Published in final edited form as:

Child Health Care. 2014 ; 43(2): 151–168. doi:10.1080/02739615.2013.837824.

Stability of Emotional and Behavioral Functioning in Youth with Inflammatory Bowel Disease

Bonney Reed-Knight^{1,2}, Debra Lobato^{1,2,4}, Sarah Hagin^{1,2,4}, Elizabeth L. McQuaid^{1,2,4}, Ronald Seifer^{2,4}, Sheryl J. Kopel^{1,2}, Julie Boergers^{1,2,4}, Jack H. Nassau^{1,2,4}, Kristina Suorsa³, Barbara Bancroft³, and Neal S. LeLeiko^{2,3}

¹The Division of Child and Adolescent Psychiatry, Department of Psychiatry, Hasbro Children's Hospital/The Rhode Island Hospital, Providence, Rhode Island ²The Warren Alpert School of Medicine at Brown University, Providence, Rhode Island ³The Division of Pediatric Gastroenterology, Nutrition and Liver Diseases, The Department of Pediatrics, Hasbro Children's Hospital/The Rhode Island Hospital, Providence Rhode Island ⁴Bradley Hasbro Children's Research Center, Providence, Rhode Island

Abstract

This study prospectively examined stability of psychological and behavioral functioning in two matched cohorts of youth with inflammatory bowel disease (IBD): (1) newly-diagnosed and (2) previously-diagnosed patients. Youth and their parents completed measures of emotional and behavioral functioning at Time 1 and 6-months later. Mean-level analyses indicated that scores at Time 1 and Time 2 were within the nonclinical range. A significant decrease occurred in Internalizing symptoms for previously-diagnosed patients. Both groups demonstrated high levels of profile stability, with no significant differences across groups. Results suggest that emotional and behavioral functioning is generally stable without targeted intervention.

Inflammatory bowel diseases (IBD), consisting of Crohn's disease and ulcerative colitis, are chronic, immune-mediated diseases of the gastrointestinal tract affecting approximately 71 out of 100,000 youth in the United States (Kappelman et al., 2007) with rising rates of incidence (Malaty, Fan, Opekun, Thibodeaux, & Ferry, 2010). IBD is characterized by unpredictable symptom flares that include abdominal pain, diarrhea, rectal bleeding, weight loss, growth and pubertal delay, fever, fatigue, and arthritis (Mackner, Sisson, & Crandall, 2004). IBD requires youth and families to manage complicated medication regimens, frequent medical appointments, disease symptoms, nutritional modifications or supplementation, school absences, and symptom related questions from friends and relatives (Fishman, Barendse, Hait, Burdick, & Arnold, 2010). In addition, youth with IBD face potentially stigmatizing disease characteristics including frequent bathroom use, cosmetic side-effects of medical treatments such as facial swelling and acne, and limitations on physical activity. Further, 19–35% of youth with IBD experience permanent impairments in

linear growth, which may place them at risk for difficulties with peer relationships (Markowitz, Grancher, Rosa, Aiges, & Daum, 1993).

Given the many disease-related challenges, youth with IBD have the potential to face a variety of psychosocial difficulties. The broader literature on children's adaptation to chronic physical illness suggests that youth with IBD are at risk for emotional and behavioral difficulties, with greatest risk for internalizing symptoms (Pinquart & Shen, 2011). However, research on psychosocial adjustment in youth with IBD has yielded equivocal results. In an early study limited by a small sample size of 20 youth with IBD, higher rates of depressive and internalizing symptoms for youth with IBD were found compared to a healthy control group (Engstrom, 1992). Mackner and Crandall (2006) reported that, compared to healthy adolescents, adolescents with IBD experienced greater anxious and/or depressed problems as well as greater social problems as measured via parent-report on the Child Behavior Checklist. Previously, however, the same authors reported that adolescents with IBD who were at least one-year post diagnosis self-reported similar levels of emotional and behavioral functioning compared to healthy peers (Mackner & Crandall, 2005). In a subsequent review of the literature, the authors indicated that across multiple studies, youth with IBD have demonstrated more symptoms of emotional difficulties and/or more internalizing symptoms such as anxiety or depression when compared to healthy adolescents (Mackner & Crandall, 2007). Although levels of symptoms are higher for youth with IBD than healthy controls, studies that have reported T-scores for determining clinical significance have consistently been in the average range (Mackner & Crandall, 2007). Results suggest that although youth with IBD may not experience clinically significant levels of symptoms, they may still experience greater levels of emotional difficulties compared to peers.

Greenley and colleagues (2010) conducted a meta-analytic review of psychosocial adjustment in youth with IBD. Results indicated that youth with IBD were at higher risk for internalizing disorders including depressive and anxiety disorders compared to youth with other chronic illnesses when measured using diagnostic interviews. Further, parents of children with IBD reported higher levels of internalizing symptoms compared to parents of healthy children, even though youth self-reported similar levels of depressive and anxiety symptoms to healthy peers. For youth experiencing psychosocial difficulties, the implications can be great and affect all aspects of life. Youth with IBD reporting both higher levels of barriers to medication adherence as well as anxiety/depressive symptoms report lower medication adherence, suggesting that the presence of depressive symptoms may have important implications for disease management (Gray, Denson, Baldassano, & Hommel, 2012). In an examination of health related quality of life in youth with IBD, Hommel, Davis, and Baldassano (2008) reported that 18.5% of the sample of youth with IBD reported clinically elevated levels of depressive symptoms using a cutoff score of 13 or higher on the Children's Depression Inventory. Depressive symptoms were found to be a significant predictor of both parent and adolescent report of overall health related quality of life.

Despite recent advances in our understanding of the prevalence of psychosocial difficulties in youth with IBD, our understanding remains limited by primarily cross-sectional designs. In addition, with the exception of the study above (Mackner & Crandall, 2005), we have limited understanding of how psychosocial difficulties may change across the disease course

from the time of diagnosis to several years after having lived with the disease. Past research has reported equivocal findings on the relationship between emotional and behavioral functioning and disease activity, suggesting that the mere presence or absence of disease symptoms is not enough to predict psychosocial outcomes (Mackner & Crandall, 2007). Despite limited research on the stability of psychosocial functioning in youth with IBD, health-related quality of life in solid organ transplant recipients has been shown to be a largely stable construct over an 18-month period (Devine, Reed-Knight, Simons, Mee, & Blount, 2010). A better understanding of the stability of psychosocial and behavioral functioning in youth with IBD would inform expectations regarding functioning across the disease course as well as the need for targeted assessment and intervention.

The purpose of the current study was to examine stability over time in psychosocial functioning for two cohorts of youth diagnosed with IBD: (1) newly-diagnosed patients and (2) patients who had been diagnosed at least one-year prior (henceforth called previously-diagnosed patients). To examine stability of psychosocial functioning, we examined (1) mean-level changes in psychosocial functioning and (2) profile or individual-level stability. We hypothesized that previously-diagnosed patients with IBD would experience greater stability in psychosocial functioning compared to newly-diagnosed patients given greater time to adjust to their disease as well as better controlled disease due to treatment. Though the available literature on which to base hypotheses is small, we also hypothesized that both groups would experience stability in emotional and behavioral functioning given the lack of systematic intervention as well as past research demonstrating stable health-related quality of life in other pediatric chronic illness groups (Devine et al., 2010).

Methods

Participants

Patients 8–17.5 years of age were recruited as part of a larger study examining behavioral health factors associated with pediatric IBD outcomes if they had a diagnosis of Crohn's disease (CD) or ulcerative colitis (UC) confirmed by endoscopic, pathologic, or radiographic findings. Eligibility for the current study was contingent upon enrollment in the Pediatric IBD Collaborative Research Group Registry ("Registry"), an ongoing, prospective, biomedical research registry being conducted at 24 pediatric gastroenterology centers in the United States and Canada collectively known as the Pediatric Inflammatory Bowel Disease Collaborative Research Group. Throughout enrollment for the current study (conducted at 1 of the 24 centers), all newly-diagnosed patients were approached for participation in the Registry, and we achieved an 88% recruitment rate. For the current study, two groups of patients were recruited from the pool of Registry participants: newly-diagnosed (enrolled within 30 days of their diagnosis) and previously-diagnosed patients who were at least one year past their initial diagnosis; previously-diagnosed patients were matched to newly-diagnosed patients on gender, diagnosis (CD v. UC), and age block (8 to < 12 years; 12 to < 15 years; 15 to 17.5 years). Over the course of recruitment for the current study, 86 eligible patients and their parents were approached for participation, with the 78 consenting representing a 91% participation rate. The resulting sample consisted of 34 previously-

diagnosed patients, on average 42 months ($SD = 16.9$) post-diagnosis, and 44 newly-diagnosed patients, on average .72 months ($SD = .79$) post-diagnosis.

Measures

Parents completed a brief socio-demographics questionnaire to assess household income and race and ethnicity data (Table 1). To assess psychological functioning, participants and parents reported on patient emotional and behavioral functioning at the time of study enrollment (Time 1) and six months later (Time 2). Patients' gastroenterologists completed indices of disease severity at Time 1 and Time 2.

Children's Depression Inventory (CDI) (Kovacs, 2003)—The *CDI* is a 27-item self-report measure of depressive symptoms designed for children ages 7–17 years. Children rate items on a range from 0 (Absence of symptom) to 2 (Definite symptom). Higher Total scores indicate greater depressive symptom severity. Scores on the *CDI* are presented as T-scores, with a mean of 50 and a standard deviation of 10. According to the manual, T-scores from 40 to 44 are considered “slightly below average,” scores from 45 to 55 “average,” scores from 56 to 60 “slightly above average,” and from 61 to 65 “above average.” The *CDI* has been used extensively to assess symptoms of depression in youth with IBD in past research (Hommel et al., 2008; Thompson, Craig, Mrakotsky, et al., 2012). The *CDI* demonstrated adequate internal consistency for newly-diagnosed patients (Time 1 Cronbach's $\alpha = .87$; Time 2 $\alpha = .80$) and previously-diagnosed patients (Time 1 $\alpha = .75$; Time 2 $\alpha = .80$).

Multidimensional Anxiety Scale for Children (MASC) (March, Parker, Sullivan, Stallings, & Conners, 1997)—The *MASC* is a 39-item self-report measure that assesses anxiety symptoms in youth ages 8 to 19 years. Children rate items on a 4-point Likert scale from 0 (“never true about me”) to 3 (“often true about me”). The *MASC* yields a Total Anxiety T-score, with a mean of 50 and a standard deviation of 10. Higher scores indicate greater symptom severity. According to the manual, T-scores from 40 to 44 are considered “slightly below average,” scores from 45 to 55 “average,” scores from 56 to 60 “slightly above average,” and from 61 to 65 “above average.” The *MASC* demonstrated adequate internal consistency for newly-diagnosed patients (Time 1 Cronbach's $\alpha = .88$; Time 2 $\alpha = .80$) and previously-diagnosed patients (Time 1 $\alpha = .91$; Time 2 $\alpha = .92$).

Child Behavior Checklist for Ages 6 to 18 (CBCL) (Achenbach & Rescorla, 2001)—The *CBCL* is a parent-report measure of children's global emotional and behavior problems, with a well-developed history of use in chronic illness populations (Pinquart & Shen, 2011). The *CBCL* consists of 113 items describing different behavior problems that are rated on a scale from 0 (not true) to 2 (very or often true). Norms are available for children 6 to 18 years. Higher scores reflect greater emotional and behavioral problems. Three composite T-scores are derived, assessing Internalizing (Anxious/Depressed, Withdrawn, Somatic Complaints), Externalizing (Delinquent Behavior and Aggressive Behavior), and Total Behavior Problems. For Internalizing, Externalizing, and Total Problems, the cut-off T-score for the normal range is <60, borderline is from 60 to 63, and the clinical range is ≥64. For the syndrome scales, the cut-off T-score for the normal range is <65, borderline is from 65 to 69, and the clinical range is ≥70. The majority of past

research on emotional and behavioral functioning in youth with IBD has utilized the CBCL, which aids in comparing current results to past research (Greenley et al., 2010; Mackner & Crandall, 2006).

IBD Disease Activity

The Abbreviated Pediatric Crohn's Disease Activity Index (abbPCDAI) (Loonen, Griffiths, Merkus, & Derkx, 2003; Shepanski, Markowitz, Mamula, Hurd, & Baldassano, 2004): Patients' gastroenterologists completed the abbPCDAI to assess disease activity in patients with CD. The abbPCDAI is a summation of 6 items from the PCDAI (Hyams et al., 1991) assessing pain, general well-being, number of stools per day, abdominal tenderness, peri-rectal disease, and body weight. Laboratory measures are not included. The abbPCDAI score ranges from 0–60: an activity score of <15=inactive disease; 15–25=mild; >25=moderate-severe. The abbPCDAI has been found to be a reliable and valid measure of disease activity in pediatric patients with Crohn's, with correlations between abbPCDAI and PCDAI ranging from .68 to .85 and between the abbPCDAI and Physician's Global Assessment reported as .64 (Turner et al., 2012).

The Pediatric Ulcerative Colitis Activity Index (PUCAI) (Turner et al., 2007): The PUCAI is a standardized measure of disease activity in pediatric ulcerative colitis patients. Patients' gastroenterologists completed the PUCAI to assess disease activity via 6 history items (abdominal pain, rectal bleeding, stool consistency, number of stools per 24 hours, nocturnal bowel movements causing waking, activity restriction). Initial validation of the PUCAI demonstrated strong correlations between PUCAI scores and colonoscopy findings ($r = .76$) and Physician's Global Assessment ($r = .91$). Disease activity scores range 0 to 85: <10=inactive; 10–34=mild, 35–64=moderate, and 65=severe.

Procedures

Recruitment took place at a children's hospital in the Northeast region of the United States. All data collection occurred during regularly scheduled IBD clinic visits. Newly-diagnosed patients were approached for participation in both the Registry and the current study, though separate consent was obtained for each protocol. Previously-diagnosed patients who served as matches for newly-diagnosed patients were recruited from active Registry participants. Following initial enrollment in the current study (Time 1), patients were re-assessed six months later (Time 2) during a regularly scheduled clinic appointment. Disease activity data (i.e., abbPCDAI and PUCAI) from the Registry were analyzed as part of the current study. All patients and their parents provided informed assent and consent prior to participating in the study, which was approved by the hospital's Institutional Review Board.

Data Analysis

Preliminary analyses examined potential demographic and disease activity differences between the newly-diagnosed and previously-diagnosed patients at Time 1 using independent samples t-tests and χ^2 tests. Because there were no matches available for 11 of the 44 newly-diagnosed patients, we also compared the two groups on match variables. To examine stability of psychosocial factors from Time 1 to Time 2, multiple indices of stability were examined including (1) group, mean-level changes examined using paired-samples t-

tests and (2) profile or individual-level stability measured via the Reliable Change Index (RCI) (Christensen & Mendoza, 1986; Jacobson & Truax, 1991) (Blonigen, Carlson, Hicks, Krueger, & Iacono, 2008; Pullmann, Raudsepp, & Allik, 2006; Terracciano, McCrae, & Costa, 2010). Fisher's r -to- z transformations were utilized to assess the significance of the difference between the correlation coefficients across newly-diagnosed and previously-diagnosed patients. Given the differences in scaling for the abbPCDAI and the PUCAI, we collapsed score ratings across participants and formed a separate variable representing disease activity for both illness groups as inactive, mild, or moderate/severe for analyses examining the relationship between disease activity and emotional and behavioral functioning.

Results

Preliminary Analyses

No differences were found between newly-diagnosed and previously-diagnosed patients in terms of gender, age, race, family income, or diagnosis (all p 's > .05; see Table 1). As would be expected, newly-diagnosed patients were experiencing greater disease activity at the time of enrollment (Table 1). Over the course of the study, newly-diagnosed patients with Crohn's disease, $t(28)=2.51$, $p = .02$ and ulcerative colitis, $t(7)=2.20$, $p=.06$, demonstrated an improvement in their disease activity, likely attributable to the initiation of treatment. No significant changes were seen in previously-diagnosed patients' disease activity over the study period.

Mean-Level Stability

Mean-level stability examines the extent to which the participants, as a group, changed on the construct of interest from Time 1 to Time 2. Table 2 includes mean scores for the newly diagnosed group and the previously diagnosed group with dependent t-tests utilized to evaluate change from Time 1 to Time 2. Effect size estimates for t-tests are reported using Cohen's d , corrected for dependence between means (Morris & DeShon, 2002). Guidelines suggested by Cohen (1988) indicate that effect sizes of 0.2, 0.5 and 0.8 roughly represent small, medium, and large effects, respectively. Previously-diagnosed patients experienced a significant decrease in Internalizing symptoms on the parent-reported CBCL from Time 1 to Time 2. Examination of effect sizes indicate that both groups demonstrated meaningful decreases in Internalizing symptoms, and newly-diagnosed patients demonstrated a decrease in the CBCL Total Score. Changes in self-reported depressive or anxiety symptoms were not observed.

Given the decrease in Internalizing symptoms experienced by both groups, we explored the three syndrome subscales that comprise the Internalizing scale: Anxious/Depressed, Withdrawn, and Somatic Complaints. Both newly-diagnosed (Time 1 $M = 60.86$, $SD = 8.39$; Time 2 $M = 57.78$, $SD = 7.03$; $t(40) = 2.55$, $p = .02$, $d = .40$) and previously-diagnosed patients (Time 1 $M = 61.00$, $SD = 7.50$, Time 2 $M = 57.45$, $SD = 7.13$; $t(33) = 2.81$, $p < .01$, $d = .49$) demonstrated significant decreases in Somatic Complaints. No changes were seen on the other two Internalizing subscales. Given the potential overlap between symptoms assessed by the Somatic Complaints scale and IBD disease activity, we computed Pearson's

correlation coefficients to examine these relationships. Disease activity was unrelated to the CBCL Internalizing symptoms for newly and previously-diagnosed patients at both Time 1 and Time 2. For the newly-diagnosed group, parent-reported Somatic Complaints on the CBCL at Time 1 ($r = .06, p > .05$) and Time 2 ($r = -.16, p > .05$) were not significantly correlated with disease activity. For the previously-diagnosed group, Somatic Complaints on the CBCL were related to disease activity at Time 1 ($r = .41, p = .02$) but not significantly related at Time 2 ($r = .26, p > .05$).

Next, we sought to graphically describe patterns of change in self-reported depressive symptoms and parent-reported psychosocial and behavioral functioning from Time 1 to Time 2. No significant differences were found between the two groups on the constructs at Time 1. As a result, we combined both groups to examine patterns of change. Using patients' Time 1 psychosocial scores, quartiles were derived to examine patients falling in the $< 25^{\text{th}}$ percentile, 25^{th} to 75^{th} percentile, and $> 75^{\text{th}}$ percentile based on sample scores at Time 1. Stability was then examined by graphing change in psychosocial scores at Time 2 based on patients' Time 1 categorization (Figure 1). Examination of distribution of CDI scores reveals that for those with low depressive symptoms at Time 1 ($< 25^{\text{th}}$ percentile corresponding to a T-score < 37), 40% remained in the lowest quartile at Time 2, while no participants moved into the $> 75^{\text{th}}$ percentile of scores. For those reporting levels of depressive symptoms within the 25^{th} to 75^{th} percentiles at Time 1, 68% remained within this category, whereas 11% improved and 20% reported increased symptoms. For those reporting relatively high levels of symptoms at Time 1 ($> 75^{\text{th}}$ percentile corresponding to a T-score > 46), 53% of patients continued to report higher levels of depressive symptoms at Time 2.

For youth with low scores on the CBCL Total score at Time 1 ($< 25^{\text{th}}$ percentile corresponding to a T-score < 41), 63% remained in the lowest quartile at Time 2. For parents reporting symptoms within the 25^{th} to 75^{th} percentiles at Time 1, 73% remained within this category at Time 2, whereas 14% improved and 7% reported a worsening of symptoms. For those reporting higher levels of symptoms at Time 1 ($> 75^{\text{th}}$ percentile corresponding to a T-score > 53), 61% reported similar symptom levels at Time 2, with the remainder reporting improvements. Overall, scores largely fall in the normal ranges, with cutoffs for the $> 75^{\text{th}}$ percentile on the CDI and CBCL Total score within the sample both falling within the average range based on normative data available for each measure.

Individual-Level Stability

Profile or individual-level stability refers to the degree of constancy of psychosocial functioning within each individual. The individual-level stability as measured via the reliable change index (RCI) measures individual-level change accounting for unreliability due to measurement error (Blonigen et al., 2008; Jacobson & Truax, 1991). The RCI measures whether changes in participants' scores are greater than would be expected by chance based on the measure's reliability. RCI scores greater than $+1.96$ or less than -1.96 represent a reliable change and correspond to a less than 5% chance that the change occurred by chance. Conversely, scores within this range can be assumed to have occurred by chance. All participants were divided into three groups ('improved', 'worsened', or 'no reliable change')

based on RCI scores (Table 3). We used retest correlations published in each measure's respective manual to compute the RCI analyses.

The majority of patients in both groups did not demonstrate a reliable change from Time 1 to Time 2 in the emotional and behavioral constructs of interest (ranging from 68% to 97%). Generally, greater percentages of patients in the newly-diagnosed group showed improvements, with 24% demonstrating improvements in Internalizing symptoms and 22% demonstrating improvements in Total Behavior Problems.

Discussion

The current study sought to evaluate stability in psychological and behavioral functioning in two prospective cohorts of youth diagnosed with IBD using two complementary indices of stability. Results build upon past cross-sectional research demonstrating that youth with IBD may be at risk for psychosocial difficulties (Greenley et al., 2010; Mackner & Crandall, 2007) by providing evidence as to the stability of psychosocial functioning across the disease course. Generally, results suggest overall functioning within normal ranges, with high levels of stability in emotional and behavioral functioning for youth both newly-diagnosed and previously-diagnosed with IBD.

Examination of mean-level stability found that both newly-diagnosed and previously-diagnosed patients demonstrated meaningful decreases in Internalizing symptoms, with particular decreases in somatic symptoms noted for both groups. Parent-reported somatic symptoms were unrelated to physician-rated disease activity for the most part, with the only significant relationship emerging for previously-diagnosed patients at Time 1. Although we had expected that newly-diagnosed patients would experience lower levels of stability as a group due to the initiation of treatment and improvement in disease symptoms, results did not generally support that previously-diagnosed patients experienced higher levels of stability in functioning.

Individual-level changes were evaluated using the RCI. Whereas mean-level change evaluated whether most patients changed in a similar way from Time 1 to Time 2, individual-level change examines profile stability and can detect changes that may not have been revealed using group-level analyses. For example, it is conceivable that a subset of patients in the previously-diagnosed group experienced increases in symptoms of anxiety whereas approximately the same number experienced decreases of similar magnitudes. When examined at the mean, group-level, these changes would have counteracted and resulted in minimal group-level indications of change.

Results of the RCI analyses indicated that the majority of patients in both groups experienced stability in psychosocial and behavioral functioning from Time 1 to Time 2. Use of the RCI is a strength of the current study as it takes into account the reliability of the measure when determining if change over time occurred. Within the newly-diagnosed group, however, 24% of patients demonstrated an improvement in Internalizing symptoms and 22% in Total Behavior Problems. Fewer participants in the previously-diagnosed group demonstrated improvements in Internalizing symptoms (15%) or Total Behavior Problems

(13%). Greater improvements in Internalizing symptoms for newly-diagnosed patients could be due to decreases in disease symptoms across the study period as well as disease-adjustment, though further longitudinal research is needed to examine how internalizing and disease symptoms relate over time.

There are several limitations to this study. The sample size for each group was relatively small, which may have limited power to detect mean-level changes. Generalizability of the findings may be limited as the majority of our sample was Caucasian and from high-income families. In addition, the lack of a matched, healthy comparison group limited our ability to compare patients' psychosocial and behavioral functioning to healthy peers beyond norm comparisons. Finally, the length of time from Time 1 to Time 2 was relatively short, potentially limiting the ability to detect changes in psychosocial and behavioral functioning that may occur across longer time periods. Although results from the current study are consistent with past research demonstrating that youth with IBD report levels of emotional and behavioral difficulties within the average range, past research has demonstrated that youth with IBD are at risk for higher levels of depressive disorders and poorer quality of life compared to healthy peers (Greenley et al., 2010; Mackner & Crandall, 2007). Consequently, future studies are needed to examine stability of psychosocial and behavioral functioning in youth with IBD across longer time periods of the disease course, relative to changing disease activity, and using different assessment methods to measure both symptoms and diagnoses. In addition, greater reliance on youth-report of disease activity may reveal relationships with psychosocial and behavioral functioning not apparent with physician and parent-report of symptoms.

Implications for Practice

Given the relatively high levels of stability in emotional and behavioral functioning found using all indices, results suggest that most youth with IBD should not be expected to necessarily change in terms of emotional and behavioral functioning with the passage of time alone. Those with nonclinical emotional and behavioral functioning, which these results indicate should be the majority of patients, may require less frequent reassessment given evidence of stability. Evidence of stability is especially important for newly-diagnosed patients experiencing emotional or behavioral difficulties who may have been expected to demonstrate improvements across the initial treatment period. For these patients, mental health services should be provided at the time that difficulties are reported as opposed to waiting for disease adjustment. Further, results from the newly-diagnosed group suggest that youth should not be expected to necessarily experience changes in psychosocial functioning, even as disease symptoms improve. Instead, youth with IBD would likely benefit from psychosocial assessment using standardized measures at the time of diagnosis to guide treatment and referrals as appropriate. More specifically, youth may benefit from initial evaluation with a mental health professional who can assess emotional and behavioral functioning; those who have more significant emotional symptoms may require focused intervention to improve. Cognitive-behavioral therapy has been shown to be effective for reducing symptoms of depression in youth with IBD (Szigethy et al., 2009; Thompson, Craig, Crawford, et al., 2012). At a systems level, results support the utility of multidisciplinary healthcare teams to address the range of difficulties faced by youth with

IBD. In an era of finite financial and service provision resources, baseline results of emotional and behavioral assessment could be used to characterize and triage patients to different levels of follow-up and care. Clinicians can rely on current results to guide decision making regarding the likelihood that patients identified as low risk will remain low risk as well as the need to advocate for patients identified as experiencing difficulties to receive additional mental health services.

Acknowledgments

Funding. This work was funded by NICHD R21 HDO58828 (Lobato/LeLeiko)

References

- Achenbach, TM., Rescorla, LA. Manual for the ASEBA School-Age Forms and Profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth and Families; 2001.
- Blonigen DM, Carlson MD, Hicks RM, Krueger RF, Iacono WG. Stability and change in personality traits from late adolescence to early adulthood: A longitudinal twin study. *Journal of Personality*. 2008; 76(2):229–266. DOI: 10.1111/j.1467-6494.2007.00485.x [PubMed: 18331280]
- Christensen L, Mendoza JL. A method of assessing change in a single subject. *Behavior Therapy*. 1986; 17:305–308.
- Cohen, J. Statistical power analysis for the behavioral sciences. 2. New York: Academic Press; 1988.
- Devine KA, Reed-Knight B, Simons LE, Mee LL, Blount RL. Prospective comparison of parent and adolescent report of health related quality of life in adolescent solid organ transplant recipients. *Pediatric Transplantation*. 2010; 14(8):1000–1006. DOI: 10.1111/j.1399-3046.2010.01392.x [PubMed: 20846240]
- Engstrom I. Mental health and psychological functioning in children and adolescents with inflammatory bowel disease: a comparison with children having other chronic illnesses and with healthy children. *Journal of Child Psychology and Psychiatry*. 1992; 33(3):563–582. DOI: 10.1111/j.1469-7610.1992.tb00891.x [PubMed: 1577899]
- Fishman LN, Barendse RM, Hait E, Burdick C, Arnold J. Self-management of older adolescents with inflammatory bowel disease: A pilot study of behavior and knowledge as prelude to transition. *Clinical Pediatrics*. 2010; 49(12):1129–1133. DOI: 10.1177/0009922810379042 [PubMed: 20837627]
- Gray WN, Denson LA, Baldassano RN, Hommel KA. Treatment adherence in adolescents with inflammatory bowel disease: The collective impact of barriers to adherence and anxiety/depressive symptoms. *Journal of Pediatric Psychology*. 2012; 37(3):282–291. DOI: 10.1093/jpepsy/jsr092 [PubMed: 22080456]
- Greenley RN, Hommel KA, Nebel J, Raboin T, Li S, Simpson P, Mackner LM. A meta-analytic review of the psychosocial adjustment of youth with inflammatory bowel disease. *Journal of Pediatric Psychology*. 2010; 35(8):857–869. DOI: 10.1093/jpepsy/jsp120 [PubMed: 20123705]
- Hommel KA, Davis CM, Baldassano RN. Medication adherence and quality of life in pediatric inflammatory bowel disease. *Journal of Pediatric Psychology*. 2008; 33(8):867–874. DOI: 10.1093/jpepsy/jsn022 [PubMed: 18337262]
- Hyams JS, Ferry GD, Mandel FS, Gryboski JD, Kibort PM, Kirschner BS, Boyle JT. Development and validation of a pediatric Crohn's disease activity index. *Journal of Pediatric Gastroenterology and Nutrition*. 1991; 12(4):449.
- Jacobson NS, Truax P. Clinical significance: A statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology*. 1991; 59(1):12–19. [PubMed: 2002127]
- Kappelman MD, Rifas-Shiman SL, Kleinman K, Ollendorf D, Bousvaros A, Grand RJ, Finkelstein JA. The prevalence and geographic distribution of Crohn's disease and ulcerative colitis in the United States. *Clinical Gastroenterology and Hepatology*. 2007; 5(12):1424–1429. DOI: 10.1016/j.cgh.2007.07.012 [PubMed: 17904915]

- Kovacs, M. Children's Depression Inventory (CDI): Technical manual update. North Tonawanda, NY: Multi-Health Systemc, Inc; 2003.
- Loonen HJ, Griffiths AM, Merkus MP, Derkx HHF. A critical assessment of items on the Pediatric Crohn's Disease Activity Index. *Journal of Pediatric Gastroenterology and Nutrition*. 2003; 36(1): 90–95. [PubMed: 12500002]
- Mackner LM, Crandall WV. Long-term psychosocial outcomes reported by children and adolescents with inflammatory bowel disease. *American Journal of Gastroenterology*. 2005; 100(6):1386–1392. DOI: 10.1111/j.1572-0241.2005.41428.x [PubMed: 15929775]
- Mackner LM, Crandall WV. Brief Report: Psychosocial adjustment in adolescents with inflammatory bowel disease. *Journal of Pediatric Psychology*. 2006; 31(3):281–285. DOI: 10.1093/jpepsy/jsj023 [PubMed: 15802606]
- Mackner LM, Crandall WV. Psychological factors affecting pediatric inflammatory bowel disease. *Current Opinion in Pediatrics*. 2007; 19(5):548–552. DOI: 10.1097/MOP.0b013e3282ef4426 [PubMed: 17885473]
- Mackner LM, Sisson DP, Crandall WV. Review: Psychosocial issues in pediatric inflammatory bowel disease. *Journal of Pediatric Psychology*. 2004; 29(4):243–257. DOI: 10.1093/jpepsy/jsh027 [PubMed: 15148347]
- Malaty HM, Fan X, Opekun AR, Thibodeaux C, Ferry GD. Rising incidence of inflammatory bowel disease among children: A 12-year study. *Journal of Pediatric Gastroenterology and Nutrition*. 2010; 50(1):27–31. DOI: 10.1097/MPG.0b013e3181b99baa [PubMed: 19934770]
- March JS, Parker JD, Sullivan K, Stallings P, Conners CK. The Multidimensional Anxiety Scale for Children (MASC): Factor structure, reliability, and validity. *Journal of the American Academy of Child and Adolescent Psychiatry*. 1997; 36(4):554–565. [PubMed: 9100431]
- Markowitz J, Grancher K, Rosa J, Aiges H, Daum F. Growth failure in pediatric inflammatory bowel disease. *Journal of Pediatric Gastroenterology and Nutrition*. 1993; 16(4):373–380. DOI: 10.1097/00005176-199305000-00005 [PubMed: 8315544]
- Morris SB, DeShon RP. Combining effect size estimates in meta-analysis with repeated measures and independent-groups designs. *Psychological Methods*. 2002; 7:107–125. DOI: 10.1037/1082-989X.7.1.105
- Pinquart M, Shen Y. Behavior problems in children and adolescents with chronic physical illness: A meta-analysis. *Journal of Pediatric Psychology*. 2011; 36(9):1003–1016. DOI: 10.1093/jpepsy/jsr042 [PubMed: 21810623]
- Pullmann H, Raudsepp L, Allik J. Stability and change in adolescents' personality: A longitudinal study. *European Journal of Personality*. 2006; 20:447–459. DOI: 10.1002/per.611
- Shepanski MA, Markowitz J, Mamula P, Hurd LB, Baldassano RN. Is an abbreviated Pediatric Crohn's Disease Activity Index better than the original. *Journal of Pediatric Gastroenterology and Nutrition*. 2004; 39(1):68–72. [PubMed: 15187784]
- Szigethy E, Craig A, Lobst EA, Grand RJ, Keljo D, DeMaso DR, Noll R. Profile of depression in adolescents with inflammatory bowel disease: Implications for treatment. *Inflammatory Bowel Diseases*. 2009; 15(1):69. doi: 10.1002/ibd.20693 [PubMed: 18831071]
- Terracciano A, McCrae RR, Costa PT. Intra-individual change in personality stability and age. *Journal of Research in Personality*. 2010; 44:31–37. DOI: 10.1016/j.jrp.2009.09.006 [PubMed: 20305728]
- Thompson RD, Craig A, Crawford EA, Fairclough D, Gonzalez-Heydrich J, Bousvaros A, Szigethy E. Longitudinal results of cognitive behavioral treatment for youths with inflammatory bowel disease and depressive symptoms. *Journal of Clinical Psychology in Medical Settings*. 2012; 19(3):329–337. DOI: 10.1007/s10880-012-9301-8 [PubMed: 22699797]
- Thompson RD, Craig A, Mrakotsky C, Bousvaros A, DeMaso DR, Szigethy E. Using the Children's Depression Inventory in youth with inflammatory bowel disease: Support for a physical illness-related factor. *Comprehensive Psychiatry*. 2012; 53(8):1194. doi: 10.1016/j.comppsy.2012.04.006 [PubMed: 22682678]
- Turner D, Griffiths AM, Walters TD, Seah T, Markowitz J, Pfefferkorn M, Levine A. Mathematical weighting of the Pediatric Crohn's Disease Activity Index (PCDAI) and comparison with its other short versions. *Inflammatory Bowel Diseases*. 2012; 18(1):55–62. DOI: 10.1002/ibd.21649 [PubMed: 21351206]

Turner D, Otley AR, Mack D, Hyams J, de Bruijne J, Uusoue K, Beaton DE. Development, validation, and evaluation of a pediatric ulcerative colitis activity index: a prospective multicenter study. *Gastroenterology*. 2007; 133(2):423–432. DOI: 10.1053/j.gastro.2007.05.029 [PubMed: 17681163]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Figure 1.

Change in psychosocial score distribution from Time 1 to Time 2 using Time 1 categorization into quartiles. Newly-diagnosed and previously-diagnosed patient combined. Number of participants shown above or within each bar.

Table 1

Demographic and Treatment Characteristics of Newly-diagnosed and Previously-diagnosed Groups at Time 1

Variables	Newly Diagnosed (N = 44)	Previously Diagnosed (N = 34)	χ^2/t	<i>p</i>
Gender (% male)	50	53	$\chi^2 (1, N=78)= 0.07$	.80
Diagnosis			$\chi^2 (1, N=78)=1.00$	.32
Crohn's disease	82%	82%		
Ulcerative colitis	18%	18%		
Race/ethnicity			$\chi^2 (4, N=78)=5.67$	.26
Caucasian	91%	79.4%		
African American	2.3%	5.9%		
American Indian	2.3%			
Mixed/Other	4.5%	14.7%		
Latino ethnicity	10.5%	12.5%		
Age (years)				
Mean (<i>SD</i>)	13.29 (2.43)	14.43 (3.12)	$t(1, 76) = 1.81$	.07
Median Family Income	\$78,749(30,023)	\$87,499(30,981)	$F(1,66)=0.21$	.65
Disease Severity at Time 1				
abbPCDAI	14.19 (12.98)	3.52 (4.96)	$F(1,56)=16.17$	< .001
PUCAI	39.50 (23.86)	7.50 (9.35)	$F(1,14)=9.67$	< .01
Disease Severity at Time 2				
abbPCDAI	7.67 (8.07)	2.59 (5.26)	$F(1,55)=7.72$	< .01
PUCAI	10.00 (15.97)	16.67 (19.92)	$F(1,15)=.57$	.46

Table 2

Mean-level stability in psychosocial functioning for newly-diagnosed and previously-diagnosed patients from Time 1 to Time 2.

	Time 1		Time 2		<i>t</i>	df	<i>p</i>	<i>d</i>
	Mean (<i>SD</i>)	Mean (<i>SD</i>)	Mean (<i>SD</i>)	Mean (<i>SD</i>)				
Newly-Diagnosed								
CDI Total	43.43 (7.99)	42.30 (6.70)	1.27	43	.21	.19		
MASC Total	47.21 (10.00)	45.84 (9.90)	1.19	43	.24	.18		
CBCL Internalizing	53.39 (9.99)	50.56 (9.32)	1.85	40	.07	.29		
CBCL Externalizing	46.37 (10.71)	46.15 (11.45)	.17	40	.87	.03		
CBCL Total	48.22 (11.45)	46.20 (10.61)	1.54	40	.13	.24		
Previously-Diagnosed								
CDI Total	41.15 (5.52)	41.56 (6.18)	-.43	33	.67	-.07		
MASC Total	45.00 (9.04)	45.01 (10.45)	-.01	33	.99	.01		
CBCL Internalizing	53.42 (7.97)	49.79 (8.19)	2.51	32	.02*	.44		
CBCL Externalizing	44.15 (7.37)	45.00 (7.42)	-.85	32	.40	-.15		
CBCL Total	46.88 (8.07)	45.61 (8.51)	.91	32	.37	.16		

Note.

* $p < .05$

Table 3

Individual-level stability in psychosocial functioning measured via the Reliable Change Index.

	Significant RCI n (%)		Not Significant RCI n (%)
	Improved	Worsened	No Reliable Change
Newly-Diagnosed			
CDI Total, n = 44	4 (9%)	0	40 (91%)
MASC Total, n = 44	8 (18%)	2 (5%)	34 (77%)
CBCL Internalizing, n = 41	10 (24%)	3 (7%)	28 (68%)
CBCL Externalizing, n = 41	4 (10%)	4 (10%)	33 (80%)
CBCL Total, n = 41	9 (22%)	3 (7%)	29 (71%)
Previously-Diagnosed			
CDI Total, n = 34	1 (3%)	0	33 (97%)
MASC Total, n = 34	2 (6%)	5 (15%)	27 (79%)
CBCL Internalizing, n = 33	5 (15%)	1 (3%)	27 (82%)
CBCL Externalizing, n = 33	1 (3%)	0	32 (97%)
CBCL Total, n = 31	4 (13%)	2 (6%)	25 (81%)