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The Contributions of Child Behavioral Functioning and Parent Distress to Family Functioning in Pediatric Inflammatory Bowel Disease

Shannon Odell,

Xavier University, Cincinnati, OH, USA

Emily Sander,

Xavier University, Cincinnati, OH, USA

Lee A. Denson,

Division of Gastroenterology, Hepatology, and Nutrition, Cincinnati Children's Hospital Medical Center, 3333 Burnet Ave., Cincinnati, OH 45229-3039, USA; University of Cincinnati College of Medicine, Cincinnati, OH, USA

Robert N. Baldassano, and

Children's Hospital of Philadelphia, Philadelphia, PA, USA; University of Pennsylvania School of Medicine, Philadelphia, PA, USA

Kevin A. Hommel

University of Cincinnati College of Medicine, Cincinnati, OH, USA; Division of Behavioral Medicine and Clinical Psychology, Cincinnati Children's Hospital Medical Center, 3333 Burnet Ave., Cincinnati, OH 45229-3039, USA

Abstract

The objective of this study was to examine the relative contributions of both parental and adolescent functioning to family functioning in adolescent patients with inflammatory bowel disease (IBD) and their families. Participants were 45 adolescents (27 male, 18 female) 13–17 years old ($M = 15.41$ years, $SD = 1.32$) with IBD and their parents. Families completed measures of patient behavioral functioning and depression, parent distress and family functioning. Disease severity assessments were completed via data provided by patients' gastroenterologists. Results indicated that parent-reported patient behavioral problems accounted for a significant 26% of variance in family functioning. Post-hoc analysis revealed that externalizing behavior problems accounted for the majority of this variance compared to internalizing behavior problems. These results suggest that externalizing problems may have a more significant impact on these families than previous research indicates. Moreover, externalizing behaviors may significantly impact family adaptation and should be taken into consideration during routine clinical care. Further research is needed to replicate and expand upon these findings.

Keywords

Inflammatory bowel disease; Family functioning; Behavior; Distress; Internalizing; Externalizing

Children and adolescents with ulcerative colitis (UC) and Crohn's disease (CD), collectively inflammatory bowel disease (IBD), experience inflammation and ulceration of the intestinal tract, and face chronic and unpredictable symptoms including abdominal pain, frequent diarrhea, rectal bleeding, weight loss, and occasionally growth delay (Drossman et al., 2003; Mackner, Sisson, & Crandall, 2004). IBD affects approximately 71 in 100,000 children and adolescents in the US, with a higher prevalence of CD (43 per 100,000) than UC (28 per 100,000 (Kappelman et al., 2007). Psychosocial challenges for patients and parents are fairly common in pediatric IBD (Burke et al., 1989; Engstrom, 1999; Mackner & Crandall, 2005; Mackner et al., 2004). However, there is limited research on how specific psychological factors relate to one another. Moreover, there is little evidence regarding the impact of patient psychosocial risk factors on family adaptation in pediatric IBD.

Much of the psychosocial research in pediatric IBD has focused on prevalence rates of behavioral problems in children and adolescents with IBD. One study found that children with IBD are more likely to demonstrate overall behavioral dysfunction than their healthy siblings (Wood et al., 1987). More recently, Mackner and Crandall found that one-third of adolescents in their IBD sample demonstrated clinically elevated overall and internalizing behavioral problems (Mackner & Crandall, 2006), though this did not differ from healthy adolescents. Research on behavioral problems in pediatric IBD has generally focused on internalizing disorders, which have been found to be especially prevalent in these patients (for review, see Hommel, Mackner, Denson, & Crandall, 2008). For example, Burke and colleagues compared depressive and anxiety disorders in 55 IBD patients to 52 cystic fibrosis (CF) patients (Burke et al., 1989). They found that depressive disorders were more prevalent in the IBD group (25%) than the CF group (12%). In addition, Engstrom and colleagues found that children with IBD had a significantly higher rate of depressive and anxiety disorders compared to healthy children (Engstrom, 1999; Engstrom & Lindquist, 1991). Another study reported depressive symptoms in approximately 25% of adolescents with IBD (Szigethy et al., 2004). Similarly, Mackner and Crandall found that adolescents with IBD had increased anxious and depressive symptoms, as well as a higher rate of clinically significant social problems than healthy adolescents (Mackner & Crandall, 2006). In contrast, there is limited research on the prevalence of externalizing disorders in IBD. Engstrom (1999) and Mackner and Crandall (2005) included an assessment of externalizing behaviors as part of studies examining overall psychosocial problems in children with IBD; yet, neither of these studies found externalizing behaviors to be clinically or significantly elevated.

Of course, chronic conditions do not only affect patients, evidence suggests that parent and family functioning are impaired in IBD. With respect to parental emotional functioning, Tojek and colleagues assessed 62 adolescents with IBD and their mothers, and found that distressed mothers had children who were more depressed and experienced more IBD-related difficulties in their school, recreational, and social functioning (Tojek, Lumley, Corlis, Ondersma, & Tolia, 2002). In addition, mothers of children with IBD are more likely than mothers of healthy children (Engstrom, 1999). to feel distress and demonstrate increased rates of depression similar to those found in mothers of children with CF (Burke et al., 1994). A primary limitation of this literature, however, is that broad assessment of parental distress or emotional functioning has been used rather than assessment of parental functioning within the context of caring for a child with a chronic condition, potentially resulting in a less sensitive assessment of parental distress. Nevertheless, there is evidence that parents of children with IBD experience increased distress. In addition, mothers of children with IBD have reported significantly greater family dysfunction compared to healthy controls (Engstrom, 1999; Wood et al., 1987). Further, IBD patients who are depressed have exhibited more family conflict and are more disengaged than non-depressed IBD patients, which suggests a relationship between family dysfunction and patient

behavioral functioning in IBD (Burke, Kocoshis, Chandra, Whiteway, & Sauer, 1990). However, the modest sample size ($n = 13$) and exclusive examination of depression significantly limits the generalizability of these findings.

Prior research on psychosocial functioning in IBD is limited by a number of methodological shortcomings, including small sample sizes, variability in administration of assessments, and use of unstandardized measures (Hommel, Mackner et al., 2008; Mackner et al., 2004). Despite these limitations, the data suggest that there is an increased prevalence of behavioral dysfunction in IBD patients and their parents. A significant gap in the IBD literature is that there are virtually no data regarding the extent to which patient and parent factors contribute to salient psychosocial outcomes such as family functioning. Thus, the primary aim of this study was to examine the relative contributions of child behavioral functioning and parent distress to variance in family functioning. We hypothesized that child behavioral problems and parent distress would independently contribute significant variance to family dysfunction; though, based on the aforementioned (albeit small scale) research demonstrating a relationship between child emotional problems and family dysfunction, it was anticipated that the strength of the relationship between child behavioral problems and family functioning would be stronger. In addition, since prior research has demonstrated increased internalizing problems in this population, we hypothesized that child internalizing behaviors would account for more variance in family functioning than externalizing behaviors.

Method

Participants

This study was part of a larger project investigating treatment adherence and behavioral functioning in pediatric IBD, which was approved by the institutional review boards at both participating hospitals. Participants were 45 adolescents (27 male, 18 female) 13–17 years old ($M = 15.41$ years, $SD = 1.32$) with IBD and their parents (89% mothers, 9% fathers, 2% other caregiver) from gastroenterology clinics at two large children's hospitals in the Northeastern and Midwestern United States. The sample was primarily Caucasian (89%), followed by African American (7%), Hispanic (2%), and other ethnic groups (2%). The modal annual household income category was US \$75,001–100,000. Inclusion criteria were diagnosis of Crohn's disease or ulcerative colitis, patient age 13–17 years, current prescription of 6-MP/azathioprine and/or 5-aminosalicylic acid, a 6-thioguanine nucleotide/6-methylmercaptopurine nucleotide assay conducted within previous month, and English fluency. Patients were excluded if they had been diagnosed with a pervasive developmental disorder, had been diagnosed with a comorbid chronic illness, or had a current prescription of >1 mg/kg/d corticosteroids. This later criteria was used as an exclusion criterion in order to accurately measure child behavioral symptoms without artificially inflating psychiatric symptoms due to the effects of corticosteroids (Kayani & Shannon, 2002; Soliday, Grey, & Lande, 1999). Of the 89 patients who were eligible, 60 were able to be contacted for recruitment, 7 declined participation (due to blood draw requirement, not enough time, and/or not interested in participating in research), and 8 did not provide complete data, resulting in a final sample of 45 patients and their parents (Crohn's disease $N = 36$; ulcerative colitis $N = 9$).

Procedure

Recruitment and data collection were conducted by trained study coordinators. Patients meeting eligibility criteria were identified via chart review and recruited either during the patient's regularly scheduled GI clinic visit or by telephone. Patients and parents were given a thorough description of the study and informed consent/assent was obtained. Demographic

and behavioral assessment measures were completed during clinic appointments or were mailed to participants for those recruited via telephone. Patients' gastroenterologists provided information for disease severity assessments in chart notes, and these data were obtained by unblinded study personnel via chart review. Disease severity was treated as a continuous variable for analyses. Disease duration was not calculable due to missing data in charts. Participants were provided with US \$25 compensation.

Measures

Behavioral Assessments

Pediatric Inventory for Parents (PIP): The PIP (Streisand, Braniecki, Tercyak, & Kazak, 2001) is a 42-item parent self-report questionnaire that measures parent stress associated with caring for a child with a medical illness. Each item includes a 5-point Likert scale and requires the respondent to rate (1) the frequency they have experienced the symptom in the past week and (2) the personal difficulty associated with that symptom. Stress is measured across four factors: Communication, Medical Care, Role Functioning, and Emotional Distress. The PIP derives a Total Frequency Scale and Total Difficulty Scale, with higher scores of frequency and difficulty representing greater parenting stress. The PIP has demonstrated adequate reliability and construct validity, with Cronbach's alpha ranging between .80 and .96 (Streisand et al., 2001). Internal consistency was .97 for the Total Frequency Scale and .95 for the Total Difficulty Scale in this sample.

Child Behavior Checklist (CBCL): The CBCL (Achenbach, 1991) is a 113-item parent-report checklist measuring a child's behavioral functioning and psychosocial distress. Parents rate the frequency of specific behaviors in their child during the previous 6 months. The CBCL yields eight factors (Aggressive Behavior, Anxious/Depressed, Attention Problems, Rule-Breaking Behavior, Social Problems, Somatic Complaints, Thought Problems, and Withdrawal/Depressed), as well as two broad measures of distress: internalizing and externalizing problems. Higher scores indicate poorer functioning. The CBCL is a widely used empirically validated and reliable measure.

Youth Self-Report (YSR): The CBCL Youth Self-Report (YSR) is the child-report version of the CBCL. This measure also rates the frequency of specific behaviors during the previous 6 months. The YSR yields the same eight factors and two broad measures of distress as the CBCL. As with the CBCL, higher scores indicate poorer functioning.

Children's Depression Inventory (CDI): The CDI (Kovacs, 1992) is a 27-item self-report measure used to assess the severity of depressive symptomatology in children and adolescents, ages 6–17. Each of the items on the CDI is a group of three statements on a 0–2 scale that measure the severity of a depressive symptom. The CDI is a reliable and valid measure of depressive symptoms in both children and adolescents. Internal consistency was .91 in this sample.

Family Assessment Device (FAD): The FAD (Epstein, Baldwin, & Bishop, 1983) is a 60-item self-report measure that assesses family functioning across six factors: Problem Solving, Communication, Roles, Affective Responsiveness, Affective Involvement and Behavior Control, as well as an overall General Functioning scale. The FAD has been used in a variety of pediatric chronic illness groups and is a valid and reliable measure of family functioning. Internal consistency estimates have been .92 for general functioning, and range from .72 to .83 for the six dimensions (Touliatos, Perlmutter, & Straus, 1990). Parents completed the FAD in this study, and internal consistency was .85 for general functioning.

Disease Severity Assessments

Pediatric Crohn's Disease Activity Index (PCDAI): The PCDAI (Hyams et al., 1991) is a well-validated, reliable and widely used measure of disease activity in pediatric patients with Crohn's disease. The scale is scored 0–100 based on subjective criteria (e.g., pain), objective criteria (e.g., physical exam), laboratory findings, and growth parameters. Scores ≤ 0 = inactive disease; 11–29 = mild disease, and ≥ 30 = moderate to severe disease activity (Hyams et al., 2005). The PCDAI has demonstrated acceptable sensitivity and specificity (Hyams et al., 2005). Study personnel completed the PCDAI using data obtained from patient chart notes and laboratory values from the clinic appointment corresponding to the study visit or from the most recent clinic appointment.

Lichtiger Colitis Activity Index (CAI): The CAI (Lichtiger et al., 1994) is scored 0–21, with higher scores representing more severe disease. It is assessed across eight ulcerative colitis related variables including number of daily stools, nocturnal diarrhea, visible blood in stool, fecal incontinence, abdominal pain or cramping, general well-being, abdominal tenderness, and need for anti-diarrheal medication. Study personnel completed the CAI using data obtained from patient chart notes from the clinic appointment corresponding to the study visit or from the most recent clinic appointment. Internal consistency was .81 in this sample.

Data Analyses

Disease severity scores from the PCDAI and CAI were combined into one score representing disease severity. This was feasible because both measures are continuous and are similarly scored (i.e., higher scores represent greater disease activity). Descriptive statistics were conducted on demographic (e.g., age, income), behavioral (e.g., depressive symptoms, parenting stress, family functioning), and disease-related study variables (e.g., disease severity). Bivariate correlations and independent samples *t*-tests were subsequently conducted to examine potential group differences and covariates for primary regression analyses. Multiple regression analyses designed to examine the relative contributions of child and parent distress to family functioning were then conducted to test the primary study hypothesis. CBCL and YSR Total Problems T scores and PIP Total Frequency and Total Difficulty scores were used as predictors; the FAD General Functioning subscale served as the primary outcome variable in these analyses.

Results

Preliminary Analyses

Bivariate correlation analyses revealed no significant correlations between the primary outcome variable and either demographic parameters (i.e., patient age, annual household income), depressive symptoms, or PCDAI or CAI disease severity. Mean disease severity was in the inactive to mild range for youth diagnosed with Crohn's disease (PCDAI = 12.71 ± 9.93) and for youth diagnosed with UC (CAI = 3.43 ± 5.03). Independent samples *t*-tests also revealed no significant differences across levels of gender, IBD diagnosis, study site, ethnicity, and parental marital status. Descriptive statistics for study variables are reported in Table 1.

Primary Analyses

A multiple linear regression analysis was conducted to examine the relative contributions of parent distress and child behavioral functioning to variance in family functioning. PIP Total Frequency, PIP Total Difficulty, CBCL Total Problems, and YSR Total Problems scores were entered simultaneously into the regression model. Results indicated that the

combination of these variables accounted for a significant 26% of variance in FAD General Functioning [$F(4, 40) = 3.44, p < .05$]. Of the four predictors, CBCL Total Problems contributed a significant portion of overall variance to FAD General Functioning ($t = 2.93, p < .01$); YSR Total Problems, PIP Total Frequency, and PIP Total Difficulty each contributed nonsignificant variance to family functioning.

Subsequently, a post-hoc linear regression was conducted to examine whether internalizing or externalizing behaviors carried the majority of the variance in family functioning. CBCL Internalizing Problems or CBCL Externalizing Problems were entered simultaneously into the regression model. Results indicated that, whereas the combination of these predictors contributed a significant 24% of variance to FAD General Functioning scores, CBCL Externalizing Problems accounted for the majority of this variance ($t = 2.39, p < .05$; see Table 2).

Discussion

Although parental distress did not predict variance in family functioning, results partially supported the primary hypothesis in that parent-reported adolescent behavioral problems contributed more variance to family functioning than did parental distress. This finding might indicate that child behavioral functioning acts as a more salient barometer of family functioning compared to parent functioning in this population. Alternatively, it may underscore the need to assess parenting stress in a manner more proximal to adjustment to IBD. We also anticipated that adolescent internalizing behaviors would account for the majority of variance in family functioning. In contrast to this hypothesis, results revealed that parent-reported *externalizing* behaviors accounted for more variance in family functioning than did internalizing behaviors, indicating that families with children who demonstrate more overt behavioral problems may have greater family dysfunction. These findings are supported by prior research on family functioning in pediatric populations in which internalizing/externalizing behaviors in children have been associated with family conflict/dysfunction (Sourander et al., 2006; Wertlieb, Hauser, & Jacobsen, 1986). However, the significant relationship between externalizing behavior problems and family functioning has not been found in pediatric IBD. This may be because externalizing behavior problems have not been a primary focus of research in this population to date. Instead, internalizing symptoms have largely been targeted in IBD studies, perhaps because of the higher prevalence of these symptoms. Consequently, the decreased focus on externalizing behaviors in prior research may have resulted in underestimation of the impact of these symptoms on adolescent psychosocial outcomes, including family functioning. Indeed, results from this study demonstrated that a greater proportion of the sample exhibited clinically significant internalizing behavior problems than externalizing behavior problems despite the latter accounting for more variance in family functioning. However, caution is warranted in interpreting this higher prevalence as the somatic complaints subscale is included in the computation of the internalizing behavior problems scale, which is likely to be inflated in a sample of IBD patients due to disease symptoms including abdominal pain. Nevertheless, the observed relationship between externalizing behavior and family functioning might suggest that while externalizing problems are less prevalent, they are more likely to inform change in family-level behavioral functioning. Moreover, family functioning might be more sensitive to subtle, yet salient child behaviors that are perceived as disruptive to the family unit.

The present findings certainly do not indicate that externalizing behaviors are more important than internalizing behaviors. Rather, externalizing behaviors may be more disruptive to family adaptation than internalizing behaviors. This may be due in part to families' anticipation and normalization of internalizing symptoms given the increased

prevalence in IBD and in adolescents in general. Thus, externalizing behaviors are perceived by families as abnormal and unsettling. Alternatively, externalizing behaviors may have a greater impact on family functioning because internalizing behaviors are often more self-regulated compared to externalizing behaviors, which require corrective feedback and are primarily managed by parents, which consequently causes stress on the family system.

The results of this study offer important clinical implications. Assessment of child behavioral functioning, as part of patients' clinical care, should also involve the extent to which it is impacting other family members' adaptation to the child's illness and its management. Family functioning in the context of a child's chronic illness may be an important factor in patient psychosocial and health outcomes. Indeed, a recent study suggests that higher family conflict may lead to difficulties in adolescent disease management (Pereira, Berg-Cross, Almeida, & Machado, 2008). Thus, early identification of child behavioral problems and dysfunctional family adjustment is critical so that these problems can be addressed appropriately. The current findings might suggest that parent perceptions of family functioning are sensitive to low levels of externalizing behavior problems; thus parent perception may be an avenue for intervention with these families. Given that pediatric gastroenterologists and other health care professionals often see these patients more than other providers, they are the most likely sources for early identification of problem behaviors and subsequent referrals for treatment. Thus, development and maintenance of referral resources that would be feasibly accessed by the patient/family for further assessment and treatment is a critical component to ensuring comprehensive care.

This study was limited by a few methodological issues that warrant discussion. First, the sample size was fairly modest, which precludes broad generalization of the findings to the overall IBD population. However, the number of participants in the sample was larger than several extant studies in pediatric IBD. In addition, the samples used were drawn from two separate sites in different regions of the U.S., which helped control the influence of site-specific subject characteristics (Drotar, 1994). Second, the study was correlational in nature; thus, causal inferences about the relationship between patient and family behavioral functioning would be inappropriate. A further limitation of the study concerns the assessment of family functioning. Although the FAD is a well-validated measure, only parent report data were obtained. These data were collected as part of a larger longitudinal study with additional child-report behavioral measures, and the exclusion of child-report data on the FAD was done in order to provide a less taxing assessment battery overall. Nevertheless, child-report of family functioning data will be an important future direction in this area of research, particularly as this will rule out relationships among the CBCL and FAD that may be influenced by the use of only one informant. Additionally, the sample was comprised of patients seen in outpatient follow-up clinic visits, which resulted in disease severity ratings in the inactive to mild range. Thus, generalization of these findings to hospitalized patients who are experiencing more severe IBD symptoms may not be warranted. Finally, the majority of this sample was Caucasian and from higher socioeconomic backgrounds. Though this sample is representative of other published studies on IBD (Mackner & Crandall, 2005), generalization of these findings to patients and families from minority or lower socioeconomic backgrounds is not recommended.

In conclusion, results of this study indicate that there is a significant positive relationship between parent-reported patient externalizing behaviors and family dysfunction, after accounting for internalizing behaviors, in pediatric IBD. Given the novelty of these findings and the limitations of this study, future research should aim to replicate these findings, taking into account patient as well as caregiver perceptions of family functioning. Additionally, future studies should expand the examination of the relationship between externalizing behaviors and additional psychosocial and/or disease outcomes in this

population. Further research is also needed to evaluate specific externalizing behavior problems that are most salient to family functioning in this population, which will also help to identify at-risk families. Research should also focus on identifying the causal relationship between child behavioral functioning and family functioning as it is also possible that family dysfunction informs change in child behavior in this population. Particular emphasis should be placed on the potential effect these constructs may have on treatment implications and clinical decisions by both providers and patients/families. Moreover, the influence of child and family functioning on patient and family outcomes including disease management behaviors should continue to be a focus of research in this population.

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Table 1

Descriptive statistics for study variables

	Mean (SD)	Minimum	Maximum	% in borderline/clinical range
PIP Total Frequency	86.06 (29.50)	42	186	N/A
PIP Total Difficulty	81.19 (25.08)	42	127	N/A
CBCL Total Problems	49.38 (11.91)	24	71	B = 16%; C = 13%
CBCL Internalizing Problems	54.84 (12.51)	33	74	B = 6%; C = 31%
CBCL Anxious/Depressed	56.82 (8.72)	50	79	B = 11%; C = 9%
CBCL Withdrawn/Depressed	56.96 (9.46)	50	89	B = 7%; C = 9%
CBCL Somatic Complaints	59.49 (8.77)	50	76	B = 18%; C = 18%
CBCL Externalizing Problems	45.82 (10.11)	34	69	B = 2%; C = 4%
CBCL Rule Breaking Behavior	51.93 (3.44)	50	63	B = 0%; C = 0%
CBCL Aggressive Behavior	53.11 (6.05)	50	78	B = 0%; C = 4%
YSR Total Problems	50.00 (10.10)	32	70	B = 9%; C = 6%
YSR Internalizing Problems	53.91 (10.69)	35	73	B = 4%; C = 24%
YSR Anxious/Depressed	56.40 (7.71)	50	76	B = 6%; C = 11%
YSR Withdrawn/Depressed	55.13 (7.46)	50	87	B = 6%; C = 4%
YSR Somatic Complaints	57.96 (7.30)	50	78	B = 11%; C = 6%
YSR Externalizing Problems	48.02 (9.08)	34	62	B = 9%; C = 0%
YSR Rule Breaking Behavior	53.36 (4.53)	50	64	B = 0%; C = 0%
YSR Aggressive Behavior	53.29 (4.49)	50	67	B = 4%; C = 0%
CDI Total	6.49 (7.01)	0	30	C = 18%
FAD General Functioning	1.71 (.39)	1	2.75	C = 24%

CBCL Child Behavior Checklist, YSR Youth Self Report, PIP Pediatric Inventory for Parents, FAD Family Assessment Device, C clinical range, B borderline range

Multiple regression analyses examining the contribution of parent and adolescent functioning to family functioning

Table 2

Analyses	Variables	β	<i>t</i> for within step predictors	R^2 change for step	Partial correlation	<i>F</i> change for step
Primary	PIP Total Frequency	.18	.85	.26	.13	3.45*
	PIP Total Difficulty	-.11	-.49		-.08	
	CBCL Total Problems	.56	2.93**		.42	
	YSR Total Problems	-.25	-1.52		-.23	
Post hoc	CBCL Externalizing Problems	.43	2.39*	.24	.35	6.64**
	CBCL Internalizing Problems	.09	.49		.08	

*
 $p < .05$

**
 $p < .01$