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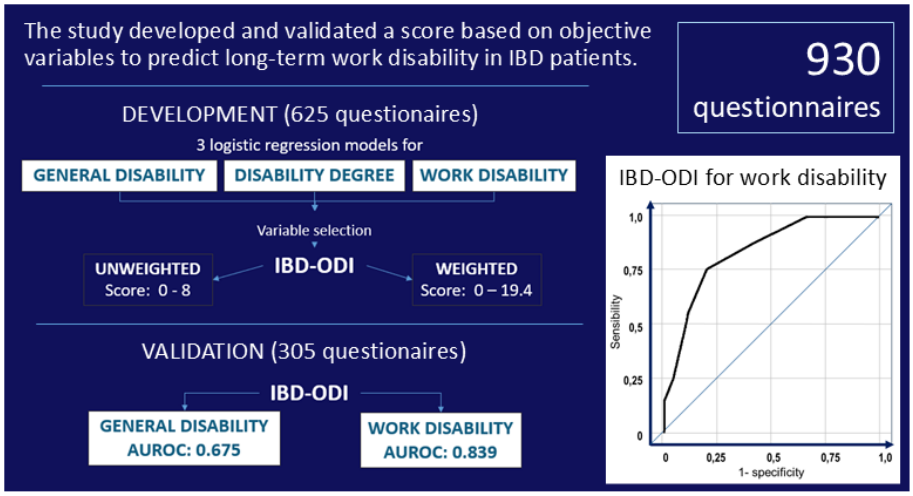

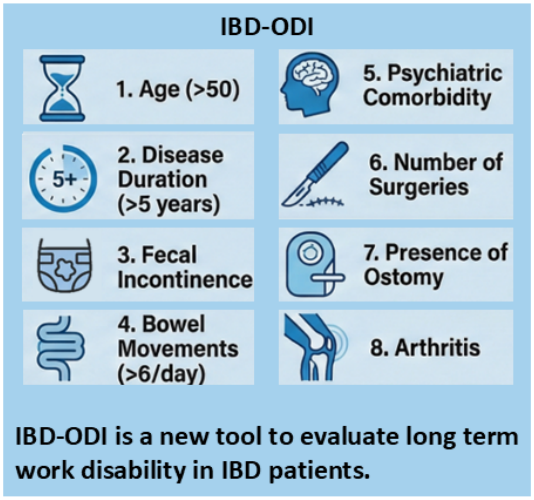

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Development and validation of the inflammatory bowel disease objective disability index (IBDODI)

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Authors' contributions:

LM and XC: study concept and design, acquisition of data; analysis and interpretation of data; drafting of the manuscript; study supervision

OV: statistical analysis

EB, AV, MV, AP, LL, OV, SL critical revision of the manuscript for important intellectual content.

All authors definitively approved the submitted version.

Lay summary: Inflammatory Bowel Disease (IBD) can result in significant general and work disabilities. The IBDODI (IBD-Objective Disability Index), the index presented in this manuscript, provides for first time an objective tool for assessing long term general and work disability in IBD.

Abstract:

Introduction: Current measuring tools for disability related to inflammatory bowel disease (IBD) rely mostly on patient-reported disability perception. It may, therefore, largely depend on patients' subjectivity, thus hindering objective evaluation. In the present study, we aimed to identify clinical plausibly objectifiable variables related to disability and to develop and validate a long-term disability index based on them.

Methods: Answering an online survey, IBD patients reported their officially recognised degree of general and work disability plus several long-term disability-related clinical variables. Responses were randomly allocated to a training or a validation dataset. Multiple logistic regression tests were performed in the training set. Variables statistically or clinically related to disability were used to model an Unweighted-IBD Objective Disability Index (U-IBDODI) -where all variables had the same weight- and a Weighted- Index (W-IBDODI), where variables were weighted according to the regression results. Both scores were subsequently validated.

Results: The analysis included 930 questionnaires. Patients' mean age was 41±11, 642 (65.4%) were women, and 582 (59.3%) had Crohn's Disease. The training dataset included 665 surveys. In the validation set (n=265), U-IBDODI mean values were 3.7+/-1.3 for patients with work disability and 2.3+/-1.4 for patients without ($p<0.001$). U-IBDODI AUROCs for predicting work and general disability were 0.839 and 0.675, respectively. The corresponding W-IBDODI values were 10.9+/-3.7 and 6.9+/-3.7 ($p<0.001$), 0.837 and 0.606.

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Conclusions: Predictive values of IBDODI scores were good for work disability and moderate for general disability. These indexes may provide a more objective evaluation of permanent disability, complementing existing indexes.

Keywords: Inflammatory bowel disease. Disability. Work disability.

Introduction

Disability is defined as a partial or total inability to perform social roles, including work activity (1). Inflammatory bowel disease (IBD) include two prevalent chronic immune-mediated conditions, Crohn's disease (CD) and ulcerative colitis (UC). Both diseases may lead to permanent functional limitations due to persistent inflammation or structural damage resulting in different degrees of disability, particularly in patients with severe disease (2–6).

Reported rates of IBD-related disability vary widely, ranging from 1.3% to 50% (1,7–14), largely reflecting differences in definitions and assessment tools. In Spain, approximately 4.1% of IBD patients receive a work disability pension (6). Several instruments have been developed to assess disability in IBD (15–22), including questionnaires previously validated by our group in both CD and UC (18,19). However, most available tools rely on patient-reported indicators and may therefore be influenced by subjective perception.

In Spain, general disability is assessed at a regional level, whereas work disability is evaluated by the national Social Security system (20). Previous work demonstrated substantial variability in administrative decisions regarding work disability pensions (23), highlighting the need for identifying clinical variables predicting disability and for tools providing a disability evaluation based on parameters as objective as possible.

In this context, identifying "objective" criteria to assess disability is probably a relevant unmet need in the management of patients with IBD. The aim of this study was, in consequence, to identify clinical variables related to long-term disability and to develop and validate an "objective" disability index for patients with IBD based on these clinical variables.

Methods

Subjects

A cross-sectional study was conducted using an online survey completed by adult patients with IBD, diagnosed at least six months before inclusion and legally resident in Spain. Patients younger than 18 years, those who did not meet inclusion criteria, or those who submitted incomplete or duplicate questionnaires (defined as fewer than 50% valid responses) were excluded.

Survey development

An online survey was conducted using the SurveyMonkey© platform between January and June 2019. The questionnaire was developed based on a previous population-based study by our group (6) and disseminated through national and regional IBD patient associations (ACCU España and ACCU Catalunya) via websites and social media. *"Objective"* variables related to disability were collected. We defined as "objective" those variables that were either clearly objective (for example: ostomy, number of surgeries, years of evolution and previous diagnoses or comorbidities) or that, although self-reported, could be plausibly objectified (for example, the number of daily bowel movements or incontinence). We seek also that these indicators could be reasonably evaluated by reviewing the clinical reports of the patients. Variables collected included demographic characteristics, disease type and duration, bowel habits, medical and surgical history, healthcare utilization, and relevant comorbidities. Patients reported their officially recognized disability status according to the Spanish social security system, including general disability and work disability. General disability was expressed as a percentage and categorized as none (0%), low (1–33%), moderate (34–55%), or severe (>55%). Work disability was defined as the granting of a work disability pension among active or past workers.

Statistical methods

Completed questionnaires were randomly assigned to a training dataset (67%) or a validation dataset (33%). In the training dataset, bivariate analyses were performed to identify variables associated with work disability, general disability (yes/no), and

degree of general disability. Continuous variables were analyzed as means with standard deviation or medians with interquartile range, as appropriate, and categorical variables as frequencies and percentages. Multivariate logistic regression models were constructed for work disability and general disability, and an ordinal logistic regression model was used for degree of general disability. Variables with a p value <0.1 in bivariate analyses were considered for inclusion in the three logistic regression models.

Variables that were significant in at least two of the three logistic regression models, together with clinically factors that have been shown to be strong predictors of disability according to previous studies, were selected to develop the IBD Objective Disability Index (IBDODI). Their inclusion aimed to preserve clinical interpretability and content validity of the index rather than relying exclusively on statistical significance in individual models. Two scoring approaches were evaluated: an unweighted score (U-IBDODI), assigning one point per variable, and a weighted score (W-IBDODI), based on the average effect size across regression models. Finally, the new IBDODI was validated in the validation dataset by assessing its discriminative ability regarding general disability, disability grade, and work disability, using ROC analysis. All analyses were performed using SAS version 9.4 (SAS Institute Inc., Cary, NC, USA).

Ethical issues

The study was approved by the Ethics Committee of Parc Taulí University Hospital (2019/523) and registered at ClinicalTrials.gov (NCT03872726). All participants provided online informed consent. The study was conducted in accordance with the Declaration of Helsinki (23), complied with the European Union General Data Protection Regulation (EU 2016/679), and followed the TRIPOD recommendations for prediction model development and validation (24).

Results

Study population

A total of 1,074 patients completed the survey, and 930 questionnaires were considered valid for analysis (Figure 1). Mean age was 41 ± 11 years, 642 were women

(65.4%), and 582 had CD (59.3%) (Table 1).

Eight-hundred patients were classified as workers (86.0%), of whom 74 (8.2%) had been granted a work-disability pension. An officially recognized degree of general disability was present in 428 patients (45.9%) (Table 1).

Baseline homogeneity analysis

Six hundred and twenty-five surveys were assigned to the training dataset and 305 to the validation dataset. Baseline characteristics are summarized in Table 1.

Compared with the validation dataset, the training dataset showed a higher prevalence of recognized general disability (49.1% vs 39.7%, $p = 0.03$), a slightly earlier age at diagnosis, and a longer disease duration, while no other relevant differences were observed.

Bivariate and multivariate analyses for work disability

A total of 544 questionnaires from active or past workers in the training dataset were analyzed; 53 patients in this group had a work disability pension.

In multivariate analysis, age, number of daily bowel movements, number of surgical interventions, number of medical tests performed in the previous year, and body mass index were independently associated with work disability (Table 2).

Bivariate and multivariate analyses for general disability

Of 618 eligible patients, 307 (49.7%) had a recognized degree of general disability. Longer disease duration, immunosuppressant treatment, psychiatric comorbidity, number of surgical interventions, ostomy, and arthropathy were independently associated with general disability (Table 2).

Bivariate and multivariate analyses of the degree of general disability

Age, disease duration, psychiatric comorbidity, number of surgical interventions, ostomy, and arthropathy were independently associated with higher degrees of general disability in the ordinal model (Table 2).

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Score modelling

Eight variables were included in the final disability score. Six variables (age, disease duration, psychiatric comorbidity, arthropathy, number of bowel movements per day and number of surgical interventions) were selected because they proved significant in at least two of the three logistic regression models. Additionally, fecal incontinence and ostomy were retained in the final index based on strong a priori clinical rationale and prior evidence linking both conditions to significant functional limitation, work impairment, and disability in patients with IBD (6,24–27) (Table2). Two scoring approaches the unweighted score (U-IBDODI), and the weighted score (W-IBDODI) were developed (Table 3).

Score validation

In the validation dataset (n=305), the mean value for the U-IBDODI was 2.61 (SD 1.66) and for the W-IBDODI was 7.3 (SD 3.9; Figure 2).

Patients with recognized general disability had higher mean U-IBDODI (3.17 ± 1.76) and W-IBDODI (8.05 ± 3.9) scores than those without general disability respectively (2.1 ± 1.47 and 5.58 ± 3.59; $p < 0.001$).

Work disability was assessed only in the subgroup of potentially employable patients eligible to apply for work disability, excluding students, retirees, and household managers. Patients with a recognized work disability showed higher mean U-IBDODI scores than those without (3.7±1.3 vs. 2.3±1.4; $p < 0.001$). Similarly, W-IBDODI values were higher in patients with work disability (10.9±3.7 vs. 6.9±3.7; $p < 0.001$).

Both scores showed good discriminative ability for work disability (AUROCs 0.839 for U-IBDODI and 0.837 for W-IBDODI; Figures 3a–b) and more modest performance for general disability (AUROCs 0.675 and 0.676; Figures 3c–d).

Discrimination in the development cohort was similar to that observed in the validation cohort. For work disability, AUROC values ranged from 0.760 to 0.771 in the training dataset and from 0.837 to 0.839 in the validation dataset. For general disability, AUROC values ranged from 0.713 to 0.765 and from 0.675 to 0.676, respectively (Supplementary table 1).

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Discussion

This study is the first to develop and validate a disability index in a large cohort of IBD patients based exclusively on clinical variables that can be verified through clinical reports. In addition, most of these variables have been related to long-term disability in previous studies including disease duration, surgical history, ostomy, psychiatric comorbidity and extraintestinal manifestations (6,18,27,28). The IBDODI showed moderate discriminative capacity for general disability and good discriminative ability for work disability, supporting its potential applicability in clinical and administrative settings. The better performance for work disability likely reflects differences in administrative frameworks and assessment criteria (23).

Unlike previously published disability instruments (supplementary table 2), which rely largely on the subjective patient-reported impact of IBD in daily activity (15–19,21,22), IBDODI focuses on clinical objective variables reflecting chronic disease burden and irreversible damage. This distinction is relevant, as disability represents a long-term outcome that should be differentiated from patient-reported outcomes evaluating disease activity or quality of life, which are more susceptible to short-term fluctuations (28). The IBDODI should, therefore, be considered complementary to existing PROM-based disability indices rather than a replacement.

Two versions of the score were developed -an unweighted and a weighted model- that showed a broadly comparable performance. Therefore, we propose the unweighted score as the primary version for routine use, prioritizing simplicity and transportability. Further external validation may be needed, however, to confirm the equivalence of both versions.

This study has several limitations. First, disability was defined according to administrative recognition, which may vary across evaluating bodies and may introduce some degree of misclassification. However, in the absence of a universal objective standard, administrative recognition remains the most pragmatic reference for identifying work and general disability in IBD patients.

Second, although the index was designed to rely on “objective” clinical variables, some components are self-reported although plausibly verifiable through clinical records or close observation. In this context, “objective” refers to variables that can reasonably

be confirmed from medical documentation rather than being exclusively based on subjective perception. The IBDODI should therefore be considered complementary to patient-reported outcome measures rather than a replacement.

Third, data were obtained through an online survey distributed via patient associations, which may overrepresent younger or more engaged patients and those with greater disease burden. Although this may introduce selection bias, it also reflects the population most likely to require formal disability recognition. In addition, applicability outside Spain should be interpreted with caution for two different reasons: first of all, disability assessment frameworks markedly differ across healthcare and legal systems and, second, language and cultural validation is necessary before applying the score to other countries.

From a methodological perspective, the development and validation cohorts were derived from the same source population using random allocation and showed minimal baseline differences. Discrimination remained stable across training and validation datasets, supporting the internal robustness of the index. Calibration may vary when prediction models are applied to populations with different baseline risk or case-mix; however, the similar performance observed across both samples suggests that any calibration differences within this study are likely to be limited. The number of predictors was limited and clinically pre-specified to reduce overfitting, and model performance was consistent across samples, suggesting that substantial overfitting is unlikely. Nevertheless, as only internal validation was performed, external validation in independent populations will be necessary to confirm generalizability and transportability.

From a practical perspective, the IBDODI may be particularly useful in settings where objective criteria are required, such as administrative disability assessments or large observational studies. For disability assessment, the study may contribute in two different ways. First, the study identifies the main variables related to disability that would ideally be described in medical reports prepared for disability evaluation. Furthermore, although additional studies might be necessary to refine the score and to establish a threshold to support decisions regarding disability awards, presenting a high score may already be of help. Although a sole score should not be the only

criterion, a high score may reasonably help to make a fair decision. As an example, a 52-year-old patient with Crohn's disease diagnosed 18 years ago reporting more than six bowel movements per day and occasional liquid fecal incontinence after three prior intestinal resections, a documented depressive disorder and peripheral arthropathy, scoring 7 points in the IBDODI might seem a good candidate for a work-disability grant.

In conclusion, the IBDODI is a simple and objective tool with good performance for assessing work disability in IBD patients. Its use may complement patient-reported measures and support more consistent clinical and administrative assessment of long-term disability. While it may also evaluate general disability, its moderate performance in this area warrants cautious use and further validation.

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Disclosure:

LM has served as a speaker and consultant for MSD, Abbvie, Janssen, Takeda, Tillotts, Kern, Chiesi. AV has served as a speaker and consultant for MSD and Abbvie. EB has served as a speaker and consultant for Jansen, Kern and Chiesi. XC has received grants for research from Janssen, Kern, Abbott, MSD, Pfizer, Galapagos and Vifor, and fees for advisory board services from Janssen, Abbvie, MSD, Takeda and Vifor. He has also given lectures for Janssen, Abbvie, MSD, Takeda, Shire and Allergan. The remaining authors do not report conflicts of interest.

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Table 1. Baseline characteristics of the cohort

	Training-set (n= 625)	**Validation-set (n= 305)**	*p*
Age	41 (± 11)	41.3 (± 11)	0.87
Biological sex (♀/♂)	401/224 (64.2/35.8)	207/98 (67.9/32.1)	0.26
CD/CU	372/253 (59.5/40.5)	180/125 (59.41)	0.8
Time of disease evolution	14.2 (± 10.1)	12.8 (± 9.9)	0.03
Treatment ● No treatment ● Mesalamine ● Immunomodulator ● Biological ● Biological+Immunomodulator	 51 (8.6) 123 (20.7) 118 (19.8) 197 (33.1) 106 (17.8)	 21 (7.3) 68 (23.7) 65 (22.6) 83 (28.9) 50 (17.4)	0.55
Biological treatment ● Infliximab ● Adalimumab ● Vedolizumab ● Ustekinumab	 112 (37) 115 (38) 31 (10.2) 31 (10.2) 14 (4.6)	 53 (39.8) 48 (36.1) 13 (9.8) 17 (12.8) 2 (1.5)	0.5

• Other			
Fecal incontinence Wexner index No incontinence Mild incontinence Moderate / severe incontinence	 6.72 (±4.3) 24 (3.8) 414 (66.2) 187 (29.9)	 6.94 (± 4.39) 14 (4.6) 187 (61.3) 104 (34.1)	 0.48 0.33
Psychiatric comorbidity Psychiatric treatments • Psychiatric disease	 348 (55.7) 151 (24.2)	 153 (50.2) 474 (75.8)	 0.1 0.2
IBD surgeries Number of surgical procedures 0 1 2	233 (37.3) 392 (62.7) 74 (11.8) 63 (10.1)	106 (34.8) 199 (65.2) 37 (12.1) 31 (10.2)	0.45 0.7

≥3 Ileostomy or colostomy Ileoanal reservoir	96 (15.4) 49 (7.8) 29 (4.6)	38 (12.5) 23 (7.5) 17 (5.6)	 0.8 0.5
Days of hospitalisation for IBD last year	6.1 (±17.8)	3.5 (10.7)	0.1
Medical tests for IBD last year	7.9 (± 9.4)	7.23 (±7.7)	0.9
Specialised medical visits for IBD last year	5.7 (± 8.9)	4.7 (± 7.9)	0.1
Work disability	55 (8.8)	29 (9.5)	0.72
General disability	307 (49.1)	121 (39.7)	0.03
Degree of general disability ● <33% ● 33-54% >54%	 74 (22.5) 190 (57.8) 29 (8.8)	 23 (16.7) 74 (53.6) 17 (12.3)	0.1

Table 2. Significant variables on the three multivariate analysis

	General Disability		**Severity of general disability**		**Work disability**	
	OR	**95 % IC**	**OR**	**95 % IC**	**OR**	**95 % IC**
Disease duration (≥6vs<5 years)	6,37	3,72 – 10,87	3,68	1,86 – 7,25		
Age			1,02	1,00 – 1,05	1,04	1,01 – 1,08
Bowel movements						
>6vs0-3			1,71	0,85 – 3,40	3,92	1,63 – 9,43
>6vs4-6			2,26	1,09 – 4,65	3,45	1,42 – 8,40
Immunosuppressive therapy	2,16	1,38 – 3,39				
Psychiatric comorbidity	2,62	1,59 – 4,31	1,78	1,09 – 2,88		
Surgical interventions						
≥3vs0	5,49	2,62 – 11,49	4,02	2,07 – 7,81	1,45	0,67 – 3,11
≥3vs1-2	2,81	1,27 – 6,21	2,33	1,18 – 7	4,74	2,08 – 10,8
Colostomy	3,32	1,07 – 10,31				
Arthralgia or arthritis	1,56	1,04 – 2,33	1,63	1,03 – 2,58		
Number of examinations (≥4vs1–3)					2,43	1,09 – 5,43
BMI (<18,5vs>18,5)					3,52	1,31 – 9,49

Table 3. IBDODI models

		W-IBDODI	U-IBDODI
Age	> 50	1.3	1
Time of disease evolution	> 5	4	1
Liquid fecal incontinence	Yes	1	1
Bowel movements per day	> 6	2.2	1
Psychiatric comorbidity	Yes	2.1	1
Surgeries	0	0	0
	1-2	2.5	0
	>2	5	1
Ostomy	Yes	5	1
Arthritis	Yes	1.6	1

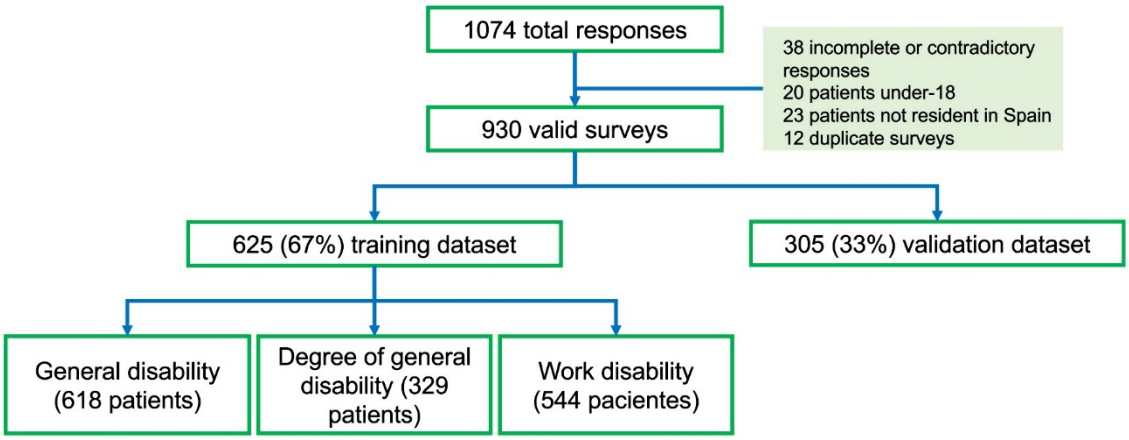

Figure 1

Figure 1: Study flowchart

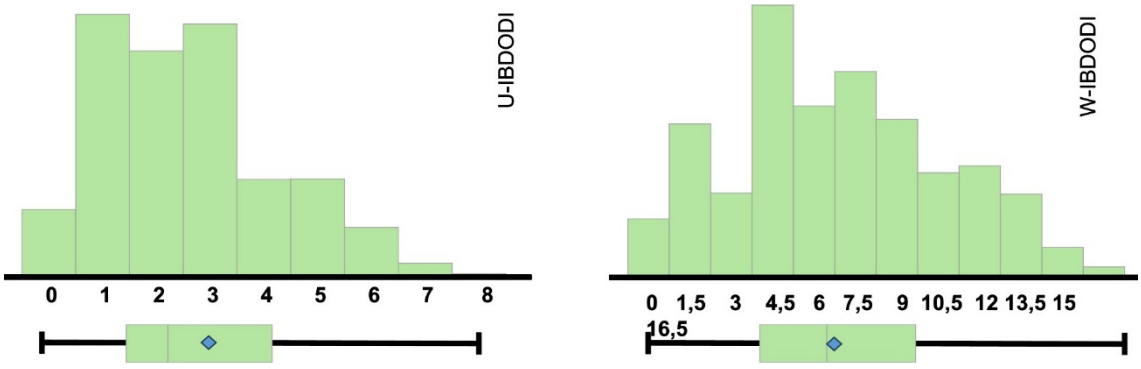

Figure 2

Figure 2: The distribution of U-IBDODI (a) and W-IBDODI (b) values in the validation dataset

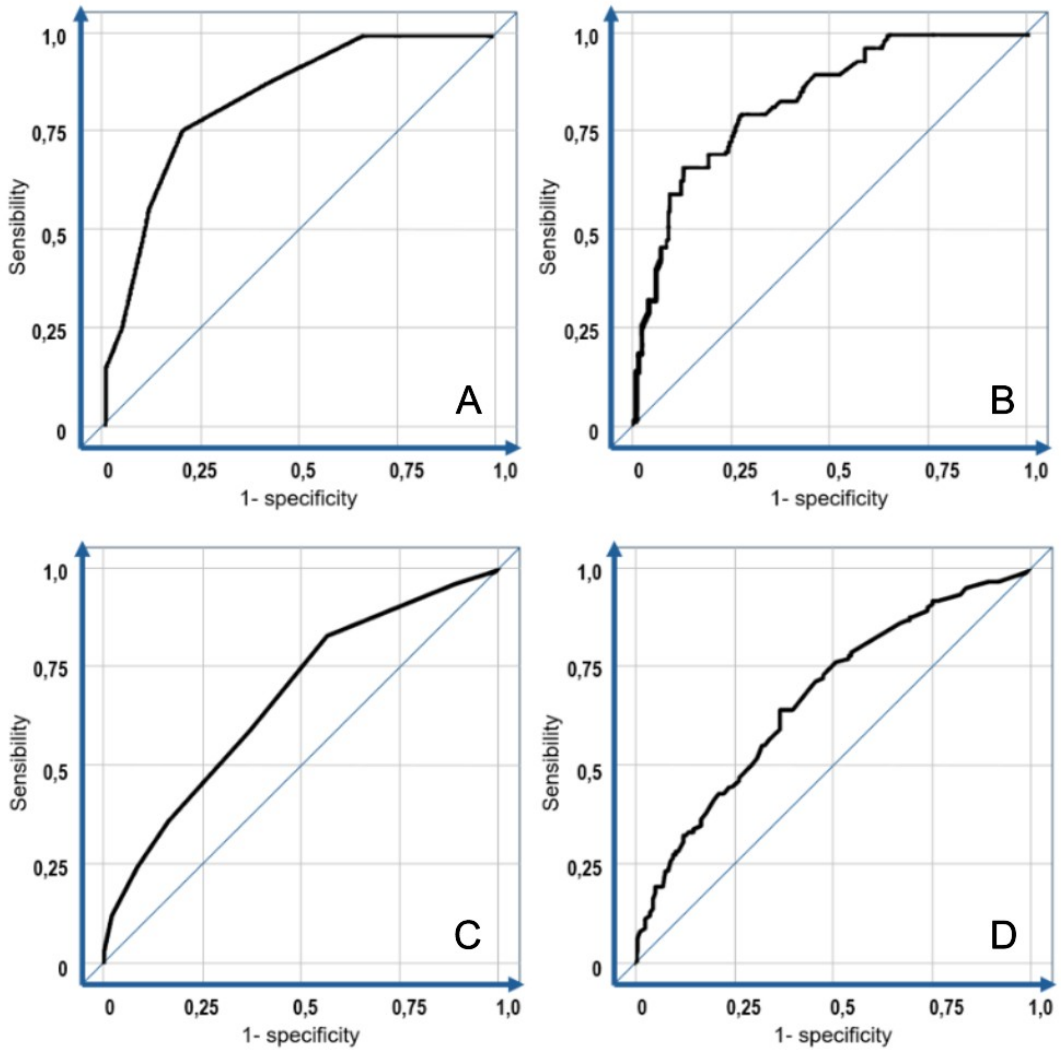

Figure 3

Figure 3: U-IBDODI and W-IBDODI AUROCs for work disability (a-b) and for general disability (c-d) in the validation dataset

Supplementary table 1: AUROC values of U-IBDODI and W-IBDODI on the training and the validation dataset.

	Training dataset	Validation dataset
Work disability		

U-IBDODI	0,760	0,839
W-IBDODI	0,771	0,837
General disability		
U-IBDODI	0,713	0,675
W-IBDODI	0,765	0,676
Degree of general disability		
U-IBDODI	0,669	0,642
W-IBDODI	0,686	0,606

Supplementary table 1: Scores used to assess disability in patients with IBD.

Score	Features
WHODAS	***Measure type:*** General disability. Non-IBD-specific. ***Items:*** 12 ***Time horizon:*** previous 30 days. ***Measures:*** Self-reported subjective impairment; 5-point Likert scale (none-extreme). ***Domains:*** Cognition, mobility, self-care, interactions, life activities, community participation.
IBD-DI	***Measure type:*** General disability Specific to IBD. ***Items:*** 28 ***Time horizon:*** 1 week. ***Measures:*** a) Self-reported subjective impairments; 5-point Likert scale (none-extreme). (n=13) b) BMI, number of stools last week, 2 dichotomous variables (weight loos, arthralgia) 1 with 3 responses (blood in stool) c) Reported by clinician plus patient, 5-point Likert scale (n=10) ***Domains:*** Overall health, bodily functions, bodily structures, activity participation, and environmental factors
IBD-Disk	***Measure type*:** General disability. Specific to IBD. ***Items:*** 10 ***Time horizon:*** 1 week. ***Measures*:** self-reported subjective impairment, visual Analogic Scale (1-10) *Domains:* Overall health, bodily functions, bodily structures, activity participation, and sexual function
IBD-DS	***Measure type:*** General disability. Specific to IBD. ***Items*:** 49 ***Time horizon:*** 1 month.

	Measures**:** self-reported subjective impairment 45 5-point Likert scale, 4 dichotomous. ***Domains*****:** Mobility, self-care, main daily life activities, digestive tract-related issues, mental health, and environmental interaction
WSAS	***Measure type:*** General disability. Non-specific to IBD, ***Items:*** 5 ***Time Horizon:*** Non specified. ***Measures*****:** self-reported subjective impairment, 8-point Likert scale, ***Domains:*** Work, household, management, private leisure, social leisure, and intimate relationships
CD-WDQ UC-WDQ	***Measure type:*** Work incapacity Specific to IBD. ***Items:*** 9 ***Time Horizon:*** previous year. ***Measures:*** Subjective evaluation, 4-point Likert scale ***Domains:*** physical and psychiatric symptoms, social impairment

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