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# Health-related quality of life in inflammatory bowel disease: Psychosocial, clinical, socioeconomic, and demographic predictors

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**Abstract**

*Background and aims:* Individuals with inflammatory bowel disease (IBD) have impaired health-related quality of life (HRQOL). Managing HRQOL is increasingly becoming an important treatment consideration in IBD. Understanding factors that impact HRQOL may facilitate interventions to improve HRQOL and overall IBD management. We hypothesized that psychosocial variables, namely perceived stress, perceived social support, and knowledge, would be associated with HRQOL among individuals with IBD.
*Methods:* A total of 134 adults with IBD were recruited online from IBD support groups. HRQOL was measured using the inflammatory bowel disease questionnaire (IBDQ). Perceived stress, perceived social support, and knowledge of IBD were measured using standardized questionnaires. Clinical and demographic variables were gathered through a 16-item study questionnaire. Univariate analyses were conducted to determine which variables were associated with HRQOL, and those that were statistically significant were entered into a multivariate regression model.
*Results:* Results from univariate analyses revealed significantly lower HRQOL in individuals who: reported higher perceived stress, higher number of previous hospitalizations and relapses, lower perceived support, lower income, were unemployed, and were female. Multivariate analyses revealed that the variables most strongly associated with HRQOL were perceived stress ($p<0.001$), number of previous IBD relapses ($p<0.001$), gender ($p<0.001$), and perceived social support ($p<0.05$).
*Conclusion:* Individuals with IBD who report higher perceived stress, lower perceived social support, greater number of relapses, or are female may be at increased risk for decreased HRQOL. Prospective studies should investigate how interventions addressing these factors may lead to improved HRQOL.


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## 1. Introduction

Inflammatory bowel disease (IBD), which encompasses ulcerative colitis (UC) and Crohn's disease (CD), is a chronic inflammatory disorder of the gut with intestinal as well as systemic manifestations.[1–3] Patients with IBD often experience periods of health (i.e. remission) alternating with periods of disease activity (i.e. relapse).[1,2,4,5] This variability, coupled with the potential long-term complications of the disease and its associated financial and emotional burdens, can be negatively impacting on a number of levels.[4] One such level is health-related quality of life (HRQOL).

HRQOL is generally defined as a multidimensional concept that incorporates the physical, emotional, and social features of health perception and health functioning.[5–7] The diagnosis of a chronic medical disorder increases stress levels and introduces difficult changes, which, in turn, can alter HRQOL. For patients with IBD, such stressors may include abdominal discomfort, rectal bleeding, diarrhea, fecal urgency, impaired appetite, weight loss, and need for long-term (immunosuppressant) medication use, hospitalization, or surgery, among others.[5] Thus, as with patients with other chronic diseases, it is not surprising that patients with IBD have poorer HRQOL compared to healthy controls.[8]

The published literature on the predictors of HRQOL in IBD is relatively limited, as are solutions to impaired HRQOL. A number of clinical and demographic factors have previously been investigated as predictors of HRQOL in IBD; a few of these factors have consistently been found to impact HRQOL, while others remain unclear. For example, factors previously found to be consistently associated with HRQOL include male gender, clinical symptoms, severity of disease, surgical interventions, recurrences per year, and co-existing disease.[9–12] Factors found to influence HRQOL on a less consistent basis include age, type of IBD, socioeconomic status and marital status.[6,13–17]

An area that, as of yet, has not been sufficiently investigated is the potential association between psychosocial factors and HRQOL in IBD. The aim of this study was to simultaneously evaluate, in a single cohort of patients with IBD, multiple psychosocial factors found to influence HRQOL across other studies, namely perceived stress, social support, and IBD-specific knowledge (i.e. knowledge about IBD). We hypothesized that HRQOL would be associated with higher perceived stress, lower social support, and lower IBD-specific knowledge.

## 2. Materials and methods

### 2.1. Participants

After receiving expedited institutional review board approval, ambulatory (i.e. outpatient) participants were recruited via convenience sampling from IBD support and advocacy groups using online electronic messages on the social network Facebook from October to December 2010. Organizers and/or presidents of each online IBD support and advocacy group were contacted and informed of the study, and participating groups ("IBD is not IBS: raising awareness," "Let's put IBD in the history books," "I support people with IBD," "Crohn's disease and IBD," "Fight against Crohn's disease," and "Crohn's disease, ulcerative colitis, and any IBD/IBS awareness") forwarded an electronic message to their members containing a link to the consent form and the study survey. Inclusion criteria were: age >18 years, residence in the United States, and a self-reported diagnosis of IBD. Individuals hospitalized at the time of the study were excluded. Participants who met the study criteria volunteered to be included in the study by electronically signing the informed consent form and completing the online survey.

### 2.2. Variables and measures

The inflammatory bowel disease questionnaire (IBDQ) was used to measure the dependent variable, HRQOL.[18] The IBDQ is the most widely used HRQOL instrument for patients with IBD.[18] The scale has 32 items scored on a 7-point Likert scale, ranging from 1 (worst health) to 7 (best health). Only the IBDQ total scores were used, with a score range from 32 to 224, with higher scores reflecting better HRQOL.[18]

The perceived stress scale (PSS-10) was used to measure perceived stress. Perceived stress has been defined as the degree to which situations in one's life are perceived as stressful to the individual.[19,20] The PSS has three versions (the PSS-14, PSS-10, PSS-4), of which the 10-item version was used in this study.[19,20] The psychometric properties of the 10-item version are regarded by the authors as stronger than those of the 14-item version,[20] with a Cronbach's alpha value (for the PSS-10) of 0.78.[20] Higher scores on the PSS-10 indicate greater perceived stress. Although there is no cut-off value indicated, Cohen et al. published various studies documenting mean scores: the mean scores for two groups of college samples were 23.18 and 23.67, and the mean score in a smoking cessation study sample was 25.[19] The mean score for the general United States population (960 males and 1427 females) was 13.02.[20]

The multidimensional scale of perceived social support (MSPSS) was used to measure perceived level of social support.[21] Perceived social support has been defined as an interaction between at least two individuals where there is an exchange of resources, perceived by the recipient as helpful or intended to enhance his or her well-being.[21–24] The MSPSS is a 12-item questionnaire and has a 7-point Likert response format with answer choices ranging from "very strongly agree" to "very strongly disagree". Cronbach's alpha was reported to be 0.88 for the total scale. Scores range from 27 to 84, with higher scores indicating higher levels of perceived social support.[21] Suggested (total) cut-off scores are as follows: high support: 69–84; moderate support: 49–68; low support: 12–48.[21–23]

The Crohn's and colitis knowledge score (CCKNOW)[25] was used to measure IBD-related knowledge. Disease-related knowledge has been defined as information acquired about a certain disease on both social and medical aspects.[26] This 30-item multiple-choice questionnaire measures an individual's knowledge of facts about the disease, medication pertaining to the disease, nutritional intake, and natural history of the disease. The CCKNOW score provides an index of overall knowledge, and psychometric tests show it to be valid and reliable, with a Cronbach's alpha level of 0.95. Higher scores on the CCKNOW are associated with more IBD-related knowledge.[25] Although cut-off values are not provided, Eaden et al. indicated that the mean CCKNOW score was 27.3 for a group of physicians, 21.9 for a group of nurses, and 9.5 for a group of ward clerks.[25]