



## EDITORIAL

## Evaluating Disability in Inflammatory Bowel Diseases: A Step Forward for Improved Care



### Avaliação da Incapacidade na Doença Inflamatória Intestinal: Um Passo em Frente Para um Melhor Tratamento

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Inflammatory bowel diseases (IBD), which include Crohn's disease (CD) and ulcerative colitis (UC), are chronic life-long diseases that evolve in a relapsing and remitting mode, causing progressive bowel damage over time. Most epidemiological studies show that there is a significant increase in IBD's incidence in most regions of the world.<sup>1</sup> Being a chronic life-long disease with a young age at onset, IBD's prevalence will likely continue to increase in the following decades. The impact of IBD in patients and society is of extreme importance, considering that it is mainly diagnosed in young age, affecting people in their most productive years, interfering in their social, familial and personal interactions, capacity to acquire education, employment prospects and work ability.<sup>2</sup>

The clinical and therapeutic approach to IBD has been classically focused in clinical and endoscopic scores of gut inflammation, and the impact of disease in the interaction between the individual and his/her environment (disability) has been neglected as compared to other chronic diseases. Furthermore, the term disability in IBD has been used in a variable way, either to describe disease features associated with a worse prognosis (as in the seminal paper by Beaugerie et al.<sup>3</sup>), or to describe specific aspect of disability (such as work disability), creating therefore some confusion around what disability really refers to. Disability is an objective way of measuring the impairments, activity limitations, and participation restrictions that are experienced in

different areas or health domains.<sup>4</sup> It is different than quality of life, which refers to the subjective way the individual feels about these limitations and restrictions.<sup>5</sup> The most comprehensive model for describing human functioning in relation to health and the environment is the International Classification of Functioning, Disability and Health (ICF), adopted by the WHO in 2001.<sup>4</sup> This model describes human functioning in terms of Body structure, Body function, Activities, and Participation. It is applicable to all people irrespective of the health condition or cultural context, allowing comparison of health conditions of different etiology.<sup>5</sup>

The concept of measuring disability in IBD has been introduced by Peyrin-Biroulet and colleagues,<sup>6</sup> who lead a formal consensus process that culminated in the development of the first tool to evaluate disability in IBD: the IBD-disability index (IBD-DI).<sup>7</sup> This index is expected to capture all specific aspects of disability that describe what it means to live with IBD. For example, it explores the limitations felt by patients in the areas of sleeping, mood, abdominal pain, defecation regulation, participation in social and work events, etc. The IBD-DI is awaiting formal validation in prospective cohorts and will likely become a widely used tool in health reporting, in assessing the effectiveness of drugs on the natural course of the disease, and in appraising the impact of structural damage on disability.<sup>8</sup>

In this issue of GE, Magalhães J et al. present the translation to Portuguese and the validation in a Portuguese population of the IBD-disability score (IBD-DS). The IBD-DS is another tool that measures disability in IBD. It was originally developed and validated by Allen et al. using items identified from articles on disability in IBD, an expert survey,

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and the ICF checklist for functioning and disability.<sup>9</sup> In the original work, this tool was found to be sensitive to discriminate between IBD and controls, and between active and inactive disease in CD, but not in UC. A strong inverse relation was found between quality of life (as measured by the SIBDQ and SF36) and the IBD-DS.<sup>9</sup>

By translating and validating the IBD-DS in Portuguese patients, Magalhães J et al. allow this important tool to be available for every doctor taking care of IBD patients, and most importantly, they introduce the theme of disability in our practice. As we are moving forward in our therapeutic strategies, targeting at sustained remission and altering the natural course of disease, the next reasonable step is to aim that our patients live the most normal life as possible, with the least disability, so that they are fully participative in society and are allowed to have the same opportunities as others. Although it is not anticipated that tools to measure disability will be used in daily clinical practice, informed clinicians might use some of the most important aspects of disability in their patient workups. Indeed many clinicians already realize the impact and disability caused by IBD in their patients, but objective ways of measuring it just now became available. Portuguese patients belong to a different social and cultural background and have a different health system organization as compared to other populations. Measuring and understanding disability in the Portuguese population will allow us to better assess the needs of our patients, and the environmental and social barriers faced by them, so that effective interventions are developed.

In the work presented by Magalhães J et al.,<sup>10</sup> the Portuguese version of the IBD-DS was completed by 55 CD, and 30 UC patients. Similar to the original work, the Portuguese authors also found a significant negative correlation between the IBD-DS and the SIBDQ. Besides that, they found the IBD-DS useful to discriminate disease activity both in CD and UC; no difference in the mean IBD-DS between CD and UC was observed. The authors went on to try to find predictors of disability in their population. Interestingly, CD females, and CD patients with extra-intestinal manifestations, and CD and UC patients on a sick leave or disability pension presented higher disability scores. Others have also correlated these findings with disability.<sup>11</sup> Previous history of hospitalization, surgery, perianal disease, disease behaviour and disease extent, which are generally considered markers of bad prognosis, had no significant impact in the IBD-DS. However, the study was overall slightly underpowered, and the numbers of patients presenting these clinical characteristics may have been too small to draw any conclusions. Further characterization of the IBD-DS or any other validated score to measure disability in a larger Portuguese population are therefore eagerly desired.

So far few studies assessed disability in IBD, mostly in a cross-sectional way, and using slightly different tools.<sup>11,12</sup> The next years will probably bring us more information

about disability measured in longitudinal cohorts and in specific sub-populations of IBD. This is even more likely with the recent demand from the FDA to incorporate patient-reported outcomes as an important factor in evaluating the success of therapeutic interventions. Predictors of disability will emerge, the result of structural damage on disability, and the potential of drugs or therapeutic strategies to prevent it will hopefully be identified.

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