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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 onset¹, unpredictable clinical course², 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 sociodemographic, 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 38¹⁶ and 211¹⁸, 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 (CDAI¹⁹) diary and a questionnaire booklet at home. This booklet consisted of validated questionnaires relating to functional gastrointestinal disorders^{20,21}, self-perceived health, neuroticism²², illness perceptions²³, coping²⁴ and HRQOL.^{25,26}In addition, sociodemographic 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 classification²⁷), current and previous medication use, CD-related surgeries and CDrelated 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 index¹⁹ 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-36³⁰): "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 *in*adequacy) 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

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