

Assessment of Quality of Life Among Children with Inflammatory Bowel Disease

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ABSTRACT

Objective: To evaluate the quality of life among children with inflammatory bowel disease (IBD) by the inflammatory bowel disease questionnaire.

Study Design: Cross-sectional study.

Place and Duration of the Study: Department of Pediatric Gastroenterology, Children's Hospital and Institution of Child Health, Lahore Pakistan, from Nov 2020 to Apr 2021.

Methodology: A total of 60 cases (Crohn's disease or ulcerative colitis) were enrolled in the study. Quality of life was measured according to the Modified IMPACT-III questionnaire.

Results: There were 38(63.3%) males and 22(36.7%) female children. The mean age was 9.57 ± 3.40 years, while 33(55.0%) children were above ten years. The mean maternal age was found to be 37.10 ± 4.09 years. There were 36(60.0%) children with Crohn's disease, while 24(40.0%) had ulcerative colitis. Children with Crohn's disease were found to have a significantly low quality of life compared to children in the ulcerative colitis group in the social domain ($p < 0.05$). In addition, children with ulcerative colitis had a significantly low quality of life with regard to bowel symptoms ($p < 0.05$).

Conclusion: Overall scores showed a low quality of life among children with IBD. Children with Crohn's disease had significantly low social QoL, while children with ulcerative colitis showed significantly low QoL regarding bowel symptoms.

Keywords: Crohn's disease, Modified impact-III, Quality of life, Ulcerative colitis.

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INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic multifactorial disorder, classified into two major groups Crohn's disease and ulcerative colitis, and an unclassified group of IBD.¹ In ulcerative colitis, the inflammatory response is restricted to the mucosa of the colon only. At the same time, in Crohn's disease, inflammation is transmural and can involve any part from the mouth to the perianal area.²⁻⁴ The major symptoms are diarrhoea (sometimes with mucous and blood), abdominal pain, malnutrition, weight loss and tiredness. The long-term need for medications, the relapsing nature of the disease, surgeries and frequent hospitalizations are challenging for patients and parents and affect their quality of life. The prevalence of IBD is higher in developed countries and is increasing worldwide.⁵⁻⁷ There is no valid epidemiological study about the incidence of IBD in Pakistan.

IBD is a chronic disease with remitting and relapsing course, affecting patients' quality of life. Several international studies have been published on this

subject, most of which support that patients with IBD significantly affect QOL compared to the normal population.⁷⁻⁹ No local study has shown the quality of life among children suffering from IBD. This study aimed to evaluate the quality of life (QoL) of children with IBD by the IBD questionnaire. We were focused on assessing the QoL in Pakistani pediatric patients of IBD and attempted to identify how the duration and type of disease in IBD patients affect patients' physical, mental and emotional well-being.

METHODOLOGY

This cross-sectional study was conducted at The Department of Pediatric Gastroenterology, Children's Hospital and Institute of Child Health, Lahore Pakistan from November 2020 to April 2021. Approval from the Institutional Ethical Committee was sought (Ref#2020-122, dated: 21-07-2020). In addition, informed consent from the parents of the patients was taken to include their data in the study.

Inclusion Criteria: Children of both genders aged six months to 14 years diagnosed with ulcerative colitis or Crohn's disease based on clinical history, physical examination, and endoscopic and histopathology findings were included from the study.

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Exclusion Criteria: Children with poor compliance, indeterminate colitis or any chronic illness were excluded from the study.

During the study period, 60 cases fulfilling inclusion criteria were enrolled from Outpatient and Inpatient from the Department of Pediatric Gastroenterology, adopting a non-probability consecutive sampling technique. Ulcerative colitis was defined as continuous inflammation restricted to the colon with histological evidence.¹⁰ Crohn's disease was labelled as skipped, non-contiguous chronic inflammation of the gastrointestinal tract with or without granulomas and reinforced by clinical, histologic and endoscopic evidence.¹¹

Demographic information like age, gender, area of residence, maternal age and education were recorded. Age at the time of diagnosis of the disease was noted. Quality of life was measured according to the modified IMPACT-III questionnaire approved by the institutional ethical review board (Table-I).¹¹

The questionnaire was translated into the local

condition. Scores above three were taken as high, while below or equal to one were taken as low. The lower the score, the higher the quality of life; the higher the score, the lower the quality of life. Crohn's disease activity index (PCDAI),¹² or the Pediatric Ulcerative Colitis activity index (PUCAI),¹³ were used to classify remission (PCDAI ≤ 10 or PUCAI ≤ 10).

Statistical Package for Social Sciences (SPSS) version 26.0 was used for the data analysis. Mean and standard deviation were computed for quantitative variables like age, age at the time of diagnosis, maternal age and QOL scores. Frequency and percentage were calculated for qualitative variables like type of IBD, gender, area of residence and maternal education. The chi-square test was applied to compare different study variables among different types of IBD disease. The independent sample t-test was employed to compare QOL scores between different types of IBD disease groups. The *p*-value less than or equal to 0.05 was considered significant.

Table-I: Modified IMPACT-III questionnaire¹¹ for measuring of Quality of Life among Children having Inflammatory Bowel Disease (IBD)

| Q | Description | Score | | | | |
|----|---|------------|------------------------|------------------|------------------|--------------|
| | | 1 | 2 | 3 | 4 | 5 |
| 1 | How many time | Not at all | Hardly any of the time | Some of the time | Most of the time | All the time |
| 2 | How many times did you need to seek medical consultation? | Not at all | Hardly any of the time | Some of the time | Most of the time | All the time |
| 3 | How many times did you feel fatigued? | Not at all | Hardly any of the time | Some of the time | Most of the time | All the time |
| 4 | You miss active participation in exercise/sports activities? | Not at all | Hardly any of the time | Some of the time | Most of the time | All the time |
| 5 | How many times did you feel low/discouraged? | Not at all | Hardly any of the time | Some of the time | Most of the time | All the time |
| 6 | How much problem did you face in gaining average weight of your/your child's age? | Not at all | Hardly any of the time | Some of the time | Most of the time | All the time |
| 7 | How many times did you feel pain in abdomen? | Not at all | Hardly any of the time | Some of the time | Most of the time | All the time |
| 8 | How many times did you have sleep disturbances? | Not at all | Hardly any of the time | Some of the time | Most of the time | All the time |
| 9 | How many times did you miss your medication? | Not at all | Hardly any of the time | Some of the time | Most of the time | All the time |
| 10 | Did your child's disease put an economic burden on you? | Not at all | Hardly any of the time | Some of the time | Most of the time | All the time |

language (Urdu), and questions were asked in the presence of parents. The questionnaire consisted of five subdomains as social (Q1,Q4), physical (Q2,Q6), emotional functioning (Q3,Q5), bowel symptoms (Q7, Q8), and economic constraints (Q9,Q10). On a 5-point Likert scale, children indicated the extent to which they were bothered by specific aspects of their health

RESULTS

Of sixty children, 38(63.3%) were males, and 22(36.7%) were females. The mean age was 9.5±3.4 years, while 33(55.0%) children were above ten years old. There were 36(60.0%) children who belonged to rural areas. The mean maternal age was 37.10±4.09 years, whereas 48(80.0%) mothers were aged above 35

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years. There were 36(60.0%) children with Crohn's disease, while 24(40.0%) had ulcerative colitis. Table-II showed the characteristics of all children with IBD, and there was no statistically significant difference between children with Crohn's disease and ulcerative colitis. Table-III showed showing assessment of QoL according to the Modified Impact-III questionnaire among children with IBD. Overall scores for questions 1-8

DISCUSSION

Assessing QoL among patients of IBD is considered a major component of medical management and decision-making. The last couple of decades have seen swift progress in measuring QoL among patients of IBD, and the number of instruments has appeared with variability in assessment methods.¹⁴⁻¹⁶ This present study from Pakistan adds to what little is already

Table-II: Characteristics of Children with Inflammatory Bowel Disease (n=60)

| Characteristics | | Crohn's Disease (n=36) | Ulcerative Colitis (n=24) | p-value |
|---------------------------------|---------------------|------------------------|---------------------------|---------|
| Gender | Male | 21(58.3%) | 17(70.8%) | 0.325 |
| | Female | 15(41.7%) | 7(29.2%) | |
| Age in years (Mean±SD) | | 9.2±4.0 | 10.2±2.2 | 0.287 |
| Residence | Urban | 15(41.7%) | 9(37.5%) | 0.747 |
| | Rural | 21(58.3%) | 15(62.5%) | |
| Maternal Age in years (Mean±SD) | | 36.39±5.0 | 38.17±1.7 | 0.099 |
| Maternal Education | Uneducated | 7(19.4%) | 6(25.0%) | 0.366 |
| | Primary | 5(13.9%) | 7(29.2%) | |
| | Matriculation | 7(19.4%) | 5(20.8%) | |
| | Intermediate | 8(22.2%) | 4(16.7%) | |
| | Graduation or Above | 9(25.0%) | 2(8.3%) | |
| Age at the time of Diagnosis | | 8.3±3.8 | 7.2±2.2 | 0.218 |
| Hospitalizations Needed | | 4(8.1%) | 3(12.5%) | 0.870 |
| Disease in Remission | | 24(66.7%) | 12(50.0%) | 0.197 |

Table-III: Assessment of Quality of Life according to Modified Impact-III Questionnaire

| Question Number | Questions | Scores (Mean±SD) | | |
|-----------------|---|------------------------|---------------------------|---------|
| | | Crohn's Disease (n=36) | Ulcerative Colitis (n=24) | p-value |
| 1 | How many times did you miss school? | 4.50±0.85 | 4.58±0.66 | 0.685 |
| 2 | How many times did you need to seek medical consultation? | 3.44±0.64 | 3.42±0.78 | 0.877 |
| 3 | How many times did you feel fatigued? | 3.89±1.17 | 3.38±0.82 | 0.067 |
| 4 | You miss active participation in exercise / sports activities? | 3.64±1.18 | 3.17±1.27 | 0.146 |
| 5 | How many times did you feel low / discouraged? | 3.64±1.06 | 3.05±1.11 | 0.012 |
| 6 | How much problem did you face in gaining average weight of your / your child's age? | 3.67±1.55 | 3.75±0.79 | 0.809 |
| 7 | How many times did you feel pain in abdomen? | 3.03±1.06 | 3.82±1.09 | 0.006 |
| 8 | How many times did you have sleep disturbances? | 3.22±0.87 | 3.75±1.15 | 0.047 |
| 9 | How many times did you miss your medication? | 2.50±1.38 | 2.29±1.12 | 0.208 |
| 10 | Did your child's disease put an economic burden on you? | 2.00±0.89 | 2.33±1.09 | 0.200 |

were high (>3). Children with Crohn's disease were found to have significantly higher scores in terms of "How many times did you feel low/discouraged?" when compared to children in the ulcerative colitis group (3.64±1.06 vs 3.05±1.11, $p=0.012$). Likewise, children with ulcerative colitis had significantly higher scores regarding "How many times did you feel pain in the abdomen?" (3.82±1.09 vs 3.03±1.06, $p=0.006$). Sleep disturbances were significantly more among children with ulcerative colitis than among Crohn's disease (3.75±1.15 vs 3.22±0.87, $p=0.047$).

known about the status of QoL among children with IBD. The research aimed to add to what is already known about the work done on the original Impact Questionnaire. Overall scores regarding QoL were high, showing the decreased quality of life among sufferers of IBD. It was seen that QoL credited to emotional functioning (Q5) was significantly decreased among children with Crohn's disease. QoL scores were significantly high in terms of bowel symptoms (Q7,Q8) among children with ulcerative colitis compared to Crohn's Disease. Children with IBD are found to report

low QoL from studies conducted all around the world.⁵⁻⁷ The present study highlighted the need to uplift the QoL among children suffering from IBD.

Ulcerative colitis and Crohn's disease affect the lives of children and adolescents differently. Bowel symptoms are more troubling and disabling to patients with ulcerative colitis, while systemic symptoms and body image concerns are greater for patients with Crohn's disease. A study from Canada highlighted the impact of Crohn's disease on the ability to function in school and leisure activities, as seen in the present study, where children with Crohn's disease had higher scores in the social domain compared to children with ulcerative colitis.¹⁷ Crohn's disease and ulcerative colitis trigger emotional responses of unfairness and frustration, but Sajadinejad *et al.* noted that anger and embarrassment are more prevalent in ulcerative colitis.¹⁸ Disparities between age groups affecting children of inflammatory bowel disease are not many and less marked than those between types of IBD.^{17,19}

Inconsistency is found in comparing the results of QoL between children with Crohn's disease and ulcerative colitis. Gallo *et al.*²⁰ and Kalafateli *et al.* revealed that no significant variation exists regarding differences in quality of life between cases of ulcerative colitis or Crohn's disease,^{20,21} while Cohen described comparatively higher degrees of poorer QoL among patients having Crohn's disease specifically because of its worse clinical course, the consistent requirement of treatment and increased likelihood for surgical intervention.²²

In the present study, we observed that children with Crohn's disease have comparatively higher QoL scores than ulcerative colitis. A study done by Seung *et al.* from Korea found no clear evidence of differences in QoL between children who have ulcerative colitis or Crohn's disease in terms of total scores (135 [23-145] versus 135 [120-147]). According to Paris Classification, a recent study from Seoul, Korea, to measure QoL among children with IBD found no significant difference between Crohn's disease/ulcerative colitis and QoL.³ The authors concluded that several clinical contributors might impact the QoL in IBD, but evaluating the net QoL based on these clinical contributors is not enough to directly measure these individuals suffering from IBD.

LIMITATIONS OF STUDY

The present study had some limitations as well. As this was a single-centre study with a comparatively small sample

size, our observations cannot be generalized. Furthermore, we could not record the impact of treatment on the QoL among children with IBD, as that would have further enlightened us about the effectiveness of current management strategies. As disease duration and age are thought to impact QoL among children suffering from IBD significantly, early diagnosis among the pediatric population should be considered the most crucial intervention period.

CONCLUSION

Overall, scores showed a low quality of life among children with IBD. For example, children with Crohn's disease had significantly low social QoL, while children with ulcerative colitis showed significantly low QoL regarding bowel symptoms.

Conflict of Interest: None.

Author's Contribution

Following authors have made substantial contributions to the manuscript as under:

HR: Conception, data acquisition, drafting the manuscript, approval of the final version to be published.

HAC & MAA: Data acquisition, data analysis, data interpretation, critical review, approval of the final version to be published.

MNA & ZF: Study design, data analysis, critical review, drafting the manuscript, critical review, approval of the final version to be published.

SSB & AS: Critical review, drafting the manuscript, approval of the final version to be published.

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

REFERENCES

1. Jones LJ, Nguyen CG, Benchimol IE, Bernstein NC, Bitton A, Kaplan GG *et al.* The Impact of Inflammatory Bowel Disease in Canada 2018: Quality of Life. *J Can Assoc Gastroenterol* 2019; 2(Suppl 1): S42-S48. doi: 10.1093/jcag/gwy048.
2. Chouliaras G, Margoni D, Dimakou K, Fessatou S, Panayiotou I, Roma-Giannikou E. Disease impact on the quality of life of children with inflammatory bowel disease. *World J Gastroenterol* 2017; 23(6): 1067-1075. doi: 10.3748/wjg.v23.i6.1067.
3. Seung K, Sowon P, Yunkoo K, Jung Eun K, Ben K, Byung-Ho C, *et al.* Can we estimate quality of life in pediatric inflammatory bowel disease patients? An Asian Multicenter Study. *J Pediatr Gastroenterol Nutr* 2019; 68(1): 45-49. doi: 10.1097/MPG.0000000002119.
4. Mueller R, Ziade F, Pittet V, Fournier N, Ezri J, Schoepfer A, *et al.* Quality of Life in Swiss Paediatric Inflammatory Bowel Disease Patients: Do Patients and Their Parents Experience Disease in the Same Way? *J Crohns Colitis* 2016; 10(3): 269-276. doi: 10.1093/ecco-jcc/jjv199.
5. Wilburn J, McKenna SP, Twiss J, Kemp K, Campbell S. Assessing quality of life in Crohn's disease: development and validation of the Crohn's Life Impact Questionnaire (CLIQ). *Qual Life Res* 2015; 24(9): 2279-2288. doi: 10.1007/s11136-015-0947-1.

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6. Engelmann G, Erhard D, Petersen M, Parzer P, Schlarb AA, Resch F, et al. Health-related quality of life in adolescents with inflammatory bowel disease depends on disease activity and psychiatric comorbidity. *Child Psychiatry Hum Dev* 2015; 46(2): 300-307. doi: 10.1007/s10578-014-0471-5.
7. Carroll MW, Kuenzig ME, Mack DR, Otley AR, Griffiths AM. The Impact of Inflammatory Bowel Disease in Canada 2018: Children and Adolescents with IBD. *J Can Assoc Gastroenterol* 2019; 2(Suppl-1): S49-S67. doi: 10.1093/jcag/gwy056.
8. Kuenzig ME, Benchimol EI, Lee L, Targownik LE, Singh H. The Impact of Inflammatory Bowel Disease in Canada 2018: Direct Costs and Health Services Utilization. *J Can Assoc Gastroenterol* 2019; 2(Suppl 1): S17-S33. doi: 10.1093/jcag/gwy055.
9. Arie L, Sibylle K, Dan T, Johanna C E. ESPGHAN revised Porto criteria for the diagnosis of inflammatory bowel disease in children and adolescents. *J Pediatr Gastroenterol Nutr* 2014; 58(6): 795-806. doi: 10.1097/MPG.000000000000239.
10. Aziz DA, Moin M, Majeed A, Sadiq K, Biloo AG. Paediatric inflammatory bowel disease: Clinical presentation and disease location. *Pak J Med Sci* 2017; 33(4): 793-797. doi: 10.12669/pjms.334.12926.
11. Otley A, Smith C, Nicholas D, Munk M, Avolio J, Sherman PM, et al. The IMPACT questionnaire: a valid measure of health-related quality of life in pediatric inflammatory bowel disease. *J Pediatr Gastroenterol Nutr* 2002; 35(4): 557-63. doi: 10.1097/00005176-200210000-00018.
12. Hyams JS, Ferry GD, Mandel FS, Gryboski JD, Kibort PM, Kirschner BS, et al. Development and validation of a pediatric Crohn's disease activity index. *J Pediatr Gastroenterol Nutr* 1991; 12(4): 439-447.
13. Turner D, Otley AR, Mack D, Hyams J, de Bruijne J. Development, validation, and evaluation of a pediatric ulcerative colitis activity index: a prospective multicenter study. *Gastroenterology* 2007; 133(2): 423-432. doi: 10.1053/j.gastro.2007.05.029.
14. Peyrin-Biroulet L, Cieza A, Sandborn WJ, Coenen M, Chowers Y, Hibi T, et al. Development of the first disability index for inflammatory bowel disease based on the international classification of functioning, disability and health. *Gut* 2012; 61(2): 241-247. doi: 10.1136/gutjnl-2011-300049.
15. Smith JJ, Netuveli G, Sleight SP, Das P, Tekkis PP, Gabe SM, et al. Development of a social morbidity score in patients with chronic ulcerative colitis as a potential guide to treatment. *Colorectal Dis* 2012; 14(5): e250-e257. doi: 10.1111/j.1463-1318.2012.02880.x.
16. Vergara M, Montserrat A, Casellas F, Gallardo O, Suarez D, Motos J, et al. Development and validation of the Crohn's disease perceived work disability questionnaire. *Inflamm Bowel Dis* 2011; 17(11): 2350-2357. doi: 10.1002/ibd.21604.
17. Griffiths AM, Nicholas D, Smith C, Munk M, Stephens D, Durno C, et al. Development of a quality-of-life index for pediatric inflammatory bowel disease: dealing with differences related to age and IBD type. *J Pediatr Gastroenterol Nutr* 1999; 28(4): S46-S52. doi: 10.1097/00005176-199904001-00009.
18. Sajadinejad MS, Asgari K, Molavi H, Kalantari M, Adibi P. Psychological issues in inflammatory bowel disease: an overview. *Gastroenterol Res Pract* 2012; 2012: 106502. doi: 10.1155/2012/106502.
19. Alrubaiy L, Cheung WY, Dodds P, Hutchings HA, Russell IT, Watkins A, et al. Development of a short questionnaire to assess the quality of life in Crohn's disease and ulcerative colitis. *J Crohns Colitis* 2015; 9(1): 66-76. doi: 10.1093/ecco-jcc/jju005.
20. Gallo J, Grant A, Otley AR, Orsi M, MacIntyre B, Gauvry S, et al. Do parents and children agree? Quality-of-life assessment of children with inflammatory bowel disease and their parents. *J Pediatr Gastroenterol Nutr* 2014; 58(4): 481-485. doi: 10.1097/MPG.000000000000236.
21. Kalafateli M, Triantos C, Theocharis G, Giannakopoulou D, Koutroumpakis E, Chronis A, et al. Health-related quality of life in patients with inflammatory bowel disease: a single-center experience. *Ann Gastroenterol* 2013; 26(3): 243-248.
22. Cohen RD. The quality of life in patients with Crohn's disease. *Aliment Pharmacol Ther* 2002; 16(9): 1603-1609. doi: 10.1046/j.1365-2036.2002.01323.x.