Inflammatory bowel disease (IBD) is associated with significant disability and morbidity, and may require hospitalization and surgery. In recently reported data from the Dutch Nationwide cohort (1), disability was more prevalent in Crohn disease than ulcerative colitis, and was mainly driven by inflammatory activity of the disease and by disease perception of the patient. A complicated disease course was not apparently related to disability. Disability has significant societal costs and more effort is needed to prevent disability from IBD to reduce the impact of it on health care costs and productivity. It is important, therefore, to introduce the most effective therapy to control inflammatory activity in a timely manner so that patients do not suffer from prolonged active inflammation. Illness identity and emotional response to IBD are also associated with disability in IBD.

Similar to other chronic disease management, specific treatment of inflammation in IBD needs to be combined with emotional support to improve coping behaviour in a multidisciplinary setting. Currently, few IBD units in Canada have a robust multidisciplinary support structure in their clinic. In a recent study from Italy (2), continuity of care and information about their disease were identified by patients as areas of concern. It will be important to explore whether improving these areas of quality of care can reduce the impact of illness identity and emotional response on disability due to IBD.

The high levels of disability in patients with IBD is of concern. Physicians tend to underestimate the impact of IBD on their patients' lives (3). In the current issue of the Journal, a survey of Canadian patients by Becker et al (4) (pages 77-84) and their family members reinforces the impact of the disease on a number of important areas of their life such as leisure activities, interpersonal relationships and emotional wellness. It is important to understand the relationship between the impact of disease on the patient's lives and their disability. Not only does the physician need to have a patient-centred perspective to appreciate the impact of disabilities on the patient's quality of life, but insurance companies need to consider the IBD disability index – or a modification of it – as a way of assessing the patient's need for support such as disability insurance and disability tax credits. For such purposes, in which third-party adjudication is necessary, patient-reported measures may not be adequate. The conventional measures of disability currently applied are often inadequate.

The disability from chronic diseases, such as diabetes mellitus, obesity, cardiovascular diseases, chronic obstructive pulmonary disease and cancer, are better appreciated by society and public policy makers and, hence, it is important to advocate on behalf of the patient with IBD so that public policy makers realize both the disability these patients experience, and the widespread impact of the disease on the lives of the patients and their families. Physicians themselves need to be trained to appreciate the cultural, social and psychological dimensions of the illness due to IBD to fully understand the impact of the disease on disability. The unpredictability of a relapse often prevents patients from planning their lives, and depression and anxiety resulting from the disease are common. The young age at onset of IBD affects lives at a time when it should be most productive. The societal costs of IBD, therefore, tend to be enormous.

Crohn's and Colitis Canada has recognized the need for urgent, further advocacy for and research investigating quality of life, symptom management, bathroom access and public policy. It is encouraging to note that the Crohn's and Colitis Canada website is a preferred source of information for many patients. This gives an opportunity for the website to emphasize the emotional dimensions of disease, strategies for adherence to therapy, support for family members and prevention of disability. Many dimensions of disability and impact of disease on IBD patients are hidden (Box 1), and require a multidisciplinary team to have coherent strategies for management – these are better developed in pediatric practice compared with adult practice. The IBD disability index provides us with the means to follow patients longitudinally and assess the impact of care pathways and therapeutic strategies on disease course, disabilities and impact of disease. We need to move on from cross-sectional studies to longitudinal, population-based studies to obtain robust data that can influence public policy.

REFERENCES

Department of Medicine, Division of Gastroenterology, University of Calgary, Calgary, Alberta, Canada
Correspondence: Dr Subrata Ghosh, Division of Gastroenterology, Department of Medicine, University of Calgary, 3280 Hospital Drive Northwest, Calgary, Alberta T2N 4N1. Telephone 403-944-8222, fax 403-944-1095, e-mail subrata.ghosh@albertahealthservices.ca
Received and accepted for publication February 2, 2014.