

Original Article

Back/joint Pain, Illness Perceptions and Coping are Important Predictors of Quality of Life and Work Productivity in Patients with Inflammatory Bowel Disease: a 12-month Longitudinal Study

Mike van der Have*¹, Lianne K. P. M. Brakenhoff*², Sanne J. H. van Erp², Ad A. Kaptein³, Max Leenders¹, Margreet Scharloo³, Roeland A. Veenendaal², Désirée M. F. M. van der Heijde⁴, Andrea E. van der Meulen-de Jong², Daan W. Hommes^{2,5}, Herma H. Fidder^{1,2}

¹Department of Gastroenterology and Hepatology, University Medical Centre Utrecht, Utrecht, The Netherlands

²Department of Gastroenterology and Hepatology, Leiden University Medical Centre, Leiden, The Netherlands

³Section of Medical Psychology, Leiden University Medical Centre, Leiden, The Netherlands ⁴Department of Rheumatology, Leiden University Medical Centre, Leiden, The Netherlands ⁵Centre for Inflammatory Bowel Diseases, UCLA Health System, Los Angeles, CA, USA

*These authors contributed equally to the article.

Corresponding author: Mike van der Have, MD, Department of Gastroenterology and Hepatology, UMCU, PO Box 85500, 3500 GA Utrecht, The Netherlands. Tel: 0031 08875 50721; Fax: 0031 08875 55533; Email: M.vanderhave@umcutrecht.nl

Abstract

Background and aims: Back and joint pain are the most common extraintestinal symptoms reported by patients with inflammatory bowel disease (IBD). We assessed the impact of back/joint pain, illness perceptions, and coping on quality of life (QOL) and work productivity in patients with IBD.

Methods: Our cohort included 155 IBD patients with and 100 without arthropathy. Arthropathy was defined as daily back pain for ≥ 3 months and/or peripheral joint pain and/or joint swelling over the last year. At baseline and at 12 months, patients completed questionnaires on the extent of back/joint pain, IBD disease activity, illness perceptions, coping, QOL, and work productivity. The impact of back/joint pain, illness perceptions and coping on QOL and work productivity was determined, using linear mixed models.

Results: In total, 204 IBD patients (72% Crohn's disease, 40% male, mean age 44 ± 14 years) completed questionnaires at both time points. At both time points, IBD patients with back/joint pain reported a significantly lower QOL and work productivity compared with IBD patients without back/joint pain. Predictors of low QOL were back/joint pain ($\beta = -1.04$, 95% confidence interval [CI] $-1.40, -0.68$), stronger beliefs about the illness consequences ($\beta = -0.39$, 95% CI $-0.59, -0.18$) and emotional impact of IBD ($\beta = -0.47$, 95% CI $-0.66, -0.28$), and the coping strategy 'decreasing activity' ($\beta = -0.26$, 95% CI $-0.48, -0.03$). Predictors of work productivity were back/joint pain ($\beta = 0.22$, 95% CI $0.07, 0.37$) and illness consequences ($\beta = 0.14$, 95% CI $0.06, 0.22$).

Conclusion: Back/joint pain, illness perceptions, and coping are significant predictors of QOL and work productivity, after controlling for disease activity.

Keywords: Arthralgia; Common Sense Model; coping; illness perceptions; inflammatory bowel disease; quality of life; work productivity

1. Introduction

Arthropathies are the most common extraintestinal manifestations in patients with inflammatory bowel disease (IBD), with prevalence rates ranging between 1 and 46%.^{1–10} In general, arthropathies affect young IBD patients at the peak of their working life and are therefore potentially associated with high morbidity and increased costs.¹¹

IBD-associated arthropathy is considered a subtype of spondyloarthropathy and may involve both peripheral and axial joints. Back and joint pain (hereafter referred to as 'back/joint pain') are the most important clinical manifestations of IBD-associated arthropathy.

Although back/joint pain is major problem in the general population,¹² data on the impact of back/joint pain on the quality of life (QOL) and work disability in patients with IBD are scarce. According to a population-based study³ and a cross-sectional study,⁴ QOL was significantly reduced in IBD patients with non-inflammatory joint pain and self-reported arthritis, respectively. Yet the impact of back/joint pain on work productivity and the relationships between back/joint pain, illness perceptions, coping, and important outcomes such as QOL and work productivity has not been assessed before.^{3,4}

It has been shown clearly that QOL and other health outcomes are associated not only with the disease itself, but also with factors such as illness perceptions and coping. The relationships between disease characteristics, illness perceptions, coping, and health outcome are supported by the Common Sense Model.^{13,14} According to this model, patients generate both cognitive and emotional representations (known as illness perceptions) in response to a perceived health threat or illness. Illness perceptions provide a framework for patients to make sense of their symptoms and create a coherent view of their illness. This in turn guides coping strategies, such as decreasing or pacing activities, with potential impact on health outcomes such as QOL and work productivity. Thus, the impact of illness perceptions on health outcomes may be attenuated by adopting a certain coping strategy.

The efficacy and validity of the Common Sense Model has been shown in patients with various chronic illnesses, such as rheumatoid arthritis and multiple sclerosis.^{15,16} Previous studies in IBD have also found strong relationships between illness perceptions, coping, and various health outcomes, including QOL, psychological distress (depression and anxiety), sexual health, and disability.^{17–25}

Improving our understanding of the relationships between back/joint pain, illness perceptions, and coping behaviors in patients with IBD may provide possible targets for biopsychosocial interventions aimed at reducing morbidity and costs and increasing patients' QOL.

In this prospective study we aimed to examine the impact of back/joint pain, illness perceptions, and coping on QOL and work productivity in a carefully selected group of IBD patients, after controlling for demographic and clinical characteristics.

2. Materials and methods

2.1. Patient population and study design

Between July 2009 and February 2010, 258 IBD patients were systematically assessed by a multidisciplinary team of gastroenterologists and rheumatologists at the JOINT outpatient clinic of the Leiden University Medical Centre. The systematic assessment consisted of a medical history (extraintestinal manifestations, medication use), physical examination (distribution of painful joints, enthesitis,²⁶ dactylitis²⁶), laboratory tests (C-reactive protein, erythrocyte sedimentation rate, HLA-B27), and signs of sacroiliitis on X-ray (optional).²⁷ Based on this assessment 155 (60.1%) patients with and 100 (38.8%) patients without arthropathy were identified.

Arthropathy was defined as chronic back pain for at least 3 months, and/or peripheral joint pain/swelling at presentation or during the previous year. Three patients (1.1%) with fibromyalgia were excluded.

Patients were then prospectively followed for 12 months. At baseline and at 12 months of follow-up, patients completed a web-based or postal questionnaire covering demographic characteristics (age, gender, and working status), the presence and extent of back/joint pain, illness perceptions, coping strategies, QOL, work productivity, and activity impairment (see below). Variables concerning IBD subtype and the Montréal classification were obtained from medical records.

As we were primarily interested in the impact of current back/joint pain on QOL and work productivity, the patient population was divided into patients with and without back/joint pain as reported at baseline. Obviously, as we relied on self-reported data, the presence of joint swelling could not be ascertained.

The study was centrally approved by the Ethics Committee of the Leiden University Medical Centre. All patients an signed informed consent form.

2.3. Predictors

2.3.1. Back/joint pain and IBD clinical disease activity

Back/joint pain was quantified using two 11-point numeric rating scales, one for back pain and one for joint pain, ranging from 0 ('no back/joint pain') to 10 ('worst imaginable back/joint pain') during the previous week. The mean score was used for patients reporting both back and joint pain. Clinical IBD activity was measured with the well-validated Harvey–Bradshaw Index (10 items, excluding the question about abdominal mass)²⁷ and the Simple Clinical Colitis Activity Index (nine items)²⁸ for patients with Crohn's disease (CD) and ulcerative colitis (UC), respectively. A score >4 indicated active disease.

2.3.2. Illness perceptions

Illness perceptions were measured with the Revised Illness Perception Questionnaire (IPQ-R).²⁹ For the present study, eight subscales of the IPQ-R were used: Illness identity (number of symptoms that patients associate with IBD); Timeline chronic (expected duration of IBD); Timeline cyclical (expected cyclical symptomatology of IBD); Consequences (negative consequences for the patients' lives); Personal control (perceived personal control over IBD); Treatment control (perceived efficacy of treatment); Emotional representations (negative emotions resulting from IBD); and Coherence (personal understanding of IBD). The Illness identity subscale is calculated by summing the symptoms (range 0–14) that patients associate with IBD. For the other subscales items are rated on a five-point Likert scale (from 'strongly disagree' to 'strongly agree'). To facilitate interpretation of these subscales, mean scores are presented. Subscales showed a high internal reliability (Cronbach's α ranging from 0.76 to 0.89), except for the Treatment control subscale (0.59), which was therefore excluded from further analysis.

2.3.3. Coping

Coping was measured with the COping with Rheumatic Stressors questionnaire (CORS), covering eight coping strategies directed at the most important stressors of immune-mediated inflammatory disease (e.g. IBD), including pain, limitations, and dependency.^{30,31} Coping strategies directed at pain included Comforting cognitions (self-encouragement, putting the pain into perspective; nine items),

Decreasing activities (eight items), and Diverting attention (thinking about something nice; eight items). Coping strategies directed at limitations included Optimism (five items), Pacing (adapting one's level of activity; 10 items), and Creative solution seeking (finding creative solutions to cope with limitations in work, household activities, leisure time, and hobbies; eight items). Coping strategies directed at dependency included Accepting (making an effort to accept one's level of dependency; six items) and Consideration (thoughtful concern for others; seven items). For each item, patients reported how often they employed a particular coping strategy (1 = 'seldom or never', 2 = 'sometimes', 3 = 'often', 4 = 'very often'). Higher scores indicate more frequent use of a particular coping strategy. Internal reliability within the subscales was high (Cronbach's α ranging from 0.78 to 0.86).

2.3.4. Health outcomes: QOL, work productivity, and activity impairment

The QOL was measured with both a disease-specific and a generic questionnaire. The Short Inflammatory Bowel Disease Questionnaire (SIBDQ) was developed as a short version of the IBDQ, and is a simple, validated 10-item questionnaire that assesses disease-specific QOL of patients with IBD.^{32,33} Total scores range from 10 to 70, with a higher score indicating better QOL. The Short-Form 36 (SF-36) is a generic questionnaire comprising 36 items, grouped within a Physical Component Score (PCS) and a Mental Component Score (MCS).³⁴ The PCS consist of physical functioning, role of limitations due to physical health problems, bodily pain, and general health perception. The MCS consists of vitality, social function, role limitations due to personal or emotional problems, and mental health. Each component score has a score ranging from 0 to 100, with a high score indicating better functional status.

The Work Productivity and Activity Impairment questionnaire (WPAI) assesses the impact of IBD on work productivity and daily activities during the previous 7 days.^{35,36} It generates four component scores: percentage of work time missed (absenteeism); percentage of impairment while working (presenteeism); percentage of overall work impairment (absenteeism and presenteeism combined); and percentage of activity impairment. Unemployed patients only answered questions relating to employment status and activity impairment. Scores for WPAI range from 0% ('no impairment') to 100% ('total loss of work productivity/activity').

2.4. Statistics

Data analyses were performed using SPSS 20.0 and SAS 9.2. Descriptive statistics were used to characterize CD and UC patients. Means and medians were reported with a standard deviation (SD) and interquartile range (IQR), respectively. Mean baseline differences with regard to QOL, work productivity, and activity impairment between patients with and without back/joint pain were determined using the paired Student's *t*-test. Univariate analyses were performed to assess associations between back/joint pain, illness perceptions, coping, and outcomes, including QOL, work productivity, and activity impairment. To correct for multiple testing, the level of significance was set at $p < 0.007$ (0.05/7) and $p < 0.006$ (0.05/8) for the illness perceptions (seven IPQ-R subscales) and coping (eight CORS subscales), respectively. Linear mixed models with random intercept were used to assess the independent effects of back/joint pain, illness perceptions, and coping on QOL, work productivity, and activity impairment. Independent variables that reached significance in univariate analyses were included. Based on previous data,³⁷ gender and disease activity were included as

covariates. To assess whether back/joint pain, illness perceptions, and coping contributed to the variance of outcomes, multiple linear mixed models were used. With the Common Sense Model as the theoretical framework, back/joint pain was entered in the first step, illness perceptions in the second step, and coping strategies in the third step. The likelihood ratio test (difference of -2 log likelihood between two steps) was performed to assess whether each step significantly improved our model.

3. Results

3.1. Baseline characteristics of study population

The baseline questionnaire was completed by 245/255 patients (response rate 96.1%), of whom 204 also completed the follow-up questionnaire at 12 months (loss to follow-up 16.7%) (Figure 1). Thus, the 204 patients who completed questionnaires at both time points constituted our study population.

Of the 204 patients, 146 (71.6%) had CD and 58 (28.4%) had UC, with a mean age of 44.3 (SD 13.7) years and a median disease duration of 15.0 (IQR 7.0–24.0) years (Table 1). In CD, ileocolonic disease (65/146; 44.5%), and inflammatory behavior (62/146; 42.5%) were the most common disease phenotypes. In UC, pancolitis (34/58; 58.6%) was the dominant disease phenotype. Based on the numeric rating scale, back/joint pain was present in 113/204 (55.4%) patients, of whom 41 (36.3%) had peripheral joint pain, 8 (7.1%) had back pain, and 64 (56.6%) had mixed complaints. At physical examination, 45/105 (42.9%) patients with peripheral or mixed joint complaints had four or more tender joints (polyarticular). Enthesitis was present in 2 (1.0%) patients, dactylitis in 2 (1.0%), and extraintestinal manifestations in 49 (24.0%) patients. Further investigations revealed an elevated C-reactive protein in 30 (14.7%) patients, elevated erythrocyte sedimentation rate in 42 (20.9%), HLA-B27 seropositivity in 7/118 (5.9%), and sacroiliitis on X-ray in 5/123 (4.1%) patients.

Online Supplementary Material A shows data on baseline demographic and clinical variables in completers and noncompleters. There were no relevant statistically significant differences between the two groups, except that noncompleters had a significantly younger mean age (38.4 versus 44.3 years, $p = 0.011$).

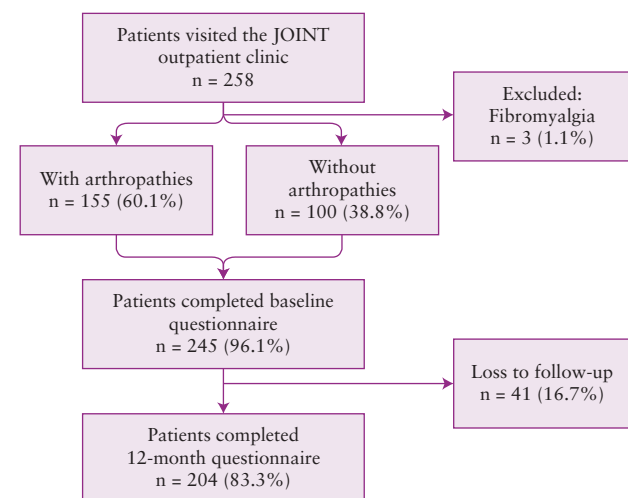


Figure 1. Study flow-chart.

3.2. Baseline levels of quality of life, work, and activity impairment

Patients with IBD who had back/joint pain had significantly lower levels of disease-specific QOL (SIBDQ 47.8 ± 10.7 versus 55.1 ± 8.7) and generic QOL (SF-36-PCS 41.9 ± 8.9 versus 52.1 ± 7.6 ; SF-36-MCS 45.1 ± 10 versus 48.7 ± 8.6) at baseline compared with IBD patients without back/joint pain (Figure 2). Additionally, IBD patients with back/joint pain had significantly higher levels of work impairment (45.0 ± 9.9 versus 22.0 ± 3.3) and activity impairment (37.0 ± 8.1 versus 19.0 ± 2.9) at baseline compared with IBD patients without back/joint pain (Figure 2).

Table 1. Demographic and clinical variables of the study population.

Variable	IBD (n = 204)
Type of IBD, n (%)	
Crohn's disease	146 (71.6)
Ulcerative colitis	58 (28.4)
Age (years), mean (SD)	44.3 (13.7)
Male gender, n (%)	82 (40.2)
Current smoker, n (%)	47 (23.0)
Disease duration (years), median (IQR)	15.0 (7.0–24.0)
Employed, n (%)	128 (62.2)
Montreal classification	
Location of CD, n (%)	
L1 ileal	36 (24.7)
L2 colonic	33 (22.6)
L3 ileocolonic	65 (44.5)
L1–3 + L4 upper	12 (9.5)
Behavior of CD, n (%)	
B1 non-stricturing/penetrating	62 (42.5)
B2 stricturing	22 (15.1)
B3 penetrating	21 (14.4)
+ Perianal disease	41 (28.1)
Extent of UC, n (%)	
E1 ulcerative proctitis	4 (6.9)
E2 left sided UC	20 (34.5)
E3 extensive UC (pancolitis)	34 (58.6)
Current medication use, n (%)	
5-Aminosalicylate	44 (21.6)
Steroids	10 (4.9)
Immunomodulators	45 (22.1)
Anti-tumor necrosis factor agents	56 (27.5)
Axial and/or peripheral joint complaints, n (%)	113 (55.4)
Peripheral joint complaints only	41 (36.3)
Back pain only	8 (7.1)
Mixed complaints	64 (56.6)
Distribution of (painful) peripheral joints, n (%)	
Monoarticular	15 (14.3)
Oligoarticular	45 (42.9)
Polyarticular	45 (42.9)
Enthesitis, ^a n (%)	2 (1.0)
Dactylitis, ^a n (%)	2 (1.0)
Extraintestinal manifestation, ^b n (%)	49 (24.0)
Elevated C-reactive protein, n (%)	30 (14.7)
Elevated erythrocyte sedimentation rate, n (%)	42 (20.9)
HLA-B27, ^c n (%)	7 (5.9)
Sacroiliitis on X-ray, ^d (%)	5/123 (4.1%)

^aEnthesitis and dactylitis are defined in accordance to reference 26.

^bSkin: psoriasis, erythema nodosum, pyoderma gangrenosum. Joints: arthritis, dactylitis, heel enthesitis, ankylosing spondylitis. Eyes: acute anterior uveitis (current or past).

^cHLA-B27 status was available in 118 patients.

^dResults of X-ray were available in 123 patients.

3.3 Predictors of QOL and work activity impairment

Based on the univariate analyses (Online Supplementary Material B), each of the illness perceptions and coping strategies were significantly associated with QOL, work impairment, and activity impairment and were therefore included in multiple linear mixed models. Clinical disease activity was significantly associated with back/joint pain ($\beta = 2.04, p < 0.00$), with a variance inflation factor of 1.00, indicating no multicollinearity.

In the first step of our multivariate model we assessed whether back/joint pain was associated with disease-specific QOL (SIBDQ), generic QOL (SF-36-PCS and SF-36-MCS), work impairment, and activity impairment (Tables 2–4), while controlling for gender and IBD activity. Back/joint pain was significantly associated with SIBDQ ($\beta = -1.04, 95\% \text{ CI } -1.40, -0.68$), SF-36-PCS ($\beta = -1.69, 95\% \text{ CI}$

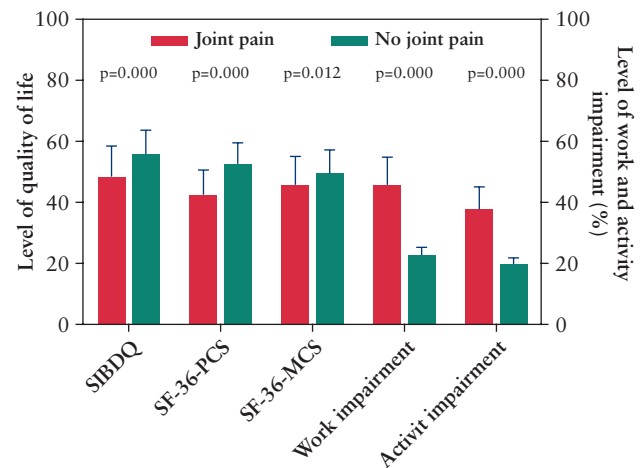


Figure 2. Mean baseline levels of generic quality of life (SF-36-PCS, SF-36-MCS), disease-specific quality of life (SIBDQ), Work and Activity Impairment (WPAI) in IBD patients with (n = 113) and without (n = 91) joint pain.

Table 2. Linear mixed model with SIBDQ as outcome variable and demographic/clinical variables (step 1), illness perceptions (step 2), and coping (step 3) as independent variables.

Predicting variables	Quality of life	
	β	95% CI
Step 1: demographic and clinical variables		
Disease activity	-1.17***	-1.41, -0.93
Joint pain	-1.04***	-1.40, -0.68
Step 2: illness perceptions		
Identity	-0.17	-0.48, 0.14
Consequences	-0.39***	-0.59, -0.18
Personal control	-0.08	-0.27, 0.10
Illness coherence	0.14	-0.08, 0.35
Timeline cyclical	-0.36**	-0.63, -0.10
Emotional representations	-0.47***	-0.66, -0.28
Step 3: coping		
Decreasing activity	-0.26*	-0.48, -0.03
Pacing	0.11	-0.06, 0.28

Results of linear mixed model showing the independent influence of predicting variables on SIBDQ, represented as β = coefficients. These coefficients refer to how many standard deviations SIBDQ will change per standard deviation increase in the predicting variable.

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 3. Linear mixed models with SF-36-PCS and SF-36-MCS as outcome variables and demographic/clinical variables (step 1), illness perceptions (step 2), and coping (step 3) as independent variables.

Predicting variables:	SF-36-PCS		SF-36-MCS	
	β	95% CI	β	95% CI
Step 1: demographic and clinical variables				
Gender	–	–	–0.90	–2.84, 1.03
Disease activity	–0.63***	–0.84, –0.42	–0.58***	–0.84, –0.31
Joint pain	–1.69***	–2.00, –1.38	–0.48*	–0.87, –0.10
Step 2: illness perceptions				
Identity	–0.34*	–0.62, –0.06	–0.01	–0.34, 0.31
Consequences	–0.59***	–0.77, –0.40	–0.21	–0.42, 0.00
Personal control	0.20*	0.03, 0.37	0.09	–0.11, 0.29
Illness coherence	–	–	0.30**	0.08, 0.52
Timeline cyclical	–	–	–0.04	–0.32, 0.23
Emotional representations	0.08	–0.07, 0.24	–0.72***	–0.93, –0.52
Step 3: coping				
Decreasing activity	–0.21*	–0.41, –0.01	–0.42**	–0.66, –0.18
Pacing	–0.17	–0.35, 0.00	0.23	–0.05, 0.51
Creative solutions	–	–	0.03	–0.16, 0.22

Results of linear mixed model showing the independent influence of predicting variables on SF-36-PCS or SF-36-MCS, represented as β coefficients. These coefficients refer to how many standard deviations SF-36-PCS or SF-36-MCS will change per standard deviation increase in the predicting variable.

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 4. Linear mixed model with work productivity and activity impairment (assessed with WPAI) as outcome variables and demographic/clinical variables (step 1), illness perceptions (step 2), and coping (step 3) as independent variables.

Predicting variables	Work productivity		Activity impairment	
	β	95% CI	β	95% CI
Step 1: demographic and clinical variables				
Gender			0.26	–0.22, 0.75
Disease activity	0.41***	0.29, 0.53	0.19***	0.12, 0.25
Joint pain	0.22**	0.07, 0.37	0.48***	0.39, 0.58
Step 2: illness perceptions				
Identity	0.05	–0.08, 0.19	0.10*	0.01, 0.19
Consequences	0.14**	0.06, 0.22	0.13***	0.07, 0.18
Personal control			–0.03	–0.08, 0.02
Illness coherence	–0.08	–0.17, 0.01	0.01	–0.05, 0.07
Timeline cyclical	–0.00	–0.11, 0.10	0.02	–0.06, 0.09
Emotional representations	0.04	–0.04, 0.12	0.06*	0.01, 0.12
Step 3: coping				
Decreasing activity	0.07	–0.02, 0.16	0.10**	0.04, 0.17
Pacing	0.04	–0.04, 0.11	0.02	–0.03, 0.07

Results of linear mixed model showing the independent influence of predicting variables on work productivity or work impairment, represented as β coefficients. These coefficients refer to how many standard deviations work productivity or work impairment will change per standard deviation increase in the predicting variable.

WPAI, Work Productivity and Activity Impairment questionnaire.

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

–2.00, –1.38), SF-36-MCS ($\beta = -0.48$, 95% CI –0.87, –0.10), work impairment ($\beta = 0.22$, 95% CI 0.07, 0.37), and activity impairment ($\beta = 0.48$, 95% CI 0.39, 0.58).

In the second step of our multivariate model we assessed whether the addition of illness perceptions significantly improved our first model, using the likelihood ratio test (difference of –2 log likelihood between the two models). The addition of illness perceptions improved the first model for all health outcomes ($p = 0.01$). Illness consequences were significantly associated with SIBDQ ($\beta = -0.39$, 95% CI –0.59, –0.18), SF-36-PCS ($\beta = -0.59$, 95% CI –0.77, –0.40), work impairment ($\beta = 0.14$, 95% CI 0.06, 0.22) and activity

impairment ($\beta = 0.13$, 95% CI 0.07, 0.18), meaning that low QOL and work and activity impairments were associated with stronger beliefs that IBD will have negative consequences for the person's life. Emotional representations were significantly associated with SIBDQ ($\beta = -0.47$, 95% CI –0.66, –0.28), SF-36-MCS ($\beta = -0.72$, 95% CI –0.93, –0.52), and activity impairment ($\beta = 0.06$, 95% CI 0.01, 0.12), meaning that low QOL and high activity impairments were associated with negative beliefs about how the illness affects one's emotional well-being.

In our third model we assessed whether the addition of coping significantly improved our second model. The addition of coping

improved the second model across SF-36-PCS ($p = 0.00$), SF-36-MCS ($p = 0.00$), and activity impairment ($p = 0.00$). Decreasing activity was significantly associated with SIBDQ ($\beta = -0.26$, 95% CI $-0.48, -0.03$), SF-36-PCS ($\beta = -0.21$, 95% CI $-0.41, -0.01$), SF-36-MCS ($\beta = -0.42$, 95% CI $-0.66, -0.18$), and activity impairment ($\beta = 0.10$, 95% CI $0.04, 0.17$). In addition, we assessed whether the impact of illness perceptions on health outcomes was mediated by particular coping strategies. Decreasing activity mediated the impact of illness identity and illness consequences on both SF-36-PCS and SF-36-MCS.

4. Discussion

In this prospective study of patients with IBD-associated arthropathy, we found that back/joint pain had a negative impact on QOL and work productivity. This negative impact on QOL and work productivity remained significant during a follow-up of 12 months, after controlling for gender and IBD activity. Additionally, the QOL and work productivity of IBD patients were also highly determined by several illness perceptions and, to a lesser extent, by coping.

To our knowledge, this is the first study to date assessing the impact of illness perceptions and coping on QOL and work productivity in patients with IBD-associated arthropathy.

Although QOL and work productivity were mainly determined by back/joint pain and activity of IBD, illness perceptions contributed significantly to the variance of these outcomes. Our findings are in line with previous studies in CD and UC assessing the impact of disease characteristics and illness perceptions on various health outcomes.^{17,18,23} In these studies, disease characteristics (mainly disease activity) contributed 49–68%^{20,21,26} and 23%¹⁷ of the variance of QOL and disability, respectively. Illness perceptions contributed an additional 9–21%^{17,18,23} and 23%¹⁷ of variance of QOL and disability, respectively. In this study we have demonstrated that a decrease in QOL was highly associated with stronger beliefs that IBD will have negative consequences for one's life (i.e. illness consequences), and negative beliefs about how IBD affects one's emotional well-being (i.e. emotional representations). The strong impact of illness consequences and emotional representations has been confirmed by previous studies in IBD. For instance, in a study of 80 IBD patients it was shown that illness consequences were moderately or strongly associated with different aspects of adjustment to their disease, including psychological distress, QOL and functional independence.¹⁷

We also examined whether coping added significantly to the variance of health outcomes, after controlling for gender, disease activity, and remaining illness perceptions. Coping is defined as ongoing cognitive or behavioral efforts to manage psychological distress.^{39,40} Coping strategies (or styles) can either be active (problem-based) or passive (emotion-based). Active coping (creative solution seeking, decreasing activities, and pacing) aims to alter or eliminate the source of stress, while passive coping (consideration, accepting, optimism) aims to reduce the emotional distress caused by the situation. Patients with IBD are more likely to rely on passive coping strategies.^{41–43} Consistent with previous evidence in IBD, we found that coping significantly added to the variance of QOL and impairments in daily activity.^{24,25} However, other studies in IBD did not observe a contributory role of coping with respect to QOL, psychological distress and functional independence.^{17,23} This may be explained by the fact that in these studies coping was assessed with a generic coping questionnaire, which tends to obscure associations between illness-specific coping, QOL, and activity and work impairments.

In the present study we used the disease-specific coping questionnaire, which addresses coping strategies directed at the most important stressors of immune-mediated inflammatory diseases, including pain, limitations, and dependency.

Additionally, we found that the behavioral coping strategy 'decreasing activities' was negatively associated with QOL and activity impairments. This association has not been observed in IBD before. In patients with rheumatoid arthritis and ankylosing spondylitis, decreasing activity has been clearly found to be negatively associated with QOL,⁴⁴ functional status,^{45,46} and work productivity.⁴⁷ It has been postulated that avoidance (i.e. decreasing activities) may have beneficial effects in the short term by facilitating healing in rheumatoid arthritis. However, in the long term it becomes a maladaptive coping strategy by limiting joint movement and inducing muscle weakness and disuse.^{48–50}

Finally, we have demonstrated that the impact of illness perceptions, in particular illness identity and illness consequences, on QOL is reduced when patients do not decrease activity in order to cope with pain. This mediating effect supports the Common Sense Model,^{13,14} which states that the impact of illness perceptions on health outcomes may be attenuated by adopting a particular coping strategy.

This study has several important strengths. First, all patients were systematically examined by a multidisciplinary team of gastroenterologists and rheumatologists. Second, patients were prospectively followed for 12 months, which enabled us to assess the predictive value of back/joint pain, illness perceptions, and coping on several important patient-reported health outcomes. Third, the results of our multiple linear mixed models strongly support the well-validated Common Sense Model.

This study has also several limitations. First, as reflected by the relatively high proportion of anti-tumor necrosis factor users, our study included a selected patient group. Therefore, extrapolation of our data to the general IBD population may be limited. However, the primary aim of the present study was to determine associations between back/joint pain, illness perceptions, and coping that are also applicable to population-based samples. Second, attrition bias may have occurred due to differences between patients who did and did not complete the follow-up period. However, demographic and disease characteristics were similar between the two groups, except for the lower age of the noncompleters. We consider that this difference did not affect our outcomes, since age was not found to be associated with QOL and work productivity ([Online Supplementary Material B](#)). Third, as the CORS has not been validated in patients with IBD-associated arthropathy, coping strategies directed at IBD-specific stressors such as abdominal pain, urgency, and diarrhea might have been missed. However, the CORS has been extensively validated in patients with rheumatoid arthritis, a comparable immune-mediated inflammatory disease with regard to pathogenesis, stressors and treatment. Besides, IBD studies that used a generic—though validated—coping questionnaire failed to identify relevant coping strategies. Fourth, although we adjusted for the most important confounders, such as gender and clinical disease activity, residual confounding cannot be completely excluded.

If these limitations are taken into consideration, we feel that this prospective study provides valuable data for clinical practice. Arthropathies are the most common extraintestinal manifestation in IBD, leading to significant morbidity, disability, and societal costs. Recently, it has been reported that self-reported joint pain is a major predictor of work disability in patients with IBD.⁵¹ Work disability is major cost driver, accounting for 18–69% of overall costs in IBD.^{52,53} Thus, adequate treatment of back/joint pain may lead to reduced

work disability and associated costs. Nevertheless, many patients with IBD-associated arthropathy remain undiagnosed.⁵⁴ Apart from providing these patients with the appropriate medical treatment, their QOL and work productivity can be further improved by behavioral interventions. These interventions should be aimed at eliciting and addressing patients' illness perceptions and stimulating adaptive coping strategies. Previous studies have already shown that behavioral interventions based on the Common Sense Model can change illness perceptions and coping strategies of patients after myocardial infarction and patients with end-stage renal disease, and thereby improve major components of QOL (e.g. return to work).⁵⁵⁻⁵⁸

In conclusion, back/joint pain persistently and negatively impacted the QOL and work productivity of patients with IBD-associated arthropathy. Illness perceptions and coping also had a significant impact on QOL and work productivity. As potentially modifiable factors, illness perceptions and coping may provide additional targets for behavioral interventions, aimed at improving QOL and increasing work productivity. Multidisciplinary teams, incorporating such interventions, are warranted.

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Conflict of Interest

None declared.

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Online Supplementary Material

Appendix A.

Demographic and clinical characteristics of completers ($n = 204$) and noncompleters ($n = 41$).

Appendix B. Univariate analysis.

^aVariables were entered into the linear mixed model.

References

- Salvarani C, Vlachonikolis IG, van der Heijde DM, et al. Musculoskeletal manifestations in a population-based cohort of inflammatory bowel disease patients. *Scand J Gastroenterol* 2001;36:1307-13.
- Vavricka SR, Brun L, Ballabeni P, et al. Frequency and risk factors for extraintestinal manifestations in the Swiss Inflammatory Bowel Disease Cohort. *Am J Gastroenterol* 2011;106:110-9.
- Palm O, Bernklev T, Moum B, Gran JT. Non-inflammatory joint pain in patients with inflammatory bowel disease is prevalent and has a significant impact on health related quality of life. *J Rheumatol* 2005;32:1755-9.
- Pizzi LT, Weston CM, Goldfarb NI, et al. Impact of chronic conditions on quality of life in patients with inflammatory bowel disease. *Inflamm Bowel Dis* 2006;12:47-52.
- D'Inca R, Podswiadek M, Ferronato A, Punzi L, Salvagnini M, Sturniolo GC. Articular manifestations in inflammatory bowel disease patients: a prospective study. *Dig Liver Dis* 2009;41:565-9.
- Bernstein CN, Blanchard JF, Rawsthorne P, Yu N. The prevalence of extraintestinal diseases in inflammatory bowel disease: a population-based study. *Am J Gastroenterol* 2001;96:1116-22.
- Lakatos L, Pandur T, David G, et al. Association of extraintestinal manifestations of inflammatory bowel disease in a province of western Hungary with disease phenotype: results of a 25-year follow-up study. *World J Gastroenterol* 2003;9:2300-7.
- Lanna CC, Ferrari ML, Rocha SL, Nascimento E, de Carvalho MA, da Cunha AS. A cross-sectional study of 130 Brazilian patients with Crohn's disease and ulcerative colitis: analysis of articular and ophthalmologic manifestations. *Clin Rheumatol* 2008;27:503-9.
- Turkcapar N, Toruner M, Soykan I, et al. The prevalence of extraintestinal manifestations and HLA association in patients with inflammatory bowel disease. *Rheumatol Int* 2006;26:663-8.
- De Vlam K, Mielants H, Cuvelier C, De Keyser F, Veys EM, De Vos M. Spondyloarthropathy is underestimated in inflammatory bowel disease: prevalence and HLA association. *J Rheumatol* 2000;27:2860-5.
- Siebert U, Wurm J, Gothe RM, Arvandi M, Vavricka SR, von Känel R. Predictors of temporary and permanent work disability in patients with inflammatory bowel disease: results of the Swiss inflammatory bowel disease cohort study. *Inflamm Bowel Dis* 2013;19:847-55.
- Picavet HSJ, Schouten JSAG. Musculoskeletal pain in the Netherlands: prevalences, consequences and risk groups, the DMC3-study. *Pain* 2003;102:167-178.
- Hagger MS, Orbell S. A meta-analytic review of the Common Sense Model of illness representations. *Psychol Health* 2003;18:141-84.
- Leventhal H, Brissette I, Leventhal EA. The Common-Sense Model of self-regulation of health and illness. In: Cameron LD, Leventhal H, editors. *The Self-Regulation of Health and Illness Behaviour*. London: Routledge; 2003: 42-65.
- Vaughan R, Morrison L, Miller E. The illness representations of multiple sclerosis and their relations to outcome. *Br J Health Psychol* 2003;8:287-301.
- Scharloo M, Kaptein AA, Weinman J, et al. Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *J Psychosom Res* 1998;44:573-85.
- Dorrian A, Dempster M, Adair P. Adjustment to inflammatory bowel disease: the relative influence of illness perceptions and coping. *Inflamm Bowel Dis* 2009;15:47-55.
- Han SW, McColl E, Barton JR, James P, Steen IN, Welfare MR. Predictors of quality of life in ulcerative colitis. The importance of symptoms and illness representations. *Inflamm Bowel Dis* 2005;11:24-34.
- Kiebles JL, Doerfler B, Keefer L. Preliminary evidence supporting a framework of psychological adjustment to inflammatory bowel disease. *Inflamm Bowel Dis* 2010;16:1685-95.
- Knowles SR, Wilson JL, Connell WR, Kamm MA. Preliminary examination of the relations between disease activity, illness perceptions, coping strategies, and psychological morbidity in Crohn's disease guided by the common sense model of illness. *Inflamm Bowel Dis* 2011;17:2551-7.
- Taft TH, Keefer L, Artz C, Bratten J, Jones MP. Perceptions of illness stigma in patients with inflammatory bowel disease and irritable bowel syndrome. *Qual Life Res* 2011;20:1391-9.
- Rochelle TL, Fidler H. The importance of illness perceptions, quality of life and psychological status in patients with ulcerative colitis and Crohn's disease. *J Health Psychol* 2013;18:972-83.
- Van der Have M, Minderhoud IM, Kaptein AA, et al. Substantial impact of illness perceptions on quality of life in patients with Crohn's disease. *J Crohns Colitis* 2013;7:e292-301.

24. Knowles SR, Gass C, Macrae F. Illness perceptions in IBD influence psychological status, sexual health and satisfaction, body image and relational functioning: a preliminary exploration using Structural Equation Modeling. *J Crohns Colitis* 2013;7:e344–50.
25. Knowles SR, Cook SI, Tribbick D. Relationship between health status, illness perceptions, coping strategies and psychological morbidity: a preliminary study with IBD stoma patients. *J Crohns Colitis* 2013;7:e471–8.
26. Heuft-Dorenbosch L, Spooenberg A, van Tubergen A, *et al.* Assessment of enthesitis in ankylosing spondylitis. *Ann Rheum Dis* 2003;62:127–32.
27. Van der Linden S, Valkenburg HA, Cats A. Evaluation of diagnostic criteria for ankylosing spondylitis. A proposal for modification of the New York criteria. *Arthritis Rheum* 1984;27:361–8.
28. Harvey RF, Bradshaw JM. A simple index of Crohn's disease activity. *Lancet* 1980;1:876.
29. Walmsley RS, Ayres RC, Pounder RE, Allan RN. A simple clinical colitis activity index. *Gut* 1998;43:29–32.
30. Moss-Morris R, Weinman J, Petrie KJ. The revised Illness Perception Questionnaire (IPQ-R). *Psychol Health* 2002;17:1–16.
31. Van Lankveld W, Naring G, van der Staak C, van 't Pad Bosch P, van de Putte L. De ontwikkeling van de CORS. Coping met Reuma Stressoren. *Gedrag en Gezond* 1993;21:40–8 [in Dutch].
32. Van Lankveld W, Naring G, van der Staak C, van 't Pad Bosch P, van de Putte L. Stress caused by rheumatoid arthritis: relation among subjective stressors of the disease, disease status, and well-being. *J Behav Med* 1993;16:309–21.
33. Irvine EJ, Zhou Q, Thompson AK. The Short Inflammatory Bowel Disease Questionnaire: a quality of life instrument for community physicians managing inflammatory bowel disease. CCRPT Investigators. Canadian Crohn's Relapse Prevention Trial. *Am J Gastroenterol* 1996;91:1571–8.
34. Han SW, Gregory W, Nylander D, *et al.* The SIBDQ: further validation in ulcerative colitis patients. *Am J Gastroenterol* 2000;92:145–51.
35. Ware JE, Sherbourne CA. The MOS 36-item Short-Form health survey (SF 36). Conceptual framework and item selection. *Med Care* 1992;30:473–83.
36. Reilly MC, Zbrozek AS, Dukes EM. The validity and reproducibility of a work productivity and activity impairment instrument. *Pharmacoeconomics* 1993;4:353–65.
37. Reilly MC, Gerlier L, Brabant Y, Brown M. Validity, reliability, and responsiveness of the work productivity and activity impairment questionnaire in Crohn's disease. *Clin Ther* 2008;30:393–404.
38. Van der Have M, van der Aalst KS, Kaptein AA, *et al.* Determinants of health-related quality of life in Crohn's disease: a systematic review and meta-analysis. *J Crohns Colitis* 2014;8:93–106.
39. Lazarus RS. Psychological stress and coping in adaptation and illness. *Int J Psychiatry Med* 1974;5:321–33.
40. Lazarus RS. Coping theory and research: past, present, and future. *Psychosom Med* 1993;55:234–47.
41. McCombie AM, Mulder RT, Geary RB. How IBD patients cope with IBD: a systematic review. *J Crohns Colitis* 2013;7:89–106.
42. Jones MP, Wessinger S, Crowell MD. Coping strategies and interpersonal support in patients with irritable bowel syndrome and inflammatory bowel disease. *Clin Gastroenterol Hepatol* 2006;4:474–81.
43. Graff LA, Walker JR, Clara I, *et al.* Stress coping, distress, and health perceptions in inflammatory bowel disease and community controls. *Am J Gastroenterol* 2009;104:2959–69.
44. Van Lankveld W, Naring G, van 't Pad Bosch P, van de Putte L. Behavioral coping and physical functioning: the effect of adjusting the level of activity on observed dexterity. *J Rheumatol* 1999;26:1058–64.
45. Evers AW, Kraaijmaat FW, Geenen R, Jacobs JW, Bijlsma JW. Pain coping and social support as predictors of long-term functional disability and pain in early rheumatoid arthritis. *Behav Res Ther* 2003;41:1295–310.
46. Scharloo M, Kaptein AA, Weinman JA, Hazes JM, Breedveld FC, Rooijmans HG. Predicting functional status in patients with rheumatoid arthritis. *J Rheumatol* 1999;26:1686–93.
47. Chorus AM, Miedema HS, Boonen A, Van Der Linden S. Quality of life and work in patients with rheumatoid arthritis and ankylosing spondylitis of working age. *Ann Rheum Dis* 2003;62:1178–84.
48. Vlaeyen JW, Kole-Snijders AM, Boeren RG, Van Eek H. Fear of movement/(re)injury in chronic low back pain and its relation to behavioral performance. *Pain* 1995;62:363–72.
49. Dekker J, Boot B, van der Woude LH, Bijlsma JW. Pain and disability in osteoarthritis: a review of biobehavioral mechanisms. *J Behav Med* 1992;15:189–214.
50. Kottke FJ. The effects of limitation of activity upon the human body. *JAMA* 1966;196:825–30.
51. Van der Valk ME, Mangen MJ, Leenders M, *et al.* Risk factors of work disability in patients with inflammatory bowel disease – a Dutch nationwide web-based survey. *J Crohns Colitis* 2013;8:590–7.
52. Van der Valk ME, Mangen MJ, Leenders M, *et al.* Healthcare costs of inflammatory bowel disease have shifted from hospitalisation and surgery towards anti-TNF α therapy: results from the COIN study. *Gut* 2014;63:72–9.
53. Yu AP, Cabanilla LA, Wu EQ, Mulani PM, Chao J. The costs of Crohn's disease in the United States and other Western countries: a systematic review. *Curr Med Res Opin* 2008;24:319–28.
54. Stolwijk C, Pierik M, Landewé R, Masclee A, van Tubergen A. Prevalence of self-reported spondyloarthritis features in a cohort of patients with inflammatory bowel disease. *Can J Gastroenterol* 2013;27:199–205.
55. Petrie KJ, Cameron LD, Ellis CJ, Buick D, Weinman J. Changing illness perceptions after myocardial infarction: an early intervention randomized controlled trial. *Psychosom Med* 2002;64:580–6.
56. Broadbent E, Ellis CJ, Thomas J, Gamble G, Petrie KJ. Further development of an illness perception intervention for myocardial infarction patients: a randomized controlled trial. *J Psychosom Res* 2009;67:17–23.
57. Karamanidou C, Weinman J, Horne R. Improving haemodialysis patients' understanding of phosphate-binding medication: a pilot study of a psycho-educational intervention designed to change patients' perceptions of the problem and treatment. *Br J Health Psychol* 2008;13:205–14.
58. Jansen DL, Heijmans M, Rijken M, Kaptein AA. The development of and first experiences with a behavioural self-regulation intervention for end stage renal disease patients and their partners. *J Health Psychol* 2011;16:274–83.