

ADVANCES IN IBD

Current Developments in the Treatment of Inflammatory Bowel Disease

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Measuring Disability in IBD: The IBD Disability Index



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G&H Given the impact on productivity and healthcare economics, why has disability in inflammatory bowel disease received so little attention?

J-FC There are at least 2 reasons why disability in relation to inflammatory bowel disease (IBD) has not received adequate attention. The first reason is that IBD, in general, has received less attention than other chronic diseases. Historically, IBD has not been considered to be as disabling as other chronic diseases, such as multiple sclerosis. Thus, the impact of IBD on disability has been quite underestimated. The second reason is that confusion exists in the IBD literature about what disability is exactly. When one looks through the data, one finds that many definitions that actually do not fit have been applied to the term “disability” along with the true definition, which has been proposed by the World Health Organization (WHO). For example, in a paper about IBD and disabling disease by Høivik and colleagues that was just published in the March 2013 issue of *Gut*, the definition of disability was “pension disability,” meaning that disabled patients were those who were receiving a pension because they were not able to work. This definition covers only one aspect of disability.

An important and very often cited paper about predictors of Crohn’s disease by Beaugerie and colleagues, published in *Gastroenterology* in 2006, defined disabling disease as the need for immunosuppressants, perianal surgery, and so on. None of this fits the true definition of disabling disease. The lack of a standard definition in the literature is a major problem in establishing what disability is in relation to IBD. The only definition of disability that should be used is the definition proposed by the WHO, which applies to all types of disease states and represents a clear standard.

G&H Specifically, then, what defines disability in IBD?

J-FC There is no specific definition of disability for IBD because the definition of disability should be the same for IBD, multiple sclerosis, diabetes, and every disease state. This point was discussed in a paper on the development of the first disability index for IBD, which I coauthored with Peyrin-Biroulet and colleagues. This paper was published in the February 2012 issue of *Gut*.

Disability, according to the WHO, refers to the objective problems that a patient may have in different areas of health. This measure is distinct from quality of life, which is subjective. For example, if we were measuring disability in a patient who has a problem with his knee, the level of disability would depend on whether the patient was a quarterback for the San Francisco 49ers who was preparing for the next Super Bowl or an office worker. The way the patient feels about what is happening is different from the objective measurement of the disability. Yet, although disability should be a term that applies to many different disease states, some challenges related to disability are specifically linked to IBD, such as access to toilets and dietary restrictions. Ultimately, though, we should be able to compare the disability caused by different chronic diseases because the same definition—the definition proposed by the WHO—would be used.

G&H Could you describe how the IBD disability index was developed?

J-FC Development was a long, stepwise process that is well described in the paper by Peyrin-Biroulet and colleagues. A systematic review of the literature was performed. The systematic review was followed by qualitative studies that

were based on patient interviews. Then, a large expert survey involving 125 experts from 37 countries was conducted. This aspect of development of the disability index was very important because disability in South America may differ from disability in the United States or Europe. All of the continents were represented in the survey. Also, all types of healthcare professionals who work with patients with IBD—doctors, nurses, psychologists, and dietitians—were represented. A cross-sectional study involving 3 different centers—1 in the United States and 2 in Europe—was conducted.

Different measures from the Red Book—that is, the WHO International Classification of Functioning, Disability and Health—were selected based on the systematic literature review, the qualitative studies, the expert survey, and the cross-sectional study. To formulate the final result, which was an international classification of function (ICF) score set for IBD, a consensus conference was organized. It took place in Switzerland in 2010 and included 20 experts from 17 countries. Nineteen ICF score sets were selected to develop the first disability index. In the paper by Peyrin-Biroulet and colleagues, the comprehensive ICF score set appears as Table 1 and a brief ICF score set appears as Table 2. The IBD index also appears in this paper. The article is available as an open-access paper online at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3245899/pdf/gutjnl-2011-300049.pdf>.

The disability index includes questions about sleep, energy, body image, pain, and so on. Very importantly, the index includes questions related to the environment of the patient. For instance, a patient living in the United States has access to most kinds of drugs developed for the treatment of IBD. This will have a strong impact on the patient's level of disability. If a patient lives in India, he or she will likely have less access to medications for IBD than a patient in a more developed country because of the cost of treatment and other issues.

The impact of environment, such as access to healthcare and its quality, is very important when assessing disability. Family dynamics, which constitute an environmental factor, also affect the level of disability. For example, patients who have family members who are caring and competent caregivers will have less disability than patients who do not have the benefit of such a family dynamic.

G&H Has the IBD disability index been validated?

J-FC The IBD disability index is not yet fully validated, but it is expected to be validated by the end of 2013. The last phase of the validation process has just begun. Patients (nonreferred) are being recruited from our population-based registry from northern France to validate the questionnaire. This study is being led by Dr. Corinne Gower-Rousseau of the Centre Hospitalier at the Uni-

versity of Lille in France. Once the IBD disability index questionnaire is validated, we will be able to examine the real impact of IBD in the daily life of patients.

In addition, results of the elaboration of the Lémann score, which measures structural damage in IBD, are about to be released. A column on this issue, titled “Measuring Structural Damage in Crohn’s Disease,” was recently published in the February 2013 issue of *Gastroenterology & Hepatology*.

G&H What unique data will be gleaned from the IBD disability index? In what setting—investigative or clinical—would use of the index be most relevant?

J-FC The data will be very important for general investigative knowledge about IBD and will perhaps be useful in clinical trials to show that a new drug or new therapeutic strategy is associated with improvement in disability scores. The disability index would not be used in daily clinical practice, but if clinicians knew about the index, they might use some of the questions that are included in the index in their patient workups. That is, if the physician knows that sleep quality or body image factors into disability, he or she may begin to routinely ask patients about these issues during workups.

Physicians might already be asking many of the right questions about disability by asking standard questions about the number and quality of stool, pain, and asthenia that appear on the Crohn’s disease activity index (CDAI). Even though the CDAI is not used in daily clinical practice, physicians are asking questions related to items that the index measures. With the introduction of the IBD disability index, informed clinicians will not only ask questions about pain, energy level, and stools but also about the disability posed by IBD.

Changing how we approach disability in patients with IBD has the potential to raise the bar on patient care and satisfaction. Colleagues have told me that they have encountered patients in great distress because they were disabled, even though the patients were told by their physicians that their IBD was in full remission based on CDAI scores and endoscopy findings. A new paradigm that better addresses disability is, therefore, needed. In this paradigm, the focus will be more on treating the patient than solely managing symptoms of the disease.

G&H What advantages in terms of prognosis and clinical care are inherent in being able to measure disability in IBD?

J-FC If disability can be measured, predictors of disability can be identified, and healthcare providers can intervene. In the past, we only focused on treating symptoms and

were content if the patient could achieve clinical remission of IBD. This focus has completely changed in the past few years. We now understand that Crohn's disease and ulcerative colitis are chronic progressive diseases that lead to bowel damage and long-term disability. Hopefully, future studies will measure damage and disability in parallel to find a correlation between the two, and new strategies that block progression of damage and disability will be found.

At present, we do not have predictors of disability. The definitions of predictors that we do have, such as young age and corticosteroid use, may not be that valuable because they are not based on a standardized definition of disability. Until we have a defined disability index, we cannot perform studies that examine disability, including its predictors, in patients with IBD. Unfortunately, once the disability index is validated, findings about predictors and issues related to therapeu-

tic optimization will not be available for several years because clinical trials take time. For example, measuring the impact of a new drug on disability and damage requires long-term studies of perhaps 3–5 years. Still, this type of research is, of course, doable and promising.

Suggested Reading

Beaugerie L, Seksik P, Nion-Larmurier I, Gendre JB, Cosnes J. Predictors of Crohn's disease. *Gastroenterology*. 2006;130:650-656.

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Høivik ML, Moum B, Solberg IC, et al. Work disability in inflammatory bowel disease patients 10 years after disease onset: results from the IBSEN study. *Gut*. 2013;62:368-375.

Peyrin-Biroulet L, Cieza A, Sandborn WJ, et al. Development of the first disability index for inflammatory bowel disease based on the international classification of functioning, disability and health. *Gut*. 2012;61:241-247.