



Original Research

Evaluation of Quality of Life and Psychosocial Status in Children with Inflammatory Bowel Disease

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Abstract

Objectives: Inflammatory bowel disease (IBD) in children is a chronic condition that affects the psychosocial status and physical activities of children and their parents. This study aimed to investigate the impact of IBD on the quality of life of adolescents and their families and the variability of behavioral and emotional adjustment issues compared to a healthy control group.

Methods: This study was designed as a prospective controlled study. A total of 159 cases were included, consisting of 84 IBD patients aged between 8-17 years and 75 healthy control subjects. All children and their parents included in the study were administered the Pediatric Quality of Life Inventory (PedsQL) and the Strengths and Difficulties Questionnaire (SDQ) for adolescents and parents.

Results: The median ages of the IBD children and the control group were 13.5 and 13, respectively. Of all 154 cases, 87 were female and 72 were male. Among the patients diagnosed with IBD, 39 had Crohn's disease, 37 had ulcerative colitis, and 8 had indeterminate colitis. It was observed that both the PedsQL and SDQ scores of children and parents with IBD were statistically significantly lower in both physical and psychosocial scoring ($p=0.01$ and $p<0.001$, respectively). A weak but statistically significant correlation was observed between the PedsQL and SDQ results applied to parents ($\rho=-0.214$, $p=0.007$) and children ($\rho=-0.208$, $p=0.008$).

Conclusion: The lower PedsQL and SDQ scores in children with IBD and their parents suggest that IBD negatively affects psychosocial, physical, and behavioral adaptations in children.

Keywords: Crohn's disease, Pediatric Quality of Life Inventory, Strengths and Difficulties Questionnaire, ulcerative colitis

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Inflammatory bowel disease (IBD) is a gastrointestinal disorder characterized by remissions and relapses, posing significant morbidity in children. It encompasses ulcerative colitis (UC), Crohn's disease (CD), and indeterminate colitis (IC) based on phenotypic features.^[1] The increasing prevalence of IBD in children leads to symptoms such as bloody

diarrhea, abdominal pain, fatigue, and anemia. Factors such as recurrent attacks, hospitalizations, outpatient clinic controls and gastrointestinal symptoms in IBD patients may create psychosocial effects on patients and affect their social lives. Furthermore, some studies in the literature have reported low physical activity and psychosocial

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functioning, irritability due to anemia, decreased academic performance, and changes in mental status in adolescents with IBD.^[2-4] However, there is no consensus on whether the psychosocial status of children with IBD differs from that of healthy children.^[2] Our study aims to comparatively assess physical activity, psychosocial functioning, and behavioral problems in children with IBD and healthy controls through surveys.

Methods

Our study is a prospective controlled trial, was conducted under the Helsinki Declaration, received approval from Şişli Etfal Training and Research Hospital Clinical Research Ethics Committee (30.01.2024, No: 2562) and was registered to ClinicalTrials.gov (NCT06270277). Written informed consent was obtained from all participants.

Eligible patients and a healthy control group enrolled in this study between 14.02.2024 and 20.02.2024. Children with IBD and healthy control group and the parents of both groups were administered the Pediatric Quality of Life Inventory (PedsQL) and Strengths and Difficulties Questionnaire (SDQ). The PedsQL is a scale used to assess physical and psychosocial functioning based on the individual's own experiences, commonly employed in clinical trials and quality improvement initiatives. The scale evaluates physical activity status and psychosocial functioning through questions related to emotional, social, and school-related issues.^[5]

Pediatric Quality of Life Inventory (PedsQL)

PedsQL was developed by Varni et al. in 2001.^[6] The Turkish validity and reliability study for ages 13-18 was conducted in 2007, and for ages 8-12 in 2008 by Çakın Memik et al.^[7,8] The inventory consists of parent, child, and adolescent forms. Scores calculated according to test guidelines and higher scores on the Pediatric Quality of Life Inventory indicate better quality of life.

Strengths and Difficulties Questionnaire (SDQ)

The Strengths and Difficulties Questionnaire (SDQ) was developed by Goodman in 1997.^[9] The Turkish validity and reliability study of the SDQ was conducted in 2008 by Güvenir et al.^[10] This questionnaire includes parent and teacher forms for children aged 4-17 years and a self-report form for adolescents aged 11-17 years. The form used in your study is the parent form for children aged 4-17 years and the adolescent form for those aged 11-17 years. Increasing scores indicate more difficulties in adolescents.

Sample Size and Statistical Analysis

Sample size analysis was conducted using the G-Power (version 3.1) software. Assuming an effect size (d) of 0.3

(Cohen's medium effect level), a confidence level (1-α) of 95%, and a test power (1-β) of 80%, the minimum required sample size per group was calculated as 64. Since the study was planned with two groups, IBD and control, the minimum total number of patients required for the study was determined to be 128.

In the study, the normality of continuous variables was assessed using the Shapiro-Wilk test. Categorical variables were presented as frequencies (%), while continuous variables were presented as median and interquartile range (IQR25-75). For comparisons between two groups of continuous variables, the Mann-Whitney U test (for data not showing normal distribution) was used, and for comparisons among more than two groups, the Kruskal-Wallis test was employed. Correlation analysis was conducted using Spearman's correlation analysis. Statistical calculations were performed using SPSS software version 22 (IBM Corp., Armonk, NY, USA). Results with a significance level of p<0.05, at a 95% confidence interval, were considered statistically significant.

Results

Our study included 84 patients diagnosed with inflammatory bowel disease (IBD), aged between 8 and 17 years, who presented to the pediatric gastroenterology outpatient clinic in January 2024, along with 75 cases without any underlying diseases. Among the patients with IBD, 39 had Crohn's disease, 37 had ulcerative colitis, and 8 had indeterminate colitis. The median ages and range values of the IBD and control groups were found to be 13.5 (8-17) and 13 (8-17) years, respectively (p=0.216). Of the cases, 87 (54.7%) were female, and 72 (45.3%) were male (p=0.44) (Table 1).

PedsQL scores were significantly lower in the IBD group compared to the control group (p=0.01). Subgroup analysis showed no significant difference between CD and UC cases (p=0.489). PedsQL parent scores in the IBD group were also

Table 1. The demographic data of the children and their families participating			
Variables	IBD (n=84)	Control (n=75)	p
Age (Median year, range)*	13.5 (8-17)	13 (8-17)	0.216**
Gender			
Female (%)	44 (54.7)	43 (45.3)	0.44**
Male (%)	40 (45.3)	32 (54.7)	0.44**
Parent age (Median year, range)*	45.5 (30-49)	44.5 (29-50)	0.39**

*Shapiro-Wilk Normality test **Mann-Whitney U test, IBD: Inflammatory bowel disease.

significantly lower than those in the control group ($p=0.02$). Both physical and psychosocial scores were lower in the IBD group than in the control group, for both patients and their parents (Table 2).

A weak, positive, and significant correlation was observed between the PedsQL child and parent scores. Similarly, the PedsQL physical and psychosocial scores also demonstrated a weak, positive, and significant correlation between children and their parents. A strong, positive, and significant correlation was found between the SDQ child and parent scores. When the PedsQL and SDQ scores were compared, a weak, negative, and significant correlation was observed between them (Table 3).

Regarding the SDQ scale, abnormal scores were observed in 78% ($n=65$) of the IBD group and 13% ($n=13$) of the control group. SDQ scores were significantly higher in IBD patients ($p<0.001$). The IBD group had higher scores across all SDQ subscales, including emotional symptoms, behavioral problems, attention deficit and hyperactivity, as well as peer and social problems (Table 4).

Discussion

Our study is the first to assess both the perceived quality of life and behavioral problems, peer relationships, and focus on problems in children with IBD and their parents. In our study, compared to the control group, children with IBD had lower levels of physical activity and psychosocial functioning, while behavioral problems, peer issues, attention deficits, and emotional instability were more prevalent. Relapses and multiple hospitalizations, repeated surgical requirements during the course of IBD, and the consequent social isolation compared to healthy children may contribute to these outcomes. Additionally, chronic disease-related anemia, malnutrition, and micronutrient deficiencies during this process may also contribute to these outcomes.^[11,12] However, a similar study conducted in Switzerland found similar questionnaire results regarding

Table 3. The correlation analysis of PedsQL and SDQ scores of the cases and their families participating

Variables	Spearman correlation coefficient	p
PedsQLChild/Parent	$\rho=0.215$	$p=0.007^*$
PedsQLChild/Parent physical	$\rho=0.379$	$p=0.001^*$
PedsQLChild/Parent psychosocial	$\rho=0.311$	$p=0.001^*$
SDQ Child/Parent	$\rho=0.876$	$p<0.001^*$
SDQ/PedsQL Child	$\rho=-0.208$	$p=0.008^*$
SDQ/PedsQL Parent	$\rho=-0.214$	$p=0.007^*$

*Spearman correlation analysis, PedsQL: Pediatric Quality of Life Inventory, SDQ: Strengths and difficulties questionnaire.

Table 4. The SDQ scores of the subjects

Variables (Median/IQR ₂₅₋₇₅)	IBD (n=84)	Control (n=75)	p
SDQ total points	19.5 (16-22)	14 (12-15)	$p<0.001^*$
Emotional Symptoms	3 (1.25-4)	2 (1-3)	$p=0.001^*$
Behavioral Problems	2 (1-3)	2 (1-2)	$p=0.003^*$
Attention Deficit and Hyperactivity	3 (1-3)	2 (1-3)	$p=0.011^*$
Peer Problems	3 (2-5)	2 (2-3)	$p<0.001^*$
Social Problems	8 (2-4)	2 (3-7)	$p<0.001^*$

*Mann-Whitney U test; IBD: Inflammatory bowel disease; SDQ: Strengths and difficulties questionnaire.

emotional and behavioral adjustment problems between the IBD and healthy groups, indicating that the difference between these two groups may vary depending on the socio-economic levels of the countries.^[2]

In the literature, although no significant difference is observed between CD and UC, some studies suggest that psychosocial status may be affected differently in CD and UC patients, and disease activity may affect psychosocial status.^[13,14] In our study, although no significant difference was observed in PedsQL scores according to IBD subgroups,

Table 2. The PedsQL scores of the cases and their families participating

Variables (Median/IQR ₂₅₋₇₅)	IBD N=84	Control N=75	Test value	p
PedsQLChild	46.15 (33.03-56.5)	55.4 (44.5-70.6)	-4.155*	$p=0.01^*$
PedsQLParent	44.78 (33.25-55.77)	58.6 (51.2-75)	-5.04*	$p=0.02^*$
PedsQLChild physical	40.6 (30.3-56.25)	50 (37.75-78.1)	-3.64*	$p=0.001^*$
PedsQLParent physical	37.5 (30-53.23)	62.45(46.84-80)	-5.1*	$p<0.001^*$
PedsQLChild psychosocial	46.6 (35-58.3)	60 (48.3-80)	-4.86*	$p=0.03^*$
PedsQLParent psychosocial	48.4 (35-62.3)	61.7 (48.4-82.5)	-4.2*	$p<0.001^*$

*Mann-Whitney U test; IBD: Inflammatory bowel disease; PedsQL: Pediatric Quality of Life Inventory.

further studies with larger series would be useful to evaluate how psychosocial status is affected in CD and UC subgroups.

It is known that the quality of life of caregivers is similarly affected as the patients themselves in children with chronic diseases.^[15] Varni et al.^[6] reported a moderate relationship between average child-adolescent and parent scale scores. In our study, a positive correlation was found between the average PedsQL scores of patients and their parents in all subgroups, which is consistent with the literature. This suggests that parents experiencing chronic disease processes are similarly affected by this process and have similar perceptions of quality of life as their children.

Several factors may contribute to the lower school-related functionality of children with IBD observed in our study. These include differences in toilet habits compared to healthy children, inability to attend school due to frequent hospital visits and, when necessary, hospitalizations, the development of side effects due to medication use, and variability in eating habits.

Majority of children participating in the study were between the ages of 10-17, and this being adolescent period may have led to a greater impact on the perceived quality of life and coping skills with difficulties compared to the chronic disease. The adolescent period is an important period in which the child undergoes physical and psychosocial changes, establishes friendships, forms connections with society, and makes plans for the future. It is reported in the literature that chronic disease processes negatively affect the physical and psychosocial development of children.^[16,17]

Studies in the literature have reported that emotional instability and behavioral problems are more common in adolescents with IBD compared to healthy children.^[18,19] However, in Herzog et al.'s study,^[2] lower scores were obtained in SDQ scoring in children with IBD compared to the control group. In our study, higher scores were observed in all categories of SDQ scores in the IBD cases compared to the control group, supporting the idea that emotional instability, behavioral problems, peer issues, and attention deficits are more prevalent in these children. Nevertheless, considering the different results in the literature, it may be necessary to conduct evaluations in larger series.

Conclusion

In our study, both IBD patients and their families exhibited a lower quality of life compared to the control group. Providing psychosocial support to both the child and their family, in addition to medical treatment, may be beneficial in improving the quality of life in this patient group.

Disclosures

Ethics Committee Approval: This study was approved by the Sisli Etfal Training and Research Hospital Clinical Research Ethics Committee (30.01.2024, No: 2562).

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