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Factors Associated with Health-Related Quality of Life
in Pediatric Inflammatory Bowel Disease

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Thesis submitted
to the Eberly College of Arts and Sciences
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in partial fulfillment of the requirements for the degree of

Master of Science in
Psychology

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anxiety

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Abstract

Factors Associated with Health-Related Quality of Life in Pediatric Inflammatory Bowel Disease

Ellen M. Manegold

Youth with inflammatory bowel disease (IBD) experience poor health-related quality of life (HRQOL; e.g., Cunningham et al., 2007; De Boer et al., 2005; Greenley et al., 2010). Previous research has demonstrated that factors such as problematic family functioning and increased general anxiety are associated with decreased HRQOL in pediatric IBD (e.g., Guilfoyle et al., 2014; Gumidyala & Greenley, 2014; Herzer et al., 2011a; Kilroy, Nolan, & Sarma, 2011). However, little was known about how specific aspects of the parent-child relationship are related to HRQOL. Furthermore, there was a gap in the literature about the relation of gastrointestinal (GI)-specific anxiety to HRQOL. Therefore, the purpose of the study was to identify more specific factors of the parent-child relationship and GI-specific anxiety that are associated with HRQOL in pediatric IBD. Thirty youth with IBD ($M_{age} = 13.90$ years, Range = 10 – 18; 60% Male) and their primary caregivers or parents were recruited from a pediatric gastroenterology clinic in West Virginia. Parents and youth each completed a series of study questionnaires. Results indicated a significant association between GI-specific anxiety and both youth- and parent-reported total HRQOL scores. There were some significant associations among parent-child relationship dimensions and youth- and parent-report of HRQOL. However, most all of these were counterintuitive and may have been a function of study limitations. Exploratory analyses with specific parent-child relationship dimensions as mediators or moderators of GI-specific anxiety and youth-reported HRQOL were non-significant. The small sample and number of analyses performed each contributed to a likely increase in Type I error. Further, the sample was underpowered to detect medium-to-large effect sizes. However, data suggests that GI-specific anxiety is an important consideration in HRQOL in this population. Future directions include expanding data collection for this study to increase statistical power through a larger sample and potentially greater generalizability of data, as well as investigate targeted interventions to improve GI-specific anxiety in this population.

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Factors Associated with Health-Related Quality of Life in Pediatric Inflammatory Bowel Disease

Inflammatory bowel disease (IBD; see Table 1 for acronyms) is a group of conditions, most commonly including Crohn's disease (CD) and ulcerative colitis (UC), which cause chronic inflammation in the gastrointestinal (GI) tract (Centers for Disease Control [CDC], 2014). This inflammation is a result of recurring abnormal immune responses to materials in the intestine (CDC, 2014). Both CD and UC involve GI-specific symptoms, including diarrhea, abdominal pain and cramping, and urgent bowel movements, as well as fever, decreased appetite, weight loss, and fatigue (Dubinsky, 2008). One important distinction between CD and UC is the location of the inflammation. CD may involve any part of the GI tract (from mouth to anus), but is most commonly present between the end of the small intestine and the beginning of the large intestine (Dubinsky, 2008). CD may also be present in patches between healthy bowel, and all layers of the intestine may be inflamed. UC is limited to the large bowel and rectum, with inflammation present in the inner intestinal layers.

It has been reported that 1.6 million Americans live with IBD, including approximately 80,000 pediatric cases (Loftus, 2004; Loftus et al., 2007; Kappelman et al., 2007). Patients are most commonly diagnosed between 15 and 35 years of age, with earlier diagnosis often indicating a more serious disease course (Van Limbergent et al., 2008). Furthermore, the incidence of IBD in children is rising (Malaty, Xiaolin, Opekun, Thibodeaux, & Ferry, 2010). IBD affects males and females equally and is more prevalent in Caucasians than other race groups (Loftus, 2004). Although the precise cause of IBD has not been identified, research supports that it is caused by the interaction between genes, the immune system, and environmental influences. There is no cure for IBD; therefore, medication, dietary modifications, and surgery are utilized to achieve and maintain symptom remission (Kozuch & Hanauer, 2008).

The disease course differs from patient to patient, with disease remission lasting from months to years (Van Limbergent et al., 2008). Flares, or periods of increased disease activity, are largely unpredictable, but it is believed that stress and diet may be triggers (Loftus, 2004). It is estimated that the annual costs of IBD in the United States total \$14.6 to \$31.6 billion (Gibson et al., 2008; Kappelman et al., 2008; Longobardi, Jacobs, & Bernstein, 2003). Given the unpredictable, painful, and potentially embarrassing aspects of IBD flares, the impact of this disease on the daily lives of youth and their families is substantial and highlights the need to consider key factors such as health-related quality of life, the parent-child relationship, and gastrointestinal (GI)-specific anxiety.

Health-Related Quality of Life (HRQOL)

CDC (2012) defines HRQOL as “a broad multidimensional concept that usually includes self-reported measures of physical and mental health.” HRQOL describes the impact health has on various aspects of a person’s life (e.g., emotional, social, physical functioning). Factors associated with HRQOL in pediatric IBD populations have included disease-related factors (e.g., disease activity, treatment), demographic variables (e.g., age, gender), psychosocial functioning (e.g., coping strategies, depressive symptoms), and relationship characteristics (e.g., social support, family functioning) (Mackner et al., 2013). HRQOL is a relevant variable in the current study because it identifies how specific areas of a youth’s life may be shaped and impacted by IBD.

In pediatric IBD samples, HRQOL has been found to be poor (Cunningham, Drotar, Palermo, McGowan, & Arendt, 2007; De Boer, Grootenhuys, Derkx, & Last, 2005; Greenley et al., 2010). In a review of the literature, Greenley et al. (2010) found that both patients with IBD and their parents reported significantly lower patient HRQOL than healthy youth. More

specifically, data showed that children with IBD rate the domains of home, physical, and emotional functioning lower than healthy peers (De Boer et al., 2005). For instance, these children exhibited more defiance with parents, experienced more somatic difficulties (e.g., abdominal pain, nausea), and had more difficulty completing schoolwork. Yet, when compared to normative data for chronically ill pediatric samples (including diagnoses of functional abdominal pain), patients with IBD and their parents reported higher patient HRQOL (Greenley et al., 2010). Research also has demonstrated that caregiver-reported HRQOL for the patient was lower than patient-reported HRQOL (Cunningham et al., 2007). This suggests that youth with IBD may be better at coping with the stresses of living with IBD than their caregivers perceive them to be; however, the measure used to assess HRQOL was not disease-specific.

In addition to recognizing that HRQOL generally is lower in youth with IBD as compared to healthy youth, researchers have identified variables that are associated with HRQOL within this pediatric population. First, higher disease severity has been correlated with lower HRQOL in pediatric IBD samples (Engelmann et al., 2015; Gray, Denson, Baldassano, & Hommel, 2011; Haapamäki, Roine, Sintonen, & Kolho, 2011). Second, internalizing symptoms were correlated with disease severity and partially predicted HRQOL in youth (Gray et al., 2011). This multi-site study had a large sample size and used an IBD-specific HRQOL measure. However, participants classified as having severe disease activity may have been underrepresented, as most of their participants had inactive or mild disease activity. Furthermore, disease activity and psychological comorbidity have been significantly related to HRQOL (Engelmann et al., 2015). A particular strength of the Engelmann et al. (2015) study was its use of disease-specific measures. Nonetheless, it was conducted in a German population, and findings may not be generalizable to youth with IBD in the United States. Another limitation in

the Engelmann et al. (2015) research was that psychological functioning was measured in terms of DSM-IV criteria cutoffs, so subclinical psychological problems in the sample were not considered. Third, abdominal pain, especially chronic, showed a negative association with HRQOL in pediatric IBD (Greenley, Kunz, Schurman, & Swanson, 2013). Though a small sample led to limited statistical power, this finding demonstrated that a specific IBD symptom was correlated with poorer HRQOL.

Gumidyala and Greenley (2014) discovered evidence for a Cumulative Risk Model (CRM) approach for HRQOL in a pediatric IBD sample. More specifically, a greater number of risk factors such as high disease activity, more internalizing symptoms, poor family functioning, and low medication adherence, were additively associated with lower HRQOL. In this study, risk factor variables were dichotomized, which did not take the continuum of risk into account. Additionally, some important variables, such as social relationships, were not included in the model. Nonetheless, the CRM shows promise for recognizing risk factors in pediatric IBD in a manner that can be clinically useful.

Parent-Child Relationship

Given that children are impacted by family units and vice versa, family functioning has also been an important variable of study in youth with IBD. Families of children with IBD have shown greater levels of dysfunction compared to those of healthy children and children with diabetes (Engström, 1991). Lower HRQOL was associated with less effective problem-solving, less effective communication, and lower general family functioning in adolescents with IBD (Herzer, Denson, Baldassano, & Hommel, 2011a). This study was innovative because it examined psychosocial predictors of HRQOL, rather than focus on disease features; nonetheless, its results may have been limited by its use of a general family functioning measure instead of a

disease-specific assessment. Similarly, in another study (Schuman, Graef, Janicke, Gray, & Hommel, 2013), family problem-solving and affective involvement (i.e., family members are either too interested or not interested enough in the activities of other members of the family) were significant predictors of adolescent depressive symptoms. Though this study targeted specific domains of family functioning, the outcome was limited to depressive symptoms as a measure of emotional functioning.

In addition to impacting the patient, family functioning can affect the family unit as well. Indeed, poorer family functioning has been associated with parent stress in pediatric IBD samples (Gray, Graef, Schuman, Janicke, & Hommel, 2013). This multi-site study had a large sample size unique to pediatric IBD literature, however the measure only included overall parent stress and did not identify specific domains of focus. Furthermore, increased parent stress was related to adolescent depressive symptoms, which served as a mediator between parent stress and HRQOL (Guilfoyle, Gray, Herzer-Maddux, & Hommel, 2014; Herzer, Denson, Baldassano, & Hommel, 2011b). Notably, parenting stress appeared to be low when the child was experiencing a period of remission or receiving outpatient care (Guilfoyle, Denson, Baldassano, & Hommel, 2012). This study was limited by the large proportion of youth with inactive or mild symptoms included in the sample. Though this indicates that parents rated stressors as low in both frequency and difficulty during this time, the sample was not large enough to make conclusions about parenting stress when the child's IBD is more severe.

GI-Specific Anxiety

Children with chronic medical conditions are at greater risk for anxiety disorders (e.g., generalized anxiety, specific phobias, social anxiety) than their healthy peers (Pao & Bosk, 2011). In addition to hypothesized biological factors, children with chronic illness are more

likely to be exposed to anxiety-provoking medical procedures, have increased somatic symptoms, and face challenges with peer interactions (Pao & Bosk, 2011). In IBD specifically, anxiety may be attributed to the unpredictable and intrusive nature of its symptoms. Though some have studied formal anxiety disorders in relation to HRQOL (e.g., Engelmann et al., 2015), other studies have accounted for subclinical levels of anxiety symptoms (Greenley et al., 2010). It is important to consider the full range of anxiety symptoms in relation to IBD and HRQOL, rather than dichotomize anxiety using clinical cutoffs. Indeed, increased anxiety levels have been shown to predict poorer HRQOL in pediatric IBD samples (Gumidyala & Greenley, 2014; Kilroy, Nolan, & Sarma, 2011). For example, in a study using a disease-specific HRQOL measure, anxiety (e.g., generalized anxiety, social phobia, and specific) was related with decreased HRQOL (Kilroy et al., 2011). This research reflects that IBD-related worries and other anxiety symptoms interfere with multiple aspects of life for this population.

A more specific construct of anxiety applicable to youth with IBD is GI-specific anxiety. GI-specific anxiety is anxiety felt about particular GI symptoms (e.g., worry about experiencing diarrhea while at school; wondering whether a particular food will lead to GI distress) (Labus et al., 2004). GI-specific anxiety was strongly correlated with general anxiety, but it may be more relevant to IBD outcomes than general anxiety (Jerndal et al., 2010; Reigada et al., 2011). In adults with irritable bowel syndrome (IBS), a condition that shares some IBD symptoms, higher GI-specific anxiety was associated with lower HRQOL in the mental and physical domains (Jerndal et al., 2010). This study included a large sample of adult patients, but its cross-sectional nature makes it difficult to determine a causal relationship with a known direction. Furthermore, little is known about how GI-specific anxiety applies to youth. One study in adolescents with IBD found that increased GI-anxiety was associated with increased social impairment and

greater healthcare service utilization (Reigada et al., 2011). These social limitations may be due to the embarrassing nature of IBD symptoms and reluctance to share their experiences with their peers (Reigada et al., 2011). Moreover, IBD symptoms may limit children from fully participating in school and other social activities (Reigada et al., 2011). Though this study was innovative in measuring GI-specific anxiety in a pediatric IBD population, the measure used to assess GI-specific anxiety was created for the study and not previously validated. Furthermore, only one domain of HRQOL (i.e., social functioning) was examined.

Summary and Rationale for Current Study

In summary, literature revealing poor HRQOL in youth with IBD (e.g., Cunningham et al., 2007; De Boer et al., 2005; Greenley et al., 2010) indicates the necessity of further research to better understand factors that relate to this important construct. Of the studies that have already been conducted, most have not utilized a disease-specific measure of HRQOL, which would best capture aspects of life specific to a pediatric IBD population. One gap in the literature of HRQOL in youth with IBD is the role of the parent-child relationship. Poorer family functioning and increased parenting stress was associated with lower HRQOL (e.g., Guilfoyle et al., 2014; Herzer et al., 2011a). However, most studies examining family factors in pediatric IBD had focused on general family functioning or were restricted to parental functioning (e.g., stress). More research is needed in this population to determine how parents and their children interact and how the parent-child relationship relates to how children cope with this chronic illness (Pao & Bosk, 2011). For these reasons, it is advantageous to investigate relevant, specific aspects of the parent-child relationship (e.g., attachment, communication) rather than broad family or parent-child relationship quality. Additionally, there is limited research on GI-specific anxiety in the pediatric IBD population. Because this construct measures anxiety more relevant to IBD

symptoms, it likely better captures the role that anxiety plays in the lives of children who have IBD. Research in adult populations with IBS indicated that increased GI-specific anxiety was associated with poorer HRQOL (e.g., Jerndal et al., 2010), yet further research is necessary to determine if this association is consistent in a pediatric population.

Considering these gaps in the literature, the overall aims for the study are:

Aim 1. To examine the association of various dimensions of the parent-child relationship with total and dimensional HRQOL scores in pediatric IBD (see Figure 1).

Based on research with pediatric IBD samples (Herzer et al., 2011a; Herzer et al., 2011b), it is hypothesized that better patient- and parent-reported HRQOL will be significantly correlated with parent report of higher level of attachment, higher quality of communication, more consistent discipline practices, greater involvement, greater parenting confidence, greater satisfaction with school, and lower relational frustration with the child.

Aim 2. To examine the association between GI-specific anxiety and HRQOL in pediatric IBD.

Based on research in adult IBS samples (e.g., Jerndal et al., 2010), it is hypothesized that patients who report lower GI-specific anxiety will have better patient- and parent-reported HRQOL.

Aim 3. To explore the nature of the relation between GI-specific anxiety, the parent-child relationship (attachment, communication, and relational frustration), and HRQOL in pediatric IBD (see Figures 2 and 3).

Considering the sample size, three dimensions intuitively hypothesized to be most relevant to youth-reported HRQOL were selected to reduce the number of analyses conducted. Because there is no literature on the association between GI-specific anxiety, the parent-child

relationship, and HRQOL, no hypothesis has been created. However, with our sample of youth with IBD, we will explore the extent to which the parent-child relationship serves as a mediator and/or moderator in the relation between GI-specific anxiety and HRQOL. For instance, a high level of attachment may account for the relation between lower GI-specific anxiety and higher HRQOL in a mediation model. Alternatively, in a moderation model, the relation between GI-specific anxiety and HRQOL may depend on the level of attachment (high or low).

Method

Participants

As part of a larger study, 30 patients and their primary caregivers completed the study. Although some children in this study had primary caregivers who were not biological parents, for the sake of consistency, all primary caregivers will be referenced as “parents” henceforth. Patients were recruited from the West Virginia University Pediatric Digestive Diseases Department during clinic appointments for either a routine follow-up or a presenting complaint (e.g., symptom flare). Included in the sample were patients who: a) were 10 to 18 years old (to be consistent with the age range for validated measures of study variables, patients typically seen for CD and UC in clinic, and samples from previous studies, e.g., Cunningham et al., 2007); b) had been diagnosed with either CD or UC for at least three months; and c) had a parent who agreed to participate. Patients who could not complete the study measures due to language barriers or cognitive deficits, as judged by a member of the healthcare or research team, were excluded from recruitment. These inclusion criteria were consistent with the larger project in progress, which is described later. Demographic characteristics of the study sample appear in Table 2. The mean patient age was 13.90 years ($SD = 2.51$, Range = 10-18), and 60% were male.

Eighty percent of patients had CD and the majority (73%) had an inactive disease state. Most parents participating in this study were mothers (83%).

Procedure

This cross-sectional study was part of a larger project examining sleep, positive and negative affect, and disease activity in children and adolescents with IBD. Eligible patients were identified by the healthcare team before their appointments. During appointments, a healthcare team member asked eligible families if they were interested in learning more about the study. Once families agreed and after their appointment was completed, members of the research team explained the study purpose, procedure, benefits, risks, confidentiality, and HIPPA policies in the clinic. Assent was obtained from patients 10 to 17 years old, and consent was obtained from patients 18 years old as well as parents. Fifty-two dyads were approached in this way. Of these, nine did not consent (eight refused due to lack of interest, not enough time, etc., and one was not eligible due to developmental delays). Of the remaining 43 dyads consented, eight were lost to follow up (numbers disconnected, did not return calls) and six withdrew (no longer interested, believed measures did not apply, were not interested in completing larger study overall).

Additionally, clinic staff mailed a recruitment letter to parents of all eligible patients in the patient registry that described the study. This letter instructed interested families to call the research staff to arrange a time to obtain assent and consent at the clinic, their residence, or a private area of a public location. One parent-child dyad was obtained in this manner. This patient was screened again via telephone to ensure s/he met inclusion criteria before assenting/consenting.

Various issues precipitated our inability to obtain the larger sample size originally proposed. For example, the patient pool in West Virginia was saturated within approximately

one year. Additionally, there were further obstacles to identifying a collaborating site and initiating data collection. For example, we subsequently reached out to several potential collaborating sites in a sequential fashion, with all but one expressing that they had limited resources to implement the study at their site or competing ongoing studies. Moreover, multiple delays occurred in obtaining IRB approval for the one site that agreed to collaborate on the project.

After assent and consent were obtained, information (e.g., phone numbers, address, and email address) was collected to contact families for reminders, to collect missing data or clarify ambiguous responses on measures, and to mail compensation. Patients were given the *IMPACT-III* and *VSI* to complete, while parents were given the *Family Information Form*, *IMPACT-III*, and *PRQ* to complete. Participants were instructed to complete the measures at home, per procedure for the larger study, and were given individual envelopes in which to place their forms as well as a large, self-addressed, stamped envelope to return the measures. Each patient and parent received a \$10 gift card (total = \$20 per family) for participation in this phase of the larger project. Compensation was mailed after the research team received the completed measures. A member of clinic staff completed either the *PCDAI* or *PUCAI* after the families consented.

Measures

Family Information Form. The *Family Information Form* (see Appendix B) is a parent-report questionnaire developed for this study to obtain relevant demographic and medical information (e.g., age, race, education level, and medical history).

***IMPACT-III* (Otley et al., 2002).** The *IMPACT-III* is a self-report or parent-report questionnaire that measures IBD-specific HRQOL during the previous two weeks over six domains: Bowel Symptoms, Systemic Symptoms, Emotional Functioning, Social Functioning,

Body Image, Treatment/Interventions. It consists of rating 35 items (e.g., “How has your inflammatory bowel disease affected your family?”, “Did you have fun during the past two weeks?”, “Are you happy with your life?”) using a 5-point Likert-type scale (0 = “The effect has been great,” 4 = “The effect has been awful”). Items are reverse coded and transformed on a scale of 0 to 100. The total score and domain scores are obtained by averaging scores to all items or items in each subscale, respectively, with higher scores indicating better HRQOL. The total and domain scores were used in data analyses. *IMPACT-III* scores demonstrated good convergent validity with parent- and patient-report QOL measures in a sample of youth with IBD (Otley et al., 2002). Furthermore, it showed excellent reliability for the total scores ($\alpha = .96$) and good reliability for all domains except tests/treatments ($\alpha = .56$) in a pediatric CD sample (Otley et al., 2006).

Parenting Relationship Questionnaire (Kamphaus & Reynolds, 2006). The *Parenting Relationship Questionnaire (PRQ)* is a parent-report questionnaire that measures seven dimensions of the parent-child relationship: attachment (e.g., “My child enjoys spending time with me”), communication (e.g., “My child tells me about his or her problems”), discipline practices (e.g., “I insist that my child follow the rules of the house”), involvement (e.g., “My child and I go on outings together”), parenting confidence (e.g., “I make good parenting decisions”), satisfaction with school (e.g., “My child is getting a good education at school”), and relational frustration (e.g., “I find it hard to talk to my child”). The *PRQ* also yields scores for three validity indexes, which measure extremely positive, extremely negative, and inconsistent responses. The *PRQ* consists of 71 items rated on a 4-point Likert-type scale (0 = “Never” to 3 = “Almost always”). Based on a normative sample from the general population, a T-score and percentile rank are computed for each subscale. The *PRQ* scores have demonstrated good

reliability ($\alpha = .78$ to $.93$ within scales in norm groups 10 to 18 years old) and yield validity indexes for each report (Kamphaus & Reynolds, 2006).

Visceral Sensitivity Index (Labus et al., 2004). The *Visceral Sensitivity Index (VSI)* is a self-report questionnaire that measures GI-specific anxiety (e.g., “I am constantly aware of the feelings I have in my belly,” “When I enter a place I haven’t been before, one of the first things I do is to look for a bathroom”). The *VSI* consists of 15 items using a 6-point Likert-type scale (0 = “Strongly disagree” to 5 = “Strongly agree”). The total score, a sum of all item responses, will be used in data analyses. Higher scores indicate higher GI-specific anxiety. *VSI* scores in an adult IBS sample demonstrated excellent reliability ($\alpha = .93$) and good content, convergent, divergent, and predictive validity (Labus et al., 2004).

Pediatric Crohn’s Disease Activity Index (Hyams et al., 1991). The *Pediatric Crohn’s Disease Activity Index (PCDAI)* is a 12-item physician-report measure of disease activity in youth with CD. It evaluates multiple characteristics of CD activity, including abdominal pain, stools, general wellbeing, and physician examination values. A total score (0 to 100) is calculated by adding the item scores, with higher scores indicating greater disease activity. These scores are grouped into three categories: inactive (≤ 10), mild (11 to 29), and moderate/severe (≥ 30 ; Hyams et al., 2005). Scores have good sensitivity and specificity to detect disease activity categories and response treatment (Hyams et al., 2005).

Pediatric Ulcerative Colitis Activity Index (Turner et al., 2007). The *Pediatric Ulcerative Colitis Activity Index (PUCAI)* is a 6-item physician-report measure of disease activity in youth with UC. It evaluates multiple aspects of disease activity, including abdominal pain, rectal bleeding, stool characteristics, and general patient functioning. A total score (0 to 85) is calculated by adding the item scores, with higher scores indicating greater disease activity.

These scores are grouped into four categories: remission (< 10), mild (10 to 34), moderate (35-64), and severe (≥ 65). For this study, the moderate and severe categories were combined to create consistency with the *PCDAI*. Scores on the *PUCAI* have excellent inter-rater reliability ($ICC = .95$) and correlate well with other disease activity measures (Turner et al., 2007).

Results

Statistical analyses were conducted using Statistical Package for the Social Sciences version 21 (SPSS 21).

Power Analyses

The sample size was calculated using G*Power based on the aim with the largest number of predictors (Aim 3). To detect a medium effect size with alpha of .05 and 80% power, a sample of 77 dyads was required. To detect a large effect size with alpha of .05 and 80% power, a sample of 36 dyads was required. Consequently, this study was proposed to be powered to detect medium to large effect sizes by recruiting 45 dyads; however, with 30 dyads in our sample, analyses likely are underpowered.

Preliminary Analyses

Missing data ($< 5\%$) were identified and addressed using multiple imputation. Data were reviewed to determine skewedness, kurtosis, and outliers, and no data modifications were necessary. Descriptive statistics for all primary study variables are included in Table 3. On the *PRQ*, two participants' reports were categorized as "extreme caution" on the *F* validity index, indicating a high likelihood that the parent was responding in an overly negative fashion. Because more qualitative information about the parent-child relationship was not available to verify these reports, these participants were excluded from analyses that involved the *PRQ*. To identify possible covariates for HRQOL, Pearson correlation coefficients (for continuous data),

Spearman's partial correlation coefficients (for categorical data), and point-biserial coefficients (for dichotomous data) were calculated for the following variables: disease severity, age, gender, disease type, and household income. Disease severity was significantly correlated with parent-report, $r(30) = -.63, p < .001$, and youth-report, $r(30) = -.44, p = .01$, of HRQOL, such that higher disease severity was related to lower quality of life. Therefore, disease severity was included as a covariate in analyses. All other correlations were not significant.

Aim 1

The first aim was to examine the association between the parent-child relationship and HRQOL. To evaluate this aim, partial correlation coefficients were calculated between parent-child relationship dimensions (*PRQ* subscales) and HRQOL (total and dimension scores of patient and parent *IMPACT-III*), controlling for disease severity.

Some correlations between dimensions of the parent-child relationship and patient-reported HRQOL were significant (see Table 4), albeit almost all in directions not hypothesized. Increased attachment was significantly correlated with decreased total HRQOL, $r(25) = -.48, p = .01$, decreased social functioning, $r(25) = -.40, p = .04$, and decreased treatment/intervention-related HRQOL, $r(25) = -.40, p = .04$. Better communication was also significantly associated with lower total HRQOL, $r(25) = -.45, p = .02$, lower emotional functioning, $r(25) = -.45, p = .02$, and lower social functioning, $r(25) = -.41, p = .03$. Higher parenting confidence was significantly correlated with lower emotional functioning, $r(25) = -.44, p = .02$. Additionally, more relational frustration was significantly associated with higher total HRQOL, $r(25) = .42, p = .03$, increased bowel symptoms, $r(25) = .45, p = .02$, and better social functioning, $r(25) = .44, p = .02$.

Analyses for parent-child relationship and parent-reported HRQOL dimensions also revealed significant findings (see Table 5), again in directions opposite of what had been hypothesized. Increased attachment was significantly correlated with decreased total HRQOL, $r(25) = -.40, p = .04$, and decreased body image, $r(25) = -.51, p = .01$. More consistent discipline practices were significantly associated with increased bowel symptoms, $r(25) = .43, p = .03$. Higher parental involvement was also significantly associated with lower HRQOL related to bowel symptoms, $r(25) = -.49, p = .01$. Furthermore, greater relational frustration was significantly associated with greater total HRQOL, $r(25) = .44, p = .02$, greater bowel symptom-related HRQOL, $r(25) = .51, p = .01$, and better emotional functioning, $r(25) = .48, p = .01$.

Aim 2

The second aim was to investigate the association between GI-specific anxiety and HRQOL. To evaluate this aim, partial correlation coefficients were calculated between GI-specific anxiety (*VSI*) and HRQOL (patient and parent *IMPACT-III*), again controlling for disease severity. There was a significant negative relation of GI-specific anxiety to child-reported HRQOL, $r(27) = -.82, p < .001$, and to parent-reported HRQOL, $r(27) = -.39, p = .04$, meaning that higher GI-specific anxiety was associated with lower reports of HRQOL for both informants.

Aim 3

The third aim was to explore the relation between GI-specific anxiety (*VSI*), various aspects of the parent-child relationship (attachment, communication, and relational frustration subscales on the *PRQ*), and HRQOL (patient *IMPACT-III*). Specifically, to evaluate this aim, dimensions of the parent-child relationship were tested as mediators and moderators in the relation between GI-specific anxiety and HRQOL.

Mediation Analyses. The mediation analyses used Baron and Kenny's (1986) approach. The first regression tested the relation between the predictor (GI-specific anxiety) and dependent variable (HRQOL). The second regression tested the relation between the predictor (GI-specific anxiety) and the hypothesized mediator (e.g., attachment). The third regression tested the relation between the hypothesized mediator (e.g., attachment) and dependent variable (HRQOL). The final regression tested the relation between the predictor (GI-specific anxiety) and hypothesized mediator (e.g., attachment), and dependent variable (HRQOL). This procedure was repeated with two additional parent-child relationship dimensions (communication and relational frustration).

In the first step of all three mediation analyses, GI-specific anxiety significantly predicted HRQOL, $\beta = -.81, p = .01$. In the second step of testing attachment as a mediator, GI-specific anxiety significantly predicted attachment, $\beta = .43, p = .04$ (see Figure 4). Next, attachment significantly predicted HRQOL, $\beta = -.43, p = .01$. Finally, with attachment included as a mediator, GI-specific anxiety significantly predicted HRQOL, $\beta = -.74, p < .001$. To test the significance of the mediation, a Sobel test was conducted. The proposed mediation of attachment was non-significant, $z = -1.68, p = .09$.

In the second step of testing communication as a mediator, GI-specific anxiety did not significantly predict communication, $\beta = .41, p = .05$ (see Figure 5). Therefore, the mediation procedure for communication was discontinued.

In the second step of testing relational frustration as a mediator, GI-specific anxiety significantly predicted relational frustration, $\beta = -.47, p = .04$ (see Figure 6). Additionally, relational frustration significantly predicted HRQOL, $\beta = .36, p = .03$. With relational frustration included as a mediator, GI-specific anxiety significantly predicted HRQOL, $\beta = -.76, p < .001$.

Using a Sobel test, the proposed mediation of relational frustration was non-significant, $z = -1.61$, $p = .11$.

Moderation Analyses. The moderation analyses used hierarchical multiple regression. The predictor (GI-specific anxiety) and hypothesized moderator (e.g., attachment) were centered on the means because they are continuous variables. The centered predictor (GI-specific anxiety) and centered hypothesized moderator (e.g., attachment) were entered in block one. The interaction of the centered predictor (GI-specific anxiety) and hypothesized centered moderator (e.g., attachment) were entered in block two. This process was repeated with the two additional parent-child relationship dimensions (communication and relational frustration).

Attachment was not found to be a moderator of GI-specific anxiety and HRQOL, as the GI-specific anxiety x attachment interaction was not a significant predictor of HRQOL, $\beta = -.04$, $p = .74$ (see Table 6). Similarly, the GI-specific anxiety x communication interaction did not significantly predict HRQOL, $\beta = -.04$, $p = .67$, therefore communication was not a moderator (see Table 7). Finally, relational frustration was not a moderator of GI-specific anxiety and HRQOL due to the non-significance of the GI-specific anxiety x relational frustration interaction, $\beta = -.01$, $p = .91$ (see Table 8).

Discussion

The aims of this study were to: 1) investigate the relation between the parent-child relationship and HRQOL in youth with IBD; 2) examine the association between GI-specific anxiety and HRQOL; and 3) explore aspects of the parent-child relationship as mediators or moderators between GI-specific anxiety and HRQOL. To address these aims, thirty youth with IBD and their parents were recruited from a pediatric GI clinic to complete a series of questionnaires measuring these constructs.

As hypothesized, GI-specific anxiety had a strong negative correlation with youth- and parent-reported overall HRQOL, above and beyond strong objective measures of physician-reported disease severity. This result is consistent with previous literature suggesting that higher general anxiety is associated with lower HRQOL in this population (e.g., Kilroy et al., 2011). Furthermore, the observed relation is in line with research on GI-specific anxiety and HRQOL in adults with IBS (e.g., Jerndal et al., 2010), indicating that this inverse pattern persists throughout adulthood. Overall, these data suggest that GI-specific anxiety, rather than simply general anxiety per se, should be an important consideration when conceptualizing HRQOL in children and adolescents with IBD. Children who have high GI-specific anxiety may experience subclinical levels of general anxiety and may not be identified as needing clinical intervention, despite experiencing significant impairment from GI-specific anxiety. This oversight suggests that the needs of these patients may not be fully addressed, thereby contributing to poorer HRQOL.

Some significant correlations between parent-child relationship characteristics and HRQOL were obtained, although most were in the opposite direction of what was hypothesized and what would make logical sense based on previous work (e.g., Guilfoyle et al., 2014; Herzer et al., 2011a). Descriptive statistics for *IMPACT-III* scores for both youth- and parent-report were consistent with previous research; therefore, it does not appear that this sample had unique HRQOL characteristics that would explain the counterintuitive results (e.g., Perrin et al., 2008). Therefore, it is the use of the *PRQ* that was potentially problematic. Though our sample's mean scores are within the "Average" classification, the *PRQ* seems to be more commonly used in clinical settings and research with general clinical populations (not pediatric), particularly in theory development and treatment outcome measurement in children with clinically significant

behavior problems (e.g., Lee, Lee, & August, 2011; Wiggins, Sofronoff, & Sanders, 2009). Because comparison between the current population and these clinical populations (e.g., youth with behavior problems) would not be appropriate, it is difficult to gauge the validity of our sample's scores and how these scores possibly may have contributed to our unanticipated pattern of results. Indeed, the current study is the first known research to apply the use of the *PRQ* in a pediatric chronic illness population. These results may also be a function of having had a small, relatively homogenous (in disease severity) sample recruited from one clinic. Moreover, there may be inflated Type I error due to the number of analyses performed and thus, some of the significant correlation coefficients may be coincidental in nature. Utilization of a more stringent alpha level may have been more appropriate to account for these issues. Consequently, these findings should be interpreted with caution.

Notably, no parent-child dimensions (i.e., attachment, communication, relational frustration) were found to be either mediators or moderators of GI-specific anxiety and youth-reported HRQOL. Given that the beta coefficients were moderate to large in size, having limited statistical power due to small sample size likely contributed to the lack of significant findings. However, consistent with results of Aim 1, it should be noted that although these coefficients were moderate to large in size, they also were counterintuitive in their direction. Consequently, like Aim 1, considerable caution should be made when interpreting these exploratory findings. Though not a focus of the current study, investigating similar models for parent-reported HRQOL is one possible direction for future research.

When considered together, the results of the current study should be interpreted in the context of multiple study limitations. Most importantly, the small sample was a shortcoming. The study was initially proposed including enough parent-child dyads to detect medium to large

effect sizes. Due to various recruitment difficulties, the proposed sample size was unable to be attained. Although the alpha level cutoff for significance was maintained at the proposed level of .05, Type I error may have been inflated and some of the results may have been spurious. Additionally, the small sample size resulted in limited variability within some variables, potentially due to the recruitment at a single clinic site. For instance, most participants were classified as having an “inactive” disease state. This is positive clinically because it indicates low levels of disease activity. At the same time, however, this sample may not be reflective of all pediatric IBD population characteristics as a whole. Moreover, more variability in disease activity may have resulted in a patient sample having more variability in our key study variables, as well. Furthermore, as is the case in all voluntary studies, self-selection bias could have resulted in differences between our study sample and those families who did not participate. The potential impact of selection bias may have been exacerbated by the additional effort required to return the measures by mail, rather than complete measures during a specified study visit (e.g., in clinic). Also, the health care providers interacted with eligible participants first, introducing another source of potential bias. In addition, the multi-rater approach was a strength of the study, but results were limited by the use of one assessment method (questionnaires). Finally, this study was cross-sectional, therefore only associations and not causal relations can be inferred.

There are future directions to consider which have the potential to address these limitations. Namely, the expansion of data collection to an additional site will increase the sample size, thereby increasing statistical power and potentially enhancing variability in disease severity and primary variables. A more diverse sample will lead to more statistically robust results that are a greater representation of the population of children and adolescents with IBD. Another potential future direction relates to the use of the *PRQ*. Although this measure has

strengths, such as the inclusion of validity indices to flag for potentially biased reporting (e.g., social desirability), it was designed for use in clinical settings. However, because this measure relies on parental report, it may not accurately represent the youth's perspective of the parent-child relationship. Thus, there is a lack of data about the research utility of *PRQ*, especially in pediatric chronic illness populations. Future research should consider continued use of this measure, but perhaps in conjunction with other measures that might help validate its results and utility. Also, by doing so, *PRQ* scores can be compared across pediatric populations.

Overall, some results from this study contribute significantly to the literature. In particular, using a validated measure of GI-specific anxiety and a disease-specific measure of HRQOL, we found that GI-specific anxiety has an overarching significant association with overall HRQOL in youth with IBD. Due to this strong relation, GI-specific anxiety is an important area of assessment for all health care team members. It appears that the *VSI* may have utility in a clinic setting given its brevity, ease for youth to complete, and simple scoring by health care providers. Future studies could examine the feasibility of using this measure as a screener and further examining its psychometric properties in this population. Furthermore, general anxiety can be treated through multiple evidence-based approaches. In a similar way, GI-specific anxiety may be targeted and modified via evidence-based cognitive-behavioral strategies, which should result in improving HRQOL. Thus, future directions can be aimed at evaluating the impact of general anxiety management strategies to lessen GI-specific anxiety, specifically on HRQOL and other clinically relevant outcomes (e.g., disease coping, patient satisfaction) in youth with IBD.

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Table 1

Abbreviations

Abbreviation	Meaning
CD	Crohn's disease
CRM	Cumulative Risk Model
GI	Gastrointestinal
HRQOL	Health-related quality of life
IBD	Inflammatory bowel disease
<i>PCDAI</i>	<i>Pediatric Crohn's Disease Activity Index</i>
<i>PUCAI</i>	<i>Pediatric Ulcerative Colitis Activity Index</i>
<i>PRQ</i>	<i>Parenting Relationship Questionnaire</i>
UC	Ulcerative colitis
<i>VSI</i>	<i>Visceral Sensitivity Index</i>

Table 2

Sample Demographics

Variable (N = 30)	n (%)
Patient gender	
Male	18 (60%)
Female	12 (40%)
Patient race	
White	26 (87%)
Mixed	3 (10%)
Black/African American	1 (3%)
Patient ethnicity	
Not Hispanic/Latino	29 (97%)
Unknown	1 (3%)
Diagnosis	
Crohn's disease	24 (80%)
Ulcerative colitis	6 (20%)
Disease activity category	
Inactive	22 (73%)
Mild	6 (20%)
Moderate/severe	2 (7%)
Caregiver relationship	
Mother	25 (83%)
Father	3 (10%)
Grandmother	1 (3%)
Legal guardian (female)	1 (3%)
Family structure ^a	
Intact	19 (63%)
Blended	7 (23%)
Single	3 (10%)
Unknown	1 (3%)
Total family income	
Less than \$10,000	1 (3%)
\$10,000 – 14, 999	3 (10%)
\$15,000 – 24,999	4 (13%)
\$25,000 – 34,999	2 (7%)
\$35,000 – 49,999	5 (17%)
\$50,000 – 74,999	4 (13%)
\$75,000 – 99,999	5 (17%)
\$100,000 – 149,999	4 (13%)
\$150,000 or more	2 (7%)

Variable (<i>N</i> = 30)	<i>n</i> (%)
Highest parent education level	
High school	7 (23%)
Some college	10 (33%)
Bachelor's degree	9 (30%)
Master's degree	2 (7%)
Unknown	2 (7%)

^a Intact = married to other biological parent; Blended = remarried to step-parent; Single = never been married, divorced, widowed, or living with boyfriend/girlfriend

Table 3

Primary Variable Descriptives

Variable	<i>M</i>	<i>SD</i>	Possible range
<i>IMPACT-III</i> , Youth-report ^a	71.55	11.75	0 - 100
Bowel symptoms	66.67	19.48	0 - 100
Systemic symptoms	69.72	16.15	0 - 100
Emotional functioning	65.83	20.52	0 - 100
Social functioning	79.17	11.40	0 - 100
Body image	66.67	17.23	0 - 100
Treatment/interventions	72.50	16.40	0 - 100
<i>IMPACT-III</i> , Parent-report ^a	68.62	12.63	0 - 100
Bowel symptoms	62.38	19.98	0 - 100
Systemic symptoms	64.44	17.08	0 - 100
Emotional functioning	63.69	19.47	0 - 100
Social functioning	77.99	10.25	0 - 100
Body image	61.67	18.65	0 - 100
Treatment/interventions	68.33	15.84	0 - 100
<i>PRQ</i> ^b			
Attachment	52.82	9.84	0 - 100
Communication	53.71	8.86	0 - 100
Discipline practices	50.79	10.24	0 - 100
Involvement	55.18	11.64	0 - 100
Parenting confidence	51.46	7.75	0 - 100
Satisfaction with school	50.07	8.96	0 - 100
Relational Frustration	45.64	7.29	0 - 100
<i>VSI</i> ^a	30.70	17.50	0 - 75

^a *N* = 30; ^b *N* = 28

Table 4

Correlations between PRQ and Child-Report IMPACT-III

		IMPACT-III						
		Total	Bowel symptoms	Systemic symptoms	Emotional functioning	Social functioning	Body image	Treatment/ interventions
PRQ	Attachment	-.48*	-.26	-.16	-.37	-.40*	-.28	-.40*
	Communication	-.45*	-.28	-.05	-.45*	-.41*	-.19	-.15
	Discipline practices	.00	.03	.23	-.19	-.02	.12	.09
	Involvement	-.30	-.24	.18	-.33	-.23	-.16	-.19
	Parenting confidence	-.37	-.34	.02	-.44*	-.29	.02	.00
	Satisfaction with school	.01	.07	-.32	.11	-.02	-.03	.02
	Relational frustration	.42*	.45*	-.14	.33	.44*	-.06	.16

* $p < .05$

Table 5

Correlations between PRQ and Parent-Report IMPACT-III

		IMPACT-III						
		Total	Bowel symptoms	Systemic symptoms	Emotional functioning	Social functioning	Body image	Treatment/ interventions
PRQ	Attachment	-.40*	-.35	-.32	-.24	-.34	-.51**	-.05
	Communication	-.26	-.26	-.10	-.22	-.22	-.27	.07
	Discipline practices	.13	.04	.43*	.10	.11	-.03	.08
	Involvement	-.35	-.49**	-.01	-.23	-.34	-.19	.00
	Parenting confidence	.07	-.13	.34	-.01	.18	-.07	.21
	Satisfaction with school	-.01	-.05	-.15	.09	.02	-.13	.06
	Relational frustration	.44*	.51**	.07	.48*	.36	.14	.06

* $p < .05$, ** $p < .01$

Table 6

Attachment Moderating GI-Specific Anxiety and HRQOL

Predictor	β	p
Disease activity	-.25	.08
GI-specific anxiety	-.72	<.001
Attachment	-.16	.16
GI-specific anxiety x attachment	-.04	.74

Table 7

Communication Moderating GI-Specific Anxiety and HRQOL

Predictor	β	p
Disease activity	-.25	.09
GI-specific anxiety	-.74	<.001
Communication	-.15	.19
GI-specific anxiety x communication	-.04	.67

Table 8

Relational Frustration Moderating GI-Specific Anxiety and HRQOL

Predictor	β	p
Disease activity	-.19	.19
GI-specific anxiety	-.76	<.001
Relational frustration	-.10	.38
GI-specific anxiety x relational frustration	-.01	.91

Figure 1. Proposed association between parent-child relationship and HRQOL.

Figure 2. Proposed mediation model of the relation between GI-specific anxiety, parent-child relationship, and HRQOL.

Figure 3. Proposed moderation model of the relation between GI-specific anxiety, parent-child relationship, and HRQOL.

* $p < .05$, ** $p < .01$

Figure 4. Attachment mediating GI-specific anxiety and HRQOL.

* $p < .05$, ** $p < .01$

Figure 5. Communication mediating GI-specific anxiety and HRQOL.

* $p < .05$, ** $p < .01$

Figure 6. Relational frustration mediating GI-specific anxiety and HRQOL.