IMPACT OF INFLAMMATORY BOWEL DISEASE AND DISEASE ACTIVITY ON THE QUALITY OF LIFE, A SINGLE CENTER STUDY
By

YASMINE NABIL OMAR[1*], AHMED FOUAD SHERIEF[1],
LOBNA ABUBAKR AZZAM[2] and MOHAMMED AWAD MANSOUR[1]
[1]Department of Tropical Medicine, Gastroenterology and Hepatology, and
[2]Department of Neuropsychiatry, Faculty of Medicine, Ain Shams University, Cairo 11566, Egypt
(*Correspondence: yasminenabil@med.asu.edu.eg Mobile: 01092774479)

Abstract
   Inflammatory bowel disease (IBD) is a group of chronic relapsing inflammatory conditions of the gastrointestinal tract. Inflammatory bowel disease has a substantial impact on quality of life. It causes considerable personal, emotional, and social burdens. The impact of IBD on quality of life places a significant burden on the patient and caregivers. The study assessed the impact of inflammatory bowel disease and disease activity on quality of life of the patients.
   This cross-section study was conducted on 88 patients with inflammatory bowel disease who attended the IBD Clinic, Ain Shams University Hospitals. An informed consent was obtained from each patient. All patients were subjected to clinical assessment, laboratory investigations, colonoscopy, assessment of disease activity and assessment of quality of life using PCASEE score.
   The eighty-eight inflammatory bowel disease patients were divided into: G1: (CD) Crohn's disease group 40 (45.5%) patients, and G2: ulcerative colitis (UC) group 48 (54.5%) patients. They were 39 (44.3%) males and 49 (55.7 %) females, with ages ranged between 19 and 52 years old (mean 33).
   The result showed negative significant correlation between clinical and endoscopic activity in UC group measured by simple clinical colitis activity index and Mayo score respectively and quality of life scores in the patients with P <0.001. In CD, there was negative significant correlation between quality of life and clinical disease activity measured by Crohn's disease activity index with P <0.001, but without endoscopic activity. There was no significant effect of inflammatory bowel disease on quality of life of the patients especially during disease activity.
   Key Words: inflammatory bowel disease, ulcerative colitis, Crohn's disease, quality of life

Introduction

   Generally, inflammatory bowel disease (IBD) is a chronic inflammatory disease of the gastrointestinal tract and is divided into Crohn disease and ulcerative colitis, occurring in genetically susceptible individuals after an exaggerated immune response to a normal stimulus such as food and intestinal flora (Colombel *et al,* 2019). Besides the GI tract, both Crohn disease and ulcerative colitis have many extra-intestinal manifestations (Dmochowska *et al,* 2018).

   Diagnosing inflammatory bowel disease (IBD) requires a combination of clinical findings, inflammatory laboratory markers, imaging findings, and endoscopic biopsies. Hematologic findings include microcytic anemia, leukocytosis, and thrombocytosis, inflammatory markers such as the erythrocyte sedimentation rate (ESR), and high-sensitivity C-reactive protein (hsCRP) were commonly elevated (Lee *et al,* 2019). But, in some patients, diagnosis may require ruling out parasitic diseases like giardiasis, amebiasis *histolytica*, and strongyloidiasis as wellas tuberculosis (Dai *et al,* 2018). Gut roles of microbes and their bio-products in the development and clinical course of IBD, and strategies by which microbiome-based therapies can be used to prevent, manage, and eventually cure IBD (Lee and Chang, 2021).

   Inflammatory bowel diseases are chronic disabling conditions, characterized by an unpredictable course with flare-ups and periods of remission, that frequently require lifelong medical follow-up and treatment,

leaving individuals worried about many aspects of life, such as bowel control, fatigue, social isolation, and fear of cancer development or sudden surgery (Suárez *et al,* 2021). This disease usually affects young individuals at a time in their lives when they are most likely to be pursuing major employment, family planning and personal milestones of critical importance. The pursuit of such critical milestones was impeded by the unrelenting and debilitating symptoms and the psychological distress associated with IBD (Jones *et al,* 2019). Work life can also be adversely affected by the disease, resulting in absence, reduced work hours, and changes in career choice, contributing to financial burden (Restall *et al,* 2016). As this disease accompanying patients for their entire life, and the quality of life (QOL) interacts with disease activity, improving QOL should be one of the main goals of therapy (Keller *et al,* 2021).

This study aimed to correlate between inflammatory bowel disease (IBD) and quality of life among patients attended the IBD Clinic, Ain Shams University Hospitals.

Materials and Methods

Study population: This was cross section study on 88 patients with inflammatory bowel disease were selected from IBD Center, Ain Shams University Hospitals during the period from December 2021 to December 2022. They were over 18 years old and IBD diagnosed for more than 6 months. All patients provided written informed consent before enrollment. Patients were excluded if they had history of malignancy, surgical history of intestinal resection. Patients with severe or uncontrolled comorbidities, such as liver cell failure, chronic renal failure and /or congestive heart failure.

Ethical approval: The study was reviewed and approved by the Ain Shams University, Faculty of Medicine, Research Ethics Committee Institutional Review Board, assurance No. FWA000017585. Besides, all the participants signed an informed consent after simplifying the study aim, and before taking any

data or doing any investigations.

Patients reported a complete medical history, underwent thorough clinical examinations. Laboratory examinations, included CBC, C-reactive protein, erythrocyte sedimentation rate, and stool analysis and culture to exclude any parasaitosis.

Also, all patients were subjected to colonoscopy up to the terminal ileum end with biopsies for histopathological confirmation,

In ulcerative colitis, the disease activity by using Mayo score and simple clinical colitis activity index (SCCAI). The Mayo Clinic Score [MCS] is a combined endoscopic and clinical scale used to assess the severity of UC. This composite instrument is scored on a scale from 0 to 12 and includes stool frequency, rectal bleeding, a physician's global assessment, and the sigmoidoscopic evaluation. (D'Haens *et al,* 2007).

The SCCAI scores ranged between 0 and 19 points including nocturnal bowel movements and fecal urgency that affected patient quality of life (Walmsley *et al,* 1998).

Disease activity Crohn's disease patients were assessed clinically by Crohn's Disease Activity Index (CDAI) and Simple Endoscopic Score for Crohn's Disease (SES-CD). The CDAI consisted of eight factors, each summer after adjustment with a weighting factor; remission was defined as the CDAI < 150, and CDAI score >450 represented severe disease (Best *et al,* 1976).

The total SES-CD, which ranged from 0 (no inflammation) to 60 (very high inflammation), was derived by summing the segment scores (Daperno *et al,* 2004).The SES-CD requires evaluation of 4 it-ems (extent of involved mucosa, extent of mucosa ulceration, size of ulcers, and presence of strictures) in 5 bowel segments; terminal ileum, right colon, transverse colon, left/sigmoid colon, and rectum (Gottlieb *et al,* 2021).

Quality of life: Assessment of quality of life of patients using PCASEE quality of life questionnaire (Bech *et al,* 1993). PCASEE quality of life scale is clinical instrument designed for interview administration (Pe-

queno *et al,* 2020). This gave information on symptoms and functioning over the last month. It is a 30- item self-rating scale completed on the basis of semi-structured interview in which the clinician completes ratings on the basis of patient's self-reports and the clinician's judgment about the patients functioning and life circumstances.

The 30-items are rated from 0-5. High scores reflect less impaired functioning and six domains are covered: (P) physical component. (C) Cognitive component, (A) Affective component, (S) Social component, (E) Economic component, and (E) Ego functioning.

Statistical analysis: Data were revised, coded, tabulated, and introduced to a PC using Statistical package for Social Science (SPSS 25). Data was presented and suitable analysis was done according to the type of data obtained for each parameter. Described as mean, standard deviation (± SD) and range for parametric numerical data, while Median and Interquartile range (IQR) for non-parametric numerical data, Frequency and non-numerical percentage.

The student T and Mann-Whitney test was used to assess significance difference between group means. Fisher's exact test and Chi-Square test was used to examine the relationship between two qualitative variables. Paired t-test was used to assess significance of difference between two means measured twice in same group. P>0.05: Non significant (NS) and P< 0.05: Significant (S).

Results

Of the 88 IBD patients included, the CD group was 40 (45.5%) patients, and the UC group was 48 (54.5%) patients. They were 39 (44.3%) males and 49 (55.7 %) females, with ages ranged between 19 and 52 years (mean 33-year-old). The mean illness duration was 6.4 years. There was no significant difference between UC & CD as to ages, sexes, and illness duration. The commonest patient symptoms in UC was bloody diarrhea 27 (56.25%) followed by rectal bleeding in 11 (23%) and diarrhea in 10(21%).

In CD, the commonest presented symptoms was abdominal pain in 16 (40%) patients, followed by the bloody diarrhoea in 11 (30%) and only diarrhoea in ten (25%) of patients.

The extra-intestinal manifestations were presented in 34 (38.6%) patients; 19 in CD group and 15 in UC group.

Regarding colonoscopy in UC, 25 (52%) patients had pancolitis, 11 (23%) suffered from left sided UC, six (12.15%) had extensive UC and another six (12.15%) had proctosigmoiditis.

Disease activity measured by Mayo score was 15 patients (31.3%) had sever disease, 14 (29.2%) had mild disease, 11 (23%) moderate disease, but eight (16.7%) was in remission.

Disease pattern in CD showed that 17 patients (41.5%) had fistulising CD, another 17 (42.5%) had inflammatory pattern and only six (15%) had stricture disease pattern. The Crohn's disease activity index score (CDAI) ranged from 40 to 455, with a mean of 246.4

The quality of life score (PCASEE score) in IBD patients ranged from 18 to 135 with a mean of 81.59**,** and median of PCASEE sc-ore was lower in Crohn's disease than in ulcerative colitis reflected poorer quality of life, but this difference was not significant**.**

There was significant difference in quality of life between patients with extraintestinal manifestations and those without (P 0.007) but, without significant correlation between quality of life and duration of illness in IBD patients**.**

The correlation between disease activity and quality of life; in ulcerative colitis patients showed negatively correlation with clinical disease activity measured by SCCAI, and endoscopic disease activity measured by Mayo score (P <0.001).

In Crohn's disease, there was significant negative correlation between clinical disease severity measured by CDAI and quality of life scores (P <0.001), but there was no significant correlation between quality of life scores and endoscopic disease activity measu-

red by SES-CD. Moreover, there was neither correlation between the quality of life (QoL) in the Crohn's disease nor in the disease pattern.

Detailed results were given in tables (1, 2, 3, 4, 5 & 6)

Table 1: Impact of IBD on quality of life assessed by PCASEE score:

Pre assessment whole group	Mean	SD	Median (IQR)	Range
Physical component (P)	12.80	6.05	12 (8.5 ± 18)	(1 - 25)
Cognitive component (C)	13.48	6.23	13.5 (8.5 ± 19)	(2 - 25)
Affective component (A)	13.98	6.19	15 (9.5 ± 19)	(2 - 24)
Social component (S)	15.14	6.58	15 (10 ± 20)	(1 - 25)
Economical component (E)	11.88	4.61	12.5 (9 ± 15)	(3 - 20)
Ego component (E)	14.33	6.53	15 (10 ± 20)	(1 - 25)
Total Score	81.59	30.29	80 (59 ± 105.5)	(18-135)

PCASEE score in IBD patients range (from 18 to 135), and mean =81.59

Table 2: Comparison between UC and CD regarding effect on quality of life (PCASEE):

Variations	Crohn's disease	Ulcerative colitis	Mann-Whitney test	
	Median (IQR)	Median (IQR)	P value	Significant
Physical component	14.5 (9 ± 15.5)	11.5 (7.5 ± 20)	0.617	NS
Cognitive component	14 (7 ± 19)	13 (10 ± 20)	0.462	NS
Affective component	15 (6 ± 18)	17 (10 ± 20)	0.042	S
Social component	14.5 (10 ± 19.5)	17.5 (12 ± 21)	0.235	NS
Economical component	10 (7 ± 15)	13.5 (10 ± 16)	0.068	NS
Ego component	14 (8 ± 20)	16 (10 ± 20)	0.248	NS
Total Score	78 (47.5 ± 100)	90.5 (61.5 ± 113)	0.141	NS

Table 3: Correlation between quality of life (PCASEE) in IBD patients and extraintestinal manifestations (EIMs):

Variations	Extra-intestinal signs		Student t-test	
	No	Yes		
	Mean ± SD	Mean ± SD	P value	Significant
PCASEE Score	88.43 ± 28.88	70.74 ± 29.68	0.007	S

Significant difference in quality of life between patients with or without EIMs

Table 4: Correlation between duration of IBD illness and quality of life score (PCASEE):

Variations		Duration of illness (Years)
PCASEE Score	Spearman's rho	0.167
	P value	0.120
	Significant	NS

Not significant.

Table 5: Impact of disease activity of UC measured by (SCCAI and Mayo score) on quality of life score (PCASEE):

Variations		SCCAI	Mayo score
PCASEE Score	Spearman's rho	-0.653	-0.553
	P value	<0.001	<0.001
	Significant	S	S

Not significant

Table 6: Impact of disease activity of CD measured by (CDAI & SES-CD scores) on quality of life (PCASEE):

Variations		CDAI	SES-CD
PCASEE Score	Spearman's rho	-0.561	-0.076
	P value	<0.001	0.639
	Significant	S	NS

Significant between clinical severity and quality of life in CD, not significant between endoscopic activity and quality of life:

Table 7: Correlation between pattern of disease in CD and quality of life (PCASEE):

Variations	Inflammatory	Stricture	Fistulizing	One Way ANOVA	
	Mean ± SD	Mean ± SD	Mean ± SD	P value	Significant
PCASEE Score	74.88 ± 33.92	88.5 ± 12.86	74.29 ± 27.65	0.564	NS

Not significant

Discussion

WHO (2002) reported that the active ageing was defined as the optimizing opportunities process for health, participation and security in order to enhance quality of life as people age. However, this set was against the term "health-related quality of life", that was a narrow concept focusing on the eff-

ects of both the illness and treatment on the human quality of life (Ferrans *et al,* 2005).

Matos *et al,* (2021) in Portugal reported that the most significant predictors of quality of life in patients with IBD were body appreciation and meaning in life. They added that the human body acceptance by others and body appreciation were the main predictors of physical QoL, and the psychological interventions for patients who suffered from IBD must address body appreciation and meaning in life.

In the present study, the quality of life of in patients of inflammatory bowel disease, and median of PCASEE score was lower in Crohn's disease (78) than in ulcerative colitis (90.5), which reflected poorer quality of life, but without significant difference. This agreed with Marinelli *et al.* (2019), they in Italy found that patients with UC had a lower risk of having impaired quality of life compared to CD patients. They added that that disability and quality of life are both associated with active disease, anemia, presence of extra-intestinal manifestations, and Crohn phenotype, but treatment was not associated with disability and QoL during disease management. Besides, Mules *et al.* (2022) in New Zealand reported that the median score was lower in CD than UC without difference significant. They added that clinicians should consider underlying mental illness in patients with IBD with active gastrointestinal symptoms. In contrast Cao *et al.* (2019) in China reported that CD patients had higher quality of score compared to UC patients. They concluded that the high prevalence of psychological disorders and malnutrition were found in IBD patients, and thereby negatively affect QoL. Disease activity was significantly associated with psychological disorders, risk of malnutrition and impaired QoL. And avoiding certain foods was related to risk of malnutrition. Thus, the poorer quality of life in CD could be related to fistula formation and malnutrition which occurs more with CD than with UC.

In the present study, as to poor quality of life in IBD patients, there was significant negative correlation between the severity of clinical and endoscopic activity of UC and the quality of life. Moreover, in Crohn's disease there was significant negative correlation between quality of life of the patients and clinical activity, but without the disease endoscopic activity.

This agreed with Mules *et al. (*2022*)*, who reported that for the UC patients, both endoscopic disease activity and symptoms were negatively associated with QoL. But, for those with CD, symptoms were negatively associated with QoL without significant association. These results also agreed with *Cao et al.* (2019); Marinelli *et al.* (2019) and Pulley *et al.* (2019), they all found that patients with active disease showed lower scores of quality of life. No doubt, clinically active disease was a significant predictor of poor quality of life (Soares *et al,* 2016).

Increasing the severity of disease activity usually associated worsening of symptoms, increase rate of hospitalization, increase risk of complications, affection of daily activity and decrease productivity (Gower-Rousseau *et al,* 2017). Therefore, the disease activity caused burden on the different quality of life parameters including physical, social and economic components.

In the present study, although factors affected the quality of life of IBD patients, but the results didn't find correlation between illness duration and quality of life. However, the patient with extra-intestinal manifestations showed lower quality of life scores when compared to free ones. However, Cao *et al.* (2019) reported that different finding long disease duration had lower QoL score. Mules *et al.* (2022) reported that longer duration since IBD diagnosis was independently associated with the better quality of life. The difference in these results could be due differences between the study populations' behaviors or life style or even the social support they received, which recommended that the illness duration was a risk factor for

poor quality of life. Peyrin-Biroulet *et al.* (2015) reported that it was believed that evaluation of quality of life is an important measure of patient-reported outcome, although subjective and mainly related to the limitations imposed by the disease. Gower-Rousseau *et al.* (2017) in France reported that a useful tool to evaluate quality of life in IBD patients until now has been represented by the IBD questionnaire (IBDQ). They added that the Inflammatory Bowel Disease Disability Index (IBD-DI) was developed according to the WHO's standard processes.

In the present study, extra-intestinal manifestation in IBD patients was considered as additional factor that contribute to poorer quality of life and increase the burden of psychiatric illness in these patients. This agreed with Rogler *et al,* (2021) in Switzerland, who reported in many patients the inflammatory bowel diseases (IBDs) are systemic diseases manifesting not only the gut and gastrointestinal tract, but also in the extraintestinal organs.

Conclusions

No doubt, the inflammatory bowel disease (IBD) is a chronic immune-mediated disorder comprised of Crohn disease and ulcerative colitis.

The outcome results showed that the inflammatory bowel disease didn't have impact on almost all components in patients' quality of life. The poor quality of life was associated with active disease, extra-intestinal manifestations, and the Crohn's phenotype.

Authors' contributions: Omar collected and analysed data, examined patients, completed study design, interpretation of the all results. Mohammed, Fouad, and Ismail supervised and scientifically reviewed all the theoretical and practical work. All authors approved the manuscript.

Authors' Declaration: The authors' declared that they neither have conflicts of interest with respect to this research, authorship or this article publication, nor received any funds.

References

Bech, P, Dunbar, GC, Stocker, MJ, 1993: Developing an instrument to measure the changes in psychiatric patients' quality of life. In: The Health Economics of Depression. Jonsson B& Rosenbaum J (eds): Wiley: Chi-0Chester.

Best, WR, Becktel, JM, Singleton, JW, *et al,* 1976: Development of a Crohn's disease activity index: National cooperative Crohn's disease study. Gastroenterol. 70:439-44.

Cao, Q, Huang, YH, Jiang, M, *et al,* 2019: The prevalence and risk factors of psychological disorders, malnutrition and quality of life in IBD patients. Scand. J. Gastroenterol. 54, 12:1458-66.

Colombel, JF, Shin, A, Gibson, PR, 2019: AGA clinical practice update on functional gastrointest- inal symptoms in patients with inflammatory bowel disease: Expert review. Clin. Gastroenterol. Hepatol. 17, 3:e380-90.

Dai, C, Jiang, M, Sun, MJ, 2018: Fecal markers in the management of inflammatory bowel disea-se. Postgrad Med. 130, 7:597-606.

Daperno, MD, Haens, G, Van Assche, G, *et al,* 2004: Development and validation of a new, simp- lified endoscopic activity score for Crohn's disease: The SES-CD. Gastrointestinal. Endos. 60:505-12.

D'Haens, G, Sandborn, W, Feagan, B, *et al,* 2007: A review of activity indices and efficacy end poi- nts for clinical trials of medical therapy in adults with UC. Offic. J. Am. Gastroenterol. Assoc. 132: 763-86.

Dmochowska, N, Wardill, HR, Hughes, PA, 2018: Advances in Imaging Specific Mediators of Inflammatory Bowel Disease. Int. J. Mol. Sci. Aug 21;19(9) 2471.doi: 10.3390/ijms1909-2471.

Ferrans, C, Zerwic, J, Wilbur, J, Larson, J, 2005: Conceptual model of health-related quality of life. J. Nurs. Scholarsh. **37**, 4:336-42.

Gottlieb, K, **Daperno, M, Usiskin, K, Sands, BE, Ahmad, H, *et al,* 2021**: Endoscopy and central reading in inflammatory bowel disease clinical trials: achievements, challenges and future developments. Gut 70, 2:418-26.

Gower-Rousseau, C, Sarter, H, Savoye, G, *et al,* 2017: Validation of the Inflammatory Bowel Disease Disability Index in a population-based cohort. Gut 66, 4:588-96.

Jones JL, Nguyen GC, Benchimol EI, *et al,* 2019: The impact of inflammatory bowel dis-

ease in Canada 2018: Quality of life. J. Cana. Assoc. Gastroenterol. 2, 1:S42-8.

Keller, R, Mazurak, N, Fantasia, L, *et al,* 2021: Quality of life in inflammatory bowel diseases: it is not all about the bowel. Intestinal Res. 19, 1:45-52.

Lee, M, Chang, EB, 2021: Inflammatory bowel diseases and the microbiome: Searching the Crime Scene for Clues. Gastroenterology 160, 2:524-37.

Lee, JS, Kim, ES, Moon, W, 2019: Chronological review of endoscopic indices in inflammatory bowel disease. Clin. Endosc. 52, 2:129-36.

Marinelli, C, Savarino, E, Inferrera, M, *et al,* 2019: Factors influencing disability and quality of life during treatment: A cross-sectional study on IBD patients. Gastroenterol. Res. Pract. Vol. 2019, Article ID 5354320.

Matos, R, Lencastre, L, Rocha, V, *et al,* 2021: Quality of life in patients with inflammatory bowel disease: the role of positive psychological factors. Hlth. Psychol. Behavioral Med. 9, 1: 989-1005.

Mules, TC, Swaminathan, A, Hirschfeld, E, *et al,* 2022: The impact of disease activity on psychol-ogical symptoms and quality of life in patients with inflammatory bowel disease, results from the stress, anxiety and depression with disease activity (SADD) Study. Ali. Pharmacol. Therapeut. 55: 201-11.

Pequeno, NPF, Cabral, NLA, Marchioni, D M, Lima, SCVC, Lyra, CO, 2020: The quality of life assessment instruments for adults: a systematic review of population-based studies Hlth. Qual. Life Outcomes. 2020Jun 30;18(1):208. doi:10.1186/ s12955-020-01347-7.

Peyrin-Biroulet, L, Sandborn, W, Sands, BE, *et al,* 2015: Selecting therapeutic targets in inflammatory bowel disease (STRIDE): Determining therapeutic goals for treat-to-target. Am. J. Gastroenterol. 110, 9:1324-38.

Pulley, J, Todd, A, Flatley, C, *et al,* 2019: Malnutrition and quality of life among adult inflammatory bowel disease patients. J. Gastroenterol. Hepatol. 4:454-60.

Restall, GJ, Simms, AM, Walker, JR, *et al,* 2016: Understanding work experiences of people with inflammatory bowel disease. Inflamm. Bowel Dis. 22:1688-97.

Rogler, G, Singh, A, Kavanaugh, A, *et al,* 2021: Extraintestinal manifestations of inflammatory bowel disease: Current concepts, treatment, and implications for disease management. Gastroentero- logy 161, 4:1118-32

Soares, JB, Pereira, R, Costa, JM, *et al,* 2016: The inflammatory bowel disease-disability index: Validation of the Portuguese version according to the COSMIN checklist. Euro J. Gastroenterol. Hep-atol. 28, 10:1151-60.

Suárez, CC, Iglesias, RF, Rey, IB, *et al,* 2021: Role of quality of life as endpoint for inflammatory bowel disease treatment. Int. J. Environ. Res. Publ. Hlth. 18, 13:71-59

Walmsley, RS, Ayres, RC, Pounder, RE, *et al,* 1998: A simple clinical colitis activity index. Gut 43:29-32.

WHO, 2002: Active Ageing: A Policy Framework. At: https://apps.who.int/iris/bitstream/ handle/10665/67215/WHO/NMH/NPH02.8.pdf;jsessionid=192A324CEE72EF90EAD6E71519F64

Explanation of figures

Fig. 1: Correlation between mayo score and quality of life in UC.
Fig. 2: Correlation between SCCAI score and quality of life in UC.
Fig. 3: Correlation between CDAI score and quality of life in CD.

F. 2

F. 3

286