



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

Anilga Moradkhani ^{a,*}, Linda J. Beckman ^a, James H. Tabibian ^b

^a California School of Professional Psychology, Alhambra, CA, USA

^b Division of Gastroenterology and Hepatology, Mayo Clinic, Rochester, MN, USA

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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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* Corresponding author at: 1000 South Fremont Ave, Unit 5, Alhambra, CA 91308, USA. Tel.: +1 818 378 1212; fax: +1 651 251 5111.
E-mail address: AMoradkhani@alliant.edu (A. Moradkhani).

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

A separate questionnaire was designed and used to collect clinical and demographic information as covariables. Questions included information on the following 16 variables: gender, ethnicity, age, annual income, state of residence, employment status (employed, unemployed), schooling status (student, not a student), highest level of education completed (high school, college, graduate school, etc.), marital status, IBD type (UC vs. CD), years with IBD, number of hospitalizations due to IBD within the past year, number of surgeries for IBD within the past year, number of IBD relapses within the past year, desire to seek psychological therapy, and prior psychological therapy.

2.3. Data analysis

To determine which psychosocial, demographic, and clinical factors were associated with HRQOL, univariate analyses were first performed between each variable listed in the previous section and total IBDQ scores, using Pearson's correlation for continuous variables and *t*-test or ANOVA for categorical variables. Factors which were statistically significant in the univariate analyses were then included in a multivariate regression model using the enter method (standard regression), with the IBDQ score as the dependent variable. Statistical analyses were conducted using Statistical Package for the Social Sciences (SPSS), version 19.0. Tests of significance were two-tailed, with an alpha level of 0.05.

3. Results

A total of 134 individuals with IBD were included in this study (Table 1). The mean participant age was 32.5 years (standard deviation [SD]=10.0), 94% were Caucasian, and 81.3% were female. Fifty-eight percent of individuals had CD and 42% had UC. Sixty-six percent were employed and 31% were students. Additional data on sample characteristics are presented in Table 1. The mean score for the study sample was 106.5 for the IBDQ, 18.6 for the CCKNOW, 20.3 for the PSS-10, and 65.9 for the MSPSS. Further information on scale scores, including SD, median, and range of each of the scores, is provided in Table 2.

Univariate analyses of all the psychosocial, clinical, and demographic variables revealed several significant associations. Specifically, individuals who had higher perceived stress, lower perceived support, higher number of previous hospitalizations, higher number of relapses, lower income, were unemployed, and were female had lower scores on the IBDQ (Table 3).

These seven variables were entered into the multivariate regression model, wherein the variable most strongly associated with lower HRQOL was higher perceived stress ($p=0.0002$). This was followed by a higher number of previous relapses ($p=0.0006$), female gender ($p=0.004$), and lower perceived social support ($p=0.02$). These results are presented in greater detail in Table 4.

4. Discussion

Managing HRQOL in chronic diseases is increasingly being considered an important treatment goal. Most patients with IBD have impaired HRQOL when compared to the normal healthy population, particularly patients with active disease and those who have had surgery.^{9,10} There is a growing

Table 1 Sample characteristics.

Variable	
<i>n</i>	134
Age in years, mean (SD)	32.5 (10)
Years with IBD, mean (SD)	10.5 (8.8)
Gender, <i>n</i> (%)	
Female	109 (81%)
Self-reported ethnicity, <i>n</i> (%)	
Caucasian	127 (94%)
Hispanic	1 (1%)
Asian	1 (1%)
African American	1 (1%)
Other/mixed	4 (3%)
Self-reported annual income, <i>n</i> (%)	
\$24,999 and below	48 (36%)
\$25,000 to \$49,999	32 (24%)
\$50,000 to \$74,999	20 (15%)
\$75,000 to \$99,999	18 (13%)
\$100,000 and above	16 (12%)
Employment status, <i>n</i> (%)	
Employed	89 (66%)
Unemployed	45 (34%)
Schooling status, <i>n</i> (%)	
Student	41 (31%)
Not a student	93 (69%)
Highest level of education completed, <i>n</i> (%)	
High school	36 (27%)
Trade/technical school	12 (9%)
College A.A., A.S., or equivalent	17 (12%)
College B.A., B.S., or equivalent	47 (35%)
Master's level	20 (15%)
Doctorate level	2 (2%)
Marital status, <i>n</i> (%)	
Single	61 (45.5%)
Married	61 (45.5%)
Divorced	12 (9%)
Type of IBD, <i>n</i> (%)	
Crohn's disease	78 (58%)
Ulcerative colitis	56 (42%)
Previous relapses, mean (SD)	2.9 (3.2)
Previous hospitalizations, mean (SD)	1.0 (1.4)
Previous surgeries, mean (SD)	0.9 (1.3)
Desire to seek psychotherapy, <i>n</i> (%)	72 (54%)
Prior psychotherapy, <i>n</i> (%)	37 (28%)

awareness that not only clinical variables, but also psychosocial variables can have considerable influence on HRQOL in chronic illness, including IBD.¹⁷ The findings of this study show that individuals with IBD who have greater perceived stress, lower perceived social support, greater number of previous relapses, and are female reported lower HRQOL scores. Of these predictor variables, perceived stress was found to be the strongest predictor of HRQOL. Fig. 1 illustrates the predictors of health-related quality of life in patients with inflammatory bowel disease based on the findings of the present study as well as findings consistently noted in prior studies.

The effect of perceived stress on HRQOL has not been thoroughly investigated in IBD.²⁵ However, stress has been

Table 2 Study sample scores on standardized scales.

Scale	Mean	SD	Median	Range
IBDQ	106.5	35.5	108	38–197
CCKNOW	18.6	4.3	19	7–28
PSS	20.3	7.2	20	1–37
MSPSS	65.9	14.2	67.5	27–84

Key: CCKNOW, Crohn's and colitis knowledge scale; IBDQ, inflammatory bowel disease questionnaire; MSPSS, multidimensional scale of perceived social support; PSS, perceived stress scale; SD, standard deviation.
Note: Higher mean scores indicate higher levels of a variable. Suggested clinical remission cut-off score for the IBDQ is 168; Cut-off scores suggested the MSPSS are as follows: high support: 69–84; moderate support: 49–68; low support: 12–48. The CCKNOW and PSS do not have cut-off scores.

found to affect gut motility, visceral sensation and possibly immune regulation of inflammatory activity in the gut,²⁷ thereby possibly predisposing to disease onset or relapse and indirectly affecting HRQOL.^{25,28} Indeed, several studies have documented a relationship between stress and generally worse outcomes in IBD.^{1,25,27,29–32} Moreover, patients report stressful events as precipitating disease onset or relapse.²⁵ With such implications, greater focus should be turned toward developing clinical interventions aimed at managing and reducing stress (i.e. increasing coping methods) when it does arise. Effective coping has been found to play a significant role in how patients with IBD adjust to their illness^{25,28} which reinforces the importance of more effective coping methods for patients with IBD. As such, one potentially helpful method of reducing stress and enhancing coping methods in this population is (early) referral of individuals with IBD to clinical health psychologists.²⁸

Clinical health psychologists receive specialized training in chronic diseases and can help comprehensively enhance management of and living with IBD by providing tailored disease-related education, emotional support, skills to address deficits in coping, and additional resources such as introduction to IBD support groups. The desire for and perceived promise of this therapeutic intervention was highlighted in our study as 54% of participants, without being primed with information on the potential benefits, reported that they would like to see a clinical health psychologist for stress management and emotional support; however, only 28% reported having seen one. Better use of and more reliance on health psychologists, among other interventions, could be valuable and possibly synergistic in improving coping techniques in a subset of individuals with IBD, thereby leading to decreased perceived stress and better HRQOL.²⁸

Lower perceived social support was also linked to lower HRQOL scores in our study. It has been previously shown that social support facilitates coping with illness and stress management in patients with IBD.³³ Specifically, family support has been found to be helpful in managing IBD.³³ With the potential for altered physical appearance, pain, fecal incontinence, and impaired sexual functioning, IBD may, in some patients, lead to embarrassment and social withdrawal.³³ Indeed, the presence of these symptoms can severely impact social interactions and relationships.²⁵ This said, interventions aimed at increasing

Table 3 Univariate relationships between predictor variables and IBDQ scores.

Variable	<i>r</i>	<i>t</i>	<i>F</i>	<i>p</i>
Psychosocial variables				
IBD knowledge (CCKNOW)	0.02			0.85
Perceived social support (MSPSS)	0.33			<0.001
Perceived stress (PSS-10 score)	–0.63			<0.001
Clinical variables				
Previous hospitalizations	–0.24			<0.001
Previous relapses	–0.44			<0.001
Previous surgeries	–0.08			0.36
Type of disease (UC or CD)			1.7	0.07
Demographic variables				
Age	–0.02			0.77
Years with IBD	0.02			0.79
Education level			2.2	0.06
Ethnicity			1.5	0.21
Gender ^a		–2.8		<0.001
Income	0.26			<0.001
Marital status		1.8		0.07
Employment status ^b		–2.0		0.04
Schooling status		–0.2		0.83

Key: CCKNOW, Crohn's and colitis knowledge scale; MSPSS, multidimensional scale of perceived social support; PSS, perceived stress scale.

Note: three variables were collected for descriptive purposes (state of residence, desire to seek psychological counseling/therapy, and prior counseling) and were not included in the univariate analyses.

^a Women were found to have lower IBDQ scores; mean score was 89.0 for women compared to 110.47 for men.

^b Employed individuals were found to have lower IBDQ scores; mean score for those who were employed was 102.0 as compared to 115.2 for those who were not employed.

social interactions and/or preventing social alienation may be valuable, and, together with interventions for decreasing perceived stress, should therefore be a goal of care. It has been suggested that referral to IBD support groups may be beneficial in this regard²⁵; this may be considered in patients who have been newly diagnosed with IBD or for those who are emotionally struggling with their diagnosis. Furthermore, as family support was previously found to be the most valuable type of support, some patients with IBD may benefit from involving family members in their treatment.

Another predictor of HRQOL in our study was the number of relapses. This is essentially in agreement with past work, wherein one of the most important HRQOL determinant for patients with IBD was the presence of disease activity.^{10,34–36} Increased disease activity and/or frequent relapses in IBD can lead to anxiety, depression, sleeping problems and stress.³⁷ In addition to optimizing medical management, a number of precautions can be taken to minimize the impact of relapse on HRQOL. One such precaution is greater emphasis on stress management.²⁸

Table 4 Multivariate regression analyses between predictor variables and IBDQ scores.

Variable	B	Beta	S.E.	t	p
Psychosocial variables					
Perceived social support (MSPSS)	0.33	0.13	0.16	2.04	0.02
Perceived stress (PSS-10 score)	-2.41	-0.49	-0.32	-7.44	<0.001
Clinical variables					
Previous hospitalizations	1.59	0.06	1.7	0.93	0.34
Previous surgeries	-3.14	-0.29	0.72	-4.35	<0.001
Demographic variables					
Gender	14.5	0.16	5.67	2.57	<0.001
Income	0.89	0.05	1.13	0.78	0.47
Employment status	3.57	0.04	4.8	0.73	0.46

Key: MSPSS, multidimensional scale of perceived social support; PSS, perceived stress scale. Total $R^2=0.74$.

This study also reproduced the prior finding of lower HRQOL in women as compared to men with IBD,^{9,10,38} although this should be interpreted with caution as the majority of individuals in this study were women. There have been various hypotheses as to why women with IBD tend to report lower HRQOL, one being that psychological factors generally play a greater role in females than males.³⁸ Others include the notion that women are more likely to express worries and concerns about being a burden or about being treated differently as a result of their illness.³⁸ They are also more likely to report concerns related to attractiveness and body image^{17,39} and rate their symptoms as being more severe.^{29,38,40,41} It should be noted that some studies have also found that in the general healthy population, women's self-rated quality of life scores are lower than that of men.³⁸ Further research is needed to determine if HRQOL in women with IBD is truly significantly worse than that of men and if the magnitude of the difference is greater than what is present in the general population.

Contrary to the hypothesis, disease-specific knowledge was not related to HRQOL. However, past studies have found that

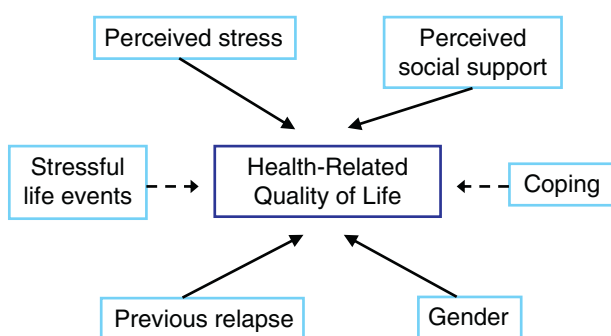


Figure 1 Predictors of health-related quality of life in inflammatory bowel disease. Predictors with dashed arrows were not evaluated in the present study but were found to be significantly associated with health-related quality of life in prior studies of patients with inflammatory bowel disease.

patient knowledge about chronic illness has been effective in reducing anxiety and perceived stress and may potentially improve health-related quality of life and symptoms of depression.⁴² Moreover, patients with a perceived lack of disease related information have been found to have less adaptive coping strategies¹⁵ and poorer HRQOL than their peers, manifested by more disease-related worries and concerns.⁴³ However, this question requires further investigation and would be beneficial to address in future studies. It should be noted that the mean knowledge score for our sample was relatively high (18.5) compared to the means reported in the original CCKNOW article (27.3 for a group of doctors, 21.9 for a group of nurses, and 9.5 for a group of ward clerks²⁵), indicating that patients in this study were relatively well-informed about their disease.

This study has several strengths. It is the first study to simultaneously examine the relationship between numerous psychosocial, clinical, and demographic predictors of HRQOL in individuals with IBD. The sample was recruited online, and as a result, it may be more representative of upcoming generations of patients with IBD who are more dependent on and better informed as a result of online data and support groups. Further, although this study was based on non-random sampling, this recruitment method enabled the incorporation of a fairly diverse sample of individuals living across the US (data not shown) with a wide spectrum of clinical and demographic features. In addition, although the three psychosocial factors we choose have been assessed individually in other studies of patients with IBD, this study is unique in that it is the first wherein these three psychosocial factors have been assessed in the same cohort of patients.

Our study also has several limitations. There were a few confounding variables that we were unable to adjust for, such as endoscopic activity or severity of IBD, medical and psychiatric comorbidities, including anxiety and depression, and the influence of dispositional characteristics. Convenience (non-probability) sampling was used for recruitment of participants. Small sample size did not allow for stratification of our sample based on IBD type nor for more complex multivariate analyses; however, it should be noted that there was no significant difference between prior surgical or hospitalization rates between individuals with UC and CD in our sample, and that type of IBD was not significantly associated with IBDQ scores. Mood-altering medications such as corticosteroids were not adjusted for, although it is unknown how and to what degree past (as compared to ongoing) use of such medications would affect present HRQOL. We cannot verify with certainty that participants were diagnosed with IBD by a medical specialist; however, the likelihood of participants not having IBD would seem low since all individuals were recruited from established IBD support and advocacy groups and participated voluntarily without remuneration. The gender distribution in our sample (81% female) does not mirror the approximately 1:1 male:female ratio in IBD and may instead be a reflection of various other factors, such as females more frequently joining support groups. Given the disproportionately small number of men in this study, the results herein should not be generalized to men unless validated by larger studies with a more proportionate gender ratio. Lastly, our results may not be broadly generalized to all individuals with IBD given that individuals herein were ambulatory (i.e. outpatient) and that this study was done via

the internet, and not all individuals with IBD have access to the internet or use it for medically-related purposes.

This study adds insight, particularly with respect to psychosocial variables, to the scientific literature about factors that may influence HRQOL in patients with IBD. It suggests that increased perceived stress, decreased social support, higher number of relapses, and possibly being female may be associated with worse HRQOL. In order to improve HRQOL in this population, these variables should be investigated further to better understand their relationship with HRQOL and to address them accordingly. For now, this can perhaps be best achieved, particularly with respect to psychosocial factors, by early referral of patients to clinical health psychologists or other mental health professionals who specialize in chronic medical disorders. Herein, patients with IBD can learn techniques that can help reduce their levels of perceived stress, obtain supplementary social and emotional support, and discover how to better adjust to and cope with their disease. Future research should focus on a multidimensional approach between medicine and health psychology in improving HRQOL and care in patients with IBD.

Conflict of interest

None.

Acknowledgments

Author contributions were as follows: (1) conception and design of the study, or acquisition of data, or analyses and interpretation of data (AM, LB, JHT), (2) drafting the article (AM) or revising it critically for important intellectual content (LB, JHT), and (3) final approval of the version to be submitted (AM, LB, JHT).

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