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Quality of care through the eyes of the patient in a Spanish inflammatory bowel disease unit

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ABSTRACT

Introduction: the quality of care perceived by the patient is a fundamental aspect of the accreditation program of inflammatory bowel disease (IBD) units. The aim of this study was to evaluate the quality of healthcare from the patient's point of view in an IBD Unit.

Methods: consecutive patients diagnosed with Crohn's disease or ulcerative colitis that

attended the IBD Unit of the Hospital Universitario de La Princesa and anonymously filled out the Quality of Care through the Patient's Eyes - Inflammatory Bowel Disease (QUOTE-IBD) questionnaire were included in the study. QUOTE-IBD is a validated 23-item questionnaire, which explores the *Importance* given by patients to care aspects and the *Performance* of medical practices and healthcare workers. Each item assesses eight care dimensions: Competence, Autonomy, Courtesy, Accessibility, Information, Costs, Continuity of care and Accommodation.

RESULTS: one hundred patients from our IBD Unit completed the QUOTE-IBD. In terms of dimensions, patients gave the highest *Importance* score to aspects related to Information (8.24), followed by Competence in IBD care (7.86). *Performance* scores ranged from 0.4 for Continuity of care to 0.01 for Cost.

Conclusions: the application of the QUOTE-IBD questionnaire to assess the level of satisfaction of our patients with the quality of healthcare provided by our unit has allowed us to identify areas of improvement in the Information and Continuity of care dimensions. The highest score according to the perspective of our patients was obtained in the Competence in care dimension.

Keywords: Inflammatory bowel disease. Quality of healthcare. Clinical practice. Questionnaire.

INTRODUCTION

Crohn's disease (CD) and ulcerative colitis (UC) are chronic recurrent diseases that are usually diagnosed at a young age, with a wide spectrum of disease severity and the possible occurrence of extraintestinal manifestations. This may lead to a high number of outpatient visits, hospitalizations and surgery, with the consequent impact on healthcare costs (1).

Quality of healthcare is defined as the degree to which health services for individuals and populations increase the likelihood of achieving health outcomes, which are optimal and in accordance with current professional knowledge (2). Quality of care has a relevant role in the quality of life of patients with IBD (3). However, there are often discrepancies between the beliefs and opinions of health professionals and those of patients, and in their perception of what things are important for quality of care (4).

In order to maintain an adequate level of quality of care, it is necessary to assess the expectations and satisfaction of patients in all aspects of their contact with the system, depending on their disease. The number of tools available to assess the level of satisfaction of IBD patients is limited (5), although the Quality of Care through the Patient's Eyes - Inflammatory Bowel Disease (QUOTE-IBD) questionnaire has been the most widely used (5-9).

The QUOTE-IBD questionnaire was developed by The Netherlands Institute for Health Services Research (NIVEL). This tool includes eight relevant dimensions of quality of care (Accessibility, costs, Accommodation, Continuity of care, Courtesy, Information, Competence in care and Autonomy), and was built based on patient participation in several stages. This questionnaire has been validated in its Spanish version and has proved to be a reliable instrument to measure quality of care in patients with CD and UC (7).

The aim of the present study was to evaluate the level of satisfaction with the quality of care received by the patients attending the Hospital Universitario de La Princesa IBD Unit, via the QUOTE-IB questionnaire.

METHODS

Study design

This was a single-center, observational, cross-sectional study.

Study population

The study population consisted of patients diagnosed with CD or UC followed-up at the Hospital Universitario de La Princesa IBD Unit. To avoid inclusion bias, the first four consecutive patients attending each session at the outpatient clinic from January to October 2015 were invited to participate.

Data collection

Patients who accepted to participate in the study and provided written informed consent received an e-mail with an access link to an electronic data collection form. This was used to anonymously fill-in an electronic evaluation questionnaire at their convenience. The evaluation questionnaire included demographic variables, age at diagnosis, smoking history,

type of IBD, year of diagnosis and history of abdominal surgery due to IBD. In addition, the patients accessed the QUOTE-IBD questionnaire through the same link. All electronic communications for the completion of the questionnaire were encrypted and no identifiable personal information was collected.

Definitions

The QUOTE-IBD consists of 23 items: ten generic and 13 disease-specific questions or items (7). These 23 items represent the total quality of care and are organized into eight dimensions: Competence in care (three items), Courtesy (four items), Accessibility (four items), Information (four items), Continuity of care (four items), Accommodation (two items), Autonomy (one item) and Costs (one item). Scoring for each item of the QUOTE-IBD survey is based on a four-point scale that allows the following to be assessed:

- *Importance* (I): defined as the weight that patients assign to various healthcare aspects. Importance is rated as follows: 0 = not important; 3 = fairly important; 6 = important; and 10 = extremely important.
- *Performance* (P) of the healthcare professionals assisting the patient, defined as the patient's experiences concerning the functioning of medical practices and healthcare personnel for each healthcare aspect. This was graded as: 0 = on the whole/yes; and 1 = no/not really.
- *Quality impact (QI):* the combined effect of *Importance* and *Performance* is defined as the QI for each one of the healthcare dimensions. QI =10 - I x P. With regard to the dimensions represented by more than one item, *Importance*, *Performance* and QI scores of each dimension were obtained by calculating the average of the scores of each item.
- *Level of satisfaction:* for each dimension of care, an insufficient level of satisfaction was considered if QI = 10 - I x D < 9. According to some authors such as Lehman and Zastowny (10), up to 90 % of the population is satisfied with the quality of the assistance received. Therefore, this value can be considered as a cut-off point to evaluate suboptimal satisfaction areas.

Ethical aspects

The study was approved by the institutional ethics review board of our center and was performed according to the Declaration of Helsinki and Good Clinical Practice guidelines.

Statistical analysis

In the descriptive analysis, quantitative variables are presented as the mean and standard deviation or median and interquartile range (IQR), depending on whether they were normally distributed or not. Ninety-five percent confidence intervals (95 % CIs) and the percentages are provided for the categorical variables. The χ^2 test was used to compare categorical variables and the Mann-Whitney U-test was used to compare quantitative variables. p values < 0.05 were considered as statistically significant.

Factorial ANOVA models were performed in order to evaluate the interactions between the clinical variables and their effect on the *Importance*, *Performance* and QI scores of healthcare dimensions. The categorical variables included in these models were age (< 45 years), gender, IBD diagnosis (CD *versus* UC), disease duration since diagnosis (< 10 years), surgery due to IBD and smoking status.

RESULTS

Study population

One hundred and thirty patients who attended the IBD Unit at the Hospital Universitario de La Princesa were invited to participate in the study. Of these, 100 patients completed the QUOTE-IBD questionnaire and were included in the study (77 % response rate). The main demographic characteristics of the study population are summarized in table 1.

Quality of care dimensions: *Importance*, *Performance* and Quality impact

Mean values for *Importance*, *Performance* and Quality impact scores for total care and the eight dimensions of QUOTE-IBD are presented in table 2. The patients gave the highest *Importance* score to aspects related to information (8.24), followed by Competence (7.86). Nevertheless, the individual items with top ratings in *Importance* did not belong to any of these categories: “Confidence in the physician” was the top individual item, followed by the patient’s request of “being taken seriously by the health care team”. On the other hand, patients gave lower scores to the Autonomy dimension of quality of care. The only individual

item included in this category, "the patient willingness to participate in treatment decisions", was also among the questions with the lowest rank in *Importance* in the questionnaire. This was just above punctuality in visits and waiting time lower than 15 minutes. Table 3 summarizes the mean scores of *Importance*, *Performance* and QI for each item of the QUOTE-IBD.

Regarding *Performance*, patients gave a higher score to aspects related to Costs, followed by Accommodation and Competence. On the contrary, Continuity of care and Information obtained lower scores. The QI of total care was 7.7. The QI of seven of the eight quality of care dimensions was < 9 (Table 2). Costs was the only dimension whose QI was > 9.

The QI of the dimensions of Accommodation, Competence, Autonomy and Courtesy were above the QI of total care (7.7). On the other hand, both Information and Continuity of care obtained the lowest QI. "The perception that patients have when they are referred to another specialist" (5.19) was the item of the Continuity of care dimension with the lowest score, whereas "the need for information on nutritional aspects of IBD" (5,27) and especially "the possible implications of the disease" (5.88) were the items with the lowest score in the Information dimension section.

Quality impact according to patient characteristics

Differences were observed in the mean score obtained for *Importance* according to sex, age of the patient, type of IBD, time of evolution of IBD and history of previous surgery for IBD ($p < 0.05$). Competence in IBD care was significantly less important for those older than 45 years and for patients with > 10 years of evolution of IBD. However, Accessibility was more important for patients with < 10 years of evolution of IBD. On the other hand, Courtesy was more relevant for male patients and for those without a history of prior surgery due to IBD, compared to females and patients who underwent surgery. UC patients gave greater importance to Accommodation than patients with CD.

No statistically significant differences were found in the *Performance* or in the QI of the eight dimensions of quality of care when sex, age, type of IBD, time of evolution of IBD or history of previous surgery were considered.

DISCUSSION

The QUOTE-IBD questionnaire was applied to the patients attending the IBD Unit of Hospital Universitario de La Princesa, in order to evaluate the level of satisfaction of our patients with the quality of care. The QI of total care was 7.7. This score is below that reported in the Spanish study, which included 103 patients and validated the Spanish version of QUOTE-IBD (7). The QI of total care was also higher in other studies performed in other countries with different health systems, even > 9 in some cases (1,7,8,11). In this sense, although QUOTE-IBD is a validated and specific questionnaire for patients with IBD, the perception of patients and their expectations can vary considerably between different health systems (1). According to our results, the overall level of satisfaction of our patients was close to 80 %. These results have allowed us to identify areas of improvement such as Information and Continuity of care.

Regarding *Importance* of the quality of care dimensions, our patients gave a higher score to Information. However, among the individual items that evaluate the Information dimension, the demand for information about nutritional aspects of IBD and the possible complications of IBD were some of the items that obtained the lowest score in *Performance* of health personnel. This difference between the expectations of the patient and the performance by health personnel would explain the low score obtained in the QI of the Information dimension. In other studies that used the QUOTE-IBD, information about different aspects of IBD, especially the nutritional aspect, have obtained the highest score in *Importance* (3,6,7,12). This suggests that what patients consider most relevant in their respective health systems is the information they receive from the health personnel. In this sense, patients with IBD value most the access to information and nutritional advice (13). Given these results, we have improved the information we provide to patients about the different aspects of IBD, by both the medical staff and nursing personnel. Likewise, we have organized information days for patients, including the topics they consider to be most relevant.

On the other hand, Autonomy was the quality of care dimension to which the patients gave a lower score in *Importance*. In fact, the only item included in this dimension, “the patient’s desire to participate in therapeutic decisions”, was one of the questionnaire items with the lowest score in *Importance*. This is consistent with other studies in which patients expressed less relevance to Autonomy (7,11). However, this finding is interesting, since strengthening the autonomy of patients by involving them in decision making about their health is one of

the quality indicators for IBD units (14). In fact, a recent study that showed quality indicators of patient care with IBD demonstrated that patients with IBD actively participated in the selection of these indicators (15).

Continuity of care was another of the quality of care dimensions that obtained a lower QI. This may be explained, to a large extent, by the low score given in *Performance* to the item "ensure that, after referral to other specialists, patients will be valued in less than two weeks" and the great *Importance* that patients gave to this item.

According to our results, Competence was one of the dimensions of quality of care that obtained the highest QI among our patients. This reflects the fact that patients value the high qualification of the health personnel of our center. In addition, Competence was one of the dimensions that obtained a higher score, both in the *Importance* given by patients and in the *Performance* of our health personnel. In our study, there were no differences in the QI of any of the eight quality of care dimensions according to sex, age of patients, type of IBD, time of evolution of IBD or history of previous surgery. Other studies have found different associations between patient characteristics and the QUOTE-IBD score (8,11). These differences suggest that there may be other factors that influence the QUOTE-IBD and explain the variations between different countries. In this sense, there is a significant variation in the quality of care of patients with IBD in the different regions, which determines the differences in the care received by these patients (16).

This study has several limitations. First, the sample size is relatively small. However, most published studies include a lower or similar number of patients. Secondly, it is a single-center study and our IBD Unit is a national reference unit with a high number of complex and difficult to manage patients. Thus, the results of QUOTE-IBD may not be comparable with those of other IBD units in which less complex patients are treated.

One of the strengths of this study is that patients answered the questionnaire anonymously, which avoids possible biases and encourages them to answer freely. In addition, it is one of the few European studies that assess the level of satisfaction from the perspective of IBD patients, with respect to the quality of care that they receive.

In conclusion, our results affirm that the application of the QUOTE-IBD allowed us to identify areas for improvement from the patient's perspective, such as the information provided to our patients and the continuity of care. Finally, our patients believe that our best

Performance is in Competence of care.

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REFERENCES

1. Bortoli A, Daperno M, Kohn A, et al. Patient and physician views on the quality of care in inflammatory bowel disease: results from SOLUTION-1, a prospective IG-IBD study. J Crohns Colitis 2014;8:1642-52. DOI: 10.1016/j.crohns.2014.07.004

2. Lohr KN, Schroeder SA. A strategy for quality assurance in Medicare. N Engl J Med 1990;322:707-12. DOI: 10.1056/NEJM199003083221031

3. van der Eijk I, Vlachonikolis IG, Munkholm P, et al. The role of quality of care in health-related quality of life in patients with IBD. Inflamm Bowel Dis 2004;10:392-8. DOI: 10.1097/00054725-200407000-00010

4. Lebow JL. Consumer assessments of the quality of medical care. Med Care 1974;12:328-37. DOI: 10.1097/00005650-197404000-00004

5. van der Eijk I, Sixma H, Smeets T, et al. Quality of health care in inflammatory bowel disease: development of a reliable questionnaire (QUOTE-IBD) and first results. Am J Gastroenterol 2001;96:3329-36. DOI: 10.1016/S0002-9270(01)03896-5

6. Pallis AG, Vlachonikolis IG, Mouzas IA. Validation of a reliable instrument (QUOTE-IBD) for assessing the quality of health care in Greek patients with inflammatory bowel disease. Digestion 2003;68:153-60. DOI: 10.1159/000075524

7. Masachs M, Casellas F, Borruel N, et al. Validation of the Spanish version of a questionnaire to measure quality of care through the eyes of patients with inflammatory bowel disease (QUOTE-IBD). Inflamm Bowel Dis 2010;16:982-92. DOI: 10.1002/ibd.21156

8. Vasudevan A, Arachchi A, van Langenberg DR. Assessing patient satisfaction in inflammatory bowel disease using the QUOTE-IBD survey: a small step for clinicians, a potentially large step for improving quality of care. J Crohns Colitis 2013;7:e367-74. DOI: 10.1016/j.crohns.2013.02.012

9. Lehmann M, Walther M, Ulitzsch S, et al. Validation and first results of the German QUOTE-IBD to measure quality of care from the perspective of patients with inflammatory bowel disease. Z Gastroenterol 2013;51:196-203.

10. Lehman AF, Zastowny TR. Patient satisfaction with mental health services: a meta-analysis to establish norms. Eval Program Plann 1983;6:265-74. DOI: 10.1016/0149-7189(83)90006-X

11. Soares JB, Nogueira MC, Fernandes D, et al. Validation of the Portuguese version of a questionnaire to measure Quality of Care Through the Eyes of Patients with Inflammatory Bowel Disease (QUOTE-IBD). Eur J Gastroenterol Hepatol 2015;27:1409-17. DOI: 10.1097/MEG.0000000000000485

12. Tolentino YF, Fogaca HS, Zaltman C, et al. Hepatitis B virus prevalence and transmission risk factors in inflammatory bowel disease patients at Clementino Fraga Filho University Hospital. World J Gastroenterol 2008;14:3201-6. DOI: 10.3748/wjg.14.3201

13. Prince A, Whelan K, Moosa A, et al. Nutritional problems in inflammatory bowel disease: the patient perspective. J Crohns Colitis 2011;5:443-50. DOI: 10.1016/j.crohns.2011.04.016

14. Calvet X, Panes J, Alfaro N, et al. Delphi consensus statement: Quality Indicators for Inflammatory Bowel Disease Comprehensive Care Units. J Crohns Colitis 2014;8:240-51. DOI: 10.1016/j.crohns.2013.10.010

15. Bitton A, Vutcovici M, Lytvyak E, et al. Selection of quality indicators in IBD: integrating physician and patient perspectives. Inflamm Bowel Dis 2019;25:403-9. DOI: 10.1093/ibd/izy259

16. Berry SK, Melmed GY. Quality indicators in inflammatory bowel disease. Intest Res 2018;16:43-7. DOI: 10.5217/ir.2018.16.1.43

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Table 1. Demographic characteristics of the patients

Variables	*Patients*
Type of IBD, n (%)	100
Crohn's disease	54 (54)
Ulcerative colitis	46 (46)
Male, n (%)	49 (49)
Mean age, years (range)	46 (23-64)
Time of IBD evolution (median, years)	10.06
Time of IBD evolution > 10 years, n (%)	49 (49)
Smoking history, n (%)	11 (11)
History of previous surgery due to IBD, n (%)	27 (27)

IBD: inflammatory bowel disease.

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Table 2. *Importance*, *Performance* and Quality impact in QUOTE-IBD

Dimensions	*Importance*		*Performance*		*Quality impact*	
	Mean	SD	Mean	SD	Mean	SD
Competence	7.86	1.70	0.25	0.29	8.06	2.46
Autonomy	6.48	2.51	0.36	0.48	7.81	3.35
Courtesy	7.53	1.44	0.34	0.23	7.80	1.89
Accessibility	7.47	1.41	0.37	0.24	7.66	1.99
Continuity of care	7.21	1.52	0.40	0.29	7.18	2.35
Information	8.24	1.58	0.39	0.34	6.78	2.94
Accommodation	7.04	2.00	0.17	0.28	8.70	2.17
Costs	7.7	2.5	0.01	0.1	9.9	1.0
Total	7.55	1.21	0.32	0.20	7.70	1.71

SD: standard deviation.

Table 3. *Importance*, *Performance* and Quality impact scores for each item of the QUOTE-IBD

Item		*Dimension*	*Importance mean (SD)*	*Performance mean (SD)*	*QI mean (SD)*
Generic questions: physicians, nurses and other health care workers…					
1	… should have a good understanding of my problems	Competence	8.92 (3.00)	0.12 (0.32)	8.92 (3.00)
2	… should allow me to have input in decisions regarding the treatment received	Autonomy	6.48 (2.51)	0.36 (0.48)	7.81 (3.35)
3	… should take me seriously	Courtesy	8.88 (1.81)	0.09 (0.29)	9.18 (2.67)
4	… should keep the appointments punctually	Courtesy	5.43 (2.59)	0.54 (0.50)	6.87 (3.45)
5	… should not keep me in the waiting room for more than 15 minutes	Accessibility	4.63 (2.78)	0.77 (0.42)	6.55 (3.03)
6	… should inform me about the prescribed medicines	Information	8.37 (2.03)	0.29 (0.46)	7.69 (3.82)
7	… should prescribe medicines which are fully covered by insurance	Costs	7.66 (2.46)	0.01 (0.10)	9.90 (1.00)
8	… should be easy to reach by telephone	Accessibility	8.06 (2.11)	0.25 (0.44)	7.86 (3.85)
9	… should make sure that I can consult a specialist within two weeks after referral	Continuity of care	6.70 (2.34)	0.71 (0.46)	5.19 (3.72)
10	… should communicate with other health care workers about required	Continuity of care	7.75 (2.15)	0.42 (0.50)	6.86 (3.97)

	services				
IBD-specific questions:					
11	Waiting areas and consulting rooms should be clean and orderly	Accessibility	6.82 (2.41)	0.11 (0.31)	9.17 (2.50)
12	Physicians and nurses should also approach my disease from a psychological point of view	Competence	6.94 (2.42)	0.49 (0.50)	6.43 (4.08)
13	Physicians and nurses should inform me clearly about the examinations I am subjected to	Information	8.37 (2.03)	0.20 (0.40)	8.28 (3.56)
14	I should usually be examined by the same physician	Continuity of care	7.45 (2.19)	0.14 (0.35)	8.94 (2.82)
15	Physicians should inform me clearly about other possible physical problems due to IBD, e.g., joint pain	Information	8.18 (2.11)	0.49 (0.50)	5.88 (4.49)
16	Nurses at the Endoscopy Department should have specific expertise in IBD	Competence	8.31 (2.14)	0.14 (0.35)	8.83 (3.04)
17	Hospitals and medical practice rooms should have good toilet facilities	Accessibility	7.26 (2.37)	0.22 (0.42)	8.24 (3.46)
18	If my physician is absent, an adequately competent substitute should be available	Accessibility	8.53 (1.99)	0.05 (0.22)	9.54 (2.05)
19	In health institutions,	Information	8.03 (2.16)	0.59 (0.49)	5.27 (4.33)

	adequate information about nutrition and IBD should be available to patients				
20	It should be possible for me to consult my doctor regularly	Continuity of care	6.95 (2.10)	0.32 (0.47)	7.74 (3.52)
21	In case of acute problems, a physician should be available within 24 hours	Accessibility	8.64 (1.90)	0.39 (0.49)	6.70 (4.32)
22	Physicians and nurses should pay attention to the influence of my IBD on my family life and/or work situation	Courtesy	6.75 (2.71)	0.66 (0.48)	5.77 (3.78)
23	As an IBD patient, I should have confidence in my physician	Courtesy	9.1 (1.9)	0.1 (0.3)	9.4 (2.3)

IBD: inflammatory bowel disease; SD: standard deviation; QI: quality impact.