# **Original Article**

# Maladaptive coping, low self-efficacy and disease activity are associated with poorer patient-reported outcomes in inflammatory bowel disease

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# **Abstract Background/Aims:** Patient-reported outcomes (PRO) are key aspects in the management of inflammatory bowel disease (IBD). This study aims to evaluate factors associated with adverse PRO, including modifiable social constructs of maladaptive coping and self-efficacy as well as physician–patient concordance on PRO.

**Patients and Methods:** This cross-sectional study was performed in patients with Crohn's disease (CD) or ulcerative colitis (UC) from September 2015 to March 2016. Validated questionnaires were used to assess quality of life (Short IBD Questionnaire), disability (IBD disability index), productivity (work productivity and activity impairment questionnaire), anxiety/depression (Hospital Anxiety and Depression Scale), coping strategies [Brief Coping Operations Preference Enquiry (Brief COPE)], and self-efficacy (General Self-Efficacy Scale). Independent physician assessment was used to compare concordance with patients.

**Results:** In all, 207 (CD: 144 and UC: 63) patients, with median age of 39 years, were included, with 42.5% males. Significant proportion of patients reported moderate/severe impairment of disability (30.5%), quality of life (29.4%), productivity (52.4%), anxiety (32.9%) and depression (23.3%). Disease activity and maladaptive coping were independently associated with unfavourable PRO, whereas self-efficacy had a positive effect in multivariate analysis. Physicians could accurately identify the magnitude of PRO impairment in standard clinical settings (r = 0.59-0.65, P < 0.001).

**Conclusion:** Disease activity and modifiable psychological constructs are associated with unfavorable PRO in patients with IBD. These factors could assist with identifying high-risk patients, many of whom may benefit from targeted interventions to improve health outcomes.

**Keywords:** Biopsychosocial, inflammatory bowel disease, patient-reported outcomes, physician–patient concordance

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# **INTRODUCTION**

# Crohn's disease (CD) and ulcerative colitis (UC) are chronic relapsing inflammatory bowel diseases (IBDs) which can lead to debilitating symptoms and complications along with significant impact on patients' well-being. The negative impacts of the disease on patient-reported outcomes (PROs) such as quality of life, disability, work productivity, depression, and anxiety have been clearly demonstrated in the IBD patient population.<sup>[1-4]</sup> Key success to patient treatment not only involves control of clinical symptoms but is also dependent on being aware of and improving these relevant PROs.<sup>[5-7]</sup>

Coping strategies are psychological or behavioral adaptations that a person may utilize to improve the outcome of complex and stressful situations such as those experienced by patients with IBD. Coping can generally be divided into maladaptive versus adaptive; that is, whether reactive behaviors were unconstructive and led to increased stress or conflicts versus those resulting in improved control of the situation.<sup>[8,9]</sup> Certain coping behaviors may be associated with poor quality of life, psychological distress, depression and anxiety in the IBD population, and risk of disease relapse.<sup>[10,11]</sup> Similarly, self-efficacy is another potentially modifiable psychological construct that is associated with health outcomes in a multitude of chronic illnesses.<sup>[12]</sup> Self-efficacy refers to a person's perceived ability to navigate and manage certain complex situations, which include adherence to complex treatment regimens, lifestyle modifications and surveillance programs in IBD. Further understanding of how these modifiable social constructs and pertinent PROs interact, may assist in identifying high-risk patients and developing adjunctive therapeutic options to improve outcomes in patients with IBD.

High discordance between physician and patient perception of health outcomes has been repeatedly demonstrated in IBD and multiple other chronic illnesses in the past.<sup>[13]</sup> Discordance in turn leads to unfavorable outcomes, decreased patient satisfaction and adherence, along with higher healthcare utilization. However, increasing awareness and emphasis on the management of PROs in the recent years may have improved physicians' ability to assess the magnitude of PRO-related impact on patients.

This study therefore aims to evaluate the factors associated with adverse PROs, including modifiable social constructs of coping and self-efficacy in a Canadian IBD cohort. We also aimed to assess the physician-to-patient concordance on these outcomes.

# PATIENTS AND METHODS

# Patient population

We conducted a cross-sectional study of consecutive patients with established CD or UC, diagnosed as per standard clinical, radiologic, endoscopic and histological criteria followed at the McGill University Health Centre (MUHC) IBD center, between September 2015 and March 2016. Patients were 18 years of age or older with a diagnosis of UC or CD and provided informed consent for study participation. Patients with indeterminate colitis, ileostomy, or colostomy were excluded.

#### Data collection and assessment tools

All patients were invited to participate in the study at the time of their outpatient clinic review by study investigators independent to the clinical service. Patients were asked to complete questionnaires during a single clinic visit. Patient demographics including age, gender, education, marital, employment, and insurance information were also collected.

Patients were assessed for PROs including quality of life, disability and productivity using validated Short IBD Questionnaire (SIBDQ),<sup>[14]</sup> IBD disability index (IBDDI),<sup>[15]</sup> and work productivity and activity impairment questionnaire (WPAI),<sup>[16]</sup> respectively. The scoring procedure and categorization of the scores into severity groups (Mild, moderate, severe or no impairment) were congruent with published studies. An SIBDQ score of less than 45 was considered as poor quality of life. IBDDI score of 36-50 was of moderate disability and more than 50 was severe. Similarly, 20%-49% of productivity loss was considered as moderate degree and 50% or more was severe. The PRO assessment of psychological distress was performed using Hospital Anxiety and Depression Scale (HADS).<sup>[17]</sup> Score of 8-10 was considered as mild symptoms and 11 or more was deemed as moderate to severe for both the anxiety and depression components.

Brief Coping Operations Preference Enquiry (Brief COPE)<sup>[9]</sup> questionnaire was used for assessing coping strategies. Specific behaviors tested in the Brief COPE include denial, substance use, behavioural disengagement, venting, self-blame, self-distraction, active coping, emotional support, instrumental support, positive reframing, planning, humor, acceptance, and religion. The former six items collectively were deemed as maladaptive coping mechanism. General Self-Efficacy Scale (GSES)<sup>[18]</sup> was used for assessment of efficacy construct, with a maximal score of 40 conferring highest

degree of self-efficacy. These questionnaires are well validated and have been used extensively in chronic illness models including IBD.

Patient's clinical information including Montreal classification,<sup>[19]</sup> disease duration, medical therapy, and disease activity assessment were also assessed. Clinical disease activity was defined using the partial Mayo score (PMS; active disease: score of >2) for UC and Harvey Bradshaw index (HBI; active disease: score >4) for CD. Fecal calprotectin (FCP) testing was performed as a surrogate assessment of endoscopic disease activity.

Treating physician was also asked to assess their subjective perception of the severity of each of the PRO at the same clinic visit using a visual analog scale of 0–10 (10 being severe impairment and 0 being no impairment). The physician was blinded to the results of patient's response and vice versa. Concordance of the results was then compared.

## Statistical analysis

Statistical analyses were performed using Statistical Package for the Social Sciences (SPSS 18.0; SPSS Inc., Chicago, IL, USA). All quantitative data were expressed as median with interquartile range (IQR). Percentages were used for qualitative variables. Pearson's correlation coefficient was calculated to assess correlation between variables. For univariate analyses, we used *t*-test and Wilcoxon rank-sum test for continuous variables and  $\chi^2$  test for proportion of discrete variables. PRO scores were categorized in the severity groups based on aforementioned cut-off values for regression analysis. Factors with a P value <0.1 in bivariate analyses were introduced into a multivariate regression model with stepwise selection to calculate the odds ratios (OR) and 95% confidence intervals (CI). All P values were two-tailed, and P values <0.05 were considered statistically significant.

## **Ethical approval**

This study was reviewed and approved by the MUHC research ethics board. The study conduct, evaluation, and documentation were undertaken in accordance with good clinical practice guidelines, applicable local law(s), and regulation(s).

# RESULTS

# **Patient characteristics**

A total of 252 patients were invited to participate in the study. Overall 207 patients (144 CD and 63 UC) agreed for enrolment and were included in the final analysis with a participation rate of 82.1%. The median age was 39 years (IQR 27–53) and 42.5% were male [Table 1].

Table 1: Baseline patient characteristics

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Total patient=207	144 CD/63 UC
Age [years (IQR)]	39 (27-53)
Gender (%)	88 Male (42.5%)
CD Montreal classification (%)	
L1	50 (35.5%)
L2	39 (27.6%)
L3	52 (36.9%)
B1 B2	86 (60.5%)
B2 B3	37 (26.1%) 19 (13.4%)
P	21 (14.6%)
UC Montreal classification (%)	21 (14.0%)
E1	15 (23.8%)
E2	14 (22.2%)
E3	34 (54%)
Medications (%)	
5ASA	56 (27.1%)
Corticosteroid	15 (7.2%)
Immunomodulators	48 (23.2%)
Monoclonal antibody	109 (52.7%)
biologic	
Disease duration (%) (years)	
<5	56 (27.1%)
5-10	29 (14%)
10	122 (58.9%)
Active disease [HBI >4 / PMS >2 (%)]	FO (04 0%)
Total UC	50 (24.2%)
CD	16 (25.4%) 34 (23.6%)
Education (%)	34 (23.0%)
Secondary	37 (17.9%)
Postsecondary/vocational	49 (23.7%)
Tertiary	114 (55.1%)
Data unavailable	7 (3.3%)
Marital status (%)	( )
Single	88 (42.5%)
Married/de facto relationship	100 (48.3%)
Divorced	10 (4.8%)
Widowed	1 (0.5%)
Data unavailable	8 (3.9%)
Employment (%)	
Employed	164 (79.2%)
Unemployed	29 (14%)
Retired	12 (5.8%)
Data unavailable	2 (1%)
Insurance status (%)	124 (50 0%)
Public/government Private	124 (59.9%) 73 (35.3%)
Data unavailable	10 (4.8%)
	10 (4.0%)

CD: Crohn's disease; UC: Ulcerative colitis; IQR: Interquartile range; 5ASA: 5-aminosalicylate acid; HBI: Harvey Bradshaw index; PMS: Partial Mayo score

The percentages for CD disease distribution involving the small bowel, colon or both were 35.5%, 27.6%, and 36.9%, respectively. The majority of patients with CD were of inflammatory phenotype (60.5) and 14.6% had perianal involvement. For UC, 54% of the patients had pancolitis. 52.7% of patients were receiving monoclonal antibody therapy (predominantly antitumor necrosis factor alpha) with 23.2% on immunomodulators, and 7.2% on corticosteroids. About 27.1% of patients were diagnosed within 5 years of study entry. Fifty patients (24.2%) had active disease as defined by the clinical criteria. Furthermore,

FCP results were available for 111 patients (53.6%), and among them 23.4% had FCP over 250  $\mu$ g/g (reference normal range: 0–50  $\mu$ g/g). Correlation between HBI/PMS and FCP was weak (r = 0.258, P = 0.007).

# Patient-reported outcomes

About 30.5% of patients reported moderate to severe disability. The median IBDDI score was 25 (IQR 13–38) and ranged from 0 to 92. A similar proportion of patients (29.4%) reported moderate to severe impairment in quality of life. The SIBDQ score ranged from 20 to 73 with median of 54 (IQR 43–61). Around 52.4% of the study participants reported moderate to severe productivity loss on WPAI. Approximately 32.9% and 23.3% of patients exhibited clinically significant anxiety (median score 6, IQR 3–9) and depressive symptoms (median score 2, IQR 2–7) on HADS, respectively. These results are summarized in Table 2.

The PRO scores correlated well with each other [Table 3]. Using IBDDI as reference, the Pearson's correlation coefficients for SIBDQ, WPAI productivity loss, HADS anxiety, and HADS depression were -0.8, -0.73, -0.69, and -0.65, respectively (P < 0.001 in each instance).

# Coping mechanisms

About 55.1% of patients exhibited the self-distraction form of maladaptive coping [Table 4]. The remainder exhibited venting (23.3%), substance abuse (21.4%), self-blame (18.8%), and denial (17.2%). Behavioral disengagement was seen in 13.2% of patients.

A substantial proportion of patients reported acceptance of their disease (79.1%) and utilized problem-based adaptive behaviors such as active coping (56%), instrumental support (54.4%), and planning (45.6%). Patients also engaged in emotional-based strategies including positive reframing (51.5%), humor (35.3%), emotional support (30.4%), and religion (18.8%).

## Self-efficacy

The median GSES score was 33 with IQR of 7. Higher perceived self-efficacy was weakly associated with education level (r = 0.209, P = 0.003), male gender (r = 0.146, P = 0.035), and inversely associated with clinical disease activity (r = -0.214, P = 0.002). No association was found with age, employment, and marital status. Patients with higher self-efficacy were more likely to report adaptive coping mechanisms (OR: 1.64, 95% CI: 1.30–2.10, P < 0.001).

#### Multivariate analysis

Factors associated with PRO of disability, quality of life

#### Table 2: Patient-reported outcomes

PRO variable	Percentage
IBDDI [median (IQR)]	25 (13-38)
No disability [0-19]	40.3%
Mild disability [20-35]	29.1%
Moderate disability [36-50]	15.5%
Severe disability [51-100]	15%
SIBDQ [median (IQR)]	54 (43-61)
Poor [<45]	29.4%
Normal [45-60]	45.2%
High [>60]	25.4%)
WPAI - productivity loss [median (IQR)]	21 (0-40)
Mild [0-19%]	47.2%
Moderate [20-49%]	32.4%
Severe [≥50%]	20.4%
HADS - anxiety [median (IQR)]	6 (3-9)
Normal [0-7]	67.1%
Borderline [8-10]	18.8%
Abnormal [11-21]	14.1%
HADS - depression [median (IQR)]	2 (2-7)
Normal [0-7]	76.7%
Borderline [8-10]	16%
Abnormal [11-21]	7.3%

IBDDI: IBD disability index; SIBDQ: Short IBD Questionnaire; WPAI: Work productivity and activity impairment questionnaire; HADS: Hospital Anxiety and Depression Scale

impairment, productivity loss, anxiety, and depression were identified using regression analysis [Table 5].

Disability was significantly associated with clinical disease activity (OR: 45.70, 95% CI: 4.30–486.62, P = 0.002) and maladaptive coping (OR: 4.56, 95% CI: 1.72–12.06, P = 0.002) in multivariate analysis. Higher self-efficacy was less likely to be associated with disability (OR: 0.70, 95% CI: 0.57–0.89, P < 0.001). Poor quality of life was also associated with disease activity (OR: 12.08, 95% CI: 2.75–53.01, P = 0.001) and maladaptive coping (OR: 2.59, 95% CI: 1.42–4.74, P = 0.002).

The risk of productivity loss was higher in female patients (OR: 4.31, 95% CI: 1.23–15.13, P = 0.023), clinically active disease (OR: 6.56, 95% CI: 1.90–22.68, P = 0.003), and stricturing CD phenotype (OR: 3.87, 95% CI: 1.14–13.16, P = 0.03); lower in those with higher self-efficacy (OR: 0.83, 95% CI: 0.71–0.97, P = 0.016) in multivariate analysis.

Anxiety was more likely to be associated with clinical disease activity (OR: 15.29, 95% CI: 2.26–103.4, P = 0.005) and maladaptive coping (OR: 2.74, 95% CI: 1.23–6.14, P = 0.014). In contrast, older patients (OR: 0.94, 95% CI: 0.88–0.99, P = 0.045) and those with higher self-efficacy (OR: 0.84, 95% CI: 0.72–0.96, P = 0.013) were less likely to report anxiety. Finally, depression was significantly associated with stricturing CD phenotype (OR: 14.75, 95% CI: 1.02–129.21, P = 0.048), clinically active disease (OR: 11.47, 95% CI: 1.18–185.21, P = 0.037),

Table 3: Correlation between patient report outcome assessment questionnaires	
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	SIBDQ	IBDDI	Productivity loss	HADS - anxiety	HADS - depression
SIBDQ	1.00				
IBDDI	-0.8	1.00			
Productivity loss	-0.73	0.72	1.00		
HADS -anxiety	-0.69	0.75	0.56	1.00	
HADS -depression	-0.65	0.69	0.42	0.81	1.00

\*All P<0.001. IBDDI: IBD disability index; SIBDQ: Short IBD Questionnaire; HADS: Hospital Anxiety and Depression Scale

#### **Table 4: Coping strategies**

	Coping strategies	Percentage
Maladaptive	Self-distraction	55.1%
	Venting	23.3%
	Substance abuse	21.4%
	Self-blame	18.8%
	Denial	17.2%
	Behavioral disengagement	13.2%
Adaptive Emotion-based	Acceptance	79.1%
	Positive reframing	51.5%
	Humor	35.3%
	Emotional support	30.4%
	Religion	18.8%
Adaptive Problem-based	Active coping	56%
	Instrumental support	54.4%
	Planning	45.6%

and maladaptive coping (OR: 4.08, 95% CI: 1.33–12.50, P = 0.014) in multivariate analysis.

Furthermore, regression analysis was performed with patients being stratified into CD or UC subgroups separately [Supplementary Tables 1 and 2]. Similar results to the above findings were found, particularly in the CD subgroup; whereas disease activity and disease duration were the main factors associated with PRO in the UC subgroup.

# Physician and patient concordance

Physician assessments on the severity of quality of life (r = -0.64, P < 0.001), disability (r = 0.65, P < 0.001), and productivity impairment (r = 0.59, P < 0.001) correlated well to patient-reported results on the dedicated questionnaires. Concordance results were less strong following adjustment for clinical disease activity (HBI/PMS), anxiety, and depression (quality of life: r = -0.32; disability: r = 0.37; productivity: r = 0.39; P < 0.001 for all).

# DISCUSSION

This cross-sectional study of a well-characterized tertiary cohort of patients with IBD has highlighted the association of biopsychosocial factors with PRO. This is also the first study to examine the psychological constructs of coping and self-efficacy against the pertinent PRO and physician-patient concordance in the same IBD cohort.

Maladaptive coping strategies were significantly associated with a majority of PROs consistently in this cohort, independent to disease activity in multivariate analysis. Other studies have also shown that the use of these strategies can be associated with social function deficits, psychological distress, perceived disability, lower rated mental, and physical health.<sup>[20,21]</sup> Conversely, adaptive coping behaviors were not associated with health outcomes in this cohort. A smaller study evaluating postoperative patients with IBD with a median follow-up of 15 months also revealed similar findings.<sup>[22]</sup> More patients in this study engaged in adaptive strategies on average than maladaptive ones. In addition to the high acceptance of their illness, a high proportion of them utilized problem-based methods such as planning and instrumental support to manage their disease. Presumably this is partly related to the common use of lifestyle and dietary modifications, among a variety of potential coping strategies to deal with disease- or treatment-associated issues.<sup>[23]</sup> Our results suggest that maladaptive and adaptive behaviors are not necessarily mutually exclusive and the various components can be utilized to varying degrees by the same patient. Specific interventions focused on maladaptive coping behaviors have shown improved outcomes in other chronic disease models including rheumatoid arthritis, human immunodeficiency virus infection, and spinal injuries.[24-26] Currently no effective psychotherapy addressing coping issues in the IBD population has been shown to result in clinically relevant or significant improvement; although this may change if intervention is provided earlier, and, to those at higher risk.<sup>[27]</sup> Further prospective studies are needed to assess if individualized therapy based on the psychometric profile of these high-risk patients would lead to additional benefits. Alternative methods of delivery of psychotherapy such as using the computerized self-guided program may also be of interest to the IBD population with its flexible time commitments, although this may be at the expense of both adherence and expert guidance.<sup>[28]</sup>

Self-efficacy is considered an important determinant of health in IBD, and it is therefore not surprising to find that this construct was associated with lower disability, productivity loss, and anxiety in our study.<sup>[29]</sup> Self-efficacy is thought to be a key factor driving the initiation and execution of disease-coping behaviors.<sup>[30]</sup> Patients with higher self-efficacy were more likely to exhibit adaptive

PRO	Variable	Multivariate analysis
Poor quality of life	Disease activity	OR 12.08 (95% CI 2.75-53.01); P=0.001
	Maladaptive coping	OR 2.59 (95% CI 1.42-4.74); P=0.002
Disability	Disease activity	OR 45.7 (95% CI 4.30-486.62);P=0.002
	Maladaptive coping	OR 4.56 (95% CI 1.72-12.06); P=0.002
	Self-efficacy	OR 0.7 (95% CI 0.57-0.85); P<0.001
Productivity loss	Female	OR 4.31 (95% CI 1.23-15.13); P=0.023
	Stricturing CD	OR 3.87 (95% CI 1.14-13.16); P=0.03
	Disease activity	OR 6.56 (95% CI 1.90-22.68); P=0.003
	Self-efficacy	OR 0.83 (95% CI 0.71-0.97); P=0.016
Anxiety	Disease activity	OR 15.29 (95% CI 2.26-103.4); P=0.005
	Maladaptive coping	OR 2.74 (95% CI 1.23-6.14); P=0.014
	Age	OR 0.94 (95% CI 0.876-0.999); P=0.045
	Self-efficacy	OR 0.84 (95% CI 0.72-0.96); P=0.013
Depression	Stricturing CD	OR 14.75 (95% CI 1.02-129.21); P=0.048
	Disease activity	OR 11.47 (95% CI 1.18-185.21); P=0.037
	Maladaptive coping	OR 4.08 (95% CI 1.33-12.5); P=0.014

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OR: Odds ratio; CI: Confidence interval; CD: Crohn's disease

behaviors in our cohort. Similarly, self-efficacy was highly predictive of adherence to surveillance colonoscopy program in patients with IBD.<sup>[31]</sup> This construct was also associated with transition readiness for adult services in adolescents with IBD.<sup>[32]</sup> Perceived self-efficacy is influenced by external experiences and self-perception, and therefore it could potentially be modified according to the social cognition theory of behavioral change.<sup>[30]</sup> A randomized controlled trial with needs-based education program for patients with rheumatoid arthritis improved patient self-efficacy as well as physical symptoms and psychological health.<sup>[33]</sup> There are also some early results in the IBD population showing promising potential of intervention on this modifiable construct.<sup>[34]</sup>

A significant proportion of patients in this study reported poor outcomes in different components of PRO. The median scores and proportion of patients affected may vary somewhat from different published cohorts, however, and this may be explained by the variability in the proportion of patients enrolled with active disease.[35,36] Clinical disease activity was shown to be a significant and consistent factor in multivariate analysis for poor quality of life, disability, reduced productivity, anxiety, and depression; which is consistent with observations reported elsewhere.<sup>[37,38]</sup> Control of disease activity would also be expected to have an impact on improving PROs. Effective therapeutic regimens such as antitumor necrosis factor alpha agents have been shown to significantly improve disease-specific quality of life and productivity.<sup>[39,40]</sup> Interestingly, FCP, an objective surrogate marker of mucosal inflammation, had weak correlation with clinical activity indices and was not significantly associated with PROs and psychosocial constructs in this study. Indeed, Gracie et al. have demonstrated similarly that psychosocial comorbidities were influenced by clinical symptoms independent of

mucosal inflammation as defined by FCP.<sup>[41]</sup> Clinical symptoms in IBD can also be contributed by other factors such as functional gastrointestinal symptoms, bile salt malabsorption, and small intestinal bacteria overgrowth, in addition to active inflammation. Therefore, treatment algorithm should also focus on managing these issues accordingly.

This study also demonstrated a strong concordance between physician and patients' perception on PRO measures. This may be associated with improved awareness and emphasis on the impact of PRO in the management of IBD in recent years. Participation in the study may also have prompted specific attention on these PROs by the treating physicians. Either way, this suggests that physicians should appreciate the severity of PROs in a standard clinical setting. This could lead to improved awareness, communication, shared decision-making, and ultimately improved outcomes for patients with IBD. However, the concordance for disability, quality of life, and productivity is less robust when it was adjusted for disease activity, anxiety, and depression. Indeed, higher psychological distress and more perceived stress were previously shown to be independently associated with physician-patient discordance.<sup>[13]</sup> Given that these patients are at a higher risk for poorer PROs, additional efforts to facilitate physician to patient communication are warranted.

The strength of this study is supported by a well-defined cohort of patients with IBD and the utilization of well-validated assessment tools on the key PROs and psychosocial constructs of interest. Limitations of this study included its cross-sectional nature which limited our ability to demonstrate a causal relationship between the associations found. We also could not account for the potential fluctuation in psychometric outcomes associated

with the relapse and remitting disease nature of IBD. There could also be selection bias with the voluntary nature of participation and interpretation bias with the use of unguided questionnaires. Patients recruited from our tertiary institution may also not be representative of the entire community of IBD patients. Larger patient size may have assisted in assessing potential differences in disease type (CD vs. UC), gender differences, and further subgroup analysis of patients with active disease versus those in remission.

In conclusion, unfavorable PROs are significantly associated with maladaptive coping and disease activity while self-efficacy had a positive effect. These modifiable constructs could assist in identifying high-risk patients, many of whom may benefit from targeted interventions to improve health outcomes.

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#### **Conflicts of interest**

There are no conflicts of interest.

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# Supplementary Table 1: Multivariate analysis for predictors of patient-reported outcomes – Crohn's disease subgroup

PRO	Variable	Multivariate analysis
-	Disease activity	OR 1.65 (95% CI 1.19-2.28) p=0.002
Poor quality of life	Disease duration >10 years	OR 0.178 (95% CI 0.03-0.99) p=0.049
Disability	Disease activity	OR 2.72 (95% CI 1.33-3.58) p=0.002
	Disease activity	OR 1.76 (95% CI 1.11-2.81) p=0.017
Productivity loss	Disease duration >10 years	OR 0.09 (95% CI 0.01-0.63) p=0.016
Anxiety	÷.	
Depression	Self-efficacy	OR 0.91 (95% CI 0.81-1.02) p=0.093 (trend)

# Supplementary Table 2: Multivariate analysis for predictors of patient reported outcomes – Ulcerative colitis subgroup

PRO	Variable	Multivariate analysis
Poor quality of life	Disease activity	OR 1.65 (95% CI 1.19-2.28) p=0.002
Poor quality of life	Disease duration >10 years	OR 0.178 (95% CI 0.03-0.99) p=0.049
Disability	Disease activity	OR 2.72 (95% CI 1.33-3.58) p=0.002
	Disease activity	OR 1.76 (95% CI 1.11-2.81) p=0.017
Productivity loss	Disease duration >10 years	OR 0.09 (95% CI 0.01-0.63) p=0.016
Anxiety		-
Depression	Self-efficacy	OR 0.91 (95% CI 0.81-1.02) p=0.093 (trend)

