The importance of the interaction between doctor and patient with inflammatory bowel disease

Inflammatory bowel disease (IBD) is no doubt the group of gastrointestinal diseases that, given their characteristics (diagnosis at an early age, chronic nature, absence of curative therapies), requires the greatest and most intense continuous interaction between clinicians and patients. During their many years with disease, a most valuable asset by patients is the presence of monographic inflammatory bowel disease units, which not only will provide them with better, faster access to both doctors and nurses but also with more rigorous, up-to-date information on potential therapies. Based on the CACHE study, supported by GETECCU and reported in the Spanish Journal of Gastroenterology (1), we may state that, in Spain, patients in our setting (n = 290) are highly satisfied with the help received from both physicians and nurses, and satisfaction degrees are even higher among patients than among physicians, which is noteworthy.

The growing importance of monographic IBD units, which facilitate doctor-patient interactions, has led the international community, and more specifically in Spain, to start multiple initiatives in an attempt to define IBD healthcare quality standards where patient participation is crucial, which confers considerable robustness (2). In the Delphi study, conducted in our setting, amongst more than 500 initial quality markers patients, nurses and physicians eventually selected 83 for which full consensus was reached. These standards covered such disparate aspects as hospital characteristics, diagnostic tests, and of course therapies and patient involvement in their selection (3).

The development and publication in this issue of the Spanish Journal of Gastroenterology of the IMPLICA questionnaire (4) represents a new advance for doctor-patient interactions regarding treatment selection. It also has the added value of having been developed to assess preferences regarding biologic drugs, arguably the drugs with the greatest impact in the lives of these patients since they, besides clinical and endoscopic effectiveness, have managed to reduce the numbers of hospital admissions and surgeries for IBD (5). The development of this questionnaire, which primarily assesses three issues, namely, administration route, treatment place and length, and whether therapy is self-administered or administered by healthcare staff, cannot be understood without knowledge of the characteristics of most IBD patients. Patients who suffer from these conditions are usually young individuals, and most receive their diagnosis while studying or shortly after starting their working life. These disorders greatly impact their quality of life, and flare-ups may result in significant absenteeism from classes or the workplace, with the resulting consequences for daily life; hence stems the importance of trying to integrate treatments used for severely diseased patients in their daily lives without a significant impact in their lifestyle. Another interesting aspect is that, once developed, a questionnaire must be validated in a...
greater number of patients, as reflected in the discussion by the authors of IMPLICA, this second part—which we wish published in the near future—allowing questionnaire applicability in everyday’s practice at a monographic unit. Looking further ahead, in the last few years new IBD diagnoses have dramatically increased in pediatric patients, with the characteristic that such patients usually present with severe disease where early therapy with biologics are highly effective, their use being now increasingly common (6). Therefore, a future questionnaire should be developed to include pediatric patients when choosing a biologic drug, taking these patients’ characteristics into account—parental perspectives (parents are usually highly involved in decision making), children perspectives, and the psychosocial consequences that receiving such therapies may entail for this subgroup of individuals.

The development and use of IBD-related questionnaires are increasingly common. Doubtless, this aspect has been a major contribution to enhanced patient involvement in disease-related decision making. Several surveys demonstrate that a major concern for patients with either Crohn’s disease or ulcerative colitis is preserving an adequate quality of life. This issue, until recently left out by major pivotal studies assessing the efficacy of drugs for IBD, has become a primary goal in newer clinical trials, where in addition to response, mucosal healing and adverse effects, quality of life is also assessed by means of not IBD-specific questionnaires such as IBDQ-36 and generic questionnaires such as SF-36 (7). Other aspects where questionnaires administered to patients have been helpful of late include the assessment of psychological changes in patients with IBD. Assessing psychological aspects such as stress, anxiety, depression, and fatigue with IBD-related questionnaires is now increasingly common. The information provided by these questionnaires is far-reaching and relevant, as patients with these conditions may have impaired sexuality, lower adherence to treatment, more emergency room or unscheduled visits, reduced work performance, and occasionally a poorer response to therapies (8). Hence, besides clinical remission, we should also reach psychological remission, an aspect that no doubt will be easier to obtain with an all-encompassing understanding and interaction between doctors and patients (9). The use of IBD-related questionnaires is also helpful to fight a most important issue among chronic patients in general and patients with inflammatory disease in particular, namely lack of adherence to chronic treatments. Such lack of compliance is usually associated with higher exacerbation rates, and only specific questionnaires can help in its identification and eradication (10). Once more, a deeper trust between doctor and patient, as based on a detailed discussion of therapies by practitioners, is the best method to enhance patient compliance.

In summary, the involvement of patients in the decision-making process regarding their IBD is increasingly common, and our responsibility as treating specialists is to offer detailed information on all related issues, and ultimately attempt to provide continual patient-centered care helping individuals not only with their clinical ailments (11) but also with their psychological troubles, aiming at eventually restoring their quality of life. Surely, should this be accomplished, care quality and both patient and clinician satisfaction will be raised, thus contributing to improve issues such as lack of adherence to therapy.

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REFERENCES


