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Health-related Quality of Life of Youth with Inflammatory Bowel Disease: A Comparison with Published Data Using the PedsQL 4.0 Generic Core Scales

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Abstract

Background—This study compared youth and parent-proxy reports of health-related quality of life (HRQoL) among youth with inflammatory bowel disease (IBD) to published comparison group data and examined concordance between youth and parent-proxy reports of HRQoL.

Method—One hundred thirty-six youth and parent-proxy reports on the PedsQL 4.0 Generic Core Scales were compared to published data from chronically ill, acutely ill, and healthy comparison groups using independent samples t-tests. Reporter agreement was examined using paired samples t-tests and intraclass correlations (ICCs).

Results—Youth with IBD reported lower psychosocial functioning than the healthy comparison group, higher physical and social functioning than the chronically ill group, and lower school functioning than all published comparison groups. Parent-proxy reports of youth HRQoL were higher than the chronically ill group, but lower than the healthy group on all scales except psychosocial functioning. Youth with active IBD reported lower physical health domain scores than youth with inactive disease. Concordance between youth and parent-proxy reports was moderate, with lowest agreement in school and social functioning.

Conclusions—Youth with IBD and their parents rate HRQoL as lower than healthy youth but do not perceive the impact of IBD to be as limiting as in other chronic conditions. Youth report suggests that IBD may be particularly detrimental to HRQoL in the school functioning domain. Moderate agreement between parent and youth reports substantiates continued use of multiple informants in studies of pediatric HRQoL.

Keywords

Inflammatory bowel disease; pediatrics; health-related quality of life; PedsQL 4.0

INTRODUCTION

Health-related quality of life (HRQoL) refers to an individual's subjective experience of his or her physical health and psychosocial functioning.¹ HRQoL is a key indicator of

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adaptation among youth with chronic diseases and has been utilized as an outcome in clinical trials and a marker of treatment efficacy.² The HRQoL in youth with inflammatory bowel disease (IBD) has received considerable recent attention, given the physical and emotional demands associated with management of the condition. IBD is a chronic relapsing inflammatory condition of the gastrointestinal system and includes Crohn's disease (CD) and ulcerative colitis (UC). Symptoms such as weight loss, fatigue, abdominal pain, diarrhea, cramping, joint pain, and delayed puberty are common. IBD treatment may include nutritional modifications, medication management, and surgical intervention.³ Although medical intervention can remediate disease related symptoms, it can also result in adverse side effects such as cushingoid symptoms, weight gain, and immune suppression,⁴ all of which may have implications for an individuals' HRQoL. Moreover, management of IBD and its symptoms can lead to increased self-consciousness and has the potential to interfere with school and social functioning.⁵

Youth with IBD are at risk for lower HRQoL than typically developing youth.^{6,7,8,9} Elevated risk for psychosocial, physical, and academic problems relative to healthy control groups has also been documented.^{5,6,9} In contrast, youth with IBD report comparable HRQoL to youth with functional abdominal pain and gastroesophageal reflux disease.¹¹ Some evidence suggests that youth with greater disease activity,^{6,10} those experiencing steroidal side effects,⁶ adolescents (versus younger children⁹), and males⁷ may be at particular risk for impaired HRQoL. Knowledge regarding the extent of impairments in HRQoL among youth with IBD is limited however, by certain characteristics of published research including small sample sizes, reliance on only one reporter of quality of life, rare use of multi-site data, and infrequent use of measures of HRQoL with published normative data. Similarly, few comparisons have been made between the HRQoL of youth with IBD and youth with other chronic illnesses.

To the authors' knowledge, no studies to date have compared HRQoL scores of youth with IBD to normative data in the US. Moreover, no studies to date have examined how the HRQoL of youth with IBD compare to a large sample of youth with chronic and acute illnesses. Such comparisons are important insofar as they allow us to document the extent to which IBD is associated with unique impairments in HRQoL domains relative to youth who have other chronic conditions. Additionally, examination of how the HRQoL of youth with IBD compares to that of youth with acute illnesses provides further information about the extent of impairments within this population. While there are advantages to using disease specific measures of HRQoL, the use of a well-established generic measure of HRQoL provides the opportunity to make comparisons across illness groups using normative data.

Examinations of HRQoL among other pediatric populations have revealed discrepancies between youth and parent-proxy ratings of HRQoL,^{2,12} and underscore the need for multisource methodology in studies of youth HRQoL. The inclusion of both youth and parent-proxy reports of HRQoL may provide complementary perspectives that aid in capturing a comprehensive picture of youth HRQoL.¹³ In the only study to examine agreement between youth and parent-proxy reports of HRQoL in the context of IBD, Loonen et al.¹⁴ found that parent-proxy reports of social functioning were significantly lower than youth reports in a sample of families from the Netherlands, but did not find significant differences between reporters in other domains (i.e., body complaints, motor functioning, autonomy, cognitive functioning, positive emotions, and negative emotions). However, agreement between youth and parent-proxy reports of HRQoL has yet to be evaluated in a sample of US families of youth with IBD.

In an effort to expand understanding of the HRQoL of youth with IBD, over one hundred youth from several US regions and their parents completed the PedsQL 4.0 Generic Core

Scales,¹² a well-established measure of pediatric HRQoL.¹⁵ The objectives of this study were to: 1) compare key domains of self-reported HRQoL of youth with IBD to published comparison group data from chronically ill, acutely ill, and healthy youth, 2) compare parent-proxy reports of youth HRQoL among families of children with IBD to published comparison group data from parents of chronically ill, acutely ill, and healthy youth, and 3) evaluate concordance between youth and parent-proxy reports of HRQoL in physical, emotional, social, and school domains. A final goal of the study was to examine differences in key domains of HRQoL as a function of disease activity.

MATERIALS AND METHODS

Participants

Data from three independent studies conducted in three regions of the United States, including sites in the upper Midwest (studies 1 and 2), and the lower Midwest and the Northeast (study 3) were combined for this manuscript.

Eligibility Criteria—Eligibility criteria for studies 1 and 2 included: 1) patient age 11–18 years, 2) biopsy-confirmed diagnosis of IBD, 3) legal guardian willing to participate, and 4) English fluency of adolescent and guardian. For study 2, an additional inclusion criterion was that the patient was prescribed a thiopurine for at least 3 months. Exclusion criteria for studies 1 and 2 included: 1) presence of another chronic medical condition requiring daily medication or 2) history of cognitive or developmental delay. In study 1, 80 families consented to participate and 68 (85%) provided complete data. In study 2, 11 families consented to participate and all provided complete data.

Eligibility criteria for study 3 included: patient age 13–17 years, 2) biopsy-confirmed diagnosis of IBD, 3) medication regimen including 6-mercaptopurine/azathioprine and/or 5-aminosalicylic acid, 4) 6-thioguanine nucleotide/6-methylmercaptopurine nucleotide (6-TGN/6-MMPN) bioassay performed at study visit or within the previous month, and 5) English fluency of patient and guardian. Exclusion criteria included: 1) presence of a comorbid chronic illness, 2) diagnosis of pervasive developmental disorder, and 3) prescription of > 1 mg/kg/day of corticosteroid medication. Of the 75 families recruited, 57 (76%) provided complete data.

Procedure

Across all sites, those who met eligibility criteria were given an explanation of the study and participants provided informed consent/assent. Participating families completed measures during outpatient clinic visits or at home, if necessary, and mailed completed forms back to study personnel. Medical chart reviews were conducted for physician-provided data to complete disease severity assessments. Families were compensated for participation.

Measures

Demographics—Demographic information was collected via a parent report questionnaire in all studies. Information acquired included youth age, sex, ethnicity, and grade in school, as well as caregiver age, sex, marital status, and annual family income.

Medical Information—Participant medical records were reviewed to obtain information about the type of IBD (CD, UC, or Indeterminate Colitis) and current disease activity. In studies 1 and 2, physician global assessment (PGA) ratings were abstracted from the medical record. Physicians rated participant disease activity as no activity, mild, moderate, or severe. This rating has been demonstrated to correlate well with more complex measures of disease activity such as Pediatric Crohn's Disease Activity Index (PCDAI),¹⁶ which was

used to measure disease activity in youth with CD for study 3. The PCDAI is a validated measure of disease activity in pediatric CD that accounts for subjective, objective, laboratory and growth parameters of disease activity. The Lichtiger Colitis Activity Index¹⁷, which assesses eight UC symptoms, was used as a measure of disease activity for youth with UC in the second study. In the present study, disease activity was dichotomized as inactive (PGA score of 0, PCDAI score of $<10^{17}$, Lichtiger score of $<10^{18}$) or active (PGA score of ≥ 1 , PCDAI score of $\geq 10^{17}$, Lichtiger score of $\geq 10^{18}$).

Health-Related Quality of Life—Youth completed the Pediatric Quality of Life Inventory, Version 4.0 (PedsQL^{12,19,20,21,22}), a 23-item measure of pediatric HRQoL. This measure yields a total HRQoL score and two summary scores: physical health (comprised of the physical health domain score) and psychosocial health (comprised of the emotional, social, and school functioning domain scores). Caregivers completed parallel parent-proxy reports consisting of nearly identical items. Participants rated the degree to which each item had been a problem for them during the past month on a 5-point Likert scale ranging from 0 (Never) to 4 (Almost Always). Items were reverse-scored and linearly transformed to a 0 to 100 scale, with higher scores reflecting better HRQoL. The PedsQL demonstrated adequate internal consistency studying the current sample (see Tables 2 and 3 for Cronbach's alpha coefficients). Published comparison group data were drawn from Varni and colleagues'¹² validation study, which included a heterogeneous sample of 963 youth (ranging in age from 5 to 18) and 1,629 caregivers. Approximately half of the validation sample was made up of boys. Chronically ill (N=683), acutely ill (N=207), and healthy youth (N=730) and their parents were recruited from pediatricians' offices for well-child checks (healthy comparison group) and from inpatient, outpatient, and specialty clinics (orthopedics, cardiology, rheumatology, and diabetes) in a hospital setting (acutely and chronically ill comparison groups). Parent reports of whether the child had a chronic illness were used to differentiate chronic from acutely ill participants.

Data Analyses

Analyses were conducted using Statistical Package for the Social Sciences, Version 15.0 (SPSS). Descriptive statistics were computed to summarize demographic and medical information. Independent samples t-tests were executed to evaluate whether HRQoL differed between youth with IBD and the three normative samples: chronically ill, acutely ill, and healthy groups. A second series of independent samples t-tests was conducted to assess whether HRQoL differed between youth with active versus inactive disease. A Bonferroni correction was used to account for the number of comparisons, and statistical significance was set at $p < .01$. Paired samples t-tests were used to detect statistically significant differences between youth and parent-proxy reports. Likewise, two-way mixed intraclass correlations (ICCs) were conducted to examine the magnitude of agreement among reporters. ICCs were interpreted as follows:²³ .40 or below, poor agreement; .41 to .60, moderate agreement; .61 to .80 good agreement; and .81 and higher, excellent agreement.

ETHICAL CONSIDERATIONS

Prior to initiating recruitment, approval for each study was obtained from the institutional review boards at each respective medical center, including the Medical College of Wisconsin, Cincinnati Children's Hospital Medical Center, and Children's Hospital of Philadelphia. Families provided consent/assent prior to participation.

RESULTS

Participant Characteristics

See Table 1 for participant demographic and medical information. 136 youth with IBD and a guardian participated. Participant mean age was 15.23 (SD = 1.93, range = 11 to 18), and the sample was 47% (n = 64) female. The majority of youth were Caucasian (92%), with 6% African American, 0.7% Asian, and 0.7% Hispanic ethnicities included. 0.7% participants identified with a different ethnic background. Nearly all caregivers were mothers (93%) who were married (85%). Most caregivers (75%) reported a yearly family income of under \$100,000.

Comparison with Published Data

Youth Reported HRQoL—No differences in total HRQoL scores were documented between youth with IBD and youth with chronic or acute illnesses (Table 2). Youth with IBD had significantly lower total HRQoL scores than healthy youth, however. Regarding the physical health summary score, youth with IBD reported significantly higher scores than the chronically ill comparison group but did not differ from the acutely ill or healthy groups. With respect to the psychosocial health summary score, youth with IBD had significantly lower scores than healthy youth, but rated their quality of life as comparable to those with chronic and acute illnesses. Finally, with respect to the domain scores, youth with IBD had significantly higher scores on the social functioning domain than youth in the chronically ill sample, but had significantly lower scores in the school functioning domain than all three groups.

Parent-proxy reported HRQoL—Parent-proxy reports of total HRQoL, psychosocial health, and physical health were significantly higher in the IBD group than the chronically ill group, but significantly lower than the healthy normative group (Table 3). Parent-proxy reports of youth with IBD emotional functioning was significantly lower than that of parent-proxy reports from the healthy normative sample, but comparable to the scores of the chronically and acutely ill groups. Although parents rated youth social functioning as significantly higher than the chronically ill group, they reported lower social and school functioning than the healthy normative group.

Concordance Rates for Youth and Parent-Proxy Reports

T-values and ICCs are presented in Table 4. Mean scores of youth and parent-proxy reports of youth HRQoL total, summary, and domain scores did not significantly differ, with one exception. Youth reported significantly lower school functioning than did parents. Moderate agreement was observed between youth and parent-proxy reports on most scales of the PedsQL, including total HRQoL, physical and psychosocial health summary scores, and the emotional functioning domain scores. Although ICCs for school and social functioning domains also fell in the moderate agreement range, these scores were nearing the poor agreement designation, suggesting the most divergence in perspectives in school and social domains.

Disease Activity and HRQoL

Significant differences as a function of disease activity (inactive vs. active) were found for the youth-reported physical health summary score, such that youth with active disease (mean = 78.57, SD = 17.99) scored significantly lower than youth with inactive disease (mean = 86.67, SD = 13.31; $t(119) = 2.81, p = .006$). Similarly, parent-proxy physical health summary scores for youth with active disease (mean = 76.65, SD = 19.45) were significantly lower than parent-proxy reports for youth with inactive disease (mean = 85.68, SD = 16.09; t

(119) = 2.73, $p = .007$). No differences as a function of disease activity were found for youth and parent-proxy reports of total HRQoL, the psychosocial health summary score, or the emotional, social, or school functioning domain scores.

DISCUSSION

This multisource, multisite study was the first to compare youth and parent-proxy reports on the PedsQL to published comparison group data in the context of pediatric IBD. The present findings suggest that, while the physical and social consequences of IBD may not be as limiting as in other chronic illness, self-report data indicate that psychosocial functioning is impaired in IBD relative to typically developing youth. Parent-proxy reports further suggest that several domains of youth functioning are compromised relative to healthy youth including total HRQoL, physical health, psychosocial health, social functioning, and school functioning. Youth with IBD also identified noteworthy deficits in school functioning, even relative to youth with chronic and acute illnesses. Factors specific to IBD that may serve as barriers to school functioning include the need to frequently use the bathroom, limits to gym class participation, and embarrassing cosmetic side effects associated with disease flares or use of certain medications.³ Such factors are difficult to conceal, and may cause youth with IBD to feel singled out among their peers in the academic environment. This is consistent with literature indicating that youth with CD missed more school and participate less in athletics and social activities than do typically developing youth.²⁴ Interestingly, despite the fact that over half of this sample had inactive disease, youth still reported deficits in school functioning relative to youth with acute illness, suggesting that school functioning impairments may continue even after disease symptoms remediate. Even when disease is quiescent, the social stigma attached to the disease may be perpetuated by frequent use of the bathroom, visits to the nurse's office, and need to take medication during the school day. It is also plausible that frequent absences during times of disease activity have long-term consequences for school functioning. Increased school absenteeism resulting in poor academic functioning and difficulties pursuing higher education has been documented in this population.²⁵ It is consequently not surprising that elevated risk for school avoidance has been implicated in the pediatric IBD population.²⁴

Ratings of emotional functioning were comparable to all three published comparison groups across reporters. Inconsistent findings are reported in the pediatric IBD literature concerning the emotional adjustment of youth with IBD, with some studies reporting higher rates of anxious and depressive symptoms^{6,26,27} and others reporting comparable rates of anxiety and depression to healthy comparison groups.²⁸ Findings from the current study lend additional support to the latter conclusion that satisfactory psychological adjustment is possible in youth with IBD. On the other hand, it should be noted that the PedsQL is not designed to evaluate the presence or absence of psychiatric disorders. Rather, it provides an estimate of general emotional functioning as related to youth adaptation to illness. Nonetheless, these findings demonstrate the value of using published comparison group data as a point of reference for identifying how particular health conditions uniquely affect HRQoL. Results from the present study also underscore the importance of examining subdomains of HRQoL, as total HRQoL scores may not be sensitive to subtle deficits in HRQoL.

Despite the fact that youth with IBD did not report significantly lower HRQoL in the physical health domain than youth from the comparison groups, our findings indicate that physical health is negatively impacted by the presence of disease activity. This is consistent with literature suggesting that youth with IBD are at risk for impaired HRQoL during times when disease symptoms are exacerbated,^{6,11} and indicates that the physical consequences

resulting from worsening IBD symptoms are perceived as considerably limiting by youth, albeit not as limiting as the physical ramifications of other chronic disease conditions.

Agreement between youth and parent-proxy reports in this population was most disparate in the school domain, but the degree of concordance was also approaching poor in the social domain. Perhaps outwardly, youth with IBD appear to be functioning better academically than chronically or acutely ill children and adolescents (i.e., maintaining an adequate grade point average), but may experience difficulties that are related to aspects of school that are not directly observable to parents (i.e., problems paying attention in class, feeling behind in schoolwork, perceived memory problems related to academics). Consequently, parents may see their child performing adequately in school, while youth may internally perceive their school functioning as negatively influenced by their medical condition. The hypothesis that child functioning may appear “better” outwardly may also explain discrepancies in youth and parent-proxy reports of social functioning.

Certain limitations should be considered when interpreting these results. Given the nature of secondary data analysis, variables such as disease activity and family income were dichotomized in order to merge the independent datasets, which resulted in a restricted range of variability. Additionally, the use of a published comparison group did not allow for group differences in demographic variables to be controlled. However, in the absence of a matched comparison group, the published comparison group data, which were drawn from large, heterogeneous samples, provided a valuable point of comparison. Third, because this study relied primarily on maternal reports, conclusions drawn from these data may not be generalizable to paternal perceptions of youth HRQoL. Fathers are underrepresented in pediatric research, but emerging studies suggest that fathers are equally affected by their child’s chronic health conditions.²⁹ Thus, fathers should be included more consistently in future studies. Fourth, the proportion of youth with UC in this sample is higher than typical rates of UC in the general IBD population which may impact the generalizability of study findings. Fifth, although the study sample was large in relation to prior studies of HRQoL among youth with IBD, it is a modest sample size, and future work would benefit from access to a larger pool of participants. Sixth, a generic measure of HRQoL was chosen for use in this study to allow for comparison of HRQoL between youth with IBD and other illness groups; yet, use of a disease-specific measure may have value in identifying other domains impacted by IBD. It is also important to note that because these data were collected at one point in time, we were unable to examine changes in HRQoL over time that may occur among preadolescent and adolescent youth with chronic illness. Likewise, the fact that data were collected in a clinical setting may have increased youth focus on disease-related aspects of functioning. Future research examining youth perceptions of social relationships and school functioning in greater depth would also be of value. Specifically, future research examining other disease-related factors that may influence school and social functioning, would be of value, as would longitudinal research documenting changes in school and social functioning over time. An additional area for future research relates to the low to moderate concordance observed between youth and parent-proxy reports in this study. Further investigation of factors that predict higher versus lower concordance between parent and youth reports would be of value.

Findings from the present study have several implications for clinicians working with families of children and adolescents with IBD. In light of the fact that deficits in school functioning were reported and the fact that school avoidance has been implicated in this population,²⁴ it is important that clinicians attend to early signs of school avoidance or academic problems during times of active and inactive disease. Assisting with the return to school by providing education to families (i.e., risk for school avoidance in this population, individual education planning) and consultation with teachers and school nurses can be

especially helpful for families during this transition. Clinicians working with youth with active disease should also be particularly attuned to youth perceptions of physical functioning, as this domain is identified by youth with IBD as markedly affected during disease flares. Findings related to the emotional functioning of youth with IBD suggest that clinicians should be cautious of pathologizing youth with IBD. Akin to research with other pediatric populations,³⁰ many children demonstrate significant resilience in the face of chronic illness. This perspective is not meant to undermine the importance of screening for adjustment problems in youth with IBD, but rather, underscores the importance of considering a diagnosis of adjustment problems, anxiety, or depression in the context of coping with a chronic illness. To facilitate the development of effective interventions for families of youth with IBD, obtaining multiple perspectives of HRQoL is imperative as sole reliance on youth or parent-proxy reports may yield incomplete or inadequate information. Assessment of multiple domains of HRQoL is also central to gaining an understanding of the unique impact of IBD on youth functioning.

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References

1. Drotar, D.; Levi, R.; Palermo, TM., et al. Clinical applications of health-related quality of life assessment for children and adolescents. In: Drotar, D., editor. *Measuring health-related quality of life in children and adolescents: Implications for research and practice*. Mahwah, NJ: Lawrence Erlbaum Associates; 1998. p. 329-339.
2. Quittner, AL.; Davis, M.; Modi, A. Health-related quality of life in pediatric populations. In: Roberts, M., editor. *Handbook of Pediatric Psychology*. New York: Guilford Publications; 2003. p. 696-709.
3. Banez, GA.; Cunningham, C. Recurrent abdominal pain, inflammatory bowel disease, and rumination disorder/cyclic vomiting. In: Roberts, M., editor. *Handbook of Pediatric Psychology*. New York: Guilford Publications; 2003. p. 462-478.
4. Buller HA. Objectives and outcomes in the conventional treatment of pediatric Crohn's disease. *J Pediatr Gastroenterol Nutr*. 2001; 33:S11-S18. [PubMed: 11685970]
5. Mackner LM, Crandall WV. Brief report: Psychosocial adjustment in adolescents with inflammatory bowel disease. *J Pediatr Psychol*. 2006; 31:281-285. [PubMed: 15802606]
6. Cunningham C, Drotar D, Palermo TM, et al. Health-related quality of life in children and adolescents with inflammatory bowel disease. *Child Health Care*. 2007; 36:29-43.
7. De Boer M, Grootenhuis M, Derkx B, et al. Health-related quality of life and psychosocial functioning of adolescents with inflammatory bowel disease. *Inflamm Bowel Dis*. 2005; 11:400-409. [PubMed: 15803032]
8. Hommel KA, Davis CM, Baldassano R. Medication adherence and quality of life in pediatric inflammatory bowel disease. *J Pediatr Psychol*. 2008; 33:867-874. [PubMed: 18337262]
9. Loonen HJ, Grootenhuis MA, Last BF, et al. Quality of life in paediatric inflammatory bowel disease measured by a generic and disease-specific questionnaire. *Acta Paediatr*. 2002; 91:348-354. [PubMed: 12022311]
10. Perrin JM, Kuhlthau K, Chughtai A, et al. Measuring quality of life in pediatric patients with inflammatory bowel disease: psychometric and clinical characteristics. *J Pediatr Gastroenterol Nutr*. 2008; 46:164-171. [PubMed: 18223375]

11. Youssef NN, Murphy TG, Langseder AL, et al. Quality of life for children with functional abdominal pain: a comparison study of patients' and parents' perceptions. *Pediatrics*. 2006; 117:54–59. [PubMed: 16396860]
12. Varni JW, Seid M, Kurtin PS. PedsQL™ 4.0: reliability and validity of the pediatric quality of life inventory™ version 4.0 generic core scales in healthy and patient populations. *Med Care*. 2001; 39:800–812. [PubMed: 11468499]
13. Varni JW, Setoguchi Y. Screening for behavioral and emotional problems in children and adolescents with congenital or acquired limb deficiencies. *Am J Dis Child*. 1992; 146:103–107. [PubMed: 1531284]
14. Loonen HJ, Derkx BH, Koopman HM, et al. Are parents able to rate the symptoms and quality of life of their offspring with IBD? *Inflamm Bowel Dis*. 2002; 8:270–276. [PubMed: 12131611]
15. Palermo TM, Long AC, Lewandowski AS, et al. Evidence-based assessment of health-related quality of life and functional impairment in pediatric psychology. *J Pediatr Psychol*. 2008; 33:983–996. [PubMed: 18430762]
16. Hyams JS, Ferry GD, Mandel FS, et al. Development and validation of a pediatric crohn's disease activity index. *J Pediatr Gastroenterol Nutr*. 1991; 12:439–447. [PubMed: 1678008]
17. Lichtiger S, Present DH, Kornbluth A, et al. Cyclosporine in severe ulcerative colitis refractory to steroid therapy. *N Engl J Med*. 1994; 330:1841–1845. [PubMed: 8196726]
18. Hyams J, Markowitz J, Otley A, et al. Evaluation of the pediatric crohn disease activity index: a prospective multicenter experience. *J Pediatr Gastroenterol Nutr*. 2005; 41:416–421. [PubMed: 16205508]
19. Varni JW, Seid M, Rode CA. The PedsQL™: Measurement Model for the Pediatric Quality of Life Inventory. *Med Care*. 1999; 37(2):126–139. [PubMed: 10024117]
20. Varni JW, Seid M, Knight TS, et al. The PedsQL™ 4.0 Generic Core Scales: sensitivity, responsiveness, and impact on clinical decision-making. *J Behav Med*. 2002; 25:175–193. [PubMed: 11977437]
21. Varni JW, Burwinkle TM, Seid M, et al. The PedsQL™ 4.0 as a pediatric population health measure: feasibility, reliability, and validity. *Ambul Pediatr*. 2003; 3:329–341. [PubMed: 14616041]
22. Chan KS, Mangione-Smith R, Burwinkle TM, et al. The PedsQL™: Reliability and validity of the Short-Form Generic Core Scales and Asthma Module. *Med Care*. 2005; 43:256–265. [PubMed: 15725982]
23. Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics*. 1977; 33:159–174. [PubMed: 843571]
24. Akobeng AK, Suresh-Babu M, Firth D, et al. Quality of life in children with Crohn's disease: a pilot study. *J Pediatr Gastroenterol Nutr*. 1999; 28:S37–S39. [PubMed: 10204523]
25. Ferguson A, Sedgwick DM, Drummond J. Morbidity of juvenile-onset inflammatory bowel disease: effects on education and employment in early adult life. *Gut*. 1994; 35:665–668. [PubMed: 8200562]
26. Engstrom I. Mental health and psychological functioning in children and adolescents with inflammatory bowel disease: a comparison with children having other chronic illnesses and healthy children. *J Child Psychol Psychiatry*. 1992; 33:563–582. [PubMed: 1577899]
27. Wood B, Watkins JB, Boyle JT, et al. Psychological functioning in children with Crohn's disease and ulcerative colitis: implications for models of psychological interaction. *J Am Acad Child Adolesc Psychiatry*. 1987; 26:774–781. [PubMed: 3667511]
28. Gold N, Issenman R, Roberts J, et al. Well-adjusted children: an alternate view of children with inflammatory bowel disease and functional gastrointestinal complaints. *Inflamm Bowel Dis*. 2000; 6:1–7. [PubMed: 10701143]
29. Phares V, Lopez E, Fields S, et al. Are fathers involved in pediatric psychology research and treatment? *J Pediatr Psychol*. 2005; 30:631–643. [PubMed: 15772363]
30. Bennett DS. Depression among children with chronic medical problems: a meta-analysis. *J Pediatr Psychol*. 1994; 2:149–169. [PubMed: 8051600]

Table 1

Sample Demographic and Medical Information

	Total Sample
	N = 136
<u>Youth:</u>	
Age M (SD)	15.21 (1.92)
Sex (% Female)	46.3%
Grade in School	9.75 (1.92)
Type of IBD	
Crohn's Disease n (%)	100 (73.5%)
Ulcerative Colitis n (%)	34 (25.0%)
Indeterminate Colitis n (%)	2 (1.5%)
Disease Activity	
Active n (%)	42 (34.7%)
Inactive n (%)	79 (65.3%)
<u>Caregivers:</u>	
Age M (SD)	45.22 (5.31)

Table 2

T-Tests Examining Differences in Youth Reported HRQoL of IBD Group Compared to Published Comparison Group Data

Scale	N	M (SD)	t-value [†]	p	Cronbach's α
PedsQL Total Score					
Study Sample	136	78.59 (13.27)			.91
Chronically III	367	77.19 (15.53)	-1.00	.32	
Acutely III	148	78.70 (14.03)	0.07	.95	
Healthy	401	83.00 (14.79)	3.25	.001	
Physical Health Domain					
Study Sample	136	82.07 (16.24)			.86
Chronically III	366	77.36 (20.36)	-2.69	.01	
Acutely III	149	78.88 (19.10)	-1.52	.13	
Healthy	400	84.41 (17.26)	1.43	.16	
Psychosocial Health Domain					
Study Sample	136	76.42 (13.88)			.88
Chronically III	367	77.10 (15.84)	0.47	.64	
Acutely III	148	78.68 (14.66)	1.33	.18	
Healthy	399	82.38 (15.51)	4.19	.000	
Emotional Functioning					
Study Sample	136	77.30 (18.63)			.81
Chronically III	366	76.40 (21.48)	-0.46	.65	
Acutely III	148	77.33 (20.04)	0.01	.99	
Healthy	400	80.86 (19.64)	1.90	.06	
Social Functioning					
Study Sample	136	87.44 (15.61)			.81
Chronically III	367	81.60 (20.24)	-3.43	.001	
Acutely III	148	82.83 (16.66)	-2.46	.02	
Healthy	399	87.42 (17.18)	-0.02	.99	
School Functioning					
Study Sample	136	68.92 (15.61)			.79
Chronically III	362	73.43 (19.57)	2.89	.004	

Scale	N	M (SD)	t-value [†]	p	Cronbach's α
Acutely Ill	143	75.68 (18.04)	3.07	.003	
Healthy	386	78.63 (20.53)	4.03	.000	

Note: Negative t-values indicate that the study IBD sample HRQoL was higher than the comparison group HRQoL.

[†]T-value reflects comparison with study IBD sample.

Table 3

T-Tests Examining Differences in Parent-Proxy Reported HRQoL of IBD Group Compared to Published Comparison Group Data

Scale	N	M (SD)	t-value [†]	p	Cronbach's α
PedsQL Total Score					
Study Sample	136	79.67 (14.35)			.93
Chronically III	662	74.22 (18.40)	-3.83	.000	
Acutely III	199	80.42 (15.26)	0.46	.65	
Healthy	717	87.61 (12.33)	6.04	.000	
Physical Health Domain					
Study Sample	136	81.91 (17.64)			.86
Chronically III	653	73.28 (27.02)	-4.68	.000	
Acutely III	199	81.81 (20.46)	-0.05	.96	
Healthy	717	89.32 (16.35)	4.54	.000	
Psychosocial Health Domain					
Study Sample	136	78.33 (15.16)			.91
Chronically III	661	74.80 (18.16)	-2.39	.02	
Acutely III	199	79.56 (15.51)	0.72	.47	
Healthy	717	86.58 (12.79)	5.96	.000	
Emotional Functioning					
Study Sample	136	77.74 (19.58)			.86
Chronically III	661	73.05 (23.27)	-2.39	.02	
Acutely III	199	78.82 (18.00)	0.51	.61	
Healthy	718	82.64 (17.54)	2.72	.01	
Social Functioning					
Study Sample	136	86.89 (15.76)			.80
Chronically III	657	79.77 (21.91)	-4.45	.000	
Acutely III	198	83.58 (18.29)	-1.76	.08	
Healthy	716	91.56 (14.20)	3.22	.002	
School Functioning					
Study Sample	136	75.15 (20.27)			.87
Chronically III	601	71.08 (23.99)	-2.04	.04	

Scale	N	M (SD)	t-value [†]	p	Cronbach's α
Acutely Ill	167	74.74 (20.95)	-0.17	.86	
Healthy	611	85.47 (17.61)	5.49	.000	

Note: Negative t-values indicate that the study IBD sample HRQoL was higher than the comparison group HRQoL.

[†]T-value reflects comparison with study IBD sample.

Table 4

Youth and Parent-Proxy Agreement on PedsQL 4.0 Generic Core Scales

PedsQL Scale	Youth Mean (SD)	Parent-Proxy Mean (SD)	t	ICC
Total PedsQL	78.59 (13.27)	79.67 (14.35)	−0.48	.54
Physical Health	82.07 (16.24)	81.91 (17.64)	.18	.56
Psychosocial Health	76.42 (13.88)	78.33 (15.16)	−1.08	.51
Emotional Functioning	77.30 (18.63)	77.74 (19.58)	−0.28	.53
Social Functioning	87.44 (15.61)	86.89 (15.76)	0.39	.45
School Functioning	68.92 (15.61)	75.15 (20.27)	−3.60*	.46

Note: ICC = Intraclass Correlation Coefficient.

*
p < .01