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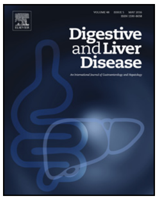

Alimentary Tract

Patient preferences for inflammatory bowel disease treatment objectives

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ABSTRACT

Background: There is currently little evidence about what treatment objectives most interest patients with inflammatory bowel disease (IBD).
Aims: To determine patient preferences regarding IBD treatment objectives, specially the attributes they value most and the symptoms to be controlled as a priority.
Methods: Prospective, observational, anonymous study conducted in 117 outpatients with Crohn's disease or ulcerative colitis.
Results: The most important treatment objectives from the patients' perspective were: improving quality of life (40.2% of patients), and completely resolving symptoms (33.3%). Only 12.8% of patients indicated having a completely normal colonoscopy as a preferred objective. The symptoms the patients considered to be most important when prioritizing their control were: abdominal pain (23.1% of patients), and bowel movement urgency (17.1%). The preferred treatment objectives were similar for Crohn's disease and ulcerative colitis patients.
Conclusions: Improving quality of life and completely controlling symptoms are the priority treatment objectives for IBD patients, with abdominal pain being the most important symptom. Conversely, therapeutic objective target goals proposed by physicians, such as healing the mucosal lesions, are not a priority for most patients. This indicates that there are discrepancies between patient and physician expectations, which should be taken into account if a patient-centered care model is to be implemented.

1. Introduction

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), is a highly incapacitating chronic intestinal immune-mediated inflammatory disease [1]. Currently, IBD treatment is aimed not only at alleviating the disease symptoms, controlling relapses and keeping the disease inactive without corticosteroids and asymptomatic as long as possible, but it is also aimed at healing the mucosal lesions [2–4]. To assess the primary treatment objectives in IBD clinical trials, clinical or endoscopic indices are usually used; however measures based on patient reported outcomes (PROs) are rarely used [5]. PROs are gradually being included as primary endpoints for evaluating the treatment in clinical trials, assessing symptoms such as abdominal pain, bowel movements, or bloody stools, and the repercussion perceived by patients expressed as their quality of life [6,7]. It is assumed that patients want to improve their quality of life, which is linked to controlling the disease and its symptoms [8]. Nevertheless, there is little evidence to date about what treatment objectives most interest IBD patients themselves. In 2014, Lönnfors et al. published the results from a survey given to 4670 patients in 25 European countries designed to learn the impact of IBD on their lives and the quality of their care, as well as their access to healthcare [9]. Among the results, the frequent presence of clinical symptoms, during relapses as well as during periods of remission, were apparent. In a 2009 survey given to 100 Canadian patients with UC to assess the preferences these patients had regarding their disease and its management, it was found that the most valued characteristics were rapid symptom relief (84% of patients) and having few side effects (74%) [10]. In 2014, a qualitative, descriptive study was published to determine the perceptions, attitudes, experiences, and satisfaction of UC patients with the management of their disease and their treatment in particular [11]. The results revealed that patients were most concerned about treatment. Similarly, the patients' main expectation was for symptoms to be relieved by the treatment. Despite the information that could be extracted, this

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Table 1
Demographic and clinical characteristics of patients.

	Crohn's disease (N = 64)	Ulcerative colitis (N = 53)	*p*
Age, median years (IQR)	38 (31–47)	43 (34–53)	ns
Gender (male/female), n	27/37	24/29	ns
Montreal classification, n			
Age at diagnosis			
A1: <16	5		
A2: 17–40	55		
A3: >40	4		
Disease location			
L1: ileal	19		
L2: colonic	12		
L3: ileocolic	28		
L1 + L4	2		
L2 + L4	3		
Disease behavior			
B1: non-stricturing, non-penetrating	40		
B2: stricturing	16		
B3: penetrating	8		
Perianal	25		
E1: proctitis		8	
E2: left sided		15	
E3: extensive		30	
Disease duration, median months (IQR)	160 (96–216)	96 (48–180)	0.06
Smoking habits (active/non-, ex-smoker), n	22/42	3/50	<0.01
Studies (primary/professional education/university)	10/27/27	8/15/30	ns
Disease activity (remission/relapse), n	58/6	49/4	ns
Extraintestinal manifestations (no/yes), n	54/10	47/6	ns
Previous surgery (no/yes), n	35/29	52/1	<0.01
Treatment, n (%)			
Mesalazine	3 (4.5)	21 (39.6)	<0.001
Thiopurines	12 (18.7)	5 (9.4)	
Tacrolimus/cyclosporine	1 (1.5)	0 (0.0)	
Anti-TNFα agents	45 (70.3)	26 (49.0)	
Other biologic agents	3 (5.0)	1 (2.0)	

IQR, interquartile range; ns, non-significant; TNF, tumor necrosis factor.

study was not able to identify which symptoms were most important for the patients, and little is known about the symptoms that most concern them. The symptoms are not even identified in specific disease perception questionnaires, such as the Brief Illness Questionnaire [12]. Knowledge about these patient concerns and expectations are considered very important given that the future of managing IBD points towards patient-centered care [13]. It is therefore necessary to be aware of patient preferences and expectations. Thus, the objective of this study was to determine patient preferences regarding IBD treatment objectives, with special interest regarding the characteristics they value most and the symptoms that should be controlled as a priority.

2. Materials and methods

This prospective, observational, anonymous study was conducted between October 2015 and March 2016 in a randomized sample of consecutive outpatients who were previously diagnosed with CD or UC and were visiting the IBD specialized unit. The study exclusion criteria were: IBD diagnosis less than 6 months ago; not receiving treatment for their IBD; presenting UC with proctocolectomy; being admitted to the hospital; poor reading comprehension; or not signing the informed consent form. All the patients completed a survey in which they had to identify, from their perspective, the two treatment objectives they considered most important for treating their disease (written as a free response in one or two sentences). They also had to select the symptom they considered to be a priority to control with treatment (abdominal pain, anal pain, rectal bleeding, bowel movement urgency, incontinence, diarrhea, increased number of bowel movements, waking at night to go to the bathroom, fatigue, flatulence, or any other symptom) and the two most important treatment outcomes (complete resolution of symptoms, avoiding surgery, avoiding ostomy, improving quality of life, reducing bloating and gas, reducing abdominal distension, disease survival, preventing relapses, not infecting anyone, being able to keep working, preventing family members or colleagues from knowing they are being treated, having a completely normal colonoscopy, or any other attribute mentioned by the patient). The study was conducted in accordance with the criteria set forth by the Declaration of Helsinki. All patients signed the informed consent form to be included in the study.

2.1. Statistical analysis

The categorical variables were expressed using relative and absolute frequencies (%), while the continuous variables were expressed using the median and the interquartile range (IQR, 25–75%). The normality of the data was verified using the Kolmogorov–Smirnov test. CD and UC were compared using Fisher's exact test for categorical variables and the Kruskal–Wallis or Mann–Whitney U test for continuous variables. Statistical significance was established for a $p < 0.05$. All the statistical procedures were performed with Graphpad Prism for Windows, Version 5.

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