Review: Psychosocial Issues in Pediatric Inflammatory Bowel Disease

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Objective To review and critically evaluate research on psychosocial issues in pediatric inflammatory bowel disease (IBD) and to provide recommendations for future research.

Methods A literature search was conducted using the Medline and PsychInfo computerized databases as well as the bibliographies of relevant articles.

Results Most of the existing research has compared children with IBD to healthy populations and other illness populations. Compared to healthy children, children with IBD may be at greater risk for difficulties in behavioral and emotional functioning as well as in family and parent functioning, but all such functioning appears similar to that found in other illness populations. It is unclear if the increased risk reaches clinical significance and what role the severity of the disease plays in adjustment.

Conclusions Future research should use a developmental perspective to investigate the process of adaptation to IBD, risk factors of poor adjustment, and the role of psychosocial factors in health outcomes in pediatric IBD.

Key words inflammatory bowel disease; psychosocial adjustment; quality of life.

Children with inflammatory bowel disease (IBD) face the challenge of a chronic, unpredictable, and potentially embarrassing disease of uncontrolled intestinal inflammation. IBD has a relapsing and remitting course, with the most common symptoms in children including frequent diarrhea, abdominal pain, and weight loss or growth delay. Associated symptoms can include fever, fatigue, decreased appetite, arthritis, perianal disease, and delayed puberty. Children with IBD can be reluctant to talk about their symptoms, and some limit their daily activities to those with ready access to a bathroom. Their frequent visits to the bathroom can be a source of embarrassment, and they may fear becoming the target of the “bathroom humor” that is popular among children and adolescents (Casati, Toner, de Rooy, Drossman, & Maunder, 2000). Short stature and delayed puberty can also contribute to feeling different from peers. Steroid medication is commonly used to treat IBD and frequently results in negative side effects such as facial swelling, increased acne, hair growth, and emotional lability, all of which may have additional implications for psychosocial adjustment.

IBD affects approximately 9 of every 100,000 children (Lindberg, Lindquist, Holmquist, & Hildebrand, 2000) and is often diagnosed in adolescence (Sandler & Eisen, 2000). IBD is generally divided into two subtypes, Crohn’s disease and ulcerative colitis, which differ primarily in the anatomical location, nature of the inflammation, and possibly the underlying causative mechanisms. Crohn’s disease may occur anywhere in the intestinal tract, but ulcerative colitis is found only in the colon (large intestine). In ulcerative colitis, the intestinal inflammation is confined to the innermost layer of the intestinal wall, while the inflammation of Crohn’s disease can extend through the entire thickness of the intestinal wall. The specific etiologies are unknown, although both genetic and microbial factors are known to be involved (Rice & Chuang, 1999). An interaction between a dysregulated intestinal immune system and intestinal bacteria is
thought to lead to the uncontrolled inflammation seen in IBD, although different immunological pathways are involved in Crohn’s disease and ulcerative colitis. IBD differs from “functional” gastrointestinal (GI) disorders, such as irritable bowel syndrome and recurrent abdominal pain (RAP), in that the functional disorders are not associated with any known structural or biochemical abnormalities.

There is no cure for IBD, so treatment focuses on controlling the inflammation. Individuals with IBD may take many medications several times a day, and many of the medications have negative side effects that may range from cosmetic effects such as weight gain and acne to more severe effects such as bone disease, high blood pressure, cataracts, diabetes, pancreatitis, suppression of the immune system, and increased cancer risk. Surgery is reserved for when medical options fail, and more than a third of people with childhood-onset IBD will require surgery to manage the disease within 20 years of diagnosis (Langholz, Munkholm, Krasilnikoff, & Binder, 1997). Removal of the colon (colostomy) essentially results in curing ulcerative colitis, but inflammation and extraintestinal symptoms can still occur. Crohn’s disease can recur after surgery. Additionally, the risk for cancer increases as individuals with IBD age.

Psychosocial issues have been well investigated in adults with IBD, but these issues in pediatric IBD have received less attention. In a review of the adult literature, Drossman (2000) concluded that adults with IBD are more likely to be diagnosed with a psychiatric disorder than healthy adults, most commonly anxiety and mood disorders. Self-reported psychological distress is also higher among those with IBD than that found in healthy adults, and more severe disease is associated with increased distress. In the area of stress and coping, stressful life events and daily hassles are associated with symptom exacerbation. Problem-solving coping strategies and social support are associated with lowered psychological distress and better health outcomes. Avoidant coping strategies and lower perceived personal control are associated with poorer health status. In the area of health-related quality of life (QOL), which involves subjective, patient-reported assessments of physical and psychosocial functioning, adults with IBD report lower QOL than the general population but better QOL than adults with arthritis or chronic back pain. Adults with IBD typically report lower psychosocial QOL than physical QOL. Finally, in the area of education, two retrospective studies conducted in the United Kingdom (UK) found that adults with IBD reported that their levels of educational attainment did not differ from that of the general population (Ferguson, Sedgwick, & Drummond, 1994) or from that of a healthy comparison group (Mayberry, Probert, Srivastava, Rhodes, & Mayberry, 1992).

The purpose of this article is to review and critically evaluate the research on psychosocial issues in pediatric IBD and to provide recommendations for future research. A systematic search of the medical and psychological literature was conducted using the Medline and PsychInfo computerized databases. Key words included inflammatory bowel disease, Crohn’s disease, ulcerative colitis, psychology/psychological, psychosocial, and quality of life. Bibliographies of articles were also used, and articles with relevance to the topic were included. The appendix presents a summary of the studies included.

Among children with IBD, behavioral and emotional functioning, family and parent functioning, and health-related quality of life (QOL) have been examined in several studies, and at least one study exists in each of the areas of stress and coping, social functioning, self-esteem, and education. Overall, much of the research is characterized by poor methodology. Many studies employed small samples, and many lacked comparison groups. Obscure measures, including unspecified and unpublished measures, were used in some studies, and it is unclear if some measures were used or administered appropriately. A few studies utilized normed measures but did not report T scores, thus limiting conclusions about clinical significance. Some researchers reported conflicting or surprising results without explanation. Finally, it should be noted that the studies by Engstrom (1991, 1992, 1999) and Engstrom and Lindquist (1991) appear to be reports based not on independent studies but on the same samples of children—those with IBD, those with other chronic illnesses, and those who are healthy.

**Behavioral and Emotional Functioning**

Rates of psychiatric disorders and specific behavioral and emotional symptoms have been examined in children with IBD, and a few studies have investigated relationships between factors such as disease severity and behavioral and emotional functioning. Structured interviews were used in all studies investigating rates of disorders, but only Burke and colleagues (Burke, Meyer, Kocoshis, Orenstein, Chandra, Nord, et al. 1989) described any interviewer training or reliability checks, which are necessary for reliable administration. Interviewer training and reliability are particularly important
for the Child Assessment Schedule (CAS; Hodges, Kline, Fitch, McKinew, & Cytryn, 1981), which is less structured than the other interviews are. Using the Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS; Chambers et al., 1983), Szajnberg, Krall, Davis, Treem, and Hyams (1993) found that 73% of 15 children with IBD met criteria for DSM-III psychiatric diagnoses, particularly internalizing disorders. A comparison group was not included, and it is unclear if the K-SADS was administered appropriately. Parent and child interviews are required for this measure, but only child interviews were mentioned. Engstrom (1991, 1992, 1999) and Engstrom and Lindquist (1991) used the same sample of children with IBD to compare rates of psychiatric disorders to healthy children, children with diabetes, and children with chronic headaches. Using the CAS, they reported that significantly more of the 20 children with IBD (60%) had a DSM-III-R psychiatric disorder, primarily depressive and anxiety disorders, than did healthy children (15%). There was little difference in rates of disorders between the IBD and other chronic-illness groups. Steinhausen and Kies (1982) reported similar rates (59%) of International Classification of Diseases, Ninth Edition (ICD-9) psychiatric diagnoses using an unspecified interview. All of these studies were limited by small sample sizes (N = 15–20).

Burke and colleagues (Burke, Meyer, Kocoshis, Orenstein, Chandra, Nord, et al. 1989) used the K-SADS to compare depressive and anxiety disorders in 55 children with IBD to 52 children with cystic fibrosis (CF). Lifetime prevalence of depressive disorders was higher in the IBD group (25%) than the CF group (12%), but there were no significant differences in current rates of depressive disorders (10% in IBD) or in lifetime or current rates of anxiety disorders (11% and 4% in IBD, respectively). In a different sample, of 36 newly diagnosed children with IBD, 14% met criteria for major depression and 28% met criteria for an anxiety disorder. No comparison group was used in this study (Burke, Neigut, Kocoshis, Chandra, & Sauer, 1994).

Several studies have examined specific behavioral and emotional symptoms using measures such as the Child Behavior Checklist (CBCL; Achenbach, 1988) and child self-report measures. Four studies reported normative T scores within the average range (Gold, Issenman, Roberts, & Watt, 2000; Ondersma, Lumley, Corlis, Tojek, & Tolia, 1997; Szajnberg et al., 1993; Wood et al., 1987). Among the studies that included comparison groups, Gold et al. (2000) found that a group of 36 children with IBD had significantly fewer symptoms on the CBCL and the Children’s Depression Inventory (CDI; Kovacs, 1992) than did 26 children with functional GI disorders. Wood and colleagues (1987) reported that average CBCL total and internalizing scores for 88 children with IBD were significantly higher than those of a sibling comparison group.

Using the same sample of children—20 with IBD and, as comparison groups, 20 healthy and 20 with other illnesses—Engstrom (1991, 1992, 1999) and Engstrom and Lindquist (1991) reported that children with IBD had significantly higher total scores and internalizing scores on the CBCL and they endorsed significantly more depressive symptoms on the CDI than did healthy children. Conflicting results were reported for CBCL externalizing scores (Engstrom, 1991, 1992, 1999; Engstrom & Lindquist, 1991). There were no significant differences between children with IBD and healthy children in self-reported anxiety symptoms, and there were few differences among the chronic illness groups. T scores were not reported, limiting conclusions about clinical significance.

The relationship between disease factors and behavioral and emotional functioning has been investigated in several studies. Three studies reported no significant relationship between behavioral and emotional functioning and disease factors such as laboratory values, growth delay, and frequency of relapse (Ondersma et al., 1997; Steinhausen & Kies, 1982; Wood et al., 1987). Among studies reporting significant relationships, Burke, Neigut, et al. (1994) reported that, in a study of 36 children with IBD, diagnosis of depression was significantly associated with less severe illness as well as with maternal history of depression, greater number of stressful life events, and family dysfunction. In another study, Burke, Meyer, Kocoshis, Orenstein, Chandra, and Sauer (1989) reported a significant correlation between greater disease severity and greater number of obsessive and compulsive symptoms for 33 children with Crohn’s disease. However, the relationship for 11 children with ulcerative colitis, which approached significance, was in the opposite direction, rendering these findings difficult to interpret. Finally, Ondersma et al. (1997) found that negative affectivity was significantly associated with subjective reports of increased disease severity, but it was not associated with objectively determined laboratory values.

To sum, reported rates of psychiatric disorders in children with IBD vary a great deal, and most results are limited by small sample sizes. The studies with larger samples reported lower rates than did studies with small
samples. In addition, discrepant information was reported in one study: 73% of children with IBD met criteria for a psychiatric diagnosis, but mean CBCL scores fell in the average range, with only 2 children in the clinically significant range (Szajnberg et al., 1994). Two research groups reported that mood and anxiety disorders were most common diagnoses (Engstrom 1991; 1992; 1999; Engstrom & Lindquist, 1991; Szajnberg et al., 1994). Approximately half of the studies employed comparison groups. Among those, children with IBD were more likely to meet criteria for a disorder than were healthy children, but rates were similar to those of children with other chronic illnesses. Studies of specific behavioral and emotional symptoms consistently demonstrated mean levels in the average range. As suggested by the few studies with comparison groups, children with IBD may have fewer symptoms than children with functional GI disorders, a similar number of symptoms to children with other chronic conditions, but a greater number of symptoms than healthy siblings and nonrelatives. Mixed results have been reported for the relationship between behavioral and emotional functioning and disease severity; furthermore, contributions of other psychosocial factors to behavioral and emotional functioning have not been well studied.

**Family Functioning**

General family functioning, parent functioning, and sibling functioning have been investigated in families with a child with IBD. Using an unpublished family interaction interview, Engstrom (1999) found that mothers of children with IBD (N = 20 children) reported significantly greater family dysfunction than did mothers of children with diabetes or mothers of healthy children. Wood and colleagues (1989) used a previously established coding system as well as a nonvalidated, project-developed coding system to rate videotaped interactions of 40 families. They reported that families with a child with Crohn’s disease had significantly greater overall family dysfunction than did families with a child who had ulcerative colitis, and the functioning of families with a child with recurrent abdominal pain fell in between the types of IBD.

Three studies examined relationships between family functioning and other factors. Tojek, Lumley, Corlis, Ondersma, and Tolia (2002) found that general family dysfunction, measured by the Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983), was significantly related to increased symptoms of pain and fatigue and the frequency of bowel movements but not to depressive symptoms in 62 adolescents with IBD. Wood et al. (1989) reported that family dysfunction was significantly associated with measures of chronic disease activity, a greater number of behavioral and emotional symptoms overall, but fewer internalizing symptoms. Using the Family Relationship Index (FRI; Moos & Moos, 1981) with 13 children with IBD, Burke, Kocoshis and colleagues (1990) found that children with IBD who were also depressed had families with significantly less cohesion and more conflict than children with IBD who were not depressed.

Several studies have examined psychiatric disorders and symptoms in parents of children with IBD. Using the Millon Clinical Multi-Axial Inventory (MCMI; Millon, 1983), Szajnberg and colleagues (1993) reported that 78% of the parents of children with IBD had DSM-III diagnoses, primarily Axis II disorders. However, this study is limited by a small sample (N = 15) and an unconventional use of the MCMI. The MCMI is not recommended for use in nonclinical populations, and it is recommended that it should be used with other information to determine a formal diagnosis (Goncalves, Woodward, & Millon, 1994). Burke, Kocoshis, et al. (1994) used the Adult Schedule for Affective Disorders and Schizophrenia, Lifetime Version (A-SADS-L; Endicott & Spitzer, 1978), and found that 51% of the 72 mothers of children with IBD had a lifetime history of depression and 10% had a current diagnosis of depression, similar to the rates of mothers with cystic fibrosis. Engstrom (1991, 1999) found that mothers of children with IBD (N = 20 children) reported significantly more psychiatric symptoms on the Symptom Checklist-90 (SCL-90; Derogatis, 1983) than mothers of healthy children. T scores were not reported for this measure, which limits conclusions about clinical significance. Two studies examined relationships between maternal symptoms and child factors. Tojek et al. (2002) reported that lower level of maternal positive affectivity was significantly associated with greater child functional disability, greater number of depressive symptoms, and more frequent bowel movements. However, Engstrom (1999) reported no relationship between parent psychological distress and child behavioral and emotional functioning.

Finally, one study investigated behavioral and emotional functioning in healthy siblings of children with IBD. Wood and colleagues (1988) reported that a sample of 51 siblings of children with Crohn’s disease...
scored significantly above the normative mean on an unspecified scale of the CBCL, whereas the mean score of the 37 siblings of children with ulcerative colitis fell at the normative mean.

The research in family functioning suggests that families with a child with IBD, particularly Crohn’s disease, may have greater family dysfunction and parental psychological distress than families without an ill child. Siblings of children with Crohn’s disease may have more behavioral and emotional difficulties than do children in healthy families. Poorer family functioning appears to be related to increased disease severity.

**Social Functioning**

In the quality of life (QOL) literature, 31% to 50% of children reported that IBD restricts their social activities (Moody, Eaden, & Mayberry, 1999; Rabbett et al., 1996), but the children reported that having IBD had not affected their number of friends (Rabbett et al., 1996). Using the Social Competence scale of the CBCL (Achenbach, 1988), Engstrom (1992) reported that a sample of 20 children with IBD scored significantly lower than healthy children, but no T scores were reported. Gold and colleagues (2000) reported an average Social Competence T score within the normal range for 36 children with IBD, but a comparison group was not investigated.

**Body Image and Self-Esteem**

Concerns about poor growth and appearance have been cited frequently in QOL studies (Akobeng, Miller, et al., 1999; Griffiths et al., 1999; Loonen et al., 2002; Richardson, Griffiths, Miller, & Thomas, 2001), but this research is limited by the descriptive nature of the studies, a lack of comparison groups, and use of measures that are not validated specifically for assessing body image. In the area of self-esteem, Engstrom (1992, 1999) reported that children with IBD scored significantly lower on a Swedish self-esteem measure than healthy children, and at a level similar to children with chronic headaches (N = 20 each group). However, Gold and colleagues (2000) reported that a group of 36 children with IBD scored significantly higher on the Piers-Harris Self-Concept scale (Piers, 1996) than did children with functional GI disorders and that T scores for both groups were above the normative mean, suggesting high self-esteem.

**Stress and Coping**

The roles that stressful life events and coping strategies play in the health status of adults with IBD have been well documented (Drossman, 2000) but have received much less attention in pediatric IBD. In one study, 36 children with IBD were compared to 38 healthy children. The children with IBD reported significantly fewer stressful events on a Perceived Stressful Life Events Questionnaire than did healthy children (Gitlin et al., 1991). On the Coping Inventory: A Measure of Adaptive Behavior (Zeitlin, 1980), children with IBD reported significantly less effective “self-coping” skills overall, as well as significantly less flexible self-coping. There were no significant differences in “environmental coping,” and neither type of coping was defined.

**Health-Related Quality of Life**

The quality of life (QOL) research in children with IBD has primarily focused on describing and ranking IBD-related concerns, using IBD-specific measures such as the IMPACT questionnaire (Griffiths et al., 1999). These measures were typically developed via interviews and focus groups in which children were asked how IBD affects their lives. In four studies using IBD-specific measures developed as such, the primary concerns identified were pain, frequent school absences, lack of energy, concerns about medicine, worries about flare-ups, and concerns about having a lifelong condition (Akobeng, Mirajkar, et al., 1999; Griffiths et al., 1999; Rabbett et al., 1996; Richardson et al., 2001). Mean scale scores on a Dutch adaptation of the IMPACT were presented in one study of 83 children, and lowest QOL scores were found in the areas of treatment and body image (Loonen, Grootenhuis, et al., 2002). On a Dutch general health-related QOL measure, lowest QOL was found in the areas of emotional functioning and somatic complaints (Loonen, Derkx, Koopman, & Heymans, 2002). One study reported a significant relationship between QOL and disease severity (Loonen, Grootenhuis, et al., 2002), whereas another did not find a relationship (MacPhee, Hoffenberg, & Feranchak, 1988).

One study examined QOL in parents and siblings of children with IBD (Akobeng, Miller, et al., 1999). Problems most frequently mentioned by 20 parents in focus groups included concerns about their child’s future, problems at school, and medication side effects. Problems most frequently identified by siblings (N = 7) included lack of information about the disease; concerns
about siblings being teased; and “fear about disease and treatment,” which was not described.

The roles of social support and coping strategies in general QOL were investigated among 30 adolescents with IBD (MacPhee, Hoffenberg, & Feranchak, 1998). Greater intimacy and satisfaction with social support networks were significantly associated with better QOL, with no relationships between QOL and size, density, or contact with social network. Adolescent coping strategies, measured by the Adolescent Coping Orientation for Problem Experiences (Patterson & McCubbin, 1991), were not significantly correlated with their QOL, but there was a significant negative relationship between parent coping strategies and adolescent QOL; that is, parents who reported that various coping strategies on the Coping Health Inventory for Parents (McCubbin, 1991) were “more helpful” had adolescents who reported lower QOL. This relationship seems somewhat counter-intuitive, and no explanation was provided by the authors. Perhaps parents of adolescents with lower QOL had a greater need to employ coping strategies (and found them helpful) than did parents of adolescents with higher QOL.

**Education**

On a QOL measure, 75% of 16 children reported that frequent absences from school were a problem (A kobeng, Mirajkar, et al., 1999). Rabbett and colleagues (1996) reported that 25% of children in the same sample reported no absences during the school year; 31% reported 1 to 20 days absent from school; 38% reported 21 to 40 days; and 1 child reported more than 40 days. None of the children had to repeat a school year. All but 1 child had been hospitalized in the past year, and 5 children (3%) had had surgery, suggesting moderate-to-severe IBD. Moody and colleagues (1999) reported that 60% of 64 children with moderate-to-severe IBD averaged 3 months of absences during the previous year, and 80% felt that they had underachieved due to ill health, although no objective measures of academic achievement were reported. Both studies relied on child report of absences with no external validation.

**Conclusions**

Much of the existing research on psychosocial issues in children with IBD is limited by methodological problems. The research has primarily focused on comparing the adjustment of children with IBD to that of healthy children, normative samples, and other illness populations. This research suggests that children with IBD may be at risk for a greater number of difficulties in behavioral and emotional functioning than healthy children, which is a similar conclusion to that based on the research on adults with IBD. It is unclear if the increased risk reaches clinical significance in children, but the difficulty experienced by children with IBD appears similar to that experienced in other chronic conditions. Families with a child with IBD may be at risk for greater difficulties in family and parent functioning than families of healthy children. Much less research exists in the areas of stress and coping, social functioning, body image and self-esteem, and school absences and attainment, so it is difficult to draw conclusions in these areas.

Although comparing children with IBD to healthy children and other illness populations provides information about the risk associated with having this chronic illness, very little research has investigated the process of adaptation to IBD to identify factors that help predict which children may have greater difficulty in adjustment. Research focusing on risk factors in the adjustment process can identify specific areas for prevention and intervention aimed at improving adjustment to IBD. However, few factors other than disease severity have been investigated in the adjustment of children with IBD, and disease severity has not been consistently associated with adjustment. This is not surprising given the research in other chronic conditions: illness factors have repeatedly been shown to be less predictive of adjustment than psychosocial factors (Thompson & Gustafson, 1996), providing further support for the importance of examining other risk factors and their contributions to poor adjustment.

Similarly, much of the previous research in pediatric IBD has been hindered by the lack of a theoretical model to guide exploration of risk factors. Several theoretical models of adaptation have been developed and applied to other pediatric illnesses, and research guided by these models has identified risk factors for poor adjustment as well as moderating and mediating relationships among risk factors (Thompson & Gustafson, 1996). Family functioning, parent adjustment, child coping strategies, body image, and self-esteem are associated with adjustment in several chronic illness populations (Thompson, Gustafson, & Gil, 1995; Varni & Setoguchi, 1991; Wallander & Varni, 1991, 1998). Children with IBD may experience risk factors similar to those experienced in other illness populations, but there may be risk factors that are unique to IBD given the potentially embarrassing symptoms and the developmental context of adolescence.
IBD is often diagnosed during the transitional period of adolescence, but the developmental context and important developmental outcomes have received little attention in IBD research. An adolescent who is diagnosed with this unpredictable chronic disease with symptoms that can be perceived as embarrassing may have additional difficulty navigating the developmental tasks of establishing an identity, developing peer and romantic relationships, and establishing autonomy. The timing of puberty, which may be delayed in IBD, and the cognitive changes that allow adolescents to appreciate broader implications of chronic illness may also have implications for adjustment (Holmbeck & Shapera, 1999).

Prospective, longitudinal research is required to thoroughly investigate developmental issues and adaptation to IBD, but almost all of the current research in pediatric IBD is cross-sectional. Investigating trajectories of adaptation over time may identify different trajectories for different subsets of children with IBD. For example, a subset of children with IBD may experience initial distress after diagnosis that lessens over time, whereas another subset may experience continued difficulty with adjustment.

Finally, the role of psychosocial factors in health outcomes has been examined in adults with IBD, but this area has not been investigated in pediatric IBD. Among adults, relationships between stress, coping, and disease flare-ups have been investigated, and relationships between psychosocial factors and health care utilization have been demonstrated (Drossman, 2000). These areas have important implications for the role of psychology in health care and may be a fruitful area of investigation in children with IBD and their families as well.

To sum, children with IBD appear to be at increased risk for difficulty adjusting to the disease, but limitations in the existing research prevent conclusions about important outcomes other than behavioral and emotional functioning or about risk factors for poor adjustment. Future research should use a developmental perspective to investigate the process of adjustment to IBD and to identify risk factors for poor adjustment by using as a guide existing theoretical models and research in other pediatric chronic conditions.

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References


**Appendix**

Akobeng, Miller, Firth, Suresh-Babu, Mir, & Thomas (1999)

**Sample.** 20 parents and 7 siblings (aged 7 to 17) of children with IBD.

**Research question.** Parent and sibling QOL.

**Study design.** Qualitative; separate parent and sibling focus group meetings.
Measures. Group interviews.

Results. Most frequent parent concerns: child’s future, school problems, medication side effects, feelings of guilt, and effect on the parent’s career. Most common sibling concerns: being kept in the dark by parents, sibling being bullied at school, and fear about the disease and treatment.

Comments. Descriptive only. Small samples, especially sibling group.

Akobeng, Mirajkar, Suresh-Babu, Firth, Miller, Mir, & Thomas (1999)

Sample. 16 children (aged 8 to 17 years) with Crohn’s disease (CD) and their families (see Rabbett et al., 1996).

Research question. Issues affecting HRQOL.

Study design. Cross-sectional; questionnaire.

Measures. Project-developed questionnaire based on information from focus groups.

Results. Most frequent concerns in rank order: anxiety, abdominal pain, anger/frustration, frequent absenteeism, lack of energy, sleep problems, and difficulty running.

Comments. Possible selection bias because participants who had psychiatric problems or who were “too emotional or sensitive about the disease” did not participate. Small sample.

Burke, Kocoshis, Neigut, Sauer, Chandra, & Orenstein (1994)

Sample. 72 mothers of children with IBD (49 with Crohn’s disease [CD], 23 with ulcerative colitis [UC]; 28 boys, 27 girls); 44 mothers of children with cystic fibrosis (CF).

Research question. Lifetime psychiatric history of mothers of children with IBD.

Study design. Cross-sectional; semistructured mother interview, mother questionnaires.

Measures. A-SADS-L.

Results. 51% of mothers of children with IBD had a lifetime diagnosis of depression. No significant differences between IBD and CF groups in rates of depression or anxiety disorders.

Comments. No mention of interviewer training or reliability on interviews.


Sample. 55 children with IBD, with mean age of 12 years (41 with CD, 14 with UC; 28 boys, 27 girls). 52 children with CF (27 boys, 25 girls).

Research question. Prevalence of depression and anxiety disorders.

Study design. Cross-sectional; semistructured child interview.

Measures. K-SADS.

Results. Lifetime prevalence of depressive disorders was significantly higher in children with IBD (25%) than in those with CF (12%). No significant differences in current depressive disorder or lifetime or current anxiety disorders.

Comments. Interviewers were adequately trained on the K-SADS.

Burke, Meyer, Kocoshis, Orenstein, Chandra, & Sauer (1989)

Sample. 44 children with IBD, with mean age of 12 years (33 with CD, 11 with UC). 46 children with CF. Gender not reported.

Research question. Prevalence of obsessive and compulsive symptoms.

Study design. Cross-sectional; child card sort.

Measures. Leyton Obsessional Inventory—Child Version (LOI-CV), disease severity.

Results. UC group reported significantly more symptoms than CD group, but not as much as the CF group. Disease severity was associated with symptoms, but the direction of the relationship differed for children with UC vs. those with CD.
Comments. Small UC sample. It is difficult to interpret the differing relationships for disease severity and symptoms for children with UC vs. those with CD.

Engstrom (1991)

Sample. 20 children with IBD (11 with UC, 9 with CD); 20 healthy children. Mean age of 16.5, matched on age and gender (see Engstrom & Lindquist, 1991).

Research question. Parental distress and social interaction.

Study design. Cross-sectional; questionnaire; semi-structured interview.

Measures. Parents: SCL-90; Interview Schedule for Social Interaction (ISSI); CBCL; sick days. Children: CAS.

Results. See Engstrom and Lindquist (1991). Also, mothers in the IBD group had significantly higher parental distress and lower social support. No significant correlations between parent distress and child mental health. No significant differences in sick days.

Comments. T scores were not reported, limiting conclusions about clinical significance. Small sample. No mention of interviewer training or reliability on CAS.

Engstrom (1992)

Sample. 20 children with IBD (11 with UC, 9 with CD); 20 healthy children. Mean age of 16.5, matched on age and gender (see Engstrom & Lindquist, 1991). Also, 20 children with diabetes and 20 children with chronic headache matched with IBD group on age and gender.

Research question. Psychological functioning.

Study design. Cross-sectional; questionnaires, semi-structured interviews.


Results. See Engstrom (1991, 1992). Also, IBD group had significantly higher levels of maternal distress and greater family dysfunction than the healthy group. No significant differences among chronic conditions. IBD group more external LOC than healthy and diabetes.


Engstrom & Lindquist (1991)

Sample. 20 children with IBD (11 with UC, 9 with CD); 20 healthy children. Mean age of 16.5, matched on age and gender (see Engstrom & Lindquist, 1991). Also, 20 children with diabetes and 20 children with chronic headache matched with IBD group on age and gender.

Research question. Psychological and family functioning.

Study design. Cross-sectional; questionnaires, semi-structured interviews.


Results. See Engstrom (1991, 1992). Also, IBD group had significantly higher levels of maternal distress and greater family dysfunction than the healthy group. No significant differences among chronic conditions. IBD group more external LOC than healthy and diabetes.


Ferguson, Sedgwick, & Drummond (1994)

Sample. 70 young adults (50 with CD, 20 with UC) a mean of 14 years after diagnosis. Mean age 26.75.

Research question. Education and employment in early adult life.

Study design. Descriptive.

Measures. Structured clinical interview or phone interview.
Results. 57% had absence from school of two or more months. School examination pass rates were similar to the general population. 50% proceeded to higher education.

Comments. No comparison group. Retrospective recall of school absences with no external validation.

Gitlin, Markowitz, Pelcovitz, Strohmayer, Dorstein, & Klein (1991)

Sample. 36 children with IBD (15 boys, 21 girls; aged 6 to 19) and 38 healthy controls (21 boys, 17 girls; aged 6 to 19).

Research question. Stress and coping.

Study design. Cross-sectional; questionnaire.


Results. Children with IBD reported fewer stressful events, less flexible coping, and less effective self-coping strategies.


Sample. 36 children with IBD (25 with CD, 11 with UC; mean age 13.3), 26 children with functional GI (FGI) complaints (mean age 11.4).

Research question. Psychosocial functioning.

Study design. Cross-sectional; questionnaire.

Measures. Questionnaire regarding children’s perception of the illness, CDI, Piers-Harris Children’s Self-Concept scale, CBCL.

Results. Mean scores not clinically significant for either group. IBD group was significantly less depressed, had fewer behavior problems and higher self-esteem than FGI group.

Comments. Patients requiring colectomy excluded.

Griffiths, Nicholas, Smith, Munk, Stephens, Durno, & Sherman (1999)

Sample. 117 children with IBD (87 with CD, 30 with UC). 26 children with functional GI complaints.

Research question. IBD specific QOL.

Study design. Cross-sectional; questionnaire.

Measures. Project-developed QOL measure based on interviews with children and professional opinion regarding an adult IBD QOL measure.

Results. Most frequent concerns: medications, worries about possible flare-ups, having a life-long condition, weight, future health problems, height, abdominal pain, “giving up doing things.”

Loonen, Derkx, Koopman, & Heymans (2002)

Sample. 81 children with IBD with mean age of 14 years (40 with CD, 39 with UC, 2 with indeterminate colitis; 45 boys, 36 girls) and their parents.

Research question. Parent-child concordance in HRQOL.

Study design. Cross-sectional; parent and child questionnaires.

Measures. TNO-AZL Children’s Quality of Life Questionnaire (TACQOL; generic QOL measure) (parent and child versions), General Health Questionnaire (GHQ).

Results. Lowest QOL in emotional functioning and somatic complaints. Children reported higher levels of QOL than parents, but concordance in most areas was good, with lower agreement in subjective domains (e.g., negative emotions).

Comments. Mailed survey with no guarantee that parents and children did not share responses.

Loonen, Grootenhuis, Last, de Haan, Bouquet, & Derkx (2002)

Sample. 83 children with IBD with mean age of 14 years (41 with CD, 40 with UC, 2 with indeterminate colitis; 45 boys, 38 girls).

Research question. To develop and evaluate a Dutch, IBD-specific QOL measure.

Study design. Test-retest; child questionnaires.

Measures. Impact-II IBD QOL measure, TACQOL, self-reported disease activity, disease course severity.

Results. IBD-related QOL was significantly associated with self-reported disease activity and severity. Correlations between IBD-related QOL and general QOL were moderate.

Comments. Potential shared-method bias of the QOL measure and self-reported disease activity.

MacPhee, Hoffenberg, & Feranchak (1998)

Sample. 37 adolescents (18 girls, 12 boys; 12 with CD, 18 with UC; aged 12 to 18), their mothers.

Research question. Adolescent and family adjustment.

Study design. Cross-sectional; adolescent and parent self-report questionnaires.

Measures. Social Support Network questionnaire, HRQOL (adolescent and parent), Coping Health Inventory for Parents, Adolescent Coping Orientation for Problem Experiences, disease activity.

Results. Adolescent HRQOL scores significantly correlated with satisfaction and degree of closeness with social support. Parental coping rather than adolescent coping significantly correlated with adolescent QOL. Severity of illness did not correlate with QOL.

Comments. Small sample size, no control group. The relation between parent coping and adolescent QOL was negative, which seems counterintuitive.
Mayberry, Probert, Srivastava, Rhodes, & Mayberry (1992)
Sample. 58 patients (mean age of 31) with CD, 23 buddy controls, 27 community controls.
Research question. Education absences and achievement.
Study design. Cross sectional; mailed questionnaire, retrospective.
Measures. Project-developed questionnaire.
Results. CD patients had similar rates of absences and academic success to controls.
Comments. Retrospective recall of school absences with no external validation.

Moody, Eaden, & Mayberry (1999)
Sample. 64 children with CD (mean age 14.1; 32 boys, 32 girls).
Research question. QOL, social and school functioning.
Study design. Cross-sectional; questionnaire.
Measures. Project-developed questionnaire.
Results. 60% had mean of 3 months school absence in last 12 months. 80% thought they had underachieved on exams due to ill health. Almost all reported restriction in social activities.
Comments. No comparison group. Child report of school absence with no external validation. Moderate to severe IBD.

Ondersma, Lumley, Corlis, Tojek, & Tolia (1997)
Sample. 56 children with IBD (31 boys, 25 girls; 34 with CD, 22 with UC; mean age of 15.1)
Research question. Negative affectivity and hostility in subjective versus objective health.
Study design. Cross-sectional; questionnaires completed at home, interviews.
Measures. RCMAS, CDI, Positive Affectivity subscale of the Positive and Negative Affect Schedule, expressive hostility factor of the Buss-Durkee Hostility Inventory, structured interview for expressed hostility, Subjective Illness Questionnaire, health care utilization, lab measures.
Results. RCMAS and CDI scores were within normal range. Subjective illness was significantly associated with health care use, but neither were associated with objective disease severity. Negative and positive affectivity were significantly related to subjective but not objective illness.
Comments. Nonstandard administration of CDI (removed suicidal ideation item).

Rabbett, Elbadri, Thwaites, Northover, Dady, Firth, Hillier, Miller, & Thomas (1996)
Sample. 16 children (aged 8 to 17 years) with CD and their families.
Research question. QOL.
Study design. Cross-sectional; questionnaire.
Measures. Children: project-developed questionnaire. Parents: project developed questionnaire.
Results. 94% had at least one hospitalization per year. 25% had zero school absences, 31% had 1–20 absences, 44% had > 21 absences. No child had to repeat a class. 31% reported limitations in social activities. 94% of parents had concerns about medications.
Comments. Possible selection bias because participants who had psychiatric problems or who were “too sensitive about the disease” did not participate. Small sample. Moderate to severe IBD.

Richardson, Griffiths, Miller, & Thomas (2001)
Sample. 117 children with IBD (87 with CD, 30 with UC; see Griffiths et al., 1999). Also, 53 British children with IBD (24 girls, 29 boys; 47 with CD, 6 with UC).
Research question. Cross-cultural comparison of QOL.
Study design. Cross-sectional; questionnaire.
Measures. Project-developed QOL measure based on interviews with children and professional opinion regarding an adult IBD QOL measure (see Griffiths et al., 1999). Mailed questionnaire.
Results. Significant correlations between the mean scores and ranks for the 96 items in both populations.

Steinhausen & Kies (1982)
Sample. 10 children with CD (2 boys, 8 girls; mean age 13.3 years), 7 with UC (5 boys, 2 girls; mean age 13.3 years), 17 healthy controls (7 boys, 10 girls; mean age 13.5 years).
Research question. To examine psychopathology and family functioning.
Study design. Cross-sectional; structured parent interview and questionnaire, child questionnaires.
Results. IBD group had significantly higher rates of psychiatric disorder than healthy (59% vs. 18%). CD group had significantly more internal LOC than healthy. Disease factors were not associated with psychopathology.
Comments. Healthy control group matched on age, gender, SES. Small sample size.
Szajnberg, Krall, Davis, Treem, & Hyams (1993)

Sample. 15 with IBD children and their families (mean age 11.6).

Research question. Psychopathology and relationship issues.

Study design. Cross-sectional; questionnaire, structured interviews.

Measures. K-SADS, CBCL, Locke-Wallace Marital Relations scale, MCMI.

Results. 60% severe or moderate marital discord, 73% of children had DSM-III diagnoses (internalizing), 78% of parents had DSM-III diagnoses (Axis II). CBCL mean scores were in the average range, and only 2 children fell in the clinically significant range.

Comments. No comparison group. Small sample. Assessment within 2 weeks of diagnosis. Somewhat discrepant findings on K-SADS vs. CBCL. The MCMI is not recommended for normal populations, and it is recommended that it be used with other information to determine diagnosis. No mention of interviewer training or reliability on K-SADS, and unclear if appropriate administration.

Tojek, Lumley, Corlis, Ondersma, & Tolia (2002)

Sample. 62 adolescents with IBD (36 with CD, 26 with UC; 33 boys, 29 girls; mean age 15.1) and their mothers.

Research question. The roles of family dysfunction, maternal physical symptoms and positive affect in health status.

Study design. Cross-sectional; questionnaire.


Results. Family dysfunction was significantly correlated with IBD symptoms. Maternal PA was significantly inversely correlated with adolescent depression, functional disability, and bowel movements.


Sample. 88 children with IBD aged 6 to 17 years (51 with CD, 37 with UC; gender not reported). 65 siblings.

Research question. To compare psychological functioning of children with IBD to siblings.

Study design. Cross-sectional; child- and parent-report questionnaires.

Measures. CBCL, Harter Perceived Competence Scale for Children (HPC), disease activity, severity and duration.

Results. Mean Total and Internalizing scores on CBCL for the IBD group were significantly higher than norms and sibling scores but were not clinically significant. CBCL scores were not associated with disease variables, but “psychological style” (E–I score difference) was significantly correlated with elevated lab values.

Comments. Mean scores on HPC were not reported. It is difficult to interpret the E–I difference when neither externalizing nor internalizing scores were significantly elevated, and the difference score was 10 points or greater for only 2 of those CD siblings. (A difference of 10 points is suggested by Achenbach [1988] to classify into either typology).


Sample. 40 children aged 11 to 16 with CD (N = 18), UC (N = 11), and functional recurrent abdominal pain (RAP; N = 11); gender not reported.

Research question. Investigating a “psychosomatic family” model.

Study design. Cross-sectional; videotaped family interactions, parent-report questionnaire.

Measures. From videotape: interpersonal boundaries, generational boundaries, enmeshment, rigidity, over-


Sample. 88 children with IBD aged 6 to 17 years (51 with CD, 37 with UC, gender not reported). 65 siblings (see Wood et al., 1987).

Research question. Psychological functioning in siblings of children with IBD.

Study design. Cross-sectional; parent-report questionnaire.

Measures. CBCL, disease activity, severity and duration.
protection, conflict avoidance, poor conflict resolution, triangulation of patient and quality of marital relationship; CBCL; acute and chronic disease activity laboratory values.

Results. CD families had significantly higher psychosomatic family scores than UC families, and RAP families scored between CD and UC families. There were significant correlations between psychosomatic family scores and chronic disease laboratory values.

Comments. Two videotape raters used a previously established coding system and a nonvalidated project-developed coding system. Interrater reliability was adequate, and raters were blind to diagnosis.