

# The Importance of the Family Context in Inflammatory Bowel Disease

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OCTOBER/NOVEMBER 1998 NUMBER 5 & 6 VOLUME 65:398-403

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## Abstract

**Background:** This study examines psychological correlates of inflammatory bowel disease (IBD) to answer these questions: What is the association between individual and family stress levels and the patient's coping ability and severity of illness? How does the level of family functioning correlate with individual coping and illness severity? To what extent are patient and family beliefs about IBD related to symptomatology?

**Methods:** Seventeen patients and 44 of their family members were studied intensively in an exploration of the psychological response to IBD. They completed a comprehensive battery of self-report questionnaires assessing stressful life events, coping related to the illness, and beliefs regarding IBD. Ratings of family functioning were made from videotaped family discussions about IBD. Treating physicians made independent ratings of past and current disease severity.

**Results:** Surprisingly, recent disease activity was negatively correlated with family stress level ( $r = -0.794$ ), but was not associated with patient stress level. However, impaired coping with IBD by affected individuals was directly correlated with both individual ( $r = 0.595$ ) and family-wide ( $r = 0.724$ ) reported stress levels. Disease severity was also found to be responsive to family communication style ( $r = 0.431$ ) and to level of family agreement ( $r = 0.531$ ) regarding the etiology and management of IBD.

**Conclusions:** These findings suggest that individual stress affects coping with IBD, whereas family-wide stress, communication style, and agreement about disease etiology and management are related to disease activity. The interrelationship of family and patient as well as individual coping with IBD should be evaluated in future studies.

**Key Words:** Crohn's disease, inflammatory bowel disease, ulcerative colitis, family, stress, coping. Inflammatory bowel disease (IBD) is a chronic medical illness with acknowledged primary organic etiology whose psychological correlates have attracted interest for a long time. Originally, psychoanalytically derived hypotheses focused on the presence of a symbiotic relationship between

the affected individual and his or her mother, and it has been proposed that unexpressed anger and disruptions in the mother-child relationship were associated with increased disease severity (1, 2). Associations between psychiatric diagnosis and IBD also have been proposed. After several decades in which inconsistent findings were reported in the literature, a meta-analysis of 138 studies involving patients with ulcerative colitis indicated that psychiatric diagnosis was not significantly correlated with disease status or severity (3). Moderately significant correlations between depression and Crohn's disease have been reported, but have not as yet been subjected to meta-analysis (4). It has also been proposed that stress can cause and exacerbate IBD. However, two recent prospective studies found no relationship between stressful life events and symptom exacerbation (5, 6).

We examined IBD from a "family systems" perspective, which views the patient in the context of his or her family environment. From this perspective, the disease process can be conceptualized as both systemic and circular. In the latter case, there is presumed to be a two-way causality between illness (denoting the experience of the disease, including stress and coping [7, 8]) and symptomatology. Though circular processes have been introduced into the IBD literature, we significantly expanded this approach to include the familial relationships in which the patient and his or her disease are embedded. Because this represents a new, uncharted perspective, this study is necessarily exploratory in its methodology. Specifically, we explored the following questions: What is the association between individual and family stress levels, and the patient's coping ability and severity of illness? How does the level of family functioning correlate with coping and illness severity? To what extent are patient beliefs about IBD and family beliefs about IBD related to symptomatology?

## **Materials and Methods**

### **Subjects**

Seventeen subjects who had either ulcerative colitis ( $n = 7$ ) or Crohn's disease ( $n = 10$ ) and 44 of their family members participated in the study. All subjects were under the ongoing care of a gastroenterologist experienced in the treatment of IBD. All subjects were seen during the course of one calendar year. Diagnoses were confirmed using clinical history, as well as standard radiographic, endoscopic and histological criteria.

Individuals were presented with the opportunity to participate in the study by their treating gastroenterologists. Physicians reported that neither the degree of psychological health nor the physical condition of the patient influenced their discussion of the study with potential subjects. Of the 51% of patients who declined participation, almost all declined because of logistic and geographic inconveniences which were not influenced by socioeconomic or ethnic factors. Physicians completed the Inflammatory Bowel Disease Severity Index at the time of patient referral to the study.

Individuals willing to participate were contacted and interviewed in person no later than 2 months after physician referral. The 13 unmarried subjects were interviewed with their parents and siblings. There was a total of 15 siblings but no family had more than 2 siblings. The 4 married subjects were interviewed with their spouses.

Interviews were conducted either at the principal investigator's office or in the family's home. After separately completing a series of questionnaires, each participant was videotaped discussing IBD, focusing on issues raised by one of the questionnaires (Inflammatory Bowel Disease Severity Inventory [IBDI]; see Table 1). Upon departure, participants were given an additional packet of

**TABLE 1**  
*Inflammatory Bowel Disease Inventory (IBDI)*

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1. What do you think ulcerative colitis (or Crohn's disease) is, actually?
  2. In your opinion, what are the causes of ulcerative colitis (or Crohn's disease)? Please put a "1" next to the cause you think is most important, a "2" next to the next-most important cause, and so on.
  3. List any precipitating events that may have led up to the onset of ulcerative colitis (or Crohn's disease) in your family.
  4. If there have been any recurrent bouts of ulcerative colitis (or Crohn's disease), list possible precipitating events.
  5. In what ways does ulcerative colitis (or Crohn's disease) present a problem for you in daily life? Please put a "1" next to the most important problem, a "2" next to the next-most important problem, and so on.
  6. In what ways does ulcerative colitis (or Crohn's disease) present a problem for your family in daily life? Please number your items as you did for question 5.
  7. How is ulcerative colitis (or Crohn's disease) treated in your family? What steps are taken to keep the disease under control and create good health?
  8. Would you be likely to join a group of families who each have a member with ulcerative colitis (or Crohn's disease) in order to discuss common problems? Why or why not?
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questionnaires to complete and mail to the senior author. All ratings and scoring of measures were done blind to physician evaluations of disease severity. All scoring and ratings in the study measures were performed by advanced clinical psychology students.

### Measures

Multiple indices were used to measure individual and family variables. With the exception of the Inflammatory Bowel Disease Inventory (IBDI) and the Family Structure and Communication Index (FSCI), both of which were created for this study, all measures have been widely used in psychological investigations of disease coping.

Disease activity was scored using the Inflammatory Bowel Disease Severity Index, a physician summary rating of both recent and long-term severity of clinical disease, that utilizes an established clinical grading system (5). A rating of 1 ("very well") indicates remission with occasional medication for minor symptom flare-ups. A rating of 4 ("severe") indicates consideration for hospitalization, significant complications and chronic steroid therapy.

Stress was indexed using the Schedule of Recent Experience (SRE), a validated scale which

measures the frequency and timing of stressful life events in the recent past (test-retest  $r = 0.78$ ) (9), as well as the Family Inventory of Life Events and Changes (FILE), a validated measure of family-wide stressful life events (test-retest  $r = 0.64$ ; Cronbach  $\alpha = 0.81$ ) (10). Two summary scores, which included chronic and recent stressors, were derived from the FILE: the Recent Life Change score and the Total FILE score.

Coping with IBD was assessed by the Experience Scale, established as a valid self-report scale for measuring psychological adjustment to living with IBD (Cronbach  $\alpha = 0.84$ ) (11), addresses such issues as the degree to which disease compromises mood, activity, and interpersonal relationships.

Beliefs regarding etiology and management of IBD were investigated using the Inflammatory Bowel Disease Inventory (IBDI), which is a self-report measure developed specifically for this study (Table 1). Interrater reliability (see **Subjects**), which was determined by dividing the number of categorizations where there was agreement between two raters by the total number of categorizations, was excellent (0.96). Additionally, the percentage of category agreement among family members was calculated, and a total family IBDI Agreement Score was computed by averaging the percentages of family agreement across questions. The degree to which beliefs were organized as blaming self or others was derived from the written IBDI responses, that is, the presence of explaining beliefs about etiology and management in terms of personal irresponsibility and neglect. Different raters evaluated the blaming dimension and the belief categorization. Interrater reliability for blame category was excellent (0.92) and was determined by dividing the the number of cases where there was agreement between two raters by the total number of cases.

Family relationship functioning was analyzed using the FSCI, a video-analysis of family relationship functioning developed specifically for this study, based on the videotaped family discussion of the 8 questions comprising the IBDI. Four theoretically basic aspects of family functioning (communication, boundaries, alliances, affect) are rated along a 7-point continuum. These are: communication (clarity, equality of participation); boundaries (rigid, invaded); alliances (flexible, dominant); and affect (open, varied). Interrater reliability, which was very good (0.84), was computed by dividing the number of agreed-upon ratings by the total number of ratings assigned.

Two other assessments were the Family Crisis-Oriented Personal Evaluation Scale (F-COPES), a well-validated self-report measure used to identify problem-solving approaches and behaviors used by families in response to problems or difficulties (test-retest;  $r = 0.81$ ; Cronbach  $\alpha = 0.77$ ) (12), and the Family Environmental Scale (FES), a widely used, multi-dimensional self-report measure of the "family environment" (test-retest  $r = 0.68$ ) (13). Scores from the interpersonal relationships dimension (FES-A) were computed only for this study.

### **Statistical Analyses**

T-tests comparing subjects with ulcerative colitis to subjects with Crohn's disease were performed for all variables, to determine whether there were any significant differences based on diagnosis. Zero-order correlations of dependent with independent variables were conducted. On a more exploratory basis, two multiple regression analyses were conducted. Predictor variables in these

analyses were entered hierarchically in relation to their presumed weighting, based on prior empirical investigations.

### **Ethical Considerations**

This study was approved by the Human Research Advisory Committee of the Mount Sinai School of Medicine. All subjects participated voluntarily and gave informed consent to participate. Subjects gave explicit consent for their treating physician to provide information to the senior author about diagnosis, course of illness, and disease severity.

### **Results**

Results of *t*-tests comparing subjects with ulcerative colitis to subjects with Crohn's disease revealed no significant differences based on diagnosis. Thus, these groups were combined in all statistical analyses.

### **Demographic Characteristics**

The mean duration of patient illness was 8 years (range, 2B22 years). The mean age of IBD patients was 24 years (range, 19B32 years) and 88% were unmarried. Subjects' families were characterized by intact parental marriages (13/17) and sibships ranging in size from 0B3 (mean, 1.5 siblings).

### **Stress and Disease Activity**

Strong negative correlations were found between recent disease activity and family stress (Table 2): Physician scores of recent disease severity from the Inflammatory Bowel Disease Severity

**TABLE 2**  
*Correlations of Dependent with Independent Variables*

	Individual Coping in IBD <sup>+</sup>	Scores Derived from the Inflammatory Bowel Disease Severity Index	
		Recent Severity Index	Past Severity Index
F-COPES <sup>(a)</sup>	0.348	-0.280	-0.432
Total FILE <sup>(b)</sup> score	-0.068	-0.775**	-0.340
TABLE 2 (cont)			
Total Recent Life Change <sup>^</sup>	-0.155	-0.794**	-0.206
FES-A <sup>(c)</sup>	-0.145	0.101	0.327
IBDI Agreement Score	-0.158	0.531*	0.758**
Mean Family Blame	-0.253	-0.043	0.333
Total FSCI <sup>(d)</sup> score	0.098	-0.431	0.200
IBD Patient			
SRE <sup>(e)</sup> -Recent	-0.595*	0.109	0.448
SRE-Longitudinal	-0.632**	0.088	0.466
Family			
SRE-Recent	-0.724**	-0.097	0.351
SRE-Longitudinal	-0.630**	-0.073	0.360

\* p&lt;0.05

\*\* p&lt;0.01

<sup>^</sup> Measured by the Family Inventory of Life Events and Changes<sup>+</sup> Measured by the Experience Scale<sup>(a)</sup> Family Crisis-Oriented Personal Evaluation Scale<sup>(b)</sup> Family Inventory of Life Events and Changes<sup>(c)</sup> Family Environmental Scale - interpersonal relationships dimension<sup>(d)</sup> Family Structure and Communication Index<sup>(e)</sup> Schedule of Recent Experiences

Index were inversely related to family Total Recent Life Change scores on the FILE ( $r = -0.79$ ,  $p < 0.01$ ) and to family Total FILE scores ( $r = -0.78$ ,  $p < 0.01$ ). This indicates that high recent disease activity is associated with low family stress, while low recent disease activity is associated with high family stress. Consistent with these results, multiple regression analysis showed recent family-wide stress to be a significant negative predictor of recent disease severity ( $p < 0.01$ ) (Table 3). Notably, patient stress (as measured by the SRE) was not predictive of recent disease severity ( $p = 0.32$ ).

### Stress and Patient Coping

A high frequency of stressful life events in the life of the patient and in the lives of individual family members, recently and over time, was found to be associated with reduced ability by the patient to cope effectively with IBD (Table 2). Patient coping (measured by the Experience Scale) was significantly associated with the patient's individual SRE scores for the past 6 months ( $r = -0.60$ ,  $p < 0.05$ ) and the past 2B3 years ( $r = -0.63$ ,  $p < 0.01$ ). It was also strongly associated with SRE scores averaged across family members for the past 6 months ( $r = -0.72$ ,  $p < 0.01$ ) and for the period extending back 2B3 years ( $r = -0.63$ ,  $p < 0.01$ ). Consistent with these results, multiple regression analysis showed patient coping (as measured by the Experience Scale) to be significantly and positively predicted only by SRE measures of recent stress in the life of the IBD patient ( $p < 0.01$ ) and the family as a whole ( $p < 0.01$ ) (Table 3)

**TABLE 3**  
*Summary of Stepwise Regression Analyses for Recent Disease Severity and Psychological Adjustment to IBD*

Psychological Variables	Recent Severity		Psychological Adjustment <sup>+</sup>	
	Significance R <sup>2</sup>	of change in R (p value)	Significance R <sup>2</sup>	of change in R (p value)
Step 1 Total Recent Life Change <sup>^</sup>	0.31	0.006 **	0.02	0.531
Step 2 IBD Patient SRE <sup>(e)</sup> -Recent	0.34	0.321	0.33	0.006 **
Step 3 Recent Severity Index			0.43	0.096
Step 4 FES-A <sup>(c)</sup>	0.34	0.977	0.44	0.477
Step 5 Total FSCI <sup>(d)</sup> score	0.54	0.013 **	0.44	0.858
Step 6 F-COPES <sup>(a)</sup>	0.54	0.811	0.47	0.429
Step 7 Mean Family Blame	0.54	0.742	0.49	0.476
Step 8 Family SRE-Recent	0.54	0.757	0.70	0.007 **
Step 9 IBDI Agreement Score	0.59	0.262	0.70	0.760

\*\*  $p < 0.01$

<sup>^</sup> Measured by the Family Inventory of Life Events and Changes

<sup>+</sup> Measured by the Experience Scale Table 3. Summary of regression analyses predicting recent disease severity.

(a), (c), (d), (e) See Table 2.

### Family Communication and Disease Severity

It is noteworthy that recent disease severity was found to be significantly and positively correlated with family IBDI Agreement Scores ( $r = 0.53$ ,  $p < 0.05$ ). Blaming of the IBD patient by the family was found to be significantly correlated with generalized blaming by the family (i.e., the family blaming someone other than the IBD patient for the patient's illness) ( $r = 0.48$ ,  $p < 0.05$ ). There was also a significant correlation between self-blame by the IBD patient and the average level of family blame ( $r = 0.48$ ,  $p < 0.05$ ). Measures of blaming and coping were not significantly related. Multiple regression analysis showed family functioning (measured by the FSCI) to be a significant predictor of recent disease severity ( $p < 0.01$ ) (Table 3). When zero-order correlations between scores on the 3 dimensions of the FSCI and ratings of disease severity were computed, only the communication dimension reached significance ( $r = 0.604$ ,  $p < 0.05$ ), indicating that poor communication within the family is associated with high disease severity.

### Discussion

This study demonstrated a number of statistically significant associations between patient and family psychological factors, and the illness experience of the patient with IBD. The intent of the study was to investigate the effects of intimate family relationships C spousal, sibling or parental C on IBD coping and symptomatology. However, the study is limited by the small number of subjects involved and the variability in family composition as described in the **Subjects** section of **Materials and Methods**. We believe that the use of multiple methods of investigation (self-report, physician rating, direct observation and rating) adds confidence to these results, in that it reduces problems associated with shared method variance. Results described should be viewed as exploratory and generative of future research toward refining the effects of relationship context on disease process.

As regards the impact of individual stress, our results are congruent with the longitudinally based finding of North et al. (5), that patient reporting of stressful life events is not significantly correlated with symptomatic exacerbation of IBD. Based on our observations of family stress, it appears that recent disease severity bears an inverse relationship to family stress level. During a flare-up, the family and patient report less experienced family stress than during a period of disease remission. These findings are consistent with Wood's report (7) of decreased disease activity in association with increased marital dysfunction in families in which the affected member has Crohn's disease. It is possible that during periods of intense family stress, patients actually underreport symptomatology to their physicians. If the patient feels that his or her family members cannot deal with another stressor, the actual experience B and certainly the expression B of symptomatology becomes more threatening.

However, an alternative explanation of this unexpected but interesting finding is that the illness may have an organizing effect on an IBD family, providing a demanding but coherent framework in which other sources of family stress take a back seat to the stress of dealing with the patient's illness. Notably, poor family communication was associated with recent severity. Thus, the urgency of dealing with a symptom flare-up and the mobilization of the family around illness management may suppress the expression of individual concerns, so that there is a kind of muted and incomplete discussion of anything other than the medical crisis.

In a kind of symptomatic family rhythm, intensive illness management becomes unnecessary and abates as the affected individual improves, whereas unresolved individual and family issues surface and are destabilizing. In this pattern of symptom oscillation, reduced disease severity is associated with increased interpersonal stress.

Such explanations are consonant with the "psychosomatic family" model, which has proved useful in understanding asthma and anorexia (14). Psychosomatic families typically exhibit conflict avoidance, overly-attuned interpersonal sensitivity (enmeshment), overprotection, and rigidity. In families in which a child has ulcerative colitis, minimization of conflict and disagreement and qualities of isolation and restrictiveness have been described (15). Families in which a child has Crohn's disease have been shown to have an atypically low rate of divorce, hypothetically linked to the psychosomatic family characteristics of conflict avoidance and overprotection (16).

There was a significant positive correlation between both recent and past disease severity, and level of family agreement regarding the etiology and management of IBD. Ongoing high levels of disease may bring the family together in agreement as a way of maintaining order in the face of an unpredictable illness. Agreement may also reflect conflict avoidance, in which potentially useful variation in attitude and perspective among family members is sacrificed to solidarity.

As regards coping with IBD, our results point to a significant relationship between individually based ratings of stress (made both by the patient and by his or her family members) and the patient's self-perceived ability to cope with IBD (such that higher levels of stress are associated with reduced self-perceived competency in coping). Drossman et al. (17, 18) have commented on the importance of coping as a variable distinct from the physical symptoms in IBD. Why and how stress on both the family and individual levels interferes with patient coping with IBD is a matter for continuing study. It is possible that an increase in stress for family members leads to a significant decline in support to the patient, which in turn impairs coping.

Also contrary to our expectations, blame was not a significant predictor of patient coping. However, a pattern of handling blame emerged, indicating that there is a significant association between self-blame by IBD patients and an overall tendency to blame in the family. Blaming provides individuals with an anchored, although inaccurate explanation for the illness, as well as a sense of control over its essential unpredictability. It thus serves as a coping mechanism, albeit with a clearly negative interpersonal effect.

The clinical implications of this study are important, as the results offer insight into the psychosocial setting of the individual with IBD. They may be useful in designing intervention and treatment regimens, and in facilitating family participation and cooperation with treatment.

It is important for a physician treating an individual with IBD to be aware that stress may affect a patient's psychological ability to cope with his or her illness, rather than be directly responsible for an exacerbation of symptoms. Second, although the data are preliminary, the treating

gastroenterologist may find it useful to listen for the effect of family influences on patient functioning during clinical flare-ups as well as during times of remission. Additional data are needed to further evaluate the scope and extent of the effect of family influence. However, the physician may find it helpful to make a referral to a family therapist when coping seems impaired in the context of active family involvement.

### **Acknowledgments**

The authors would like to thank Drs. Steven Fochios, Charles D. Gerson, William Perlow, Daniel H. Present and David B. Sachar for referring their patients for this study. Thanks also are due to Dr. Sachar for his encouragement and support of this project, and Elizabeth A. Nelson, Dr. Charles D. Gerson, and especially Dr. Daniel H. Present for their helpful editorial work on the final draft of the manuscript.

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