

# World Journal of *Clinical Cases*

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**MINIREVIEWS**

- 12066** Review of risk factors, clinical manifestations, rapid diagnosis, and emergency treatment of neonatal perioperative pneumothorax  
*Zhang X, Zhang N, Ren YY*

**ORIGINAL ARTICLE****Clinical and Translational Research**

- 12077** Integrative analysis of platelet-related genes for the prognosis of esophageal cancer  
*Du QC, Wang XY, Hu CK, Zhou L, Fu Z, Liu S, Wang J, Ma YY, Liu MY, Yu H*
- 12089** Comprehensive analysis of the relationship between cuproptosis-related genes and esophageal cancer prognosis  
*Xu H, Du QC, Wang XY, Zhou L, Wang J, Ma YY, Liu MY, Yu H*
- 12104** Molecular mechanisms of Baihedihuang decoction as a treatment for breast cancer related anxiety: A network pharmacology and molecular docking study  
*Li ZH, Yang GH, Wang F*
- 12116** Single-cell RNA-sequencing combined with bulk RNA-sequencing analysis of peripheral blood reveals the characteristics and key immune cell genes of ulcerative colitis  
*Dai YC, Qiao D, Fang CY, Chen QQ, Que RY, Xiao TG, Zheng L, Wang LJ, Zhang YL*

**Retrospective Study**

- 12136** Diagnosis and treatment of tubal endometriosis in women undergoing laparoscopy: A case series from a single hospital  
*Jiao HN, Song W, Feng WW, Liu H*
- 12146** Different positive end expiratory pressure and tidal volume controls on lung protection and inflammatory factors during surgical anesthesia  
*Wang Y, Yang Y, Wang DM, Li J, Bao QT, Wang BB, Zhu SJ, Zou L*
- 12156** Transarterial chemoembolization combined with radiofrequency ablation in the treatment of large hepatocellular carcinoma with stage C  
*Sun SS, Li WD, Chen JL*
- 12164** Coexistence of anaplastic lymphoma kinase rearrangement in lung adenocarcinoma harbouring epidermal growth factor receptor mutation: A single-center study  
*Zhong WX, Wei XF*

**Observational Study**

- 12175** Prognostic values of optic nerve sheath diameter for comatose patients with acute stroke: An observational study  
*Zhu S, Cheng C, Wang LL, Zhao DJ, Zhao YL, Liu XZ*
- 12184** Quality of care in patients with inflammatory bowel disease from a public health center in Brazil  
*Takamune DM, Cury GSA, Ferrás G, Herrerias GSP, Rivera A, Barros JR, Baima JP, Saad-Hossne R, Sasaki LY*
- 12200** Comparison of the prevalence of sarcopenia in geriatric patients in Xining based on three different diagnostic criteria  
*Pan SQ, Li XF, Luo MQ, Li YM*

**Prospective Study**

- 12208** Predictors of bowel damage in the long-term progression of Crohn's disease  
*Fernández-Clotet A, Panés J, Ricart E, Castro-Poceiro J, Masamunt MC, Rodríguez S, Caballol B, Ordás I, Rimola J*

**Randomized Controlled Trial**

- 12221** Protective effect of recombinant human brain natriuretic peptide against contrast-induced nephropathy in elderly acute myocardial infarction patients: A randomized controlled trial  
*Zhang YJ, Yin L, Li J*

**META-ANALYSIS**

- 12230** Prognostic role of pretreatment serum ferritin concentration in lung cancer patients: A meta-analysis  
*Gao Y, Ge JT*

**CASE REPORT**

- 12240** Non-surgical management of dens invaginatus type IIIB in maxillary lateral incisor with three root canals and 6-year follow-up: A case report and review of literature  
*Arora S, Gill GS, Saquib SA, Saluja P, Baba SM, Khateeb SU, Abdulla AM, Bavabeedu SS, Ali ABM, Elagib MFA*
- 12247** Unusual presentation of Loeys-Dietz syndrome: A case report of clinical findings and treatment challenges  
*Azrad-Daniel S, Cupa-Galvan C, Farca-Soffer S, Perez-Zincer F, Lopez-Acosta ME*
- 12257** Peroral endoscopic myotomy assisted with an elastic ring for achalasia with obvious submucosal fibrosis: A case report  
*Wang BH, Li RY*
- 12261** Subclavian brachial plexus metastasis from breast cancer: A case report  
*Zeng Z, Lin N, Sun LT, Chen CX*
- 12268** Case mistaken for leukemia after mRNA COVID-19 vaccine administration: A case report  
*Lee SB, Park CY, Park SG, Lee HJ*
- 12278** Orthodontic-surgical treatment of an Angle Class II malocclusion patient with mandibular hypoplasia and missing maxillary first molars: A case report  
*Li GF, Zhang CX, Wen J, Huang ZW, Li H*

- 12289** Multiple cranial nerve palsies with small angle exotropia following COVID-19 mRNA vaccination in an adolescent: A case report  
*Lee H, Byun JC, Kim WJ, Chang MC, Kim S*
- 12295** Surgical and nutritional interventions for endometrial receptivity: A case report and review of literature  
*Hernández-Melchor D, Palafox-Gómez C, Madrazo I, Ortiz G, Padilla-Viveros A, López-Bayghen E*
- 12305** Conversion therapy for advanced penile cancer with tislelizumab combined with chemotherapy: A case report and review of literature  
*Long XY, Zhang S, Tang LS, Li X, Liu JY*
- 12313** Endoscopic magnetic compression stricturoplasty for congenital esophageal stenosis: A case report  
*Liu SQ, Lv Y, Luo RX*
- 12319** Novel *hydroxymethylbilane synthase* gene mutation identified and confirmed in a woman with acute intermittent porphyria: A case report  
*Zhou YQ, Wang XQ, Jiang J, Huang SL, Dai ZJ, Kong QQ*
- 12328** Modified fixation for periprosthetic supracondylar femur fractures: Two case reports and review of the literature  
*Li QW, Wu B, Chen B*
- 12337** Erbium-doped yttrium aluminum garnet laser and advanced platelet-rich fibrin+ in periodontal diseases: Two case reports and review of the literature  
*Tan KS*
- 12345** Segmental artery injury during transforaminal percutaneous endoscopic lumbar discectomy: Two case reports  
*Cho WJ, Kim KW, Park HY, Kim BH, Lee JS*
- 12352** Pacemaker electrode rupture causes recurrent syncope: A case report  
*Zhu XY, Tang XH, Huang WY*
- 12358** Hybrid intercalated duct lesion of the parotid: A case report  
*Stankevicius D, Petroska D, Zaleckas L, Kutanovaite O*
- 12365** Clinical features and prognosis of multiple myeloma and orbital extramedullary disease: Seven cases report and review of literature  
*Hu WL, Song JY, Li X, Pei XJ, Zhang JJ, Shen M, Tang R, Pan ZY, Huang ZX*
- 12375** Colon mucosal injury caused by water jet malfunction during a screening colonoscopy: A case report  
*Patel P, Chen CH*
- 12380** Primary malignant pericardial mesothelioma with difficult antemortem diagnosis: A case report  
*Oka N, Orita Y, Oshita C, Nakayama H, Teragawa H*
- 12388** Typical imaging manifestation of neuronal intranuclear inclusion disease in a man with unsteady gait: A case report  
*Gao X, Shao ZD, Zhu L*

- 12395** Multimodality imaging and treatment of paranasal sinuses nuclear protein in testis carcinoma: A case report  
*Huang WP, Gao G, Qiu YK, Yang Q, Song LL, Chen Z, Gao JB, Kang L*
- 12404** T1 rectal mucinous adenocarcinoma with bilateral enlarged lateral lymph nodes and unilateral metastasis: A case report  
*Liu XW, Zhou B, Wu XY, Yu WB, Zhu RF*
- 12410** Influence of enhancing dynamic scapular recognition on shoulder disability, and pain in diabetics with frozen shoulder: A case report  
*Mohamed AA*
- 12416** Acute myocardial necrosis caused by aconitine poisoning: A case report  
*Liao YP, Shen LH, Cai LH, Chen J, Shao HQ*
- 12422** Danggui Sini decoction treatment of refractory allergic cutaneous vasculitis: A case report  
*Chen XY, Wu ZM, Wang R, Cao YH, Tao YL*
- 12430** Phlegmonous gastritis after biloma drainage: A case report and review of the literature  
*Yang KC, Kuo HY, Kang JW*
- 12440** Novel *TINF2* gene mutation in dyskeratosis congenita with extremely short telomeres: A case report  
*Picos-Cárdenas VJ, Beltrán-Ontiveros SA, Cruz-Ramos JA, Contreras-Gutiérrez JA, Arámbula-Meraz E, Angulo-Rojo C, Guadrón-Llanos AM, Leal-León EA, Cedano-Prieto DM, Meza-Espinoza JP*
- 12447** Synchronous early gastric and intestinal mucosa-associated lymphoid tissue lymphoma in a *Helicobacter pylori*-negative patient: A case report  
*Lu SN, Huang C, Li LL, Di LJ, Yao J, Tuo BG, Xie R*

**LETTER TO THE EDITOR**

- 12455** Diagnostic value of metagenomics next-generation sequencing technology in disseminated strongyloidiasis  
*Song P, Li X*
- 12458** Diagnostic value of imaging examination in autoimmune pancreatitis  
*Wang F, Peng Y, Xiao B*

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## Observational Study

## Quality of care in patients with inflammatory bowel disease from a public health center in Brazil

Debora Mayumi Takamune, Giovana Signorelli Astolfi Cury, Giulia Ferrás, Giedre Soares Prates Herrerias, Adriana Rivera, Jaqueline Ribeiro Barros, Julio Pinheiro Baima, Rogerio Saad-Hossne, Ligia Yukie Sasaki

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## Abstract

### BACKGROUND

Inflammatory bowel diseases (IBDs) are chronic diseases that demand continuous interaction between patients and healthcare providers. Quality of care (QoC) is a factor that contributes to a patient's adherence to treatment and its success.

### AIM

To evaluate QoC in patients from a single IBD reference center.

### METHODS

This cross-sectional study included 133 patients from a single Brazilian IBD public health center. QoC was evaluated through the QoC Through the Eyes of Patients with IBD (QUOTE-IBD) questionnaire (based on patient perspectives), which measures eight dimensions of care. We compared QoC among patients with Crohn's disease and ulcerative colitis and analyzed the clinical and psychological factors associated with QoC satisfaction. Clinical evaluations assessed disease characteristics, quality of life, anxiety, and depression levels.

### RESULTS

Sixty-nine patients with Crohn's disease and 64 with ulcerative colitis were

interviewed. The mean age was 37.26 years  $\pm$  13.05 years, and 63.91% of the patients were women. The mean duration of the disease was 8.44 years  $\pm$  7.59 years, where most patients were in remission (70.31% of patients with ulcerative colitis and 62.32% with Crohn's disease). The total QoC score of the sample was 8.61 years  $\pm$  1.31 points, indicating that the QoC provided by the center was unsatisfactory. According to univariate logistic regression, patients with Crohn's disease had higher satisfaction rates than those with ulcerative colitis [odds ratio (OR): 2.746; 95% confidence interval (CI): 1.360-5.541;  $P = 0.0048$ ] and patients on infliximab (OR: 2.175; 95% CI: 1.037-4.562;  $P = 0.0398$ ).

### CONCLUSION

Patients from the IBD public center reported good doctor-patient relationships, but had problems related to the healthcare structure. Evaluation of healthcare centers is of paramount to improve QoC for the patients involved.

**Key Words:** QUOTE-IBD questionnaire; Quality of care; Crohn's disease; Ulcerative colitis; Inflammatory bowel disease; Doctor-patient relationship

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**Core Tip:** Inflammatory bowel disease (IBD) is an immune-mediated disease that requires a close relationship between the patient and their healthcare service provider. Quality of care (QoC) is a crucial factor for the success of IBD treatment. The present study evaluated QoC in a public center in Brazil. The center was well-evaluated, showing good doctor-patient relationship but had problems especially those relating to the structure of healthcare practices. Evaluation of healthcare centers is of paramount importance, encouraging improvements that provide better care, disease control, and quality of life for the patients involved.

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## INTRODUCTION

Inflammatory bowel diseases (IBD), including Crohn's disease and ulcerative colitis, are chronic and recurrent diseases that require frequent interaction between patients and their healthcare service providers. The quality of care (QoC) offered by a healthcare service provider is a predictor of a patient's adherence to treatment, quality of life, and general health status[1,2].

The Institute of Medicine defined quality in medical care as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge"[3]. In 2020, the European Crohn's and Colitis Organization published a position paper on 111 standards of quality care in IBD patients, based on scientific evidence, interdisciplinary expert consensus, and patient-oriented perspectives[4]. The standard points were grouped into three main domains, including structure, process, and outcomes of standard quality care, and included important information regarding the use of a multidisciplinary team (composed of at least one gastroenterologist or endoscopist, nurse, radiologist, pathologist, and surgeon dedicated to IBD), in collaboration with a dietician. The ideal IBD unit should offer active management of appointments, offer facilities for diagnosis and monitoring, inform the patient of the benefits and risks associated with therapy, promote regular monitoring of side effects, and empower the patient to practice self-care and shared decision making with the IBD multidisciplinary team[4].

Every IBD referral center must offer the best service possible for patient care, and the performance of the unit must be as measurable as possible. Assessment of healthcare center services, from patient perspectives, can be a useful tool for improving the QoC provided to patients and their families. Quality metrics are important for standardizing practice in these centers[5]. Positive aspects of the center must be recognized and adequately rewarded, while negative aspects must be carefully analyzed and corrected. Thus, it is important to identify the QoC dispensed by a service. Nevertheless, few studies have evaluated the QoC provided to patients with IBD[6-8]. To our knowledge, in Latin America, no study has been published in this regard.

Therefore, the aim of this study was to assess patients' self-reported QoC from a public Brazilian IBD reference center, using the QoC Through the Eyes of Patients with IBD (QUOTE-IBD) questionnaire. This study compared QoC results among patients with Crohn's disease and ulcerative colitis, and identified the clinical and psychological factors associated with satisfaction of the center-provided QoC.

## MATERIALS AND METHODS

### **Study design**

This study was an observational study based on a cross-sectional survey, to assess patient perspectives of QoC.

### **Participants**

This cross-sectional study enrolled 133 patients with IBD, including 69 with Crohn's disease and 64 with ulcerative colitis, from the outpatient department and infusion center in a tertiary hospital of São Paulo State, Brazil. The study duration lasted nine months (from October 2018 to June 2019).

The inclusion criteria required patients to be of  $\geq 18$  years of age, undergo a follow-up period of  $\geq 6$  mo, and have a confirmed diagnosis of IBD. IBD diagnoses were based on established clinical, endoscopic, radiologic, and histological criteria[9]. Exclusion criteria included the diagnosis of indeterminate colitis; chronic comorbidities, such as decompensated diabetes, cancer, heart failure, chronic infectious diseases (such as HIV, hepatitis B, or hepatitis C virus), renal or hepatic diseases, or other clinical or psychological conditions that could interfere with the research; and failure to fill in the requested questionnaires.

The original sample consisted of 300 patients, who were recruited *via* follow-up at the healthcare service center. Through non-probabilistic sampling, an eventual sample size of 133 patients was recruited. The study was approved by the local Research Ethics Committee (CAAE: 85661018.0.0000.54 11). After receiving explanations about the study objectives and expected results from their treating physicians, all participants voluntarily completed the questionnaires and signed the informed consent form.

### **Clinical and sociodemographic variables**

The following data were collected from the participants: age, sex, marital status, family income, employment status (not working, studying, working), years of study (primary, secondary, or tertiary education), the presence of comorbidities (see "Participants" section), lifestyle-related variables (such as smoking status and access to the internet), and social economic classification. Social economic classification was based on the Brazilian Market Research Association Classification[10]. Disease activity in Crohn's disease patients was assessed using the Crohn's Disease Activity Index (CDAI)[11], while disease activity in ulcerative colitis patients was based on the nine-point partial Mayo score[12]. The extent of either disease was based on the Montreal classification[13,14]. Other assessed variables included time since diagnosis, number of previous hospitalizations or surgeries, the presence of ostomy, and routine limitation in daily life (imposed by the disease). The use of the following medications was investigated: Mesalazine, azathioprine, corticosteroid, biological therapy (such as infliximab, adalimumab, or certolizumab pegol), or no medication.

### **Quality of life, anxiety and depression, and self-esteem assessments**

Quality of life was assessed using an IBD-specific questionnaire [the IBD Questionnaire (IBDQ)] and a generic questionnaire [the 36-Item Short-Form Health Survey (SF-36)] both of which have been validated in a Brazilian population[15,16]. The IBDQ comprises four domains: Bowel function, emotional status, systemic symptoms, and social function. The total achievable score of the IBDQ ranges from 32 to 224, with higher scores reflecting better quality of life[17]. The SF-36 comprises eight dimensions: physical function, physical aspects, bodily pain, general health, vitality, mental health, emotional role limitations, and social function. The total achievable score of the SF-36 ranges from 0 to 100, with higher scores reflecting more favorable health statuses[15]. Symptoms of anxiety and depression were evaluated using the Hospital Anxiety and Depression Scale (HADS), validated in Brazil [18]. The HADS consists of two subscales, of which seven items refer to anxiety and seven refer to depression. The global score for each subscale ranges from 0 to 21[18], where a score above 8 suggests probable anxiety and/or depression[18]. Self-esteem was evaluated using the Rosenberg self-esteem scale[19,20], and patients could be classified as having low ( $< 26$  points), medium (26-36 points) or high ( $> 36$  points) self-esteem.

### **Characteristics about using the IBD center**

Variables relating to the use of three parts of the IBD center (the IBD outpatient clinic, clinic hospital, and infusion center) were analyzed. Analyzed variables included a history of hospitalization or surgery in the hospital, visits to the emergency room, visits to the digestive endoscopy service department, and

the annual number of medical appointments and complementary tests (such as blood tests, X-ray exams, abdominal computed tomography, and colonoscopy) the patients had undergone. In addition, variables related to external factors that could interfere with the evaluation of QoC, such as time of travel to the IBD center, waiting time for the consultation, and stress from waiting for the medical consultation, were evaluated.

### QUOTE-IBD

The QUOTE-IBD questionnaire was specifically designed for patients with IBD. The questionnaire consists of 23 questions (10 generic and 13 IBD-specific) about the care received at the reference healthcare service provider, during the year prior to the survey[1]. The questionnaire was translated and validated into the Portuguese language in 2015[21]. The questionnaire explores three aspects of health: (1) The weight that patients assign to different dimensions of health care (Importance); (2) the facilities, operation of health services, and work of healthcare providers in these different dimensions of health care (performance); and (3) the combined effect of Importance and Performance (impact of quality). The score of the QUOTE-IBD questionnaire pertains to each of these aspects: (1) Importance (I) is rated from 0 to 10, with zero being “not important” and ten being “very important”; (2) performance (P), relates to the patient having had a positive experience with the service, with 0 indicating “yes” and 1 indicating “no”; and (3) Impact of Quality (IQ) involves the previous two aspects, according to the formula  $IQ = 10 - I \times P$ . The 23 questions that compose the questionnaire are grouped into eight health dimensions: accessibility, cost, accommodation, continuity of care, courtesy, information, competence, and autonomy [1]. Total care is based on the average score of the 23 questions. Each dimension, as well as the total care score, is classified as satisfactory (score  $\geq 9.0$ ) or unsatisfactory (score  $< 9.0$ ).

### Statistical analysis

Continuous data were expressed as mean  $\pm$  SD, and qualitative data as frequency (proportion). Chi Square and Fisher’s exact tests were used to assess associations between categorical variables among patients with Crohn’s disease or ulcerative colitis. *T*-tests were used to assess associations in continuous variables between patients with Crohn’s disease or ulcerative colitis, in addition to assessing satisfaction (according to QUOTE-IBD results) and the variables analyzed. Pearson’s correlation test was performed to assess associations between QUOTE-IBD questionnaire scores, and the clinical and psychological variables studied. Univariate logistic regression was performed to assess associations between clinical and psychological variables and patient satisfaction (according to QUOTE-IBD results). A *P* value of  $< 0.05$  was considered statistically significant. All statistical analyses were performed using SAS, version 9.4 for Windows (SAS Institute Inc., Cary, NC, United States). All authors had access to the study data. Statistical review of the study was performed by a biomedical statistician.

## RESULTS

In total, 156 outpatients were invited to the study. Of these, 15 refused to participate, four were excluded due to incomplete QUOTE-IBD questionnaire data, and four were excluded due to unconfirmed diagnoses. The study included 133 patients in the final analysis. The mean age of the patients was 37.26 years  $\pm$  13.05 years, and among these, eighty-five (63.91%) were women. More than half of the patients were employed (58.65%) and classified as having a regular or good socioeconomic classification. Socio-demographic data are available in [Table 1](#).

### Clinical characteristics of patients with Crohn’s disease and ulcerative colitis

Of the interviewed patients, 69 (51.88%) had Crohn’s disease and 64 (48.12%) had ulcerative colitis. The mean time since diagnosis (disease duration) was 8.44 years  $\pm$  7.59 years, where disease duration was higher among patients with Crohn’s disease than in those with ulcerative colitis ( $P = 0.0171$ ). According to the CDAI (62.32%) and partial Mayo (70.31%) scores, most of the patients were in disease clinical remission, despite the extensive involvement and presence of complications in these patients ([Table 2](#)). Among patients with Crohn’s disease, the most commonly used medications were azathioprine (60.87%) and infliximab (44.93%); among those with ulcerative colitis, the most commonly used medications were mesalazine (46.88%) and azathioprine (35.94%; [Table 2](#)). Most patients (93.18%) received their medication for free from the State Government’s medication-dispensing program. The frequency of previous hospitalization ( $P = 0.0132$ ) and surgery ( $P < 0.0001$ ), as well as the presence of ostomy ( $P = 0.0471$ ), was higher among patients with Crohn’s disease compared to those with ulcerative colitis ([Table 2](#)).

Patients’ quality of life, measured through the IBDQ questionnaire, was classified as good (45.45%; [Table 3](#)). Despite this, 48.87% of patients with IBD stated that IBD limits their daily routine. According to the SF-36 questionnaire, mental health ( $P = 0.0137$ ), the presence of anxiety ( $P = 0.0203$ ), and explanations surrounding the higher frequency of psychological monitoring ( $P = 0.005$ ) were more compromised in patients with ulcerative colitis compared to patients with Crohn’s disease ([Table 3](#)). Most patients presented high self-esteem (81.95%) and trust in the proposed clinical treatment (89.47%;

**Table 1 Socio-demographic and clinical characteristics of patients with inflammatory bowel disease**

	IBD (n = 133)	Crohn's disease (n = 69)	Ulcerative colitis (n = 64)	P value <sup>2</sup>
Age (yr)	37.26 ± 13.05	37.06 ± 12.75	37.48 ± 13.46	0.8515
Female gender, n (%)	85 (63.91)	38 (55.07)	47 (73.44)	0.0276
Family income (BRL)	2240.11 ± 1216.62	2.436.60 ± 1374.45	2237.12 ± 1023.55	0.3092
Marital status, n (%)				0.5349
Married	71 (53.38)	34 (49.28)	37 (27.82)	
Single	51 (38.35)	28 (40.58)	1 (1.56)	
Widowed	4 (3.00)	3 (4.35)	23 (35.94)	
Separated/Divorced	7 (5.26)	4 (5.80)	3 (4.69)	
Employment situation, n (%)				0.9394
Employed	78 (58.65)	40 (57.97)	38 (59.38)	
Unemployed	21 (15.79)	11 (15.94)	10 (15.63)	
Student	6 (4.51)	4 (5.80)	2 (3.13)	
Medical leave	5 (3.75)	2 (2.90)	3 (4.69)	
Housewife	13 (9.77)	6 (8.70)	7 (10.94)	
Retired	10 (7.52)	6 (8.70)	4 (6.25)	
Years of study, n (%)				0.5247
≤ 5	5 (3.79)	2 (2.90)	3 (4.69)	
5 < X ≤ 9	12 (9.02)	4 (4.80)	8 (12.50)	
9 < X ≤ 12	66 (49.63)	35 (50.73)	31 (48.44)	
> 12	50 (36.58)	28 (30.14)	22 (34.37)	
Social economic Stratum <sup>1</sup> , n (%)				0.4626
A	6 (4.88)	5 (7.69)	1 (1.72)	
B	66 (53.66)	34 (52.31)	32 (55.17)	
C	44 (35.77)	23 (35.38)	21 (36.21)	
D	7 (5.69)	3 (4.62)	4 (6.90)	
Comorbidities, n (%)	42 (31.58)	19 (27.54)	23 (35.94)	0.2977
Smoking, n (%)	6 (4.51)	5 (7.25)	1 (1.56)	0.0623
Alcohol use, n (%)	7 (2.27)	5 (7.35)	2 (3.13)	0.4649
Internet access, n (%)	121 (90.98)	66 (95.65)	55 (85.94)	0.0507

<sup>1</sup>Brazil Social Economic Stratum (Brazilian Market Research Association, 2015). Social economic Stratum: A (20888 BRL/mo), B1 (9254 BRL/mo), B2 (4852 BRL/mo), C1 (2705 BRL/mo), C2 (1625 BRL/mo), D (768 BRL/mo).

<sup>2</sup>P value (Crohn's disease vs ulcerative colitis).

Data are expressed as mean ± SD or frequency (proportion). IBD: Inflammatory bowel disease; BRL: Brazilian currency.

Table 3).

### Patient evaluation of the IBD center

Most of the patients reported that they had previous experience of using hospital structure, services such as colonoscopy (88.72%) and the emergency room (73.68%), and of undergoing previous hospitalization (58.65%; [Supplementary Table 1](#)). Regarding medical procedures, the average number of consultations in the IBD outpatient clinic was 4.46 ± 4.08; the average number of blood tests was 4.70 ± 3.21, for each patient; and the average number of colonoscopies was 1.42 ± 1.09 exams per year—each of these parameters showing no differences between patients with Crohn's disease and with ulcerative colitis ([Supplementary Table 1](#)). The mean travel time from patients' homes to the IBD healthcare center was 1.27 h ± 0.96 h, and the waiting time for consultations averaged 2.10 h ± 1.28 h. Due to the long waiting time period, 44.70% of patients reported that they experienced stress while waiting for their

Table 2 Clinical characteristics of patients with Crohn's disease and ulcerative colitis

	IBD (n = 133)	Crohn's disease (n = 69)	Ulcerative colitis (n = 64)	P value <sup>1</sup>
Time since diagnosis (years)	8.44 ± 7.59	9.64 ± 9.02	7.14 ± 5.45	0.0171
Disease extent, n (%)				
Proctitis			13 (20.31)	
Left-sided colitis			17 (26.56)	
Extensive/Pancolitis			34 (53.13)	
Montreal classification				
Age at diagnosis, n (%)				
A1 (< 17 years)		16 (23.19)		
A2 (17-40 years)		46 (66.67)		
A3 (> 40 years)		7 (10.14)		
Disease location, n (%)				
L1 (ileal)		16 (23.19)		
L2 (colonic)		9 (13.04)		
L3 (ileocolonic)		44 (63.77)		
Disease behavior, n (%)				
B1 (non-stricturing, non-penetrating)		24 (34.78)		
B2 (stricturing)		25 (36.23)		
B3 (penetrating)		20 (28.99)		
Perianal disease, n (%)		28 (40.58)		
Disease activity, n (%)				
Remission		43 (62.32)	45 (70.31)	
Mild		13 (18.84)	1 (1.56)	
Moderate		10 (14.49)	13 (20.31)	
Severe		3 (4.35)	5 (7.81)	
Partial Mayo score (points)			2.14 ± 2.72	
CDAI score (points)		140.63 ± 112.48		
Medications in use, n (%)				
Mesalazine	31 (23.31)	1 (1.45)	30 (46.88)	< 0.0001
Azathioprine	65 (48.87)	42 (60.87)	23 (35.94)	0.0041
Corticosteroid	9 (6.77)	3 (4.35)	6 (9.38)	0.2488
Infliximab	45 (33.83)	31 (44.93)	14 (21.88)	0.0050
Adalimumab	20 (15.04)	14 (20.29)	6 (9.38)	0.0785
Certolizumabe pegol	1 (0.75)	1 (1.45)	-	-
No medication	4 (3.01)	2 (2.90)	2 (3.13)	1.0000
Previous hospitalization, n (%)	31 (23.31)	47 (68.12)	30 (46.88)	0.0132
Number of previous hospitalizations	0.79 ± 1.24	1.02 ± 1.46	0.55 ± 0.91	0.0061
Previous surgery, n (%)	44 (33.08)	37 (53.62)	7 (10.94)	< 0.0001
Number of previous surgeries	0.56 ± 1.19	0.98 ± 1.50	0.14 ± 0.50	< 0.0001
Presence of ostomy, n (%)	14 (10.53)	11 (15.94)	3 (4.69)	0.0471

<sup>1</sup>P value (Crohn's disease vs ulcerative colitis).

Data are expressed as mean  $\pm$  SD or frequency (proportion). IBD: Inflammatory bowel disease; CDAI: Crohn's disease activity index.

**Table 3** Assessment of quality of life, anxiety and depression, and self-esteem of patients with inflammatory bowel disease

	IBD (n = 133)	Crohn's disease (n = 69)	Ulcerative colitis (n = 64)	P value <sup>2</sup>
Quality of life (IBDQ) <sup>1</sup> , n (%)				0.0469
Excellent	25 (18.94)	12 (17.65)	13 (20.31)	
Good	60 (45.45)	38 (55.88)	22 (34.38)	
Regular	32 (24.24)	14 (20.59)	18 (28.13)	
Poor	15 (11.36)	4 (5.88)	11 (17.19)	
IBDQ score (points)				
Bowel function	52.61 $\pm$ 13.62	55.21 $\pm$ 11.49	49.84 $\pm$ 15.18	0.0427
Systemic symptoms	22.17 $\pm$ 7.19	23.12 $\pm$ 7.25	21.16 $\pm$ 7.05	0.1177
Social function	26.62 $\pm$ 8.22	27.51 $\pm$ 7.67	25.67 $\pm$ 8.72	0.2653
Emotional status	58.34 $\pm$ 16.84	60.88 $\pm$ 14.96	55.64 $\pm$ 18.36	0.0737
Total score	159.73 $\pm$ 42.72	166.72 $\pm$ 38.56	152.31 $\pm$ 45.88	0.0524
SF-36 (points)				
Physical aspects	60.34 $\pm$ 42.77	64.49 $\pm$ 40.31	55.86 $\pm$ 45.15	0.5028
Physical function	72.22 $\pm$ 29.31	77.90 $\pm$ 24.78	66.09 $\pm$ 32.62	0.1216
Bodily pain	49.70 $\pm$ 8.34	50.00 $\pm$ 8.91	49.38 $\pm$ 7.74	0.6677
General health	54.66 $\pm$ 19.67	56.16 $\pm$ 19.02	53.05 $\pm$ 20.37	0.3638
Mental health	60.12 $\pm$ 22.07	64.64 $\pm$ 21.35	55.25 $\pm$ 21.95	0.0137
Vitality	52.44 $\pm$ 22.78	56.01 $\pm$ 22.86	48.59 $\pm$ 22.23	0.0602
Emotional aspects	60.15 $\pm$ 43.90	63.29 $\pm$ 42.06	56.77 $\pm$ 45.88	0.5176
Social function	47.37 $\pm$ 15.24	49.82 $\pm$ 14.46	44.73 $\pm$ 15.72	0.0538
SF-36 total score	57.13 $\pm$ 18.09	60.29 $\pm$ 17.36	53.71 $\pm$ 18.39	0.0511
Presence of anxiety, n (%)	53 (40.46)	21 (30.88)	32 (50.79)	0.0203
Presence of depression, n (%)	38 (29.01)	19 (27.94)	19 (30.16)	0.7799
Anxiolytic and antidepressant use, n (%)	31 (23.30)	12 (17.39)	19 (29.69)	0.0938
Psychological monitoring, n (%)	21 (15.79)	5 (7.25)	16 (25.0)	0.0050
Self-esteem scale, n (%)				0.5120
Low self-esteem	5 (3.76)	2 (2.90)	3 (4.69)	
Medium self-esteem	19 (14.29)	12 (17.39)	7 (10.94)	
High self-esteem	109 (81.95)	55 (79.71)	54 (84.38)	
Routine limitation by IBD, n (%)	65 (48.87)	31 (44.93)	34 (53.31)	0.3447
Trust in medical treatment, n (%)	119 (89.47)	63 (91.30)	56 (87.50)	0.4750

<sup>1</sup>n = 68 patients with Crohn's disease.

<sup>2</sup>P value (Crohn's disease vs ulcerative colitis).

Data are expressed as mean  $\pm$  SD or frequency (proportion). IBD: Inflammatory bowel disease; IBDQ: Inflammatory Bowel Disease Questionnaire; SF-36: 36-Item Short Form Survey.

appointment.

Regarding the evaluation of the IBD service, according to the QUOTE-IBD questionnaire, 51.88% of the patients rated the QoC offered by the healthcare service provider as satisfactory. A higher percentage of patients with Crohn's disease (63.77%), compared to those with ulcerative colitis (39.06%), believed that the QoC they received was satisfactory ( $P = 0.0044$ ; Table 4). Considering the average score

**Table 4** Quality of Care Through the Eyes of Patients with Inflammatory Bowel Disease questionnaire category and total care scores, and satisfaction with care in patients with inflammatory bowel disease

	IBD (n = 133)	Crohn's disease (n = 69)	Ulcerative colitis (n = 64)	P value <sup>1</sup>
Score of QUOTE-IBD categories				
Accessibility	8.31 ± 1.65	8.58 ± 1.55	8.02 ± 1.71	0.0498
Accommodation	7.83 ± 3.25	8.28 ± 2.85	7.25 ± 3.57	0.0456
Autonomy	9.37 ± 2.08	9.42 ± 1.94	9.31 ± 2.23	0.7665
Competence	8.78 ± 1.79	8.99 ± 1.69	8.56 ± 1.89	0.1734
Continuity of care	8.05 ± 2.36	8.52 ± 1.91	7.55 ± 2.69	0.0186
Courtesy	9.27 ± 1.31	9.43 ± 1.24	9.09 ± 1.37	0.1256
Cost	9.48 ± 1.93	9.64 ± 1.59	9.31 ± 2.22	0.3385
Information	8.65 ± 2.02	9.05 ± 1.63	8.22 ± 2.31	0.0189
QUOTE-IBD Total Care	8.61 ± 1.31	8.92 ± 1.16	8.27 ± 1.38	0.0042
Satisfaction according to QUOTE-IBD categories, n (%)				
Accessibility	55 (41.35)	32 (46.38)	23 (35.94)	0.2219
Accommodation	86 (64.66)	49 (71.01)	37 (57.81)	0.1115
Autonomy	121 (90.98)	63 (91.30)	58 (90.63)	0.8913
Competence	87 (65.41)	49 (71.01)	38 (59.38)	0.1585
Continuity of care	66 (49.62)	38 (55.07)	28 (43.75)	0.1919
Courtesy	97 (72.93)	55 (79.71)	42 (65.63)	0.0677
Cost	123 (92.48)	65 (94.20)	58 (90.63)	0.5203
Information	81 (60.90)	49 (71.01)	32 (50.00)	0.0131
QUOTE-IBD Total Care, n (%)	69 (51.88)	44 (63.77)	25 (39.06)	0.0044

<sup>1</sup>P value (Crohn's disease *vs* ulcerative colitis).

Data are expressed as mean ± SD or frequency (proportion). Test T and Chi Square test. QUOTE-IBD: Quality of Care Through the Eyes of Patients with Inflammatory Bowel Disease; IBD: Inflammatory bowel disease.

from the QUOTE-IBD results, autonomy-, courtesy-, and cost-related parameters were classified as satisfactory (score ≥ 9.0; **Table 4**). According to the final score (based on the average score from each question), the IBD healthcare service was (overall) classified as unsatisfactory, with a higher score among patients with Crohn's disease (8.92 ± 1.16) than in those with ulcerative colitis (8.27 ± 1.38; *P* = 0.0042; **Table 4**).

The individual score for each question in the QUOTE-IBD questionnaire is detailed in **Supplementary Table 2**. The best scores related to doctor-patient relationships were classified according to the understanding of problems by health professionals and trust in doctors, in addition to the doctor-concern regarding the patient access to medication. The lowest scores related to service structure problems (such as difficulty in contacting the team by telephone), the referral of the patient for consultation with another specialist such as the rheumatologist, and physical infrastructure (such as inadequate bathroom facilities).

In the exploratory analysis that identified variables associated with satisfaction in total care from the service, the presence of Crohn's disease (*P* = 0.0044), the use of infliximab (*P* = 0.0381), and having had previous surgery (*P* = 0.0228) were associated with greater satisfaction with the service received. The use of mesalazine (*P* = 0.0370), the presence of psychological monitoring (*P* = 0.0198), and a longer waiting time for consultation (*P* = 0.0270) were associated with lower satisfaction with the service received (**Supplementary Table 3**). No associations between variables relating to quality of life, anxiety, depression, or self-esteem and satisfaction with the total care (based on QUOTE-IBD results) were found (**Supplementary Table 3**).

From Pearson's correlation tests, a positive association between total QUOTE-IBD score and the use of infliximab (*r* = 0.2223; *P* = 0.0101) was observed, and a negative association with waiting time for consultation (*R* = -0.267; *P* = 0.004) and the presence of ulcerative colitis (*R* = -0.2467; *P* = 0.0042) was found (**Table 5**).

**Table 5 Clinical-, quality of life-, and psychological-related variables and Quality of Care Through the Eyes of Patients with Inflammatory Bowel Disease total care in patients with inflammatory bowel disease**

	Correlation co-efficient (R)	P value
Age (yr)	-0.0080	0.9240
Female gender	0.1647	0.0581
Family income (BRL) <sup>1</sup>	-0.0060	0.9480
Time since diagnosis (yr)	0.0770	0.3760
Disease (ulcerative colitis <i>vs</i> Crohn's disease)	-0.2467	0.0042
CDAI (points)	-0.0320	0.7920
Partial Mayo score (points)	-0.0630	0.6200
Disease activity (no <i>vs</i> yes)	-0.0284	0.7454
Medication in use (no <i>vs</i> yes)		
Mesalazine	-0.1702	0.0501
Azathioprine	0.1032	0.2369
Corticosteroid	-0.0567	0.5169
Infliximab	0.2223	0.0101
Adalimumab	-0.0223	0.7988
Certolizumab	0.02904	0.7400
Previous hospitalization (no <i>vs</i> yes)	0.1364	0.1172
Previous surgery (no <i>vs</i> yes)	0.1179	0.1762
Psychological monitoring (no <i>vs</i> yes)	-0.0294	0.7366
Infusion center consultation	0.1577	0.0698
Time of travel to the IBD center (h)	0.0090	0.9190
Waiting time for consultation (h)	-0.2670	0.0040
IBDQ score (points)		
Bowel function	0.0790	0.3660
Systemic symptoms	0.1560	0.0740
Social function	0.0020	0.9820
Emotional status	0.0200	0.8220
Total score	0.0600	0.4970
SF-36 Questionnaire (points)		
Physical aspects	0.0980	0.2620
Physical function	0.0830	0.3430
Bodily pain	-0.0630	0.4700
General health	-0.0020	0.9840
Mental health	0.0760	0.3840
Vitality	0.1040	0.2340
Emotional aspects	0.1200	0.1700
Social function	-0.0200	0.8190
Total score	0.1040	0.2340
HADS Anxiety (points)	-0.0750	0.3930
HADS Depression (points)	-0.0600	0.4990
Self-esteem scale (points)	0.0820	0.3490

<sup>1</sup>BRL: Brazilian currency.

Correlation co-efficient (R) values determined *via* Pearson's correlation test. QUOTE-IBD: Quality of Care Through the Eyes of Patients with Inflammatory Bowel Disease; CDAI: Crohn's Disease Activity Index; IBDQ: Inflammatory bowel disease questionnaire; SF-36: 36-Item Short-Form Health Survey; HADS: Hospital Anxiety and Depression Scale.

According to univariate logistic regression analyses, patients with Crohn's disease reported higher satisfaction rates than those with ulcerative colitis [odds ratio (OR): 2.746; 95% confidence interval (CI): 1.360-5.541;  $P = 0.0048$ ] and patients using infliximab (OR: 2.175; 95%CI: 1.037-4.562;  $P = 0.0398$ ; **Table 6**). Regarding variables related to the IBD service, patients who previously had surgery at the same service provider reported higher satisfaction rates (OR: 2.368; 95%CI: 1.118 -5.015;  $P = 0.0243$ ), while long waiting times for consultation (OR: 0.713; 95%CI: 0.525-0.969;  $P = 0.0370$ ) and the stress experienced while waiting for the consultation (OR: 0.485; 95%CI: 0.241-0.973;  $P = 0.0418$ ) produced lower satisfaction rates (**Table 6**). In the evaluation between quality of life and psychological variables, an association between systemic IBDQ score and QUOTE-IBD-related satisfaction was found (OR: 1.069; 95%CI: 1.016-1.125;  $P = 0.0097$ ), indicating that greater satisfaction with the service was associated with better quality of life for the patient (**Table 6**). Disease activity was not associated with satisfaction with the care received at the IBD healthcare center.

## DISCUSSION

Increasing evidence shows that satisfaction with the QoC provided by a healthcare service is an important aspect in improving patient adherence to treatment and effectiveness of treatment[22]. Improvements in these variables directly impacts reduction of treatment costs, improvement of patient care, and the implementation of the best practices for IBD management, producing better IBD outcomes [8,23,24]. The present study aimed to evaluate the QoC provided by a single public IBD healthcare center, using the QUOTE-IBD questionnaire. As per QUOTE-IBD results, the best scores were related to doctor-patient relationships (based on the understanding of problems by health professionals, trust in the doctor, and doctor-concern regarding the patient access to medication. Moreover, patients with Crohn's disease had higher satisfaction rates than those with ulcerative colitis, as patients with Crohn's disease had more frequent contact with their healthcare service providers.

The QUOTE-IBD questionnaire was proposed in 2001, by van der Eijk *et al*[1]. The QUOTE-IBD questionnaire aims to represent the opinion of IBD patients on the quality of health care provided by a particular healthcare service, comprising several dimensions related to the treatment received and conditions of care. According to our results, the main strengths of the healthcare service in question were related to cost, autonomy, and courtesy (based on QUOTE-IBD questionnaire results). Satisfaction with cost is explained by providing a public service and free supply of medication (by the national health system) to patients. In addition, the application of infusion medications is carried out in the infusion center of the hospital, facilitating the patient's adherence to treatment. Autonomy and courtesy relate to health professionals considering patient opinions (regarding their treatment) and empowerment. The care provided by the multidisciplinary team facilitates doctor-patient relationships and subsidizes this relationship in being healthy and bidirectional, encouraging the patient's participation in decision-making. Multidisciplinary care allows for a holistic approach to patient treatment and integrates various areas involved in treatment, such as the clinic involved, surgery, psychology, nursing, and nutrition.

Despite satisfaction with the cost of treatment, since the center forms part of a public health service, problems with access to some medications is apparent-especially those relating to biological therapy. When this study was conducted, anti-TNFs and vedolizumab therapy were not available for patients with ulcerative colitis. Additionally, thus far, the public services of the center did not have access to new biologics (such as vedolizumab and ustekinumab) for patients with Crohn's disease. Problems with access to certain medications explain the favorable scores relating to doctors' concerns with patients' access to medication.

Patients with Crohn's disease had higher scores on the QUOTE-IBD questionnaire compared to those with ulcerative colitis. This observation was likely due to the fact that patients with Crohn's disease had more frequent and intense contact with the healthcare service providers, which could be explained by the higher frequency of complications arising from the disease, the need for hospitalization and surgeries, and the use of infusion biological therapy (such as infliximab, which is applied in the center itself).

QUOTE-IBD categories yielding unsatisfactory scores included those relating to accommodation, continuity of care, accessibility, information, and competence, reflecting issues regarding infrastructure and service overload. It is worth noting that the evaluated healthcare service provider serves a population of approximately two million people, from 68 cities in the region. The institution thus faces obstacles relating to a large volume of patients, lack of human resources, lack of adequate patient

**Table 6 Univariate logistic regression between clinical-, quality of life-, and psychological-related variables and satisfaction with care (according to Quality of Care Through the Eyes of Patients with Inflammatory Bowel Disease results) in patients with inflammatory bowel disease**

	Odds Ratio	95% Confidence Interval	P value
Age (yr)	0.997	0.971-1.024	0.8292
Gender (female <i>vs</i> male)	0.582	0.284-1.195	0.1402
Family income (BRL)	1.000	1.000-1.000	0.7521
Time since diagnosis (years)	1.061	0.971-1.064	0.4914
Crohn's <i>vs</i> ulcerative colitis	2.746	1.360-5.541	0.0048
CDAI (points)	0.999	0.995-1.004	0.7725
Partial Mayo score (points)	0.941	0.777-1.141	0.5375
Disease activity (yes <i>vs</i> no)	0.834	0.407-1.713	0.6216
Medication in use (yes <i>vs</i> no)			
Mesalazine	0.417	0.181-0.960	0.0399
Azathioprine	1.487	0.750-2.946	0.2559
Corticosteroid	0.439	0.105-1.836	0.2598
Infliximab	2.175	1.037-4.562	0.0398
Adalimumab	1.159	0.446-3.012	0.7620
Previous hospitalization (yes <i>vs</i> no)	1.653	0.826-3.309	0.1555
Previous surgery (yes <i>vs</i> no)	2.368	1.118-5.015	0.0243
Psychological monitoring (yes <i>vs</i> no)	0.311	0.112-0.861	0.0245
Infusion center consultation (yes <i>vs</i> no)	1.643	0.793-3.404	0.1817
Time of travel to the IBD center (hours)	0.996	0.687-1.444	0.9822
Waiting time for consultation (hours)	0.713	0.525-0.969	0.0370
Stress while waiting for consultation (yes <i>vs</i> no)	0.485	0.241-0.973	0.0418
IBDQ score (points)			
Bowel function	1.018	0.992-1.044	0.1814
Systemic symptoms	1.069	1.016-1.125	0.0097
Social function	1.024	0.982-1.068	0.2635
Emotional status	1.016	0.995-1.037	0.1435
Total score	1.007	0.999-1.015	0.0980
SF-36 Questionnaire (points)			
Physical aspects	1.007	0.999-1.016	0.0770
Physical function	1.010	0.998-1.022	0.1094
Bodily pain	1.005	0.964-1.047	0.8225
General health	1.001	0.984-1.019	0.8709
Mental health	1.012	0.997-1.028	0.1249
Vitality	1.012	0.996-1.027	0.1358
Emotional aspects	1.008	1.000-1.016	0.0569
Social function	0.998	0.975-1.020	0.8334
Total score	1.019	0.999-1.039	0.0572
Anxiety (yes <i>vs</i> no)	0.765	0.380-1.540	0.4535
HADS Anxiety (points)	0.939	0.873-1.009	0.0881

Depression (yes vs no)	1.087	0.511-2.315	0.8279
HADS Depression (points)	0.966	0.898-1.039	0.3501
Self-esteem scale (points)	1.024	0.991-1.059	0.1583

QUOTE-IBD: Quality of Care Through the Eyes of Patients with Inflammatory Bowel Disease; CDAI: Crohn's Disease Activity Index; IBDQ: Inflammatory bowel disease questionnaire; SF-36: Medical Outcomes Study 36-Item Short-Form Health Survey; HADS: Hospital anxiety and depression scale.

assessment structures (such as complementary exams) and inpatient beds, and a lack of specialized personnel. It is worth noting that the situation of the healthcare institution worsened after the onset of the pandemic, since patients affected by SARS-CoV-2 were prioritized over patients with other diseases. As a result, we observed a reduction in the number of outpatient visits, as well as restricted access to complementary exams (such as endoscopic and radiological exams). The situation is expected to normalize after gaining control of the pandemic, re-establishing care for patients with IBD and restructuring the hospital to provide the quality care that patients are entitled to receive. In places dealing with the pandemic, some adaptations can maintain QoC for patients with IBD. These adaptations include the use of telemedicine, maintenance of infusion centers (relocated to covid-free areas), implementation of drug home delivery, education of patients, and IBD networking (as successfully experienced by the IBD team at the Humanitas Clinical and Research Center (Rozzano, Milan, Italy)[25].

Long travel times to the service center and the stress generated by lengthy waiting times for appointments were aspects that negatively interfered with patient satisfaction with the service. Despite being well-structured and able to offer complete and quality treatment, the hospital has public funding, limiting its capacity to serve a large population. Policies to expand the service and invest in trained human resources in the area must be implemented to improve aspects of the center that contribute to patient dissatisfaction.

Surprisingly, there was no association between disease activity and the care received at the IBD healthcare center. Patients with no control of the inflammatory process tended to negatively evaluate the care received. One of the explanations might be that patients with disease activity were monitored more closely with consultations every 14 d, thus increasing patient care and providing greater contact with the multidisciplinary team. Another explanation could be that disease activity was based on clinical scores, such as the CDAI and nine-point partial Mayo score, since the endoscopic assessment of disease activity was not available for all patients and fecal calprotectin assessment is not available in the public services in Brazil. Considering that clinical scores are not the best measures for evaluating disease activity, some patients could have been mistakenly classified as clinically active while the symptoms presented were related to other factors such as irritable bowel syndrome. Regarding the association between the use of mesalazine and lower satisfaction with the service, we hypothesized that most of the patients prescribed mesalazine had ulcerative colitis, which would explain the lower satisfaction with the service when compared to patients who did not use the medication.

Regarding other studies that explore the quality of IBD care, IBD2020 was a global forum for the discussion of standards of care for IBD patients, involving the participation of professionals and patients [26]. Overall, from 2013 to 2014, 7507 patients from Canada and Europe were surveyed about disease characteristics of IBD, its impact on their life and work, access to a multidisciplinary team, and perceived QoC. Half the respondents rated their care as excellent or very good, and five factors were associated with perceived overall QoC. Three factors were directly associated with excellent or very good QoC (including the quality of specialist communication, adequate length of review consultations, and speed at which advice was provided by a healthcare professional in the case of an IBD flare-up), and two factors were indirectly associated with worse QoC (including failure to share past information about the disease and no access to a dietician). The most important driver of QoC, as per the patients' perspectives, was communication with their healthcare provider, even though only half of the patients (50.9%) described communication with their healthcare provider as being excellent or very good. In contrast with this result, most of our patients were satisfied with the communication received from the multidisciplinary team, with this aspect being deemed as one of the strengths of the examined healthcare service provider.

The QUOTE-IBD questionnaire[1] was the first questionnaire to assess the QoC provided by an IBD healthcare center, and has been validated in other languages, such as Portuguese[21], Spanish[27], Germany[28], and Greek[29]. Despite the questionnaire being long to complete (inducing respondent fatigue), it proves to be an adequate and efficient tool for detecting the demands and deficiencies of the healthcare service in question, thus making it a tool that can potentially improve quality of life for patients with IBD. An example of this improvement is observed in the patients with Crohn's disease from this study. Despite the greater psychological and clinical risks associated with Crohn's disease, patients with Crohn's disease reported greater satisfaction rates regarding QoC offered by the center—especially related to the aspects of doctor-patient relationships. Presently, other questionnaires that assess patient-directed care are available in the literature, and these include tools such as the WE-CARE IBD (validated in 2021)[6] and the IQCARO QoC Decalogue (developed in 2020)[7].

Regarding services assessment, a recently published article established indicators for QoC in IBD centers through IBD Quality Care Evaluation Center (IBDQCC)[30], in China. The committee has developed structure, process, and outcome indicators based on 28 core and 13 sary indicators such as facilities for diagnosis and evaluation of disease, diagnosis and treatment, follow-up, quality of life, and patients' perspective. The services are classified as regional IBD units or IBD units of excellence, showing the importance of stratifying the IBD centers to promote gradual improvement.

Our study had some limitations. Evaluations were done in only a single center in Brazil, and thus our findings do not represent the real situation of the national service offered to Brazilian patients with IBD. Despite this limitation, this is the first study that has evaluated the care offered to patients with IBD in Brazil and Latin America. Aiming for national data, we are expanding the study and conducting a survey with the same theme, but with national coverage (*via* social media), encompassing both the public and private spheres-at all levels of care. Thus, we hope that this new stage of the project better reflects the QoC given to Brazilian patients with IBD and allows us to identify points that must be improved for the comprehensive and humanized care that patients with IBD require. A limited number of parameters were used to determine the quality of the service in our study. Other parameters that could be used include; the composition of the IBD team, degree of knowledge, and qualification of the team, as well as the efficacy of the treatment, rates of complications, and surgeries as outcomes. However, the evaluation of these parameters is beyond the objective of the current article, and future studies in the care provided to patients with IBD should further explore these measures.

## CONCLUSION

The assessment of the quality of service given by a healthcare service provider, based on patient perspectives, is an important tool in identifying deficiencies that can interfere with the effectiveness and cost of the treatment that is offered. Positive aspects of the service provided by the IBD center included good healthcare team-patient relationships and concern for the holistic care of IBD patients. Negative aspects of the service included lack of investment in the structure of the service and in human resources. Our results should encourage the development of public policies to create better care strategies, to improve the care given to IBD patients, their quality of life, and outcomes of their disease.

## ARTICLE HIGHLIGHTS

### **Research background**

Crohn's disease and ulcerative colitis are immune-mediated diseases that compromises the patient's quality of life. Quality of care (QoC) is of paramount importance to ensure adherence to medical treatment and to achieve treatment success.

### **Research motivation**

QoC assessment is a useful tool to detect the positive and negative aspects of the care provided, providing improvements in the quality of the center. Quality metrics are important for standardizing practice in inflammatory bowel disease (IBD) centers.

### **Research objectives**

The aim of the present study was to assess patients' self-reported QoC, using the QoC Through the Eyes of Patients with IBD (QUOTE-IBD) questionnaire, in a public Brazilian IBD reference center.

### **Research methods**

An observational study was conducted, with the inclusion of 133 patients with IBD. Clinical evaluations assessed disease activity, medication in use, quality of life, and presence of anxiety and depression.

### **Research results**

According to the QUOTE-IBD questionnaire, 51.88% of the patients rated the QoC offered by the IBD center as satisfactory. The best scores were related with categories such as autonomy, courtesy and cost (of treatment). The categories with the lowest scores were accommodation, continuity of care and accessibility. Patients with Crohn's disease had higher satisfaction rates compared to patients with ulcerative colitis, showing that greater contact with the team conveys security and a greater feeling of welcoming to the patient.

### **Research conclusions**

This is the first study that evaluated the care offered to patients with IBD in Brazil and Latin America. Future studies exploring this issue should be encouraged. Other parameters can be included in this

assessment, such as the composition of the IBD team, the presence of a multidisciplinary team, the qualification of the team, as well as data regarding the effectiveness of the treatment, rates of complications and surgeries, and measures of disease outcomes.

### Research perspectives

The assessment of the QoC provided by a service provider is essential to improvements in this area. Future studies in the care provided to patients with IBD should be encouraged.

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## FOOTNOTES

**Author contributions:** Takamune DM, Cury GSA, Ferrás G, Herrerias GSP, Rivera A, Barros JR, Baima JP, Saad-Hossne R, and Sasaki LY contributed to the conception and design of the study, the acquisition, analysis and interpretation of data, drafting the article, and revising it critically for important intellectual content and approving the final version to be submitted; Rivera A had substantial contributions to interpretation of data, revising it critically for important intellectual content and final approval of the version.

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