultations, which should be appropriately adapted to the patients' characteristics and needs[11]. These consultations could be an appropriate opportunity to explain the test results to patients, as well as the role of colonoscopy for colon cancer surveillance.

CLINICAL SCENARIOS AND KEY ELEMENTS DURING CLINICAL CONSULTATION IN PATIENTS WITH ACTIVE DISEASE

Relapses are common in UC, and they are associated with a significant impact on different aspects of patients' lives[3,18]. Thus, the impact of disease activity should be carefully assessed, and physicians should thus perform therapeutic adaptations that should be discussed with the patients. Accordingly, the patients will thus feel accompanied.

The emotional impact should be included in the information/education package as disease symptoms. Physical remission does not imply the absence of psychological comorbidity in a high percentage of patients[29]. Therefore, it is essential to provide information about physical symptoms, including diarrhea, abdominal pain, and fever; emotional symptoms like anxiety, depression, irritability, mood changes, and behavioral symptoms, such as decreased activity, restriction of social relations, and isolation[19].

On the other hand, psychological treatments exert beneficial therapeutic effects, as they decrease the worsening cycle of symptoms and positively influence the patients' general well-being[13].

The integration of psychosocial factors into routine clinical practice is likely instrumental in improving quality of life of IBD patients[19].

Considering the treatment, informed shared decision-making is especially relevant in this domain [30]. At this point, physicians may be confronted with patients who are refractory to different treatment lines or types. Apart from detailed information about different treatment options, including surgery, it is even more relevant to discuss the treatment goals and get approval about them ("What is the target we want to achieve?").

CLINICAL SCENARIOS AND KEY ELEMENTS DURING CLINICAL CONSULTATION IN PATIENTS ON TOPICAL THERAPIES

The efficacy of topical therapies, especially in patients with moderate UC, has been extensively described[31]. However, the adherence to topical therapies appears to be lower when compared with oral treatments[32]. This might be related to reluctances, taboos, or other factors. Asking patients about their feelings regarding topical therapy may help anticipate a lack of adherence, thus providing the physician with the opportunity to adapt topical therapy to each patient[8].

Discussing treatment goals with the patient and setting a temporal limit may be of help when addressing topical treatments[8].

CLINICAL SCENARIOS AND KEY ELEMENTS DURING CLINICAL CONSULTATION WHEN STARTING A NEW TREATMENT

During follow-up, a number of patients may require a change in therapy due to a lack or loss of efficacy, or safety reasons. This might be associated with changes in daily life, particularly when the first immunomodulator or biologic agent is being considered. Along with all that has been previously discussed regarding patients with active disease, it must be ensured that the patient has properly understood the implications of starting a new treatment.

When starting new treatments, false beliefs such as "if I change treatment, I will worsen" or "the disease is more serious" should be dismissed. Concerns about the limit of treatments to be used, possibility of surgery, or need for an ostomy should also be addressed.

CLINICAL SCENARIOS AND KEY ELEMENTS DURING CLINICAL CONSULTATION IN REFRACTORY DISEASE PATIENTS

In daily consultation, some patients may display several failures to treatment, including biologics; they may experience frustration and despair[22]. Therefore, it is crucial to distribute positivity but also reality, given that new treatments with different mechanisms of action are being made available[19]. In some centers, authorized treatments/strategies might be considered, including off-label uses, clinical trial participation, as well as other treatments. Screening for depression/dysthymia may be required given such a clinical scenario.

It is necessary to train non-psychologists in assessing and managing emotional aspects, such as identifying symptoms related to stress, anxiety, and depression, which are among the most common [19].

CLINICAL SCENARIOS AND KEY ELEMENTS DURING CLINICAL CONSULTATION IN PATIENTS WITH EXTRA-INTESTINAL MANIFESTATIONS

As estimated, up to 50% of IBD patients experience at least one extra-intestinal manifestation, which can even occur before the IBD is being diagnosed[33]. In view of an early detection, patients should be aware that different symptoms or signs may occur, which are actually related to UC, while deserving specific actions, including consultation with other specialists. In addition, information about multidisciplinary care and coordination among health professionals will likely help control fears and doubts[19,25].

CLINICAL SCENARIOS AND KEY ELEMENTS DURING CLINICAL CONSULTATION IN PATIENTS WITH NEGATIVE FEELINGS OR MISTRUST

Finally, some patients may experience negative emotions, as they are reluctant to accept existing problems or proposed solutions, disadvantages, insufficient answers, *etc.* Such scenarios can be particularly frustrating during the consultation. Considering these patients, one should not try to "convince them", given that they are likely to become even more isolated. Instead, making them understand that we are on their team, and that they are actually responsible for their disease management is crucial[25]. In some cases, a referral to a psychologist could be an appropriate solution[34].

Healthy lifestyle information should be based on guidelines on how to handle stressful situations. Illness is a source of stress, and stress is considered a risk factor for increased severity of physical symptoms[13]. For this purpose, it is advisable to refer to reliable web pages, brochures, conferences, workshops, or even patient associations, as some of them do provide psychological assistance.

CONCLUSION

UC is a chronic, heterogeneous, and evolving disease, whose clinical features and disease impact, as well as patients' needs, opinions, and preferences may completely differ depending on the disease status[3-6,11]. In daily practice, the clinical picture of patients at early disease stages compared with that of patients with long-standing disease is not at all the same. Therefore, the physicians' attitudes and decisions should take these facts into account during the clinical consultation. Moreover, there is growing evidence suggesting that there is improved performance in this area to the benefit of both patients and clinicians[9,35].

Effective communication has emerged as a very valuable tool to superior informed decisions by patients during the clinical consultation[9]. Communication is crucial in establishing trust with UC patients, gathering patient information, addressing patient emotions, and assisting patients in the decision-making about their care[9,35]. This article sought to discuss some guidelines for physicians about how to implement effective communication during clinical consultation, as adapted to several clinical scenarios in which the objectives, attitudes, and messages most likely differ. Simple, practical, and implementable key elements including empathy, open questions, patient-centered care and information, solution-focused approach, or MI have herein been proposed.

Along with effective communication, we also suggest other actions like preparing the consultation or using appropriate verbal and non-verbal language, which have already demonstrated an effect on patient's management[36].

Some of the strengths of this work are as follows: innovation in the treatment of UC patients, how to initiate an updated patient management model, using a check list to prepare the different consultations, as well as having a specialist nurse and psychologist as external evaluators. The article's weaknesses comprise the lack of clinical evaluation or the absence of other scenarios that would have been interesting to address, such as the transition of the child to adult unit or continuity of care during admissions. Nevertheless, we consider that these items were beyond the paper's scope of interest.

In conclusion, research in UC clearly shows that it is essential to build a physician-patient partnership, focusing on the problem at hand, laying out the treatment options available along with their benefit/risk balance, eliciting the patient's views and preferences on treatment options, and agreeing on a course of action *via* shared decision-making. For these purposes, specific communication skills are necessary; they all can be learned and should be implemented during clinical consultations. We are confident that the guide provided in this article for clinical consultation will help physicians better manage UC patients.

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FOOTNOTES

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