

Embracing complexity: what determines quality of life in inflammatory bowel disease?

Susan Levenstein

- Psychological characteristics profoundly affect health-related quality of life in inflammatory bowel disease.
- Stress and distress can worsen tissue inflammation and clinical course in animal models and clinical populations with inflammatory bowel disease.
- Interventions aimed at improving mood and coping capacities could set into motion a virtuous cycle of psychological and physical well-being.
- Evaluating such interventions should be on the research agenda.
- The complexities of disease processes can best be understood within a biopsychosocial model.

A subset of patients with inflammatory bowel disease have markedly impaired quality of life. In this issue, Mussell *et al.* report that patients' self-rated health status and disease-related concerns were determined at least as strongly by their habitual use of depressive coping patterns as by their disease activity. Although past disease severity may have confounded these results, the finding that quality of life is better for patients armed with a positive approach to problem-handling suggests that

In the second half of the 20th century, the triumphant march of biomedical science brought a corresponding triumph of biological reductionism as an explanatory model. Now that the dust has settled, interactions between mind and body can take back their rightful place in medical thinking, following a biopsychosocial model that is all about embracing complexity to explore the reciprocal interactions among levels and realms of functioning ranging from the genetic through the physiological to the societal [1]. If we are serious in our goal of healing the sick we must seek to understand the influence of personality, behavior, life stress, interpersonal relations, socioeconomic status and cultural context on disease and, conversely, the effects of illness on all of these.

A central element in the biopsychosocial model is the concept of health-related quality of life, the impact of medical conditions on a person's existence. It is clear that subjective experience of disease varies enormously

psychologically oriented interventions could have far-reaching benefits for selected patients. Since evidence is accumulating that stress and distress can worsen tissue inflammation and clinical course in animal models and in clinical populations with inflammatory bowel disease, we may dare to hope that interventions aimed at improving patients' stress tolerance, depressive symptoms, and coping capacities might not only improve perceived quality of life but could potentially decrease bowel inflammation and reduce some patients' need for toxic medications or surgery. Designing, applying, and evaluating such interventions should be a major item on the agenda of psychosomatic medicine in gastroenterology, and biological reductionism should be replaced by the biopsychosocial model. *Eur J Gastroenterol Hepatol* 16:1–3 © 2004 Lippincott Williams & Wilkins

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Aventino Medical Group, Rome, Italy.

Correspondence to Dr Susan Levenstein, Aventino Medical Group, Via della Fonte di Fauno, 22, 00153 Rome, Italy.
Tel: +39 06 578 0738; fax: +39 06 578 0738;
e-mail: slevenstein@compuserve.com

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from individual to individual. All seasoned clinicians have had patients who were obsessively preoccupied with a medical condition that most might consider minor – one patient of mine was haunted for years by the loss of part of one small toe to gangrene – and others who maintain their productivity, their good cheer, and their sense of control over their destiny despite devastating medical conditions such as dependence on an iron lung [2].

Most patients with inflammatory bowel disease (IBD) manage to cope well with their disease, maintaining remarkable psychological wellbeing and intact life styles [3,4]. But a subset have a markedly impaired quality of life, sometimes out of apparent proportion to the degree of bowel inflammation. In an article in this issue, Mussell *et al.* [5] explore this phenomenon amongst a group of IBD patients with relatively quiescent disease and report that psychological characteristics profoundly affected health-related quality of life.

Patients' self-rated health status was as strongly determined by their habitual coping mechanisms as by their disease activity, and the presence of depressive coping patterns was much more important than disease characteristics in predicting patients' disease-related concerns as measured by the Rating Form of IBD Patient Concerns (RFIPC) [6].

The RFIPC, a central outcome variable in this study, holds a particular position among quality-of-life measures because it investigates the patient's cognitive preoccupations rather than assessing physical limitations, psychiatric symptoms, or daily activities. To some extent a patient's concerns will reflect the specific pattern and severity of disease – a patient with extensive ulcerative colitis is likely to be particularly concerned over developing cancer – but the level and patterns of concerns can also be affected by such factors as ethnicity or nationality [7,8]. It has also been reported that IBD patients who have sought psychological counseling express a high level of interpersonal concerns on the RFIPC [9], although the direction of causality is unclear: anxiety and depression may heighten these patients' perception of potential disease consequences, and concern over disease may, vice versa, be a reason for their psychological distress. Similar issues can be raised regarding findings of Mussell and colleagues; the complexity and reciprocity of biopsychosocial interactions often make it difficult to tease out cause from effect.

In addition, past disease severity may have confounded the results. Since the only measure of disease severity examined by Mussell and colleagues was a single rating of current activity, their study was limited in its ability to determine how much the observed associations among psychological and quality-of-life variables might be influenced by variations in the biological severity of disease. For example, a patient who is finally doing well on infliximab after years spent battling fistulas and abscesses might have high disease-related concerns, use depressive coping mechanisms, and report deterioration of work and social function as a direct consequence of a stormy recent course that is not reflected in their current Crohn's Disease Activity Index of only 120.

But these limitations of the study should not keep us from recognizing that IBD patients armed with psychological resilience and a positive approach to problem-handling are likely to have a better quality of life, as has been shown for coronary artery disease in a study which achieved better adjustment for disease severity [10]. Since the goal of medical treatment in a chronic but rarely fatal condition such as IBD is arguably less to prolong life than to optimize its quality, it is important for clinicians to appreciate the potential importance of mood disorders and counterproductive

coping styles in conditioning their patients' illness experience.

This study's finding of a strong association between depressive coping and quality of life further suggests that psychologically oriented interventions could have a far-reaching effect on some patients' quality of life by helping them cope better with stressors related or unrelated to their disease. Admittedly, trials of such interventions in IBD patients have thus far encountered only limited success [11,12], and attempts to address cognitive concerns by educational programs have not succeeded in allaying anxiety [13]. It makes sense nonetheless to hope that improvement in mood and in coping strategies could have a moderating influence on patients' level of concern by decreasing their engagement with their disease, and could bring overall improvement in their health-related quality of life. Mussell's is among several groups currently pursuing this possibility [14].

It was lamentable that IBD patients were long stigmatized as "psychosomatic", and the radical negation of psychological factors during the 1980s [15] was to some extent a salutary corrective. Now the pendulum is swinging to a point of balance as a result of accumulated evidence in animal models [16] and clinical populations [17–19] that stress and distress can worsen tissue inflammation and clinical course in inflammatory intestinal conditions, plausibly through effects on gut permeability [20], immune reactivity [21], luminal flora [22] and behavioral mediators such as sleeplessness [17], smoking, and adherence to medical regimens [23]. In light of this evidence that disease course can be affected by psychological states, we may dare to hope that interventions aimed at improving patients' stress tolerance, depressive symptoms, and coping capacities might not only improve quality of life but could potentially decrease bowel inflammation and reduce some patients' need for toxic medications or surgery.

In conclusion, psychologically vulnerable IBD patients may find their suffering magnified by the effects of distress and maladaptive coping on their disease experience, in turn eroding their quality of life and perhaps even intensifying the disease process itself in a vicious cycle of inflammation and misery. Appropriate interventions might not only improve the mood and coping capacities of selected patients but could conceivably set into motion a virtuous cycle of psychological and physical wellbeing. Designing, applying, and evaluating such interventions should be a major item on the agenda of psychosomatic medicine in gastroenterology.

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