Correlates of Health-Related Quality of Life in Pediatric Inflammatory Bowel Disease: A Cumulative Risk Model Approach

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Objective To examine associations between disease-related, individual, and contextual risk factors and health-related quality of life (HRQoL) in a sample of youth with inflammatory bowel disease using a cumulative risk model framework. Methods Participants were 50 youth (58% male; M age = 15 years). Youth and parents completed measures of HRQoL, psychological functioning, and family functioning. Disease information was collected from medical record reviews. Medication adherence was electronically monitored via MEMS cap bottles. A cumulative risk index (CRI) was constructed based on disease activity, disease type, gender, anxiety/depression, medication adherence, general family functioning, disease-specific family functioning, and socioeconomic status. Results The CRI was associated with all youth- and mother-reported HRQoL domains. Furthermore, contextual domain factors were most consistently associated with youth and maternal reports of HRQoL. Conclusion These results show promise in supporting the value of the CRI in identifying potential risk factors for lower HRQoL in a cross-sectional sample.

Key words adolescents; inflammatory bowel disease; quality of life.

Introduction

Inflammatory bowel disease (IBD) is a chronic gastrointestinal condition that includes ulcerative colitis (UC), Crohn’s disease (CD), and indeterminate colitis. IBD prevalence is 71 cases per 100,000 in U.S. youth (Kappelman et al., 2007). Common IBD symptoms include diarrhea, fatigue, abdominal pain, and growth delay (Cunningham & Banez, 2006). Managing IBD poses challenges for the health-related quality of life (HRQoL) of affected youth. HRQoL is a multidimensional construct representing one’s subjective assessment of the impact of one’s health on physical and psychosocial functioning (Matza, Swensen, Flood, Secnik, & Leidy, 2004). Youth with IBD have lower HRQoL compared with healthy peers (Cunningham, Drotar, Palermo, McGowan & Arendt, 2007; Greenley et al., 2010; Kunz, Hommel, & Greenley, 2010), and poorer school-related HRQoL than healthy or chronically ill youth (Kunz et al., 2010).

Past research has examined correlates of HRQoL in this population. Wallander and Varni’s (1998) disability-stress-coping model specifies three categories of risk factors that contribute to maladjustment in pediatric chronic illnesses: Disease-related factors, individual functioning, and contextual factors. This model is valuable in categorizing specific factors shown to influence HRQoL in patients with IBD. Disease-related factors previously associated with lower levels of HRQoL in pediatric and adult IBD samples include higher levels of disease activity (Bernklev et al., 2004; Casellas et al., 2005; Han et al., 2005; Otley et al., 2006; Pallis, Vlachonikolis, & Mouzas, 2002; Vidal et al., 2008) and diagnosis of CD rather than UC (Bernklev et al., 2004; Nordin, Pahlman, Larsson, Sundberg-Hjelm, & Loof, 2002). Individual factors associated with lower HRQoL in adult IBD populations include female gender (Bernklev et al., 2004; Lopez Blanco, Moreno-Jimenez, Devesa Mugica, & Rodriguez Munoz, 2005) and anxiety...
or depressive symptoms (Mussell, Bocker, Nagel, & Singer, 2004; Petrak et al., 2001). Additionally, among youth with IBD, greater medication adherence has been associated with higher HRQoL (Hommel, Davis, & Baldassano, 2008; Schurman, Cushing, Carpenter, & Christenson, 2010). With regard to contextual variables, some data suggest that higher levels of parent and family dysfunction occur among families affected by pediatric IBD compared with families without a chronically ill child (Mackner, Crandall, & Szigerth, 2006; Greenley & Cunningham, 2009). Furthermore, youth with IBD endorsing elevated levels of family dysfunction also reported experiencing significantly poorer HRQoL in general well-being and social functioning domains (Herzer, Denson, Baldassano, & Hommel, 2011). Similarly, among families with youth with other chronic health conditions, higher family conflict and higher parental distress were related to poorer adjustment and lower adherence (Barakat et al., 2007; Drotar, 1997; Drotar & Bonner, 2009; Fredericks, Lopez, Magee, Shieck, & Opipari-Arrigan, 2007).

Although the current literature has been informative in describing risk factors for impaired HRQoL in pediatric IBD, the conclusions that can be drawn from these studies are limited in several ways. First, many past studies have relied on a single reporter rather than using a multireporter strategy, which limits the construct validity of the measurements (Holmbeck, Li, Schurman, Friedman, & Coakley, 2002). Second, existing studies typically address factors associated with lower HRQoL in isolation, rather than examining how an accumulation of risks may affect HRQoL outcomes. Examination of the influence of multiple risk factors simultaneously more closely approximates how risk factors operate in the real world.

The cumulative risk model (CRM) offers one strategy for examining concurrent influences on youth HRQoL across multiple domains. This model purports that as the number of risk factors increases, irrespective of the nature of each specific factor, youth psychosocial functioning is likely to be negatively impacted (Sameroff, Seifer, Baldwin, & Baldwin, 1993). Thus, the model provides a framework in which to conceptualize the additive risk of multiple disease-related, individual, or contextual risk factors on the outcome of interest. Whereas traditional methods of examining the impact of a single risk factor on a given outcome may provide an incomplete picture of youth at high risk for negative outcomes, the CRM allows for an examination of the additive influence of multiple risk factors on key adjustment domains (Flouri & Kallis, 2007). The CRM can be useful for both clinicians and researchers in identifying subsets of youth who are high-risk for psychosocial adjustment problems as a result of a combination of multiple risk factors. Additionally, the model allows for concurrent examination of factors at many different levels (e.g., individual, contextual), thus yielding potential information about multiple targets for intervention.

Support for the CRM’s predictive utility exists for diverse psychosocial outcomes (e.g., depressive symptoms, social competence, youth behavioral outcomes, and family burden) among samples of youth with and without chronic medical conditions and for predicting HRQoL in caregivers (Everhart, Fiese, & Smyth, 2008; Jones, Forehand, Brody, & Armistead, 2002; Josie, Greenley, & Drotar, 2007; Kerr, Black, & Krishnakumar, 2000; Seifer et al., 1996). In many of these studies, demographic factors such as socioeconomic status (SES) repeatedly surfaced as a relevant risk factor. However, no literature to date has applied the CRM to examining correlates of HRQoL in the context of pediatric IBD. This model may be particularly relevant to evaluate among youth with IBD because a number of risk factors for lower HRQoL have been identified, but no data on the importance of multiple risk factors in adversely impacting HRQoL currently exist.

The present study examined associations between several potential risk factors and HRQoL in a sample of youth with pediatric IBD using the CRM approach. Based on the existing literature and guided by the aforementioned theoretical model, we examined two disease-related factors (i.e., disease activity and type of IBD), three individual factors (i.e., gender, presence of depression or anxiety symptoms, and medication adherence), and three contextual factors (i.e., SES, general family functioning, and disease-specific family functioning) as measures of risk. We hypothesized that a greater number of risk factors would be associated with lower youth- and mother-reported total HRQoL, and lower physical and psychosocial functioning HRQoL domain scores. We also hypothesized that within each risk domain (disease, individual, and contextual), presence of a greater number of risk factors would be associated with lower youth and mother reports of total, physical, and psychosocial HRQoL scores.

Materials and Methods
Participants
Fifty youth who met the following criteria participated: (1) medically confirmed IBD diagnosis, (2) prescribed oral thiopurine medication for at least 3 months, (3) female caregiver willing to participate, and (4) age 11–18 years. Inclusion criteria 2 and 4 were required for the broader aim of the research program focused on oral medication adherence in preadolescents and adolescents. Youth with significant cognitive impairments, non-English-speaking youth...
or caregivers, and youth with another medical condition requiring daily medication were excluded. Sample demographics are provided in Table I. Sixty families were approached to participate, resulting in an 83% participation rate. Participants \((n = 50)\) did not differ from nonparticipants \((n = 10)\) in age \((t [56] = -.27, p = .79)\) or sex distribution \((\Phi = .03, p = .81)\).

### Procedure

This study was approved by institutional review boards of participating institutions. Patients were consecutively approached during outpatient gastroenterology appointments at a Midwestern children’s hospital. Interested families provided written consent or assent (for minor youth). Youth and at least one caregiver independently completed assessments of adolescent, parent, and family functioning via paper-and-pencil surveys. For the purposes of this study, only maternal reports were included in analyses. Assessments were completed in the clinic under supervision of the research assistant. If families requested to take forms home, they were instructed to independently complete the measures. Additionally, families were given an MEMS cap pill bottle for use with their thiopurine medication and were instructed regarding its use. MEMS data were downloaded after 6 months of use. Participants were compensated.

### Measures

#### Demographic Information
Youth gender, race/ethnicity, age, date of birth, and annual family income were provided by mothers using a form developed for this study.

#### Disease Information
Diagnosis date and type of IBD were abstracted from medical records. Physicians provided disease activity ratings using the validated physician global assessment (PGA) scale. Physicians rate disease activity using a 4-point rating scale \((0 = \text{no symptoms to } 3 = \text{severe disease activity})\). PGA ratings correlate highly with more complex measures of disease activity (Hyams et al., 1991).

#### Youth Internalizing Symptoms
Adolescents completed the 47-item Revised Children’s Depression and Anxiety Scale (RCADS; Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000). This measure yields assessments of six symptom domains, including separation anxiety disorder, social phobia, obsessive-compulsive disorder, panic disorder with agoraphobia, generalized anxiety disorder, and major depressive disorder. Age and grade-based T-scores were calculated, with higher scores reflecting more symptoms. Previous research with samples of medically healthy youth documented high internal consistencies for each diagnostic category \((\alpha > .70)\), high 1-week test–retest reliability, and good concurrent validity (Chorpita et al., 2000). Further validation of the measure showed that the RCADS is better suited to identifying specific clinical syndromes compared with other well-validated measures such as the Revised Children’s Manifest Anxiety Scale or the Children’s Depression Inventory (Chorpita, Moffitt, & Gray, 2005). High subscale internal consistencies were found in the present sample \((\alpha_s = .75–.85)\).

#### Family Functioning
Family functioning was assessed via two measures: Maternal report on the PedsQL Family Impact Module

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### Table I. Operationalization of Risk Versus Nonrisk Status for Disease-Related, Individual, and Contextual Risk Factor Domains and Proportion of Sample Meeting Each Risk Criterion

<table>
<thead>
<tr>
<th>Risk factor operationalization</th>
<th>(n) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disease-related domain</strong></td>
<td></td>
</tr>
<tr>
<td>Disease activity</td>
<td></td>
</tr>
<tr>
<td>Nonrisk: Physician global assessment rating = 0</td>
<td>38 (76)</td>
</tr>
<tr>
<td>Risk: Physician global assessment rating = 1–3</td>
<td>12 (24)</td>
</tr>
<tr>
<td><strong>Disease type</strong></td>
<td></td>
</tr>
<tr>
<td>Nonrisk: Ulcerative colitis or indeterminate colitis</td>
<td>7 (14)</td>
</tr>
<tr>
<td>Risk: Crohn’s disease</td>
<td>43 (86)</td>
</tr>
<tr>
<td><strong>Individual domain</strong></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Nonrisk: Male</td>
<td>29 (58)</td>
</tr>
<tr>
<td>Risk: Female</td>
<td>21 (42)</td>
</tr>
<tr>
<td>Anxiety/Depression (Revised Children’s Anxiety and Depression Scale)</td>
<td></td>
</tr>
<tr>
<td>Nonrisk: (t) score &lt;70 on all subscales</td>
<td>47 (94)</td>
</tr>
<tr>
<td>Risk: (t) score (\geq 70) on any subscale</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Medication adherence (MEMS cap)</td>
<td></td>
</tr>
<tr>
<td>Nonrisk: (\geq 80%) adherence rate</td>
<td>35 (70)</td>
</tr>
<tr>
<td>Risk: (&lt; 80%) adherence rate</td>
<td>13 (30)</td>
</tr>
<tr>
<td><strong>Contextual domain</strong></td>
<td></td>
</tr>
<tr>
<td>General family functioning (family assessment device)</td>
<td></td>
</tr>
<tr>
<td>Nonrisk: Total score (\leq 2.49) on either youth or mother report</td>
<td>45 (90)</td>
</tr>
<tr>
<td>Risk: Total score (&gt; 2.49) on either youth or mother report</td>
<td>5 (10)</td>
</tr>
<tr>
<td>Disease-specific family functioning (PedsQL-Family Impact Module)</td>
<td></td>
</tr>
<tr>
<td>Nonrisk: Total score (&gt; 63.94)</td>
<td>42 (84)</td>
</tr>
<tr>
<td>Risk: Total score (\leq 63.94)</td>
<td>8 (16)</td>
</tr>
<tr>
<td>Socioeconomic status (median annual income)</td>
<td></td>
</tr>
<tr>
<td>Nonrisk: (\geq 60,000)</td>
<td>42 (84)</td>
</tr>
<tr>
<td>Risk: (&lt; 60,000)</td>
<td>8 (16)</td>
</tr>
</tbody>
</table>
(PedsQL-FI; Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004) and youth and mother report on the Family Assessment Device General Functioning Scale (FAD; Epstein, Baldwin, & Bishop, 1983). The 36-item PedsQL-FI measures the extent to which domains of parent functioning (physical, emotional, social, cognitive, communication, and worry) and family functioning (daily activities and family relationships) have been a problem for the mother or the family as a result of the child’s health. In the current study, the total score was used to assess family functioning, with a higher score indicative of more adaptive family functioning. Initial validation studies with parents of patients with complex chronic health conditions demonstrated high internal consistency reliability (total score, \( \alpha = .97 \)). A previous study of mothers and fathers of 11–18-year-olds with IBD provides additional support for the measures reliability, with subscale alphas ranging from .92 to .96 (Kunz, Greenley, & Howard, 2011). Internal consistency estimates in the current sample were high (\( \alpha = .97 \)).

The FAD General Functioning Scale is a 12-item measure of general family functioning, which has been deemed a “well established” measure with respect to use in pediatric chronic illness populations (Alderfer et al., 2008). Higher scores on the FAD reflect greater family dysfunction. The scale displayed good internal consistency in the current sample (\( \alpha = .86 \) for child report and \( \alpha = .90 \) for mother report), as it has in previous studies of youth with IBD (\( \alpha > .85 \) for parent report; Herzer et al., 2011; Odell, Sander, Denson, Baldassano, & Hommel, 2011; Tojek, Lumley, Corlis, Ondersma, & Tolia, 2002). PedsQL-FI scores were only modestly correlated with PEDS-FI scores (\( r = .20 \)), suggesting they were tapping related but distinct constructs. Both measures were used in the present study, given the important conceptual distinction between health-related and general family functioning and empirical evidence to support that they are distinct.

**Medication Adherence**

MEMS pill caps were used as an index of oral thiopurine adherence. MEMS caps record the date and time of pill bottle openings and are an evidence-based method of adherence assessment with high convergent and predictive validity (Quittner, Modi, Lemanek, Ievers-Landis, & Rapoff, 2008). At enrollment, families were provided with the MEMS device and instructed on its use. MEMS data were downloaded after 6 months of continuous use. Adherence rates were computed using the following formula: Number of actual openings/number of prescribed openings × 100. Higher percentages reflected greater adherence.

**HRQoL**

Mothers and youth completed the PedsQL 4.0 Generic Core Scale (Varni, Seid, & Kurtin, 2001). This 23-item measure examines youth HRQoL in physical, emotional, social, and school functioning domains. A total score and two summary scores, a psychosocial health summary score (composed of the emotional, social, and school functioning domains) and a physical health summary score (composed of the physical functioning domain) can be computed, with higher scores on each scale reflecting better HRQoL. The PedsQL 4.0 is a well-validated instrument with high internal validity (\( \alpha \geq .75 \) for total and summary scores across reporters) in the present study.

**Data Analyses**

Analyses were conducted using Statistical Package for the Social Sciences, v. 17.0 (SPSS, Chicago, IL). Descriptive statistics summarized demographic and medical information. Initial analyses focused on construction of the cumulative risk index (CRI), which was an independent variable in subsequent analyses. In calculating a CRI, risk scores were first assigned to each of the eight factors: Disease activity, type of IBD, gender, presence of depression or anxiety symptoms, medication adherence, general family functioning, family functioning related to the child’s health, and SES (Table I). Factors were grouped into risk or nonrisk categories based on previous literature and clinical cutoffs when available (Begle, Dumas, & Hanson, 2010; Price & Hyde, 2009; Sylvestre & Mérette, 2010). For example, presence of disease activity, female gender, diagnosis of CD, and presence of medication nonadherence were all assigned the categorization of “risk,” as past literature supports that individuals in these categories have lower HRQoL than those with no disease activity, with a diagnosis of UC or indeterminate colitis, those who are male, or those who are more adherent to medication, respectively (Bernklev et al., 2004; Lopez Blanco et al., 2005; Otley et al., 2006; Rapoff, 2010). Similarly, poorer family functioning, lower SES, and lower psychosocial functioning, which negatively impact youth HRQoL (Everhart et al., 2008; Herzer et al., 2011; Pizzi et al., 2006), were assigned the “risk” categorization. Additionally, clinical cutoff scores reported in the literature for family functioning variables and the RCADS were used to categorize scores into “risk” or “nonrisk” (Table I; Epstein et al., 1983; Varni et al., 2004; Weiss & Chorpita, 2011). Finally, for SES, the median annual income level in the state of Wisconsin...
was used as the cutoff for risk versus nonrisk. Using the aforementioned procedures, a CRI score ranging from 0 to 8 (higher scores reflect greater risk) was computed. Bivariate correlations assessed associations of the CRI with HRQoL.

Results
Fifty youth (42% female; M age = 15 years) participated. Approximately 86% of the sample was diagnosed with CD, and 92% of the sample was Caucasian. Additional demographic information is provided in Table I. The CRI was composed of eight factors from three different domains: Two disease-related factors (disease activity and type of IBD), three individual factors (gender, presence of depression/anxiety symptoms, and medication adherence), and three contextual factors (SES, general family functioning, and disease-specific family functioning). Each of these risk factors (except for the anxiety/depression risk factor) had at least 10% of individuals categorized as “at risk” (Table I). Data screening indicated that the total risk index, domain risk indices, and HRQoL outcomes were all reasonably normally distributed (Table II).

Six bivariate correlations were conducted to examine relationships between the CRI and both youth- and maternal-reported HRQoL total, physical, and psychosocial health summary scores. All three youth-reported HRQoL variables were negatively correlated with the CRI ($r = -.42$ to $-.49$, $p < .01$), and showed medium effect sizes, consistent with our hypotheses (Table III). Similarly, all three mother-reported HRQoL variables were negatively correlated with the CRI ($r = -.46$ to $-.54$, $p < .01$; Table III), with medium effect sizes. However, given the possibility that disease type may have been driving the relationship between the CRI and HRQoL, as a majority of the participants (86%) were given a risk score of 1 for disease type, an additional set of correlation analyses were run using a CRI that excluded disease type. Once again, all three youth-reported HRQoL variables were negatively correlated with the seven variable CRI ($r = -.48$ to $-.56$, $p < .05$), as were all three mother-reported HRQoL variables ($r = -.50$ to $-.58$, $p < .01$; Table III). The CRI accounted for 23–31% of the variance found in youth-reported HRQoL and 25–34% of the variance in mother-reported HRQoL.

In follow-up analyses, we deconstructed the CRI into the component risk domains (contextual, individual, and disease-related risk factors) to examine the magnitude of influence of each domain on HRQoL (Table III). Analyses were conducted separately for youth and maternal reports of youth HRQoL. The contextual domain risk score was significantly correlated with all six youth- and mother-reported HRQoL outcomes ($r = -.37$ to $-.44$, $p < .01$), explaining 16–19% of the variance in youth report and 14–19% of the variance in mother report of HRQoL. Effect sizes were medium in magnitude. The individual domain risk score was significantly correlated with all youth-reported HRQoL outcomes ($r = -.34$ to $-.40$, $p < .05$) and with the psychosocial ($r = -.32$, $p < .05$) and total ($r = -.33$, $p < .05$) mother-reported HRQoL domains. The individual domain risk index explained 11–16% of the variance in youth-reported HRQoL. For maternal-reported psychosocial functioning and total HRQoL scores, the individual domain risk index accounted for 10 and 11% of the variance, respectively. The disease-related domain score, however, was associated only with mother report of youth physical ($r = -.41$, $p < .01$) and total HRQoL ($r = -.37$, $p < .01$), both medium effects.

Discussion
The current study examined cross-sectional relationships among several potential risk factors and HRQoL in a sample of youth with IBD using the CRM framework. The CRM suggests that the total number of risk factors to which a child is exposed, irrespective of the nature of each specific factor, leads to an increased risk of maladjustment (Sameroff et al., 1993). We hypothesized that a higher number of risk factors would be associated with lower youth HRQoL total scores, as well as lower HRQoL scores in the physical and psychosocial health domains. Overall, our findings offered support for the value of the CRM in explaining variance in HRQoL of youth with IBD. As hypothesized, higher risk scores were associated with

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Range</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cumulative risk index</td>
<td>2.30</td>
<td>1–7</td>
<td>1.39</td>
</tr>
<tr>
<td>Contextual domain risk index</td>
<td>.42</td>
<td>0–3</td>
<td>.70</td>
</tr>
<tr>
<td>Individual domain risk index</td>
<td>.78</td>
<td>0–3</td>
<td>.76</td>
</tr>
<tr>
<td>Disease-related domain risk index</td>
<td>1.10</td>
<td>0–2</td>
<td>.51</td>
</tr>
<tr>
<td>YR HRQoL total score</td>
<td>86.78</td>
<td>60.87–100.00</td>
<td>10.33</td>
</tr>
<tr>
<td>YR HRQoL physical health score</td>
<td>89.75</td>
<td>59.38–100.00</td>
<td>10.60</td>
</tr>
<tr>
<td>YR HRQoL psychosocial health score</td>
<td>85.19</td>
<td>55.00–100.00</td>
<td>11.10</td>
</tr>
<tr>
<td>MR HRQoL total score</td>
<td>86.93</td>
<td>66.30–100.00</td>
<td>10.47</td>
</tr>
<tr>
<td>MR HRQoL physical health score</td>
<td>88.31</td>
<td>56.25–100.00</td>
<td>12.48</td>
</tr>
<tr>
<td>MR HRQoL psychosocial health score</td>
<td>86.20</td>
<td>63.33–100.00</td>
<td>11.55</td>
</tr>
</tbody>
</table>

Note: YR = youth report; MR = mother report; HRQoL = health-related quality of life.
lower mother and child reports of HRQoL. Even when disease type was removed from the analyses, the relationship between the CRI and HRQoL remained significant, suggesting that disease type alone was not driving the association. These results support the potential value of the CRM in understanding risk factors for impaired HRQoL in this population.

The current findings build on past research in several ways. First, our findings support that the accumulation of risk factors across domains was associated with lower ratings of both child- and mother-reported HRQoL, consistent with previous research highlighting associations between increased number of risks and lower psychosocial adjustment (Jones et al., 2002) and decreased social functioning (Seifer et al., 1996). Second, our findings replicate those of the adult literature in suggesting that individual demographic and psychosocial factors are associated with youth HRQoL. Our findings also extend research findings from other illness groups by supporting the value of contextual risk factors as an additional domain of correlates of youth HRQoL. Finally, our findings diverge somewhat from the existing literature on associations between disease-related factors and youth HRQoL. Although past research with pediatric and adult IBD samples has documented poorer HRQoL among those with increased levels of disease activity and those with CD (Bernklev et al., 2004; Casellas et al., 2005; Han et al., 2005; Otley et al., 2006; Pallis et al., 2002; Vidal et al., 2008, Nordin et al., 2002), among our sample of youth with IBD, this domain of risk was not significantly related to youth-reported HRQoL. Furthermore, in deconstructing the CRI into contextual, individual, and disease-related risk factors, our findings revealed that contextual factors (family functioning and SES) were most consistently associated with cross-sectional mother and youth perceptions of youth HRQoL.

The contextual domain was the only domain associated with all HRQoL total and domain scores across both reporters and shared the greatest amount of variance with the HRQoL outcomes (up to 19%). Contextual factors such as family functioning may have been most consistently associated with HRQoL given the important developmental role that parents and families play in this age-group, and the fact that parents constitute the most proximal influence on youth well-being (Kazak, Rourke, & Navsaria, 2009). Similar to the contextual variables, individual factors consisting of gender, depression and anxiety disorders, and medication adherence were also pertinent in explaining significant variance in youth-reported HRQoL and all but physical HRQoL for mother reports. Interestingly, disease-related factors, such as disease activity and disease type, were only associated with mother reports of physical and total functioning. However, a trend in the same negative direction existed for youth report of HRQoL, but findings were smaller magnitude.

With regard to the discrepant findings seen in analyses between mother and youth report, there are several possible explanations. It is possible that mothers may have less insight into nonobservable factors that contribute to their child’s HRQoL. This could help to explain why only mother but not youth reports of youth HRQoL were associated with the disease-related risk index. In contrast, youth perceptions of their own HRQoL may be less dependent on the type and severity of their disease and more dependent on other factors, such as their ability to engage in social activities and the degree to which their daily lives are disrupted. It is also possible that other factors are differentially influencing the mother report of youth HRQoL, such as her own level of stress or psychological functioning. Such factors may differentially impact associations of disease-related risks and HRQoL because they may affect

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**Table III. Correlations of the Total Cumulative Risk Index, and Disease-Related, Individual, and Contextual Risk Domains Risk Indices With Mother and Youth Reports of Youth HRQoL**

<table>
<thead>
<tr>
<th>HRQoL variable</th>
<th>CRI (8 item)*</th>
<th>CRI (7 item)b</th>
<th>Individual domain risk score</th>
<th>Contextual domain risk score</th>
<th>Disease domain risk score</th>
</tr>
</thead>
<tbody>
<tr>
<td>YR total</td>
<td>-0.49**</td>
<td>-0.56*</td>
<td>-0.40**</td>
<td>-0.44**</td>
<td>-0.13</td>
</tr>
<tr>
<td>YR physical health</td>
<td>-0.41**</td>
<td>-0.48**</td>
<td>-0.34*</td>
<td>-0.40**</td>
<td>-0.06</td>
</tr>
<tr>
<td>YR psychosocial health</td>
<td>-0.49**</td>
<td>-0.55*</td>
<td>-0.39**</td>
<td>-0.42**</td>
<td>-0.16</td>
</tr>
<tr>
<td>MR total</td>
<td>-0.54**</td>
<td>-0.58**</td>
<td>-0.33*</td>
<td>-0.43**</td>
<td>-0.37**</td>
</tr>
<tr>
<td>MR physical health</td>
<td>-0.49**</td>
<td>-0.53**</td>
<td>-0.26</td>
<td>-0.30**</td>
<td>-0.41**</td>
</tr>
<tr>
<td>MR psychosocial health</td>
<td>-0.46**</td>
<td>-0.50**</td>
<td>-0.32*</td>
<td>-0.37**</td>
<td>-0.28</td>
</tr>
</tbody>
</table>

Note. HRQoL = health-related quality of life; CRI = cumulative risk index; YR = youth report; MR = mother report.

*8-item CRI includes all factors from disease-related, individual, and contextual risk domains.

*7-item CRI includes all factors from individual and contextual risk domains. From the disease-related risk domain, only disease activity is included and disease type is excluded.

*p < .05, **p < .01.
how the mother perceives the youth to be experiencing their disease. Additionally, measurement of youth HRQoL often relies solely on parent or guardian report. However, these findings highlight the importance of obtaining youth report, as youth may have different perspectives about the impact of their IBD on their HRQoL as compared with their parents.

**Limitations and Future Research Directions**

The current study has several limitations that serve as avenues for future research. First, the majority of the sample reported high levels of psychosocial functioning and low levels of disease activity. It is possible that our measure of disease activity (PGA ratings) was less sensitive to subtle disease symptoms that would be detectable only based on laboratory or biopsy data. Additionally, our measure of disease activity may not have adequately captured certain transient symptoms, such as abdominal pain or fatigue, which may affect youth HRQoL. Future studies may benefit from including examination of specific symptoms that are rated over a given period rather than a global measure of disease activity. Another limitation is the restricted range within the disease-related domain. In the present study, only factors that were consistently supported as showing relationships with HRQoL in the pediatric literature were used. However, inclusion of other disease-related correlates, such as length of time since diagnosis, might influence how the disease-related domain impacts HRQoL and should be explored in future research. Similarly, the use of the PedsQL as a measure of HRQoL may not have been sensitive to disease-specific symptoms indicative of HRQoL impairment in the context of IBD. In addition, the sample was primarily Caucasian, middle to high income, and limited to adolescents, which makes generalizability to patients of more diverse ethnic, SES, and age backgrounds questionable. Furthermore, SES is a complex and multidimensional construct, and our operationalization of SES using family income only captures one facet of SES. Additionally, although the current study used Wallander and Varni’s (1998) disability-stress-coping model as a framework for developing the examined risk factors, not all possible domains of influence on adjustment were included (i.e., stress processing, psychosocial stress, or functional independence). Future research examining the role of these factors in combination with factors included in this study would be of value in elucidating additional domains of risk. Similarly, although our study used a multireporter method, only maternal ratings were included for assessment of family functioning as it relates to the youth’s health. Inclusion of multiple reporters, particularly when examining family functioning, would be important.

Future research should be aimed at recruiting other family members such as fathers or siblings to enhance external validity. Additionally, a number of families completed questionnaires at home after medical appointments, whereas others completed questionnaires in the clinic after an outpatient appointment. No data were gathered on location of questionnaire completion, and as such, no analysis of the impact of setting on responses could be conducted. However, it should be noted that families in both contexts were instructed to complete questionnaires independently and were informed that the questionnaires generally had no right or wrong answers and that the researchers were interested in the various perceptions of each family member, in an effort to reduce family members likelihood of discussing responses or attempting to provide a unified set of responses. Another limitation of the study was its cross-sectional nature, which limits the ability to make causal inferences between the CRI and youth HRQoL. Future studies examining longitudinal associations may be valuable in determining the predictive utility of a CRI on youth HRQoL. Additionally, although the CRM was useful in examining the additive influence of several risk factors, the present study assumed linear associations between variables. It is possible that nonlinear patterns of risk may exist, and future research could examine the utility of linear versus nonlinear models in contributing to youth HRQoL. Use of the CRM also necessitated dichotomizing variables into presence or absence of risk, which results in information loss. Furthermore, it is possible that the absence of risk could actually serve as a protective factor in certain instances. However, this hypothesis cannot be evaluated within the CRM framework. Future studies could consider a conceptual and statistical approach that allows for simultaneous evaluation of risk and protective factors.

**Clinical Implications**

This study is the first to present a model in which integration of multiple established risk factors and their association with youth HRQoL in pediatric IBD could be examined. Several implications for working with children and adolescents with IBD exist. First, an increased number of risk variables across several domains were associated with poorer levels of HRQoL cross-sectionally. This suggests that clinical assessment should include attention to disease-related, individual, and contextual factors to facilitate development of a comprehensive picture of which youth are at risk for lower levels of HRQoL. Second, our study also highlights the importance of obtaining youth report of functioning, as we saw evidence of only moderate concordance rates between youth and mother reports.
Further, several of the domains of risk evaluated in the current study could be viable points of intervention to help improve HRQoL, given their modifiable nature. In particular, contextual domain variables such as family functioning and individual domain variables such as anxiety or depression symptoms and medication adherence were found to be associated with youth HRQoL. Therefore, interventions targeted at these contextual or individual factors may help ameliorate short-term impairments in HRQoL. Finally, whereas it may not always be feasible to address or resolve the most complicated issue during a brief medical visit, this model suggests that simply addressing any risk factor could have an incremental impact on improving HRQoL.

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