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Health-Related Quality of Life Predicts Psychology Referral in Youth with Inflammatory Bowel Disease

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ABSTRACT

Purpose: The current study sought to explore psychosocial data gathered from routine screening within an interdisciplinary IBD program, with two-fold aims: 1) to examine parent-child agreement across health-related quality of life domains and 2) to evaluate the differential predictive value of child and parent ratings of health-related quality of life domains on referrals for psychological services.

Design and methods: A convenience sample of 92 youth (ages 8–18) and their parents completed the Pediatric Quality of Life Inventory.

Results: Children and parents showed moderate to good agreement across health-related quality of life domains. Additionally, regression analyses revealed that child and parent-proxy reports of emotional difficulties, parent report of school difficulties, and child report of physical symptoms were significantly predictive of psychology referral status.

Conclusions: Study findings suggest moderate to good agreement among child and parent-proxy reporters and support the shared value of both child and parent ratings of health-related quality of life in predicting psychology referrals in youth with IBD.

Practice implications: Routine psychosocial screening among youth with IBD can promote the early identification of emotional and behavioral needs, and family receipt of appropriate, evidence-based intervention.

Introduction

Among youth with Inflammatory bowel disease (IBD), the unpredictable onset of disease flares, bowel symptoms, complex treatment regimen, and medication side effects cause significant distress among children and parents alike. This can impact normal socialization, school attendance, and health-related quality of life (HRQOL) (Greenley et al., 2010; Mackner et al., 2013; Mackner, Bickmeier, & Crandall, 2012). Child HRQOL has been well studied within pediatric IBD and shown to be associated with various medical and psychological risk factors (Engelmann et al., 2015; Gray, Denson, Baldassano, & Hommel, 2011; Reed-Knight, Lee, Greenley, Lewis, & Blount, 2016). HRQOL has also been found to predict healthcare utilization among youth with IBD, including hospital admissions, psychology and GI clinic visits, and telephone contact (Ryan et al., 2013). Although existing literature is mixed, children with IBD generally report poorer HRQOL than healthy controls (Greenley et al., 2010; Varni et al., 2015) Specific concerns regarding physical appearance, bothersome gastrointestinal symptoms, and frequent bathroom visits are especially common among youth with IBD, and may impact with child adjustment and psychosocial functioning. Furthermore, psychological factors, such as anxiety symptoms, depressive symptoms, and behavioral dysfunction, have been associated with poorer HRQOL (Gray et al., 2011; Loreaux, Gray, Denson, & Hommel, 2015; Reed-Knight et al., 2016) and in fact, a subset of children with IBD exhibit clinically significant internalizing symptoms, such as anxiety or depression (Engelmann et al., 2015; Herzer, Denson, Baldassano, & Hommel, 2011). As such, HRQOL is an important marker of psychosocial functioning in youth with chronic medical conditions.

When youth and parent HRQOL ratings are compared, they typically demonstrate moderate-to-excellent agreement (Gallo et al., 2014; Kunz, Hommel, & Greenley, 2010; Loonen, Derkx, Koopman, & Heymans, 2002); however, parent-child discordance has been noted across discrete domains of functioning in pediatric IBD and other pediatric illness populations (Huang et al., 2009; Ingerski et al., 2010). Evaluating parent-child agreement in HRQOL and the impact on treatment

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referrals can be an essential component for treatment planning, as parents' perceptions of children's HRQOL might determine the utilization of mental health services. Discordance between HRQOL ratings might lead to barriers to seeking medical or psychosocial treatment. For example, if a parent perceives greater concerns than the child, that child might be a less willing or engaged participant in treatment referrals. Alternatively, if a child endorses concerns in the absence of parental concerns, parents may underestimate the need for treatment and not seek appropriate care. In fact, several studies of children's healthcare use have shown that maternal worry and parental concern about child health and well-being significantly predicts healthcare utilization and engagement in healthcare services (Cushing, Bishop-Gilyard, Boles, Reiter-Purtill, & Zeller, 2013; Janicke, Finney, & Riley, 2001). As such, information on parent-child agreement can further guide the development of screening protocols, particularly pertaining to use of single or multi-informants of child psychosocial functioning.

Given the risk for psychosocial morbidity among youth with IBD, a biopsychosocial approach to IBD management, including integration of behavioral health services, is increasingly being recognized and recommended (Leichtner et al., 2013; Szigethy et al., 2017). However, only a handful of studies to date have reported use of such practices and published on relevant clinical outcomes or value added to existing services (Maddux, Bass, Geraghty-Sirridge, Carpenter, & Christenson, 2013; Moser, Plante, LeLeiko, & Lobato, 2014). Relatedly, while routine screening is increasingly being employed in pediatric primary care, implementation remains far from universal, thus underscoring the importance of screening procedures in alternative settings for high risk populations like IBD. Pediatric subspecialty clinics have employed routine screening to an even lesser extent, despite data supporting this practice among some chronic illness populations (e.g., cancer, diabetes) (Kazak et al., 2012; Schwartz, Cline, Axelrad, & Anderson, 2011). To our knowledge, only one study has specifically evaluated the feasibility and acceptability of screening among youth with IBD seen in a GI clinic, and found that a standardized approach for depression and global health screening was both feasible and effective to prompt further assessment and behavioral health referrals (Iturralde et al., 2017). In the absence of integrated care models, youth with IBD may not receive the appropriate resources thus hindering timely interventions when clinically indicated. Routine screening within pediatric IBD may facilitate early identification of emotional and behavioral problems among children with a chronic medical illness, and guide treatment planning and delivery, including referrals for psychological services.

The current study explored psychosocial data gathered as part of a routine screening process within an interdisciplinary IBD clinic, with two-fold aims: 1) to examine parent-child agreement across HRQOL domains and 2) to evaluate the differential predictive value of HRQOL domains on referrals for psychological services. We hypothesize that youth with IBD will demonstrate strong agreement with their parents across HRQOL domains. Additionally, given the inverse relationship between child HRQOL and psychological factors, including perceived stress, self-esteem, anxiety, depression, and child behavior (Gray et al., 2011; Iglesias-Rey et al., 2014; Reed-Knight et al., 2016), HRQOL-ratings are expected to generate referrals for psychological services among youth with IBD.

Methods

Procedures

Over a period of 1½ years, all children with newly diagnosed IBD (8–18 years; *M* age = 13.7) and their parents (*N* = 92) completed the Pediatric Quality of Life Inventory™ Generic Core Scales (PedsQL™)[30] as part of a standard-of-care screening process. The PedsQL™ is completed independently by patients and parents in the same clinic room at the start of the clinic visit. Standardized instructions are provided by clinic nurses or nurse coordinators once the patient/parents are in a clinic room, patients and parents are informed that the coordinators are available for assistance with the questionnaires, and a clinic administrative assistant subsequently scores questionnaires.

Participants

All participants were active patients within an interdisciplinary IBD Clinic at a pediatric medical center in the Midwest. This IBD Clinic provides interdisciplinary care to approximately 600 young patients with IBD and is staffed by three pediatric gastroenterologists, two nurse practitioners, one pediatric psychologist, one social worker, one dietician, and two nurse coordinators. Most patients are seen by the interdisciplinary team within 1–4 weeks of initial IBD diagnosis and subsequently continue follow up with their primary gastroenterologist for routine medical care thereafter. Institutional Review Board approval was obtained for all study procedures.

Measures

Pediatric Quality of Life Inventory (PedsQL™) (Varni et al., 2015)

The PedsQL™ Generic Core Scales is a 23-item well-established, reliable, and valid measure of child HRQOL with good internal consistency (child, Cronbach's $\alpha = 0.86$; parent, Cronbach's $\alpha = 0.84$) within this sample. Total and subscale scores were used to denote overall HRQOL, and physical, emotional, social, and school-HRQOL, based on child and parent-proxy report. Respondents were asked to rate how much of a problem each item had posed within the past month on an anchored Likert scale, with higher scores suggesting improved HRQOL.

Psychological referral

A licensed clinical psychologist on the interdisciplinary IBD team facilitated all referrals for psychological services; these included an internal referral for psychological services (e.g., outpatient therapy, psychological evaluation), an external referral for psychological services in the community, follow-up with the IBD team psychologist during a future GI clinic visit (e.g., for brief targeted intervention), or continuation of pre-existing mental health services.

Disease severity

Disease severity was assessed using the Short Pediatric Crohn's Disease Activity Index (PCDAI) (Kappelman et al., 2011) and the Pediatric Ulcerative Colitis Activity Index (PUCAI) (Turner et al., 2007). The Short PCDAI is a 6-item measure used to assess disease severity in pediatric Crohn's disease patients. Patient are asked items assessing general well-being, abdominal pain, stools, weight, abdominal exam, and extra-intestinal manifestations. Higher scores are indicative of more severe disease. Internal consistency was 0.83 in this sample. The PUCAI is a 6-item measure used to assess disease severity in pediatric ulcerative colitis patients. Patients are asked items assessing abdominal pain, rectal bleeding, stool consistency, number of stools per 24 h, nocturnal stools, and activity level. Higher scores are indicative of more severe disease. Internal consistency was 0.80 in this sample.

Statistical analyses

All statistical analyses were performed using SPSS, Version 23. Descriptive statistics were used to describe the demographic and medical characteristics of this sample. Pearson's correlations and multivariate analyses of variance (MANOVAs) explored the relationships between HRQOL and demographic characteristics (i.e., patient age, gender, dichotomized minority status, or parent-respondent type). Parent-child concordance on the PedsQL™ was assessed using intraclass correlation coefficients (ICCs) and paired-samples *t*-tests. ICCs examined the magnitude of agreement among reporters (range: ≥0.40 poor to fair agreement; 0.41–0.60 = moderate agreement; 0.61–0.80 = good agreement; ≥0.81 = excellent agreement) (Landis & Koch, 1977) and independent samples t-tests explored mean differences by reporter type. Logistic regression analyses explored the relative contribution of child- and parent-HRQOL ratings (i.e., physical, social, emotional, school subscales) in predicting psychology referral status. Moreover, independent samples t-tests examined mean differences between parent- and child-HRQOL ratings by referral status (i.e., referred versus non-referred). Psychology referral was dichotomized for all statistical analyses (0 = no referral, 1 = referral).

Results

Sample characteristics

Sample characteristics were generally representative of the pediatric IBD population (Crandall et al., 2012; Kappelman et al., 2011; Long et al., 2011). Participants were primarily Caucasian, equally distributed by gender (51% male), and had a confirmed diagnosis of either Crohn's Disease (74%) or Ulcerative Colitis (26%). The majority of parent respondents on the PedsQL™ were mothers (87%), which is consistent with the larger child clinical research (Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). See Table 1 for full demographic and medical characteristics.

Univariate analyses

Pearson's correlations and chi-squared tests found no relationship between psychology referral status and demographic or disease characteristics. Similarly, Pearson's correlations and MANOVAs revealed no significant relationship between HRQOL and demographic characteristics (i.e., patient age, gender, dichotomized minority status, or parent-respondent type). Significant differences emerged between patients with active versus quiescent disease on child report of Emotional HRQOL (Active-Disease: $M = 72.90$, $SD = 17.44$; Remission: $M = 83.54$, $SD = 19.01$; $F(1, 89) = 7.72$, $p < .01$) and School HRQOL (Active-Disease: $M = 64.40$, $SD = 18.97$; Remission: $M = 75.12$, $SD = 16.30$; $F(1, 89) = 8.16$, $p < .01$).

Table 1
Demographic and disease characteristics of youth with IBD.

	Crohn's disease (n = 68, 73.9%)	Ulcerative colitis (n = 24, 26.1%)
	M (SD)	
Age	13.53 (2.61)	14.18 (3.16)
Time since diagnosis (days)	41.48 (44.43)	24.04 (20.74)
	N (%)	
Gender		
Male	38 (55.9)	9 (37.5)
Race/ethnicity		
Caucasian	60 (88.2)	18 (75.0)
African American	7 (10.3)	2 (8.3)
Hispanic/Latino	1 (1.5)	1 (4.2)
Asian American	0 (0)	1 (4.2)
Other	0 (0)	2 (8.4)
Disease severity		
Remission	29 (43.3)	13 (54.2)
Mild	37 (55.2)	4 (16.7)
Moderate-severe	1 (1.5)	7 (29.2)
Referral status		
Referral	23 (33.8)	8 (33.3)
No referral	45 (66.2)	16 (66.7)
Referral type		
Internal	7 (10.3)	1 (4.2)
External	4 (5.9)	3 (12.5)
GI clinic follow-up	9 (13.2)	3 (12.5)
Continuation with PES	3 (4.4)	1 (4.2)
None	45 (66.2)	16 (66.7)
Parent respondent type		
Mother	56 (82.4)	24 (100.0)
Father	12 (17.6)	0 (0.0)

Note. N = 92. PCDAI = Short Pediatric Crohn's Disease Activity Index, PUCAI = Pediatric Ulcerative Colitis Activity Index, PES = Pre-existing services.

Table 2
Child-parent agreement across HRQOL domains.

HRQOL domain	M (SD)		*t*	ICC
	Child	Parent		
Total score	78.46 (12.85)	75.82 (14.32)	−1.85	0.66
Physical	79.72 (15.23)	76.14 (19.06)	−1.98	0.66
Social	87.07 (14.07)	85.76 (15.83)	−0.77	0.58
School	69.08 (18.47)	69.62 (21.55)	0.25	0.63
Emotional	77.28 (19.14)*	70.98 (20.24)*	−2.72	0.53

Note. HRQOL = Health-Related Quality of Life, ICC = Intraclass correlation coefficient. ICC range: ≥0.40 poor to fair agreement; 0.41–0.60 = moderate agreement; 0.61–0.80 = good agreement; ≥0.81 = excellent agreement (Landis & Koch, 1977).
Paired-samples *t*-tests revealed significant differences between child and parent-proxy ratings of Emotional-HRQOL.

* $p < .01$.

ICCs

See Table 2 for a full list of descriptive statistics and ICCs; moderate to good agreement was found between children and parents across all domains of HRQOL. Paired-samples *t*-tests revealed significant differences between child and parent-proxy ratings of Emotional-HRQOL, $t(91) = -2.72$, $p = .008$.

Logistic regression

The overall model accounted for unique variance in psychology referral, χ^2 (8, 91) = 32.38, $p = .000$, correctly classifying 80.2% of cases. See Table 3 for the relative contribution of each predictor variable. Child and parent-proxy reports of poorer Emotional HRQOL, and parent-proxy report of poorer School HRQOL accounted for increased likelihood of referral, whereas, child report of poorer physical HRQOL predicted lower chances of referral. Additionally, significant differences emerged in parent-proxy ratings of total HRQOL across the referred (M = 69.17, SD = 14.11) and non-

Table 3
Predictors of psychology referral among youth with IBD.

Predictor variable	*χ2 = 32.38*			
	B	SE	OR [95% CI]	*p*
Youth-HRQOL	–	–	–	–
Physical	0.086	0.031	1.09 [1.03–1.16]	.006**
Emotional	−0.041	0.020	0.96 [0.92–1.00]	.042*
Social	0.000	0.025	1.00 [0.95–1.05]	.993
School	−0.029	0.019	0.97 [0.94–1.01]	.126
Parent-HRQOL	–	–	–	–
Physical	0.000	0.019	1.00 [0.96–1.04]	.985
Emotional	−0.044	0.019	0.96 [0.922–0.994]	.022*
Social	0.020	0.023	1.02 [0.97–1.07]	.401
School	−0.041	0.018	0.96 [0.93–0.99]	.019*

Note. Unstandardized (B) coefficients with standard error, odds ratio (OR) with confidence intervals and corresponding *p*-values between all predictors and the criterion variable. Logistic regression analyses revealed that the overall model accounted for unique variance in psychology referral.

* $p < .05$.

** $p < .01$.

referred youth ($M = 79.20$, $SD = 13.31$), $t\ (90) = 3.35$, $p = .001$, with those referred for psychological services displaying poorer HRQOL. Child ratings of total HRQOL did not differ by referral status.

Of note, among those patients who received recommendations for an internal referral or follow-up during a future GI clinic visit, 80.0% followed through with the recommendation. Primary reasons for lack of follow-up included resolution of presenting concerns ($n = 2$), time constraints ($n = 1$), and the family's decision to transfer the child's medical care to another facility ($n = 1$).

Discussion

HRQOL is an important patient-based health outcome. In pediatrics alone, HRQOL is identified as an important marker of psychological health and has been linked to anxiety symptoms, depressive symptoms, and behavioral difficulties. Given the risk for internalizing symptoms and reduced HRQOL among youth with IBD (Mackner et al., 2013), routine screening is a valuable addition to integrated behavioral health services, allowing for early detection of at-risk patients and timely provision of referrals for treatment.

Youth with IBD and their parents showed moderate to good agreement in their HRQOL ratings. However, significant differences emerged between child and parent ratings of emotional functioning, such that parents were more inclined to perceive their children as having emotional difficulties than were children themselves. Children may be less inclined to report emotional difficulties for fear that doing so may lead to stigma or cause their parents to worry. Our clinical experience supports the tendency of some youth to underestimate/underreport symptoms across domains of HRQOL to keep parental worry to a minimum. Caregiver psychological functioning (e.g., parenting stress, illness-related distress) or parental concern for their child's overall well-being may also impact parental perceptions of child emotional adaptation and HRQOL. Extant research demonstrates that HRQOL ratings between parents and children may impact the perceived need for psychological services and engagement in such services (Cushing et al., 2013).

Both child and parent ratings of HRQOL differentially predicted referral status. That is, child and parent perceptions of emotional difficulties (e.g., symptoms of depression and anxiety), parent-report of school difficulties (e.g., school absences), and child-report of physical symptoms (i.e., symptoms of pain and functional impairment) were significantly predictive of psychology referrals. Consistent with our clinical observations, parents of youth with IBD are most often distressed by school functioning concerns, given the disruption this poses on their own work attendance and concerns that arise from schools regarding the child's absenteeism or academic problems. Additionally, children who reported improved physical functioning were more likely to be referred for psychological services. It may be that patients who have achieved better disease control and functioning are more apt to report on mental health symptoms, now that underlying physical concerns have been addressed. Overall, study findings support the relative importance of child and parent perspectives in predicting child HRQOL and the use of multi-informant assessment to inform psychosocial screening.

Disease severity was found to differentially affect child report of Emotional and School HRQOL, such that youth with active disease reported poorer emotional and school functioning compared to those experiencing disease remission. This reflects the emotional toll that disease symptoms and treatments place on youth, as well as the impact on patients' ability to attend school regularly. In fact, within the IBD Clinic, disease symptoms are commonly cited as a barrier to school attendance and represent a significant source of distress among young patients. Apart from the pain and discomfort that disease symptoms cause, physical symptoms can heighten emotional distress through their impact on school attendance; that is, increased stress about missed assignments and staying caught up, keeping up with peers, missed opportunities to interact with friends and remain “in the know,” and perceptions of being different from peers.

Results must be interpreted within the context of study limitations. While participants were demographically similar to the larger IBD population, use of a small convenience sample and cross-sectional design may limit generalizability of findings. This study also assessed psychosocial functioning at a single time point, thus precluding any conclusion about changes in youth's psychosocial functioning over time. Future studies should follow patients over the course of the disease, from diagnosis through disease maintenance, in order to evaluate any changes in psychosocial functioning and subsequent need for psychological services.

The availability of HRQOL ratings to the IBD team at the time psychological referrals were made could be deemed a potential confound; however, these ratings were not used in isolation. Rather, several clinical data points that were obtained and reviewed by the team prior to referral disposition were used in combination to make referral decisions. Data reviewed by the IBD team included the child's disease and treatment (e.g., IBD type, severity, and medications), information on the patient's medical and psychosocial history obtained from the medical record or from other medical providers, as well as information obtained during the clinical interview with the patient and family. Specifically, the patient's academic/school functioning (e.g., receipt of school-based services, frequency and cause of absences), social functioning (e.g., extracurricular activities, interference of disease on preferred activities), coping/adjustment to the new diagnosis, medication adherence, and pain management were each areas of focus during this clinical interview. If the patient, parent, or provider identified an area of difficulty or concern, a referral for psychological services was further determined by whether the patient and/or parent was distressed by the difficulty/concern, whether the patient and/or caregiver perceived that such difficulty/concern was significantly impacting the patient's daily function or health, and whether the patient and/or caregiver perceived that the difficulty/concern could be successfully managed without additional supports or services.

Conclusion

Study findings demonstrate the clinical utility and manner in which psychosocial screening may be used to facilitate referrals for psychological services among youth with IBD. HRQOL, specifically, is linked to symptoms of anxiety and depression among youth with chronic illnesses, and is thus an important marker of psychosocial health broadly. The use of validated psychosocial screening tools may increase family buy-in by providing objective data on the child or adolescent's emotional or behavioral functioning and how this compares to other youth. In fact, in the current study, 80% of patients following through on the recommendation for an internal psychology referral or follow-up at their next GI clinic visit. It is important to note that routine psychosocial screening can occur even in the absence of an embedded psychologist. Medical providers and social workers are key players in screener administration, interpretation, and facilitation of appropriate mental health referrals. In fact, several pediatric practice organizations, including the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN), have published practice recommendations for physicians and other clinicians to be directly or indirectly involved in routine psychosocial screening among youth with IBD (Rufo et al., 2012).

Given that few IBD programs are implementing screening procedures as a standard of clinical care, further efforts are needed to explore the barriers associated with integrated services and co-located care and how we might most efficiently and meaningfully screen for psychosocial difficulties in youth with IBD. HRQOL taps into various aspects of biopsychosocial health that is highly relevant to youth with chronic medical conditions, and has implications for emotional and behavioral functioning more broadly. Based on the current findings, the PedsQL™

represents one option for incorporating psychosocial screening into a biopsychosocial approach to care among pediatric patients with IBD and their families. In fact, preliminary data suggest that both youth and parent ratings of HRQOL uniquely predict referrals for psychological services; thus, supporting the inclusion of child and parent-proxy report of HRQOL within a psychosocial screening battery and suggesting the value added from multi-informant assessment among youth with IBD.

Declarations of interest

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Alana Goldstein-Leever: Conceptualization, Data curation, Formal analysis, Investigation, Writing - original draft, Writing - review & editing. **Julie A. Bass:** Conceptualization, Data curation, Investigation, Writing - review & editing. **Alka Goyal:** Conceptualization, Data curation, Investigation, Writing - review & editing. **Michele H. Maddux:** Conceptualization, Data curation, Formal analysis, Investigation, Writing - original draft, Writing - review & editing.

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