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Substantial impact of illness perceptions on quality of life in patients with Crohn's disease

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Abstract

Background and aims: Crohn's disease (CD) negatively impact patients' health-related quality of life (HRQOL). We used the common sense model to examine the contribution of illness perceptions and coping to HRQOL, in addition to clinical and socio-demographic characteristics. This provides insight into potential targets for psychological interventions aimed at improving HRQOL.
Methods: Consecutive CD patients undergoing colonoscopy were included. Disease activity was assessed by a clinical and an endoscopic index. Patients completed questionnaires assessing illness perceptions (IPQ-R), coping (Utrecht Coping List), self-perceived health, neuroticism, and HRQOL. Hierarchical multiple regression analyses were performed to assess the contribution of illness perceptions and coping to HRQOL. Illness perceptions were compared to patients with rheumatoid arthritis, myocardial infarction (MI), and head and neck cancer (HNC).
Results: Of 82 CD patients, mean age was 42 ± 14 years. Clinical and endoscopic active disease was present in 42 (52%) and 49 (60%) patients, respectively. HRQOL was strongly impaired by clinical active disease ($r = -0.79$), self-perceived health ($r = -0.60$), and perceived consequences of CD ($r = -0.54$), but correlated poorly with endoscopic disease activity ($r = -0.29$). Illness perceptions significantly contributed 3–27% to HRQOL. Coping had no contributory role. CD patients perceived similarly strong consequences of their illness as patients with MI and HNC and had the strongest thoughts about the chronic nature of their illness.
Conclusions: CD has a similar impact on patients' daily lives as was observed in patients with MI and HNC. Illness perceptions contribute to HRQOL and should therefore be incorporated in clinical practice, thereby improving HRQOL.
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1. Introduction

Crohn's disease (CD) is a chronic, progressive and potentially disabling disease. Its early age of onset[1], unpredictable clinical course[2], and disease and treatment-related complications pose problems for patients' physical, psychological and social functioning: health-related quality of life (HRQOL). CD patients have a worse HRQOL than healthy individuals, but a similarly impaired HRQOL as patients with rheumatoid arthritis.[3] The importance of HRQOL in CD has been increasingly recognized, because of its implications for patients' psychological well-being, their social adjustment to the illness, and the use of health resources.[4,5] Nevertheless, less is known about the determinants of HRQOL in CD.

A low HRQOL has been related to socio-demographic and clinical variables, including higher age, female gender, lower education level, irritable bowel syndrome (IBS)-like symptoms, longer disease duration and increased disease activity.[5–8] However, HRQOL is not strongly determined by these variables.[9] A substantial amount of empirical evidence supports the contributory role of behavioral variables, such as illness perceptions and coping behavior.[10,11] In contrast to static variables such as age, gender, and disease duration, behavioral variables are potentially modifiable through psychological interventions.

A well-validated model to examine the impact of socio-demographic, clinical and behavioral variables on HRQOL (or other outcomes) is Leventhal's common sense model of self-regulation.[12,13] The common sense model states that an individual generates both cognitive and emotional representations (known as illness perceptions) in response to a perceived health threat (characterized by clinical variables). 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 avoidance or seeking social support, with potential impact on clinical outcomes (i.e. HRQOL).

In inflammatory bowel diseases (IBD), data on illness perceptions are scarce. A PubMed search performed on May 8th 2012, using "illness perceptions" and "inflammatory bowel diseases" OR "ulcerative colitis" OR "Crohn", yielded 65 studies, of which 5 studies examined illness perceptions properly.[14–18] These five studies are summarized in Table 1. Sample sizes of these studies varied between 38[16] and 211[18], with only one study restricted to CD patients.[17] Two studies of different methodology have examined the utility of the common sense model in IBD-patients, of which one used HRQOL as an outcome measure.[14,17] In this study of 80 IBD patients, Dorrian et al. demonstrated that maladaptive illness perceptions had a significant adverse impact on HRQOL, whereas coping had no significant additional effect on this outcome.[14]

The aims of this study were to: 1) examine associations between socio-demographic, clinical and behavioral variables, and HRQOL; 2) examine the contribution of illness perceptions and coping to HRQOL, controlling for various socio-demographic and clinical variables, including endoscopic disease activity, in a carefully phenotyped group of CD patients; and 3) compare illness perceptions and coping behavior of our CD cohort with various reference groups.

2. Materials and methods

2.1. Patients

Between 2004 and 2006, adult patients with a confirmed diagnosis of CD for at least 6 months and a clinical indication for colonoscopy were consecutively recruited from a tertiary referral center. Patients with a (sub)total colectomy or endostomy were excluded.

2.2. Study protocol and measurements

Before patients underwent a colonoscopy, they filled out the Crohn's disease activity index (CDAI[19]) diary and a questionnaire booklet at home. This booklet consisted of validated questionnaires relating to functional gastrointestinal disorders[20,21], self-perceived health, neuroticism[22], illness perceptions[23], coping[24] and HRQOL.[25,26] In addition, socio-demographic data, including gender, level of education, marital status and age at inclusion – and smoking status – were obtained. Clinical variables that were obtained from medical records included disease duration, localisation and behavior of the disease (Montréal classification[27]), current and previous medication use, CD-related surgeries and CD-related admissions (one year prior to the date of inclusion). The research protocol was approved by the institutional Medical Ethics Committee.

2.2.1. Disease activity

Disease activity was determined by the Crohn's disease activity index[19] and the Crohn's disease endoscopic index of severity (CDEIS).[28] The CDAI is a well-validated index of clinical disease activity. Clinical remission is defined by a CDAI score less than 150. The CDEIS is based on the presence of mucosal lesions (pseudopolyps, ulcers, and stenosis) and the percentage of the surface involved in 5 segments of the gut (ileum, right colon, transverse colon, left and sigmoid colon and rectum). Inactive disease is frequently defined as a CDEIS score of less than 3.[29]

2.2.2. Self-perceived health and neuroticism

Patients rated their perceived health on a single general health item from the Medical Outcomes Survey Short-Form 36 (SF-36[30]): "How would you feel your health is in general?" Responses ranged from "excellent" (1), to "very poor" (5). In addition, patients were asked "How do you feel your health is, compared with other people of your age?" Responses are categorized into "better" (1), "about same" (2), and "worse" (3). Negative moods were assessed by the neuroticism (or inadequacy) subscale of the Dutch personality questionnaire (NPV-IN). Patients were asked whether the 21 statements of this subscale applied to them ("yes" or "no").[22] For example: "I often hate myself." Higher scores indicate a higher tendency toward emotional instability.

2.2.3. Illness perceptions

The Revised Illness Perception Questionnaire (IPQ-R) contains three parts.[23] In the first part, illness identity was assessed by using a 12-item checklist of common symptoms. Patients were asked whether or not they have experienced symptoms after being diagnosed, and if they believe these

Table 1 Summary of 5 studies on illness perceptions in IBD patients.

First author Year of publication Country Reference	Number of patients Type of IBD	Outcome(s)	Main results
Dorrian 2009 IRE [14]	80 Crohn and UC	Quality of life Psychological Distress Functional independence	Illness perceptions, particularly perceptions of consequences of IBD, were the most consistent variables explaining outcomes. Coping did not mediate between illness perceptions and outcomes.
Han 2004 UK [15]	111 UC	Quality of life	Illness perceptions accounted for 4–14% of the observed variation in quality of life scores. Disease activity was the major explanatory variable.
Kiebles 2010 USA [16]	38 Crohn and UC	Quality of life Disability Psychological functioning	All outcomes were strongly correlated with an emotional representation of illness and coping.
Knowles 2011 AUS [17]	96 Crohn	Anxiety Depression	Disease activity had an indirect impact on outcomes via illness perceptions and, in turn coping. Emotion- and problem-focused coping styles acted as mediators between illness perceptions and depression.
Taft 2009 USA [18]	211 Crohn and UC	Quality of life Psychological distress	Perceived stigma accounted for 10–22% of the variance in quality of life and 4–16% for psychological distress.

symptoms can be attributed to the illness ("yes" or "no"). The summed yes-rated items on the second question constitute the *Identity scale*, with higher scores indicating a stronger belief that the experienced symptoms are part of the patient's illness. The second part includes 38 statements which are all scored on a five-point Likert scale and provides separate scores for the following seven subscales: *Consequences*, *Timeline* (divided into cyclical and acute/chronic timeline), *Control* (divided into personal and treatment control), *Illness coherence* and *Emotional representations*. High scores on the *Consequences scale* indicate stronger beliefs that the illness will have negative consequences for the person's life. High scores on the *Timeline scales* (acute/chronic, cyclical) indicate the held belief that the illness is enduring and/or cyclical. With regard to the *Control scales* personal control and treatment control, high scores indicate personal control over the illness and positive beliefs about the effectiveness of treatment. High scores on the *Illness coherence scale* represent personal understanding of the condition, while high scores on the *Emotional representation subscale* represent negative beliefs about how the illness affects one's emotional well-being. The third part includes 18 questions about the following four causal attributions (considered as subscales): *Psychological factors* (for example stress), *Risk factors* (for example smoking), *Immunity* (for example a germ of virus), and *Accident or Chance* (for example chance or bad luck). Again, all items are scored on a five-point Likert scale. The internal reliability (Cronbach's alpha) for each subscale ranged from 0.67 to 0.93, except for the causal attributions *Immunity* and *Accident or Chance*, which showed a low internal reliability (<0.50), and were therefore excluded from further analysis.

2.2.4. Coping

The Utrecht Coping List (UCL[24]) has been validated and/or applied in patients with various chronic diseases, including vestibular schwannoma, rheumatoid arthritis, psoriasis, chronic obstructive pulmonary disease, chronic fatigue syndrome, Addison's disease and patients with chronic pain.[31–34] It includes 47 statements divided into 7 subscales: *Active coping* (score ranging from 7 to 28), *Seeking distraction* (score ranging from 8 to 32), *Avoidance* (score ranging from 7 to 28), *Seeking social support* (score ranging from 6 to 24), *Passive coping* (score ranging from 7 to 28), *Expressing emotions* (score ranging from 3 to 12) and *Reassuring thoughts* (score ranging from 5 to 20). All statements are scored on a four-point Likert scale, ranging from "seldom/never" to "often". The higher the score on each subscale, the greater the extent to which this coping style is employed. The internal reliabilities (Cronbach's alpha) for the subscales ranged between 0.74 and 0.86.

2.2.5. Outcomes

Health-related quality of life was measured by the Dutch translation of the Inflammatory Bowel Disease Questionnaire, encompassing 32 items (IBDQ-32[25,26]), with a graded response range of "worst" (1) to "best" (7) and a possible total score of 32–224. The 32 items can be divided into four dimensional scores, including *Bowel symptoms* (10 items), *Systemic symptoms* (5 items), *Emotional well-being* (12 items) and *Social function* (5 items). The internal reliabilities (Cronbach's alpha) ranged between 0.75 and 0.93.

2.3. Reference groups

Illness perceptions and coping behavior of CD patients were compared to those of various reference groups. With regard to illness perceptions, reference groups were chosen based on the comparable clinical course or their life-threatening character. Patients with rheumatoid arthritis were chosen, because of their comparable pathogenesis and clinical course. Patients with myocardial infarction were chosen, because of their acute life-threatening course. Patients with head and neck cancer were chosen, because they have a serious life-threatening disease. With regard to coping behavior, reference groups were chosen based on their comparability (rheumatoid arthritis) and availability (chronic pain), apart from population norms.

Illness perceptions of CD patients were compared to those of 75 out-patients with rheumatoid arthritis (25 males, 50 females, mean age 59 years SD 15)[35], 202 patients with a recently diagnosed myocardial infarction (144 males, 58 females, mean age 64 years SD 15)[36], and 68 patients with head and neck cancer (48 males, 20 females, median age 60 years IQR 41–84).[37]

Coping behavior of CD patients was compared to those of three reference groups, namely an a-select group of 712 women[24], 84 out-patients with rheumatoid arthritis[32] and 59 patients with chronic pain.[34] The first group consisted of nurses with a mean age 30 years and a random selection from the Dutch population with a mean age 47 years. The minority of RA patients were male (21/84; 25%), with a mean age of 52 years (SD 13). The last group consisted of patients with chronic hip or knee pain with a mean age 64 (SD 6). Of these patients the minority was male (15/59; 25%).

2.4. Statistical analysis

Means were calculated for all subscales of the UCL and the IPQ-R and compared between CD patients and reference groups, using Student's t test. To correct for multiple testing, the level of significance was set at $p<0.01$. Associations between socio-demographics, clinical variables, behavioral variables and HRQOL were assessed by means of Pearson's (parametric), and Spearman's (non-parametric) correlation analyses. To examine the contribution of socio-demographic, clinical and behavioral variables (illness perception and coping) to HRQOL of CD patients, hierarchical multiple regression analyses were performed. Behavioral variables showing both a significant association and a correlation coefficient of 0.20 or above were entered in the regression model, with socio-demographic and clinical variables as controlling variables.

3. Results

3.1. Data collection (Table 2)

Eighty-two patients were eligible for this study, of which all were willing to participate and therefore enrolled in our study. Almost all patients (80/82; 98%) were outpatients. Two patients were admitted with a flare. Each questionnaire was filled out completely by at least 95% of patients. The proportion of missing socio-demographic and clinical data was 3%. Eighty-two CD patients underwent a colonoscopy, 23 (28%) for surveillance and 59 (72%) for assessing disease activity. The majority of patients were female (52/82; 63%), with a mean age of 42 years (SD 14). Regarding education level and marital status, CD patients were representative of the general Dutch population.[38]

Table 2 Socio-demographic, clinical and behavioral variables in Crohn's disease patients (n = 82).

Socio-demographic variables		
Age (years), mean (SD)		42 (14)
Male (%)		30 (37)
Education (scale [a]), mean (SD)		2.2 (0.2)
Married (%)		50 (61)
Smoker (%)		51 (62)
Clinical variables		
Age of onset (years), mean (SD)		28 (10)
Disease duration (years), median (IQR)		12 (7–22)
Montréal classification:		
Involved location (%)	Ileal	8 (10)
	Colonic	19 (23)
	Ileocolonic	53 (65)
	Ileocolonic + upper GI disease	2 (2)
	+ Perianal disease	17 (21)
Disease behavior (%)	Inflammatory	46 (56)
	Stricturing	18 (22)
	Penetrating	6 (7)
	Both	12 (15)
Active disease		
Clinical (%)	CDAI < 150	39 (48)
	CDAI ≥ 150	42 (52)
Endoscopic (%)	CDEIS < 3	33 (40)
	CDEIS ≥ 3	49 (60)
IBS-like symptoms	Yes	43 (52)
	No	36 (48)
Medication (%)	No	6 (7)
	5-ASA	51 (62)
	Steroids	28 (34)
	Immunosuppressive drugs [b]	42 (52)
	Anti-TNF compounds	18 (22)
CD-related operations (%)	None	28 (34)
	Ileocolonic resection	20 (24)
	Hemicolectomy	10 (12)
	Partial small bowel resection	7 (9)
	Sigmoid resection	3 (4)
CD-related admission last year (%)	One admission	10 (12)
	Two admissions	2 (2)

[a] Scale ranging from 1 (primary school) to 5 (university).
[b] Methotrexate and thiopurines.

3.2. Health-related quality of life

3.2.1. Associations (Table 3)

HRQOL showed a moderate inverse association with female gender and disease duration, and a strong inverse association with self-perceived health, clinical disease activity, and neuroticism. Endoscopic disease activity was poorly correlated with HRQOL. In addition, the IPQ-R dimensions *Identity*, *Consequences*, *Timeline cyclical*, and *Emotional representations*, were all significantly inversely correlated with HRQOL.

Table 3 Pearson's or Spearman's correlations between socio-demographic, clinical and behavioral variables, and HRQOL.

Variable	HRQOL (IBDQ-32)
Socio-demographic	
Age at inclusion	0.08 (NS)
Female	−0.44[**]
Disease duration	−0.34[**]
Education	0.10 (NS)
Clinical	
Clinical disease activity index (CDAI)	−0.79[**]
Crohn's disease endoscopic index of severity (CDEIS)	−0.29[*]
IBS-like symptoms	−0.32[**]
Behavioral	
Self-perceived health	−0.60[**]
Dutch personality questionnaire-IN (neuroticism)	−0.52[**]
Illness perceptions	
Illness identity	−0.41[**]
Consequences	−0.54[**]
Timeline	
Acute/chronic	0.00 (NS)
Cyclical	−0.39[**]
Control	
Personal control	0.10 (NS)
Treatment control	0.07 (NS)
Illness coherence	0.25[*]
Emotional representations	−0.41[**]
Psychological factors	−0.19 (NS)
Risk factors	−0.11 (NS)
Coping	
Seeking distraction	−0.27[*]
Expressing emotions	−0.11 (NS)
Seeking social support	−0.16 (NS)
Avoiding	−0.16 (NS)
Fostering reassuring thoughts	−0.31[**]
Passive coping	−0.47[**]
Active coping	0.10 (NS)

The italicized data represent subscales of the questionnaires.

[*] $p<0.05$.
[**] $p<0.01$.

More specifically, fewer symptoms attributed to CD, less perceived consequences, less strong thoughts about its cyclical nature and less strong emotional response were significantly associated with a higher HRQOL. The UCL sub-scales *Fostering reassuring thoughts* and *Passive coping* were significantly inversely associated with HRQOL.

3.2.2. Contribution of illness perceptions and coping to HRQOL (Table 4, Fig. 1)

To determine the contribution of socio-demographic, clinical and behavioral variables (illness perceptions and coping behavior) to various domains of the IBDQ-32 (*Bowel*, *Systemic*, *Social* and *Emotional symptoms*), multiple hierarchical regression analyses were performed. These variables were force-entered in a step-wise fashion as different blocks. Socio-demographic and clinical variables − including age, sex, disease duration, education level, CDEIS and CDAI (block 1) − contributed to a significant proportion of the variance in all IBDQ domains (38% to 67%). Adding IBS-like symptoms as a clinical variable had no additional effect on HRQOL and was therefore excluded from further analysis. Illness perceptions significantly added to the variance explained in *Systemic symptoms* (9%), *Emotional symptoms* (27%) and *Social symptoms* (7%). No significant additional effect on *Bowel symptoms* was found (3%, $p=0.14$). Coping had no significant additional effect on any of the IBDQ domains. The contribution of illness perceptions and coping behavior to the HRQOL of CD patients did not differ between men and women.

3.3. Comparison with reference groups

3.3.1. Illness perceptions (Table 5)

CD patients' beliefs about the consequences of their illness were similarly strong as those of patients with head and neck cancer and patients with myocardial infarction. CD patients had significantly stronger beliefs about the chronic nature of the illness than patients with acute myocardial infarction and head and neck cancer, and similar strong thoughts about the cyclical nature of their illness as patients with rheumatoid arthritis. Patients with CD and rheumatoid arthritis have a similar coherent understanding of their illness and similar strong beliefs about their treatment as an effective way of controlling their illness. Furthermore, CD patients perceived significantly less strong personal control than patients with rheumatoid arthritis and patients with myocardial infarction, and less strong treatment control than patients with head and neck cancer and patients with myocardial infarction.

3.3.2. Coping (Table 6)

CD patients had similar scores on all coping scales as RA patients. CD patients had significantly lower scores on the *Active coping* and *Seeking social support scale*, compared to an a-select sample of the Dutch population. Compared to patients with chronic pain, CD patients scored significantly lower on the *Fostering reassuring thoughts scale*.

4. Discussion

In the present study we examined the contribution of illness perceptions and coping behavior of CD patients to their

Table 4   Summaries of hierarchical multiple regression analyses testing the significance of change in explained variance on IBDQ-32 domains.

IBDQ-32 domain	Step 1: Demographic and clinical variables [a]			Step 2: IPQ-R subscales [b]			Step 3:UCL Subscales [b]		
	R^2	ΔR^2	F of change	R^2	ΔR^2	F of change	R^2	ΔR^2	F of change
Total	0.68	–	24.7***	0.79	0.11	7.2***	0.80	0.01	0.7 (NS)
Bowel	0.67	–	24.4***	0.70	0.03	1.9 (NS)	0.70	0	0.2 (NS)
Systemic	0.60	–	17.9***	0.69	0.09	3.9**	0.72	0.03	2.3 (NS)
Emotional	0.38	–	7.2***	0.65	0.27	9.9***	0.67	0.02	1.1 (NS)
Social	0.60	–	17.6***	0.67	0.07	3.4*	0.67	0	0.3 (NS)

 [a] Including age, sex, disease duration, education level, CDEIS and CDAI.
 [b] Variables with significant correlations of an absolute value of 0.20 or above were entered.
  * $p<0.05$.
 ** $p<0.01$.
 *** $p<0.001$.

HRQOL, controlling for socio-demographics and clinical variables. It was found that illness perceptions but not coping behavior contributed significantly to HRQOL, except for bowel symptoms.

Dorrian et al. reported that illness perceptions accounted for 21% of the variability in health-related quality of life, which is considerably higher than the 11% reported in our study. Dorrian et al. used the CDAI for survey research, which consists of questions relating to general well-being, frequency of soft stools and abdominal pain.[39] Other important variables, such as extraintestinal symptoms, are not taken into account. The IPQ-R has not been validated in the IBD population and variables that are not included in the CDAI for survey research might affect the IPQ-R. This may have overestimated the contribution of illness perception to the HRQOL in Dorrian et al.'s study (Fig. 2).

In addition, differences in baseline characteristics between both samples may have accounted for this difference. For example, 35−43% of IBD patients in Dorrian's study had a colostomy/ileostomy as compared to 0% in our study. Possibly, IBD patients with an endostomy have stronger illness perceptions.[14]

Coping behavior had no contributory role. Consistent with previous data on patients with IBD, RA, psoriasis and chronic obstructive pulmonary disease, the assumption of the common sense model that coping is a mediating factor
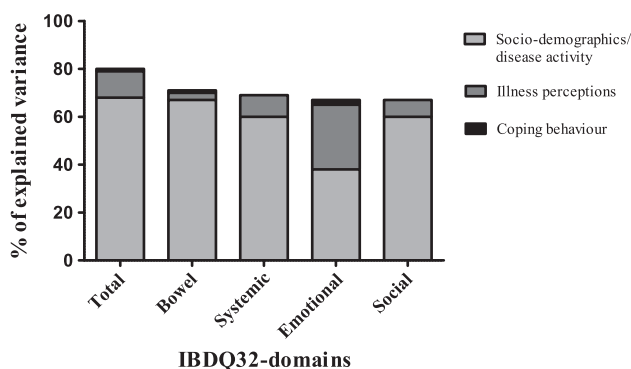

Figure 1   Percentages of variance in IBDQ-32 domains explained by socio-demographics/clinical variables (step 1), IPQ-R (step 2) and UCL (step 3).

between illness perceptions and outcomes (including HRQOL), could not be corraborated.[14,32] The main reason for this somewhat surprising finding seems to be that in these studies coping is assessed in a global, generic fashion, which tends to obscure any associations. Disease specific coping may have associations with various outcome measures.[14,32]

As expected, we found a strong association between clinical disease activity ($r=-0.79$) and HRQOL.[5−8,14−17] In contrast, endoscopic disease activity was poorly associated with HRQOL ($r=-0.29$). Several hypotheses for this discrepancy exist. First, the construct validity of the IBDQ-32 was proven by comparing its performance with that of the CDAI. Second, the relationship between endoscopic disease activity and HRQOL may have been mediated by other (intermediate) variables, including clinical and behavioral variables. In line with previous studies, a strong correlation was found between neuroticism and HRQOL.[40,41] Neurotic patients are more prone to experience negative emotions such as fear, sadness and anger in response to stressful life events (e.g. illness), which lowers their HRQOL.[42,43] As the self-perceived health questionnaire measures general well-being, our finding that this variable was strongly associated with HRQOL, did not come as a surprise. On the other hand, it clearly demonstrates that one third of patients' HRQOL can be explained simply by asking two questions: "How would you feel your health is in general?" and "How do you feel your health is, compared with other people of your age?" In accordance with previous studies, a strong emotional response[15] or illness identity[16,18], and strong beliefs about the consequences[16,18], showed a significant moderate to strong association with HRQOL.

In contrast with previous research[13], perceptions of personal and treatment control were not significantly associated with HRQOL. This may be explained by the fact that the IPQ-R has not been validated in IBD patients. Therefore, other factors related to personal and treatment control, such as the frequency of exacerbations or hospitalizations (personal control) and adherence (treatment control), may not be measured by the IPQ-R.

This is the first study that compared illness perceptions and coping behavior of CD disease patients with various reference groups. Hereby, we aimed to put our findings into perspective and/or to support the construct validity

Table 5 Mean scores of the Revised Illness Perception Questionnaire (IPQ-R) subscales of patients with Crohn's disease (CD) (n=82), rheumatoid arthritis (RA) (n=75), head and neck cancer (HNC) (n=68) and myocardial infarction (MI) (n=202).

Demographic and clinical variables	CD	RA	HNC	MI
Age (years), mean (SD)	42 (14)	59 (15)	60 (41–84 [a])	64 (15)
Male (%)	30 (37)	25 (33)	48 (71)	144 (71)
Disease duration (years), mean (SD)	12 (7–22 [a])	16 (12)	NA	NA
Clinical variables	CDAI 160 (102) [b]	NR	Tumor stage: III/IV 62% [c]	EF ≤ 40%: 32% [d]
Mean IPQ-R scores (SD)				
Identity	6.2 (2.6)	7.3 (0.4 [e]) **	2.3 (2.5) **	NR
Consequences	19.0 (5.1)	21.4 (0.6 [e]) **	19.4 (4.3)	18.2 (4.6)
Timeline:				
Acute/chronic	25.7 (3.2)	23.4 (0.6 [e]) **	17.1 (4.4) **	20.0 (5.4) **
Cyclical	14.8 (3.3)	13.8 (0.4 [e])	9.9 (3.1) **	10.8 (2.9) **
Control:				
Personal control	17.9 (3.9)	20.0 (0.5 [e]) **	18.8 (3.8)	21.3 (3.9) **
Treatment control	15.5 (3.3)	16.7 (0.4 [e])	17.5 (2.9) **	18.1 (3.2) **
Illness coherence	18.2 (4.1)	16.8 (0.6 [e])	15.8 (3.8) **	17.9 (3.9)
Emotional representations	15.3 (5.9)	NR	19.2 (5.5) **	16.7 (4.8)
Causal attributions:				
Psychological factors	13.8 (5.1)	15.9 (0.6 [e])	NR	NR
Risk factors	15.3 (4.2)	12.2 (0.4 [e]) **	NR	NR

NA = not applicable, NR = not reported or not measured.

[a] Interquartile range.
[b] Mean score on Crohn's disease activity index (SD).
[c] Tumor stage according to the American Joint Commission on Cancer/Union Internationale Controle Cancer (AJCC/UICC).
[d] Ejection fraction ≤ 40%.
[e] Standard error.
** $p < 0.01$.

of the IPQ-R in a population of Crohn's disease patients. Noteworthy, patients with CD, head and neck cancer, and patients recently diagnosed with myocardial infarction, had similar strong perceptions about the consequences of their illnesses. This indicates that CD has a major impact on patients' daily lives, relationships and financial matters. The strong impact of IBD on patients' lives has recently been corroborated in a large multinational European study. This study found that 34% of patients believed their IBD had caused the end of their relationship. Furthermore, 96% and

Table 6 Mean scores (SD) of self-perceived health, neuroticism, and the Utrecht Coping List (UCL) in patients with Crohn's disease (n=82), rheumatoid arthritis (n=84) and chronic pain (n=59) or an a-select sample from the Dutch populations (n=712).

Self-perceived health/neuroticism/coping	CD	RA	Chronic pain	A-select sample Dutch population
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Self-perceived health [a]	6.1 (1.3)	NR	NR	NR
Neuroticism [b]	13.4 (9.0)	NR	NR	NR
UCL subscales [c]:				
Active coping	17.3 (3.8)	18.0 (4.1)	16.4 (4.2)	19.3 (5.1) **
Seeking distraction	17.4 (3.7)	18.6 (4.1)	16.8 (3.9)	17.3 (6.1)
Avoiding	16.6 (3.3)	16.2 (2.9)	16.2 (3.1)	15.2 (6.0)
Seeking social support	12.5 (3.4)	11.7 (3.4)	10.2 (2.9) **	14.5 (4.9) **
Passive coping	12.3 (3.8)	11.3 (3.1)	11.7 (3.8)	10.9 (5.4)
Expressing emotions	5.6 (1.9)	5.2 (1.4)	5.3 (1.7)	6.4 (2.3)
Fostering reassuring thoughts	12.8 (2.8)	13.1 (2.9)	13.3 (3.2)	12.1 (3.80)

[a] Scale ranging from 2 to 8.
[b] Scale ranging from 0 to 42.
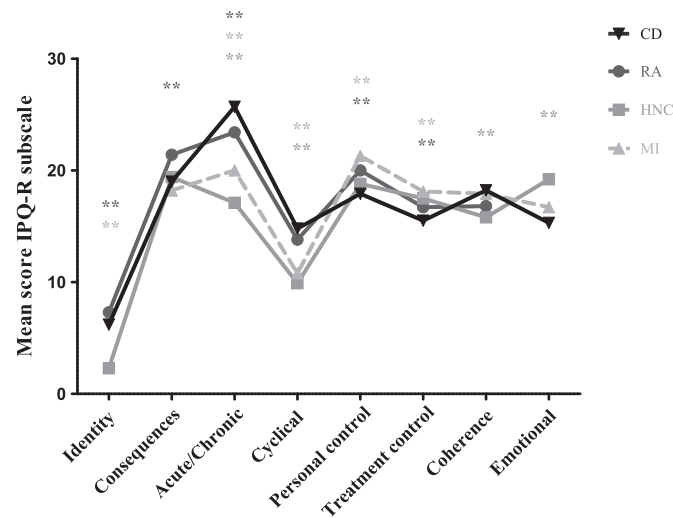[c] Scales ranging from 0 to 20.
** $p < 0.01$.

Figure 2 Mean scores on IPQ-R subscales of patients with CD (n=82), rheumatoid arthritis (n=75), head and neck cancer (n=68), and myocardial infarction (n=202).

83% of patients felt tired, weak, and worn out in daily life during a flare and in remission, respectively.[44]

Furthermore, CD patients had the strongest beliefs regarding the unpredictable cyclical nature of their disease. This may explain the fact that CD patients perceived less personal control than patients with RA.[35] Previously, it has been shown that the uncertain nature of CD was one of patients' main worries, besides worries concerning the need for surgery/endostomy or low energy.[45] Accordingly, many CD patients in this group struggle with their unpredictable and chronic illness with all its implications for HRQOL, adherence, and medical management. CD and RA patients have a comparable pathogenesis and medical treatment. Therefore, our findings that both patient groups have similar coherent understanding of their illness and similar strong beliefs about their treatment as an effective way of controlling their disease did not come as a surprise.

Although CD patients and RA patients had a similar coping behavior, adaptive coping strategies — including active coping and seeking social support — were less frequently employed by CD patients compared with healthy Dutch controls.[25,32] Compared to patients with chronic pain, CD patients sought less reassuring thoughts.[35] This indicates that CD patients reported less effective coping strategies compared to the normal Dutch population, but apparently use more effective coping strategies compared to patients with chronic pain.

Our study has several important strengths. First, we obtained many relevant socio-demographic, clinical, and behavioral variables, including IBS-like symptoms, neuroticism, self-perceived health, illness perceptions and coping behavior. Contrary to similar studies, disease activity was also assessed endoscopically.[14,15,17] Second, our hierarchical regression analyses were strongly supported by the well-validated common sense model of self-regulation.

Our study has limitations as well. Due to the cross-sectional character of this study it was not possible to make statements about causalities between socio-demographic, clinical and behavioral variables and HRQOL. Furthermore, a sample size of over 140 is sometimes suggested for this study design

(i.e. 10 cases of data per predictor).[46] However, as our study and its statistical strategy were guided by the theoretically and empirically solid common sense model, it was likely that the associations we found were causal. For the same reason, a smaller sample size seemed to be appropriate.

Our findings underscore the importance of addressing and understanding patients' perceptions of CD. This relevant information allows clinicians to guide counseling and tailor psychological interventions to patient's specific needs. Earlier studies have already shown that psychological interventions based on the common sense model of self-regulation, can change illness perceptions of patients after myocardial infarction and patients with end-stage renal disease, and thereby improve major components of HRQOL (e.g., return to work).[47–50] According to our results, psychological interventions should incorporate patients': 1) beliefs about the symptoms attributed to the illness; 2) beliefs about the (cyclical) nature of CD; 3) the perceived consequences in daily life and in relationships; and 4) the emotional response.

In conclusion, our results clearly show the additive value of illness perceptions in explaining HRQOL of patients with CD. Further research should focus on identifying disease-specific coping strategies which may influence HRQOL. Subsequently, psychological interventions incorporating illness perceptions as stated above should be tested in clinical trials for their efficacy at enhancing patient-reported outcomes such as HRQOL, adherence and healthcare use.

Conflict of interest

The authors declare no conflict of interest.

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