

Original Article



Quality of Life in Children and Adolescents with Inflammatory Bowel Disease: Impact and Predictive Factors

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Conflict of Interest

The authors have no financial conflicts of interest.

ABSTRACT

Purpose: Inflammatory bowel disease (IBD) in children and adolescents is associated with high morbidity and possibly has a significant negative impact on their quality of life. This study aimed to evaluate the quality of life of children and adolescents with IBD and define the variables that impact these individuals.

Methods: We administered the Pediatric Quality of Life Questionnaire (PedsQL) to 35 children and adolescents diagnosed with IBD and with available quantitative data from clinical records on epidemiology, clinical evolution, complementary tests, medical interventions, and disease activity. Data were evaluated according to the IBD type and compared with a control group of healthy children.

Results: The study group showed a significantly lower PedsQL score than the control group ($p < 0.01$). Significant factors contributing to poor overall quality of life included female sex, Crohn's disease, surgery, and food restrictions. Symptoms such as diarrhea and the fear of using public toilets were associated with low physical scores. Feeling sick had a negative impact on the emotional PedsQL scores. Patients with a fear of using public toilets, anthropometric scores below the 3rd percentile, and greater disease activity scored lower in the social domain. Regarding school and psychosocial evaluations, younger children with symptom onset after the age of 2 years had lower scores than younger children with symptom onset before the age of 2 years.

Conclusion: IBD negatively affects the quality of life of children and adolescents based on its impact on the physical, emotional, social, and psychosocial statuses of these patients.

Keywords: Inflammatory bowel disease in pediatrics; Health-related quality of life; Pediatric Quality of Life Questionnaire 4.0 *Generic Core Scale* questionnaire

INTRODUCTION

Inflammatory bowel disease (IBD), which includes Crohn's disease (CD), ulcerative colitis (UC), and inflammatory bowel disease unclassified (IBDU), can exhibit a wide range of clinical presentations, characterized by periods of remission and relapse of inflammation in the digestive tract. IBD is also associated with considerable morbidity. Recent studies have shown an increase in the prevalence of IBD [1,2], with approximately 25% of cases observed in

children [3,4]. In the United States, the number of cases of IBD may reach 7/100,000 children [5]. Current studies have shown an increasing number of cases in Brazil, with a growing trend of early diagnosis, mostly in children aged 10 years and above, besides adolescents and young adults, with 8% of children being diagnosed with IBD before the age of 4 years [3,4]. Compared to UC, a higher incidence and prevalence of CD has been reported internationally [5,6].

IBD in children is always associated with a high morbidity. Thus, it can have a significant negative effect on the children's quality of life [7-13]. To improve the care of children affected by these chronic diseases, it is significantly important to develop support systems and measures that enable children and adolescents to adapt better to these diseases. In this context, in an effort to help evaluate overall patient health, health-related quality of life (HRQoL) in pediatrics measurements and questionnaires have been increasingly developed and utilized over recent years. Therefore, treatment of IBD should not solely focus on healing the intestinal mucosa but should also aim to improve the perception of health and quality of life in these patients over extended follow-up periods.

This study aimed to evaluate the quality of life of children and adolescents with IBD and define the variables that impact these individuals.

MATERIALS AND METHODS

Patients and study design

A cross-sectional, analytical case series study of children and adolescents between the ages of 3 and 18 years diagnosed with IBD were evaluated at a tertiary pediatric gastroenterology service in Brasilia. The diagnosis of IBD followed the clinical, laboratory, imaging, and endoscopic criteria, as previously defined in the literature [14]. This study focused on a total of 35 patients and their caregivers, after the terms of assent and consent. Patients were interviewed on the day of follow-up consultation. Of those contacted, patients unable to attend the follow-up and patients with incomplete questionnaires were excluded.

The control group comprised 62 healthy children and adolescents from a local school. Out of these 62 participants, 28 (45.2%) were male, and the mean age of all participants was 12.9 (± 4.7) years.

Epidemiological, clinical, and complementary data

After reviewing the participants' medical records, epidemiological data, and clinical and complementary examinations, the following information was obtained: age and sex; age of diagnosis and interval from symptom onset to diagnosis; nutritional evaluation; classification of IBD; severity of the disease according to the Pediatric Ulcerative Colitis Activity Index (PUCAI) [15] and Pediatric Crohn's Disease Activity Index (PCDAI) [16]; laboratory data such as red blood cell count (to assess anemia), platelet count (platelet count $>450,000$ per microliter, to assess thrombocytosis), erythrocyte sedimentation rate and C-reactive protein levels, and albumin level (albumin level <3.5 g/dL, to assess hypoalbuminemia); and therapeutics (drugs and surgery), which followed previously published recommendations [17,18].

To evaluate the signs and symptoms, a questionnaire (**Supplement**) was administered to evaluate the presence of digestive diseases (diarrhea, intestinal bleeding, abdominal pain,

and perianal lesions) and extraintestinal manifestations (fever, conjunctivitis, uveitis, arthralgia, arthritis, erythema nodosum, pyoderma gangrenosum, pubertal retardation, and delayed growth or development). The questionnaire also included queries regarding the child's feelings toward the disease, focusing on the following aspects: whether they can do what they like to do despite their condition, feeling sick, whether their condition bothers them, whether other children understand their condition, whether they can eat what they like, and whether they have a fear of using public toilets.

Quality of life assessment

From July 2015 to March 2016, and after obtaining approval from the research ethics committee, the Pediatric Quality of Life Questionnaire (PedsQL) 4.0 (*Pediatric Quality of Life Inventory – PedsQL 4.0 Generic Core Scale*) questionnaire, which evaluates the quality of life, was applied and translated into Portuguese and validated in Brazil [19]. In this study, a single interviewer administered the questionnaire in person.

The PedsQL 4.0 is widely used in other countries and is easy to apply. It focuses on the following domains: physical (eight items), emotional (five items), social (five items), and school (five items). The PedsQL 4.0 is administered to children aged between 2 and 25 years, with child self-report and parent proxy-report. All items for each of the forms are essentially identical, differing only in language. In this study, the parent's form was only used in cases where the child was unable to answer the questionnaire. The answers are rated on a five-point scale (0=never, 1=almost never, 2=sometimes, 3=often, 4=almost always). The items are inversely scored and transposed on a 0 to 100 scale (0=100, 1=75, 2=50, 3=25, 4=0). Thus, the greater the score, the higher the quality of life. The total score is a sum of the scores across the four dimensions evaluated. The physical summary corresponds to the mean of the physical dimension (eight items), while the psychosocial summary (15 items) covers the emotional, social, and school domains.

Statistical analyses

Sample characterization was performed using mean and standard deviation measurements. In correlations and associations, the variables were evaluated in pairs and in a multivariate analysis. Pearson's correlation analysis was used for quantitative variables. For cases in which an association was identified between the quantitative variables and categorical variables, the Welch's *t*-test was used to compare the means. When an association existed between two categorical variables, the chi-squared test was used. The R3.2 (www.r-project.org) software was used for all statistical analyses. The level of significance adapted in the analysis was 5%. A *p*-values <0.05 were considered statistically significant.

Ethical considerations

This study was approved by the Health Sciences Teaching and Research Foundation (FEPECS), State Health Department of the Federal District (SES-DF), Research Ethics Committee (approval number: 1.107.514).

RESULTS

Epidemiological, clinical, and complementary data

This study comprised (**Table 1**) 35 patients: 1 (2.8%) with IBDU, 17 (48.6%) with CD, and 17 (48.6%) with UC. The male to female ratio was 2.2:1.0, with a mean age of 13.1 (\pm 4.6) years.

Table 1. Characteristics of the sample

Variable	Value (n=35)
Age (yr)	13.1±4.6
Age at symptom onset (yr)	
<2	5 (14.3)
>2	30 (85.7)
Sex	
Female	11 (31.4)
Male	24 (68.6)
Type of IBD	
CD	17 (48.6)
UC	17 (48.6)
IBDU	1 (2.9)
Disease activity index	
PCDAI	36.03±14.40
Mild	7 (41.2)
Moderate and severe	10 (58.8)
PUCAI	40.88±12.70
Mild	4 (23.5)
Moderate and severe	13 (76.5)
Time for diagnosis (mo)	
CD	2.90±7.00
UC	9.23±15.80
Clinical data	
Diarrhea	31 (88.6)
Diarrhea with blood	24 (68.6)
Abdominal pain	19 (54.3)
Extraintestinal manifestation	10 (28.6)
W or BMI <P3	14 (40.0)
Fistulas	8 (22.9)
Laboratory*	
Anemia	18 (51.4)
Thrombocytosis (plat >450,000 per μ L)	10 (28.6)
High ESR	14 (40.0)
Elevated CRP	9 (25.7)
Hypoalbuminemia (alb <3.5 g/dL)	9 (25.7)

Values are presented as mean±standard deviation or number (%).

IBD: inflammatory bowel disease, CD: Crohn's disease, UC: ulcerative colitis, IBDU: inflammatory bowel disease unclassified, PCDAI: Pediatric Crohn's Disease Activity Index, PUCAI: Pediatric Ulcerative Colitis Activity Index, W: weight, BMI: body mass index, P3: 3rd percentile, Plat: platelet, ESR: erythrocyte sedimentation rate, CRP: C-reactive protein, Alb: albumin.

*Laboratory data: prior to the initiation of treatment.

Most patients showed moderate to severe disease activity at the time of diagnosis, based on the PUCAI and PCDAI scores. The interval between the symptom onset and the diagnosis was nearly 3 months for CD and approximately 9 months for UC, with 9.7 years as the mean age at the time of diagnosis. Five patients (14.3%) had a symptom onset before the age of 2 years (infant-onset IBD).

In this study, 15 patients reported feeling dissatisfied with their disease condition, while five described feeling sick. Only eight reported that they could eat the food of their choice, while four stated that they feared of using public toilets. Twenty patients reported that the disease did not interrupt their daily activities (they could accomplish everything independently, regardless of the disease), while 20 claimed that their friends understood their health condition.

Quality of life assessment

Assessment of the HRQoL showed that (Table 2) IBD patients achieved an average of 68.1 points (standard deviation+21.6) in the total PedsQL score. The physical, educational,

Table 2. Statistical analysis of the Pediatric Quality of Life Questionnaire scores (inflammatory bowel disease X control group and Crohn's disease X ulcerative colitis)

Variable	IBD	Control group	p-value	CD	UC	p-value
PedsQL total	68.12±21.6	84.41±15.5	<0.01	60.4±22.6	75.0±18.8	0.0501
PedsQL physical	70.71±26.2	86.33±14.1	<0.01	64.3±25.6	76.8±26.7	0.1741
PedsQL emotional	66.17±21.4	78.87±22.6	<0.01	58.4±17.5	72.3±23.1	0.0602
PedsQL social	82.28±19.6	89.91±16.4	0.0559	80.8±22.2	83.8±17.0	0.5497
PedsQL school	61.28±20.0	83.60±17.5	<0.01	61.1±21.6	65.0±18.0	0.3961
PedsQL psychosocial	69.53±17.9	82.88±19.4	<0.01	69.7±18.3	73.3±17.6	0.2079

Values are presented as mean±standard deviation.

IBD: inflammatory bowel disease, CD: Crohn's disease, UC: ulcerative colitis, PedsQL: Pediatric Quality of Life Inventory.

emotional, and psychosocial domains showed significantly poor ratings, with the highest score in the social domain.

When comparing various forms of IBD, UC patients registered higher scores for all evaluated domains, although statistical significance was not achieved.

In the domain scores, the average physical PedsQL score for the study group was 15.6 points lower than that for the control group (70.7 and 86.3, respectively; $p=0.002$; 95% confidence interval [CI], 6.0–25.2). The average emotional PedsQL scores in the study and control groups were 66.1 and 78.8, respectively ($p=0.008$; 95% CI, 78.8–66.1). The IBD group showed worse school function, with school PedsQL scores at 61.2 and 83.6 for the study and control groups, respectively ($p<0.01$; 95% CI, 14.2–30.4). The average social PedsQL score for the study group was 7.6 points lower than that in the control group ($p=0.05597$; 95% CI, 0.2–15.4), but it was not statistically significant. Finally, the study group showed a psychosocial PedsQL score of 69.5 versus 82.8 in the control group ($p=0.001$; 95% CI, 5.5–21.1).

Quality of life predictors

To assess the association between HRQoL and other variables in the study (Table 3), a multiple linear regression model was analyzed with the PedsQL as the response variable. Based on this model, patients with UC scored 10 points more in the total PedsQL score than those with CD. Female children and adolescents also scored 14 points higher on average. In the study sample, only three patients (8.6%) had surgery and displayed a 28-point reduction in the total PedsQL score. Patients who stated they could eat what they wanted showed a nearly 30-point increase in the total PedsQL score.

A second statistical model used to assess the association between physical PedsQL and the other variables was also used. According to the estimated parameters, children with diarrhea or who were afraid of using public toilets showed a 34- and 53-point decrease in the scores, respectively. Patients with UC scored 30 points higher on average than those with CD; women also showed higher scores than men. The disease activity index revealed an inverse association with physical PedsQL, in which children being treated with biologics (infliximab and adalimumab) had a 29-point increase in their score.

The emotional PedsQL domain revealed that children with CD, children with a higher rate of disease activity (PCDAI and PUCAI), and children who reported feeling sick had lower rates of PedsQL.

In the social PedsQL evaluation, children who reported a fear of using public toilets had a reduction of 45 points in the score. Children registering anthropometric values below the 3rd percentile and children having stronger disease activity also had lower scores. Regarding

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Table 3. Results for multiple linear regression model of the Pediatric Quality of Life Questionnaire on predictor variables

Coefficients	Estimated beta	Default error	t	p-value
PedsQL total				
Intercept	47.887	5.659	8.462	<0.001
CD or UC	10.566	5.994	1.763	0.0907
Female sex	14.534	6.597	2.203	0.0374
Symptom onset <2 years	20.259	9.525	2.127	0.0439
Surgery	-28.612	11.755	-2.434	0.0228
Eat what they like	30.601	7.126	4.294	<0.001
PedsQL physical				
Intercept	68.5471	11.5263	5.947	<0.001
CD or UC	30.1518	6.7194	4.487	0.0002
Female sex	19.7676	7.8239	2.527	0.0205
Symptom onset <2 years	25.1058	10.6060	2.367	0.0286
High CRP	20.3091	8.1622	2.488	0.0222
Disease activity	-0.7933	0.2901	-2.734	0.0131
Eat what they like	35.6916	7.7935	4.580	0.0002
Abdominal pain	36.0874	8.9510	4.032	0.0007
Diarrhea	-34.2441	11.0629	-3.095	0.0059
Fear of using public toilets	-53.3287	10.2631	-5.196	<0.001
Biologics	29.7755	8.0709	3.689	0.0015
PedsQL emotional				
Intercept	53.4965	7.9433	6.735	<0.001
CD or UC	37.9007	6.3601	5.959	<0.001
Disease activity	-0.9158	0.2230	-4.107	0.0006
Biologics	16.9448	5.5494	3.053	0.0065
Surgery	44.9825	11.2677	3.992	0.0007
Eat what they like	15.6972	5.6046	2.801	0.0114
Feeling sick	-34.2259	6.7270	-5.088	<0.001
Extraintestinal manifestations	14.9801	6.4646	2.317	0.0318
Diarrhea with blood	14.1345	6.1925	2.283	0.0341
Albumin <3.5	14.1783	5.7046	2.485	0.0224
PedsQL social				
Intercept	94.3186	7.9637	11.844	<0.001
CD or UC	15.3318	5.4900	2.793	0.0112
Disease activity	-1.2361	0.2367	-4.815	0.0001
Weight or BMI <P3	-18.0620	5.5978	-3.227	0.0042
Abdominal pain	30.8541	6.7321	4.583	0.0001
Plat >450,000 per µL	22.7950	8.0342	2.837	0.0101
Biologics	42.9337	7.1244	6.026	<0.001
Fear of going to bathroom	-45.2244	8.5353	-5.299	<0.001
Hb <12 g/dL	10.1175	5.7238	1.768	0.0923
High CRP	-14.4373	7.7018	-1.875	0.0755
PedsQL school				
Intercept	13.716	11.342	1.209	0.2378
Age	2.861	0.791	3.617	0.0013
Symptom onset <2 years	44.155	10.425	4.236	<0.001
Eat what they like	26.818	5.421	4.947	<0.001
Albumin <3.5 g/dL	-10.417	5.957	-1.749	0.0926
PedsQL psychosocial				
Intercept	31.6870	11.6305	2.724	0.0115
Age	2.3921	0.7953	3.008	0.0059
Symptom onset <2 years	40.2479	10.1063	3.982	<0.001
Eat what they like	22.1131	5.6390	3.921	<0.001
Extraintestinal manifestations	-13.0193	5.3175	-2.448	0.0217

PedsQL: Pediatric Quality of Life Inventory, CD: Crohn's disease, UC: ulcerative colitis, CRP: C-reactive protein, BMI: body mass index, P3: 3rd percentile, Plat: platelet, Hb: hemoglobin.

PedsQL total: n=30; R² adjusted=0.5563; Statistics F: 8.271 with 5 and 24 degrees of freedom; p-value: 0.0001173.

PedsQL physical: n=30; R² adjusted=0.7171; Statistics F: 8.35 with 10 and 19 degrees of freedom; p-value: 4.544e-05.

PedsQL emotional: n=30; R² adjusted=0.7287; Statistics F: 9.358 with 9 and 19 degrees of freedom; p-value: 2.603e-05.

PedsQL social: n=30; R² adjusted=0.6438; Statistics F: 6.825 with 9 and 20 degrees of freedom; p-value: 0.0001811.

PedsQL school n=30; R² adjusted=0.5517; Statistics F: 9.922 with 4 and 25 degrees of freedom; p-value: 5.985e-05.

PedsQL psychosocial: n=30; R² adjusted=0.5224; Statistics F: 8.929 with 4 and 25 degrees of freedom; p-value: 0.0001273.

school and psychosocial domains of children with IBD, according to the PedsQL summary, those who stated that they could eat what they like and those whose symptoms began before the age 2 years had significantly higher scores. In the psychosocial evaluation, PedsQL scores decreased for children with extraintestinal manifestations.

The graphical and correlation analyses showed no evidence ($p=0.061$) of a linear association between the total PedsQL score and the PUCAI and the PCDAI disease activity indexes or between the average total PedsQL score for the patient groups with mild and moderate to severe disease. However, the PUCAI and PCDAI values decreased with an increase in the physical PedsQL values, thus indicating a significantly negative association ($p<0.05$).

The Welch's *t*-test showed no significant difference in the mean total PedsQL for patients with or without extraintestinal manifestations. However, the results suggested that the values for the physical PedsQL are different, with the estimated means indicating that patients without extraintestinal manifestations scored higher values ($p<0.05$).

The correlation analysis revealed no evidence to suggest a linear association between the total PedsQL, physical PedsQL, or emotional PedsQL scores with delayed diagnosis.

DISCUSSION

This study demonstrates that IBD has a relevant negative effect on HRQoL. In addition to assessing the quality of life in pediatric IBD patients and comparing between CD and UC, this study also identified the factors that have the highest association with the impact on quality of life regarding various domains, as shown in **Table 3**.

In the IBD patient group, the male sex was predominant, which is similar to a previously published study [6], but different than the results in an also previously published study [20]. The prevalence of CD and UC was equal, although in the literature CD has been reported to have a higher prevalence than UC, with data indicating prevalence of 43/100,000 and 28/100,000 for CD and UC, respectively, in patients aged less than 20 years in the United States [6].

The mean age in this study was 13.1 years (± 4.6), and 14.3% of patients had the symptom onset before the age of 2 years, demonstrating a tendency toward increasingly early clinical manifestation, but still exhibiting a predominance in adolescents and young adults. Recent studies on pediatric IBD have revealed that very early-onset IBD differs in several domains, including a more severe disease behavior. In an American study, the prevalence of IBD was higher in the age group of 15 to 20 years than that of the other age groups [6].

Regarding clinical and laboratory data, diarrhea and abdominal pain were the most prevalent symptoms, as noted in another American study that included 49 children with IBD [21]. Based on the data from Varni et al.'s study [22], who prepared the quality of life questionnaire used in this study (PedsQL), the difference in the scores, considering the physical and psychosocial factors between the patient and control groups, was clinically relevant [22,23]. Existing reports have revealed a higher occurrence of psychological disturbances, particularly anxiety and depression, in children affected by IBD and other chronic illnesses compared to healthy children [24,25]. These studies have also reported issues with self-image and social interaction among these children [26,27]. Some studies have shown the effectiveness of

cognitive behavioral therapy in patients with chronic diseases [28]. Others emphasize that the increased severity of IBD is associated with emotional and stress factors [26,28,29]. In a meta-analysis of 1,167 patients, children with IBD had poorer total psychosocial and physical quality of life than healthy children when assessed using generic instruments [30]. Another study revealed that children with IBD had significantly lower scores for the physical, school, psychosocial, and total quality of life variables than healthy children [8].

When comparing quality of life scores between CD and UC patients, patients with UC had a 10-point higher score on average in the total PedsQL than patients with CD. Considering the extent of the involvement of the gastrointestinal tract in both the diseases and the more extensive general impairment in CD, the result is understandable. Another report available in the literature reported similar findings [31,32].

In the multivariate analysis, one of the key factors attributed to the difference in the total PedsQL value was the ability of the children to eat what they like. It is important to note that only 24.2% of patients stated that they eat what they like. A previous study demonstrated that dietary limitations, accompanied by abdominal pain, are the quality of life predictors with the most influence on isolation among children affected by CD [33,34]. The female sex was found to be associated with higher total PedsQL scores, a finding that is supported by several studies in the literature [33,34].

In the physical PedsQL domain, children reporting diarrhea or fear of using public toilets had lower scores, which were clearly evident during the time of disease exacerbation, and children with IBD were reportedly susceptible to a worse quality of life when the symptoms were aggravated [21].

In the emotional domain, feeling sick was associated with poorer quality of life. Anxiety and depressive symptoms in children with IBD have been described in the literature [21,35-37]. Anthropometry below the 3rd percentile also had a negative impact on social PedsQL. It has been described that children with CD participate less in social and athletic activities and miss school more often than children with typical growth [8], which may justify the association observed.

Older children had better school PedsQL scores than younger children; this result is inconsistent with that of another study in which older ages were associated with poorer disease-related quality of life [13].

Fear of using public toilets was another significant factor, with a significant decrease in the PedsQL score, specifically in the psychosocial assessment, keeping in mind the frequency of diarrhea as the most common symptom in this sample. Psychosocial dysfunction was associated with a poorer quality of life in children with IBD, including a higher occurrence of psychiatric disorders, as reported in the literature [29,35,38]. The presence of extraintestinal manifestations was only relevant in psychosocial PedsQL domain, with no effect on the physical dimension, which is surprising considering the most common extraintestinal manifestations.

In this study, the overall quality of life was associated with the disease activity index, similar to that reported in other studies [11,13,31]. However, the findings of the present study suggest a trend of increasing physical PedsQL scores with decreasing PUCAI and PCDAI values. Kunz et al. [8] reported a significant difference as a function of disease activity in the physical quality of life score, with no difference in other areas. Chouliaras et al. [39] highlighted

that disease activity was the main factor affecting the quality of life in children with IBD, analyzed either globally or in separate spheres, highlighting the significance of achieving and maintaining disease remission [39].

Thus, increasing psychosocial support, avoiding unnecessary dietary restrictions, and having a multidisciplinary team for the management of these patients will lead to an improvement in care and patient outcomes. Identifying possible factors that interfere with IBD patients' quality of life and attempting to correct them should be included in the IBD therapy.

In conclusion, the findings show that IBD negatively affects the quality of life of children and adolescents. The total PedsQL score in the study group was significantly lower than that in the control group, with important predictors of poorer quality of life being female sex, CD, surgery, and food restrictions. Diarrhea, fear of using public toilets, and worse disease activity were associated with significantly poor scores in the physical domain. Feeling sick had a negative influence on emotional PedsQL score. Fear of using public toilets, anthropometric values below the 3rd percentile, and increased disease activity led to lower scores in the social domain. In school and psychosocial domains, two domains interfered in lower scores: younger age at the time of the interview and symptom onset after the age of 2 years. The use of biologics was associated with a better quality of life. Therefore, in addition to aiming to achieve clinical remission with mucosal healing, patient care for those affected by IBD should also focus on the holistic health of the child or adolescent and involve the services of an interprofessional team focused on physical, emotional, social, and school domains.

SUPPLEMENT

Questionnaire

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