

## Low Prevalence of Disability Among Patients With Inflammatory Bowel Diseases a Decade After Diagnosis

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**BACKGROUND & AIMS:** Disability is defined by chronic limitations that preclude the ability to engage in usual daily activities. Studies of disability in patients with inflammatory bowel disease (IBD) have focused on work and employment, with few descriptions of more general disability among multiple domains. We examined disability and the factors associated with it a decade after diagnosis in a population-based cohort of IBD patients.

**METHODS:** We interviewed 125 patients with Crohn's disease (CD) and 119 with ulcerative colitis (UC) from the population-based Manitoba IBD Cohort study a median of 12.3 years after diagnosis. Disability was assessed by using 2 validated measures. Disease activity was assessed semi-annually, and long-term activity was defined as symptoms of active IBD at more than 65% of semiannual assessments.

**RESULTS:** Mean levels of disability were significantly higher among patients with CD than those with UC ( $P < .01$ ). On the basis of the Work and Social Adjustment Scale, rates of disability were 19% among patients with CD vs 11% among those with UC ( $P < .05$ ). Results from the World Health Organization Disability Assessment Schedule v.2 and the Work and Social Adjustment Scale correlated ( $r = 0.58$  for patients with CD and  $0.60$  for those with UC;  $P < .01$ ). Disability was associated with reduced quality of life. Long-term active disease and a lifetime history of major depression were associated with disability, whereas history of IBD-related surgeries or hospitalizations was not.

**CONCLUSIONS:** A minority of patients with IBD have significant disability after a decade of disease, although a higher proportion of patients with CD are disabled than those with UC. Long-term active disease and psychological factors are important predictors of disability. Depression should be treated as aggressively as the IBD itself.

*Keywords:* IBD; Disability; WHODAS2; QoL.

Disability has been defined as chronic limitation(s) that interfere with the ability to engage in usual daily activities. In general terms, disability may include a physical impairment (a problem in body function or structure), an activity limitation (a difficulty encountered by an individual in executing a task or action), and a participation restriction (a problem experienced by an individual in involvement in life situations). Thus, disability is a complex phenomenon, reflecting an interaction between features of a person's health and features of the society in which he or she lives.<sup>1</sup> Ideally, measurement of disability includes evaluation across several domains in which activities of daily life occur (eg, work, home, social leisure) to reflect this complexity.

Inflammatory bowel diseases (IBDs) including Crohn's disease (CD) and ulcerative colitis (UC) are chronic,

lifelong immune-mediated diseases characterized by acute flares and in some cases by persistent chronic symptoms. IBD has been found to adversely affect quality of life (QoL), with negative impact on psychological, familial, social, and occupational dimensions of life.<sup>2,3</sup>

*Abbreviations used in this paper:* BSI, Brief Symptom Inventory; CD, Crohn's disease; CI, confidence interval; CIDI, Comprehensive International Diagnostic Interview; CPSS, Cohen Perceived Stress Scale; IBD, inflammatory bowel disease; IBDQ, Inflammatory Bowel Disease Questionnaire; MIBDI, Manitoba Inflammatory Bowel Disease Index; QoL, quality of life; UC, ulcerative colitis; WHODAS, World Health Organization Disability Assessment Schedule v.2.0; WSAS, Work and Social Adjustment Scale.

The level of disability an IBD patient experiences can affect the overall QoL, although these are 2 distinct concepts. It has been suggested that the difference between disability and QoL is that the former reflects the limitations and restrictions that a patient has in different life domains, whereas the latter measures how a patient feels about these limitations.<sup>4</sup> Nonetheless, there is some overlap between disability scales and QoL indices, because both are reported subjectively by the patient, and certain domains (eg, emotional) are measured similarly in both.

To date, most disability studies in IBD have focused narrowly on work and employment. Information about the prevalence and impact of more general disability across multiple domains is limited. Measurement of the full scope of disability in IBD is important to better assess disease burden and the impact of interventions.

The aims of this study were to examine disability at least a decade after diagnosis in a population-based cohort of IBD patients by using well-validated scales of disability, to examine the interrelations among the disability scales and with a disease-specific QoL scale, and to assess disease and psychological parameters that may predict disability.

## Materials and Methods

### Participants

The Manitoba IBD Cohort Study was established in 2002. It is an ongoing study of adults initially recruited within 7 years (mean, 4 years) of their diagnosis of IBD and tracked prospectively through semiannual surveys and annual in-person interviews. The participants were recruited from a validated population-based research registry.<sup>5</sup> The Cohort is described in previous reports by our group.<sup>3</sup> The Cohort has been shown to have excellent representativeness of the provincial IBD population, with comparable age distribution, sex distribution, and rural/urban residence.<sup>6</sup> The Cohort Study was approved by the University of Manitoba Health Research Ethics Board, and participants provided written informed consent.

The primary outcome of interest, disability, was measured 96 months (ie, 8 years) after study entry, at which time there were 244 individuals (125 CD, 119 UC) with complete diagnostic and disease activity information over all 17 semiannual assessments since enrollment. Information on psychological functioning and QoL was collected concurrently at 96 months. We compared the study group with those individuals from the cohort who did not have complete information (for 56 CD patients and 57 UC patients). There was no significant difference between groups regarding any of the demographic parameters listed in [Table 1](#).

**Table 1.** Demographic and Clinical Information for CD and UC Participants

	CD (n = 125)	UC (n = 119)
Background characteristics		
Age (y)		
Mean age (SD)	46.5 (14.2)	51.2 (14.3)
Younger than 50 (%)	63	46
50 and older (%)	37	54
Female (%)	62	61
White (%)	90	93
Marital status (%)		
Married or common law	68	71
Single, never married	20	13
Separated, divorced, widowed	12	16
Education (%)		
No postsecondary	41	35
Trade school, diploma	32	31
University certificate/degree	27	34
Work status previous 12 months (%)		
Working full-time or part-time	84	83
Not working	16	17
Disease information		
Mean years since diagnosis (SD)	13.2 (4.1)	12.4 (2.1)
Mean number of active disease periods (SD)	7.9 (4.8)	6.7 (4.3)
Long-term active disease (≥11/17 active periods) (%)	34	22
Ever hospitalized for IBD (%)	69	36
Hospitalized in past year for IBD (%)	4	2
IBD-related surgery history (% ≥2 [CD] or ≥1 [UC])	38	13
UC only: site of disease (%)		
Limited to rectum	—	16
Limited to left colon	—	38
Extensive disease (pancolitis)	—	32
Pelvic pouch	—	7
CD only: site of disease (%)		
Ileal	43	—
Colonic	19	—
Ileocolonic	37	—
Upper gastrointestinal	1	—
CD only: disease phenotype (%)		
Inflammatory	42	—
Complicated disease (stricturing or penetrating/fistulizing)	58	—
Perianal disease	17	—

SD, standard deviation.

### Measures

**Disability.** Disability was assessed by using 2 validated scales, the World Health Organization Disability Assessment Schedule v.2.0 (WHODAS),<sup>7</sup> which is a generic scale for disability, and the Work and Social Adjustment Scale (WSAS). The WSAS was developed for psychiatric research, but it has been widely used with both mental and physical disorders.<sup>8</sup> The WHODAS does

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