

Brief Report: Psychosocial Adjustment in Adolescents with Inflammatory Bowel Disease

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Background Inflammatory bowel disease (IBD) is an ideal disease for investigating adolescent adjustment to chronic illness, given its embarrassing, socially limiting, appearance-changing symptoms and adolescent onset. **Objective** To compare psychosocial adjustment among adolescents with a chronic illness to that of healthy adolescents and examine the role of adolescent disease onset. **Methods** Participants were 50 adolescents with IBD and their parents, and parents of 42 healthy comparison adolescents who completed questionnaires assessing behavioral, emotional, social, and family functioning. **Results** Adolescents with IBD were reported to have worse anxious and/or depressed and social problems than healthy adolescents. More adolescents with IBD were reported to have clinically significant social problems. Those diagnosed during adolescence were reported to have significantly worse social competence scores. **Conclusions** Adolescents with a chronic illness such as IBD may be at higher risk for specific psychosocial difficulties than healthy adolescents. Diagnosis of a chronic illness during adolescence may have implications for social functioning.

Key words adolescent development; inflammatory bowel disease; psychosocial adjustment.

Adolescence is a complex transitional period that is developmentally distinct from childhood. Biological, psychological, and social changes occur, all with implications for psychosocial adjustment. Risk factors may have the greatest impact during transitions such as this, but chronic illness onset during adolescence has not been well studied (Holmbeck, 2002). Research on adjustment to pediatric chronic illness has focused primarily on children, and if adolescents are included, they are often grouped in the same sample with younger children. Furthermore, the chronic conditions that primarily have been examined are early-onset diseases such as cystic fibrosis. The onset of a chronic illness during adolescence likely has very different implications for development than earlier onset (Spirito, DeLawyer, & Stark, 1991).

Inflammatory bowel disease (IBD) is an ideal disease for investigating chronic illness onset in adolescence. Onset often occurs during adolescence, and the symptoms

can be embarrassing, socially limiting, and lead to changes in physical appearance. Symptoms include frequent diarrhea, abdominal pain, weight loss or growth delay, and possibly fever, fatigue, perianal disease, and delayed puberty. When the disease is active, these adolescents may spend a great deal of time in the bathroom and may fear becoming a target of "bathroom humor." They may limit their social activities to those with easy bathroom-access, thus preventing developmentally appropriate socialization (e.g., visiting a mall and playing sports). Adolescents with IBD can also be smaller than their peers and in earlier stages of puberty. These challenges could affect psychosocial adjustment at any age, but they are particularly salient during adolescence.

IBD is caused by chronic inflammation of the gastrointestinal tract and affects up to 1 million people in the United States. (Crohn's & Colitis Foundation of America, 2002). The primary subtypes, Crohn's disease and ulcerative colitis, differ in anatomical location and

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nature of the inflammation. There is no cure, so patients may take many medications to control the inflammation and symptoms. More than one-third of those with childhood-onset IBD will eventually require surgery (Langholz, Munkholm, Krasilnikoff, & Binder, 1997). Research on psychosocial adjustment of children with IBD suggests that they may be at risk for more difficulty than healthy children, but average scores on measures such as the Child Behavior Checklist (CBCL; Achenbach, 1991) do not reach clinical significance. It is unclear if a subset of children do have clinically significant difficulties (Mackner, Sisson, & Crandall, 2004). Most importantly, none of the studies focused specifically on adolescents despite the clear implications of IBD on adolescent development.

This study investigated psychosocial adjustment among adolescents with a chronic illness and examined the role of adolescent disease onset. Adolescent adjustment to chronic illness has been neglected, and to our knowledge, no previous research has examined the impact of chronic illness diagnosis during adolescence. We examined behavioral, emotional, social, and family adjustment, given the importance of social functioning and the increase in family conflict during adolescence (Brown, 1990; Buchanan, Eccles, & Becker, 1992). We also provided a more comprehensive picture than currently available by comparing group differences in means and rates of clinical significance and by reporting odds ratios for clinically significant problems.

Method

Participants were 50 adolescents with IBD and their parents and parents of 42 healthy comparison adolescents (M age = 14.39 years, 59% male, 87% Caucasian). Adolescents had IBD for at least one year (M = 3.39 years) and were identified via chart review. Most were currently in remission (62%) or had mild symptoms (32%), and 58% were diagnosed in adolescence. Eligible healthy adolescents had no history of a chronic illness (no 6-month or longer condition requiring treatment by a medical subspecialist) and were recruited via ambulatory clinics and hospital employees. There were no significant group demographic differences.

After Institutional Review Board approval, parents provided written informed consent, and adolescents gave written assent. Parents completed a demographics questionnaire, CBCL (Achenbach, 1991), and Family Assessment Device (FAD; Miller, Epstein, Bishop, & Keitner, 1985). Gastroenterologists completed the Pediatric Crohn's Disease Activity Index (PCDAI; Hyams et al.,

1991) during a clinic visit within a week of questionnaire completion. The CBCL is a normed, validated and reliable measure that yields a Total Problems score, Internalizing Problems score (Withdrawn, Anxious/Depressed, and Somatic Complaints subscales), and an Externalizing Problems score (Delinquent Behavior and Aggressive Behavior subscales), and three additional subscales that contribute to the Total score (Social, Thought, and Attention Problems). The CBCL also yields a Social Competence score that is distinct from the problem scales and consists of the number and amount of participation in sports, activities and organizations, number of friends, frequency of contact with friends, and behavior with others. The FAD assesses family functioning in the areas of problem-solving, communication, roles, emotional responsiveness, emotional involvement, and behavior control. A General Functioning Scale provides an overall measure of family functioning. Crohnbach α 's for the subscales range from .72–.92. The FAD correlates well with other measures of family functioning, and it discriminates clinic-referred families from nonclinic-referred families (Miller, Epstein, Bishop, & Keitner, 1985). The PCDAI is a measure of illness severity that is comprised of patient recall items (pain severity, stool frequency and limitation of activities), physical examination items, and laboratory data. The PCDAI was validated in 12 pediatric gastroenterology centers and correlates well with independent physician global assessment of severity and a previously developed measure for adults. Additional information was obtained via chart review.

Results

Mean group differences were compared via t tests, and differences in rates of clinically significant CBCL T scores were compared with χ^2 analyses. Clinical significance is $T > 66$ for syndrome scales, $T > 59$ for Total, Internalizing and Externalizing scores, and $T < 34$ for the Social Competence score (Achenbach, 1991). Illness severity was not significantly associated with any outcome measure or age at diagnosis. Analyses were conducted with and without Somatic Complaints items of the CBCL. Results did not differ, so full CBCL results are reported.

Behavioral or Emotional Functioning

For the CBCL Total, Internalizing, and Externalizing scores, there were no significant group differences. Mean scores were in the normal range (Table I). Almost a third of adolescents with IBD were reported to have Internalizing or Total scores in the clinically significant

Table I. Group Means (and Standard Deviations) by Disease Status

	Inflammatory bowel disease	Healthy
Child Behavior Checklist		
Total	51.88 (12.92)	47.71 (10.46)
Internalizing	53.90 (12.11)	49.33 (11.26)**
Externalizing	48.86 (11.31)	47.81 (9.97)
Social competence	43.90 (9.41)	49.33 (5.95)**
Withdrawn	55.69 (7.84)	54.17 (7.57)
Somatic complaints	58.27 (8.83)	55.64 (7.22)
Anxious/depressed	56.59 (7.77)	53.33 (5.67)*
Social problems	55.61 (6.65)	52.36 (4.13)**
Thought problems	54.35 (6.01)	52.74 (4.58)
Attention problems	54.53 (7.07)	53.10 (4.96)
Delinquent behavior	52.94 (5.02)	53.81 (6.84)
Aggressive behavior	54.73 (7.58)	52.93 (4.58)
Family Assessment Device		
General Functioning	1.88 (0.47)	1.81 (0.44)
Problem-solving	2.08 (0.40)	1.98 (0.43)
Communication	2.09 (0.40)	1.92 (0.38)*
Roles	2.24 (0.36)	2.28 (0.30)
Affective responsiveness	1.91 (0.49)	1.86 (0.48)
Affective involvement	2.00 (0.35)	1.99 (0.39)
Behavior control	1.63 (0.35)	1.63 (0.35)

Higher Family Assessment Device scores indicate more dysfunction.

* $p < .05$.

** $p < .01$.

*** $p = .067$.

range, but not significantly more than healthy adolescents. On the syndrome scales, adolescents with IBD were reported to have more anxious or depressed symptoms, $t(89) = 2.52, p < .05$, and social problems, $t(89) = 2.75, p < .01$, with mean scores in the normal range. More adolescents with IBD (14%) were reported to have clinically significant social problems than healthy adolescents, 0%, $\chi^2(1, N = 92) = 6.36, p < .05$. The difference for anxious or depressed symptoms (10% IBD vs. 2% healthy) did not reach significance, but the odds ratio (4.56) suggests that the odds of clinically significant symptoms were 4.6 times higher among those with IBD. IBD onset during adolescence was associated with reports of increased somatic complaints, $t(47) = 2.38, p < .05$, but no other differences in current adjustment (see Table II).

Social Functioning

Social Competence scores reported by parents of adolescents with IBD were lower than healthy adolescents, $t(89) = 3.23; p < .01$, with mean scores in the normal range (Table I). Social Competence scores were clinically significant in 22% of adolescents with IBD, compared to 2% of healthy adolescents, $\chi^2(1, N = 92) = 7.75, p < .01$. The odds of a clinically significant Social

Table II. Means (and Standard Deviations) by Age Group at Diagnosis (IBD only)

	Age group at diagnosis	
	Childhood (<11 years, $n = 21$)	Adolescence (≥ 11 years, $n = 29$)
Child Behavior Checklist		
Total	51.52 (10.66)	52.14 (14.58)
Internalizing	53.43 (10.45)	54.25 (13.39)
Externalizing	47.86 (9.31)	49.61 (12.72)
Social competence	47.67 (7.72)	41.07 (9.69)*
Withdrawn	55.14 (6.32)	56.11 (8.91)
Somatic complaints	54.95 (7.47)	60.75 (9.08)*
Anxious/depressed	56.52 (6.82)	56.64 (8.53)
Social problems	56.00 (7.51)	55.32 (6.06)
Thought problems	52.62 (4.57)	55.64 (6.68)
Attention problems	54.52 (7.86)	54.54 (6.56)
Delinquent behavior	51.86 (3.29)	53.75 (5.94)
Aggressive behavior	53.38 (5.72)	55.75 (8.68)
Family Assessment Device		
General functioning	1.89 (0.47)	1.87 (0.48)
Problem-solving	2.07 (0.40)	2.08 (0.40)
Communication	2.07 (0.35)	2.11 (0.44)
Roles	2.25 (0.36)	2.22 (0.36)
Affective responsiveness	1.83 (0.36)	1.98 (0.56)
Affective involvement	2.02 (0.38)	1.98 (0.34)
Behavior control	1.58 (0.34)	1.67 (0.35)

Higher Family Assessment Device scores indicate more dysfunction.

* $p < .05$.

Competence score were 11.6 times higher among adolescents with IBD. Among specific items, those with IBD were reported to have fewer close friends, $t(89) = 2.03; p < .05$, but similar opportunities to see friends outside of school. Adolescents with IBD were reported to participate in fewer organized activities, but this difference only approached significance, $t(89) = 1.83; p = .07$. The groups had similar ability to get along with other children, but those with IBD were reported to have more difficulty in playing or working alone, $t(89) = 3.14; p < .01$. Adolescent onset of IBD was associated with lower Social Competence scores, $t(47) = 2.38, p < .05$. Scores were clinically significant in 35% of those diagnosed in adolescence, compared to 5% with childhood onset, $\chi^2(1, N = 50) = 6.27, p < .05$, with an odds ratio of 10.53.

Family Functioning

Family functioning reported by parents of adolescents with IBD was similar to that of healthy adolescents, except for the family communication subscale, $t(90) = 2.09, p < .05$ (Table I). Diagnosis of IBD in adolescence was not associated with family functioning (Table II).

Discussion

Adolescents with a chronic illness such as IBD may be at higher risk for difficulties in social functioning and anxiety or depression symptoms than healthy adolescents, but the difficulties do not reach clinical significance for most adolescents. Additionally, family functioning was generally similar among healthy adolescents and those with IBD. Research in other health conditions suggests that the most adjustment occurs within the first year (Kovacs et al., 1986), and the adolescents in the current study had been diagnosed with IBD for at least a year. In addition, most adolescents were in remission or experiencing mild symptoms. Given this context, the results highlight the resiliency of many adolescents with IBD.

However, the results also suggest long-term difficulty for some who continue to experience clinically significant problems a year after diagnosis and in the absence of significant disease symptoms. Diagnosis of a chronic illness during adolescence may have a different impact on psychosocial functioning than childhood diagnosis, with specific implications for social functioning. Being diagnosed with IBD during adolescence was associated with lower social competence scores, even a year after diagnosis. Given the importance of social functioning in adolescence, psychologists and other health professionals should be alert to social difficulties among those with chronic illnesses, and these adolescents should be encouraged to participate in social activities. It may be helpful to identify activities that the adolescent can successfully participate in and problem-solve about coping with disease symptoms while participating. Support groups, camps, and websites can provide resources for identifying activities and coping strategies as well as supportive peers who may have similar concerns. In fact, a recent study found that attending an IBD camp was related to significant quality of life improvement in the area of social functioning (Shepanski, Hurd, Culton, Markowitz, Mamula, & Baldassano, 2005). The Crohn's and Colitis Foundation of America (<http://www.cffa.org>) provides camps and support groups for adolescents with IBD, and the Teens With Crohn's Disease website (<http://pages.prodigy.net/mattgreen/>) provides a message board and a chat room.

This study is limited by use of single-method, parent report. The CBCL offers a limited assessment of psychosocial adjustment, especially social competence. Differences exist in parent- and self-report of adolescent externalizing and internalizing symptoms, social activities and peer relations, but self- and teacher-report were not utilized. In addition, peer acceptance and behavioral

reputation are important in adolescence, but are not assessed by this measure.

Knowledge gaps remain in the area of adolescent adjustment to chronic illness. Disease onset during adolescence has been neglected but may have important implications for adjustment. Social functioning in particular should be examined further. Sociometric techniques that assess peer acceptance, friendships, and behavioral reputation have been used with children with other chronic diseases (Reiter-Purtill, Vannatta, Gerhardt, Correll, & Noll, 2003), but adolescents have been neglected. Future research should investigate risk factors to identify which adolescents are most likely to have difficulty. Existing theoretical models and research in adjustment to chronic illness have focused on children, but some research suggests that predictors of adolescent adjustment may differ from those for children (Thompson, Gustafson, & Gil, 1995). Therefore, it is unclear if the existing research is generalizable to adolescents.

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