# EDITORIAL

## Deconstructing Disability in Inflammatory Bowel Disease

In this issue of *Clinical Gastroenterology and Hepatology*, Israeli et al[1] describe their findings of a relatively low incidence of disability in a community-based population of inflammatory bowel disease (IBD) patients. Not surprisingly, disability was associated with a reduced quality of life. Long-term active disease and lifetime history of depression were important predictors of disability in their patients, whereas IBD-related surgeries or hospitalizations were not.

This study is an important contribution to a confusing and challenging arena in IBD. By using the Manitoba IBD database, the authors where able to evaluate a community-based cohort for several factors associated with disability. (The subjects in this study completed 7 different validated instruments measuring a host of different functional and health aspects of life that were not necessarily IBD-specific.) There was a relatively low rate of disability. Nineteen percent of Crohn's disease patients and 11% of ulcerative colitis patients were found to be disabled. The higher rate of disability in Crohn's disease compared with ulcerative colitis corresponds with previous studies.

The strengths of the study include the robust details of the Manitoba database compared with larger, less detailed administrative databases and the longitudinal nature of the study that permitted dissection of precursor factors that correlated with the development of disability.

The authors identify potential weaknesses in their own study. Disability was assessed cross-sectionally rather than longitudinally. Therefore, we cannot discern whether there was a transient disability associated with a disease flare or a long-term disability. General instruments to measure disability were used rather than one specific to IBD. Therefore, some dimensions of IBD-related disability may not have been adequately assessed.

To put this article in an appropriate context, it is important to consider the following questions: What exactly do we mean by disability? How is disability measured? How common is disability? What factors affect disability?

### What Is Disability?

There is no simple definition of disability. When clinicians think of disability, it is usually when a patient hands them a form that requires answers for a series of odd questions asking whether the patient can stand or sit for 30 minutes or lift 10 pounds. These are the typical assessments required for work disability. Work disability is essentially a binary calculus, either disabled or not.

As Israeli et al[1] note, employment outcomes are concrete and measurable but can fail to detect significant problems in multiple areas of an individual's life. In contrast, a more global assessment of disability takes into account the "human experience of impaired body functions and structures, activity limitations and participations restrictions in the interaction with the environmental factors."[2] Global evaluations of disability are scaled rather than dichotomous. Global disability generally overlaps with quality of life and includes parameters that measure health-related quality of life but also include more objective measures.

In progressive and irreversible diseases, once disability occurs, it is generally considered permanent. However, in episodic diseases with waxing and waning activity and the possibility of therapeutic amelioration, disability may not be permanent. Bureaucracies are already challenged to make a basic determination of disability. The consideration of disability that might be reversible is a significant confounding variable that has been difficult to address. Several studies refer to short-term disability, which in the United States may be classified instead as sick leave. The present study did not dissect the short-term vs long-term disability conundrum.

There are unique situations that do not fit into the conventional definitions of disability. For diseases such as IBD that may affect younger patients, how do you measure disability in a teenager or college student? Although there may be no work disability, the disease may significantly but subtly impact on educational decisions and employment choices, factors not generally measured in most instruments. Disease may alter decisions about classes, colleges, and careers. There are few studies that specifically address the issue of disability in students.

### How Is Disability Measured?

Ideally, the development of a comprehensive, widely accepted tool to evaluate disability and permit comparison across different health care environments over time would be a major advance in this field. Unfortunately, we are not quite there yet.

The most common work disability measurement that is used in the United States is Social Security Disability Insurance (SSDI). This measures the ability to do any kind of work. In contrast, most physicians are fortunate enough to have disability insurance tied to their specific profession and/or subspecialty. It is important to recognize that SSDI is underfunded, overwhelmed, and fraught with fraud.[3,4] It can be a challenge to sort through the labyrinthine series of requirements to obtain SSDI.

In the present study, Israeli et al[1] used 2 different instruments to measure global disability: (1) Work and Social Adjustment Scale, which was developed primarily for psychiatric disorders,[5] and (2) World Health Organization Disability Assessment Schedule 2.0, which is part of the World Health Organization's Disability Assessment Schedule of International Classification of Function, Disability and Health (ICF), a concerted effort to develop systematic measurements of global disability.[6] There was a good correlation between these 2 instruments. The ICF provides a comprehensive, structured framework to classify and describe functioning, disability, and health in patients with any disease or health limitations. ICF initiatives seek to adopt integrative social models of disability that focus on "the human experience of impaired body functions and structures, activity limitations and participation restriction in the interaction with environmental factors."[6]

Several other measures of disability have been used.[7–10] The Inflammatory Bowel Disease Questionnaire/Short Inflammatory Bowel Disease Questionnaire have become mainstays of quality of life assessments that are integral to many clinical trials. There is an overlap between the metrics of quality of life and global disability instruments, and the distinctions can be somewhat blurred. As an example, difficulties with walking would be a disability, but frustrations about mobility would be a quality of life metric. To complicate things further, there is now a push by the Food and Drug Administration to consider patient-reported outcomes as an important parameter in evaluating the success of therapeutic interventions.[11,12] This may result in a proliferation of different instruments measuring overlapping clinical characteristics.

Recently, a specific adaptation of ICF for IBD has been developed through a comprehensive process involving a systematic literature review, a qualitative study, expert survey and a cross-sectional study, and an ICF consensus conference of international experts. The ICF core set included items directed at body functions, body structures, activities and participation in daily life events, and environmental and societal factors.[2] This new instrument may eventually become the gold standard of measuring disability, but despite all the detailed preliminaries, it has not yet been put to clinical reality testing.

## How Common Is Disability?

Estimates of IBD disability vary considerably. There are several reasons for this. There are expected differences that are based on how disability is defined, eg, work disability vs global disability. The ability to obtain work disability depends very much on governmental policies in one country compared with another. An individual may have difficulty finding employment because of disease but has not been granted work disability. In addition, the economic environment at a particular time and place may have a significant impact on the job seeking behavior of individuals with chronic diseases. Sick leave and long-term disability have been lumped together frequently. The selection of the patient population studied is also critical. A lower rate of disability would be expected in a community-based study when compared with patients enrolled from a clinical trial.

Although the present study reports a lower rate of disability than many other studies, it is not dissimilar to an earlier study from the same group in Manitoba a decade earlier.[13] However, that earlier study that focused on work disability rather than global disability reported a disability rate of around 2%, pointing out how much impact the different definitions of disability can provide on different results in basically the same population.

By using a similar 10-year time frame of disease, 70% of Crohn's disease patients were fully able to work, 10% partially capable, and 20% unable in a study from Denmark.[14] In the Netherlands, 18.3% of Crohn's disease patients were fully disabled, and 8.8% were partially disabled; 9.5% of ulcerative colitis patients were fully disabled, and 5.4% were partially disabled.[10] The classifications of disability (complete, partial) may reflect the generosity of the social welfare support system, in which partially disabled represents what may be considered transient problems possibly caused by flare of disease.

By using data from the National Health Interview Survey, Longobardi et al[15] estimated that 31.5% of individuals with IBD were out of the labor force, which is not necessarily the same thing as disabled. Procaccini and Bickston[16] reported that 20.4% of IBD patients considered themselves disabled, but that approximately one-third had been denied disability.

The TREAT registry of patients on long-term anti–tumor necrosis factor treatment reported an overall disability rate of 25%. However, there was a large variation in disability rates depending on the specific country, ranging from a low of 20% in the United States to a high of 34% in European nations.[8]

## Factors That Affect Disability

In this study, 2 variables emerged as significantly associated with disability in Crohn's disease: lifetime major depression and long-term disease activity. In contrast, there were no independent variables that predicted disability in ulcerative colitis. Disability was also strongly associated with higher perceived stress levels and emotional distress in ulcerative colitis and Crohn's disease.

It is implicitly obvious that more severe disease leads to more disability. Crohn's disease carries a greater risk of disability than ulcerative colitis. Prior studies have