Systematic Review

Determinants and measurement of quality of life in patients with Inflammatory Bowel Disease: A Systematic Review

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Objective: To explore the determinants of quality of life in patients with inflammatory bowel disease and evaluate the specific measurement instruments used.
Methodology: This systematic review had Literature searches across five databases: PubMed, Scopus, Web of Science, Embase, and Google Scholar. Studies published between January 1, 2004, and January 1, 2024, that utilized validated QoL measurement tools and statistically analyzed associated factors were included.
Results: The 19 included studies summarized three main dimensions that affect quality of life: social dimension, physical dimension and psychological dimension.
Conclusion: QoL is influenced by the complex interplay of social, physiological, and psychological factors. While existing measurement tools are reliable, they vary in sensitivity, particularly in capturing individual patient experiences and specific symptoms such as fatigue. Uneven geographical distribution of studies, a lack of large-scale longitudinal research, and underrepresentation of key populations hinder a comprehensive understanding of the chronic progression and diverse needs of IBD patients. Future efforts should prioritize patient-centered strategies, including the development of more specific tools to address these gaps and implement targeted interventions to effectively enhance the QoL of IBD patients.

Keyword: Quality of life, inflammatory bowel disease, psychosocial factors, instrumentation.

INTRODUCTION

Inflammatory bowel disease (IBD) is a complex intestinal disorder mediated by multiple factors, with immune abnormalities playing a prominent role.[1] It is characterized by chronic and recurrent intestinal inflammation, with some patients also experiencing involvement of the upper gastrointestinal tract. Unlike common gastrointestinal disorders, IBD manifests systemic responses and extraintestinal complications, such as fever, fatigue, malnutrition, peripheral arthritis, primary biliary cholangitis, and ankylosing spondylitis, which severely impact patients' daily lives' follows a prolonged course, with alternating periods of relapse and remission.[2,3]

Despite ongoing research, its underlying mechanisms remain unclear, though environmental, genetic, infectious, and immune factors are considered significant contributors.[3] As a chronic, incurable disease, IBD predominantly affects younger individuals with low mortality, leading to rising prevalence and placing a significant burden on healthcare systems and society.[4] It also imposes considerable physical and psychological strain on patients. Quality of life (QoL).[5]

Effectiveness of therapeutic strategies, and patient-centered feedback to optimize treatment plans, ultimately enhance overall QoL.[6,7] Compared to healthy individuals or those with other chronic diseases, IBD patients generally face higher levels of daily stress and exhibit consistently lower QoL.[8,9] This review aimed to explore the factors influencing QoL of IBD patients by synthesizing existing evidence, providing a theoretical foundation for future QoL research, and offering references for developing relevant interventions to ultimately improve the overall well-being of IBD patients.

METHODOLOGY

This systematic review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews (PRISMA) guidelines (Fig. 1). Literature searches were performed across five databases: PubMed, Scopus, Web of Science, Embase, and Google Scholar, covering studies published between January 1, 2004, and January 1, 2024. Search terms included condition-specific keywords such as "inflammatory bowel disease", "ulcerative colitis", and "Crohn's disease", outcome-related terms like "quality of life/QoL", "health-related quality of life/HRQoL", and "patient-reported outcomes", as well as associated factors like "risk factors", "psychosocial factors", "determinants", and "predictors". Boolean operators (AND, OR, NOT) combined these terms, for example, ("inflammatory bowel disease" OR "ulcerative colitis" OR "Crohn's disease") AND

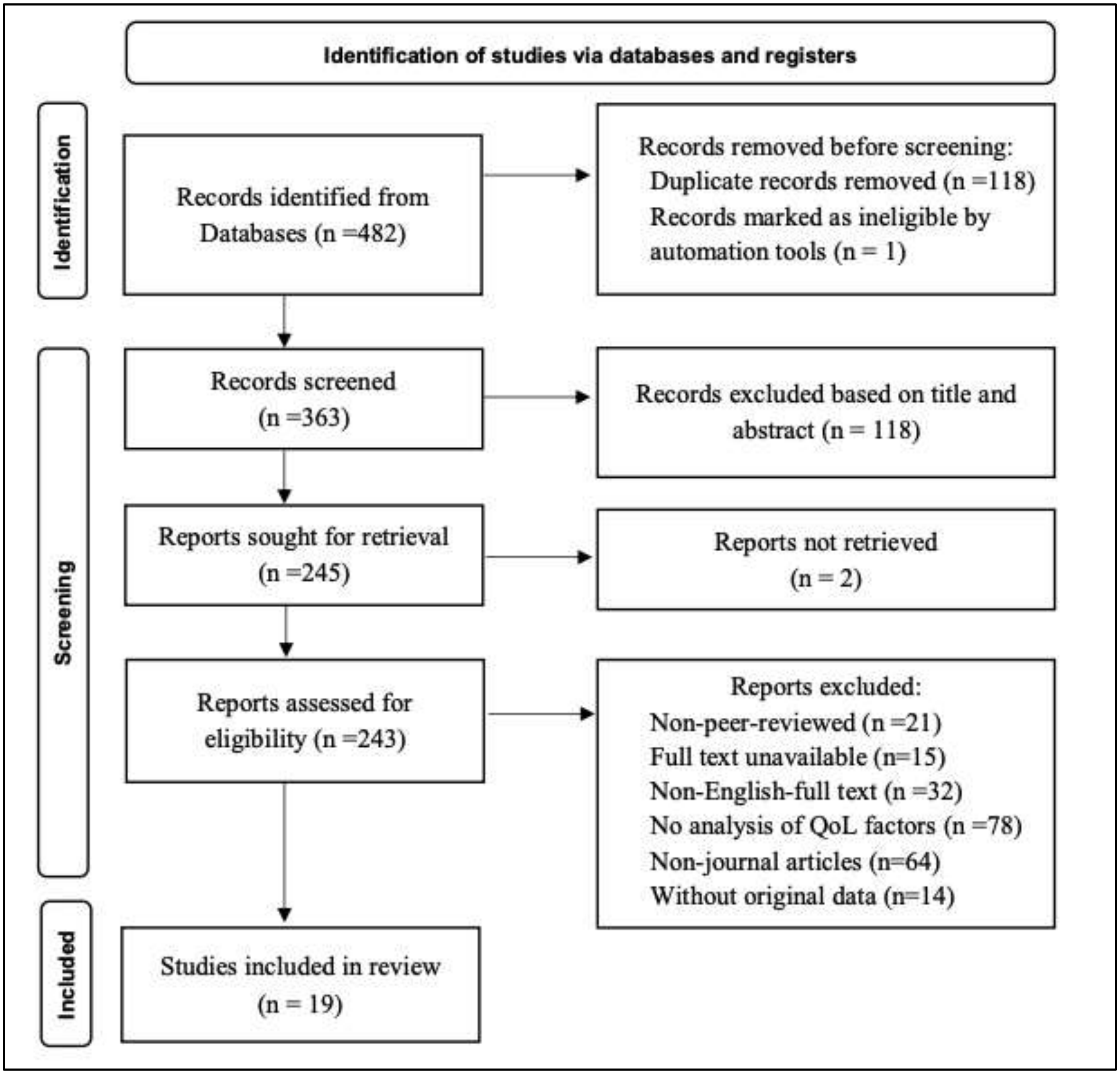

Fig. 1: PRISMA Diagram for study selection.

(“quality of life” OR “health-related quality of life”) AND (“risk factors” OR “determinants”). Truncation symbols (e.g.,*) and MeSH terms ensured inclusion of word variations and standardized indexing.

Inclusion Criteria: Studies assessing QoL using validated standard questionnaires and analyzing factors associated with QoL using statistical methods, published in English and peer-reviewed journals from January 1, 2004, and January 1, 2024.

Exclusion Criteria: Full text not available, including publications as conference proceedings, case-control studies, reports, letters, or medical trial studies, did not contain original data specifically related to QoL.

The literature screening process was conducted independently by two researchers (Honyun and Lining), to ensure methodological rigor and reduce the risk of selection bias. Any discrepancies arising during the screening were reviewed and resolved through deliberation by an additional two team members.

Quality Consideration: All included articles underwent peer review and each article provided a clear description of the research methodology, inclusion and exclusion

Table 1: Quality of life questionnaires measuring IBD patients.

Tools (Year)	Number of Items	Recall period	Likert Scales	Score Range (worst-best)	Target	Reliability
1BDQ-32 (1989)	32	2 weeks	7-Point Likert Scale (range from1to7)	32-224	IBD	Cronbach's alpha 0.76-0.92
SIBDQ (1994)	10	2 weeks	7-Point Likert Scale	10-70	IBD	Cronbach's alpha 0.70-0.90
IBDQ-36 (1990)	36	2 weeks	7-Point Likert Scale	36-252	IBD	Cronbach's alpha 0.78-0.86
IBDQ-9 (2006)	9	2 weeks	7-Point Likert Scale	0-100	IBD	Cronbach's alpha 0.75-0.88
CUCQ-8 (2004)	8	2 weeks	4-Level Likert scale, ranging from 0 to 3, or ordinal format with a range of 0 to 14.	90-0	IBD	Cronbach's alpha 0.70-0.90

Note: IBDQ-32: Inflammatory Bowel Disease Questionnaire-32; SIBDQ: Short Inflammatory Bowel Disease Questionnaire; IBDQ-36: Inflammatory Bowel Disease Questionnaire-36; IBDQ-9: Inflammatory Bowel Disease Questionnaire-9; CUCQ-8: Crohn's and Ulcerative Colitis Questionnaire-8.

criteria, descriptions of the analytical methods used, and the ethical approval reference number.

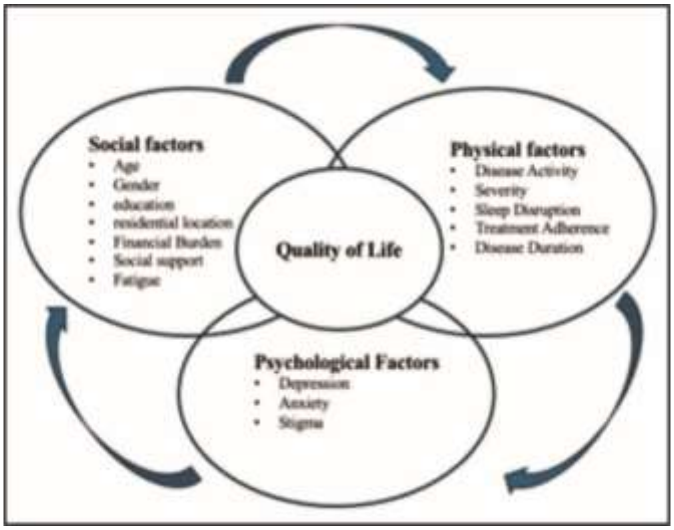

Fig. 2: Conceptual framework: Interconnected factors influencing QoL in IBD patients.

RESULTS

Measurement instrument: The studies have summarized a total of 5 specific measurement tools for QoL in IBD patients (Table 1). Many tools used have been validated.[10] A cohort study from France in 2017 reported that more than 50% of IBD patients had severely impaired QoL,[10] and a similar study from Greece reached the same conclusion.[1] Several questionnaires are currently used to measure quality of life in patients with IBD, the most widely used being the Intestinal Bowel Disease Questionnaire 32 (IBDQ-32) and the Inflammatory Bowel Disease Questionnaire 36 (IBDQ-36).[1,8,11]

Characteristics of studies: This review includes 19 studies. Among these, most of the quantitative research (n=14) utilized cross-sectional surveys to explore factors influencing QoL. The qualitative study (n=1) employed semi-structured interviews with IBD patients. Additionally, four reviews were included in the analysis following careful consideration. Regarding the research content, social factors were addressed in 9 studies, examining variables such as education, occupation, marital status, and social support. Physical factors were analyzed in 6 studies, focusing on disease activity, symptom severity, and comorbidities. Psychological factors were examined in 10 studies, investigating the effects of depression, anxiety, and stress.

Conceptual framework: QoL is defined by WHO as an individual's perception of their position in life within the context of their culture, goals, and expectation.[8] QoL is a complex, subjective evaluation involving emotional responses, life satisfaction, and personal fulfillment. Early researchers emphasized quantitative health metrics but later recognized that disease symptom relief, happiness, and mood are equally vital for patient well-being.[12]

The social, physical, and psychological factors are intricately interconnected, collectively determining the QoL for patients with IBD. Social factors, such as financial burden and support, influence both physical and psychological health. Physical symptoms impact psychological well-being and limit social participation.[13] Psychological issues, like depression and anxiety, can reduce treatment adherence, worsen physical symptoms, and deter social support-seeking.[2,4] These three dimensions dynamically interact, with changes in one affecting the others, ultimately shaping overall QoL (Fig. 2). Based on this framework, an IBD-specific QoL questionnaire was developed.[8]

Social factors: The onset of IBD exhibits two distinct peaks. The first peak occurs during the second or third decade of life and the second peak emerges after age 65.[14] Various factors affecting the QoL include sociodemographic variables such as education, residential location, professional activity, marital status etc.[3,7,15] In a 2014 study encompassing 100 patients with IBD, statistically significant disparities were observed across four domains: "physical health", "level of independence", "social relationships", and "spirituality/religion/personal beliefs."[16]

In a 2022 cross-sectional study from Poland, Chrobak-Bień et al, observed no significant differences in QoL based on age.[7] However, this finding varied across countries and regions.[7] For example, in Saudi Arabia, individuals aged 20-30 reported better QoL compared to those aged 30 and above.[17] From a socio-economic perspective, Poland offers a comprehensive healthcare system with relatively broad coverage for its residents, whereas Saudi Arabia's universal healthcare system is still in the process of gradual development and improvement. In addition, it can also be attributed to the fact that young individuals in this stage of life are often in a "supported" phase, characterized by fewer responsibilities and greater economic, emotional, and social security, which enhances their QoL. Conversely, adults over the age of 30 typically shoulder greater family and financial responsibilities, resulting in heightened psychological and economic stress that negatively affects their quality of life.

In a cross-sectional study involving 73 IBD patients, no statistically significant relationship was observed between gender and domains of QoL ($p>0.05$).[15] Consistently, a 2022 study from Brazil reported that gender did not demonstrate a statistically significant association with the QoL of IBD patients.[6] However, these findings are not universally consistent, as evidenced by prior studies.[18] Moreover, the interaction between social support and QoL is complicated and affected by variables including negative emotions and opinions of spouse support.[19] Besides, high medical costs or financial burdens have been associated with lower HRQOL.[20]

Studies from Japan have revealed that IBD sufferers' financial burden could reduce their QoL.[21] Additionally, fatigue is prevalent among Crohn's disease patients, significantly impacting their QoL.[5] Although symptoms may improve or disappear during disease remission, persistent or recurrent fatigue affects up to 40% of patients, even in the absence of active inflammation.[22]

Physical factors: Increased disease activity ($p=0.01$) and severity ($p<0.01$) are key determinants, often resulting in heightened symptoms such as abdominal pain, diarrhea, and fatigue.[13,23] These symptoms not only impair physical health but also contribute to psychological distress, further diminishing overall QoL.[4,24] Additionally, poor treatment adherence can compromise the effectiveness of therapeutic interventions, exacerbating symptoms and disease progression, which subsequently leads to a decline in QoL.[2]

The data from the SF-36 questionnaire revealed that as the duration of the disease increased, there was a corresponding decline in the patients' QoL ($p<0.05$) regarding changes in health status (HT). However, this correlation was not evident across any domains of the specific IBDQ questionnaire.[7]

Furthermore, the presence of comorbidities serves as another critical determinant affecting the QoL. Common comorbidities such as arthritis, liver disease, and mental health disorders often necessitate additional medical interventions and lifestyle modifications, adding to the physical and psychological burden and further reducing their QoL.[3] For example, arthritis exacerbates physical discomfort and mobility issues, while anxiety and depression may impede coping mechanisms, leading to poorer disease self-management and reduced treatment adherence.[25,26]

These comorbidities also increase healthcare utilization and financial burdens, which can further impact the QoL. Comorbidities further complicate disease management, adding to the challenges faced by IBD patients.[25] Hospitals and gastroenterology departments are encouraged to establish multidisciplinary clinics, offering coordinated care through regular joint consultations to streamline treatment, reduce redundancy, and optimize resource utilization.

For patients with mobility challenges or financial constraints, tailored medical services and comprehensive home care plans should be developed to minimize the need for frequent hospital visits. Regular screening of high-risk populations for early indicators, such as bone density and liver function, should also be integrated into regional healthcare planning to enable early detection and timely intervention.

Psychological Factors: Stress, anxiety, and depression are critical determinants of QoL in IBD patients. Williet et al, conducted a study involving 1,115 IBD patients, finding that approximately 49% experienced depression, while 20% reported anxiety.[10] Those with depression had significantly lower QoL compared to non-depressed patients ($p=0.005$).[4,9] A study of 172 people with IBD also found that those who had moderate to serious stress, depression, anxiety, and low QoL had much higher disease severity indices.[2]

Recognizing this relationship, effective psychological interventions can significantly improve patient outcomes.[23,25,26] Approaches like cognitive-behavioral therapy (CBT) and mindfulness-based stress reduction (MBSR) have been shown to help patients better cope with their condition, alleviating emotional burdens while enhancing their ability to manage symptoms.[26] A U.S. survey on stigma revealed that only one-third of patients and their families could correctly answer questions related to IBD, and among seven types of immune diseases, IBD patients experienced the highest levels of stigma.[27] This further emphasizes the importance of considering the interplay between the three dimensions of QoL model when addressing the well-being of IBD patients.

Role of healthcare professionals in managing quality of life: The 19 included articles all looked forward to the important role of healthcare personnel in disease management. The lack of systematic and structured testing may hinder patients' disease management. As the most trusted role of patients, medical staff play an important role in patients' self-management.[13,28] Some regions have solved this problem by establishing specialist clinics or integrating community services to provide extended care through telephone and home visits. Additionally, telemedicine also plays a growing role in improving QoL by facilitating remote electronic monitoring and online video consultations.[28] Studies suggest that patients engaged in telehealth programs demonstrate better adherence to prescribed regimens, which positively impacts their physical and psychological well-being.[28]

Patient-centered instrument adaptation: Tools used to assess QoL each have distinct strengths and limitations. The IBDQ series, including the IBDQ-32 and IBDQ-36, is specifically designed to capture the multidimensional impact of IBD, encompassing physical symptoms and psychosocial factors.[8,28] The relatively lengthy nature of these questionnaires could lead to lower response rates and reduced data accuracy. In contrast, shorter tools such as the SIBDQ and CUCQ-8 offer greater efficiency and reduce the burden on participants but provide only limited coverage of QoL dimensions.

Generic instruments like the WHOQOL-36, SF-36, and EQ-5D are broadly applicable across various conditions but lack specificity for IBD, making them less sensitive to disease-specific symptoms such as diarrhea and fatigue.[5,23] To achieves a more objective and comprehensive quantification of patients' QoL, it is recommended that clinical practitioners adopt a mixed assessment approach.[8] This could involve integrating qualitative interviews with standardized tools, such as combining generic instruments (e.g., SF-36) with disease-specific questionnaires.

Future research should prioritize the development of tools that strike a balance between efficiency and comprehensiveness while actively incorporating patient input during the design process. Expanding the scope of research to include underrepresented groups, such as pregnant women, frail elderly patients, and adolescents, is essential.

CONCLUSION

Despite significant progress in the treatment and management of IBD patients, existing measurement tools still have certain limitations. The cultural and regional variability of IBD, even within the same country, results in an uneven distribution of cases and a lack of large-scale, multicenter studies, particularly longitudinal and qualitative research, which are critical for understanding the chronic progression and evolving nature of the disease.

While cross-sectional studies are widely used, they are insufficient for establishing causal relationships, especially for patients with long disease durations. Moreover, key populations, such as women planning pregnancy, elderly patients with comorbidities, and adolescents in transitional phases, are underrepresented in current research, leaving significant gaps in understanding their unique challenges. Future studies should adopt more inclusive and comprehensive approaches to explore QoL from the perspectives of diverse patient groups.

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