



ARTÍCULO ORIGINAL

Perceived quality of life using IMPACT-III in a sample of Colombian children with IBD in remission: a cross-sectional study

Percepción de la calidad de vida mediante el IMPACT-III en una muestra de niños colombianos con EII en remisión: un estudio transversal

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ABSTRACT

Introduction: No data on quality of life (QoL) in paediatric IBD in Colombia. The aim of this study was to determine QoL using the IMPACT-III questionnaire in a sample of patients from different centres. **Materials and methods:** Cross-sectional study of paediatric IBD patients followed in 3 centres in different cities, between June and November 2022. Eligible subjects were identified, information was collected on different dates, and the IMPACT-III questionnaire (score ranges from 35 to 175, with higher scores indicating better QoL) was administered once. **Results:** 33 patients were included. 23/33 (69.7%) female, mean age 14.9 (range 6-17.9) years. 94% with inactive or mild disease. 20 patients with ulcerative colitis (UC), 13 with Crohn's disease (CD). The median score in UC was 147 (122-152), while in CD it was 126 (105-135). Systemic symptoms and emotional functioning were most affected, with median scores of 13 (12-14) and 27 (20-31) in UC and 11 (9-11) and 23 (20-26) in CD. No statistically significant differences were observed. **Conclusions:** The quality of life of children with IBD is challenging due to several factors. More support and education is needed for these patients.

Keywords: Inflammatory Bowel Diseases; Colitis, Ulcerative; Crohn Disease; Quality of Life; Surveys and Questionnaires (source: MeSH NLM).

RESUMEN

Introducción: No existen datos sobre la calidad de vida (CdV) en niños con enfermedad inflamatoria intestinal (EII) en Colombia. El objetivo de este estudio fue determinar la CdV utilizando el cuestionario IMPACT-III en una muestra de pacientes de diferentes centros. **Materiales y métodos:** Estudio transversal en pacientes pediátricos con EII atendidos en tres centros de diferentes ciudades, entre junio y noviembre de 2022. Se identificaron los sujetos elegibles, se recopiló información en diferentes fechas y se aplicó el cuestionario IMPACT-III (puntaje de 35 a 175, donde puntuaciones más altas indican mejor CdV) una sola vez. **Resultados:** Se incluyeron 33 pacientes. 23/33 (69,7%) eran mujeres, con una edad promedio de 14,9 años (rango 6-17,9 años). El 94% presentaba enfermedad inactiva o leve. Veinte pacientes tenían colitis ulcerosa (CU) y 13 enfermedad de Crohn (EC). La mediana del puntaje en CU fue de 147 (122-152), mientras que en EC fue de 126 (105-135). Los síntomas sistémicos y el funcionamiento emocional fueron los más afectados, con medianas de 13 (12-14) y 27 (20-31) en CU, y 11 (9-11) y 23 (20-26) en EC. No se observaron diferencias estadísticamente significativas. **Conclusiones:** La calidad de vida de los niños con EII es un desafío debido a múltiples factores. Se requiere mayor apoyo y educación para estos pacientes.

Palabras clave: Enfermedades Inflamatorias del Intestino; Colitis Ulcerosa; Enfermedad de Crohn; Calidad de Vida; Encuestas y Cuestionarios (fuente: DeCS Bireme).



INTRODUCTION

Inflammatory bowel disease (IBD) is a systemic chronic autoimmune inflammatory condition, with the digestive tract as its main target organ, and between 20%-30% of cases presenting during childhood or adolescence ⁽¹⁾. It affects life's various aspects including physical, mental, familiar and social. Gastrointestinal symptoms and extraintestinal manifestations have a negative impact on quality of life (QoL), and lead to increased likelihood of stunted growth, delayed puberty, surgical interventions, frequent hospitalizations, and low self-esteem ⁽²⁻⁴⁾. All of these complications affect QoL, and evaluating it is critical to measure the impact of these chronic diseases by focusing on individual functioning ⁽⁵⁾.

IMPACT-III is a validated questionnaire to assess QoL in children with IBD, being a self-reported questionnaire for patients aged 9 to 17 years, specific to the disease, and is currently the standard tool to assess QoL in children with IBD ⁽⁶⁾. The original version was prepared by expert opinion ⁽⁷⁾, based on the adaptation of a version of a QoL questionnaire specifically for adults with IBD ⁽⁸⁾, and since then, this questionnaire has been evaluated in studies in different regions simplifying the use of words and modifying the analogous scales by a Likert scale ^(9,10). The current IMPACT-III questionnaire comprises 35 items, and its use is proposed for cross-cultural adaptation to assess QoL in pediatric patients through six domains: gastrointestinal symptoms, systemic, emotional and social function, body image and treatment/interventions ^(6,10,11).

The incidence of childhood IBD is increasing rapidly in Latin America, with potential epidemiological and clinical implications, and for which new information is still being learned ⁽¹²⁻¹⁴⁾. In Colombia, the clinical and therapeutic characteristics of pediatric patients with IBD are being just described ^(15,16). In a recent report of the Colombian Registry of IBD in children and adolescents which is in editing process (C), 209 patients are included with 53.06% with typical UC, 26.53% with CD, 9.18% with unclassifiable IBD, 5.61% to colonic CD and the same percentage for atypical UC. 13.4% of these patients present extraintestinal manifestations. No studies evaluating QoL have been carried out in Colombia. The main objective of this study is to determine the perception of QoL through the IMPACT-III questionnaire, as well as identifying the most compromised domains in children and adolescents with IBD in Colombia, based on information collected from a sample of pediatric patients diagnosed with IBD.

MATERIALS AND METHODS

Study design and data extraction

A cross-sectional study, by convenience sampling, was conducted from June 2022 to November 2022 with a target population of pediatric patients diagnosed with IBD followed in three IBD reference centers of Gastroenterology

and Coloproctology, in different cities of Colombia. These centers are linked to FUNEICO (Colombian Foundation of Inflammatory Bowel Disease), a non-profit organization of mixed origin, founded in 2019, which seeks to raise awareness of inflammatory bowel disease (IBD), provide help to patients with IBD and their families and find solutions for comprehensive treatment, provide resources to medical professionals and health institutions and increase detection, knowledge and treatment coverage of IBD. The participating institutions were Hospital Internacional de Colombia in Bucaramanga, Clínica GastroKids SAS in Pereira, and Hospital de La Misericordia in Bogotá, being the main institutions for pediatric IBD management in the country, with 75 patients under active follow-up.

Inclusion criteria: Patients from 0 to 18 years old, whose parents / guardians consented to participate in the study and assent obtained from the minors, with communication ability in Spanish and having an official diagnosis of IBD in clinical remission confirmed by disease activity index. For patients with UC using the Pediatric Ulcerative Colitis Activity Index (PUCAI) score ⁽¹⁷⁾ which defines clinical remission as a total score of 2 or less in all individual categories, and, for CD, the Pediatric Crohn's Disease Activity Index (PCDAI) ⁽¹⁸⁾ which defines clinical remission as a score of less than 10 points.

Patients with a history of cognitive delay, and subjects unable to complete the questionnaire, were excluded.

Patients with indeterminate colitis were included since they share symptomatology and clinical presentations with patients with a specific diagnosis. Required information on eligible patients included date of birth, age at time of survey, gender, and confirmed active clinical follow-up at each study institution.

Treating physicians identified eligible patients by medical judgment. Evaluation was carried out in person in the office and by virtual consultation. An investigator, the parent or caregiver, and the patient were always present. The children were instructed to answer the questionnaire, and any questions were resolved immediately. It should be mentioned that the IMPACT-III questionnaire has not yet been validated in Spanish, so there is no history about previous experience of its use in this language.

Questionnaire

The IMPACT-III questionnaire was used ⁽⁷⁾. This is a questionnaire that consists of 35 items, covering 6 proposed domains: Intestinal symptoms (7 items), Systemic symptoms (3 items), Social functioning (12 items), Body image (3 items), Treatment / Interventions (3 items) and Emotional functioning (7 items). The answers are on the Likert scale of 1 (worst case) to 5 (best case), the result ranges from 35 to 175, and higher scores indicate better quality of life ⁽⁷⁾. The questionnaire also includes an open-ended question in which participants are asked to comment on anything

else they consider important. As the questionnaire had not been used before in Colombia, a cross-cultural adaptation was necessary. This adaptation was made to ensure the validity of the content of the questionnaire. A direct and reverse translation of experts and the cognitive report was performed according to Beaton *et al.* ⁽¹⁹⁾ with paraphrasing to determine understanding of each question and group of answers, and interpretation according to as intended. After receiving approval of the translation process, the IMPACT-III questionnaire was used.

At the time of application of the questionnaire, the clinical and demographic history were verified. This information was corroborated by at least two researchers in the medical records of each of the participating institutions.

Data collection

Over a period of six months, information was collected on different dates at the various institutions included in the study. The medical records and the questionnaire applied were used as the primary source of information. Sociodemographic and clinical variables were collected, including current age, type of IBD, and date of diagnosis. Also, type of pharmacological treatment, related surgeries, presence of extraintestinal manifestations, and hospitalization requirement in the last year, educational level, and living arrangements.

Definitions

To measure the scores obtained in the questionnaire, the Likert psychometric scale was used ⁽²⁰⁾. To obtain a measure of the overall QoL, a total score was calculated by adding the 35 items. The range of the score was 35 to 175, and, the higher the score, the higher the quality of life. Similarly, a score was obtained in each of the domains that were evaluated in the questionnaire, which include Intestinal symptoms (7 items), Systemic symptoms (3 items), social functioning (12 items), body image (3 items), Treatment/Interventions (3 items) and Emotional functioning (7 items). Each of these domains had a specific number of questions, giving them a score from 1 to 5. Digestive symptoms are assigned 7 questions, and therefore, score ranged from 7 to 35 points. Systemic symptoms domain included 3 questions with a score range from 3 to 15. Social functioning domain had 12 questions with possible scores ranging from 12 to 60 points. Body image domain included 3 questions with a range in scores from 3 to 15. Treatment/ interventions domain included 3 questions giving a range of scores between 3 and 15. Finally, the emotional domain had 7 items and scores ranged between 7 and 35 points. Pediatric age groups were defined according to national legislation, as follows: Infant as those under 2 years, preschool as those subjects aged 2 to 5 years, school as 6 to 11 years, and adolescent from 12 years to 18 years. BMI was also calculated and adjusted according to age and sex. Also, time since diagnosis was documented and categorized into periods: ≥ 5 years, 1-5 years, and < 1 year.

Statistical analysis

The database was developed in Excel version 2019. Confidentiality of information was guaranteed, and no records contained sensitive information about patient identities. Revision of data completed by three different investigators. Information processing was carried out in the social science program SPSS version 26.0. For the descriptive analysis of quantitative variables, arithmetic mean, median, minimum, maximum, interquartile range and standard deviation were used. For qualitative variables, absolute and relative frequencies were used. The statistical evaluation of the data was based on the Chi-square test and Fisher's test for proportions, and non-parametric mean comparison tests. Univariate analysis was performed to explore the relationship between IMPACT-III scores and sociodemographic and clinical variables. In all tests, the significance level of 0.05 was used.

Ethical considerations

This research was reviewed and approved by the Research Ethics Committee of each participating institution. The study was initially proposed and was approved by the research ethics committee of the International Hospital of Colombia, under file number CEI-2024-06800. In its design, the requirements established in the Declaration of Helsinki, version 2013, in Fortaleza, Brazil ⁽²¹⁾ and resolution 8430 of 1993 of the National Ministry of Health of Colombia ⁽²²⁾ were considered, deeming this a risk-free investigation. Confidentiality of the information collected was guaranteed. Informed consent was obtained from participants' caregivers or assent from participants, supervised by their parents or caregivers.

RESULTS

Clinical and demographic characteristics

35 patients were invited to respond, of whom 33 answered the questionnaire, with a response rate of 94.3%. We included 33 pediatric patients, predominantly women (60.6%), with a mean age of 14.9 years (SD 3.4), with a minimum age of 6 years and a maximum age of 17.9 years. Predominantly with disease remission or mild stage (94%). Regarding the type of IBD, UC predominated, with a UC:CD ratio of 2:1 cases. Mean age of diagnosis of CD was later but with no significant difference ($p=0.063$). (Table 1) The mean time elapsed since diagnosis of the disease was 5.1 (range 1-15; OF 4.1) years. 75.8% of subjects had previous exposure to biological or small molecule therapy, and the frequency of surgical history for IBD, extraintestinal manifestations, and hospitalization requirement in the last year was 18.2%, 15.2%, and 6.1%, respectively (Table 1). Also, most of the participants came from urban areas, and were in high school. The median IMPACT-III score was lower in subjects with CD compared to UC.

Table 1. Clinical and sociodemographic characteristics of patients included in the study.

	UC (n=20)	CD (n=13)	Total (n=33)
Age median (SD)	14.37 (4.12)	15.59 (1.55)	14.85 (3.36)
Years since diagnosis (SD)	5.57 (4.15)	4.36 (4.05)	5.1 (4.1)
Median Z-score for BMI for age (SD)	16.75 (3.8)	15.74 (2.5)	16.34 (2.34)
Median Z-score for weight/ height (SD)	0.15 (1.2)	1.36 (2.68)	0.62 (1.97)
BMI average (SD)	18.54 (3.72)	18.51 (3.9)	18.53 (3.73)
Sex			
Male, n (%)	5 (25)	5 (38.46)	10 (30.3)
Female, n (%)	15 (75)	8 (61.5)	23 (69.69)
Clinical history			
Presence of anemia, n (%)	1 (5)	4 (30.7)	5 (15.15)
Use of biologic/ small molecule, n (%)	13 (92.3)	12 (92.3)	25 (75.6)
Hx of surgery for IBD, n (%)	2 (30.7)	4 (30.7)	6 (18.2)
Extraintestinal manifestations, n (%)	1 (5)	4 (30.7)	5 (15.15)
Hx of hospital admission last 12 mo, n (%)	0	2 (15.4)	2 (6)
Hx of perianal disease, n (%)	0	3 (23)	3 (9)
Hx of stenosing disease, n (%)	0	2 (15.4)	2 (6)
Hx of fistulizing disease, n (%)	0	3 (23)	3 (9)
Disease activity			
Inactive, n (%)	18 (90)	6 (46.15)	24 (72.7)
Mild, n (%)	2 (38.4)	5 (38.5)	7 (21.2)
Moderate, n (%)	0	1 (7.7)	1 (3.3)
Severe, n (%)	0	1 (7.7)	1 (3.3)
Current therapy			
Corticosteroids, n (%)	7 (35)	8 (61.5)	15 (45.5)
5-ASA, n (%)	18 (90)	5 (38.46)	23 (69.7)
Azathioprine, n (%)	12 (60)	11 (84.6)	23 (69.7)
Methotrexate, n (%)	0	1 (7.7)	1 (3)
Biologics, n (%)	13 (65)	12 (92.3)	25 (75.8)
Previous therapy			
Corticosteroids, n (%)	18 (84.6)	11 (84.6)	29 (87.8)
5-ASA, n (%)	13 (65)	1 (7.7)	14 (42.4)
Azathioprine, n (%)	11 (55)	13 (100)	24 (72.7)
Methotrexate, n (%)	2 (10)	0	2 (6)
Biologics, n (%)	7 (35)	8 (61.5)	15 (45.4)
Surgery			
None	0	1 (7.6)	1 (3)
Resection	0	1 (7.6)	1 (3)
Colostomy	0	1 (7.6)	1 (3)
Proctocolectomy	1 (5)	1 (7.6)	2 (6)
Socioeconomic background			
Educational level			
High school, n (%)	15 (75)	11 (84.6)	26 (78.8)
Elementary school, n (%)	5 (25)	2 (15.38)	7 (21.2)
Residency			
Rural, n (%)	2 (10)	3 (23.1)	5 (15.15)
Urban, n (%)	18 (90)	10 (76.9)	28 (84.8)
Total score			
IMPACT-III, median score (RIQ)	147 (122-152)	126 (105-135)	130 (107-149)

Table 2. Descriptive statistics of the six domains according to IMPACT-III according to IBD type.

Domain according to IMPACT-III	Type of IBD	IMPACT-III scores			
		Minimum value	Maximum value	Media (DE)	Median (RIQ)
Systemic symptoms	UC	3	15	12 (3)	13 (12-14)
	EC	6	14	10 (2)	11 (9-11)
Intestinal symptoms	UC	10	35	26 (7)	28 (24-31)
	EC	9	29	22 (7)	26 (17-27)
Emotional functioning	UC	11	35	25 (7)	27 (20-31)
	EC	10	32	22 (6)	23 (20-26)
Social functioning	UC	33	56	48 (7)	50 (44-54)
	EC	21	51	43 (8)	44 (40-49)
Treatment / intervention	UC	4	15	11 (3)	11 (9-14)
	EC	4	14	10 (4)	11 (7-13)
Body image	UC	5	15	12 (2)	12 (11-14)
	EC	4	15	10 (3)	11 (8-12)

UC: ulcerative colitis. SD: standard deviation. CD: Crohn's disease. IBD: inflammatory bowel disease. N: number. RIQ: interquartile range.

Perception of quality of life

When evaluating the statistics according to domains according to type of IBD (Table 2) and considering that the IMPACT-III scores did not follow normal distribution, analysis was carried out using non-parametric mean comparison tests. All domains evaluated in IMPACT-III were more affected in CD compared to UC, and those less compromised were the domains of treatment / intervention and social functioning. The most affected domains were systemic symptoms and emotional functioning.

Relationship between the characteristics of patients with inflammatory bowel disease and the total score of the IMPACT-III questionnaire

In the univariate analysis of clinical and socio-demographic variables in the different categories, characteristics with greater impact in QoL observed were male gender, duration of the disease between 1 to 5 years, history of perianal involvement, fistulizing or stenotic disease, history of surgery for IBD, hospitalization in the last 12 months for IBD and severe disease activity (Table 3). No statistically significant differences were found in clinical or sociodemographic variables. Considering the sample size of the study, the methodological design and the absence of statistically significant associations in the univariate analysis, multivariate analysis was not performed.

DISCUSSION

This is the first study to describe the perception of QoL in a sample of Colombian patients under 18 years of age with IBD. Information about pediatric IBD in Latin American countries is of special interest because data is scarce. To date, there are no population studies illustrating its epidemiological behavior in Colombia, and the information is merely descriptive with no information on QoL in this population. The strength of this study is the heterogeneous population sample coming from 3 reference centers in IBD. Therefore, presenting new knowledge on QoL perception of a poorly studied patient population.

In the present study, the majority of the patients were women, which is discordant from previous studies.⁽²³⁾, in which the male sex predominated. An UC diagnosis predominated over CD, which differs from studies in the U.S.⁽²⁴⁾. The mean age was 14.8 years and the average time since the diagnosis of the disease was 5.1 years, which shows a tendency of the disease to present increasingly during the first decade of life, although IBD continues to predominate in adolescents. In our study, some of the patients' clinical characteristics include the appearance of earlier clinical manifestations and greater severity of the disease, which are of interest to consider in studies with a larger number of subjects.

Table 3. Relationship between the clinical and sociodemographic characteristics of patients with inflammatory bowel disease and the total score of the IMPACT-III questionnaire.

Feature	IMPACT-III total score, median	<i>p</i>
Type of disease		
EC	126	0,424
UC	147	
Sex		
Female	131	0,32
Male	130	
BMI		
Low weight (<18,5kg/m ²)	128	0,248
Normal (18,5-24,9kg/m ²)	140	
Overweight (25-29,9kg/m ²)	127	
Duration of illness		
< 1 year	127	0,621
1-5 years	123	
≥ 5 years	137	
Use of biological or small molecule		
Yes	130	0,815
No	131	
History of perianal disease		
Yes	115	0,092
No	129	
History of fistulizing disease		
Yes	115	0,162
No	130	
History of stenosing disease		
Yes	150	0,359
No	78	
IBD surgery		
Yes	106	0,292
No	130	
Hospitalizations for IBD activity in the past 12 months		
Yes	130	0,95
No	109	
Extraintestinal manifestations		
Yes	133	0,162
No	129	
Disease activity		
Inactive	137	0,199
Slight	121	
moderate	140	
Grave	78	
Educational level		
High school	129	0,621
Primary	147	
Area of residence		
Rural	123	0,162
Urban	134	

UC: ulcerative colitis. CD: Crohn's disease. IBD: inflammatory bowel disease. BMI: Body Mass Index.

The total mean IMPACT-III score in this sample was higher than that described in other countries ⁽²⁵⁻²⁷⁾. This could have been the result of a combination of different variables including the sample size, the high percentage of patients in remission, their multidisciplinary management and their knowledge base. Previous studies have shown that IBD activity is associated with worse QoL ^(26,28,29). QoL improvement has been demonstrated in IBD patients receiving management by a multidisciplinary team ⁽³⁰⁾, including psychological services especially for adolescent patients ⁽³¹⁾. In the present study, all participating institutions have a dedicated multidisciplinary team for management of the patient with IBD leading to higher remission rates and a holistic approach with improved QoL in this pediatric sample. Increased awareness is still required to establish this team approach and improve QoL of all pediatric patients with IBD in Colombia.

We found that the scores of patients with UC and CD were different, with a lower score in patients with CD in line with previous studies ⁽²⁷⁾ in which a greater negative impact was found in patients with CD compared to those with UC. Factors contributing include chronic medication use, complications leading to hospitalizations and surgical interventions and associated with a significant negative impact on leisure activities and interpersonal relationships ^(5,25). Also, in our sample it was found that children with disease onset at an earlier age or with a longer duration of the disease had a better QoL, which is in agreement with some studies ^(25,27), and at odds with others ⁽²⁶⁾. When compared with other studies, our sample was smaller, with a greater percentage of patients in remission and lower frequency of hospital admissions.

Multiple studies have shown that although patients in remission have better QoL than patients with active disease ^(32,33), several factors may negatively influence their QoL, potentially impacting specific domains ⁽³²⁾. In our study, no marked differences were found among the affected domains, supporting the notion that children and adolescents may fail to distinguish between systemic symptoms, digestive symptoms, and treatment side effects.

The cross-sectional design and small sample size are key limitations of this study. These limitations may have masked significant associations that could have been detected in a larger cohort. However, the pediatric IBD population in our setting is small, and this sample is representative of that population. In Colombia, pediatric IBD is a rare condition, with approximately 209 registered patients according to the national registry. Its prevalence and incidence are much lower than in adults, and the condition remains poorly understood. Furthermore, the participating centers are the main institutions managing IBD, with fewer than 100 patients in active follow-up. Most patients outside these reference centers are treated in lower-level facilities in peripheral regions. As national reference centers for IBD, the participating institutions

tend to manage more complex cases, which may have influenced the sample's disease severity. To minimize bias and ensure accuracy, data were independently verified, and surveys were administered by two separate investigators. Another limitation is that remission was defined by clinical criteria only; biochemical, endoscopic, and histologic remission were not confirmed in all patients. Additionally, comorbidities with significant psychological impact were not assessed. However, the investigators are clinicians specialized in pediatric IBD with extensive experience in applying clinical criteria. Finally, at the time the questionnaire was administered, no prior version existed in Spanish. A cross-cultural adaptation was therefore developed, preserving the structure of its components and domains based on input from patients, caregivers, healthcare professionals, and researchers.

Although the study is purely descriptive and does not document statistically significant associations, it offers an initial overview of QoL perceptions in pediatric IBD patients who have achieved therapeutic goals and are under multidisciplinary care. It also serves as a starting point for efforts to improve QoL in pediatric IBD patients in a Latin American context.

In conclusion, the assessment of QoL in children with IBD should be an integral part of clinical care to monitor and understand patients' overall functioning and well-being. The results of this study highlight that pediatric IBD poses significant challenges to quality of life, with several factors extending beyond disease control that must be addressed in routine clinical practice. Studies with a larger number of patients are required, in which the IMPACT III questionnaire is validated in Spanish. It is necessary to continue strengthening the support, and education of pediatric patients with IBD and their caregivers, with a comprehensive and multidisciplinary approach, which will result in improvement of QoL impacting activities of daily living and assimilation of the disease.

Consent to publication

In its design, the requirements established in the Declaration of Helsinki, version 2013, in Fortaleza, Brazil, and resolution 8430 of 1993 of the National Ministry of Health of Colombia were considered deeming this a risk-free investigation. Confidentiality of the information collected was guaranteed.

Availability of data and material

The data and material available for publication are in the manuscript and no information is omitted.

Disclosures

The data and material available for publication are in the manuscript and no information is being omitted. Authors declare that they did not receive any editorial support, nor did they pay for assistance. There was no third-party participation.

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