

Disability and quality of life before and during the COVID-19 outbreak: A cross-sectional study in inflammatory bowel disease patients

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Abstract

Background/Aim: Inflammatory bowel disease (IBD) is a chronic disorder affecting patients' health-related quality of life (HRQoL) which adds to their disability. Little is known about the impact of the COVID-19 pandemic on HRQoL of IBD patients. We aimed to evaluate HRQoL in IBD patient's pre- and post-COVID-19 pandemic using the IBD-disk questionnaire and explore associations between socio demographic factors, disease types, severity and impaired HRQoL in patients with IBD.

Patients and Methods: A cross-sectional study was conducted at a tertiary care centre in Saudi Arabia between November 2019 and March 2020 at the outpatient IBD clinics. The HRQoL of patients was assessed using the 10-item IBD-disk questionnaire.

Results: A total of 59 IBD patients (40 Crohn's disease, 19 Ulcerative colitis) with a mean disease duration of 3.5 years were included. Most of the patients (77.97%) were on biologics while 35.59% were on immune modulators, 16.94% on 5-ASA, and 3.38% were on corticosteroids. There was no difference between any of the 10 IBD-disk variables pre and post-COVID-19 pandemic apart from the perception of body image, where there was a slightly more negative perception with an increase from 2.53 to 3.39 ($P = 0.05$) There was no significant difference in HRQoL between patients with ulcerative colitis and Crohn's disease in any of domains.

Conclusion: The current study showed that disability and HRQoL appears to be unaffected by the COVID-19 pandemic among our cohort, however further studies with longer follow up and larger sample size is needed.

Keywords: COVID-19, disability, DISK, IBD-DI, inflammatory bowel disease, quality of life

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INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic disabling condition that negatively impacts on the physical, psychological, familial and social dimensions of those

affected by it.^[1] Furthermore, IBD has been found to be associated with psychological disorders, which lead to an impaired health-related quality of life (HRQoL)^[2-5] as well

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as increased healthcare costs.^[6,7] Our current targets in the care for patients effected by IBD is to alleviate disease symptoms, decrease the incidence of flares, prevention of long term complications, as well as to 'improve patients HRQoL.^[8,9] Numerous studies have focused on HRQoL assessment to measure and provide insight on the disability status of IBD patients.^[10,11] There is growing evidence that psychological distress can predict disease severity and early clinical recurrence.^[12,13] The IBD Disability Index (IBD-DI), a questionnaire comprised of 28 items, provides a robust tool to evaluate the functional status of patients with IBD.^[14] However, it needs to be conducted by a health care professional. The modified version of the IBD-DI, comprised of 14 disability-related questions, was validated in a population-based IBD cohort in France.^[15] However, both tools lack direct patient involvement, which can be meaningful to patients. More recently, attention has focused on the mental health needs of IBD patients as well as its assessment during outpatient visits.^[16] Gosh and his colleagues validated a self-administered 10-item visual instrument named IBD-Disk based on the Psodisk platform.^[17] Psodisk is a patient-reported outcome measure that includes items relevant to disability and provides the physician and patient with visual representation of the disease burden for that individual.^[18] The outbreak of the new severe acute respiratory syndrome coronavirus 2 (SARS-CoV2), which causes the novel coronavirus disease 2019 (COVID-19), was reported in China in December 2019 and has rapidly spread worldwide. Patients with IBD could experience levels of psychological distress due to this pandemic. This situation can lead to mental health problems, such as stress, anxiety, and fear among IBD patients, which needs to be explored. During any crisis, traumatization with variable degree of damage such as loss of appetite, fatigue, physical decline, sleep disorder, and irritability can exceed emotional tolerance. Therefore, identifying and providing care at an early stage is important. To the best of our knowledge, no studies have investigated the role of psychological distress, functional status during COVID-19 crisis, and the disease parameters of IBD patients.

The aims of this study are to: 1) evaluate the HRQoL in IBD patients pre and post COVID-19 pandemic using the IBD-disk questionnaire and scoring disk, 2) evaluate whether disease type (ulcerative colitis, Crohn's disease), disease status (active, remission) impacts the outcomes, and 3) explore associations between socio-demographic factors and impaired HRQoL in patients with IBD.

PATIENTS AND METHODS

This was a cross-sectional study using convenient sampling.

A total of 59 consecutively enrolled patients with a diagnosis of IBD who were receiving regular outpatient gastroenterology service at an academic tertiary care center in Riyadh, Saudi Arabia were recruited. Inclusion criteria were: (1) A confirmed diagnosis of IBD based on clinical, endoscopic, radiological and histopathological evidence, in accordance with standard diagnostic criteria,^[19,20] (2) Age more than 16 years, (3) Being able to communicate and comprehend the questionnaires. Exclusion criteria included those currently hospitalized, having a co-morbid psychotic or substance use disorder, or the presence of severe co-existing diseases potentially affecting the HRQoL.

Demographic, socioeconomic and clinical information were collected. These included aspects like sex, age, marital status, monthly income, type of IBD, disease duration, severity (at the time of diagnosis), current medications and their combinations, as well as the disease activity was assessed. The disease activity of our Crohn's disease cohort was measured based on Harvey-Bradshaw Index (HBI) and the partial Mayo Score/Disease Activity for ulcerative colitis patients. Laboratory parameters including haemoglobin level and C-reactive protein (CRP), which was done within 3 months from the time of the interview, were included as well.

Survey tool - the IBD-disk

The IBD-disk questionnaire was developed through an iterative Delphi consensus process as a shorter version of the IBD Disability Index (IBDDI), which assesses the functional status of individuals with IBD.^[17] The questionnaire consists of 10 items that includes the domains of abdominal pain, regulatory defecation, interpersonal interactions, education and work, sleep, energy emotions, body image, sexual functions, as well as joint pain. Each question is rated on a 10-point scale, where 0 and 10 correspond to the best and worst function level, respectively. Every subject was asked about his or her feeling over the past 3 weeks. The results are displayed in a visual format called a Psodisk which has been used mainly in Psoriasis.

Survey delivery method

The survey was initially performed during the pre-COVID-19 pandemic in the outpatient IBD clinics during November-December 2019, and was then performed again in February and March 2020 during the COVID-19 pandemic. For those who were not interviewed in the period before the COVID-19 pandemic they were only interviewed once in February and March of the year 2020. Informed consent was obtained from all participants. An IBD patient support specialist who received training in

using the IBD-Disk questionnaire conducted the survey through face to face interviews during the pre-COVID-19 pandemic, and the second interview for the cohort post-COVID-19 was conducted over the telephone. Expert consultants in the field of IBD performed the Arabic translation of the questionnaire.

Statistical analysis

Descriptive statistics were computed for continuous variables, including minimum and maximum values, means, standard deviations (SDs), as well as 95% confidence intervals (CIs) and frequencies for categorical variables where appropriate. If hypothesis testing was used, Pearson's Chi-square *t*-test and, where appropriate, Fisher's exact tests were used.^[21] A one-way analysis of variance to test for differences among groups when comparing more than one group was performed where appropriate.

R Studio^[22] was used for analysis using the R statistical language.^[23] Numerous statistical packages were used for statistical calculations and data visualization. A statistical significance threshold of $P = 0.05$ was adopted. No attempt at imputation was made for missing data.

The study was approved by the institutional review board (IRB) as part of an IBD cohort study (E-11-538).

RESULTS

Demographics of survey respondents

Out of the total of 59 participants in the study, 29 who attended their regular follow-up appointments in the clinics during November and early December 2019 were interviewed twice; the first interview was during the pre-COVID-19 pandemic. They were then re-interviewed in March 2020 during the COVID-19 pandemic. The remaining 30 participants were interviewed only once in February and March 2020 during the COVID 19 pandemic.

The mean age of participants was 33.9 years (SD = 11.73) and females represented 57.6% of the study population. The majority of the participants were married (66.1%) and 52.5% had at least one child. The average disease duration was 3.5 years. Crohn's disease represented 67.8% of the respondents and 69.5% were in remission while 91.52% had either moderate or severe disease at the time of diagnosis. It was noted that more patients with Crohn's disease had moderate or severe disease when compared to those with ulcerative colitis [Table 1].

Most of the patients (77.97%) were on biologics 35.59% were on immune modulators, 16.94% on 5-ASA, and 3.38% were on corticosteroids. When comparing between

patients with Crohn's disease and ulcerative colitis, more patients with Crohn's disease were on biologics and immunomodulators [Table 1].

There was no difference in the age, haemoglobin or CRP level between the patients with Crohn's disease or ulcerative colitis [Figure 1a-c] or when these variables were compared based on disease severity [Figure 2a-c].

Baseline IBD-Disk results

In those patients who had the questionnaire delivered twice, there was no difference between any of the 10 IBD- disk variables apart from the perception of body image where there was a slightly more negative perception, with an increase from 2.53 to 3.39 ($P = 0.05$) [Table 2].

Subgroup analysis

There was no difference in the scores of the IBD-Disk when compared between patients with Crohn's disease and ulcerative colitis in any of the domains. Similarly, there was no difference between the groups when analyzed on the basis of disease severity.

DISCUSSION

In the present study, we found that the current COVID-19 pandemic did not impact on HRQoL in our cohort of IBD patients over the 5-month study period. Unfamiliar quarantine strategies have been implemented globally to contain the spread of the SARS CoV2 infection, which can make people feel anxious and unsafe. Patients with chronic medical diseases could experience stress disorders (like irritability, insomnia, emotional distress, mood disorders, fear and panic) due to the uncertainties around the current crisis.^[24] Psychological well-being has been identified as a key factor in the care of patients with IBD. The prevalence of major depression was found to be 27.2% in IBD patients which is higher when compared to the general population (OR 2.20, 95%CI; 1.64 to 2.95).^[24] A case control study has demonstrated a higher rate of anxiety disorder with an incidence rate ratio (IRR) of 1.39 (95%CI; 1.26 to 1.53) among IBD patients.^[25] In another study, the psychological burden was variable based on the activity of the disease, being increased in those with active disease compared to those in a state of remission.^[26] This has also been found in a systematic review, which has shown that depressive symptoms could reach up to 40% during active disease.^[27] In a large Swiss study, it was found that the presence of anxiety and depression were associated with disease flares,^[28] while another US study found the presence of a psychiatric disorder to be associated with a lower response to therapy.^[29] Whether modifying both these factors would influence disease activity remains to be seen.

Table 1: Characteristics of those who responded to the questionnaire

Variable	Total cohort, n=59 (%)	Crohn's disease, n=40 (%)	Ulcerative colitis, n=19 (%)	P
Age (years)	33.89	33.90	33.89	1.00
Sex				
Male	25 (42.37%)	15 (37.50%)	10 (52.63%)	0.27
Female	34 (57.63%)	25 (62.50%)	9 (47.37%)	
Married	39 (66.10%)	27 (67.50%)	12 (63.16%)	0.74
Having children	31 (52.54%)	22 (55.00%)	9 (47.37%)	0.58
Monthly Income in Saudi Riyals (SR)				
less than SR 5000	10 (16.95%)	7 (17.50%)	3 (15.79%)	0.98
Around SR 5000	31 (52.54%)	21 (52.50%)	10 (52.63%)	
More than SR 5000	18 (30.51%)	12 (30.00%)	6 (31.58%)	
Disease status				
Active	18 (30.51%)	12 (30.00%)	6 (31.58%)	0.90
Remission	41 (69.49%)	28 (70.00%)	13 (68.42%)	
Severity of disease				
Mild	5 (8.47%)	1 (2.50%)	4 (21.05%)	0.05*
Moderate	27 (45.76%)	19 (47.50%)	8 (42.11%)	
Severe	27 (45.76%)	20 (50.00%)	7 (36.84%)	
Medications				
5-ASA	4 (6.77%)	0 (0.00%)	4 (21.05%)	<0.01*
Corticosteroids > 15 mg/day	1 (1.69%)	1 (2.50%)	0 (0.00%)	
Immune modulators	3 (5.08%)	3 (7.50%)	0 (0.00%)	
Biologics	26 (44.07%)	21 (52.50%)	5 (26.32%)	
Immune modulators and biologics	13 (22.03%)	12 (30.00%)	1 (5.26%)	
Immune modulators & 5-ASA	5 (8.47%)	1 (2.50%)	4 (21.05%)	
5-ASA, corticosteroids and biologics	1 (1.69%)	0 (0.00%)	1 (5.26%)	
5-ASA and biologics	2 (3.39%)	0 (0.00%)	2 (10.53%)	
Corticosteroids and biologics	4 (6.77%)	2 (5.00%)	2 (10.53%)	
Haemoglobin	12.71	12.64	12.86	0.66
C reactive protein	13.97	11.13	19.96	0.19

*Statistically significant

Also, a large population study from South Korea found that the risk of developing anxiety and depression were higher after being diagnosed with IBD, with the highest risk during the first year.^[30] This bidirectional association is easy to grasp and reflects the interrelationship between both factors. The burden of psychological stress increases the complexity

of managing patients with IBD as it can compound the effect of the disease on their social functioning, apart from their the compliance to medications, hospital visits and workups. As such, dedicated integrated approaches for providing behavioral and pharmacological interventions, when needed, in patients with IBD have been described.^[2,31]

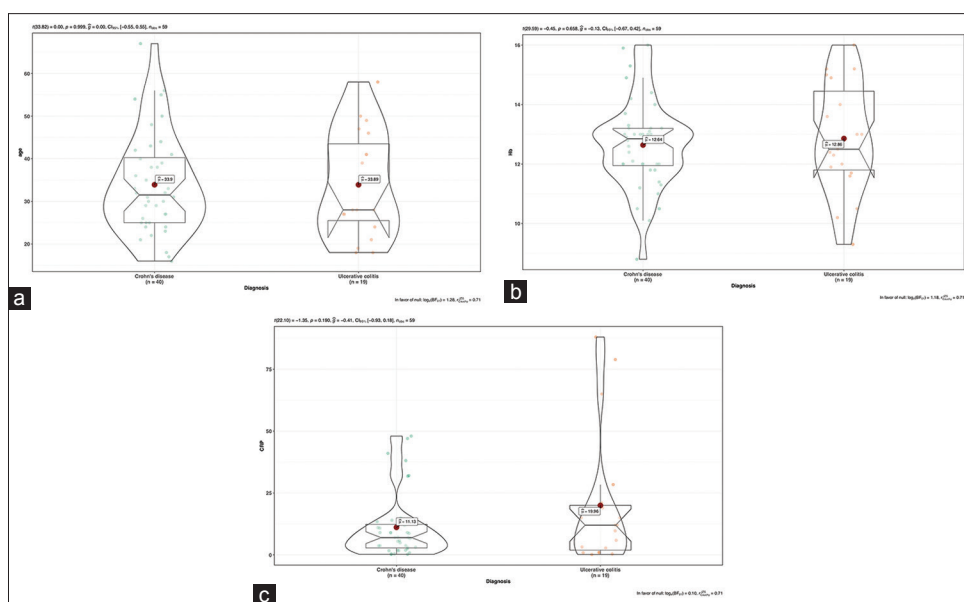


Figure 1: (a) Age comparison between patients with Crohn's disease and ulcerative colitis. (b) Comparison of the hemoglobin level between patients with Crohn's disease and ulcerative colitis. (c) Comparison of the CRP level of patients with Crohn's disease and ulcerative colitis

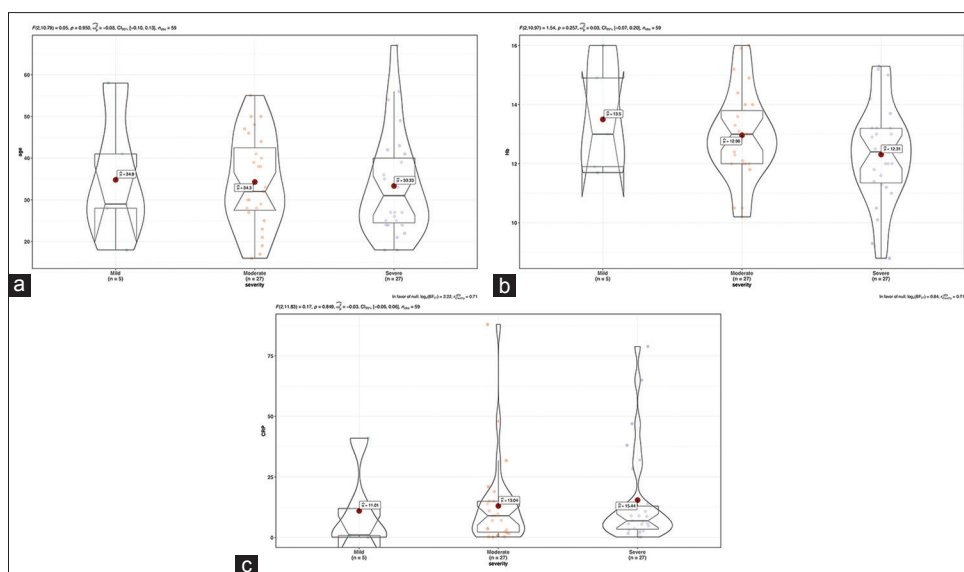


Figure 2: (a) Comparison between the age of patients based on disease severity. (b) Comparison between the hemoglobin levels of patients based on disease severity. (c) Comparison between the CRP levels of patients based on disease severity

Table 2: Difference between symptoms in the patients with IBD who had the disc assessment before and after the COVID-19 outbreak

Variable	Before	After	Difference	95% CI	P
Abdominal pain	3.67	2.36	-1.03	-2.39-0.32	0.13
Regulating defecation	4.27	3.53	-0.73	-1.93-0.46	0.22
Interpersonal interaction	1.70	2.20	0.50	-0.54-1.54	0.33
Education and work	2.77	2.6	-0.17	-1.78-1.44	0.83
Sleep	2.40	3.07	0.67	-0.83-2.17	0.37
Energy	3.97	3.57	-0.4	-1.75-0.95	0.55
Emotions	4.13	4.40	0.27	-1.37-1.90	0.74
Body image	2.53	3.93	1.4	-0.02-2.82	0.05*
Sexual functions	1.63	2.24	0.61	-0.61-1.82	0.31
Joint pain	2.84	3.87	1.03	-0.12-2.18	0.08

*Statistically significant

IBD-DI has been developed^[14] and extensively used and has been validated in numerous languages.^[15,32,33] The shortened IBD-Disk is thought to be easier to incorporate into daily practice with the aim of gathering important patient reported outcome measures^[34] and has been incorporated in usual medical care in some institutions^[35] with a smart phone application. However, the IBD-Disk tool has been criticized that it does not add much to the original IBD-DI questionnaire.^[36] Despite that the questionnaire was developed to be self-administered as an option as opposed to the IBD-DI, which is physician-administered, we initially opted to deliver the IBD-Disk questionnaire in person to be sure that patients understood the questions correctly as there is no validated translation to Arabic as of yet. The current study did not show any difference between any of the 10 IBD-disk variables among our cohort, apart from the perception of body image where there was a slightly more negative perception with an increase from 2.53 to 3.39 ($P = 0.05$), which may not be stress-related *per se*, but might be associated with the change in body weight with

the medical management that was received, although we do not have the data to support this assumption. The length of the questionnaires might be a barrier to patients' willingness to participate where some have used questionnaires consisting of 80 items.^[37] The visual representation of the patient's functionality is thought to be an advantage of the IBD-Disk questionnaire although radar diagrams have been criticised. For instance, these graphs promote comparison between different axes on the same ordinal scale although a value of 6 on the "Regulating defecation" or "Abdominal pain" parameters might not be of equal bearing as "Body image" or "Energy" axes. Neither are these parameters independent. so when one is affected others are also affected as a consequence. Also, changing the order of the variables could result in different shapes and visual perception of areas although the values are not changed. Nonetheless, the IBD-Disk questionnaire remains a valuable quick tool that could be incorporated in clinical practice to compare a patient's evolution overtime as long as its limitations are understood. We could not account for factors that might have affected the psychological functioning of individuals in the present study during the COVID-19 epidemic. For instance, it has been found that individuals with IBD, although initially could be challenged by their disease, could later adjust and not only cope with the disease but would also be considered as resilient, but some even thrive after their initial illness.^[38] These are affected by the capacity for coping efficacy, acceptance of illness, and perceived social support.^[38-40]

Other limitations include the small sample size of the study but given that it was implemented just before the onset of the pandemic, we could not recruit a larger number of

participants. Also, the time when the questionnaire was administered might have not been long enough to provoke any emotions of stress. However, to our knowledge this is the first study to have investigated the role of psychological distress, functional status and disease's parameters of IBD patients during the COVID-19 crisis. In conclusion, the current study showed that disability and quality of life does not appear to be affected by the COVID-19 pandemic among our IBD cohort, however further studies with longer follow up and larger samples are needed.

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Conflicts of interest

There are no conflicts of interest.

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