

# The impact of inflammatory bowel diseases on the quality of life of Saudi pediatric patients: A cross-sectional study

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## Abstract

**Background:** Inflammatory bowel disease (IBD) is a chronic gastrointestinal tract disorder characterized by periods of exacerbations and remissions that affect multiple aspects of a pediatric patient's quality of life. The purpose of this study is to describe the health-related quality of life of Saudi pediatric IBD patients and to determine the influencing factors which can affect it.

**Methods:** This is a single center cross-sectional descriptive study, conducted between December 2019 and December 2021. Patients aged between 9 and 16 years diagnosed with IBD were included; IMPACT III quality of life questionnaire was used.

**Results:** Thirty-eight patients participated in the study, 57.9% being male, with a mean age of  $12.48 \pm 2.72$  years, and 55.3% of patients were diagnosed with Crohn's disease (CD). The most frequent medications were aminosalicic acids derivatives, followed by immune-modulators and biologics. The IMPACT III quality of life questionnaire has shown lower scores in IBD patients in comparison to healthy control groups. Patients with active disease have lower total and sub-domain scores than patients with inactive disease. We found no correlation between health-related quality of life (HrQOL) and the number of medications used, disease duration, or gender.

**Conclusions:** Pediatric IBD patients have significantly lower HrQOL scores than healthy children. Disease activity was found to be a predictor for poor HrQOL outcome.

**Keywords:** Disease activity, IMPACT III questionnaire, inflammatory bowel disease, pediatric, quality of life, Saudi

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## INTRODUCTION

Inflammatory bowel diseases (IBDs) are immune-mediated gastrointestinal tract disorders characterized by chronic inflammation with periods of exacerbations and remissions. It includes Crohn's disease (CD), ulcerative colitis (UC), and IBD unclassified (IBDU).<sup>[1]</sup>

Various epidemiological studies demonstrated a rising rate of IBD in most countries with a great variation in their incidence and prevalence. In fact, around 25% of diagnosed patients are children and adolescents.<sup>[2-4]</sup>

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Pediatric IBD patients often have a more complex and extensive disease course than adults.<sup>[5,6]</sup> Additionally, IBD has a potentially negative impact on growth and pubertal development of patients indicating that pediatric-onset IBD requires a specific management approach.<sup>[7-9]</sup> Besides their medical condition, these children are highly vulnerable to complex social, cognitive, and emotional difficulties which might affect their HrQOL.<sup>[10,11]</sup> Therefore, improving the perception of health and quality of life (QOL) in these patients is a vital part of IBD management.<sup>[12]</sup>

Local data shows that the number of adults and children with IBD has significantly increased over time in Saudi Arabia.<sup>[13-15]</sup> Impaired HrQOL of pediatric IBD patients has been documented in several studies, but as far as we are aware, none of them were conducted in our region. The main objective of this study is to describe the impact of IBD on HrQOL compared to controls and to identify risk factors by using the IMPACT-III questionnaire.

## MATERIALS AND METHODS

### Study design and participants

This is a cross-sectional study conducted at the Pediatric Gastroenterology Clinic of King Fahad Specialist Hospital-Dammam (KFSH-D), Saudi Arabia, between December 2019 and December 2021. The inclusion criteria consisted of patients aged from 9 to 16 years with a confirmed diagnosis of IBD for a period longer than four months, based on the revised Porto diagnostic criteria.<sup>[16]</sup> Children under 9 years of age, incomplete questionnaires, or those who were diagnosed with a known chronic disease (i.e., diabetes, lung disease, and psychiatric illness) or genetic syndromes causing IBD-like symptoms were excluded. The control group included 69 healthy children and adolescents from 9 to 16 years of age from local schools. The students were selected randomly and the questionnaire was explained thoroughly by the assigned researcher.

### Procedure

The study was approved by the Institutional Research Ethics Board at KFSH-D (IRB# PED 0304). A meeting was held with the caregivers of patients four months after the IBD diagnosis was made by the Pediatric Gastroenterology Clinic or Infusion Unit, and was conducted by an assigned physician from the research group who explained the details of the study and obtained informed consent.

At the time of evaluation, medical and demographic data were extracted from participants' medical records including age and sex; age at diagnosis, disease duration, classification

of IBD and current treatment including type and number of medications, presence of active perianal disease, and if any surgeries were performed on the participant.

Disease severity was assessed according to the Pediatric Crohn's Disease Activity Index (PCDAI)<sup>[17]</sup> and Pediatric Ulcerative Colitis Activity Index (PUCAI).<sup>[18]</sup> For PCDAI, disease severity is measured on a scale of 0 to 100, whereas for PUCAI the scale ranges from 0 to 85 points. Based on the activity indices, patients were classified as being in remission ( $PCDAI \leq 10$  or  $PUCAI \leq 10$ ), in relapse with mild activity ( $10 < PCDAI \leq 30$  or  $10 < PUCAI \leq 34$ ), and in relapse with moderate/severe activity ( $PCDAI > 30$  or  $PUCAI > 34$ ). Remission/disease activity can be determined with high accuracy to differentiate patients with active vs. inactive disease if the cutoff score is less than 10 of the PUCAI/PCDAI.

### Health-related quality of life assessment

HrQOL was assessed by using the IMPACT-III questionnaire, a 35-question-long, self-administered, validated health-related QOL tool for pediatric IBD patients between the ages of 9 and 16 years old. We used the new four domains IMPACT-III, which offers better reliability and model fitting than the original IMPACT domain structure.<sup>[10,11]</sup> It measures four domains of patient health, which include: Well-being (12 questions), Social functioning (7 questions), Emotional functioning (11 questions), Body Image (4 questions), and question 31, which does not fall under any of the four domains. There are 5-Likert response options per question, scored 0 to 4 from right to left in Arabic translation, indicating a better QOL toward the right and a lower QOL toward the left. After that, scores are linearly transformed on a range of 0-100 as follows: 0 = 100; 1 = 75; 2 = 50; 3 = 25; 4 = 0. The final score for each domain equals the average of all transformed scores and the total IMPACT-III score is obtained by adding the four domains' scores with question 31 and dividing it by 35. A better HrQOL was indicated by a higher score and vice versa. The control group of the questionnaire has been walked through symptoms or concerns-related questions regarding having them during the last two weeks. Participants were free to choose answers related to them. With regards to IBD-related questions, evaluators stressed that if the child felt that the issue raised by a particular question is not a problem for him/her, then they ought to mark it as "best quality of life" response.

We used the original Arabic-translated version of the questionnaire after obtaining permission from Mira Research "Pediatric Inflammatory Bowel Disease Working

Group on Quality of Life Represented by Dr. A. Otley, IWK Health Centre, Halifax, N.S.O. The Arabic version of the IMPACT-III questionnaire is certified with linguistic validation but has not been clinically validated.

### Statistical analysis

We used SPSS 24 (IBM, Armonk, NY, United States) for the analysis. Continuous variables are denoted as mean  $\pm$  SD. The Shapiro-Wilk test was used to assess the normality of continuous variables and guide the selection of a parametric or nonparametric test for the comparison of variables. The variables were compared using Welch's t-test, Student t-test, and Mann-Whitney U test. Categorical variables are presented as frequencies and percentages and compared using the Chi-squared or Fisher's exact tests where appropriate. All independent variables from univariate linear regression analysis with  $P < 0.05$  were entered into a multivariate linear regression model to examine the association with IMPACT III total score. All reported  $P$  values are two-sided and  $P$  values  $< 0.05$  were considered to indicate a statistical significance.

## RESULTS

Patients' demographic and clinical characteristics are summarized in Table 1. A total of 38 patients were included in the study, of whom 21 (55.3%) had CD, whereas 16 (42.1%) patients had UC and 1 (2.6%) had IBDU. The mean age was  $12.48 \pm 2.72$  years with males accounting for 57.9% of participants. Almost all patients except one were on medications at the time of evaluation and 57.9% of them needed two or more medications. The utilized immunomodulators were Azathioprine in 19 patients and Methotrexate in one patient only, and the Biologic treatments were Anti-TNF in 16 patients, Ustekinumab in two patients, and vedolizumab in two patients. More than two-thirds of patients had inactive or mild disease activity based on the PUCAI and PDAI scores. With regards to disease location and extent, two patients with ulcerative colitis had proctitis, four had left sided colitis, and ten had pancolitis, while four patients had stricture and three patients had fistulizing UC. Crohn's disease patients, on the other hand, were 17 with ileocolonic/Crohn's colitis and four with ileal disease/upper.

### HrQOL for IBD patients and differences with controls

Table 2 illustrates the comparison of scores of IMPACT III total and sub-group domains between the IBD and control groups. No significant differences in gender distribution ( $P = 0.91$ ) or age ( $P = 0.314$ ) were detected between them. Patients achieved significantly lower scores

**Table 1: IBD patients' baseline characteristics, total, and sub-domain IMPACT III scores**

| Characteristics                       | Total<br>n=38    | CD<br>n=21      | UC<br>n=16      | P     |
|---------------------------------------|------------------|-----------------|-----------------|-------|
| Age                                   | 12.48 $\pm$ 2.72 | 12.5 $\pm$ 2.9  | 12.4 $\pm$ 2.6  | 0.892 |
| Gender                                |                  |                 |                 |       |
| Female                                | 16 (42.1%)       | 9 (42.9%)       | 6 (37.5%)       | 1     |
| Male                                  | 22 (57.9%)       | 12 (57.1%)      | 10 (62.5%)      |       |
| Age onset                             | 8.8 $\pm$ 3      | 9.4 $\pm$ 3     | 8.2 $\pm$ 2.9   | 0.206 |
| Duration                              | 3.8 $\pm$ 2.5    | 3.5 $\pm$ 2.3   | 4.3 $\pm$ 2.9   | 0.495 |
| In remission*                         | 12 (31.5%)       | 6 (28.6%)       | 5 (31.3%)       | 1     |
| Medications                           |                  |                 |                 |       |
| Corticosteroid                        | 7 (18.4%)        | 4 (19%)         | 3 (18.8%)       | 1     |
| 5-ASA <sup>†</sup>                    | 22 (56.8%)       | 9 (42.9%)       | 12 (75%)        | 0.093 |
| Immuno-modulators                     | 20 (52.6%)       | 13 (61.9%)      | 7 (43.8%)       | 0.331 |
| Biologic                              | 20 (52.6%)       | 14 (66.7%)      | 6 (37.5%)       | 0.104 |
| Antibiotic                            | 2 (5.2%)         | 1 (4.8%)        | 1 (6.3%)        | 1     |
| None                                  | 1 (2.6%)         | 1 (4.8%)        | 0 (0%)          | 1     |
| Medications                           |                  |                 |                 |       |
| <2 drugs                              | 16 (42.1%)       | 7 (33.3%)       | 8 (50%)         | 0.336 |
| ≥ drugs                               | 22 (57.9%)       | 14 (66.7%)      | 8 (50%)         |       |
| Disease Activity Score (PCDAI, PUCAI) |                  |                 |                 |       |
| Remission                             | 11 (29.7%)       | 6 (28.6%)       | 5 (31.3%)       | 0.592 |
| Mild                                  | 15 (40.5%)       | 10 (47.6%)      | 5 (31.3%)       |       |
| Moderate-severe                       | 11 (29.7%)       | 5 (23.8%)       | 6 (37.5%)       |       |
| Surgery history                       | 1 (2.6%)         | 1 (4.8%)        | 0 (0%)          | 1     |
| Perianal disease <sup>‡</sup>         | 2 (5.3%)         | 1 (4.8%)        | 1 (6.3%)        | 1     |
| IMPACT III                            |                  |                 |                 |       |
| Well-being                            | 57.3 $\pm$ 23    | 57.4 $\pm$ 22.6 | 56 $\pm$ 24.5   | 0.964 |
| Emotional Functioning                 | 53 $\pm$ 20.5    | 50.9 $\pm$ 21.9 | 54.5 $\pm$ 18.9 | 0.280 |
| Social Functioning                    | 61.7 $\pm$ 18.9  | 62.7 $\pm$ 20.2 | 58.6 $\pm$ 16.4 | 0.797 |
| Body image                            | 58.9 $\pm$ 21.2  | 58 $\pm$ 19.5   | 59 $\pm$ 24.1   | 0.751 |
| Total Score                           | 58.4 $\pm$ 17.8  | 58.1 $\pm$ 17.8 | 57.3 $\pm$ 17.9 | 0.820 |

\*For patient with IBDU, clinical and biochemical markers as well as fecal calprotectin used to assess remission. <sup>†</sup>5-ASA; Amino salicylic acids. <sup>‡</sup>Active perianal disease during interview

of HrQOL on the total and all sub-domains compared to controls. The mean total scores for patients were  $58.4 \pm 17.8$  which is -26.1 (-31.2 to -21.0) points lower than the control ( $P < 0.001$ ). In the domain scores, emotional functioning rated the lowest among all while the mean for patients and control groups were  $53 \pm 20.5$  and  $80.2 \pm 12.7$ , respectively ( $P < 0.001$ ).

The well-being, body image, and social aspects all reported significant differences, where one control group had the "social" aspect as the highest domain reported by

**Table 2: Control vs. IBD patients total and sub-domain IMPACT III scores**

| Characteristics       | Total<br>n=107  | Control<br>n=69 | IBD<br>n=38     | P      |
|-----------------------|-----------------|-----------------|-----------------|--------|
| Age (years)           | 11.9 $\pm$ 2.7  | 11.5 $\pm$ 2.7  | 12.5 $\pm$ 2.7  | 0.091  |
| Gender                |                 |                 |                 |        |
| Female                | 53 (49.5%)      | 37 (53.6%)      | 16 (42.1%)      | 0.314  |
| Male                  | 54 (50.5%)      | 32 (46.4%)      | 22 (57.9%)      |        |
| Impact III score      |                 |                 |                 |        |
| Well-being            | 77.8 $\pm$ 21.7 | 89 $\pm$ 8.9    | 57.3 $\pm$ 23   | <0.001 |
| Emotional Functioning | 70.6 $\pm$ 20.5 | 80.2 $\pm$ 12.7 | 53 $\pm$ 20.5   | <0.001 |
| Social Functioning    | 77.3 $\pm$ 18.2 | 85.9 $\pm$ 10.6 | 61.7 $\pm$ 18.9 | <0.001 |
| Body image            | 66.6 $\pm$ 21.6 | 70.8 $\pm$ 20.9 | 58.9 $\pm$ 21.2 | 0.006  |
| Total score           | 75.2 $\pm$ 17.8 | 84.5 $\pm$ 8.7  | 58.4 $\pm$ 17.8 | <0.001 |

patients. The “impact of the disease on family” had the most prominent influence on the “emotional” domain with a standardized effect size of Hedge’s  $g = 3.05$ , 95% CI 2.49-3.62 followed by the “rules and limitation due to disease” and “fears of having bloody stool”. “Missing hobbies” and “worrying about having flare-up” had significant impact in the well-being domain with an effect size of Hedge’s  $g = 2.36$ , (95% CI 1.85-2.86) and 2.18, 95% CI 1.69-2.68. For more details, refer to supplementary materials.

**HrQOL differences according to type of disease**

According to disease type, patients showed almost similar scores for all evaluated domains, and there were no significant differences regarding the HrQOL between CD and UC patients [Table 1].

**HrQOL differences according to disease activity**

The total IMPACT III score was inversely related to disease activity assessed by PUCAI or PCDAI (“ $\leq 10$ ” vs “ $> 10$ ”:  $73.4 \pm 10.7$  vs  $51.2 \pm 15.7$ , respectively,  $P < 0.001$ ) [Table 3]. No association was detected between disease activity and age, gender, or duration. Sub-domain scores also confirmed similar relation with disease activity, where “future health” and “having chronic disease” were the two most concerning issues for those with active disease in relation to the patient in remission [Figures 1 and 2]. For more details, refer to supplementary materials.

**HrQOL association with baseline characteristics**

A multiple linear regression analysis was performed to

**Table 3: In remission vs. active disease**

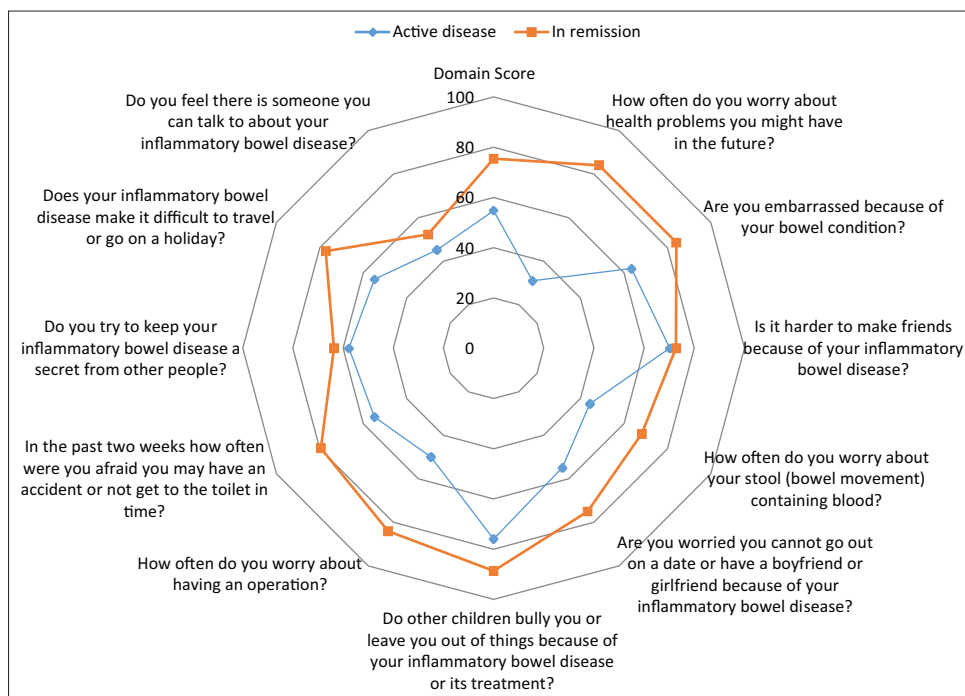
| PUCAI or PCDAI        | $\geq 10$<br>n=11 | $> 10$<br>n=26 | P      |
|-----------------------|-------------------|----------------|--------|
| Age                   | 13.2±1.5          | 12.1±3.1       | 0.485  |
| Gender                |                   |                |        |
| Female                | 6 (54.5%)         | 9 (34.6%)      | 0.295  |
| Male                  | 5 (45.5%)         | 17 (65.4%)     |        |
| Age onset             | 9.3±1.7           | 8.7±3.4        | 0.949  |
| Duration (yr)         | 4.1±2.5           | 3.8±2.6        | 0.657  |
| Impact III score      |                   |                |        |
| Well-being            | 76.1±12.5         | 48.6±21.7      | <0.001 |
| Emotional Functioning | 67.5±14.9         | 46±19.3        | 0.002  |
| Social Functioning    | 75.4±13.9         | 54.8±16.9      | 0.001  |
| Body image            | 71±21             | 53.1±19.5      | 0.025  |
| Total score           | 73.4±10.7         | 51.2±15.7      | <0.001 |

study the association between baseline characteristics and IMPACT III total score. After adjusting the model to account for age and gender, only having IBD had significant association ( $\beta = -0.683$ ,  $P < 0.001$ ).

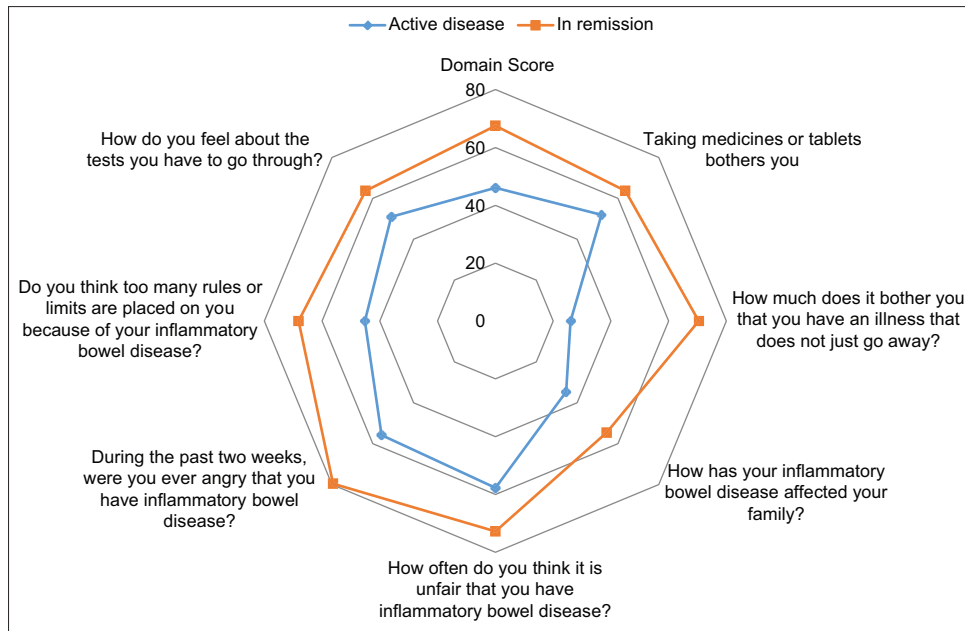
We examined the association in IBD patients as well, wherein only being in remission was found to be significantly related to a higher total score ( $\beta = -0.448$ ,  $P = 0.005$ ) [Table 4].

**DISCUSSION**

Children’s HrQOL can be assessed by using generic and disease-specific measures. Additionally, results can be used to make comparisons between patients with different diseases and healthy controls. However, these tools may not sufficiently capture the effects of disease-specific problems



**Figure 1: Radar figure showing the mean score of each component in active disease and remission in the “social domain”**



**Figure 2:** Radar figure showing the mean score of each component in active disease and remission in the “Emotional domain”

and treatment procedures. The IMPACT questionnaire, a validated assessment which was created for children with all forms of IBD, is currently the most widely used tool for assessing HrQOL,<sup>[19]</sup> and is used in European, South American and Asian countries.<sup>[20-22]</sup> We adopted the four-domain IMPACT III questionnaire to assess our patients’ health-related QOL.<sup>[23]</sup>

In our study, the male-to-female ratio was higher, and CD was the most common disease type, similar to previously published data.<sup>[13,14]</sup> Our patients’ mean age at diagnosis was (8.83) years, which is lower than previously reported data. This could be due to the fact that the maximum age of our pediatric population is only 16 years.<sup>[20,24]</sup> However,

our data is similar to what had been published previously in Saudi Arabia.<sup>[25]</sup>

Children with IBD, as well as those with other organic or functional gastrointestinal diseases, are at risk of experiencing lower HrQOL than their healthy peers.<sup>[12,26,27]</sup> It is not only due to the chronic nature of the disorders that affect children at the physical level but it also impacts them and their families on emotional and psychological levels. In addition, there are reports of impaired self-images and social interaction among these children.<sup>[28,29]</sup> The present study showed that compared with healthy children, IBD was associated with a significant negative effect on HrQOL. Experiencing symptoms that are unpleasant,

**Table 4: Linear regression, association between total score and characteristics for IBD patients only**

|                  | Crud      |        |        |        | Multivariate |       |       |       |
|------------------|-----------|--------|--------|--------|--------------|-------|-------|-------|
|                  | B         | SE     | Beta   | P      | B            | SE    | Beta  | P     |
| Age              | 0.742     | 1.079  | 0.114  | 0.496  |              |       |       |       |
| Gender           |           |        |        |        |              |       |       |       |
| Female           | 5.458     | 5.844  | 0.154  | 0.357  |              |       |       |       |
| Male             | Reference |        |        |        |              |       |       |       |
| IBD type         |           |        |        |        |              |       |       |       |
| UC               | 2.351     | 5.3    | 0.074  | 0.660  |              |       |       |       |
| CD               | Reference |        |        |        |              |       |       |       |
| Onset age        | 0.686     | 0.993  | 0.114  | 0.494  |              |       |       |       |
| Duration         | -0.380    | 1.165  | -0.054 | 0.746  |              |       |       |       |
| Disease activity |           |        |        |        |              |       |       |       |
| Remission        | 21.134    | 5.39   | 0.547  | <0.001 | 17.305       | 5.724 | 0.448 | 0.005 |
| Active           | reference |        |        |        |              |       |       |       |
| Biologics        | -10.532   | 5.579  | -0.3   | 0.067  |              |       |       |       |
| Corticosteroids  | -12.323   | 7.248  | -0.273 | 0.098  |              |       |       |       |
| 5-ASA            | -2.389    | 5.901  | -0.067 | 0.688  |              |       |       |       |
| Immuno-modulator | -2.027    | 5.839  | -0.058 | 0.730  |              |       |       |       |
| Antibiotics      | -11.467   | 12.937 | -0.146 | 0.381  |              |       |       |       |



many of which are embarrassing to discuss, involve invasive diagnostic procedures and treatment regimens that are long-term, and not without adverse effects. In our sample, most of our patients have active diseases and are under 14 years of age, making it more challenging for them to cope with disease-related psychological and social stress. Moreover, we noted that emotional functioning has been the sub-domain most negatively affected by the disease, with the impact of the disease on family dynamic having the most prominent effect. This is clearly noted in a recent review by Cushman *et al.*<sup>[30]</sup> who emphasize the importance of assessing parent and family functioning in pediatric IBD. In addition, Herzer *et al.*<sup>[29]</sup> also found that adolescent depressive symptoms might serve as the mechanism through which parent distress is linked to poorer HrQOL in adolescents with IBD. Hence, it is important to consider how parents and family members' functioning influences the health and psychosocial development of a child with IBD. Failure to do so will lead to a narrow view of a child's diagnosis and will limit options for promoting optimal health.

Children with IBD were found to have issues with self-image, social interaction, and behavioral disturbances. As shown in our analysis, fear of bloody stools, restrictions on patients' daily lives and hobbies were the most obvious adversely affected elements in these sub-domains. Consequently, these findings might be the cause that lead to school absence, social isolation, and psychosocial distress, as evidenced by other studies.<sup>[28,31]</sup>

Existing reports have been inconsistent when comparing patients with CD and UC in terms of HrQOL. Several studies report no such difference,<sup>[24,32,33]</sup> while others describe patients with CD having a poorer QOL, which was attributed to their worst clinical course, treatment complications, and a high incidence of surgical intervention.<sup>[34,35]</sup> However, we found no significant differences in quality-of-life scores between patients who had CD or UC. In addition to the small sample size, the reasons might be due to the fact that the majority of our CD patients have not had surgery yet, and only one patient had active perianal disease.

A major finding of our study is that the disease activity significantly influences the HrQOL of IBD patients. Those in remission reported better HrQOL in relation to all sub-domains especially to well-being and social functioning aspects as well as to a higher total HrQOL score. Additionally, patients in relapses use more medications, experience more worry about their future health, and are burdened by a chronic disease that has no cure, which

negatively influenced their social and emotional function and general well-being. Several previous publications indicated an inverse relationship between low QOL in IBD patients and disease activity regardless of age group.<sup>[36-38]</sup> We believe that achieving disease remission is one of the main objectives in treating IBD patients and this might lead to not only relief of symptoms, but also improvement of psychosocial aspects and a better QOL.

Data about the effects of different medications on HrQOL are conflicting in general, particularly with corticosteroids.<sup>[37,39,40]</sup> According to our findings, two medications, corticosteroids and biologics, have a numerically negative association with HrQOL. This could be because of the small number of patients who were included, or further explained by a higher disease activity and severity, as more than half of our patients with active disease were on biologic and five out of six corticosteroid users were on relapse. Kalafateli *et al.*,<sup>[41]</sup> reported similar findings with the use of biologic in UC patients with severe disease, who have past surgical intervention and short disease duration.

The assessment of the association between disease duration and HrQOL in pediatric IBD populations has generated controversial results.<sup>[41]</sup> Although some studies have shown no clear association, others have found that patients with a long disease duration have a higher HrQOL and reported positively for bowel symptoms, emotional functioning and social functioning.<sup>[32,42,43]</sup> We found no significant difference regarding HrQOL and disease duration, perhaps because we did not evaluate patients during the first few months of their illness and after prolonged periods of time (such as five years), as most of our patients would be transferred to adult care before they turn 16 years old.

There is a well-documented negative relationship between female gender and HrQOL in adult studies,<sup>[44,45]</sup> however, pediatric data are less conclusive.<sup>[42]</sup> Our data indicate no correlation between the female sex and the IMPACT III score, though girls scored higher than boys. In a previous survey conducted in Saudi Arabia, the health-related QOL of 489 healthy children was assessed. It has been found that boys had lower scores than girls in several domains, depending on their age group. It may represent sociocultural factors in our region which lead to discrepancies between girls and boys in terms of the assistance and emotional support received from their parents, and subsequently influence their health-related QOL.<sup>[46]</sup>

A variety of psychosocial interventions have been demonstrated to have positive effects on HrQOL, coping with

illness, anxiety and depression in patients with IBD. Cognitive behavioral therapy (CBT) has the most empirical evidence to support its use. M Mussell *et al.*,<sup>[47]</sup> had found a significant decrease in disease-related concerns and depression among adult patients with IBD receiving CBT. Another study reported significant improvements in HrQOL and anxiety scores in adults with UC randomized to a comprehensive lifestyle modification program (stress-management, education, and self-care strategies) vs conventional treatment.<sup>[48]</sup> Hence, in our center identifying patients with low HrQOL allowed us to address them in a timely manner, as two female patients had been evaluated by both a clinical psychologist and psychiatric specialists before being transferred to adult care. Other patients' treatment revisions had a positive impact on their overall health.

Our study is limited in its cross-sectional design, which does not allow us to determine a cause-and-effect relationship. Secondly, a small sample size, relatively young age, and short disease duration may prevent the findings from being extrapolated and reaching statistical significance. In spite of that, it allows the estimation of factors influencing QOL. Lastly, the current study sample is limited to single-center population; hence, our findings cannot be generalized.

Future prospective studies are needed in our local area to investigate other socioeconomic factors that have a direct relation to HrQOL scores such as level of education, social support, economic status, and access to a healthcare facility.<sup>[45,49]</sup> Furthermore, the influence of a low HrQOL on healthcare costs and utilization should be addressed, as this had been linked to an increase in medical consultations and unnecessary healthcare utilization in a previous report.<sup>[50]</sup> To our knowledge, adding routine HrQOL screening to pediatric IBD patients might allow for early identification of patients with poor HrQOL and intervention to improve the overall health outcomes.

In conclusion, this cross-sectional study found that Saudi pediatric IBD patients have significantly lower HrQOL scores compared to healthy controls. Disease activity is the only negative predictor of low HrQOL. This supports that patients living with chronic illness in our community suffer from psychosocial and emotional distress; therefore, we emphasize the importance of integrating HrQOL into the assessment of pediatric IBD patients to promote better disease control and satisfactory QOL in children during their long journey of IBD. This integration should include parents and caregivers as part of assessment and management.

#### Financial support and sponsorship

Nil.

#### Conflicts of interest

There are no conflicts of interest.

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## SUPPLEMENTARY MATERIALS

**Table 1: Control vs. IBD detailed items**

| Characteristics  | Total<br>107 | Control<br>69 | IBD<br>38 | P      | Effect<br>size* | 95% CI |       |
|--|--------------|---------------|-----------|--------|-----------------|--------|-------|
|  |              |               |           |        |                 | lower  | upper |
| Well-being domain  | 77.8±21.7    | 89±8.9        | 57.3±23   | <0.001 | 2.05            | 1.56   | 2.53  |
| How much has your stomach been hurting you in the past two weeks?  | 75±28.5      | 84.4±23.5     | 57.9±29.1 | <0.001 | 1.03            | 0.61   | 1.45  |
| How often has your inflammatory bowel disease prevented you from eating what you want in the past two weeks?   | 84.6±28.2    | 99.3±4.2      | 57.9±33.3 | <0.001 | 2.04            | 1.56   | 2.52  |
| How often have you been worrying about having a flare-up (increase of symptoms) in the last two weeks?   | 82.3±30.3    | 98.6±8.4      | 52.7±33.2 | <0.001 | 2.18            | 1.69   | 2.68  |
| How much energy did you have during the past two weeks?  | 81.6±26.6    | 88.8±23.7     | 68.4±27   | <0.001 | 0.81            | 0.4    | 1.22  |
| How often did you have to miss out on certain things (hobbies, play, parties) because of your inflammatory bowel disease in the past two weeks?                | 81.6±30.5    | 98.6±5.9      | 50.7±33   | <0.001 | 2.36            | 1.85   | 2.86  |
| How often have you been bothered by diarrhea (loose or frequent bowel movements) in the past two weeks?  | 79±29.4      | 90.6±18.2     | 57.9±33.9 | <0.001 | 1.3             | 0.87   | 1.73  |
| Did you have fun during the past two weeks?  | 59.8±39.3    | 64.5±40.5     | 51.3±35.8 | 0.097  | 0.34            | -0.06  | 0.73  |
| How often did you feel sick to your stomach in the past two weeks?   | 79.4±28.3    | 92±13.2       | 56.6±33.7 | <0.001 | 1.55            | 1.11   | 2     |
| How did you feel during the past two weeks?  | 82.9±24.7    | 90.9±17.1     | 68.4±29.5 | <0.001 | 1               | 0.59   | 1.42  |
| How tired have you felt in the past two weeks?   | 79.9±26      | 89.9±16.2     | 61.8±30.6 | <0.001 | 1.24            | 0.81   | 1.67  |
| Does your inflammatory bowel disease get in the way of playing sports the way you would like to?   | 68.5±34.7    | 80.4±30.9     | 46.7±30.9 | <0.001 | 1.08            | 0.66   | 1.51  |
| In the past two weeks how often were you able to go to school? (If you are in the middle of a school break or the summer holidays, answer as if school was on) | 78.5±33.2    | 90.6±23.5     | 56.6±37.1 | <0.001 | 1.16            | 0.74   | 1.59  |
| Emotional domain   | 70.6±20.5    | 80.2±12.7     | 53±20.5   | <0.001 | 1.7             | 1.24   | 2.16  |
| Taking medicines or tablets bothers you  | 56.6±33.9    | 58±37.7       | 53.9±25.7 | 0.514  | 0.12            | -0.28  | 0.51  |
| How much does it bother you that you have an illness that does not just go away?   | 60.5±35      | 71.4±31       | 40.8±33.5 | <0.001 | 0.95            | 0.53   | 1.37  |
| How has your inflammatory bowel disease affected your family?  | 78.5±33.9    | 99.3±4.2      | 40.8±31.5 | <0.001 | 3.05            | 2.49   | 3.62  |
| How often do you think it is unfair that you have inflammatory bowel disease?  | 81.8±28.4    | 92±22.5       | 63.2±28.9 | <0.001 | 1.15            | 0.72   | 1.57  |
| During the past two weeks, were you ever angry that you have inflammatory bowel disease?   | 79.9±28      | 88.8±23.7     | 63.8±28.3 | <0.001 | 0.97            | 0.56   | 1.39  |
| Do you think too many rules or limits are placed on you because of your inflammatory bowel disease?  | 81.5±27.8    | 97.1±10.1     | 53.3±27.4 | <0.001 | 2.4             | 1.89   | 2.9   |
| How do you feel about the tests you have to go through?  | 55.2±31.9    | 55.1±36.3     | 55.3±22.6 | 0.972  | -0.01           | -0.4   | 0.39  |
| Social Functioning domain  | 77.3±18.2    | 85.9±10.6     | 61.7±18.9 | <0.001 | 1.71            | 1.25   | 2.16  |
| How often do you worry about health problems you might have in the future?   | 65.7±35.2    | 75.4±31.6     | 48.2±34.8 | <0.001 | 0.82            | 0.41   | 1.23  |
| Are you embarrassed because of your bowel condition?   | 87.2±21.5    | 96.4±15       | 70.4±21.6 | <0.001 | 1.46            | 1.02   | 1.9   |
| Is it harder to make friends because of your inflammatory bowel disease?   | 88.1±22.8    | 97.1±11.8     | 71.7±28.5 | <0.001 | 1.3             | 0.87   | 1.73  |
| How often do you worry about your stool (bowel movement) containing blood?   | 80.6±29.1    | 96±11         | 52.7±31.1 | <0.001 | 2.1             | 1.61   | 2.59  |
| Are you worried you cannot go out on a date or have a boyfriend or girlfriend because of your inflammatory bowel disease?                                      | 81.3±28.3    | 92±18.9       | 61.9±32.2 | <0.001 | 1.23            | 0.8    | 1.65  |
| Do other children bully you or leave you out of things because of your inflammatory bowel disease or its treatment?  | 92.5±16.9    | 99.3±4.2      | 80.3±23.4 | <0.001 | 1.32            | 0.89   | 1.76  |
| How often do you worry about having an operation?  | 39.5±37      | 29±36.5       | 58.6±29.8 | <0.001 | -0.86           | -1.27  | -0.44 |
| In the past two weeks how often were you afraid you may have an accident or not get to the toilet in time?   | 81.8±24.4    | 92±15.7       | 63.2±26.5 | <0.001 | 1.42            | 0.98   | 1.86  |
| Do you try to keep your inflammatory bowel disease a secret from other people?   | 81.3±28.3    | 92.8±19.7     | 60.5±30   | <0.001 | 1.34            | 0.91   | 1.78  |
| Does your inflammatory bowel disease make it difficult to travel or go on a holiday?   | 79.2±27.8    | 88.4±21.3     | 62.5±30.6 | <0.001 | 1.03            | 0.61   | 1.45  |
| Do you feel there is someone you can talk to about your inflammatory bowel disease?  | 72.9±33.6    | 86.2±27.3     | 48.7±30.7 | <0.001 | 1.31            | 0.87   | 1.74  |
| Body Image domain  | 66.6±21.6    | 70.8±20.9     | 58.9±21.2 | 0.006  | 0.57            | 0.16   | 0.97  |
| How do you feel about your weight?   | 56.3±32      | 58.7±34.2     | 52±27.5   | 0.270  | 0.21            | -0.19  | 0.61  |
| How do you feel about the way you look?  | 74.8±25.6    | 80.4±23.4     | 64.5±26.4 | 0.002  | 0.65            | 0.24   | 1.05  |
| Are you happy with your life?  | 61±34.9      | 63.8±37.3     | 55.9±29.9 | 0.238  | 0.22            | -0.17  | 0.62  |
| How do you feel about your height?   | 74.3±28.4    | 80.4±25.7     | 63.2±30.1 | 0.002  | 0.63            | 0.22   | 1.03  |
| Q31 How often did you have to pass gas in the past two weeks?  | 88.1±20.1    | 97.8±7.1      | 70.4±23.8 | <0.001 | 1.79            | 1.32   | 2.25  |
| Total IMPACT-III Score   | 75.2±17.8    | 84.5±8.7      | 58.4±17.8 | <0.001 | 2.05            | 1.57   | 2.53  |

\*The corrected effect size, or Hedges's g with its 95% confidence interval