Published in final edited form as:

J Pediatr Gastroenterol Nutr. 2015 June ; 60(6): 749–753. doi:10.1097/MPG.0000000000000696.

Health-related quality of life in youth with Crohn's disease: The role of disease activity and parenting stress

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Abstract

Objectives—Health-related quality of life (HRQOL) is an important, but understudied construct in pediatric IBD. Family-level predictors of HRQOL have been understudied as are the mechanisms through which disease activity impacts HRQOL. The current study examines the relationship between a family-level factor (parenting stress) and HRQOL in youth with Crohn's disease. Parenting stress is examined as a mechanism through which disease activity impacts HRQOL.

Methods—99 adolescents with Crohn's disease and their parents were recruited across three sites. Adolescents completed the IMPACT-III (IBD-specific HRQOL). Parents completed the Pediatric Inventory for Parents, a measure of medically-related parenting stress that assesses: 1) stress due to the occurrence of medical stressors and 2) stress due to the perceived difficulty of stressors. Disease activity was obtained from medical records.

Results—Parenting stress due to the occurrence of medical stressors partially mediated the disease severity-HRQOL relationship, reducing the relationship between these variables from 49.67% to 31.58% ($B = -.56$, $p < .0001$). Bootstrapping analysis confirmed that the indirect effect of disease severity on HRQOL via parenting stress significantly differed from zero. Parenting stress due to the perceived difficulty of medical stressors partially mediated the disease severity-

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Conflict of Interest

The authors have no conflict of interest to report.

HRQOL relationship, reducing the relationship from 49.67% to 30.29% ($B = -.55$, $p < .0001$). The indirect effect was confirmed via bootstrapping procedures.

Conclusions—As disease severity increased, parenting stress also increased, and adolescent HRQOL decreased. Parenting stress should be considered and assessed for along with medical factors as part of a comprehensive approach to improving HRQOL in adolescents with Crohn's disease.

Keywords

adolescents; inflammatory bowel disease; pediatric; mediation; family

Introduction

Approximately 20-25% of all IBD cases have an onset in childhood or adolescence (mean age of diagnosis = 15 years)¹. In treating IBD, there are many important outcomes for gastroenterologists to consider, including disease severity and remission. Another important outcome is health-related quality of life (HRQOL). HRQOL is often included as a primary endpoint in clinical trials² and several prominent organizations (e.g., World Health Organizations) and initiatives (e.g., Healthy People 2020) have emphasized the importance of considering HRQOL along with other important health outcomes^{3,4}. HRQOL has been well researched in the adult literature⁵⁻⁷ but is understudied in pediatric IBD research. Within pediatrics, much attention has been given to identifying HRQOL correlates at the individual-level, such as adherence⁸, mood symptoms⁹, fatigue symptoms¹⁰, coping style¹¹, and disease activity^{9,12}. However, if we are to adopt a comprehensive, biopsychosocial approach to treating IBD, the impact of other factors on HRQOL must also be considered.

Bronfenbrenner's Ecological Systems Theory¹³ states that an individual is impacted by their interactions with other systems, including their family. As family members, not peers, comprise a larger part of an adolescent with IBD's social support network¹⁴, the limited attention to the role of family factors affecting adolescent HRQOL is a significant gap in the literature. The degree to which a family member is able to provide support to an adolescent, is likely limited by the extent to which they are managing their own stressors¹⁵ and having a child with a chronic, unpredictable medical condition, such as IBD, is in itself a stressor. This is particularly true when IBD is more active¹⁶.

Disease activity is associated with both adolescent HRQOL^{9,12} and the family-level variable of parenting stress¹⁶. However, disease activity only explains about 20% of the variance in HRQOL⁹ and the mechanisms through which disease activity affects HRQOL have not been fully explored. We do not know how parenting stress relates to adolescent HRQOL or how these three constructs (disease activity, parenting stress, and HRQOL) collectively relate as HRQOL research in pediatric IBD is currently a fragmented assortment of studies examining these variables in isolation. To date, no study has included these variables in a single model, thus limiting our ability to understand how these interrelated constructs operate as a whole. We propose that parenting stress is a mechanism through which disease activity relates to HRQOL. In addition to examining these constructs in a single, theory-driven predictive model, our study is a novel contribution as it expands our understanding of

HRQOL in adolescents with IBD by moving beyond the examination of individual-level factors to include an important parent/family-level variable: parenting stress. By broadening our understanding of HRQOL in adolescents to include factors beyond the individual, we hope to bring increased clinical attention to the impact of the family system on HRQOL and provide guidance to clinicians on how to identify and address situations in which such factors are impacting this important patient-reported outcome.

Materials and Methods

Participants and Procedure

This is an observational, cross-sectional survey-based study that comes from a larger IRB-approved multi-site investigation of psychosocial functioning in pediatric IBD. The current study focuses exclusively on patients with Crohn's disease as patients with ulcerative colitis, who comprised a small portion of the larger study sample, lacked a valid measure of disease activity. 99 adolescents with Crohn's disease and their parents were recruited from one of three pediatric gastroenterology clinics in the Northeastern (N = 36), Midwest (N = 38), or Southern (N = 25) United States. Adolescents (ages 13-17 years) and caregivers completed separate pencil and paper measures and were compensated \$10 (at sites not conducting a blood draw) and \$25 (for sites with blood draw as part of the larger study). The current study is a subsample of a larger study with an overall recruitment rate of 82.4%.

Measures

Participating adolescents and their caregivers completed the following pencil-and-paper measures:

Demographic questionnaire—Parents completed a brief questionnaire created for this study to collect basic sociodemographic information for the patient and the family.

Disease activity—Disease activity was assessed using the Pediatric Crohn's Disease Activity Index – Short Form¹⁷ (Short PCDAI), an abbreviated version of the Pediatric Crohn's Disease Activity Index (PCDAI)^{18,19}. Compared to the PCDAI, the Short PCDAI-SF contains fewer items and only contains those items that are most practical to complete/obtain via physical examination (e.g., weight change, abdominal tenderness, extra-intestinal manifestations) or patient-report (e.g., number of stools per day, general functioning/well-being). This 6-item measure is strongly correlated with its full-form counterpart ($r = .66$) and discriminates well between different levels of disease activity. According to published guidelines²⁰, a score <15 indicates inactive disease, 15-29 indicates mild disease, and 30 and above indicates moderate-severe disease.

Parenting stress—Parenting stress was assessed using the Pediatric Inventory for Parents (PIP)²¹. The PIP is specifically designed to assess parenting stress associated with caring for a child with a medical illness. For each stressor, caregivers rate the frequency of occurrence as well as the perceived degree of difficulty/stress. Scores are summed to yield PIP Frequency and PIP Difficulty scores. This dual approach is consistent with the transactional model of stress and coping²², which states that an individual's stress level is impacted by the

occurrence of a stressor as well as the individual's cognitive appraisal or perception of the stressor. For both PIP scales, possible scores range from 42 to 210, with higher scores indicating more stress. The PIP has been used and validated in several pediatric populations including cancer^{21,23}, diabetes²⁴, and inflammatory bowel disease²⁵. Internal consistencies of both the PIP Frequency and PIP Difficulty scores for the current sample were good ($\alpha = .96$, both scales).

Health-related quality of life—Adolescent-reported health-related quality of life was assessed with the IMPACT-III²⁶, a well-validated measure of quality of life in children and adolescents with IBD. For the current study, responses were summed to yield a Total Score. Scores on this scale range from 35 to 175, with higher scores indicating better quality of life. Total score reliability for the current sample was good ($\alpha = .94$).

Statistical Analyses

Formal mediation analyses were conducted. For a more thorough explanation of the steps involved in testing mediation, please see Baron and Kenny²⁷ and Preacher and Hayes²⁸. To understand how disease activity indirectly affected HRQOL via parenting stress, bootstrapping was conducted using publically available macros: <http://www.afhayes.com/spssas-and-mplus-macros-and-code.html>. Bootstrapping is an increasingly popular method of testing mediation, particularly when working with small samples. Bootstrapping is preferred over the more traditional Sobel test, which is very conservative and has low power to detect true findings in small samples²⁹. In the current study, 95% confidence intervals were used. Mediation is confirmed when a bootstrapped confidence interval does not contain the number 0. Because parenting stress was measured in terms of occurrence (PIP Frequency) and perceived difficulty (PIP Difficulty), two separate mediator analyses were conducted. As the mere fact of running more than one test can increase the likelihood of arriving at significant findings due to chance alone (Type I error), a correction factor was implemented (.05 / 2) for each test of the indirect effect³⁰ (1 per mediation analysis). As such, the level of significance was set to $p < .025$.

Results

Participant Characteristics

Data were collapsed across sites and analyzed as one sample. However, as family income for the site in the Southeastern United States was lower compared to the sites in the Midwest or Northeast, $F(2, 82) = 5.21$, $p < .001$, family income was entered as a covariate in the mediation models. However, family income did not appear to have a significant influence in either mediation model. Participant demographics are presented in Table 1. Overall, 99 adolescents between the ages of 13 and 17 years ($M = 15.16$, $SD = 1.37$) completed study measures.

Disease Activity, Parenting Stress, and Quality of Life

Demographic characteristics were not associated with disease activity, quality of life, or parenting stress. Similar to prior studies with adolescents with IBD³¹⁻³³, the majority of

youth had inactive disease (54.5%). Smaller percentages had mild (25.3%) or moderate-to-severe disease activity (14.4%).

To aid in the interpretation of parenting stress scores obtained for the current sample, scores were compared to previously published values from a pediatric cancer sample²¹. On average, parenting stress related to the frequency of occurrence of stressful events (PIP Frequency) did not significantly differ from a pediatric cancer sample (89.87 ± 30.06 vs. 94.0 ± 33.3 , $t[214] = 0.93$, $p = .35$). Parenting stress due to the perceived difficulty of medical stressors (PIP Difficulty), was significantly lower (80.97 ± 28.34 vs. 112.4 ± 35.1 ; $t[214] = 7.02$, $p < .0001$), suggesting that parenting stress due to the perceived difficulty of medical stressors is lower in pediatric Crohn's disease than pediatric cancer.

Similar to previously published research using the IMPACT-III⁹, the mean quality of life score for the total sample was 133.13 ± 18.91 .

Parenting stress as a mechanism through which disease activity relates to quality of life

Disease activity was significantly associated with parenting stress frequency ($N = 75$; $B = .62$, $p < .025$) and HRQOL ($B = -.70$, $p < .0001$), meeting the first two criteria for mediation. Parenting stress frequency was associated with HRQOL after considering disease activity ($B = -.23$, $p < .001$), meeting the third criteria. Finally, when both disease activity and parenting stress frequency were entered into the same model predicting HRQOL, the relationship between disease activity and HRQOL decreased from 49.67% to 31.58% ($B = -.56$, $p < .0001$), indicating partial mediation (Figure 1). Partial mediation was confirmed via bootstrapping procedures (95% CI $[-.31, -.05]$).

The above mediation analyses were replicated using PIP Difficulty stress scores as the proposed mediator ($N = 75$). Similar to prior analyses, disease activity was significantly associated with HRQOL ($B = -.71$, $p < .0001$) and parenting stress difficulty ($B = .64$, $p < .001$). Above and beyond the effects of disease activity, parenting stress difficulty was significantly associated with HRQOL ($B = -.24$, $p < .025$). The inclusion of parenting stress difficulty into this final model reduced the relationship between disease activity and HRQOL from 49.67% to 30.29% ($B = -.55$, $p < .0001$; Figure 2), indicating partial mediation. Partial mediation was confirmed via bootstrapping (95% CI $[-.34, -.05]$).

Discussion

The current study expands our understanding of HRQOL in adolescents with IBD beyond individual-level factors by examining disease activity, parenting stress, and HRQOL in a single comprehensive model. As a result, we were able to examine how these variables operate together and unify the fragmented literature focusing on these variables. Study findings speak to the importance of parent-level variables on adolescent HRQOL and the need for clinicians to consider the impact of parent functioning as part of a comprehensive biopsychosocial approach to treating IBD.

As family members are the primary source of social support for adolescents with IBD¹⁴, it is no surprise that something that occurs at the parent-level (parenting stress) might impact

quality of life at the individual, adolescent-level. Parents who are experiencing stress may be less able to recognize signs of distress in their children and respond accordingly. They may also unintentionally allow their distress to permeate into their communications with their adolescent, thereby affecting HRQOL. This hypothesis is partially supported by research linking poorer family communication with lower HRQOL in pediatric IBD³⁴.

In this study, parenting stress served as a mechanism through which disease activity impacted HRQOL. This expands our understanding of HRQOL in adolescents by highlighting the essential role of parents and providing support for a comprehensive approach to improving adolescent HRQOL that targets parents along with medical (e.g., disease activity) and individual (e.g., mood symptoms, adherence) correlates. Gastroenterologists and nurses are on the front lines of treating adolescents with IBD and thus are uniquely positioned to identify situations in which either medical or non-medical factors, such as parenting stress, may be impacting HRQOL. As not all patients with IBD have access to routine psychological care, it is important for gastroenterologists and other health professionals who see adolescent patients with IBD on a regular basis to be attuned to both medical and psychosocial factors impacting HRQOL and provide timely and appropriate intervention, when needed.

Assessing for parenting stress can be done in several ways. Maintaining an open dialogue with parents regarding their functioning may encourage them to disclose difficulties and seek out support. Providing anticipatory guidance to parents of youth with IBD by acknowledging that IBD affects the entire family and that it is common for parents to experience stress may open the door for further communication. For those interested in more formal assessment, the Pediatric Inventory for Parents (PIP)²¹ may be ideally suited for in-clinic use due to its brief nature and the ability for providers to visually scan responses to obtain a quick overview of parent functioning. A completed PIP can also be used to initiate conversations with parents who might otherwise not discuss their own functioning during their child's medical appointment. Parents who report difficulty coping with IBD-related parenting stress may benefit from referral to an IBD support group or a mental health professional.

Study findings must be considered in light of study strengths and limitations. The multi-site nature of our study allowed for the inclusion of a pediatric Crohn's disease sample larger than that typically reported in the IBD literature, which is primarily comprised of single-site research. As we were able to recruit across three geographically-distinct sites and had a high recruitment rate (82.4%), our findings are less likely to be subject to sample bias than previous single-site studies. Additionally, our use of multiple sources of information (medical data, parent report, adolescent report) minimizes shared-method bias. Regarding limitations, the cross-sectional nature of our study limits our ability to make causal inferences. Second, although our recruitment rate was relatively high, we cannot rule out potential selectivity in our sample as those who declined may have differed in some way from those who chose to participate. Finally, due to the occurrence of IBD in certain groups of individuals, patient and family characteristics were somewhat homogeneous in our sample. Although participants were similar to previously published studies in pediatric IBD³¹⁻³³, our findings cannot be extended to the smaller number of ethnic minorities who

have IBD or those from lower socioeconomic backgrounds. Additionally, as most respondents were mothers, we cannot assume that the relationships reported in this study equally extend to fathers. Fathers are consistently underrepresented in pediatric research³⁵.

Several areas should be explored in future research to further increase our understanding of HRQOL in adolescents with IBD. It is important to obtain a better understanding of how parenting stress specifically impacts family interactions and how these interactions, in turn, affect HRQOL. Additionally, although our study expanded our understanding of HRQOL correlates in youth beyond individual-level factors, other important variables, such as provider variability, need to be assessed. Finally, additional attempts to integrate the HRQOL literature should be made. Currently, the literature consists of a fragmented assortment of individual variables associated with HRQOL. A unified model of how all of these factors work together to impact HRQOL would greatly advance our understanding of this important construct and possibly lead to the development of interventions to improve this important outcome in adolescents with IBD.

Acknowledgments

Source of Funding: This study was supported by a grant from the University of Florida Center for Pediatric Psychology and Family Studies (awarded to the first author) and a career development award K23 DK079037) and grants from the National Center for Research Resources (UL1 RR026314) and Procter & Gamble Pharmaceuticals and Prometheus Laboratories (awarded to the last author). The study sponsors had no role in the study design, in the collection, analysis, and interpretation of data, in the writing of the manuscript, or in the decision to submit the manuscript for publication.

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What is known about this subject?

- Health-related quality of life (HRQOL) is an important treatment outcome in pediatric IBD.
- Higher disease activity is associated with poorer adolescent HRQOL and higher parenting stress.
- The mechanisms through which disease activity impacts HRQOL are not well understood but may involve systems-level variables such as parenting stress.

What are the new findings and/or what is the impact on clinical practice?

- Disease activity impacts adolescent HRQOL via parenting stress.
- A comprehensive approach to improving adolescent HRQOL should target parent stress along with previously identified medical (e.g., disease activity) and behavioral (e.g., adherence) correlates.
- Identifying parent stress during clinic visits and intervening, if needed, may optimize HRQOL outcomes in adolescents with IBD.

Figure 1.

Parenting stress frequency mediating relationship between disease activity and adolescent health-related quality of life. * $p < .025$; ** $p < .001$; *** $p < .0001$

Figure 2. Parenting stress difficulty mediating relationship between disease activity and adolescent health-related quality of life. * $p < .025$; ** $p < .001$; *** $p < .0001$

Table 1

Participant demographics

	% or Mean $\pm$ SD
N = 99	
Gender (% female)	44.4%
Age	15.16 $\pm$ 1.37
Race/ethnicity	
White/Caucasian	79.8%
Black/African-American	8.1%
Hispanic	2.0%
Other/unknown	10.1%
Crohn's Disease Activity	
Inactive	54.5%
Mild	25.3%
Moderate-Severe	14.1%
Missing/Unknown	6.1%
Caregiver relationship to child (% mothers)	80.8%
Caregiver marital status (% married)	78.8%