



Observational Study

## Estimation of quality of life in Cypriot patients with inflammatory bowel disease

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### Abstract

#### AIM

To investigate the health-related quality of life (HRQoL) of patients suffering with idiopathic inflammatory bowel disease (IBD).

#### METHODS

The Greek validated version of the Short Inflammatory Bowel Disease Questionnaire was used for evaluating the quality of life of IBD patients. The questionnaire was distributed to 100 consecutive patients suffering from IBD and presenting for a clinic appointment at the endoscopy unit of Larnaca General Hospital during the period from October to November 2012. The criteria for participating in this study were constituted by the documented diagnosis of either ulcerative colitis (UC) or Crohn's disease (CD) after endoscopy and histologic examination at least 6 months before the study, adult patients (18 years old or older), the capability of verbal communication and the patient's written consent for attending this study. The majority of the questionnaires were completed by a nurse practitioner who specializes

in IBD patient care.

## RESULTS

Regarding the physical dimension in patients with UC, males scored significantly higher than females (4.2 *vs* 3.4,  $P = 0.023$ ). Higher scores were also observed in UC patients younger than 35 or older than 50 years (4.0 and 4.2 *vs* 3.2, respectively,  $P = 0.021$ ). The psychological dimension revealed similar results in patients with UC, with males, and older ages scoring higher (5.0 *vs* 3.0,  $P = 0.01$  and 4.7 *vs* 2.7,  $P < 0.5$ , respectively), whereas regarding CD higher scores were observed in married compared to unmarried (3.83 *vs* 2.33,  $P = 0.042$ ). No statistical differences in any parameters in the social dimension were observed. Regarding the treatment of, patients with CD, overall higher scores were observed when treated with biological factors compared to standard therapy in all dimensions but with statistical significant difference in the social dimension (5.00 *vs* 3.25,  $P = 0.045$ ).

## CONCLUSION

The study reveals a negative impact of IBD on HRQoL. Increased risks are age and gender in patients with UC and family status in patients with CD.

**Key words:** Crohn's disease; Health related quality of life; Quality of life; Short inflammatory bowel disease questionnaire; Ulcerative colitis

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**Core tip:** The study reveals an overall negative impact of idiopathic inflammatory bowel diseases on health-related quality of life (HRQoL), mostly in patients with Crohn's disease (CD). Increased risks for decreased HRQoL are age and gender in patients with ulcerative colitis and family status in patients with CD. This is the first application of the validated Greek version of the short inflammatory bowel disease questionnaire in a patient population in Cyprus.

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## INTRODUCTION

The idiopathic inflammatory bowel diseases (IBD) is a general term used to describe a group of chronic inflammations and relapsing disorders of the gastro enteric route, with Crohn's disease (CD) and ulcerative colitis (UC) being the most common ones. These diseases are characterized by an inadequate immune reaction that causes a characteristic inflammatory

response<sup>[1]</sup>. The physical history of both diseases is characterized by relapses that can have a direct effect on the patient's lives<sup>[2]</sup> and can considerably influence their quality of life<sup>[3]</sup>.

Activity indexes are used as a conventional way of evaluating the severity of IBD but they do not take into consideration other aspects that may affect the patient's life. As a result the indicators are proved less sensitive and come in contrast with the patient's perception of health<sup>[4,5]</sup>.

This fact led researchers to the development of other tools to investigate the subjective sensation of health including the quality of life that is distinctively linked to medical care and health related experience<sup>[4]</sup>.

The term health related quality of life (HRQoL) was developed in order to better understand and evaluate the consequences of the disease on quality of life. According to Drossman this is a general estimation of the patient's condition regarding their disease, how it influences their activities both in the psychological and social sectors and the way they are experiencing these activities<sup>[6]</sup>.

The aim of this study was to assess the HRQoL in patients with IBD in Cyprus by using a validated disease-specific questionnaire and to investigate the factors that influence their quality of life.

## MATERIALS AND METHODS

The validated Greek translation of the Short Inflammatory Bowel Disease Questionnaire (SIBDQ) was used<sup>[7]</sup> for estimating the quality of life of IBD patients. It is a specific tool for measuring the quality of life of these patients<sup>[8]</sup> and was used after obtaining a licensing agreement from McMaster University, United States. The questionnaire is composed of 10 questions measuring psychological, social and physical status and is scored on a 7-point Likert scale from 1 (severe problem) to 7 (no problems at all). The absolute score ranges from 10-70, consistent with poor to optimum HRQoL. The SIBDQ has been tested for its validity and reliability revealing a Cronbach's factor of 0.78<sup>[7]</sup>. The Cronbach's alpha of the present sample was 0.89 and was judged as very satisfactory. The questionnaire was distributed to 100 consecutive patients suffering from IBD and presenting for an outpatient clinic appointment at the endoscopy/GI unit of Larnaca General Hospital during the period from October to November 2012. The criteria for participating in this study were a confirmed diagnosis of either UC or CD after endoscopy and histologic examination at least 6 mo before the study, adult patients (18 years old or older), the capability of fluent verbal communication in Greek and the patient's written consent for participating in this study. The completion of the questionnaires was overseen by a nurse practitioner who specializes in IBD patient care. The study was performed after approval by the Cyprus National Bioethics Committee, Cyprus Data Protection

**Table 1** Demographic and disease characteristics of the study population *n* (%)

	Total <i>n</i> = 100	CD <i>n</i> = 40	UC <i>n</i> = 60	<i>P</i> value
Sex				0.198
Male	54 (53.5)	61.5%	48.3%	
Female	46 (46.5)	38.5%	51.7%	
Age (yr) ( <i>n</i> = 97)		<i>n</i> = 38	<i>n</i> = 59	
18-35	39 (39.8)	16 (41.0)	23 (39.0)	0.979
35-50	28 (28.6)	11 (28.2)	17 (28.8)	
> 51	30 (31.6)	11 (30.8)	19 (32.2)	
Smoking	32 (33.0)	43.2%	26.7%	0.092
Education				0.673
Primary or less	17.3%	18.4%	16.7%	
Secondary	49.0%	42.1%	53.3%	
Tertiary or above	33.7%	39.5%	30.0%	
Employment status				0.349
Government officials	19.8%	22.9%	18.3%	
Private employee	44.8%	44.4%	45.0%	
Self-employed	4.2%	8.3%	1.7%	
Unemployed	31.3%	25.0%	35.0%	
Family status				0.822
Married	62.6%	59.0%	65.0%	
Unmarried	32.3%	35.9%	30.0%	
Divorced	5.1%	5.1%	5.0%	
Surgery	20.9%	36.1%	11.7%	0.004
Mean disease duration (yr)	12.63%	10.28%	14.07%	0.118
Treatment				0.019
Immunosuppressive treatment	65.0%	55.0%	71.7%	
Immunosuppressive treatment + corticosteroids	16.0%	12.5%	18.3%	
Treatment with biologic agents	19.0%	32.5%	10.0%	
Treatment with corticosteroids	22.0%	17.5%	25.0%	0.375%

CD: Crohn's disease; UC: Ulcerative colitis.

Authority and the Health Ministry Scientific Promotion Committee.

### Statistical analysis

Statistical analysis was performed using SPSS 20.0 for Windows (SPSS Inc. Chicago, IL, United States). Categorical data were expressed as numbers with percentages, and continuous data were expressed as medians with a range. *P* values less than 0.05 were considered to indicate statistical significance.

## RESULTS

The demographic characteristics of the study population are shown in Table 1. One hundred patients with IBD were investigated, 40% with Crohn's disease and 60% with ulcerative colitis. In the CD group a predominance of men (61.5% vs 38.5%) was observed, whereas in the UC group the proportion of females was slightly higher (51.7% vs 48.3%).

Patients with CD scored overall lower on the SIBDQ (Table 2). Regarding the physical dimension in patients with ulcerative colitis, males scored significantly higher than females (4.2 vs 3.4, *P* =

**Table 2** Short inflammatory bowel disease questionnaire score by dimension and type of disease (*n* = 100), mean ( $\pm$  SD) *n* (%)

	Crohn's disease	Ulcerative colitis
Physical dimension	18.53 (7.55)	19.52 (6.74)
Psychological dimension	10.68 (5.31)	11.88 (4.49)
Social dimension	7.92 (3.03)	8.63 (3.18)
Overall SIBDQ	33.79 (13.36)	36.30 (11.39)

SIBDQ: Short inflammatory bowel disease questionnaire.

**Table 3** Physical Dimension scores of health-related quality of life in patients with Crohn's disease and ulcerative colitis and their association to demographic parameters

	Physical dimension	
	Crohn's disease, median	Ulcerative colitis, median
Gender		
Male	3.3	4.2
Female	3.5	3.4
<i>Z</i>	-0.015	-2.274
<i>P</i> value	0.988	0.023
Age		
< 35	3.1	4.0
35-50	3.8	3.2
> 50	3.8	4.2
$\chi^2$	1.232	7.767
<i>P</i> value	0.540	0.021

0.023), whereas no gender difference was observed in patients with CD. Higher scores were also observed in ulcerative colitis patients younger than 35 or older than 50 years compared to the age group of 35-50 years old (4.0 and 4.2 vs 3.1, respectively, *P* = 0.021). Further details of the physical dimension are shown in Table 3.

The psychological dimension revealed similar results in patients with UC, with males, and older ages scoring higher (5.0 vs 3.0, *P* = 0.01 and 4.7 vs 2.7, *P* = 0.5, respectively), whereas regarding Crohn's disease higher scores were observed in married compared to unmarried (3.83 vs 2.33, *P* = 0.042) (Table 3). Further details of the psychological dimension are shown in Table 4.

No statistical differences in any parameters in both CD and UC were observed regarding the social dimension. Regarding the treatment of patients with CD, overall higher scores were observed when treated with biological factors compared to standard therapy in all dimensions but with statistical significant difference in the social dimension (5.00 vs 3.25, *P* = 0.045) (Table 5).

## DISCUSSION

SIBDQ is a validated instrument measuring the subjective perception of health state and identifying problems in IBD patients. However, quality of life

**Table 4 Psychological dimension scores of health-related quality of life in patients with Crohn's disease and ulcerative colitis and their association to demographic parameters**

	Psychological dimension	
	Crohn's disease, median	Ulcerative colitis, median
Gender		
Male	3.17	5.00
Female	2.83	3.00
Z	-0.456	-3.474
P value	0.648	0.001
Age		
< 35	2.83	4.00
35-50	2.33	2.67
> 51	4.67	4.67
$\chi^2$	1.011	5.979
P value	0.603	0.0503
Family status		
Married	3.83	4.00
Single	2.33	3.50
Z	6.351	-0.663
P value	0.042	0.507

HRQoL: Health-related quality of life.

measures have not been widely integrated into routine clinical practice till now, although they seem to be potentially useful in improving patients' health and delivering high quality health services that can come up to the patients' needs and expectations<sup>[9]</sup>. Furthermore, investigating the factors, which are associated to poor HRQoL, important information can be obtained on the way the disease influences all aspects of a patient's health and can also help health professionals in dealing with these problems more adequately<sup>[10]</sup>.

In the present study the overall SIBDQ score as well as the single scores in all dimensions were lower in patients with CD, indicating thus the poorer quality of life in these patients. Furthermore, the scores were associated with demographic parameters such as gender and age in UC patients and to marital status in CD patients. In agreement with these results Mikocka-Walus *et al.*<sup>[11]</sup> reported that 31 patients with CD had a worse physical HRQoL compared to 33 patients with UC.

Several studies have documented a relationship between gender and HRQoL, pointing out female patients with IBD having worse outcomes<sup>[12-17]</sup>. Possibly the lower scores are related to the higher sensibility of women compared to men towards gastrointestinal symptoms<sup>[18]</sup>. Besides surgical intervention Williet *et al.*<sup>[19]</sup> mentioned that other factors, associated with depression and anxiety, affect IBD patients and here mainly women as the female gender is more susceptible to depression and anxiety. However, other researchers did not reveal any differences between gender regarding the HRQoL in both patients with UC and CD<sup>[20-22]</sup>.

The effect of age on HRQoL in IBD was also

**Table 5 Scores of health-related quality of life in patients with Crohn's disease and ulcerative colitis in association to medication treatment**

	Medication	Median	Z	P value
Physical dimension	Biological factors	5.00	-1.484	0.138
	Standard treatment	3.20		
Psychological dimension	Biological factors	4.67	-1.584	0.113
	Standard treatment	2.67		
Social dimension	Biological factors	5.00	-2.004	0.045
	Standard treatment	3.25		

HRQoL: Health-related quality of life.

reported in other studies, revealing patients in mid ages having lower scores<sup>[18]</sup>. Similarly, in a Greek study, IBD patients younger than 40 years old scored higher in HRQoL compared to higher age groups<sup>[23]</sup>. Several former studies reported also an association between age and HRQoL scores<sup>[24-26]</sup>. It is also worth mentioning that in the present study the differences in gender and age are observed mainly in patients with ulcerative colitis with effect to female UC patients revealing the similar low scores as females with CD.

In the physical dimension of quality of life of patients with IBD, women gathered lower scores, a fact that was mentioned by other researchers as well<sup>[13-18]</sup>. The results of the present study are related with the results of other studies that revealed lower score of women with gastrointestinal diseases compared to men<sup>[18]</sup>. Through a number of studies taken place among patients suffering by CD and UC no relation was emerged in between gender and HRQoL<sup>[21,22]</sup>. However, on the other hand many studies have reported that there is a relation between age and HRQoL<sup>[23-26]</sup>, a fact that is already revealed through the present study. This correlation may result from the concerns and aspects of daily life, work and other factors at different stages of life with age being an important factor reflecting in measuring the quality of life in different age groups. Results of other studies come in full agreement with the present study revealing the fact that middle aged groups have lower scores of HRQoL<sup>[18-23]</sup>.

The psychological dimension of this study highlights lower scores of HRQoL in women which stands in agreement with other studies that have reported higher levels of anxiety and depression among women than in male population<sup>[27]</sup>, mentioning as well the deep concerns of women regarding their disease and especially the fact that they have to depend on others for help<sup>[28,29]</sup>.

A number of potential interpretations and limitations for the results of the two dimensions of the SIBDQ can be provided. First, low scores of HRQoL in physical dimension may also reduce the scores of HRQoL in the psychological dimension or conversely and second there is a possibility of this interaction to be an additive effect of the two dimensions presenting

independently. The low score of HRQoL in unmarried patients may be attributed to the fact that family is a fundamental social institution that offers security, guidance and assistance to the members thus providing positive affects to their health and this is fundamental for the protection and promotion of their mental and physical health. Other researches mention the positive affection of the family to the progress of the illness<sup>[30,31]</sup>.

The social dimension showed to be improved by taking biological agents. According to many researches positive reaction was observed to CD after the treatment with biological agents<sup>[32-34]</sup>. Kalafateli reports that the use of biological factors was found to have a negative impact on the HRQoL of all patients with IBD in relation to the systematic symptoms of the disease<sup>[35]</sup>. Since the introduction of biological agents in IBD treatment in Cyprus is relatively recent, it will be interesting to evaluate this dynamic in a subsequent follow up trial.

## COMMENTS

### Background

The idiopathic inflammatory bowel diseases (IBD) are nosological entities which are characterized by chronic relapsing of the immune system and inflammation of the gastrointestinal tract. They occur with remissions and relapses and their effect on the way of life of these patients is immediate, resulting in poorer quality of life (QoL) compared to the general population. However, in Cyprus the traditional way of assessing the gravity of the IBD does not include the overall impact of the disease on the health of the patient, nor the point of view of the patient regarding the disease and its impact mainly on the psychological and social sector. Identifying the factors associated with poor QoL, important information is offered on how the disease affects other aspects of the patient's health.

### Research frontiers

In Cyprus the number of IBD patients in recent years has grown rapidly. However in Cyprus, the overall effect of the disease in relation to the psychological, physical and social well-being of the patient has never been researched. This research offers important information on how the disease affects all aspects of patient health; the result of this was for the research to be important help to the health care professionals in dealing with the problems of these patients in a more round and comprehensible perspective and thus contribute to make better their life through time.

### Innovations and breakthroughs

It became apparent that the general health status of the patients with IBD is not only determined by clinical-laboratory assessment of the disease, but also by factors such as psychological situation, vocational, social and love life, cultural and other ideologies and primarily complications and side effects of the treatment. This study is the only one addressing Cypriot patients to measure the quality of life in relation to IBD. It became noticeable that the patients are affected regarding the physical, the psychological and the social dimension because of the disease. Women with ulcerative colitis (UC) seem to be more vulnerable than men in connection with the symptomatology and the psychological field. Patients with Crohn's disease (CD) that take biological agents were indicated to have better QoL in relation to their social activities and those who are married were designated to have better QoL compared to single people in the psychological field.

### Applications

The results of this study could improve the treatment of patients with IBD, to reduce their symptoms and to help them depend less on health services.

Promoting self-care of these patients, assistance in managing stress arising from diseases through alternative techniques, appointing clinical psychologist, creating specialized clinics with suitably trained individuals and social support programs especially for women at the ages 35-50, are possible ways to improve the HRQoL of IBD patients, in Cyprus.

### Terminology

IBD means inflammatory bowel disease that are chronic inflammatory diseases of the intestine and are characterized by remissions and relapses. CD is a chronic inflammatory bowel disease that can infect any part of the digestive tract or the colon where as UC being also a chronic inflammatory bowel disease infects the colon. SIBDQ is a specific questionnaire used for measuring the quality of life of patients with IBD.

### Peer-review

Available papers regarding measuring the quality of life of patients with IBD in Cyprus do not exist. The authors of this study investigated the QoL of patients with IBD related to physical, psychological, and social dimension. This study showed that aspects of life of these patients are affected more than those which are apparent in their laboratory tests. The results of the survey are interesting as they provide new information for Cypriot patients with IBD, enriching the scientific sector of Cyprus and open the way to new studies specializing even more in this sector aiming at improving the QoL of these patients.

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