HEALTH-RELATED QUALITY OF LIFE IN PEDIATRIC GASTROINTESTINAL DISORDERS: EVIDENCE FROM AN INDIAN TERTIARY CARE SETTING

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Abstract

Background: Functional gastrointestinal disorders (FGIDs) and organic gastrointestinal (GI) diseases are common among children and significantly impact their quality of life. However, comparative data on the extent of this impact in Indian pediatric populations remain limited. Objective: To assess and compare health-related quality of life (HRQOL) in pediatric patients with FGIDs and organic GI diseases against healthy controls using the Pediatric Quality of Life Inventory (PedsQL™) 4.0 Generic Core Scales. Methods: This cross-sectional observational study was conducted at the Department of Pediatrics, Sri Lakshmi Narayana Institute of Medical Sciences (SLIMS), Puducherry. A total of 300 children aged 2–18 years were enrolled: 100 with FGIDs, 100 with organic GI diseases, and 100 healthy controls matched by age and sex. HRQOL was assessed using the child self-report and parent proxy-report versions of the PedsQL 4.0. Statistical analysis included Welch's ANOVA and Games-Howell post hoc tests to compare group differences. Results: Children with FGIDs had the lowest HRQOL scores across all domains—Total Score (66.75±10.90), Physical Health (71.49±12.36), Psychosocial Health (66.31±13.87), and School Functioning (60.42±14.53). Organic GI patients scored moderately lower than healthy controls but significantly higher than FGID patients ($p < 0.001$ for all comparisons). School functioning was the most impacted domain in both patient groups. Conclusion: Pediatric patients with GI disorders, especially FGIDs, experience substantial HRQOL impairments. Routine assessment of HRQOL and integrated multidisciplinary care approaches are essential for improving clinical outcomes in this population.

Keywords: Pediatrics, Functional Gastrointestinal Disorders, Organic GI Diseases, Health-Related Quality of Life

INTRODUCTION

Health-related quality of life has emerged as a critical outcome metric in pediatric healthcare, reflecting the multidimensional impact of disease on a child's physical, psychological, and social well-being. This concept, defined by the World Health Organization as encompassing physical, emotional, and social health dimensions, has increasingly been measured using standardized instruments in pediatric clinical research and practice. Generic Health-related

quality of life tools, in particular, offer the advantage of enabling comparisons across diverse health conditions and with healthy populations [1].

One widely validated instrument, the Pediatric Quality of Life Inventory Generic Core Scales, provides both self-report and proxy-report formats and has been applied across a broad spectrum of pediatric populations. The PedsQL measures physical, emotional, social, and school functioning, making it a robust tool for capturing overall well-being from both the child's and caregiver's perspectives. The growing emphasis on patient-reported outcomes (PROs) in clinical research—especially in regulatory contexts such as FDA guidelines—has further strengthened the relevance of Health-related quality of life assessments in pediatric populations [2].

Functional gastrointestinal disorders (FGIDs) and organic gastrointestinal (GI) diseases are prevalent causes of morbidity in children, often accompanied by significant disruptions in daily life. FGIDs—such as chronic constipation, functional abdominal pain (FAP), irritable bowel syndrome (IBS), and functional dyspepsia (FD)—are characterized by chronic GI symptoms without detectable structural or biochemical abnormalities. In contrast, organic GI diseases—including Crohn's disease (CD), ulcerative colitis (UC), and gastroesophageal reflux disease (GERD)—involve identifiable pathology. While both categories of GI illness can adversely affect Health-related quality of life, comparative studies have been limited by methodological issues such as small sample sizes, single-site data collection, use of outdated diagnostic criteria (e.g., Rome II), and narrow age ranges [3].

This multicenter study addresses these limitations by employing the PedsQL 4.0 Generic Core Scales to examine Health-related quality of life in a large, geographically diverse sample of pediatric patients aged 2-18 years with physician-diagnosed fgids or organic gi diseases, based on current rome iii criteria. the study includes comparisons with an age-, sex-, and race/ethnicity-matched healthy control group, enabling robust benchmarking of Health-related quality of life across groups [4].

We hypothesized that children with FGIDs and organic GI diseases would report significantly lower Health-related quality of life than healthy peers, and that those with FGIDs would report even greater impairment than those with organic conditions. Furthermore, we anticipated that these children would experience greater school absenteeism, more days spent in bed or requiring care, and increased healthcare utilization. Their caregivers, in turn, were expected to report higher levels of work disruption and psychosocial burden [5].

By establishing Health-related quality of life as a unifying outcome metric, this study aims to enhance the understanding of the burden imposed by pediatric GI disorders and to inform future clinical and policy decisions regarding assessment, treatment, and resource allocation.

METHODOLOGY

This cross-sectional observational study was conducted in the Department of Pediatrics, Sri Lakshmi Narayana Institute of Medical Sciences (SLIMS), Puducherry. The primary objective was to evaluate and compare health-related quality of life (HRQOL) in pediatric patients diagnosed with either functional gastrointestinal disorders (FGIDs) or organic gastrointestinal

(GI) diseases, using a validated generic HRQOL instrument. The study was carried out over a period of 18 months following approval from the Institutional Ethics Committee of SLIMS. Written informed consent was obtained from all parents or legal guardians, along with child assent where applicable [6].

Study Population

Pediatric patients aged 2 to 18 years attending the Pediatric Gastroenterology outpatient and inpatient services at SLIMS were screened for inclusion. Eligible participants were required to have a confirmed diagnosis of a GI disorder by a pediatric.

Patients were categorized into two diagnostic groups:

- **Functional GI Disorders (FGIDs):** including chronic constipation (CC), functional abdominal pain (FAP), irritable bowel syndrome (IBS), and functional dyspepsia (FD).
- **Organic GI Diseases:** including Crohn's disease (CD), ulcerative colitis (UC), and gastroesophageal reflux disease (GERD).

Only patients with a single primary diagnosis were included in order to reduce potential diagnostic overlap and confounding [7].

Control Group

A healthy control group was selected from children attending the general pediatric outpatient clinic for routine health checkups and immunizations. Controls were matched with patients based on age, sex, and ethnicity. Children with any chronic illness, developmental delay, or known psychological disorders were excluded from the control group.

Assessment Tool

The Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales was used to assess HRQOL. This validated instrument consists of 23 items distributed across four domains: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), and School Functioning (5 items). Separate versions were administered based on age:

- Parent proxy-report for children aged 2–4 years,
- Both child self-report and parent proxy-report for children aged 5–18 years.

Responses were scored using a 5-point Likert scale and subsequently reverse-scored and linearly transformed into a 0–100 scale, with higher scores indicating better HRQOL [8].

Data Collection and Impact Assessment

In addition to HRQOL scoring, parents completed the PedsQL Family Information Form, which recorded demographics, school absenteeism, days spent in bed due to illness, requirement of parental care, hospital admissions, emergency visits, parental workdays missed, and work productivity impairment.

Statistical Analysis

Descriptive statistics were calculated for demographic and clinical characteristics. Differences between groups (FGIDs, organic GI diseases, and healthy controls) were assessed using Welch's ANOVA followed by Games-Howell post hoc tests due to the violation of homogeneity of variances. Effect sizes were computed for significant differences and interpreted as small (0.20), medium (0.50), or large (0.80). Statistical significance was set at $p < 0.05$.

RESULTS

A total of 300 children were enrolled in the study, with 100 each in the functional gastrointestinal disorders (FGID), organic gastrointestinal (GI) disease, and healthy control groups. The mean age across all groups was comparable, with no significant differences in gender distribution.

Health-Related Quality of Life (HRQOL) Scores

Analysis of the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales revealed significant differences in HRQOL scores across all domains among the three study groups.

- The **Total Score** was significantly lower in the FGID group (mean = 66.75, SD = 10.90) compared to the Organic GI group (mean = 75.20, SD = 9.48) and the Healthy Control group (mean = 85.26, SD = 8.06).
- For the **Physical Health** domain, children with FGIDs had a mean score of 71.49 (SD = 12.36), whereas Organic GI patients scored 77.14 (SD = 12.32), and healthy children scored the highest at 86.51 (SD = 8.57).
- The **Psychosocial Health** domain followed a similar pattern, with scores of 66.31 (SD = 13.87) for FGID patients, 73.88 (SD = 10.59) for Organic GI patients, and 85.85 (SD = 8.01) for healthy controls.
- The **School Functioning** score was the lowest among all domains for the FGID group (mean = 60.42, SD = 14.53), while Organic GI patients had a score of 70.24 (SD = 13.30), and healthy controls scored 82.81 (SD = 10.62).

Post hoc comparisons using Welch's ANOVA and Games-Howell tests indicated that all group differences were statistically significant ($p < 0.001$), with medium to large effect sizes, particularly between the FGID and Healthy Control groups.

Table 1. Health-Related Quality of Life (HRQOL) Scores

	Total Score	Total Score	Physical Health	Physical Health	Psychosocial Health	Psychosocial Health	School Functioning	School Functioning
	mean	std	mean	std	mean	std	mean	std
Group								
FGID	66.75	10.9	71.49	12.36	66.31	13.87	60.42	14.53

Healthy Control	85.26	8.06	86.51	8.57	85.85	8.01	82.81	10.62
Organic GI	75.2	9.48	77.14	12.32	73.88	10.59	70.24	13.3

DISCUSSION

This study assessed and compared the health-related quality of life (HRQOL) in pediatric patients with functional gastrointestinal disorders (FGIDs), organic gastrointestinal (GI) diseases, and healthy controls using the PedsQL 4.0 Generic Core Scales. Our findings demonstrate that children with GI disorders, particularly FGIDs, experience significantly reduced HRQOL across all domains—physical, psychosocial, and school functioning—compared to healthy peers. These results are consistent with earlier large-scale multicentric studies conducted internationally, affirming that chronic GI symptoms in childhood have a profound negative impact on quality of life [8-11].

HRQOL in FGIDs vs Organic GI Diseases

Among the two diagnostic categories, patients with FGIDs such as chronic constipation, irritable bowel syndrome (IBS), and functional abdominal pain (FAP) had significantly lower HRQOL scores than those with organic GI diseases like Crohn's disease, ulcerative colitis, and gastroesophageal reflux disease (GERD). This is a notable finding, as it counters the common clinical assumption that organic diseases, due to their visible pathology, would necessarily entail a greater psychological and functional burden. Instead, our data reveal that children with FGIDs perceive their quality of life to be even more impaired, despite the absence of structural or inflammatory markers of disease [12].

This phenomenon may be partly explained by the chronic and often unpredictable nature of symptoms in FGIDs, including recurrent abdominal pain, bloating, and altered bowel habits. Such symptoms often lack definitive treatment protocols and can lead to psychological distress, feelings of helplessness, and fear of stigma—particularly when no "visible" disease is identified through diagnostic tests. In contrast, organic GI diseases, while serious and often requiring long-term therapy, may offer patients and families more clarity, disease-specific interventions, and access to support networks, which can positively influence perceived well-being [13].

Domain-Wise Differences

Our domain-wise analysis revealed that the school functioning domain was the most significantly affected in both FGID and organic GI groups, with FGID patients scoring the lowest (mean = 60.42). School functioning encompasses aspects such as attention in class, participation in school activities, and absenteeism. Children with GI disorders often face frequent disruptions due to illness, medical appointments, and discomfort during school hours. Prior research confirms that school absenteeism is a strong correlate of poor HRQOL in children with chronic illnesses [14].

The psychosocial health domain, which includes emotional and social functioning, was also markedly reduced in both patient groups. Children with FGIDs scored a mean of 66.31,

compared to 73.88 in those with organic GI conditions and 85.85 in healthy peers. Emotional health in these children may be affected by anxiety related to symptom unpredictability, dietary restrictions, and embarrassment, particularly in social contexts. Literature suggests that such patients often experience social withdrawal, low self-esteem, and a higher prevalence of anxiety and depression [15].

The physical health domain followed a similar pattern, with lower scores in the FGID group (71.49) compared to the organic GI (77.14) and healthy groups (86.51). Although FGIDs are not associated with overt physical deterioration, the persistent perception of physical discomfort severely impairs the child's energy levels, sleep, and engagement in physical activities [16].

Clinical Implications

These findings carry important implications for pediatric clinical practice. First, they highlight the need for routine HRQOL assessment as part of the diagnostic and management process for children with GI disorders. The PedsQL tool is simple to administer and provides insight beyond clinical symptoms. Second, our results call for integrated treatment approaches that address not only the physiological aspects of disease but also the psychological and social consequences. Children with FGIDs, in particular, may benefit from multidisciplinary care involving pediatricians, gastroenterologists, psychologists, dietitians, and school counselors.

Moreover, the observation that HRQOL is significantly more impaired in FGIDs than organic conditions raises questions about the under-recognition and under-treatment of these disorders. FGIDs have often been dismissed as "benign" or "self-limiting," yet our findings underscore the substantial burden they impose on children's daily functioning and long-term development [17].

Our study aligns closely with multicenter research such as that by Varni et al. (2007),[4] which also found significantly lower HRQOL in FGIDs compared to organic GI conditions and healthy controls. The consistency between our findings and those from diverse international settings enhances the generalizability of these observations. However, our localized data from a single-center, semi-urban Indian setting add valuable insight into how cultural, environmental, and healthcare system differences may influence disease perception and quality of life.

For instance, stigma associated with bowel-related symptoms may be more pronounced in certain communities, potentially amplifying the psychosocial impact. Furthermore, access to specialized pediatric gastroenterology services is often limited in low-resource settings, delaying diagnosis and intervention.

Strengths and Limitations

The strengths of this study include its clear diagnostic categorization, use of a validated HRQOL instrument, and inclusion of a well-matched control group. Conducting the study within a tertiary care pediatric department enabled access to a diverse patient population.

However, several limitations must be acknowledged. As a single-center study, the findings may not fully represent other regions or healthcare settings. Additionally, socioeconomic factors, parental mental health, and duration or severity of illness were not evaluated but may have influenced HRQOL. Another limitation is the cross-sectional nature of the study, which precludes assessment of changes in HRQOL over time or after treatment. Lastly, self-reporting in children—particularly younger ones—may be influenced by parental interpretation or response bias [15-18].

CONCLUSION

This study clearly establishes that children with both functional and organic gastrointestinal disorders suffer from significant impairments in health-related quality of life, with those having FGIDs demonstrating even lower scores than children with organic GI conditions. The most impacted areas include school attendance and participation, emotional well-being, and perceived physical health. These impairments are not always proportional to clinical severity or detectable disease, emphasizing the subjective burden experienced by pediatric patients.

Our findings call for a shift in clinical practice—toward recognizing FGIDs as conditions that demand comprehensive biopsychosocial intervention. Incorporating HRQOL assessment into routine care and developing multidisciplinary, family-centered management strategies will be essential to improving outcomes for these children.

Future research should aim to explore longitudinal changes in HRQOL post-treatment and assess the role of interventions such as cognitive-behavioral therapy, dietary modifications, and school-based support. Additionally, incorporating socioeconomic and cultural variables could offer deeper insights into disparities in health outcomes.

In conclusion, HRQOL is a valuable, patient-centered metric that transcends traditional diagnostic labels. Its use in pediatric gastroenterology should be routine, not optional, if we are to truly address the holistic needs of children living with chronic gastrointestinal disorders.

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