



# Impaired Quality of Working Life in Inflammatory Bowel Disease Patients

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## Abstract

**Background** Work-related aspects are important determinants of health for inflammatory bowel disease (IBD) patients.

**Aims** We aimed to describe quality of working life (QWL) in IBD patients and to assess variables that are associated with QWL.

**Methods** Employed IBD patients of two tertiary and two secondary referral hospitals were included. QWL (range 0–100) was measured using the Quality of Working Life Questionnaire (QWLQ). Work productivity (WP), fatigue, and health-related quality of life (HRQL) were assessed using the Work Productivity and Activity Impairment questionnaire, Multidimensional Fatigue Inventory, and Short Inflammatory Bowel Disease Questionnaire, respectively. Active disease was defined as a score > 4 for the patient-reported Harvey–Bradshaw index in Crohn's disease (CD) or Simple Clinical Colitis Activity Index in ulcerative colitis patients.

**Results** In total, 510 IBD patients were included (59% female, 53% CD, mean age 43 (SD 12) years). The mean QWLQ score was 78 (SD 11). The lowest subscore (54 (SD 26)) was observed for “problems due to the health situation”: 63% reported fatigue-related problems at work, 48% agreed being hampered at work, 46% had limited confidence in their body, and 48% felt insecure about the future due to their health situation. Intermediate/strong associations were found between QWL and fatigue ( $r = -0.543$ ,  $p < 0.001$ ), HRQL ( $r = 0.527$ ,  $p < 0.001$ ), WP loss ( $r = -0.453$ ,  $p < 0.001$ ) and disease activity ( $r = -0.331$ ,  $p < 0.001$ ). Independent predictors of impaired QWL in hierarchical regression analyses were fatigue ( $B = -0.204$ ,  $p < 0.001$ ), WP loss ( $B = -0.070$ ,  $p < 0.001$ ), and impaired HRQL ( $B = 0.248$ ,  $p = 0.001$ ).

**Conclusions** IBD-related problems at work negatively influence QWL. Fatigue, reduced HRQL, and WP loss were independent predictors of impaired QWL in IBD.

**Keywords** Inflammatory bowel disease · Quality of working life · Job satisfaction · Work performance · Fatigue · Quality of life

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## Introduction

Inflammatory bowel disease (IBD), including Crohn's disease (CD) and ulcerative colitis (UC), can lead to disabling symptoms, such as abdominal pain, bloody diarrhea, perianal disease, fatigue, anxiety, and depression. IBD is often diagnosed at an early age, a decisive period in which patients often begin their careers. It has been shown that IBD negatively influences work productivity and that it leads to higher unemployment and work disability rates compared to the healthy population [1, 2].

The working life of IBD patients has been studied in terms of work disability, work productivity losses, and the type of problems at work leading to work productivity loss.

IBD disease activity plays a crucial role in the amount of work productivity loss [3]. In addition, a large proportion of IBD patients experience problems at work even while their disease is in remission [4, 5]. The majority of patients relate these problems to fatigue [4, 5]. Patients who struggle with IBD-related problems at work often experience increased stress levels and impaired quality of life which is why, in certain cases, accommodations to the workplace are needed in order to cope with their illness and (in)ability to work [4, 6]. Job satisfaction is an important factor influencing work performance, and poor work satisfaction might even lead to desertion from the organization [7, 8]. Furthermore, work-related experiences including job satisfaction and occupational balance are considered some of the most important determinants of health for people with Crohn's disease (CD), yet they are not covered in existing patient-reported outcome (PRO) measurements used in CD [9].

The few studies that investigated the type of problems that IBD patients experience in more detail used different (mainly unstructured) strategies to assess work-related problems. For cancer survivors returning to work, the Quality of Working Life Questionnaire (QWLQ) has been developed to objectively measure quality of working life (QWL) [10]. Using the QWLQ, QWL is measured based on five subscales, including the meaning of work for the patient, their impression and perception of the work situation, the atmosphere in the working environment, understanding and recognition of their health situation in the organization, and problems at work due to the health situation. The primary aim of this study was to describe QWL using the QWLQ in an employed IBD cohort. Secondary, we aimed to assess variables that are associated with QWL in IBD.

## Methods

### Study Design and Population

This cross-sectional study was conducted as part of the WORK-IBD study, a prospective web-based study in employed IBD patients [5]. IBD patients between the age of 16 and 63 years old who attended the outpatient clinic at one of four academic and non-academic hospitals between May 1, 2017, and August 31, 2017, were invited to participate by letter. Patients who gave consent for participation and who were employed were eligible for inclusion. Employment was defined as: (1) working as an employee, (2) working as an independent entrepreneur (self-employed), or (3) partially disabled and partially working (receiving partial disability benefits).

### Data Collection and Outcome Measurements

Surveys were completed online by use of the cloud-based Castor Electronic Data Capture (EDC) platform or by paper questionnaire according to patient preference [11]. For this cross-sectional study, data of the baseline questionnaire were analyzed. Questionnaires included the QWLQ to measure QWL [10]. This questionnaire was developed to measure QWL in cancer survivors returning to work and was validated to be used in clinical and occupational healthcare and research settings for this patient population. Other questionnaires included the Work Productivity and Activity Impairment (WPAI) questionnaire [12], the Multidimensional Fatigue Inventory (MFI) [13], and the Short Inflammatory Bowel Disease Questionnaire (SIBDQ) [14] to measure work productivity loss, fatigue, and IBD-specific health-related quality of life (HRQL), respectively. To determine clinical disease activity, patient-reported simple clinical colitis activity index (p-SCCAI) for UC patients and patient-reported Harvey–Bradshaw Index (p-HBI) for CD patients were used [15, 16].

The QWLQ consists of 23 items and is divided into five subscales: (1) meaning of work, (2) impression/perception of the work situation, (3) atmosphere in the working environment, (4) understanding and recognition in the organization, and (5) problems due to the health situation [10]. QWLQ responses were scored on a 6-point scale [totally disagree (1) to totally agree (6)] and higher scores indicated better QWL [17]. Total QWLQ score (0–100) and the five subscale scores (0–100) were calculated when at least 50% of the items were answered [17]. When the “not applicable” category was filled in the case of self-employed patients, this was scored as missing. Work productivity loss was measured with the Work Productivity and Activity Impairment questionnaire and quantified using the percentage absenteeism (calculated based on the percentage of hours missed due to IBD during the past week), presenteeism (based on a 0–10 score of work impairment due to IBD while working), and overall work productivity loss due to IBD in the past week (calculated using the formula:  $\text{absenteeism} + (1 - \text{absenteeism}) \times \text{presenteeism}$ ) [12]. The 20-item Multidimensional Fatigue Inventory (total score 20–100) is divided into five subscores: general fatigue, physical fatigue, reduced activity, reduced motivation, and mental fatigue [13]. A higher score indicates more severe fatigue. The Short Inflammatory Bowel disease Questionnaire consists of 10-items, and the total score ranges from 10 to 70 (best health) [14].

## Statistical Analysis

Continuous data were depicted as mean with standard deviation (SD) or median with interquartile range (IQR) according to distribution, categorical data as frequencies with percentages. Categorical variables were compared using Chi-square tests or Fisher's exact tests, and continuous data were compared using independent samples *T* tests or Mann–Whitney *U* tests depending on distribution. To analyze potential associations among QWL and other variables (including patient-related, IBD-related, and work-related variables) or patient-reported outcomes (including fatigue, HRQL, and work productivity loss), Pearson's correlations were performed. A correlation coefficient (*r*) value that ranged between 0.5 and 1.0 or  $-0.5$  and  $-1.0$  was considered as a strong association. A low strength of association was assumed for values between 0.1 to 0.3 and  $-0.1$  to  $-0.3$  and intermediate strength for values between 0.3 to 0.5 and  $-0.3$  to  $-0.5$ , respectively. Hierarchical regression analyses were used to assess independent predictors of QWL in IBD patients. In the first step, all significantly ( $p < 0.05$ ) associated patient- and disease-related variables were included; in the second step, all significantly correlated treatment- and work-related variables were included; and in the third step, other patient-reported outcomes that were found to be significantly associated with QWL were added. Outcomes were presented using unstandardized (*B*) and standardized ( $\beta$ ) coefficients and associated *p* values. The amount of variance in QWLQ score explained by the model was presented in terms of the *R* squared ( $R^2$ ) value. A *p* value  $< 0.05$  was considered statistically significant. All analyses were performed with IBM® SPSS® Statistics version 26.

## Results

### Patient Characteristics

In total, 1590 (potentially employed) IBD patients between 15 and 63 years of age were identified out of which 768 (48%) responded to the initial invitation. From these 767 patients, 563 (73%) were eligible, 86 patients declined, and 119 were not eligible. Baseline questionnaires were completed by 536 (95%) patients, after which another 26 patients had to be excluded for complete work disability. A detailed flow diagram of included and excluded patients was published in the previous work [5]. Characteristics of 510 included patients are summarized in Table 1. Patients had a mean age of 43 (SD 12) years, a median disease duration of 11 (IQR 5–20) years, and 59% were female. Forty-eight percent of the patients were diagnosed with UC, 52% had CD, and 21% of the patients reported clinical

**Table 1** Patient demographics

	Total <i>n</i> = 510
Age (years)	43 ± 12
Female gender	299 (59%)
Low level of education <sup>a</sup>	87 (17%)
Active smoking	56 (11%)
Working ≥ 36 h per week	242 (47%)
Managerial position	116 (23%)
Self-employed	85 (17%)
Breadwinner position	270 (53%)
Blue-collar work	25 (5%)
Disease duration (years)	11 (5–20)
Ulcerative colitis	242 (48%)
Proctitis (E1)	39 (16%)
Left sided (E2)	82 (34%)
Extensive (E3)	113 (47%)
Crohn's disease	268 (53%)
Ileal (L1)	83 (31%)
Colonic (L2)	67 (25%)
Ileocolic (L3)	113 (42%)
Upper GI (+L4)	19 (7%)
Stricture or penetrating (B2 or B3)	103 (38%)
Clinical disease activity <sup>b</sup>	107 (21%)
Active perianal disease <sup>c</sup>	28 (10%)
Active arthralgia	163 (32%)
Failed ≥ 1 biological	166 (33%)
Corticosteroid use	28 (6%)
Mesalamine use	184 (36%)
Immunomodulator use <sup>d</sup>	154 (30%)
Anti-TNF use	123 (24%)
Vedolizumab use	26 (5%)
Ustekinumab use	12 (2%)
Stoma	28 (6%)
Ileal pouch-anal anastomosis	14 (3%)

<sup>a</sup>Low level of education includes elementary school (no secondary or higher education); anti-TNF, anti-tumor necrosis factor; <sup>b</sup>Patient-reported Simple Clinical Colitis Activity Index or patient-reported Harvey–Bradshaw index  $> 4$ ; <sup>c</sup>Only measured in Crohn's disease patients; <sup>d</sup>Immunomodulatory included thiopurines or methotrexate

disease activity at the time of completing the questionnaires. Almost half of the patients (47%) reported an employment contract of at least 36 h per week and 17% were self-employed.

### Quality of Working Life

Mean (SD) scores of the QWLQ subscales and QWLQ total score are depicted in Fig. 1. The mean QWLQ score was 78 (SD 11). In general, high mean scores were found

for the subscales importance of work [mean 84 (SD 15)], impression/perception of the work situation [mean 82 (SD 13)], atmosphere in the working environment [mean 81 (SD 14)], and understanding and recognition in the organization [mean 76 (SD 17)]. For these subscales, more than 70% of patients scored 5 or 6 on the 6-point scale for all individual items [totally disagree (1) to totally agree (6)], indicating substantial agreement with statements such as “working provides structure in my life,” “I feel a positive atmosphere in my work environment,” “my manager understands my health situation,” and “employees with health complaints are treated well within my organization.” The item “I am satisfied with my salary” was the only statement that less than 70% of patients substantially agreed to (score of 5 or 6). The lowest mean score of 54 (SD 26) was found for the subscale “problems due to the health situation.” In the total IBD cohort, 63% (317/507) of patients reported having problems at work that were associated with fatigue and low energy, 48% (145/507) agreed being hampered at work due to their health situation, 46% (231/507) had limited confidence in their body, and 48% (245/507) of patients felt insecure about the future due to their health situation (Table 2).

**Variables Associated with Quality of Working Life (QWL)**

A strong positive association was found between QWL and HRQL ( $r=0.527, p<0.001$ , Fig. 2a). Significant positive associations of low strength were detected between QWL and level of education ( $r=0.124, p=0.005$ ) and the number of working hours (contract hours) per week ( $r=0.157, p<0.001$ ). A strong negative association was observed between QWL and fatigue ( $-0.543, p<0.001$ , Fig. 2b). Associations of intermediate strength were found amid QWL and the percentage of overall work productivity loss (absenteeism + presenteeism) in the past week related to IBD ( $r=-0.453, p<0.001$ , Fig. 2c) and between QWL and clinical disease activity ( $r=-0.331, p<0.001$ ). Arthralgia

( $r=-0.170, p<0.001$ ) and corticosteroid use ( $r=-0.105, p=0.018$ ) were significantly associated with QWL, yet the association was of low strength. Differences in mean (SD) QWLQ scores according to the presence or absence of the variables clinical disease activity, arthralgia, and corticosteroid are shown in Fig. 3. Other factors, including type of diagnosis (CD versus UC,  $r=-0.049, p=0.270$ ), gender ( $-0.003, p=0.949$ ), age ( $r=0.058, p=0.196$ ), active perianal disease ( $r=-0.003, p=0.966$ ), prior surgery ( $-0.006, p=0.888$ ), and disease duration ( $r=0.022, p=0.618$ ), were not significantly correlated with QWL.

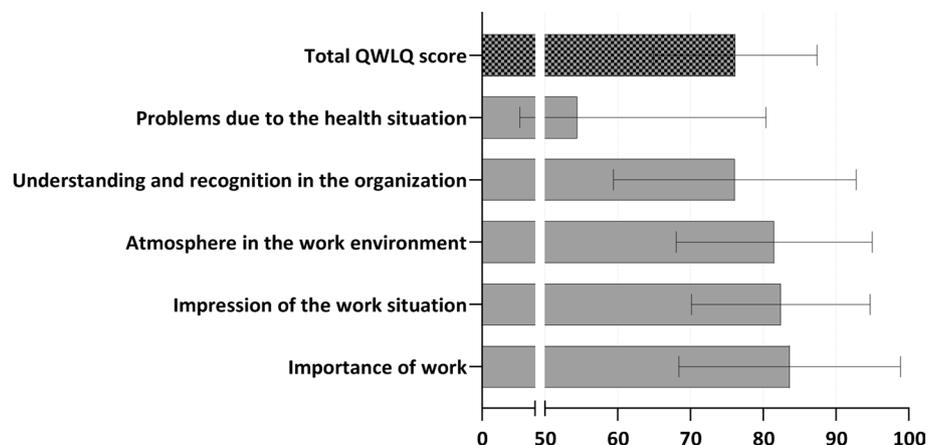
**Predictors of Impaired Quality of Working Life**

Multivariable hierarchical regression analyses (Table 3) revealed that work productivity loss ( $B=-0.070, p<0.001$ ) and fatigue ( $B=-0.204, p<0.001$ ) were independent negative predictors of QWL. HRQL was found to be an independent positive predictor of QWL ( $B=0.248, p=0.001$ ). The model comprising the factors such as clinical disease activity, active arthralgia, oral corticosteroid use, amount of contract hours per week, level of education, percentage work productivity loss, fatigue, and HRQL explained the proportion of variance in QWL by 37% ( $R^2=0.369$ ).

**Discussion**

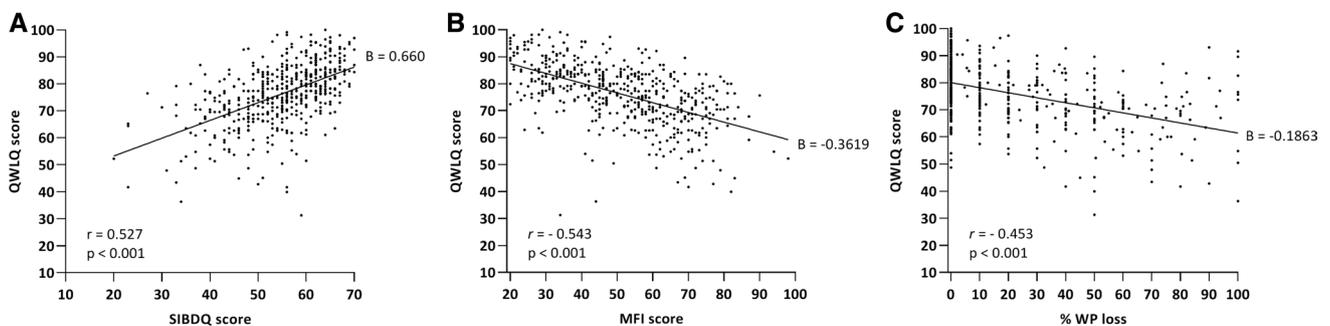
We here explored QWL in IBD patients using the QWLQ that was initially developed to objectively measure QWL in cancer survivors returning to work [10]. Since other available QWL questionnaires were developed for healthy employees and did not include effects of an existing disease, the QWLQ seems the best available QWL questionnaire to be used in IBD to date [18]. Important items in the QWLQ that were formulated based on focus groups with cancer survivors were: (1) problems with fatigue that negatively influence work, (2) poor confidence in their own body, and

**Fig. 1** Quality of working life in inflammatory bowel disease patients. Mean (SD) total Quality of Working Life Questionnaire (QWLQ) score and subscores of the total IBD cohort



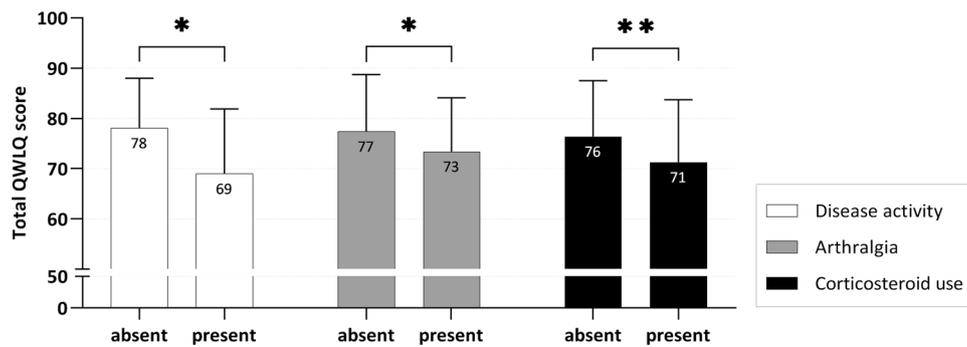
**Table 2** Quality of Working Life Questionnaire (QWLQ) scores per item

	Substantial disagreement <i>N</i> (%)	A little disagreement <i>N</i> (%)	A little agreement <i>N</i> (%)	Substantial agreement <i>N</i> (%)	Total answers <i>N</i>
<i>Meaning of work</i>					
1 Work provides structure in life	12 (2.4)	4 (0.8)	60 (11.9)	430 (85.0)	506
2 Work is important/valuable	7 (1.4)	6 (1.2)	23 (4.5)	470 (92.9)	506
3 Work provides a goal in life	26 (5.1)	17 (3.3)	90 (17.6)	374 (73.9)	506
4 My job is important	8 (1.6)	8 (1.6)	60 (11.9)	430 (85.0)	506
<i>Perception of work situation</i>					
5 I am doing my job well	2 (0.4)	3 (0.6)	29 (5.7)	472 (93.3)	506
6 Feeling confident at work	5 (1.0)	16 (3.2)	69 (13.6)	416 (82.2)	506
7 Feeling competent for job	3 (0.6)	8 (1.6)	28 (5.5)	467 (92.3)	506
8 Feeling in charge while working	17 (3.4)	12 (2.4)	90 (17.8)	388 (76.5)	507
9 Feeling powerless at work	430 (84.8)	21 (4.1)	41 (8.1)	15 (3.0)	507
<i>Atmosphere in working environment</i>					
10 Positive atmosphere in work environment	19 (3.7)	32 (6.3)	69 (13.6)	387 (76.3)	507
11 Being taken seriously by people in work environment	9 (1.8)	12 (2.4)	43 (8.5)	443 (87.4)	507
12 Satisfied with job	22 (4.3)	25 (4.9)	63 (12.5)	396 (78.3)	506
13 Good relationships with colleagues	9 (1.9)	8 (1.7)	34 (7.1)	435 (91.0)	478
14 Feeling valuable to colleagues	5 (1.0)	7 (1.5)	46 (9.6)	422 (87.9)	480
<i>Understanding/recognition in organization</i>					
15 Manager understands health situation	17 (4.8)	15 (4.2)	46 (13.0)	277 (78.0)	355
16 Good relationship with manager	14 (3.2)	15 (2.4)	47 (10.8)	359 (82.5)	435
17 Employees with health complaints are treated well within organization	26 (6.3)	25 (6.1)	61 (14.8)	299 (72.7)	411
18 Satisfied with fringe benefits	29 (7.6)	10 (2.6)	47 (12.3)	296 (77.5)	382
19 Satisfied with salary	59 (11.6)	30 (5.9)	118 (23.3)	300 (59.2)	507
<i>Problems due to health situation</i>					
20 Problems at work with fatigue and energy due to health situation	167 (32.9)	23 (4.5)	151 (29.8)	166 (32.7)	507
21 Hampered at work due to health situation	220 (43.4)	42 (8.3)	142 (28.0)	103 (20.3)	507
22 Limited confidence in body due to health situation	229 (45.2)	47 (9.3)	136 (26.8)	95 (18.7)	507
23 Insecure about future due to health situation	218 (43.0)	44 (8.7)	127 (25.0)	118 (23.3)	507



**Fig. 2** Associations between quality of working life and fatigue, IBD-specific health-related quality of life, and work productivity loss. **a** Association between quality of working life (quality of working life questionnaire (QWLQ) score) and health-related quality of life (short inflammatory bowel disease questionnaire (SIBDQ) score). **b** Association between quality of working life (QWLQ score) and fatigue

(Multidimensional Fatigue Inventory (MFI) score). **c** Association between quality of working life (QWLQ score) and overall work productivity loss due to IBD in the past week (percentage of work productivity (WP) loss). *B* unstandardized regression coefficient, *r* Pearson's correlation coefficient



**Fig. 3** Quality of working life according to the presence of disease activity, arthralgia and corticosteroid use. Mean (SD) total Quality of Working Life Questionnaire (QWLQ) scores compared between

the absence and presence of clinical disease activity (p-HBI or p-SCCAI > 4), arthralgia and corticosteroid use at the time of completing the questionnaire. \* $p < 0.0001$ ; \*\* $p = 0.018$

**Table 3** Predictors of quality of working life (hierarchical regression analysis)

	<i>B</i>	$\beta$	<i>R</i> <sup>2</sup>	<i>p</i> value
<i>Step 1</i>				
Clinical disease activity <sup>a</sup>	-8.487	-0.308	0.113	0.000
Active arthralgia	-1.659	-0.069		0.122
<i>Step 2</i>				
Clinical disease activity <sup>a</sup>	-8.024	-0.291	0.143	0.000
Active arthralgia	-1.316	-0.055		0.216
Oral corticosteroid use	-4.633	-0.094		0.024
Contract hours per week	0.111	0.109		0.010
Level of education <sup>b</sup>	1.214	0.083		0.051
<i>Step 3</i>				
Clinical disease activity <sup>a</sup>	-0.991	-0.036	0.369	0.427
Active arthralgia	1.438	0.060		0.128
Oral corticosteroid use	-3.062	-0.062		0.085
Contract hours per week	0.040	0.039		0.293
Level of education	0.946	0.064		0.078
Work productivity loss (%)	-0.070	-0.169		0.000
Fatigue (total MFI score)	-0.204	-0.307		0.000
HRQL (total SIBDQ score)	0.248	0.197		0.001

<sup>a</sup>Defined as a patient-reported Simple Clinical Colitis Activity Index or patient-reported Harvey–Bradshaw index score > 4; <sup>b</sup>Unstandardized regression coefficient,  $\beta$  standardized regression coefficient, *MFI* Multidimensional Fatigue Inventory, *HRQL* health-related quality of life, *R*<sup>2</sup> the proportion of the variance in Quality of Working Life Questionnaire (QWLQ) score explained by the model, *SIBDQ* Short Inflammatory Bowel Disease Questionnaire

(3) feeling insecure about the future, items that are known problems reported by patients with IBD [5, 19, 20]. The QWLQ measures QWL based on five concepts, including the meaning of work for the patient, the perception of the work situation, the atmosphere in the working environment, understanding and recognition of the health situation in the organization, and problems at work due to the

health situation. It was previously shown that CD patients consider work-related aspects, such as job satisfaction and occupational balance, among the most important determinants of health. Still, this factor is not covered in existing PRO measurements used in IBD [9]. In addition, job satisfaction is known to influence work performance, and poor satisfaction might even lead to desertion from the organization [7, 8]. A mean QWLQ score of 78 (SD 11) was found in our IBD cohort (scale 0–100), which is comparable to the mean QWLQ score of 75 (SD 12) that was observed in cancer survivors returning to work [21]. The relatively high QWLQ score that we found is in line with results of a French nationwide study that revealed job satisfaction in 76% of IBD patients, despite the fact that 50% of them stated that working with IBD was a problem [22]. As expected, IBD patients scored the lowest on the subscale “problems due to the health situation” (mean 54, SD 26). This subscore was slightly higher compared to cancer survivors who had returned to work (mean 49, SD 27) [21].

Disease-related variables that were associated with impaired QWL in IBD patients included clinical disease activity, presence of arthralgia, and systemic corticosteroid use. However, in multivariable hierarchical regression analyses only PROs that measured fatigue, HRQL, and work productivity loss were found to be independent predictors of QWL. These results are in line with previous work from our group in which we revealed that, despite disease activity, fatigue is the most relevant factor accounting for work productivity loss in IBD [5]. In addition, arthralgia complaints were significantly correlated with the presence of severe fatigue [5]. Fatigue is a frequently mentioned symptom expressed by IBD patients at the outpatient clinic. It affects approximately 50% of patients in clinical remission and > 80% of patients with active disease and significantly impairs daily life of IBD patients [23]. Therefore, awareness of this association between fatigue and impaired QWL is of great importance. However, the pathophysiology of fatigue

is complex and multidimensional. Healthcare professionals who treat IBD patients should address potential causes of fatigue, by timely optimization and upscaling of therapies in patients with active inflammation, recognizing potential side effects and comorbidities, evaluating nutrient deficiencies and addressing psychological comorbidities and sleep disturbances [23]. Patients might benefit from psychological interventions, physical activity, or even pharmacological or microbiota-directed interventions [23].

In cancer survivors returning to work, QWL was impaired in patients without a managerial position, in patients that worked less than 100% of their contract hours (work productivity loss), in patients with a lower gross income (< €1000) and in patients with high physically demanding work [21]. In contrast, we did not find significant associations with regard to QWL considering the variables managerial position and blue-collar (physical demanding) work. Yet, in line with results obtained in cancer survivors, we found associations of low strength between impaired QWL and lower education level (which may be associated with a lower income) and between impaired QWL and a lower number of working hours per week. Although these factors were not independently predictive for impaired QWL after associations were corrected for fatigue, HRQL, and work productivity loss.

This is the first study in which QWL was explored in IBD patients using the QWLQ, an objective and validated PRO. In addition, we used validated PROs to measure fatigue, IBD-specific HRQL, and work productivity loss. For this study, a relatively large number of IBD patients were included from secondary and tertiary referral hospitals. This has led to a variety of IBD patients with different disease severity stages and treatment regimens, which has contributed to external validity. However, certain limitations need to be addressed. First, while the QWLQ is a validated PRO tool to measure QWL in cancer survivors returning to work, it has not been validated to measure QWL in the IBD population. It might be that certain questions in the QWLQ are not that meaningful for IBD patients when compared to cancer survivors. Lack of IBD-specific questions in the QWLQ could have led to the absence of a significant association between disease activity and impaired QWL in our multivariable analyses after introducing other patient-reported outcomes. On the contrary, the QWLQ only contains generic questions without disease-related symptoms and was developed using a healthy control group. Nonetheless, the comparable QWLQ scores between IBD patients and cancer survivors and the (univariable) association of QWL with disease activity and fatigue suggest that the QWLQ is useful to measure QWL in IBD patients. Although validated PROs were used to measure fatigue, disease-specific HRQL, and work productivity, it was recently shown that the majority of PROs appear to have low-quality content validity and lacked patient involvement in the development and

evaluation [24]. Other limitations include the cross-sectional study design and potentially induced selection bias due to patients who declined participation. In addition, the response rate of patients that participated seemed low (510 eligible participants out of 1590 potentially eligible IBD patients). However, the actual response rate might be higher due to the fact that a selection of the 1590 invited IBD patients was not employed and therefore was not eligible to participate in the first place. Lastly, IBD disease activity was measured using a PRO tool, while no biochemical or endoscopic parameters were used. Self-reported disease-activity sometimes correlates poorly with endoscopic disease activity, especially in CD patients [25, 26], and this might therefore be an indicator of perceived burden of disease.

This cross-sectional study demonstrates that disease-related variables that indicate the presence of active disease (such as clinical disease activity, arthralgia and corticosteroid use) are associated with impaired QWL in IBD patients, yet these variables are not independently predictive for QWL. However, fatigue, impaired IBD-specific HRQL, and work productivity loss were revealed to be independent predictors of impaired QWL. This study will hopefully increase the awareness regarding the presence of IBD-related problems at work that negatively impact QWL, even in the absence of disease activity. Based on this knowledge, it is important to identify patients with increased risk of impaired QWL at an early stage. These patients might benefit from support (for example, by occupational health physicians) to increase QWL and in certain cases accommodations to the workplace are needed in order to cope with their illness and (in)ability to work. This in turn might lead to less work productivity loss, increased overall quality of life, and lower work disability and unemployment rates in IBD patients. QWL might be considered a new and important PRO in future studies in IBD. The QWLQ is an interesting tool that can be used as a basis for future development of an IBD-specific QWL questionnaire.

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## Compliance with Ethical Standards

**Conflict of interest** SG: none; NB: has served as a speaker for AbbVie, Takeda, and MSD. He has served as consultant and principal investigator for Takeda and TEVA Pharma B.V. He has received a (unrestricted) research grant from Dr. Falk, TEVA Pharma B.V, MLDS, and Takeda; MG: none; SR: none; KG: has received consultancy fees and/or speaker's honoraria from AbbVie, Celltrion, Ferring, Immunic Therapeutics, Janssen, Pfizer, Roche, Sandoz, Samsung Bioepis, Takeda, and Tillotts; CP: has served as a speaker for Takeda, Tillotts, and Roche. He has served as advisor for Takeda, Pliant, and Shire. He

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**Ethical approval** For this study a waiver was granted by the Medical Ethics Review Committee of the Academic Medical Center. The Medical Research Involving Human Subjects Act (WMO) did not apply to this study (W17\_190).

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