Parent Quality of Life in the Context of Pediatric Inflammatory Bowel Disease

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Objective To describe the quality of life (QoL) of parents of youth with inflammatory bowel disease (IBD) and examine youth disease activity (DA) and youth QoL as predictors of parent QoL. Methods Forty-nine youth with IBD (ages 10–18) and a parent completed measures of demographics, parent QoL, and youth QoL. Youth DA ratings were obtained from medical records. Results Parental QoL was higher in several domains compared to the normative sample, with the greatest differences reported in physical functioning domains. Although patient demographic factors did not explain significant variance in parent QoL, greater DA was associated with lower parent QoL in mental health (MH) and physical health (PH) domains. Higher youth QoL was associated with higher parent QoL in the MH domain only. Conclusions Although as a group parental QoL was high, when youth are experiencing disease exacerbations or impaired QoL, parents may benefit from assessment and support.

Key words chronic illness; inflammatory bowel disease; parents; quality of life.

Inflammatory Bowel Disease (IBD) is a chronic inflammatory disease of the gastrointestinal system which includes three distinct diagnostic categories: ulcerative colitis (UC), Crohn’s disease (CD), and indeterminate colitis (IC). IBD is diagnosed during childhood or adolescence in 25–30% of cases, with estimates suggesting the prevalence of CD as 4.56 per 100,000 and UC as 2.14 per 100,000 (Kugathasan et al., 2003). During active phases of the disease, individuals may experience significant abdominal pain, fatigue, weight loss, diarrhea, cramping, and joint pain. Medical management of IBD includes pharmacological, nutritional, and surgical interventions aimed at controlling symptoms and inducing and maintaining disease remission.

To promote optimal child health, parents of youth with a chronic medical condition such as IBD typically are involved in the child’s treatment management regimen, in addition to balancing their normal childrearing responsibilities. Parents of youth with chronic illnesses may be faced with a number of ongoing stressors related to their child’s medical regimen including managing the daily treatment responsibilities (e.g., medication administration, dietary restrictions), attending medical appointments, and addressing the functional limitations the child experiences as a result of their symptoms (Quittner, Davis, & Modi, 2003). Although these issues are shared across various chronic conditions, other IBD-specific stressors that parents may experience include managing unpredictable periods of disease remission and exacerbation, dealing with fears that their child may be at risk for future colorectal cancer, and coping with concerns about possible teasing that their child may experience as a result of medication side effects (e.g., cushingoid appearance, acne) or disease symptoms (e.g., growth delay; Cunningham & Banez, 2006).

The added responsibilities and stressors imposed by the presence of a pediatric chronic condition have the potential to negatively influence parent and family functioning. Among families affected by pediatric IBD, research suggests that a subset of mothers of youth with IBD display impairments in psychosocial functioning (see Mackner, Sisson, & Crandall, 2004 for a review). For example, Burke and colleagues (Burke, Neigut, Kocoshis, Chandra, & Sauer, 1994) documented a lifetime depression rate of 51% in mothers of youth with IBD. Moreover, 10% of their sample was currently depressed. Similarly, Engstrom (Engstrom, 1991, 1999) found significantly

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more psychiatric symptoms among mothers of children with IBD than among mothers of healthy children, as well as higher rates of maternal reported family dysfunction in the context of pediatric IBD when compared to a healthy comparison group and to a sample of youth with diabetes. No differences in father-reported individual or family functioning were reported across groups (Engstrom, 1991, 1999); however, sample sizes of fathers in these studies were small and may have been underpowered to detect significant differences.

Whereas most studies have examined parental psychopathology, less attention has been directed toward examining changes in roles or strain in daily activities that parents may experience as a result of managing their child’s IBD. A focus on the impact of a child’s IBD on parent quality of life (QoL) helps to “depathologize” parent adaptation to child chronic illness (Quittner, Davis, & Modi, 2003). Moreover, understanding how the presence of a pediatric chronic medical condition influences parent QoL helps to identify additional areas (outside of psychiatric symptomatology) in which parents may benefit from behavioral health support.

Little is known about the QoL of parents of youth with IBD. Akobeng and colleagues collected data on parent QoL utilizing a focus group methodology (Akobeng, Suresh-Babu, Firth, Miller, & Thomas, 1999). Of the twenty participating parents, 65% reported worry about the effects of their child’s disease on the child’s future, and 55% indicated concerns about the effects of their child’s condition on the child’s education. A smaller subset of parents reported concerns about the impact of their child’s condition on the parent’s career (15%) or the family’s lifestyle (5%). Similarly, Rabbet et al. (1996) examined parent QoL among 16 parents of youth with CD via a survey measure designed for their study. Parents in this study reported that their child’s condition had contributed to parent work-related difficulties (44%), interfered with family plans (38%), resulted in increased financial burden (13%), and contributed to strain on their marital relationship (6%). Although these two studies are suggestive of potential impairments in parent QoL in the context of pediatric IBD, these studies are characterized by several methodological limitations including a failure to use validated instruments, lack of comparison groups, and reliance on small samples that may not be representative of the larger population of affected families.

Information about how parent QoL varies as a function of child IBD disease characteristics or youth QoL is lacking. Because disease severity is variable both within and across individuals, it is important to understand the extent to which condition-related variables may influence parent QoL. Among other pediatric conditions including asthma and diabetes, greater disease severity (Halterman et al., 2004) and more disease-related demands (Faulkner & Clark, 1998) have been associated with poorer parent QoL. Among parents of youth with IBD, youth symptoms such as greater pain, more fatigue, increased frequency of bowel movements, and greater disease activity (DA) have all been associated with higher parent distress and family dysfunction (Tojek, Lumley, Corlis, Ondersma, & Tolia, 2002; Wood et al., 1989); however, no data on how disease characteristics relate to parent QoL exist. Past research also has found impairments in the QoL (both physical and psychological domains) of youth with IBD relative to physically healthy youth based on parent report (Cunningham, Drotar, Palermo, McGowan, & Arendt, 2007). Only one study has examined the relationship between youth QoL and parent adjustment in the context of pediatric IBD, with findings revealing an association between higher adolescent QoL and more adaptive parental coping (MacPhee, Hoffenberg, & Feranchak, 1998). Among other chronic illness populations such as pediatric asthma, youth QoL has been positively associated with parent QoL (Juniper et al., 1996). As is true of the relationship between child disease characteristics and parent QoL, understanding the extent to which youth QoL relates to parent QoL may help to identify subpopulations of parents or families who may benefit from preventive behavioral health interventions focused on enhancing their daily functioning.

The current study seeks to describe the QoL of parents of youth with IBD via a widely-used and well-validated generic measure of QoL, the RAND 36 Health Survey 1.0 (Hays, Sherbourne, & Mazel, 1993). Additionally, this study compares the QoL of parents of youth with IBD to a normative population of US adults. The use of a validated questionnaire and comparison to normative data affords the opportunity to document the extent to which managing a pediatric chronic condition poses additional strain for parents. Given past descriptive research which suggests impairments in parent QoL in pediatric IBD (Akobeng et al., 1999; Rabbet et al., 1996), we anticipate that the QoL of parents in our sample will be lower than that of a normative population. A final goal of the current study is to examine the extent to which youth DA and QoL are associated with parent QoL. We expect lower DA and higher youth QoL to each be uniquely associated with higher parent QoL. Since youth QoL is multidimensional, we are particularly interested in the extent to which youth QoL in physical functioning (PF) and mental health (MH) domains relates to parent QoL. Youth PF is an important domain to consider, since a chronic condition such as IBD
may impact youth’s perceptions of their ability to engage in age-appropriate physical tasks (Cunningham et al., 2007). Youth MH functioning is also an important QoL domain to examine, given that it provides an indication of the degree to which the youth is experiencing emotional distress and given data to support that youth with IBD are at risk for emotional difficulties (Mackner et al., 2004).

Method
Participants
Participants were recruited from an outpatient pediatric gastroenterology clinic at a large tertiary care children’s hospital. Eligibility criteria included being 10–18 years old with a diagnosis of IBD and a patient of the pediatric gastroenterology clinic at which the study was conducted. Of the 64 families invited to participate, 55 (86%) agreed to participate. Information on reasons for declining participation was not collected. Because of incomplete data for six participants, the final analytic sample consisted of 49. No differences with respect to youth age or sex existed between participants and those who declined participation.

Participating parents were primarily Caucasian (n = 45, 92%), the patient’s mother (n = 39, 80%), and married or living with a domestic partner (n = 37, 76%). Parents ranged in age from 31 to 64 years (M = 42.86 years, SD = 6.33 years). Median annual family income fell in the $60,000–$69,999 range, and 59% of participating parents (n = 29) held a college or professional degree. Participating youth were primarily Caucasian (n = 44, 90%) and female (n = 27, 55%), with a mean age of 14.96 years (SD = 2.23). On average, youth had been diagnosed with IBD for 2.81 years (SD = 2.19, range = 0–10 years). At their most recent clinic visit, 33% of participating youth reported abdominal pain and 27% reported liquid stools, both indicators of DA. Twenty six percent of participating youth had been previously hospitalized for IBD-related issues.

Procedure
This study was approved by the Institutional Review Board of the academic medical center at which the study was conducted. Families were approached during a regularly scheduled clinic appointment, informed about the study procedure, and invited to participate. Upon providing consent/assent, parents and youth completed questionnaires assessing various domains of youth and family functioning.

Measures
Demographics
Demographic information for the participating child and parent was collected via a questionnaire developed for the current study. Information obtained included youth age, ethnicity, sex, age of diagnosis, as well as caregiver age, ethnicity, sex, marital status, education, and annual family income.

Parent QoL
The RAND 36 Item Health Survey 1.0 (Hays et al., 1993) is a 36-item generic health status questionnaire that assesses eight domains of QoL including: PF, role limitations due to physical health (PH) problems, role limitations due to personal or emotional problems, bodily pain, general health perceptions, energy/fatigue, social functioning, and emotional well-being. From these eight domains, PH (comprised of the PF, role limitations due to PH problems, pain, and general health perceptions domains) and MH summary scores (comprised of role limitations due to personal or emotional problems, energy and fatigue, social functioning, and emotional well-being) are computed. Domain and summary scores range from 0 to 100, with higher scores reflecting better QoL. This measure has evidenced adequate psychometric properties in past research, including concurrent validity with other measures of QoL and good internal consistency (α > .78) in the general US adult population (Hays et al., 1993).

Youth QoL
The Child Health Questionnaire-Child Form 87 (CHQ-CF 87; Landgraf & Abetz, 1997; Landgraf, Abetz, & Ware, 1996), a multidimensional generic QoL instrument, was used to assess youth QoL. Youth completed the CHQ-CF87, which assesses 14 domains of child (e.g., PF), caregiver (e.g., impact on parental personal time), and family (e.g., family cohesion) functioning. In the present investigation, the MH and PF scale scores were utilized and evidenced high internal consistency (α = .99 for both). The MH score consists of sixteen items assessing emotional functioning over the past 4 weeks (e.g., feeling sad, worry about things, and feeling bothered or upset). The PF subscale includes 9 items assessing the extent to which it has been difficult for the youth to engage in physical activities such as participating in sports, walking around the block, and performing daily self-care activities. Scores range from 0 to 100 with higher scores reflecting better QoL. The CHQ-CF87 has evidenced good psychometric properties in previous studies (Landgraf & Abetz, 1997).

Disease Activity
The Myren modification of the Harvey Bradshaw Simple Index (Myren HBSI; Myrenet al., 1985) was used as a measure of DA. The HBSI examines general well-being, abdominal pain, number of liquid stools per day, abdominal mass,
and other complications related to IBD. Scores range from 0 to 22 with higher scores indicative of greater DA. Prior research suggests concurrent validity of the HBSI index (Hyams, Ferry, Mandel, Gryboski, Kibort, Kirschner, 1991) in relation to other indices of DA including the Pediatric Crohn’s DA Index and physician global assessment ratings (r’s > .80). Information to compute the HBSI was obtained via review of patient medical records. For 75% of participants, medical information was obtained from an outpatient appointment which occurred on the same day of study participation. The remaining 25% of participants were unable to complete the questionnaires during their scheduled clinic appointment because of demands associated with that appointment. These participants returned the questionnaires at a later date (within 2 months of their medical appointment).

Results
Internal Consistency Analyses
RAND 36 domain scores and summary scores all evidenced adequate internal consistency with scores above .70 in all domains. Internal consistencies for the domain scores were as follows: PF \( \alpha = .92 \); Role limitations due to PH \( \alpha = .87 \); Role limitations due to emotional problems \( \alpha = .74 \); Energy/Fatigue \( \alpha = .79 \); Emotional well-being \( \alpha = .79 \); Social functioning \( \alpha = .80 \); Pain \( \alpha = .84 \). Internal consistency estimates for the summary scores were also high: PH summary score \( \alpha = .93 \); MH summary score \( \alpha = .89 \).

Parent QoL Descriptive Analyses
Parents reported that their QoL was highest in the physical and social functioning domains (Table I) and lowest in the energy/fatigue and general health domains. Differences between the scores on the RAND 36 for the sample of participating parents \( n = 49 \) and the US normative sample of men and women \( n = 2471 \) (Hays et al., 1993) were examined. These differences were expressed as a \( z \)-score which was calculated by standardizing the differences between the sample and population means. Results of these analyses suggested that parents of youth with IBD evidenced significantly higher QoL in five of eight domains when compared to the normative group: PF, role limitations due to PH, role limitations due to emotional problems, energy/fatigue, and general health (Table I).

Associations between Independent and Dependent Variables
Correlation analyses examined interrelationships among independent variables (Table II). Youth age was not associated with youth QoL or youth DA. Youth DA was not significantly associated with youth QoL. Finally, youth QoL in the MH domain was positively associated with youth QoL in the PF domain. No differences in DA \( (t (43) = -.026, p = .98) \) or youth QoL in the PF domain \( (t (45) = 1.26, p = .22) \) as a function of youth sex were documented. However, youth QoL in the MH domain was significantly higher for boys than for girls \( (t (44) = 2.29, p = .03) \).

Correlation analyses also examined relationships between independent and dependent variables (Table II). Significant positive associations between parent QoL in the PH and MH domains and youth QoL in MH and PF

Table I. Comparison of RAND 36 QoL IBD Sample Ms (SDs) with Normative Data

<table>
<thead>
<tr>
<th>QoL domain</th>
<th>IBD Sample M (SD) ( n = 49 )</th>
<th>Normative population M (SD) ( n = 2471 )</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>84.46 (21.38)</td>
<td>70.61 (27.42)</td>
<td>4.47**</td>
</tr>
<tr>
<td>Role functioning/physical</td>
<td>80.00 (33.96)</td>
<td>52.97 (40.78)</td>
<td>5.27**</td>
</tr>
<tr>
<td>Role functioning/emotional</td>
<td>81.16 (31.94)</td>
<td>65.78 (40.71)</td>
<td>3.22**</td>
</tr>
<tr>
<td>Energy/fatigue</td>
<td>59.15 (18.66)</td>
<td>52.15 (22.39)</td>
<td>2.48*</td>
</tr>
<tr>
<td>Emotional well-being</td>
<td>72.18 (16.25)</td>
<td>70.38 (21.97)</td>
<td>0.73</td>
</tr>
<tr>
<td>Social functioning</td>
<td>83.24 (20.57)</td>
<td>78.77 (25.46)</td>
<td>1.47</td>
</tr>
<tr>
<td>Pain</td>
<td>76.86 (23.85)</td>
<td>70.77 (25.46)</td>
<td>1.73</td>
</tr>
<tr>
<td>General health</td>
<td>68.80 (20.60)</td>
<td>56.99 (23.12)</td>
<td>3.89**</td>
</tr>
</tbody>
</table>

IBD, inflammatory bowel disease; QoL, quality of life.  
*p < .05, **p < .01.

Table II. Bivariate Correlations between Independent and Dependent Variables

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Youth age</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Disease activity</td>
<td>0.23</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Youth MH QoL</td>
<td>-0.04</td>
<td>-0.12</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Youth PF QoL</td>
<td>0.23</td>
<td>-0.18</td>
<td>0.50***</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>5. Parent MH QoL</td>
<td>-0.16</td>
<td>-0.40**</td>
<td>0.42**</td>
<td>0.37**</td>
<td>1.00</td>
</tr>
<tr>
<td>6. Parent PH QoL</td>
<td>-0.04</td>
<td>-0.31*</td>
<td>0.38*</td>
<td>0.32*</td>
<td>0.52***</td>
</tr>
</tbody>
</table>

MH, mental health; PF, physical functioning; PH, physical health; QoL, quality of life.  
*p < .05, **p < .01, ***p < .001.
domains were found, while significant negative associations between parent QoL and youth DA were documented. No significant associations between youth age and parent QoL in PH or MH domains were observed. No mean differences in parent PH ($t$ (45) = 0.52, $p = .61$) or MH ($t$ (45) = 1.53, $p = .13$) domains of QoL were found as a function of youth sex.

**Regression Analyses**

Two regression analyses were conducted to examine the contributions of DA and child QoL (in MH and PF domains) in predicting parent QoL (MH and PH summary scores only). Only variables that demonstrated significant correlations with the two dependent variables were included in regression models. Since neither youth age nor youth sex were associated with parent QoL, these variables were excluded from regression analyses. Multiple linear regressions were conducted to examine if youth QoL in PF or MH domains contributed unique variance beyond that explained by DA in the prediction of parent QoL in MH and PH domains. Results of regression analyses are presented in Table III.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>$\beta$</th>
<th>$R^2$ change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent QoL in PH domain</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td>Youth disease activity</td>
<td>-2.44</td>
<td>1.21</td>
<td>-0.31*</td>
</tr>
<tr>
<td>Step 2</td>
<td>Youth disease activity</td>
<td>-2.02</td>
<td>1.19</td>
<td>-0.26</td>
</tr>
<tr>
<td></td>
<td>Child QoL PF domain</td>
<td>0.19</td>
<td>0.24</td>
<td>0.14</td>
</tr>
<tr>
<td></td>
<td>Child QoL MH domain</td>
<td>0.38</td>
<td>0.29</td>
<td>0.23</td>
</tr>
<tr>
<td><strong>Parent QoL in MH domain</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1</td>
<td>Youth disease activity</td>
<td>-2.63</td>
<td>0.99</td>
<td>-0.39*</td>
</tr>
<tr>
<td>Step 2</td>
<td>Youth disease activity</td>
<td>-2.18</td>
<td>0.95</td>
<td>-0.32*</td>
</tr>
<tr>
<td></td>
<td>Child QoL PF domain</td>
<td>0.26</td>
<td>0.19</td>
<td>0.22</td>
</tr>
<tr>
<td></td>
<td>Child QoL MH domain</td>
<td>0.31</td>
<td>0.23</td>
<td>0.22</td>
</tr>
</tbody>
</table>

MH, mental health; PF, physical functioning; PH, physical health; QoL, quality of life.

*p < .05.

**The Role of DA**

DA explained a significant amount of variance (10%) in the prediction of parent QoL in the PH domain ($R^2 = .10$, $F$ (1, 39) = 4.10, $p = .050$). Similarly, youth DA explained 15% of the variance in the prediction of parent QoL in the MH domain ($R^2 = .15$, $F$ (1, 39) = 7.03, $p = .012$). These findings were consistent with prediction.

**The Role of Youth QoL**

Multiple regression analyses also examined whether youth QoL in PH and MH domains contributed additional variance beyond that explained by youth DA in the prediction of parent QoL. With respect to parent QoL in the PH domain, the addition of child PF and MH QoL failed to contribute additional variance to the prediction of parent QoL ($R^2$ change = .10, $F$ change (2, 37) = 2.25, $p = .120$). This finding was contrary to prediction. Youth QoL did offer unique explanatory value in the prediction of parent QoL in the MH domain, beyond the variance accounted by youth DA. The addition of youth PF and MH QoL to the regression model resulted in an additional 14% of the variance being explained in parent MH QoL ($R^2$ change = .14, $F$ change (2, 37) = 3.78, $p = .032$), a finding that was consistent with hypothesis.

**Discussion**

The current study summarized parent QoL in the context of pediatric IBD using a standardized measure. The study also examined the extent to which youth disease characteristics and youth QoL influenced parent QoL. Findings revealed that the RAND 36 can be reliably used among parents of youth with IBD. Interestingly, whereas past studies utilizing small sample sizes and less standardized approaches to the assessment of parent QoL suggested impairments in key domains (Akobeng et al., 1999; Rabbett, 1996), the current findings revealed that the QoL of parents surveyed was not significantly lower than that of a normative sample of US adults in any domain assessed. Furthermore, our findings suggested that in five of eight areas, parents in this study evidenced significantly higher levels of QoL compared to the normative sample. Areas in which parent QoL was significantly higher than that of the normative sample tended to be in domains related to physical well-being and energy. These findings illustrate the important role that a comparison population can play in determining whether or not stressors are enhanced in the context of parenting a child with a chronic medical condition. Whereas past studies reported some negative impact on QoL of parenting a child with a chronic condition, the present findings suggest that overall
participating parents were functioning quite well in managing the added responsibilities and changes to roles associated with rearing a child with a chronic medical condition. Because our sample tended to be predominantly Caucasian, well-educated, and of middle to upper-middle socioeconomic status, participants in this sample may have had greater resources to cope with daily stressors in comparison to the resources available within the normative population. These greater resources may have contributed to the higher QoL documented within our sample relative to the normative group. It is also conceivable that those who agreed to participate in the present investigation may have been experiencing fewer stressors than those who declined to participate, thus contributing to differences between our sample and the normative group.

Given that IBD is a condition that is characterized by periods of symptom remission and exacerbation, it is important to understand the role of youth DA in predicting parent QoL, as this may help to elucidate subgroups of parents who may be at risk for impaired QoL. Our findings did suggest that as DA increases, parent QoL in both MH and PH domains decreases. During times in which the child is experiencing a disease exacerbation, parents may be expected to experience greater demands (e.g., administering “as needed” medication, attending medical appointments, monitoring their child’s symptoms more closely). These added demands may contribute to greater physical strain and worry, thus impacting negatively on parent QoL. We were also interested in understanding the role of youth QoL in offering additional explanatory value to the prediction of parent QoL. Interestingly, youth QoL was an independent predictor of parent QoL in the MH domain only. Youth adjustment appears to play a more influential role in parent emotional adjustment than it does in parent PF.

The current findings should be interpreted within the context of several limitations which provide avenues for future research. First, our sample size was relatively small and was underpowered to detect differences between mothers and fathers. Moreover, our sample was limited to parents of youth ages 10–18. Since school age children and adolescents can assume some responsibility for their own condition management, it is possible that parental QoL may be more negatively impacted among parents of younger youth (i.e., preschool age) with IBD than it was among parents in our sample. Third, our sample consisted primarily of youth who had been diagnosed two or more years ago. Parents of newly diagnosed youth may experience more stress or role strain as they adjust to the “newness” of managing a chronic pediatric condition, and as such the current findings may not totally generalize to this group. Additionally, several participants in our study did not have DA ratings from exactly the same day as their study participation and only one rater completed DA ratings. It is also possible that parents who declined participation may have been experiencing greater psychosocial stress than parents who agreed to participate. Thus, future studies which include both mothers and fathers, incorporate a wider age range of participants, utilize DA ratings from the same day as study participation, and include youth with both newly diagnosed and longstanding IBD would be of value. Fifth, this study was cross-sectional in nature, which limits the ability to document how parent QoL changes over time in response to child disease or psychosocial functioning. Future research which incorporates a longitudinal approach would, therefore, be of great benefit. Of particular benefit would be longitudinal models that examine moderators and mediators of the association between youth disease or emotional characteristics and parent QoL. For example, longitudinal studies could ascertain whether increased caregiver burden is the mechanism by which youth DA affects parent QoL. Sixth, although both DA and youth functioning explained a significant portion of variance in parent QoL, their explanatory value was modest. Future research which examines other predictors of parent QoL in the context of pediatric IBD would be useful (e.g., parent coping skills, quality of parent marital relationship, social support, etc.). Finally, our normative group was comprised of individuals from the general US population and, as such, may have been racially and socioeconomically different from our participants. These demographic differences could have contributed to the higher QoL scores documented within our sample. As such, future research which utilizes comparison groups of (a) parents of healthy youth matched for key demographic factors and/or (b) matched comparison groups of parents of youth with other chronic illnesses would help to more clearly determine the unique influence of pediatric IBD on parent QoL.

The present findings have several implications for the provision of family-centered care by psychologists and other health-care professionals. First, our findings indicate that the RAND 36 can be used as a reliable screener of parent QoL. Moreover, associations between greater DA and lower parent QoL lend preliminary support to the measure’s validity within this population. The current findings offer recommendations for which parents should receive targeted assessment of QoL. Specifically, parents of children experiencing disease exacerbations should be formally screened for added role strain or impairments in daily functioning using a standardized QoL measure.
In addition, parents whose children are experiencing impaired QoL may also benefit from formal screening. For those parents who are experiencing added strain, interventions to maximize parental QoL could then be implemented. In other chronic condition groups, providing social support to parents has been effective in reducing anxiety and worry (e.g., Chernoff, Ireys, DeVet, & Kim, 2002; Ireys, Chernoff, DeVet, & Kim, 2001); educational, relaxation, and communication training interventions have been associated with reduced maternal distress (e.g., Streisand, Rodrigue, Houck, Grahan-Pole & Berlant, 2000; and problem-solving training has improved parent adjustment (e.g., Sahler et al., 2005; Sahler et al., 2002). Interventions targeting these areas also may be beneficial in the context of improving the QoL of parents of youth with IBD. Attention to parent well-being during times in which youth are in the active phases of their disease may serve a useful preventive function in terms of reducing parent strain. Moreover, since parents are important sources of support for youth, maximizing parent QoL may indirectly benefit the well-being of youth.

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References


