

Title:

Using the internet to evaluate the opinion of patients with inflammatory bowel disease with regard to the available information

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DOI: 10.17235/reed.2018.5331/2017

Link: [PubMed \(Epub ahead of print\)](#)

Please cite this article as:

Martín Fernández Carmen, Maroto Martín Carlos, Fernández Salazar Luis. Using the internet to evaluate the opinion of patients with inflammatory bowel disease with regard to the available information. Rev Esp Enferm Dig 2018. doi: 10.17235/reed.2018.5331/2017.

Enero 2017 • Volumen 109 • Número 1 • Páginas 1-86

Revista Española de Enfermedades Digestivas
THE SPANISH JOURNAL OF GASTROENTEROLOGY

Acceso al texto completo en: www.reed.es o www.sagepub.com

Factor de impacto 100 (ISI) JCR: 1.455 (2016)
SCR: 0.34 (2016)

ORGANO OFICIAL DE:
SOCIEDAD ESPAÑOLA DE PATOLOGÍA DIGESTIVA, SOCIEDAD ESPAÑOLA DE ENDOSCOPIA DIGESTIVA Y ASOCIACIÓN ESPAÑOLA DE ECOGRAFÍA DIGESTIVA

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OR 6331 inglés

Using the internet to evaluate the opinion of patients with inflammatory bowel disease with regard to the available information

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Recibido: 28/10/2017

Aceptado: 24/01/2018

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ABSTRACT

Background and aims: patients need information for shared decision making. The aims of the study were to ascertain how patients with inflammatory bowel disease (IBD) felt about the information available and the way that their doctors informed them. In addition, how patients used the internet and factors that predicted a positive information evaluation were also assessed.

Method: a 39-item survey was designed that was distributed via the internet, principally using a Spanish Facebook site.

Results: four hundred and twenty completed surveys were received. Patients rated the information available with a mean of 8 points (maximum of 10) and 71% felt that their doctor informed them well or very well. Various deficiencies were found such as little information available at the time of diagnosis (58%); doubts after seeing the specialist (70%); insufficient information about IBD complications, disease course and dietary aspects; and a lack of appropriate internet webpage recommendations from specialists or pharmacists. Patients ranked the internet fourth as an information source, followed

by their specialist, patient associations and other patients. Independent predictive factors of feeling well informed (≥ 8) included age, OR 1.539 (CI 1.047-2.261), $p = 0.028$; education, OR 1.544 (CI 1.110-2.147), $p = 0,010$; IBD evolution time, OR 1.267 (CI 1.003-1,601), $p = 0.047$; and good or very good information from the specialist, OR 3.262 (CI 2.425-4.388), $p < 0.001$.

Conclusions: patients generally felt that they were well informed. However, there were aspects that needed improvement, such as information for younger patients or a lower education level, the information provided at diagnosis, information about specific or insufficiently covered IBD aspects and suggestions from doctors about high quality websites.

Key words: Internet. Crohn's disease. Ulcerative colitis. Information. Social media. Survey.

INTRODUCTION

The doctor-patient relationship has changed during the last few decades. This has evolved from a dependent relationship in which the patient accepts the doctors' opinions to a relationship in which the patient is informed, gives opinions and shares or disputes the decisions of the doctor. For this relationship to work well, in addition to a minimum understanding on both parts, the patient must have adequate information with regard to the situation. However, this understanding depends on the limits of communication and determines the points of view of the physician and patient with regard to the disease and its implications. This has been recently shown in inflammatory bowel disease (IBD) in Spain (1). Actually, the peculiarities and organization of the Spanish health-care services, and perhaps our physician capacities, do not allow a proper evaluation of the needs of every patient that attends the clinic. This is important in order to establish a satisfactory doctor-patient relationship and provide the patients with all the information that they deserve.

In spite of the omnipresence of the internet, doctors are still considered to be the patients' most important source of information. Several studies have shown that the internet, with its advantages and disadvantages, is the main alternative source of

patient information. The sites consulted can include general information, marketing, or be general or specific medical consultation websites. There are also blogs, patient association websites or social network sites such as Facebook or Twitter (2-4).

Quality of life of IBD patients correlates with their worries and concerns (5,6) and therefore, adapting information to the patient is of great interest. The objectives of the study were to determine how patients felt about the degree of available information and the information that their usual doctors (specialists) provided them. We also determined how patients used the internet as a resource and identified factors that predicted a sense of being better informed.

MATERIALS AND METHODS

A 39-item survey was designed that was aimed at patients with IBD (Annex 1). The survey evaluated the information that the patients had available, which was scored on a scale from 1 to 10 (1 being the worst and 10, the best). Furthermore, their opinion of the information provided by the specialist was evaluated as poor, adequate, good and very good. The survey also covered demographic information such as age, sex, educational level and work status, as well as clinical data such as IBD type, disease course, assessment of IBD severity in the last year, treatment type, anxiety level according to the of HAD scale (7,8), how the information influenced treatment adherence and the use of “alternative medicine”. Other related information sources on IBD aspects, the use and influence of the internet and pages consulted were also assessed.

GoogleForms (<https://www.google.com/intl/es/forms/about/>) was used to design both the survey itself and a page about the study objectives. The Valladolid and León (Spain) province chapters of the Association for Patients with Crohn’s Disease and Ulcerative Colitis (ACCU is the acronym in Spanish) emailed the forms to their members on the 19th of December 2016. The survey and the objectives page were also uploaded to three internet forums for patients with IBD on the 30th of December 2016. In addition, they were uploaded on the 11th of January 2017 to the “Crohn’s and UC, the C Team (Facebook Group United by IBD)” (“Crohn’s & UC”) Facebook page after contacting the site administrator. This website was created in Spain on the 8th of

February 2011, the official language is Spanish and it has 4,596 members.

Returning the survey to us was considered as acceptance to participate in the study. The study was approved by the Ethics Committee of the Hospital Clínico Universitario in Valladolid (TFG-599). Replies to the survey questions were analyzed and expressed using absolute and relative frequencies. Scale scores were expressed as a mean and interquartile range (IQR). The Chi-squared test was used to analyze the association between discrete variables. Uni- and multivariate binary regression analyses were used for predictive factors to rate the information with scores of 8 or more points on a scale of 1 to 10 (minimum to maximum). The OR and CI values were calculated. Statistical significance was set to $p = 0.05$.

RESULTS

Forty-four replies were received from the surveys disseminated to the patient associations and the three forums for patients with IBD. After uploading the survey to the "Crohn's & UC" Facebook page, 376 replies were received in five days. Therefore, a total of 420 surveys were returned, 70% of which were answered by women. Less than 4% of the patients were over 60 years old and 95% had secondary or university studies. Patients with Crohn's disease (CD) predominated over patients with ulcerative colitis (UC) (74% and 25%, respectively). Time from diagnosis varied considerably, between five and 20 years. With regard to treatment, 52% of the patients received immunosuppressants, 45% received biological drugs and 22% corticoids, and 20% had undergone surgery at least once. Almost one in five patients indicated that they had experienced a flare-up in the last year and almost one in three had to go to the ER or cancel an appointment or commitment due to the illness. Only 3% of patients followed an alternative treatment such as acupuncture, homeopathy or phytotherapy. Table 1 presents the patient characteristics in detail.

Patients rated the information available to them with a mean score of 8 (IQR 2) on a scale from 1 (minimum score) to 10 (maximum). Specialist-provided information was considered as good or very good by 71% of patients. However, only 38% of patients considered that the information received at diagnosis was adequate and less than 30% said that there were no doubts after seeing the specialist. Almost a fourth of patients

acknowledged that they had thought about stopping treatment due to a lack of information. When patients scored their available information with 8 or more points, they thought about stopping treatment due to a lack of information less frequently than if the score was less than 8 (18.6% vs 30.7%, $p = 0.001$). Patient evaluation of specialist-provided information (poor, adequate, good or very good) was also associated with thinking about stopping treatment due to a lack of information in 67.7%, 35.4%, 18.6% and 14.1% ($p < 0.001$) (Fig. 1) of cases and linked to alternative medical treatments such as homeopathy, acupuncture or phytotherapy in 14.3%, 2.1%, 2.5% and 2.1%, respectively ($p = 0.015$). Nearly half the patients considered that being better informed was associated with having fewer flare-ups and most patients felt that society needed to be better informed about IBD. Responses to questions related to the evaluation of the patient-available information and its importance are shown in table 2.

The three aspects for which patients sought information most frequently were IBD complications, IBD evolution and dietary aspects. Information sources considered to be useful were the specialist (87%), patient associations (ACCU) (55%), other patients (54%) and the internet (28%). A fourth of patients indicated that they did not consult the internet. Patients who used the internet conducted searches after seeing the specialist (38%) or both before and after the visit (25%). The websites consulted most frequently were specific pages in social networks such as Facebook (62%), patient association websites (59%) and patient forums (47%). Specialists and patient associations rarely recommend webpages about IBD to patients. Only 11% of patients considered that the internet had any significant influence in their decisions. The internet had no influence in 20%, 32%, 42% and 65% of patients poorly, adequately, well or very well informed by their doctor, respectively ($p < 0,001$) (Fig. 2). Table 3 shows the responses to questions about the aspects for which information was sought, as well as the patient information sources.

The predictive factors for a score ≥ 8 (from 1 to 10) for the patient-available information by univariate analysis were age, OR 1.578 (CI 1.158-2.150), $p = 0.004$; education level, OR 1.513 (CI 1.144-2.002), $p = 0.004$; time from diagnosis, OR 1.432 (CI 1.184-1.731), $p < 0.001$; treatment with salicylates, OR 0.553 (CI 0.367-0.833), $p =$

0.005; treatment with biologicals, OR 1.701 (CI 1.141-2.534), $p = 0.009$; anxiety, OR 0.951 (CI 0.908-0.931), $p = 0.031$; and specialist-provided information, OR 3.399, (CI 2.561-4.512), $p < 0.001$. Independent predictive factors identified via the multivariate analysis that included the univariate-analysis predictive factors as well as sex were age, OR 1.539 (CI 1.047-2.261), $p = 0.028$; education level, OR 1.544 (CI 1.110-2.147), $p = 0.010$; time from diagnosis, OR 1.267 (CI 1.003-1.601), $p = 0.047$; and information from the specialist, OR 3.262 (CI 2.425-4.388), $p < 0.001$.

DISCUSSION

According to our data, the patients consider themselves acceptably well informed about their IBD condition as the variable about available information scored 8 or more (from 0 to 10). Information and knowledge have been linked in several studies with factors related to quality of life (9) as well as healthcare and efficacy aspects (10,11). However, it is necessary to distinguish between the patient's perception of being better or worse informed and the true knowledge of the patient, which can be measured using different scales (12-14).

The fact that access to the survey and sending the replies was via the internet (and a large proportion of patients that subscribed to the Facebook page) implies that the patients analyzed had at least an average internet knowledge and regularly used internet and social networks. The majority of the 420 patients included in the study were female, had secondary or university studies, were younger than 60 years old and half of them received either immunosuppressant or biological drug treatment. A poorer quality of life in females has been reported previously (15). Women also tend to worry to a higher degree with regard to different aspects of IBD (16) and this could explain their higher participation rate in the survey. Furthermore, social or healthcare spheres were also affected by IBD, 37% of cases had to cancel an arrangement or an activity due to their illness in the last year, 34% had to increase treatment, and 32% went to the emergency services at least once.

It is very encouraging that this study gained access to the patients and received their responses via a website (a Spanish website) in a social network such as Facebook. This is a tool that should be explored and taken into consideration in the future. The

advantages are obvious, such as obtaining patient responses quickly and easily. The limitations are also obvious: the bias in the selection of patients with specific characteristics, the truthfulness of the responses (inherent in questionnaires), and the impossibility to determine the patients' geographic location (there was no geographic reference in the survey).

The patients felt that they were well informed as they rated the information available to them with a score of 8 or more. This information seemed to come mainly from the specialist. Eighty-seven per cent of patients considered them to be the main source of useful information and most patients thought that the specialist-supplied information was good or very good. This probably reflects the good work of the IBD doctors in Spain. In 2004, a Spanish study reported that more than 80% of patients felt that they were well informed (17). Another Spanish study of 385 patients in Levante in 2008 also reported a 96% satisfaction rate with regard to information that came from the doctor (4). Other information sources viewed as useful were conversations with other patients, patient associations and the internet. Although, the frequency was lower than that described in a Swiss study (18) and a Spanish study from hospitals in Levante (4). A Canadian study with a lower number of recently diagnosed patients also reported the internet as the second most important source of information after doctors (2).

Although the information received score highly in our study, certain features that the specialists or healthcare institutions should improve have been identified. Marín-Jiménez et al. recently demonstrated some limitations with regard to the clinical management of psychological aspects and the impact on quality of life of the patients (1). Those highlighted in our study included the information that patients receive at diagnosis, as well as the information provided during standard specialist follow-up. Nearly 60% of our patients felt that the information provided when they were diagnosed was inadequate, a considerably higher percentage than the 24% described by Bernstein et al. described in Canada (2). Furthermore, 25% of our patients indicated that they were left with a lot of doubts after seeing the specialist. These data are consistent with other studies with regard to the information required by the patients about certain aspects of the illness (most likely because these aspects were

infrequently addressed by their doctor), such as IBD causes, evolution and complications, and dietary considerations (17,19). In one of the aforementioned Spanish studies, patients requested labor rights and clinical trial information (4). According to Pittet et al., (18) the need for one type of information or another can vary depending on the phase of the disease course. Bernstein et al. recognized that giving a broad and substantial amount of information is very difficult in the clinic and prefer written information or web sites recommendations (2).

Information is important for the patients and the healthcare system. A greater risk of flare-up was thought to be linked to insufficient information by 48% of our patients. We noted that patients often search the internet before or after seeing their specialist and we also found a link between the perception of information quality and treatment adherence. In countries such as Switzerland, non-adherence is as high as 18% and low adherence is more common among patients that consider that the information available to them was insufficient (20,21). Information was also important in other circumstances for patients. They believe that social awareness should also be improved; over half of our patients have experienced an embarrassing or unfair situation related to their illness in the work environment or in a restaurant.

Multivariate analysis identified factors that independently predict whether patients consider themselves as better informed. Elderly patients (most patients were less than 60 years old), a longer time since IBD diagnosis, higher education level and cases that felt well informed by the specialist tended to view themselves as better informed. Univariate analysis also revealed a relationship with treatment. Patients who received mesalazine felt poorly informed, while patients under biologic treatment felt well informed. Obviously, this may be related to the time spent explaining the obligatory information for complex treatments. We also found via univariate analysis that anxiety was associated with the level of information considered as inadequate by the patient.

The link between anxiety and information can be complicated. Patients who are very anxious may be more demanding with regard to information (18), and increased anxiety has been associated with worse information (9). However, it has also been shown that increased anxiety is linked to a greater knowledge of the illness (22) and we also saw that knowledge about different aspects of IBD increased concerns in

patients and relatives (23).

Even though our contact with the patients for the survey was via the internet, 25% of cases indicated that they did not look for information about IBD on the internet. In addition, most of them said that information on the internet had little or no effect on them. Other studies have revealed that patients would like doctors or healthcare institutions to create websites where they can get information (24,25). The doctors' lack of interest in the internet is clear in our study; the specialists, pharmacists and patient associations make no effort to recommend one website or another to patients. This has far-reaching effects as the quality of websites varies significantly. In the USA, 60% of gastroenterologists recommend websites where their patients can obtain appropriate information (26). Spain has an excellent website created by professionals that provides information and makes things easier for patients (<https://www.educainflamatoria.com>). The Spanish Group for the Study of Crohn's Disease and Ulcerative Colitis (GETECCU, Spanish acronym) and obviously ACCU Spain have a website where patients can obtain reliable information. In the United States and Canada, the Crohn's & Colitis Foundation of America (CCFA) website is most often consulted by cases in these countries (3, 27). Commitment to the internet for informing patients and facilitating healthcare seems necessary. The "Constant-Care" from Denmark and Ireland has shown that remote clinical follow-up using the internet is feasible, reliable and efficient, and can reduce flare-ups and improve the quality of life of patients with UC (28). Other projects on the influence of technology in communication and information about IBD have identified other advantages of these methods (29). The fact that the vast majority of our survey responses were via a Facebook page is interesting. Social network pages are obviously what patients most commonly visit. In the United States, Facebook, Instagram, Pinterest and Twitter are most visited by patients with IBD (27). Doctors and healthcare institutions will probably have to accept their presence on Facebook and Twitter. Although there are advantages and drawbacks, this is necessary if we are to keep up with patient concerns and provide them with accurate and reliable information.

Our patients are satisfied with the information available and that provided by their specialist. However, there are some deficiencies that should be addressed, such as the

information at the time of diagnosis and more extensive information for younger patients, those with a lower educational background and with less complicated disease presentations. There is room for improvement for healthcare professionals, healthcare institutions and medical societies to create or participate in websites. Furthermore, specialists need to recommend websites that patients could consult. These two practices would help to ensure that patients have access to accurate and reliable information.

AUTHOR'S CONTRIBUTIONS

CMF, CMM and LFS: study concept and design, survey design and interpretation of the data.

LFS: drafting of manuscript.

CMF, CMM and LFS: review and approval of the final manuscript before submission.

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Table 1. Characteristics of patients

Male:Female	126 (30%):294 (70%)
<i>Age</i>	
< 20 years	22 (5.2%)
20-40 years	209 (49.8%)
40-60 years	173 (41.2%)
> 60 years	16 (3.8%)
<i>Education</i>	
No formal education	3 (0.7%)
Primary School	56 (13.3%)
Secondary School	191 (45.5%)
University studies	170 (40.5%)
<i>Employment status</i>	
Employed/self-employed	219 (52.1%)
Student	39 (9.3%)
Housewife	29 (6.9%)
Retired/pensioner	51 (12.1%)
Unemployed	63 (15%)
Other	19 (4.5%)
<i>Diagnosis: Ulcerative colitis: Crohn's disease</i>	
	106 (25.2%):314 (74.8%)
<i>Time from diagnosis</i>	
< 5 years	137 (32.6%)
5-10 years	93 (22.1%)
10-20 years	127 (30.2%)
> 20 years	63 (15%)
<i>Treatment</i>	
Salicylates	156 (37.1%)
Corticoids	96 (22.9%)
Immunosuppressants	220 (52.4%)
Biologics	192 (45.7%)

Surgery	79 (18.9%)
Alternative medicine (homeopathy, phytotherapy, acupuncture, etc.)	12 (2.9%)
<i>Social and clinical case history in the last year</i>	
The number of attacks has increased	82 (19.5%)
Cancelled an activity/appointment because of the condition	156 (37.1)
Went to emergency services	135 (32.1%)
Was admitted to hospital	70 (16.7%)
Needed surgery	48 (11.4%)
Had to change to a stronger treatment	143 (34%)
<i>Anxiety (HAD scale)</i>	9 (6)

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Table 2. Assessment of the information the patients had available and the importance given to the information

<i>Generally speaking, how well informed are you about your disease? 8 (2)</i>	
<i>(1-10)</i>	
<i>How well do you consider that your doctor has informed you?</i>	
Poorly	21 (5%)
Adequately	96 (22.9%)
Well	161 (38.3%)
Very well	142 (33.8%)
<i>When you were told that you had inflammatory bowel disease, did you feel that the amount of information given to you at that time was:</i>	
Adequate	162 (38.6%)
Lacking	245 (58.3%)
Excessive	6 (1.4%)
Do not know/No answer	7 (1.7%)
<i>Have you ever thought about stopping (or have you stopped) treatment due to a lack of information (not knowing the objective, what the treatment was for, adverse effects, etc.)?</i>	
No	312 (74.3%)
Yes	98 (23.3%)
Do not know/No answer	10 (2.4%)
<i>How do you feel that information influences the control of the course of your illness?</i>	
The MORE information I have, the MORE flares I get	13 (3.1%)
The MORE information I have, the FEWER flares I get	201 (47.9%)
Do not know/No answer	206 (49%)
<i>How often are you left with unanswered questions after seeing your doctor?</i>	
Always; no explanations are given	20 (4.8%)
Always; excessively technical language is used (the doctor explains things poorly)	5 (1.2%)
Frequently	86 (20.5%)

Sometimes	191 (45.5%)
Never; the doctor answers my questions using appropriate language	128 (28.1%)
<i>Have you ever felt in an uncomfortable/unfair situation due to a lack of knowledge about the disease in our society (i.e., conversations at work, in a restaurant, etc.)?</i>	
Yes	257 (61.2%)
No	146 (34.8%)
Doesn't know /Doesn't answer	17 (4%)
<i>Do you think it is necessary to perform more awareness campaigns about inflammatory bowel disease?</i>	
Yes	412 (98.1%)
No	4 (1%)
Doesn't know/Doesn't answer	4 (1%)

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Table 3. Information needs and sources

<i>What type of information were you looking for?</i>	
Complications	236 (56.2%)
Disease course	199 (47.4%)
Diet	194 (46.2%)
Causes of IBD	175 (41.7%)
Influence on family	159 (37.9%)
Tests	154 (36.7%)
Treatment	152 (36.2%)
Day-to-day IBD management	130 (31%)
Pregnancy	94 (22.4%)
Surgery	84 (20%)
Level of disease activity	61 (14.5%)
Tobacco	54 (12.9%)
<i>What information do you think is the most useful in clearing up your doubts?</i>	
Information provided by the specialist	365 (86.9%)
Information provided by associations (ACCU)	231 (55%)
Information provided by another person with the same condition	229 (54.5%)
Information from the internet	117 (27.9%)
Information provided by the hospital pharmacist	62 (14.7%)
Information provided by your usual pharmacy	23 (5.4%)
There is no information that is especially useful	10 (2.3%)
<i>If you do look for IBD information on the internet, when do you usually do this?</i>	
Before seeing my doctor; I feel it is important to be informed when seeing my doctor	48 (11.4%)
After seeing my doctor; I am left with doubts after the consultation	162 (38.6%)
Before and after seeing my doctor	105 (25%)
I do not consult internet sources	104 (24.8%)
<i>What kind of websites do you use?</i>	

Verified medical portals (e.g., Medline, Medscape)	166 (39.6%)
Websites that are not specifically medical (e.g., Wikipedia)	73 (17.4%)
Patient association/organization websites (ACCU)	250 (59.7%)
Medical forums from verified sites	59 (14.1%)
Forums that are not specifically medical (e.g., car forums, Vogue, etc.)	11 (2.6%)
Forums for patients with Crohn's Disease (e.g., http://crohncolitis.foroactivo.com/)	197 (47%)
Social network groups (e.g., sites for those affected by Crohn's on Facebook or Twitter)	259 (62%)
<i>Who recommended the websites to consult?</i>	
Nobody	287 (68.3%)
Another patient	68 (16.2%)
Association (ACCU)	56 (13.3%)
Specialist	33 (7.9%)
Pharmacist	4 (1%)
<i>Internet influences you...</i>	
Not at all	188 (46.1%)
A bit	169 (41.4%)
A fair amount	47 (11.5%)
A lot	4 (1%)

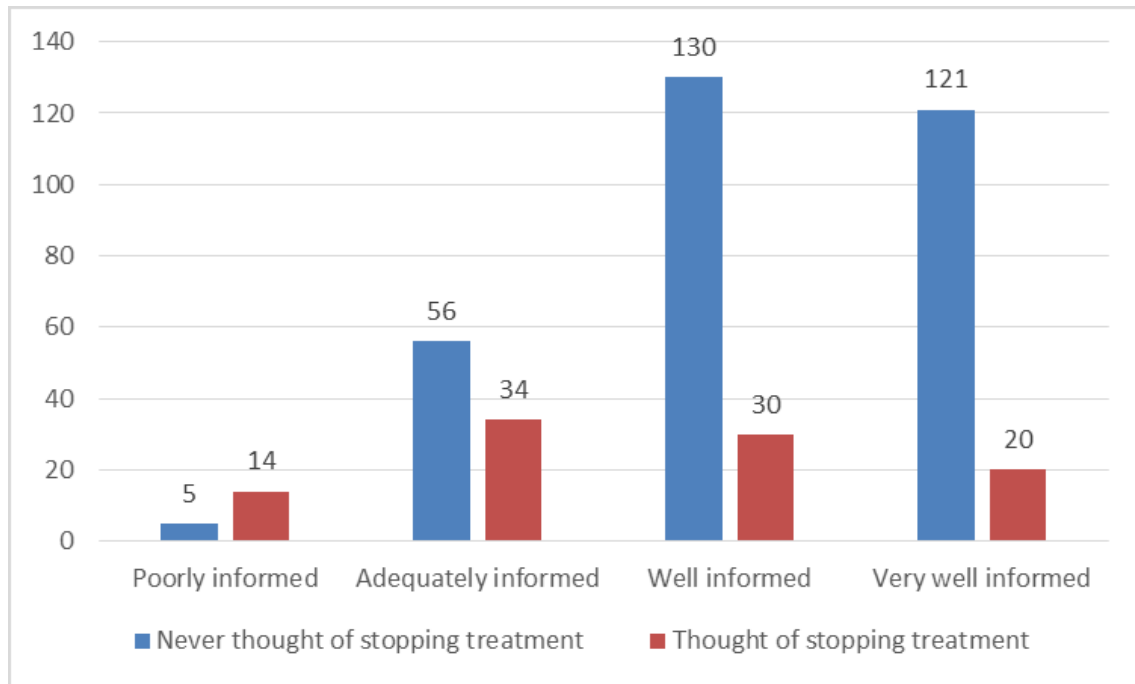


Fig. 1. Association between the degree of information from the doctor and adherence to treatment (Chi-squared test, $p < 0.001$; linear by linear association test, $p < 0.001$).

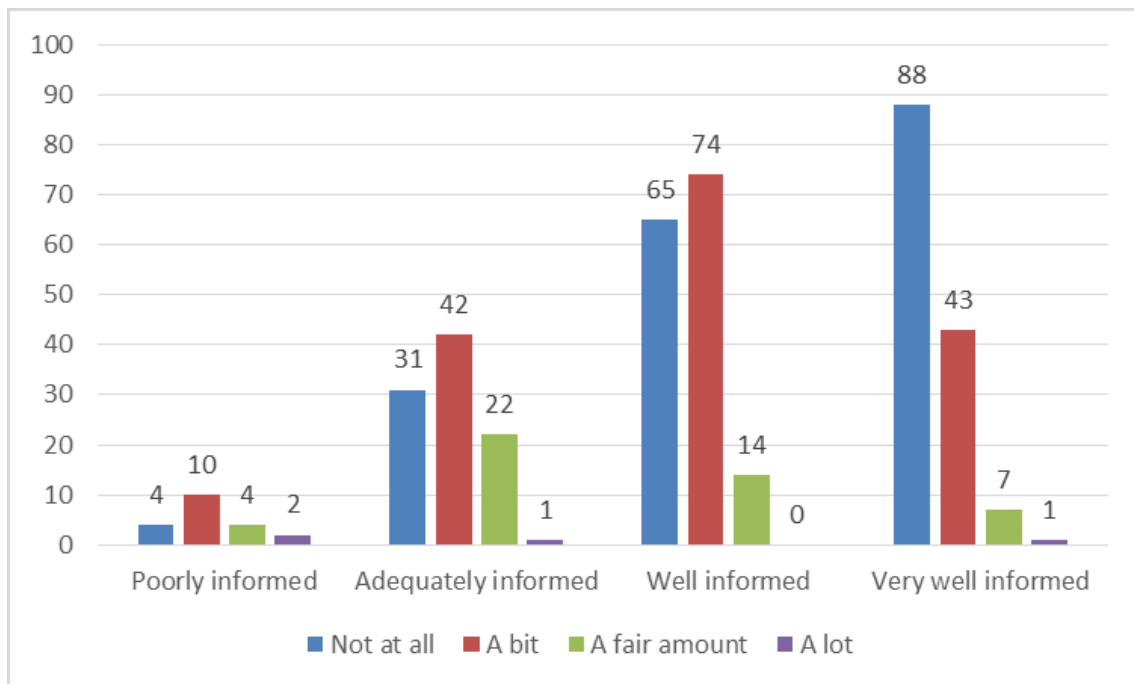


Fig. 2. Association between the quality of information from the doctor and internet influence (Chi-squared test, $p < 0.001$; linear by linear association test, $p < 0.001$).

Annex 1

INFORMATION ABOUT INFLAMMATORY BOWEL DISEASE

- 1 Age
 - a. < 20 years old
 - b. 20-40 years old
 - c. 40-60 years old
 - d. > 60 years old

- 2 Sex
 - a. Male
 - b. Female

- 3 Education
 - a. No formal studies
 - b. Primary school
 - c. High school
 - d. University studies

- 4 Employment status
 - a. Employee/self-employed
 - b. Retired/pensioner
 - c. Housewife
 - d. Student
 - e. Unemployed
 - f. Other

- 5 What illness do you have?
 - a. Crohn's disease
 - b. Ulcerative colitis

- 6 Time passed since the diagnosis of the illness
- < 5 years
 - 5-10 years
 - 10-20 years
 - > 20 years
- 7 Type of treatment you currently receive and/or have received in the last year:
(indicate all that apply)
- Mesalamine* (Claversal, Lixacol, Asacol, Mezavant, Pentasa, and Salofalk)
 - Sulfasalazine* (Salazopyrin)
 - Corticoids* (Beclometasone-Clipper; Budesonide-Entocort or Intestifalk; Deflazacort-Dezacort or Zamene; Dexamethasone; Hydrocortisone; Methylprednisolone-Urbason, Prednisone-Dacortin)
 - Immunosuppressants* (Imurel, Mercaptopurine EFG, Sandimmune neoral, Bertanel, Metoject, Methotrexate, Cellcept, Mycophenolate Mofetil, Myfenax)
 - Biologicals* (Humira, Remicade, Simponi, Inflectra, Remsima, Entyvio)
 - Alternative medicine* (homeopathy, phytotherapy, acupuncture, etc.)
 - Surgery*
- 8 In the last year: (indicate all that apply)
- You have had more attacks
 - You have had to cancel an activity/doctors' appointment due to the condition
 - You have had to go to emergency service
 - You have had to be admitted to hospital
 - You have had to have surgery
 - You have had to change to a stronger treatment
- 9 I feel tense or anxious:
- Almost all day
 - Most of the day
 - Occasionally

d. Never

10 I feel a type of fear, as if something bad was going to happen:

- a. Yes, and it's very intense
- b. Yes, but it's not very intense
- c. Yes, but it doesn't bother me
- d. I don't feel that at all

11 My head is full of worries:

- a. Almost all day
- b. Most of the day
- c. Occasionally
- d. Never

12 I can sit calmly and relaxed:

- a. Always
- b. Often
- c. Rarely
- d. Never

13 I have an unpleasant feeling of "anxiety and butterflies" in my stomach:

- a. Never
- b. Only occasionally
- c. Often
- d. Very often

14 I feel nervous, as if I can't sit still:

- a. A lot
- b. Considerably
- c. Not very much
- d. Never

15 I suddenly have feelings of great anxiety or fear:

- a. Very often
- b. Somewhat frequently
- c. Rarely
- d. Never

16 In general, how well informed about your disease do you consider yourself to be?

(Circle your answer; 1 is the worst and 10 is the best)

1	2	3	4	5	6	7	8	9	10
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17 How well do you consider that *your doctor has informed you*?

- a. Poorly
- b. Adequately
- c. Well
- d. Very well

18 When you were told that you had inflammatory bowel disease, did you feel that the amount of information given to you at that time was:

- a. Adequate
- b. Lacking
- c. Excessive
- d. Don't know/No answer

19 Have you ever thought about stopping (or have you stopped) treatment due to a lack of information (not knowing the objective, what the treatment was for, adverse effects, etc.)?

- a. Yes
- b. No
- c. Don't know/No answer

- 20 How do you feel that information influences the control of the course of your illness?
- The MORE information I have, the MORE flare-ups
 - The MORE information I have, the FEWER flare-ups
 - Doesn't know/Doesn't answer
- 21 How often are you left with questions after seeing your doctor?
- Never; your doctor addresses your concerns using appropriate terminology
 - Sometimes
 - Often
 - Always; he/she uses language that is too technical (explains poorly)
 - Always; no explanations are given
- 22 What type of information were you looking for? (indicate all that apply)
- Causes of the disease
 - Disease course
 - Complications that might occur
 - Influence of tobacco
 - Diet
 - Day-to-day IBD management
 - Type of activities that can routinely be performed
 - Diagnostic tests (what is it going to be like, what is its purpose, etc.)
 - Changes in the treatment (why the treatment is being modified; what the objective of the new treatment is)
 - Need for surgery
 - Likelihood of other relatives having the condition
 - Pregnancy
 - Other (indicate what):
- 23 What information do you think is most useful in clearing up your doubts?
- Information provided by the specialist

- b. Information provided by associations (ACCU)
 - c. Information provided by the hospital pharmacist
 - d. Information provided by your usual drug store/pharmacy
 - e. Information from the internet
 - f. Information given by another person with the same condition
 - g. There isn't any information that is especially useful
- 24 If you do look up IBD information on the internet, when do you usually do so?
- a. Before seeing my doctor; I feel it's important to be informed when seeing the doctor
 - b. After seeing my doctor; I'm left with doubts after the consultation
 - c. Before and after seeing my doctor
 - d. I don't consult internet sources
- 25 What kind of websites do you use? (indicate all that apply)
- a. Verified medical portals (such as Medline or Medscape)
 - b. Websites that aren't specifically medical (for example, Wikipedia)
 - c. Patient association/organization websites (ACCU)
 - d. Medical forums from verified websites
 - e. Forums that are not specifically medical (e.g., car forums, Vogue, etc.)
 - f. Forums for patients with Crohn's disease (e.g., <http://crohncolitis.foroactivo.com/>)
 - g. Social network groups (e.g., Facebook or Twitter sites for those affected by Crohn's)
- 26 Who recommended which websites to consult?
- a. Nobody
 - b. Specialist
 - c. Pharmacist
 - d. Association (ACCU)
 - e. Another patient

27 To what extent does the information you find on internet influence you in making decisions about your condition?

- a. Not at all
- b. A bit
- c. A fair amount
- d. Very much

28. Have you ever experienced an embarrassing/unfair situation due to society's lack of knowledge about the condition (such as conversations at work, in a restaurant, etc.)?

- a. Yes
- b. No
- c. Doesn't know/Doesn't answer

29. Do you think it's necessary to carry out more awareness campaigns about intestinal bowel disease?

- a. Yes
- b. No
- d. Do not know/No answer