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.

See editorial on page 1338; see similar articles on pages 1246, 1315, 1324, and 1349 in this issue of *Clinical Gastroenterology and Hepatology*.

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.[1] 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

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.**

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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.[2,3]

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.[4] 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.[5] The Cohort is described in previous reports by our group.[3] The Cohort has been shown to have excellent representativeness of the provincial IBD population, with comparable age distribution, sex distribution, and rural/urban residence.[6] 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),[7] 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.[8] The WHODAS does

not have a set cut point to define disability. Both scales are described in detail in the Supplementary Material.

Disease-related Variables

Disease activity. This was assessed by using the Manitoba IBD Index (MIBDI),[9] a patient-report scale evaluating symptom persistence in the previous 6 months. The scale has been validated, demonstrating good concordance with a variety of clinical disease indices.[9] The MIBDI was obtained semiannually and yielded 17 separate points of assessment. Individuals were classified as long-term active if they reported active disease on the basis of the MIBDI on at least 1 of the 17 ($\geq$65%) previous assessments.

Crohn's disease phenotype. CD phenotype was described according to the Montreal classification on the basis of clinical record review at 60 months from study entry.

Previous surgeries. Respondents reported at enrollment and annually whether they had undergone any intra-abdominal surgeries related to their IBD. Respondents were categorized as having significant surgery history if they had 2 or more surgeries for CD (versus 0 or 1), or if they had 1 or more surgeries for UC (versus none).

Inflammatory bowel disease–related hospitalizations. Respondents were asked at 96 months if they had ever been hospitalized for their IBD symptoms and were classified accordingly (ie, yes/no).

Psychological Variables

Lifetime history of major depression (yes or no) was assessed by using the Comprehensive International Diagnostic Interview (CIDI), developed by the World Health Organization.[10] It was measured at 24 months after entry into the Manitoba IBD Cohort Study, which was 6 years before disability assessment. The CIDI is a standardized structured psychiatric interview that reliably identifies the presence of major psychiatric disorders.

The Cohen Perceived Stress Scale (CPSS) is a 14-item questionnaire that assesses the individual's appraisal of their stress level, with higher scores indicating greater stress (score range, 0–56). It is a widely used instrument that has been validated as a tool to examine the role of stress in disease.[11]

The Brief Symptom Inventory (BSI)[12] is a well-established measure of current emotional distress related to multiple psychological symptoms across 9 dimensions including depression, interpersonal sensitivity, and anxiety. Higher scores indicate greater distress, with many items expected to be 0 because of the specific nature of questions (score range, 0–212).

Quality of Life

The Inflammatory Bowel Disease Questionnaire (IBDQ) is a 32-item QoL measure that has been well-validated and extensively used in IBD research.[13]

Statistical Analyses

The data were described by using means and frequencies. Pearson correlation coefficients (r) were calculated to assess concordance of the 2 disability measures and their relationships with concurrent disease-specific QoL and psychological functioning measures. Multiple logistic regression analysis was used to test the associations of clinical and demographic variables with disability by using the WSAS as a dichotomous variable (ie, disabled/nondisabled). To assess goodness of fit of the logistic regression model, the C statistic was computed; this is equivalent to the area under the receiver operator characteristic curve for dichotomous outcomes. Values of this statistic between 0.7 and 0.8 suggest acceptable levels of discrimination, whereas values above 0.8 suggest excellent model discrimination.

For the WHODAS, a continuous measure of disability, multiple linear regression analyses were used to test associations with the same independent variables. The model adjusted R^2 provided a measure of explained variation. To assess linearity, a plot of the model residuals was visually examined for any deviations from a horizontal line. All analyses were conducted by using SPSS (SPSS Inc, Chicago, IL) software, version 20.

Results

Demographic and clinical information for the sample is shown in Table 1. About 60% of the sample was female; the majority were married and working full-time or part-time. The mean time from initial diagnosis was 13.2 $\pm$ 4.1 years for CD and 12.4 $\pm$ 2.1 for UC. The majority of CD patients were younger than 50 years of age. Just more than two-thirds (69%) with CD had been hospitalized for IBD at some point previously, whereas approximately only one-third (36%) with UC had a prior IBD-related hospitalization.

Levels of Disability, Psychological Function, and Quality of Life

Table 2 presents the means and standard deviations for the general (WHODAS) and specific (WSAS) disability measures, as well as the concurrent psychological functioning and QoL levels. The disability scores were significantly higher for the CD participants compared with the UC participants on both the WHODAS and WSAS. CD patients also reported significantly greater emotional distress, higher stress levels, and poorer QoL.

The proportion of respondents categorized with significant disability by using the WSAS cutoff score of 17 was 19% for CD versus 11% for UC ($P < .05$). Supplementary Figure 1 shows the distribution of the WHODAS scale. Participants with CD and UC clustered toward the lower end of the disability scale. Overall, 27% of the sample had a history of major depression.

Table 2. Mean Scores of the Disability, Psychological Functioning, and QoL Scales, Comparing CD and UC Participants

	CD, mean (SD)	UC, mean (SD)	*P* value
Disability: WHODAS	8.0 (13.1)	3.2 (6.3)	.001
Disability: WSAS	7.4 (9.2)	4.4 (6.5)	.004
Perceived stress (CPSS)	21.9 (10.4)	18.9 (9.1)	.021
Distress (BSI)	26.6 (26.0)	18.7 (16.7)	.006
QoL (IBDQ)	174.0 (28.9)	184.3 (25.1)	.004

SD, standard deviation.

However, among the subset of those with significant disability on the WSAS measure, 57% with CD and 37% with UC had a history of major depression ($P = .34$).

Table 3 presents the mean WSAS scores for each domain of functioning, showing the percentage of those categorized as having at least moderate disability (score $\geq$4) in each of the specific domains. About 11%–19% of those with CD and 6%–14% of those with UC described themselves as having at least moderate impairment in each of these domains. Disability scores were significantly higher for CD as compared with UC participants for home management and maintaining close relationships.

Relationships of Disability With Psychological Functioning and Quality of Life

The WSAS and WHODAS disability scales were strongly correlated in both the CD ($r = 0.58$) and UC groups ($r = 0.60$). Supplementary Table 1 shows the associations between the disability scales and the psychological functioning and QoL measures. For those with CD, the IBD-specific disability (WSAS scale) was strongly correlated with all the psychological measures (all correlations, $r \geq 0.59$). The WHODAS showed a similar pattern, although the correlations were uniformly somewhat lower (absolute $r = 0.41$–0.62). In respondents with UC, the QoL total score and subscales were consistently strongly correlated with both disability measures. Distress was moderately correlated with disability as measured by the WSAS ($r = 0.45$) and only weakly correlated with disability as measured by the WHODAS ($r = 0.23$), with similar results for perceived stress (WSAS, $r = 0.37$; WHODAS, $r = 0.20$). These lower correlations may be related to the distribution of the WHODAS scores toward the lower end of the distribution, as shown in Supplementary Figure 1. Among the IBDQ subscales, social functioning showed the strongest relationship with disability for both disability measures and across both CD and UC participants (absolute $r = 0.52$–0.79).

Variables associated with the WHODAS are presented in Table 4. For CD patients, lifetime history of major depression ($b = 0.37$, $P < .001$), as well as disease duration ($b = 0.19$, $P < .05$), were significantly associated with disability. For UC patients, the only independent predictor to emerge with a statistically significant relationship to disability was long-term disease activity ($b = 0.37$, $P < .001$). For both models an examination of the residual scatter plot indicated a departure from linearity and skewness in the residuals.

The logistic regression analysis assessing IBD-specific disability on the basis of the WSAS scale is detailed in Table 5. The models showed excellent discrimination between the high and low disability groups for both disease types (C statistic = 0.82 for CD model, C statistic = 0.84 for UC model). For CD, 2 variables emerged as statistically significant, lifetime major depression (odds ratio, 3.86; 95% confidence interval [CI], 1.22–12.29) and long-term disease activity (odds ratio, 7.69; 95% CI, 1.99–29.61), suggesting that those with a history of depression or more persistent active symptoms were more likely to be disabled 13 years after diagnosis. For UC, there were no independent variables that were associated with disability.

Discussion

In this analysis of a well-characterized and representative IBD cohort, we determined that persons with

Table 3. Mean Disability Scores and Proportion Reporting Definite Disability for Each Domain on WSAS, Comparing CD and UC Participants

	CD (n = 124)		UC (n = 108)	
Domain/activities[a]	Proportion reporting definite disability (%)	Mean rating (95% CI)	Proportion reporting definite disability (%)	Mean rating (95% CI)
Ability to work	16	1.7 (1.3–2.1)	14	1.1 (0.8–1.5)
Home management	19	1.6 (1.2–2.0)	10	0.9 (0.6–1.2)
Social leisure activities	19	1.8 (1.4–2.2)	12	1.2 (0.8–1.5)
Private leisure activities	11	1.2 (0.8–1.5)	6	0.7 (0.4–1.0)
Maintaining close relationships	13	1.1 (0.8–1.4)	7	0.5 (0.3–0.7)

[a]Score range for each domain is 0–8; definite impairment defined as $\geq$4.

Table 4. Relationship of Demographic and Clinical Characteristics With the WHODAS Disability Scale on the Basis of Multiple Linear Regression

Predictor	Disability standardized beta	
	CD	UC
Age at diagnosis	0.08	–0.04
Sex (female)	0.05	–0.05
Lifetime major depression	0.37[a]	0.12
Disease duration	0.19[b]	0.13
Previous IBD surgeries[c]	–0.01	0.04
Ever hospitalized for IBD	–0.02	–0.02
Long-term active IBD	0.16	0.37[a]
Disease phenotype (inflammatory vs stricturing/penetrating)[d]	0.06	N/A
Adjusted R^2	0.16	0.10

[a]$P < .001$.
[b]$P < .05$.
[c]For the CD model, 2 or more CD-related surgeries; for the UC model, at least 1 previous surgery.
[d]Perianal disease was nonsignificant and did not affect the other parameters in this model significantly.

CD had higher levels of disability than those with UC, with significant disability experienced by 1 of every 5 CD patients and 1 of every 10 UC patients. Higher disability levels were associated with higher psychological distress, greater levels of perceived stress, and poorer QoL.

Previous studies of disability in IBD have primarily focused on work and employment outcomes and concluded that unemployment rates are higher for IBD patients than for the general population. Baseline data from the ACCENT I trial revealed that 39% of the study cohort were unemployed.[14] The TREAT registry reported an overall work disability rate of 25%, with high variability dependent on the country, ranging from 20% in the United States to 34% in Europe.[15] The magnitude of disability in these reports may be biased because they included persons with IBD who used antibody to tumor necrosis factor (infliximab), who are likely to be the most symptomatic or complicated of IBD patients. However, 25%–28% of individuals in a U.S. population-based data set were found to be out of the workforce, which was significantly higher than the general population.[10] Employment outcomes are one concrete measure of disability, but chronic disease can interfere in multiple areas of a person's life. In this study, disability was defined more broadly by using 2 different, well-validated scales (WSAS and WHODAS). Both included items that measure interference in daily activities in relation to domains of work, home, private and social leisure, and relationships, with the WHODAS including more task-specific items and specifying a recent time frame. There was a strong relationship between the 2 disability scales for CD as well as UC, suggesting they were measuring some common but also distinct aspects of disease impact. Figure 1[16–19] shows a comparison of the mean WHODAS scores in our study with other chronic health conditions measured in population-based studies. In the context of inflammatory diseases, the mean WHODAS score was higher for multiple sclerosis as well as ankylosing spondylitis than for IBD with a comparable duration of disease.

Table 5. Relationship of Demographic and Clinical Characteristics With the WSAS Disability Scale on the Basis of Multiple Logistic Regression

Predictor	Disability	
	CD,[a] adjusted odds ratio (95% CI)	UC,[b] adjusted odds ratio (95% CI)
Age at diagnosis	1.01 (0.97–1.06)	1.04 (0.97–1.11)
Sex (female)	0.71 (0.21–2.46)	3.46 (0.64–18.71)
Lifetime major depression	3.86 (1.22–12.29)	1.84 (0.32–10.43)
Disease duration	1.11 (0.85–1.45)	1.05 (0.67–1.65)
Previous IBD surgeries[c]	1.14 (0.33–3.96)	1.51 (0.22–10.65)
Ever hospitalized for IBD	0.95 (0.22–4.05)	0.29 (0.04–1.87)
Long-term active IBD	7.68 (1.99–29.61)	4.48 (0.83–24.32)
Disease phenotype (inflammatory vs stricturing/penetrating)[d]	1.22 (0.38–3.93)	N/A

[a]C statistic for CD model = 0.82.
[b]C statistic for UC model = 0.84.
[c]For the CD model, 2 or more CD-related surgeries; for the UC model, at least 1 previous surgery.
[d]Perianal disease was nonsignificant and did not affect the other parameters in this model significantly.

Impairment related to IBD was not limited to work functioning and home management, because similar proportions reported at least moderate impairment in social leisure activities. Participants with CD reported higher disease interference in home management and maintaining close relationships than those with UC. A recent survey of IBD patients in Greece reported that 55% found the disease had a significant impact on their social lives.[20] The impact of IBD on the social domain of functioning may be under-recognized in clinical practice.

The findings from this study indicated that disability was strongly associated with both higher perceived stress levels and emotional distress. Perceived stress reflects the level of stress load an individual is experiencing, whereas emotional distress is a parameter that manifests with clinical symptoms across a spectrum of mental health concerns. Viazis et al[20] found that 65% of IBD patients reported feeling stressed and 60% reported feeling depressed in a recent online survey. Other studies have found higher rates of distress and depression in IBD,[21] although they have not specifically examined the contribution to IBD-related disability. The effects may be bidirectional such that higher levels of disease interference in daily functioning may result in greater distress, and high levels of stress may undermine one's ability to manage the disease and the impact on daily tasks and responsibilities.

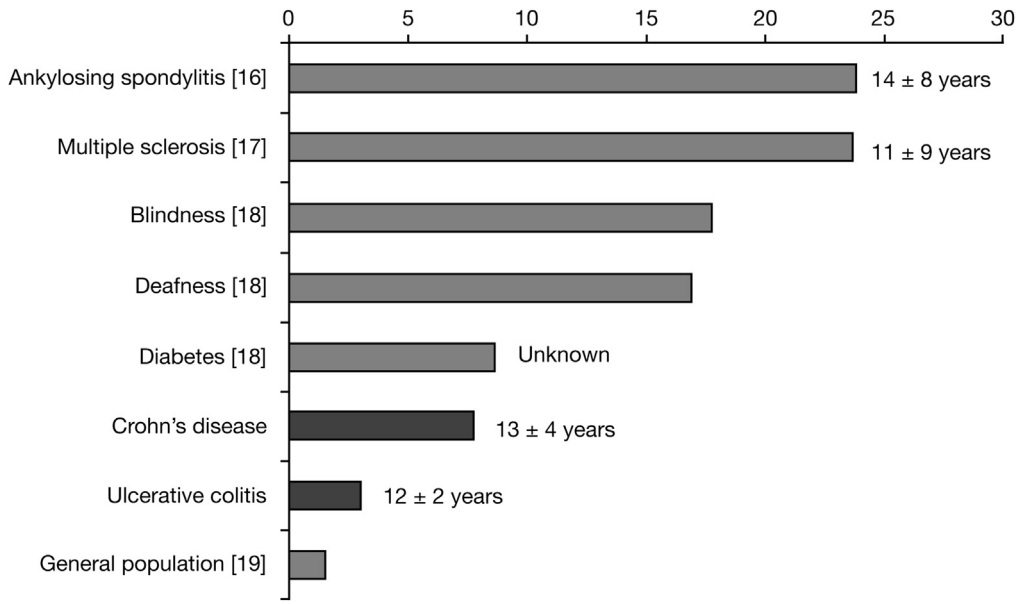

Figure 1. Mean disability scores in chronic disease samples by using the WHODAS.

Because of the longitudinal nature of our study we were able to consider a broad range of factors as predictors of disability after a decade of disease. Of all of these factors, the only predictors of disability by using the WHODAS measure were lifetime major depression and disease duration for CD and long-term active disease for UC. The only predictors for the WSAS measure were lifetime major depression and long-term active IBD for CD, with no predictors for UC. In our study, major depression often predated the development of the IBD[21] and was assessed well before the assessment of disability.

Factors related to disease course have been shown to increase the risk of disability in cross-sectional analyses, including higher pain, more recent disease onset, and medical hospitalizations.[15,22] The occurrence of IBD-related surgeries has also been found to predict work-related disability in the short-term,[15,22] likely both because of recovery from the surgery and because the need for surgery suggests more severe disease. However, we did not find that a history of IBD-related surgeries was predictive of disability levels after a decade of disease. This is in keeping with the results of a Swedish study of UC patients undergoing colectomy, which showed that although rates of unemployment rose from 7% before surgery to 13% in the first year of follow-up,[23] the majority of patients ($\geq$50%) in that study did not experience any work loss by 3 years after colectomy. This likely reflects that surgical resection in UC leads to long-term remission of symptoms, and that many persons are able to go to work once their acute convalescence is complete. In addition, there can be opposite effects of surgery for IBD patients during the long-term regarding the impact on disability. On the one hand, surgery may be necessitated because of severe disease, and some of these patients may have significant symptoms during convalescence or even months post-operatively. Furthermore, repeat surgeries may result in a short bowel, all of which can adversely affect daily functioning. On the other hand, surgery can effectively treat complications of the disease, with an outcome of long-lasting clinical remission.

A main strength of our study is the measurement of multiple dimensions of disability and the use of a scale (WHODAS) that was validated in a range of other inflammatory as well as noninflammatory diseases. The longitudinal and prospective measurement of symptomatic disease activity over multiple years provides in-depth information on disease course that has not been available in other studies.

This study has a number of limitations to consider, particularly because disability can be challenging to measure. Disability was not assessed longitudinally, but rather it was measured cross-sectionally, representing a mean of disease duration of 13 years. This information is relevant, nevertheless, because it provides important insight into the impact of IBD after many years of disease. Also, it provides information on disability at a relatively homogenous point of follow-up, whereas this was not the case for most prior studies. However, it is possible that for some of the participants, disability at this point was temporary and was associated with a recent flare of the disease or recent surgery. Another potential limitation is that the items of the general disability measure (the WHODAS) that assess the physical aspects of disability may not be relevant for IBD (eg, difficulty standing for 30 minutes) and thus may underestimate the impact of the disease on physical functioning. The WSAS was used to more specifically identify the level of disability in each life domain attributable to IBD; however, it does not include task-specific functioning. An IBD-specific disability scale was recently developed. This scale includes a core set of items such as abdominal pain and regulating defecation.[4] The use of this type of scale would have the potential to better define the physical aspects of disability in patients

with IBD but may be more problematic for comparison of disability levels with other chronic diseases. These comparisons can guide health policy and evaluate societal burden. Finally, disability based on the WSAS was defined by using a cutoff that was established for a different chronic health issue,[24] and this cutoff has not been specifically validated for IBD patients. Nevertheless, the cutoff value of 17 was established with appropriate statistical analysis (ie, receiver operator characteristic curve) and was well above the value of 10, which was identified by the scale developers as being associated with significant functional impairment.

One additional consideration is that there may have been insufficient power to determine predictors of disability for the UC group on the WSAS measure because of the small proportion who reached the threshold for significant disability on the WSAS.

In summary, overall, long-term active disease and a history of major depression were predictive of disability, although disability was not specifically related to a history of IBD-related surgery or hospitalizations. Our study highlights the connection of psychological functioning with disability among those with IBD. The strong predictive effect of lifetime history of depression on disability in CD suggests that when depression is identified, clinicians should be as aggressive in its treatment as they are in treating the luminal manifestations of the disease. Future studies are needed to examine whether specific treatment of psychological dysfunction may ameliorate disability in IBD patients.

Supplementary Material

Note: To access the supplementary material accompanying this article, visit the online version of *Clinical Gastroenterology and Hepatology* at www.cghjournal.org, and at http://dx.doi.org/10.1016/j.cgh.2013.12.009.

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Reprint requests
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Conflicts of interest
These authors disclose the following: Laura Targownik has served as a consultant to Astra Zeneca Canada, Merck Canada, Janssen Canada, and Speakers' Board for Pfizer Canada and has received research grants provided by Abbvie Canada and Pfizer Canada. Charles Bernstein has served as a consultant for Abbott Canada, Abbvie Canada, Vertex Pharmaceuticals, Bristol Myers Squibb, Takeda Canada, Forest Canada, and Hospira and has received research grants provided by Abbott Canada and Abbvie Canada and an educational grant provided by Aptalis. The remaining authors disclose no conflicts.

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Supplementary Material

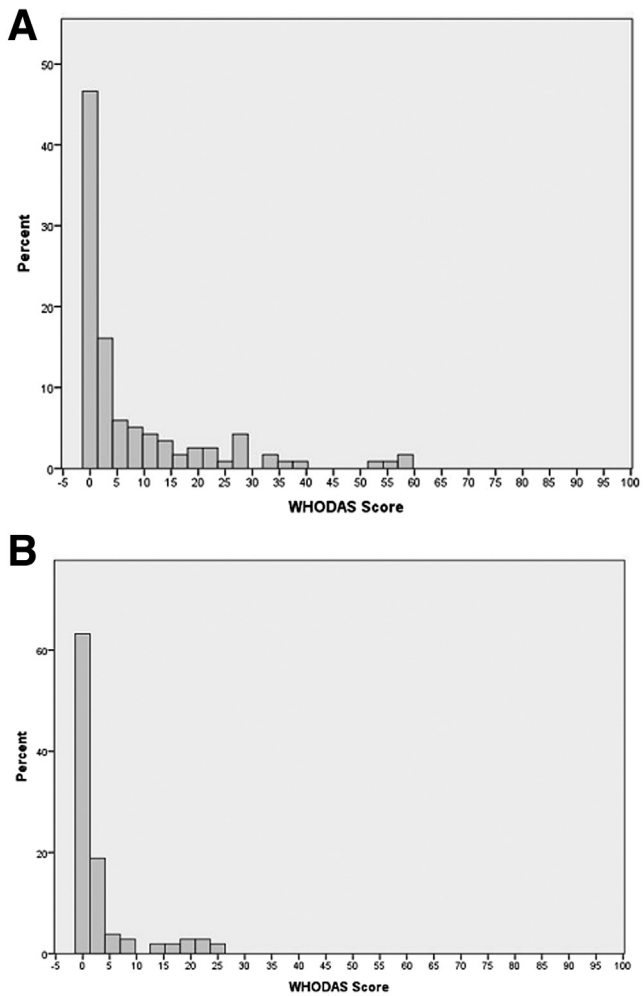
Detailed Description of World Health Organization Disability Assessment Schedule v.2.0 and Work and Social Adjustment Scale

WHODAS v.2.0[14] is a 12-item measure in which respondents rate the level of difficulty experienced with everyday tasks during the previous 30 days, taking into consideration how they usually do the activity. The 12 items cover a wide range of activities including standing for 30 minutes, performance of household responsibilities, learning a new task, joining community activities, emotional effect of health problems, concentrating for 10 minutes, walking a kilometer, washing your whole body, getting dressed, dealing with people you do not know, maintaining a friendship, and day-to-day work. The items are scored on a 5-point scale (none = 1 to extreme/cannot do = 5). A total score is generated as the weighted sum of all items, ranging from 0–100, with a higher score indicating greater disability. The items on the WHODAS showed good discriminative validity across the spectrum of disability. The internal consistency and test-retest reliability of the WHODAS are high, concurrent validity in comparison to other disability measures has been established in both general and clinical populations, and the scale has been used widely across different diseases, countries, and languages of administration. The WHODAS does not have a set cut point to define disability.

The WSAS assesses disease impact in 5 domains (work, home management, private leisure, social leisure, and close relationships). The wording may be adapted for the health condition or disease being evaluated. As an example, one item states: "Because of my IBD, my ability to form and maintain close relationships with others, including those I live with, is impaired." The 5 items are each rated on a scale of 0–8, which are summed to create a total score ranging from 0–40, with higher scores reflecting greater disability. It has shown moderate to high reliability in a variety of patient samples and demonstrated convergent validity across mental disorders. The measure has been dichotomized into low vs high disability by using a cutoff score of 17 or more to represent high levels of disability.

Association Between Disability Scales and the Psychological Functioning and Quality of Life Measures

Supplementary Table 1 shows the associations between the disability scales and the psychological functioning and QoL measures. For those with CD, the IBD-specific disability (WSAS scale) was strongly correlated with all the psychological measures (all correlations, $r \geq 0.59$), indicating that higher disability is associated with higher perceived stress, emotional distress, and poorer QoL. The WHODAS showed a similar pattern, although the correlations were uniformly somewhat lower (absolute $r = 0.41$–0.62). In respondents with UC, the QoL total score and subscales were consistently strongly correlated with both disability measures. Distress was moderately correlated with disability as measured by the WSAS ($r = 0.45$) and only weakly correlated with disability as measured by the WHODAS ($r = 0.23$), with similar results for perceived stress (WSAS, $r = 0.37$; WHODAS, $r = 0.20$). These lower correlations may be related to the distribution of the WHODAS scores toward the lower end of the distribution, as shown in Supplementary Figure 1). Among the IBDQ subscales, social functioning showed the strongest relationship with disability for both disability measures and across both CD and UC participants (absolute $r = 0.52$–0.79).



Supplementary Figure 1. WHODAS distributions in CD (*A*) disease and UC (*B*) groups.

Supplementary Table 1. Pearson Correlations of Disability Scales With Concurrent Psychological Functioning and QoL for CD and UC Participants

	WHODAS		WSAS	
	CD (*r*) (95% CI)	UC (*r*) (95% CI)	CD (*r*) (95% CI)	UC (*r*) (95% CI)
Perceived stress (CPSS)	0.55 (0.41–0.66)	0.20 (0.01–0.37)	0.61 (0.49–0.71)	0.37 (0.20–0.52)
Distress (BSI)	0.55 (0.41–0.66)	0.23 (0.04–0.40)	0.66 (0.55–0.75)	0.45 (0.29–0.59)
QoL (IBDQ) total	–0.62 (–0.72 to –0.50)	–0.63 (–0.73 to –0.50)	–0.72 (–0.80 to –0.62)	–0.67 (–0.76 to –0.55)
IBDQ subscales				
Bowel symptoms	–0.41 (–0.55 to –0.25)	–0.48 (–0.61 to –0.32)	–0.59 (–0.69 to –0.46)	–0.49 (–0.62 to –0.33)
Emotional health	–0.42 (–0.56 to –0.26)	–0.50 (–0.63 to –0.34)	–0.68 (–0.76 to –0.57)	–0.48 (–0.61 to –0.32)
Systemic symptoms	–0.46 (–0.59 to –0.31)	–0.47 (–0.61 to –0.31)	–0.63 (–0.73 to –0.51)	–0.52 (–0.65 to –0.37)
Social functioning	–0.52 (–0.64 to –0.38)	–0.54 (–0.66 to –0.39)	–0.79 (–0.85 to —0.71)	–0.59 (–0.70 to –0.45)