



# Health-related quality of life among inflammatory bowel disease patients

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## Abstract

**Background:** Inflammatory bowel disease (IBD) is a group of chronic disorders: Crohn's disease and ulcerative colitis that result in inflammation or ulceration (or both) of the bowel. Both disorders have striking similarities but also several differences. Approximately 10% to 15% of patients with IBD have characteristics of both disorders and cannot be definitively diagnosed with either disorder and are classified as having indeterminate colitis. The prevalence of IBD in the United States has increased in the past century; it is estimated that 1.3% of adults are diagnosed with IBD (CDC, 2019).

**Aim:** Study aims to assess health-related quality of life among Inflammatory Bowel Disease patients.

**Methodology:** A descriptive study design was conducted at Al-Najaf city in the southern region of Iraq in Al-Najaf Al-Ashraf Health Directorate/ Specialized Hospital for Gastrointestinal and Liver Disease and Surgery from February 20th, 2023, to May 21th, 2023, in order to assess Health-related quality of life among Inflammatory Bowel Disease patients. The methodological strategies for data collection used an assessment questionnaire survey

**Results:** As the study shows, that the total health-related quality of life of patients with inflammatory bowel disease is moderate.

**Conclusion:** The study concludes that the level of health-related quality of life for patients who suffer from inflammatory bowel disease is less than the ideal, in addition, patients' age affect their health-related quality of life.

**Recommendations:** Further research should be carried out to improve and explore effective methods to improve the health-related quality of life for patients with inflammatory bowel disease, besides, since the nurses still with the patients 24 hours daily, the health management should be activated and to increase nurse's roles in health education process that improve the patients' knowledge regarding improving their quality of life.

**Keywords:** quality of life, Inflammatory Bowel Disease (IBD)

## Introduction

Inflammatory bowel disease (IBD) is a group of chronic disorders: Crohn's disease and ulcerative colitis that result in inflammation or ulceration (or both) of the bowel. Both disorders have striking similarities but also several differences. Approximately 10% to 15% of patients with IBD have characteristics of both disorders and cannot be definitively diagnosed with either disorder and are classified as having indeterminate colitis. The prevalence of IBD in the United States has increased in the past century; it is estimated that 1.3% of adults are diagnosed with IBD (CDC, 2019). Prevalence is highest in Europe (particularly in Germany and Norway), the United States, and Canada, although the incidence has been increasing in South America, Africa, and Asia (Janice L. Hinkle *et al.*, 2022) [6].

Quality of life (QoL) can be defined in many ways, making its measurement and incorporation into scientific study challenging. QoL is defined by the World Health Organization as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns". The symptoms of IBD have a negative impact on

patients' well-being and quality of life because dysfunctions usually affect daily activities, performance in school, ability to work, and social life. Mental health is an important part of caring for these patients but is often overlooked (Mitropoulou *et al.*, 2022) [13].

The prevalence of IBD in Portugal was 146 per 100,000 inhabitants, according to a study conducted between 2003 and 2007. The authors of this study acknowledged the difficulty to conduct population studies and to update data on the prevalence of IBD due to its low incidence. However, there is evidence of an increased prevalence of IBD worldwide, and this growth seems to be associated with globalization and industrialization, as the highest prevalence rates of IBD are reported in North America and Europe. QoL of patients diagnosed with IBD can be affected by multiple factors, such as emotional distress and high medical care costs. Patients may also have concerns about a possible impairment of their daily functioning, even during remission phases (Matos *et al.*, 2021) [12].

## Study significance

Inflammatory bowel disease (IBD) is a chronic disease of unknown etiology. The disease occurs early in life and the

burden of symptoms is significant. Patients need to perform self-care to handle their symptoms, but knowledge about what kind of self-care patients do is limited and these individuals need to learn how to manage the symptoms that arise (Lovén Wickman *et al.*, 2016) [10]. Health-related quality of life (HR-QOL), defined as the functional effect of an illness and its treatment on a patient as perceived by the patient, is important clinical outcome in chronic diseases such as IBD. Self-reported HR-QOL would be expected to be worsened during periods of active disease. However, some studies have shown a direct correlation between disease activity and HRQOL, whereas other studies have shown otherwise. There is a growing interest in the role that psychosocial factors play in determining HR-QOL in IBD. provided to patients with IBD (Zhang *et al.*, 2013) [17].

Health-related quality of life (HRQoL) is a quantitative measurement of subjective perception of health state, including emotional and social function and has a recognized importance to evaluate, manage and follow up patients. Many studies have investigated the HRQoL in IBD, which appears to be impaired (Kalafateli *et al.*, 2013) [7].

**Methodology**

**Study design**

A descriptive study design was conducted at Al-Najaf city in the southern region of Iraq in Al-Najaf Al-Ashraf Health Directorate/ Specialized Hospital for Gastrointestinal and Liver Disease and Surgery from February 20th, 2023, to May 21th, 2023, in order to assess Health-related quality of life among Inflammatory Bowel Disease patients. The methodological strategies for data collection used an assessment questionnaire survey.

**Population and study sample**

A Non-probability (convenience) sample of (48) patients who visit the Specialized Hospital for Gastrointestinal and Liver Disease and Surgery.

**Data collection tool**

A questionnaire was constructed by researcher to measure the variables of interest. The final study instrument consisting of two parts: the first part is the demographic data, the second part regarding the health-related quality of life scale (SF-36).

**Statistical methods**

The data analysis process entailed using Statistical Package for Social Sciences computer software. Statistical analysis was performed using Statistical Package for Social Sciences version 21.0 for Windows. Descriptive statistics were used to present the demographic data and patterns of answers to the different questionnaire items; categorical variables were presented as frequency and percentage, whereas numerical ones were presented as mean ± standard deviation (S.D). Chi-Square test

(X<sup>2</sup>) to test independency distribution of observed frequencies, and for measuring the association between the studies variables according to its type.

**Results**

**Table 1:** Characteristics and sociodemographic data of the study participants

Demographic Data	Rating and Interval	Freq.	%
Age	<= 36	32	66.7
	37 - 47	10	20.8
	48 - 58	4	8.3
	59+	2	4.2
Gender	Male	23	47.9
	Female	25	52.1
Educational level	Illiterate	7	14.6
	Able to Read and Write	9	18.8
	Primary School Graduate	4	8.3
	Intermediate School Graduate	6	12.5
	Preparatory School Graduate	9	18.8
	Institute Graduate	5	10.4
Socio-economic status	College Graduate	8	16.7
	Sufficient	7	14.6
	Sufficient to some extent	37	77.1
Residence	Insufficient	4	8.3
	Rural	15	31.3
Marital status	Urban	33	68.8
	Single	17	35.4
Occupation	Married	28	58.3
	Widowed	3	6.3
	Retired	9	18.8
Diagnosis	Housewife	14	29.2
	Employee	7	14.6
	Jobless	18	37.5
	Ulcerative colitis	28	58.3
Disease duration since diagnosis	Crohn's disease	20	41.7
	1 - 5	31	64.6
	6 - 10	14	29.2
	11 - 15	3	6.3

Table (1) shows that the most of participant age groups are less than (36 years old). considered as the highest percentage (66.7%) among the study sample. Regarding gender of the study sample, the study indicates that (52%) are females, also this table present that the majority of the participant (18.8%) able to read and write and (18.8%) preparatory school. The results illustrated that (77.1%) of study sample had sufficient to some extent monthly income, (68.8%) are living in urban residential area. The majority of the study participants (58.3%) are married. Concerning occupational status, about (37.5%) jobless of the study participant. Regarding study participant was (58.3%) had suffered from ulcerative colitis, and the (64.6%) of the study participant had from (1-5 years') duration of disease.

**Table 2:** Assessment of health-related quality of life among patients with inflammatory bowel disease

n	Items	Ms.	Asses.
Q1	In general, would you say your health is	36.46	Moderate
Q2	Compared to one year ago, how would you rate your health in general now	62.50	Moderate
Q3	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	40.63	Moderate
Q4	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	46.88	Moderate
Q5	Lifting or carrying groceries	53.13	Moderate

Q6	Climbing several flights of stairs	61.46	Moderate
Q7	Climbing one flight of stairs	92.71	Good
Q8	Bending, kneeling, or stooping	85.42	Good
Q9	Walking more than a mile	65.63	Moderate
Q10	Walking several blocks	42.71	Moderate
Q11	Walking one block	54.17	Moderate
Q12	Bathing or dressing yourself	92.71	Good
Q13	Cut down the amount of time you spent on work or other activities	39.58	Moderate
Q14	Accomplished less than you would like	41.67	Moderate
Q15	Were limited in the kind of work or other activities	47.92	Moderate
Q16	Had difficulty performing the work or other activities (for example, it took extra effort)	45.83	Moderate
Q17	Cut down the amount of time you spent on work or other activities	47.92	Moderate
Q18	Accomplished less than you would like	45.83	Moderate
Q19	Didn't do work or other activities as carefully as usual	41.67	Moderate
Q20	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?	52.56	Moderate
Q21	How much bodily pain have you had during the past 4 weeks?	38.33	Moderate
Q22	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	47.40	Moderate
Q23	Did you feel full of pep?	46.25	Moderate
Q24	Have you been a very nervous person?	41.25	Moderate
Q25	Have you felt so down in the dumps that nothing could cheer you up?	50.83	Moderate
Q26	Have you felt calm and peaceful?	57.92	Moderate
Q27	Did you have a lot of energy?	45.42	Moderate
Q28	Have you felt downhearted and blue?	35.42	Moderate
Q29	Did you feel worn out?	30.42	Poor
Q30	Have you been a happy person?	47.50	Moderate
Q31	Did you feel tired?	35.83	Moderate
Q32	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?	56.77	Moderate
Q33	I seem to get sick a little easier than other people	48.44	Moderate
Q34	I am as healthy as anybody I know	48.44	Moderate
Q35	I expect my health to get worse	42.71	Moderate
Q36	My health is excellent	52.60	Moderate

This table reveal that the patient's participant responses to the assessment of health-related quality of life is moderate, while the assessment was (good) for the items numbered (7,8,12) and

only one item (29) is poor. The total assessment of health-related quality of life is (moderate).

**Table 3:** ANOVA table for the relationships between the level of health-related quality of life among patients with inflammatory bowel disease and their demographic characteristics

Demographic Data	Rating and Interval	Mean	SD	F	p-value
Age	<= 25	51.39	12.45	2.84	0.04*
	26 - 36	55.60	13.68		
	37 - 47	51.21	8.31		
	48 - 58	39.06	10.99		
	59+	31.46	6.97		
Gender	Male	52.25	11.54	0.70	0.41
	Female	49.15	13.89		
Educational level	Illiterate	45.22	16.64	0.64	0.70
	Able to Read and Write	49.15	12.45		
	Primary School Graduate	46.56	6.79		
	Intermediate School Graduate	50.21	7.30		
	Preparatory School Graduate	51.10	14.99		
	Institute Graduate	53.89	12.23		
Socio-economic status	College Graduate	56.84	13.71	0.16	0.85
	Sufficient	53.12	15.25		
	Sufficient to some extent	50.11	13.04		
Residence	Insufficient	51.18	5.76	1.83	0.18
	Rural	46.96	9.95		
Marital status	Urban	52.30	13.69	2.17	0.13
	Single	53.73	13.50		
	Married	47.73	12.19		
	Widowed	60.23	6.04		

Occupation	Retired	58.43	13.93	2.11	0.11
	Housewife	47.62	12.63		
	Employee	54.68	6.18		
	Jobless	47.51	12.96		
Diagnosis	1	50.98	14.65	0.05	0.83
	2	50.16	9.92		
Disease duration since diagnosis	1 - 5	51.58	12.53	0.39	0.68
	6 - 10	48.10	13.47		
	11 - 15	52.69	15.38		

This table shows that there is a significant relationship between the level's health-related quality of life patients with inflammatory bowel disease and their age from their demographic characteristics at  $p$ -value less than 0.05.

### Discussion

The present study reveals the most of participant age groups are less than (36 years old). This result is supported by (Knowles *et al.*, 2018) <sup>[9]</sup> this study is systemic reviews from 37 study shows that mean of age (36-39 years old). Regarding gender of the study sample, the study indicates that barely equals are females to male. This result is supported by (Iglesias-Rey *et al.*, 2014) <sup>[5]</sup>, also this table present that the majority of the participant equal between able to read and write and preparatory school. This result is supported by (Moradkhani *et al.*, 2013) <sup>[14]</sup>. The results illustrated that most of study sample had sufficient to some extent monthly income. This result is agree with (Kitahata *et al.*, 2022) <sup>[8]</sup> and disagree with (Agrawal *et al.*, 2019) <sup>[1]</sup> this study shows low household income. Regarding living of the study participant, the most of them lived in urban residential area. This result is agree with (Luo *et al.*, 2021) <sup>[11]</sup> (Cohen *et al.*, 2014) <sup>[3]</sup>. The majority of the study participants are married. This result is supported by (Matos *et al.*, 2021) <sup>[12]</sup> (Lovén Wickman *et al.*, 2016) <sup>[10]</sup>. Concerning occupational status, about most of responses is jobless. This result is supported by (Hanlin *et al.*, 2020) <sup>[4]</sup>. Regarding study participant was most of them suffered from ulcerative colitis. This result is supported by (Xu *et al.*, 2022) <sup>[16]</sup> (Lovén Wickman *et al.*, 2016) <sup>[10]</sup>. Concerning of the study participant most of them had from (1-5 years') duration of disease. This result is supported by (Barello *et al.*, 2021) <sup>[2]</sup>. Concerning the assessment of health-related quality of life among patients with inflammatory bowel disease, the study results show that the final assessment of the patients' knowledge regarding health-related quality of life among patient's inflammatory bowel disease which is moderate. These results disagree with (Pallis *et al.*, 2012) <sup>[15]</sup>; whose results shows that the overall assessment health related quality of life is low. These results reveal that there a knowledge deficient among patients about health-related quality of life among patient's inflammatory bowel disease, this is due to many reasons the first one lack of knowledge and Lack of understanding between association health-related quality of life and benefit of good healthy outcome, reduce of symptom and complication, inflammatory bowel disease for this condition.

Regarding the relationship between the level of health-related quality of life of patients with IBD and their sociodemographic data, the study shows that there is a significant relationship between the levels health-related quality of life patients with inflammatory bowel disease and their age from their

demographic characteristics. The treatment options are those used in younger patients, but a series of considerations related to potential pharmacological interactions and side effects of the drugs must be taken in account. The risks associated with the use of some IBD medications may be increased in older patients, but so is the risk of under-treated IBD and surgery.

### Conclusion

The study concludes that the level of health-related quality of life for patients who suffer from inflammatory bowel disease is less than the ideal, in addition, patients' age affect their health-related quality of life.

### Recommendations

The authors recommend that further research should be carried out to improve and explore effective methods to improve the health-related quality of life for patients with inflammatory bowel disease.

In addition, health education programs should be applied to increase the patients' knowledge regarding improving the level of their health related quality of life. A booklet containing an explanation and instructions about inflammatory bowel disease and how it affects quality of life and should be distributed to patients. Besides, since the nurses still with the patients 24 hours daily, the health management should be activated and to increase nurse's roles in health education process that improve the patients' knowledge.

### Study Limitations

The chosen participants may not have been an adequate sample size to be generalized to the larger population. Also, some patients were less cooperative than others, or uncooperative at all.

### Ethical considerations

The researcher obtains an approval from the nursing specialists department in the faculty of nursing /University of Kufa. Also, an official permission is attained from the Specialized Hospital for Gastrointestinal and Liver Disease and Surgery, in order to interviewing each subject. And finally, subject agreement also obtained from the patient himself after the researcher explain the purpose of the study to them; seeks informed consent; and offer a respect to participants' confidentiality as well as making the participation voluntary, to answer the questionnaire.

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### Conflicts of interest

The author declares no conflict of interest to declare for publication.

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### References

1. Agrawal M, Cohen-Mekelburg S, Kayal M, Axelrad J, Galati J, Tricomi B, *et al.* Disability in inflammatory bowel disease patients is associated with race, ethnicity and socio-economic factors. *Alimentary Pharmacology and Therapeutics.* 2019;49(5):564-571. <https://doi.org/10.1111/apt.15107>.
2. Barello S, Guida E, Leone S, Previtali E, Graffigna G. Does patient engagement affect IBD patients' health-related quality of life? Findings from a cross-sectional study among people with inflammatory bowel diseases. *Health and Quality of Life Outcomes.* 2021;19(1):1-9. <https://doi.org/10.1186/s12955-021-01724-w>
3. Cohen BL, Zoëga H, Shah SA, Leleiko N, Lidofsky S, Bright R, *et al.* Fatigue is highly associated with poor health-related quality of life, disability and depression in newly-diagnosed patients with inflammatory bowel disease, independent of disease activity. *Alimentary Pharmacology and Therapeutics.* 2014;39(8):811-822. <https://doi.org/10.1111/apt.12659>
4. Hanlin F, Kaminga AC, Peng Y, Feng T, Wang T, Wu X, *et al.* Associations between disease activity, social support and health-related quality of life in patients with inflammatory bowel diseases: The mediating role of psychological symptoms. *BMC Gastroenterology.* 2020;20(1):1-8. <https://doi.org/10.1186/s12876-020-1166-y>
5. Iglesias-Rey M, Barreiro-De Acosta M, Caamaño-Isorna F, Rodríguez IV, Ferreiro R, Lindkvist B, *et al.* Psychological factors are associated with changes in the health-related quality of life in inflammatory bowel disease. *Inflammatory Bowel Diseases.* 2014;20(1):92-102. <https://doi.org/10.1097/01.MIB.0000436955.78220.bc>
6. Janice L Hinkle, Kerry H Cheever, Kristen J Overbaugh. No Title SUDDARTH'S, BRUNNER & OF, TEXTBOOK Medical-Surgical Nursing. In *wolters kuwer* (15th editi, Vol. 15th, Issue 3729), 2022.
7. Kalafateli M, Triantos C, Theocharis G, Giannakopoulou D, Koutroumpakis E, Chronis A, *et al.* Health-related quality of life in patients with inflammatory bowel disease: a single-center experience, 2013, 243-248.
8. Kitahata S, Furukawa S, Miyake T, Shiraishi K, Tange K, Hashimoto Y, *et al.* Association between socioeconomic status and mucosal healing in Japanese patients with ulcerative colitis: A cross-sectional study. *BMJ Open Gastroenterology.* 2022;9(1):1-7. <https://doi.org/10.1136/bmjgast-2022-001000>
9. Knowles SR, Keefer L, Wilding H, Hewitt C, Graff LA, Mikocka-Walus A. Quality of Life in Inflammatory Bowel Disease: A Systematic Review and Meta-analyses - Part II. *Inflammatory Bowel Diseases.* 2018;24(5):966-976. <https://doi.org/10.1093/ibd/izy015>
10. Lovén Wickman U, Yngman-Uhlin P, Hjortswang H, Riegel B, Stjernman H, Hollman Frisman G. Self-Care among Patients with Inflammatory Bowel Disease. *Gastroenterology Nursing.* 2016;39(2):121-128. <https://doi.org/10.1097/SGA.000000000000120>
11. Luo D, Zhou M, Sun L, Lin Z, Bian Q, Liu M, *et al.* Resilience as a Mediator of the Association Between Perceived Stigma and Quality of Life Among People with Inflammatory Bowel Disease. *Frontiers in Psychiatry.* 2021;12(August):1-10. <https://doi.org/10.3389/fpsy.2021.709295>
12. Matos R, Lencastre L, Rocha V, Torres S, Vieira F, Barbosa MR, *et al.* Quality of life in patients with inflammatory bowel disease: the role of positive psychological factors. *Health Psychology and Behavioral Medicine.* 2021;9(1):989-1005. <https://doi.org/10.1080/21642850.2021.2007098>
13. Mitropoulou MA, Fradelos EC, Lee KY, Malli F, Tsaras K, Christodoulou NG, *et al.* Quality of Life in Patients With Inflammatory Bowel Disease: Importance of Psychological Symptoms. *Cureus,* 2022, 14(8). <https://doi.org/10.7759/cureus.28502>
14. Moradkhani A, Beckman LJ, Tabibian JH. Health-related quality of life in inflammatory bowel disease: Psychosocial, clinical, socioeconomic, and demographic predictors. *Journal of Crohn's and Colitis.* 2013;7(6):467-473. <https://doi.org/10.1016/j.crohns.2012.07.012>
15. Pallis AG, Vlachonikolis IG, Mouzas IA. Assessing health-related quality of life in patients with inflammatory bowel disease, in Crete, Greece. *BMC Gastroenterology.* 2012;2:4-11. <https://doi.org/10.1186/1471-230X-2-1>
16. Xu Y, Liu T, Jiang Y, Zhao X, Meng F, Xu G, *et al.* Psychosocial Adaptation Among Inflammatory Bowel Disease Patients and Associated Factors: A Cross-Sectional Study. *Psychology Research and Behavior Management.* 2022;15(August):2157-2167. <https://doi.org/10.2147/PRBM.S376254>
17. Zhang CK, Hewett J, Hemming J, Grant T, Zhao H, Abraham C, *et al.* The influence of depression on quality of life in patients with inflammatory bowel disease. *Inflammatory Bowel Diseases.* 2013;19(8):1732-1739. <https://doi.org/10.1097/MIB.0b013e318281f395>.