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Review Article

Health Literacy: A Pathway to Better Health for Patients with Inflammatory Bowel Disease-An Integrative Literature Review

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Abstract

Background: Low health literacy affects patients with inflammatory bowel disease, increasing their risk for poorer health outcomes and preventing them from adhering to treatment and health information. Health literacy is needed to understand, appraise, and apply health information to patients with inflammatory bowel disease. **Aim:** To explore health literacy in patients with inflammatory bowel disease. **Methods:** This integrative review involved a systematic search of the PubMed, CINAHL, and ASSIA electronic databases. A systematic strategy was used to select and analyze 17 peer-reviewed articles on health literacy in patients with inflammatory bowel disease. This review examined research literature published until August 2024. **Results:** The analysis identified three descriptive themes: knowledge level, disease-related knowledge, and compliance with knowledge and treatment. The literature review underscores the role of education and knowledge, recommending that patients be guided to the official websites of healthcare and patient support organizations. Evidence-based online educational portals can support patients in better understanding prescribed medications, and participation in educational programs can enhance treatment adherence and health outcomes. Healthcare professionals can improve patients' adherence to knowledge and health outcomes through communicative strategies and regular follow-up. **Conclusion:** Education and knowledge in managing inflammatory bowel disease increase treatment adherence. Patients need reliable sources and evidence-based educational portals. Healthcare professionals can enhance patients' understanding of their medications and treatment plans with effective communication strategies and regular follow-ups to support patients' journey toward better health, leading to improved health outcomes.

Keywords: Health knowledge; Health literacy; Inflammatory bowel disease; Integrative review; Patient knowledge

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Background

Living with Inflammatory Bowel Disease (IBD) is a challenge. Patients with IBD have special needs and often feel powerless, depressed, ashamed, and isolated from family and friends. Support from others is important in dealing with these feelings. Furthermore, the fear of financial worries and frustration is a common concern. Adults living with IBD are advocating for themselves throughout their lifetime to ensure their overall well-being [1].

Health literacy is patients' ability to analyze and evaluate health information and develop health-promoting problem-solving and actionability. This requires that healthcare meets patients' information needs and considers their expertise in collaboration with respect to the content and structure of care. The starting point for health literacy is that individuals can promote health, solve health problems, and be active partners in the choice of actions and decisions [2]. Definitions of health literacy refer to the capacity of patients and families to access, understand, appraise, and apply health information to make judgments and decisions in everyday life concerning healthcare, disease prevention, and health promotion to understand health-related information, interpret and evaluate information on health-related issues and form a reflected opinion on health [3,4].

Low health literacy is associated with poorer health, disease, and health inequalities. Health literacy refers to the capacity of patients to access, understand, assess, and apply health information to make judgments and decisions in everyday life about health care, disease prevention, and health promotion to maintain or improve their quality of life [5]. Health literacy is defined as 'the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' [4,6]. Health literacy can include a variety of individual skills, both basic and interactive, as well as critical. This means that a patient understands the basics of examinations, prevention, diagnosis, and treatment. Furthermore, it is about the patient's ability to analyze and evaluate health information and develop health-promoting problem-solving and action abilities [7]. Health literacy enables individuals to promote health, solve problems, and actively participate in healthcare decisions. These dynamic and context-dependent skills arise from interactions with the environment, such as family and healthcare settings [8]. There are two main approaches to defining health literacy: a functional understanding focusing on basic skills to comprehend health information and a more complex view recognizing a range of skills interacting with social and cultural contexts [9]. Redefining health literacy to emphasize societal responsibility in providing accessible information could impact research indexing and interpretation [10]. Health literacy is classified into three levels: functional, basic reading, writing, and numeracy skills; interactive, advanced cognitive and social skills for active participation and information application; and critical, the ability to analyze information and exert control over life events [11]. Improving health literacy is crucial for empowering patients with IBD by enhancing their ability to access and use health information effectively [12].

The consequences of health literacy include improved self-reported health status, health care costs, increased health knowledge, shorter hospitalizations, and less frequent use of health care services. Health literacy enhances nurses' ability to assess their health literacy more accurately, thus identifying those at risk for misunderstanding health care instructions, shame associated with inadequate reading skills, and inability to adhere to health care recommendations [13]. A systematic literature review revealed that urban populations generally exhibit greater health literacy than rural populations do, with this difference being more pronounced in developing countries than in developed countries. However, studies that included covariate analysis suggested that rurality might not be a significant factor in determining health literacy [14]. Another study on older patients with long-term conditions revealed that poor health literacy was linked to lower scores across all four quality of life (QoL) domains-physical, psychological, and social relationships-even after accounting for the effects of multiple chronic conditions, depression, social support, and sociodemographic factors. At the 12-month follow-up, low health literacy significantly predicts declines in the physical, psychological, and environmental QoL domains, although it does not predict a decline in social relationship QoL [8].

Low health literacy is currently described as a threat to the health of patients living with IBD. Health literacy is crucial for empowering patients with IBD. Health literacy is needed to understand, appraise, and apply health information to patients with IBD. Every visit to gastroenterological clinics or primary care depends on health literacy. To strengthen patients, healthcare professionals must know the predictors of health literacy in their everyday work to reassure patients with IBD in their decision-making process. The decision-making process can be facilitated by an increased understanding of how information can be applied to patients with IBD. There are good reasons to assume that if the health care system can support patients' ability for health knowledge, both individuals and society have much to gain. Improving collaboration and including patients in the care process is paramount. Collaboration provides an opportunity to promote resources and increase health literacy.

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Objectives

This study aimed to explore health literacy among patients with inflammatory bowel disease.

Methods

Design

An integrative literature review was conducted to gain a deeper understanding of health literacy in patients with IBD. An integrative review allows for the inclusion of experimental and nonexperimental research, combining data from theoretical and empirical literature to understand health literacy more fully in patients with IBD. The review entailed identifying, critiquing, and synthesizing the literature [15].

Identifying the research question and eligibility criteria

The objective of the research question was applied via the population, exposure, and outcome (PEO) framework. For inclusion in this study, the papers had to meet the following criteria and be conducted in compliance with the PEO model: population-patients with inflammatory disease, Crohn’s disease, or ulcerative colitis; exposure-education OR information; outcome-health literacy OR health knowledge OR patient knowledge. No limits were applied regarding dates to allow as comprehensive an inclusion of papers as possible, but papers had to be in English.

Information sources and search strategy

The search keywords and their combinations were performed in close collaboration with a librarian. Database of thesauruses and MeSH terms that generated synonyms. Electronic searches were conducted across PubMed, CINAHL Complete (EBSCO), and Applied Social Sciences Index & Abstracts (ASSIA) from May to August 2024. The inclusion criteria for the integrative review required studies to be academically published in English in peer-reviewed journals on the basis of original empirical data analysis and reporting on health literacy, health knowledge, or patient knowledge in adult patients with IBD. Studies were excluded if they did not address health literacy, health knowledge, or patient knowledge in the title or abstract; did not report patients’ health literacy experiences; or focused on family planning and adolescents. The search strategy was not limited by publication date or methodology. The database searches were supplemented by hand-searching Google Scholar and the reference sections of the retained papers. Titles and abstracts were screened via Rayyan software to exclude articles that did not meet the inclusion criteria. The authors screened the full texts of the remaining studies for eligibility via Rayyan software. Free-text searches, relevant subject headings, and truncations were applied when appropriate, in combination with the Boolean operators OR and AND, to identify relevant articles (Table 1).

Table 1: Search strategy.

Order of search	Search action	Cinahl	ASSIA	PubMed	Total no. of articles
1	((MH “Inflammatory Bowel Diseases”) OR (MH “Colitis, Ulcerative”) OR (MH “Crohn Disease”)) OR TI (“inflammatory bowel disease*” OR “crohn disease*” OR “crohns disease*” OR “crohn´s disease*” OR “ulcerative colitis”) OR AB (“inflammatory bowel disease*” OR “crohn” OR “crohns” OR “crohn´s” OR “ulcerative colitis”)	24921	731	145059	
2	(“Health Education+”) OR (“Patient Education+”) OR	285971	52980	389926	
	(“Health Promotion+”) OR (“Consumer Health Information+”) OR (“Health Literacy”)) OR TI (“educational program*” OR “information need*” OR “Health Education” OR “health information” OR “health promotion” OR “health literac*” OR “patient education” OR “patient training*”) OR AB (“educational program*” OR “information need*” OR “Health Education” OR “health information” OR “health promotion” OR “health literac*” OR “patient education” OR “patient training*”) 1				
3	#1 AND #2	498	41	770	
4	Filter: English language	463	41	711	1215
5	Reduction of duplicates (-)				471

The original search yielded 1,215 papers after filtering for the English language, and 744 remained after the Rayyan software removed duplicates. During the title and abstract review phase, the author determined that 477 articles did not meet the inclusion criteria (e.g., not expressing health literacy, health knowledge, or patient knowledge in the title or abstract). An additional 462 articles were excluded because they did not meet the inclusion criteria. The reasons for exclusion were the population (e.g., adolescent patients, family planning or outcomes (e.g., discussions with providers; other chronic diseases or those outside a priori inclusion criteria), nonquantitative design (e.g., case studies; reviews), and duplicates not captured by Rayyan software. After the abstracts were screened, the literature search (Table 1) yielded 14 studies considered eligible for full-text reading. After three other full-text articles, 17 full-text articles were included in the integrative literature review, all of which included adult patients with IBD (Figure 1) [16].

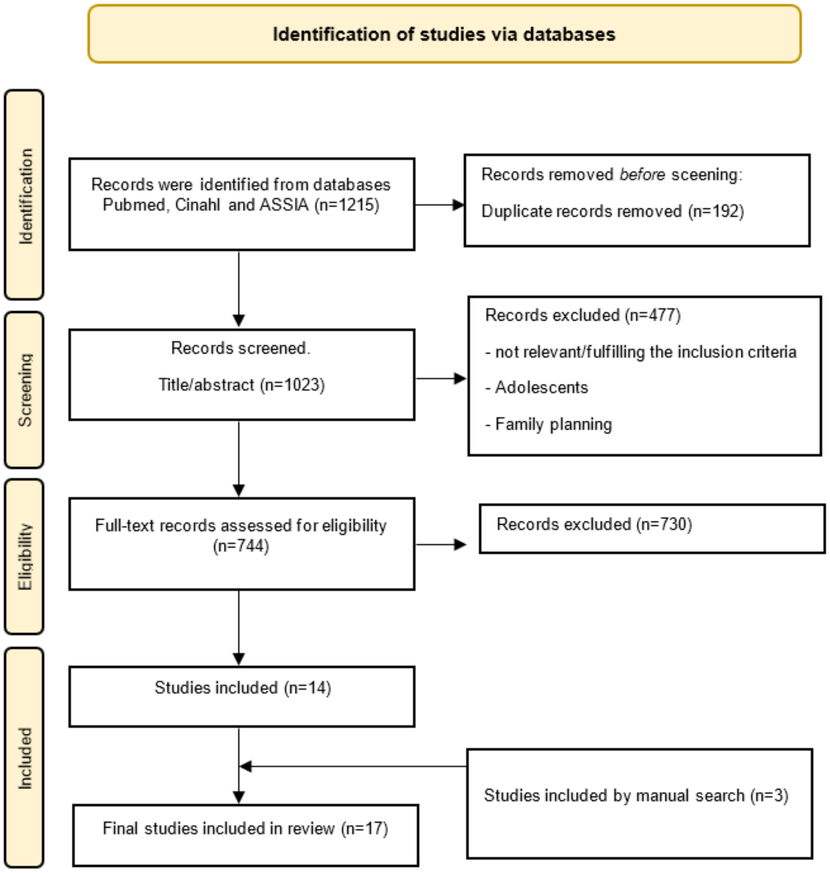

Figure 1: The PRISMA flowchart [16].

Quality Assessment

Seventeen studies underwent quality assessment. Both authors calculated quality scores via the Mixed Methods Appraisal Tool (MMAT) for all eligible studies [17]. The MMAT, designed specifically for reviews, includes methodological appraisal questions on the basis of each study's design. The scoring system assesses qualitative, quantitative experimental, quantitative observational, and mixed methods research studies. Quantitative and qualitative methodologies were used in all included studies. The authors appraised each article and quality score to identify the potential contribution of each study to the overall findings.

The appraisal process was divided into stage 1, with two questions, and stage 2, consisting of five questions with answer options of yes (1 point), no (0 points), or cannot tell (0 points) (Table 2) [17]. In stage 2, the remaining studies ranked high, middle, and low quality. After the appraisal, all studies in the integrative review were presented (Table 2).

Table 2: Articles in the review (n=17).

Author/s Year, Country	**Title**	**Method**	**Participants**	**Health literacy**	**Quality assessment**
1. Carels, et al (2021). Belgien	Health Literacy and Quality of Life in Young Adults From The Belgian Crohn's Disease Registry Compared to Type 1 Diabetes Mellitus	Prospective and observational study	A total of 52 patients with CD (median [IQR] age of 25.0 [23.8-27.0], 64% male	Education provides more knowledge	High
2.Casellas, et al (2019). Spain	Development and validation of the QUECOMIICAT questionnaire: a tool to assess disease-related knowledge in patients with inflammatory bowel disease	Questionnaire development	A total of 200 patients had UC 154 had CD Of the patients, 182 of 290 respondents were members of NACC	Knowledge improves when patients with IBD receive an educational program	High
3. Dos Santos Marques et al.(2020) US	Low Health Literacy Exists in the Inflammatory Bowel Disease (IBD) Population and Is Disproportionately Prevalent in Older African Americans	Observational study	175 patients with IBD patients, 59% women, 23% African Americans, 91% Crohn disease, and mean age was 46 years	Education provides more knowledge	High
4. Eaden, Abrams & Mayberry (1999). UK	The Crohn's and Colitis Knowledge Score: a test for measuring patient knowledge in inflammatory bowel disease	Questionnaire development	76 patients	Education provides more knowledge	High
5. Harvey et al, (2022) Canada	Health Care Perspectives of Adult Patients with Lower Educational Attainment in Inflammatory Bowel Disease: A Qualitative Study	A qualitative study	23 patients	Interactions with physicians and nurses were strong factors of satisfaction and dissatisfaction with care.	High
6. Hu & Xu, (2024). China	Relationship between fear of progression and quality of life in inflammatory bowel disease: Mediating role of health literacy and self-care	A cross-sectional study.	241 participants	How should we increase adherence to knowledge?	High
7. Jones, et al (1993). UK	A patient knowledge questionnaire in inflammatory bowel disease	Questionnaire development		Interest groups are important for knowledge about their disease	Medium
8. Kaps, et al (2022) Germany	Health literacy in gastrointestinal diseases: a comparative analysis between patients with liver cirrhosis, inflammatory bowel disease and gastrointestinal cancer	Observational, study	86 patients with IBD,	Education provides more knowledge	High

9. Kim, et al, 2021 US	The effect of gastrointestinal patients' health literacy levels on gastrointestinal patients' health outcomes	Observational study	589 gastrointestinal patients	Knowledge of outcomes	High
10. Park et al. (2020). Korea	Higher levels of disease-related knowledge reduce medical acceleration in patients with inflammatory bowel disease	Cross-sectional study	289 patients	Knowledge of outcomes	High
11. Park, Kim, & Yoon, (2024). Korea	Quality controlled YouTube content intervention for enhancing health literacy and health behavioral intention: A randomized controlled study	A randomized controlled trial	505 participants intervention group, n = 255	Educational interventions with quality improve knowledge	High
12.Selinger, et al (2017). UK	The relationship between different information sources and disease-related patient knowledge and anxiety in patients with inflammatory bowel disease	An observational, cross-sectional study	307 patients (165 Crohn's disease, 142 ulcerative colitis) 60.6% were female.	Education should be conducted by a specialist in IBD, and interest groups are important for knowledge about their disease.	High
13.Simian, et al (2017). Chile	Assessment of disease-related knowledge and possible factors associated with the knowledge level among Chilean patients with inflammatory bowel disease	An observational, cross-sectional study	203 patients were included, 62% were female, and 66% were diagnosed with ulcerative colitis	Disease-related knowledge and associated factors	High
14.Tae, et al (2016) Korea	Importance of Patients' Knowledge of Their Prescribed Medication in Improving Treatment Adherence in Inflammatory Bowel Disease	A prospective survey study	At baseline, 138 patients with IBD completed a self-report survey	Patient knowledge of adherence	High
15. Tormey. et al (2019) US	Limited Health Literacy Is Associated With Worse Patient-Reported Outcomes in Inflammatory Bowel Disease	A cross-sectional study	99 patients	An educational online portal can improve IBD patients' knowledge	High
16. Verma, Tsai, & Giaffer, (2001). UK	Does better disease-related education improve quality of life? A survey of IBD patients	A cross-sectional study	250 patients with IBD	Educational interventions with quality improve knowledge	High
17. Wierstra, et al. (2018). Canada	Innovative Online Educational Portal Improves Disease-Specific Reproductive Knowledge Among Patients with Inflammatory Bowel Disease	A randomized controlled trial	111 patients with IBD, median age 29.3, Crohn's disease 69.2%,	Educational interventions with quality improve knowledge	High

Data Analysis

The methodological approach included five stages that guided the review design: (1) problem identification, which ensures that the research question and purpose are clearly defined; (2) literature search, which incorporates a comprehensive search strategy; (3) data evaluation, which focuses on the authenticity, methodological quality, informational value and representativeness of the available primary studies; (4) data analysis, which includes data reduction, display, comparison and conclusions; and (5) presentation, which synthesizes findings in a model that comprehensively portrays the integration process and that describes the implications for practice and research as well as the limitations of the review [15,18]. Data from the included studies were extracted and entered into a table (Table 2). Data comparison involves an iterative process of examining data to identify patterns, themes, or relationships. The studies were then analyzed to synthesize the results. This integrative literature review was also conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [16]. All the measurements used for patient knowledge or health literacy in the study are presented in Table 3.

Table 3: Measurement of patient knowledge and health literacy in the studies.

A Patient Knowledge Questionnaire in Inflammatory Bowel Disease [19]
BRIEF Health Literacy Screening Tool [20]
Crohn's and Colitis Pregnancy Knowledge survey (CCPKnow), which measures IBD-specific reproductive knowledge [21]
IBD – Know questionnaire [22]
Knowledge of the prescribed medication was measured using a valid and reliable tool [23]
Newest Vital Sign (NVS) [24,25]
The Chinese version Health Literacy Scale for Chronic Disease [26]
The Crohn's and Colitis Knowledge Score (CCKnow) [27]
The Health Literacy Questionnaire (HLQ) [6,28,29]
The eHealth Literacy Questionnaire (eHLQ) [30]
QUECOMIICAT questionnaire [31]

Ethical Considerations

Studies included in the study were reviewed according to the Declaration of Helsinki. The articles included need ethical reasoning to clarify similar considerations of ethics and human rights. The literature included in this study met these requirements. Relating to ethics is part of research practice, which highlights the importance of the study with respect to the area in question [32,33].

Results

This review yielded three themes: knowledge level, disease-related knowledge, and compliance with knowledge and treatment. The reviewed studies were conducted in the UK (n=4), the US (n=3), Korea (n=3), and Canada (2), and studies were conducted in Belgium, Chile, China, Germany and Spain (Table 4).

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Table 4: Themes and subthemes.

Knowledge level	**Disease related knowledge**	**Compliance to knowledge and treatment**
• Prevalence of health literacy	• Outcomes of health literacy	• Support systems
• Gender, age and health literacy	• Impact of hospitalization	• Educational interventions with quality, improve knowledge
• Education and knowledge		• Developing tailored communication strategies
• Comparison with other diseases		• Ensuring regular follow-ups

Knowledge level

Prevalence of health literacy

The results revealed the prevalence of low health literacy for patients with IBD (24-47.5%) [20,30-33]. The median health literacy is similar for patients with CD (14.0 [11.0–16.0]). Equal proportions of sufficient and inadequate health literacy have been observed for patients with Crohn's disease. The proportion of adequate health literacy was lower for patients with CD with recent hospitalization and/or surgery than for those without (31 vs. 69%). Problematic health literacy is greater in hospitalized patients than in other groups [34]. For 203 patients, the median disease-related knowledge score was 9 (range 1-20). Only 29% of the patients answered more than 50% of the questions correctly [35]. In another study of 289 patients, the mean IBD-KNOW score was 11.7±4.7 (median, 11; range, 1-23) [36].

Gender, age, and health literacy

Gender was not significantly associated with health literacy. However, in one study, male patients had a greater prevalence of low health literacy than female patients did [37]. Three studies explored the associations between health literacy and age [30,34,35]. Low health literacy is associated with older age and African American race. Older age is associated with lower health literacy scores. Every year in terms of age, the probability of low health literacy increases by 15%. Every year in terms of age, the probability of low health literacy increases by 15%. For every year in terms of age, the probability of having low health literacy for white patients increased by 12%. For every year in terms of age, the probability of African American patients having low health literacy increased by 41% [37].

Three studies highlighted that younger age and longer intervals between clinic visits are associated with lower adherence to treatment [20,38,39]. One study revealed that younger age, longer intervals between visits to the clinic, and limited knowledge of their prescribed drugs tended to be associated with lower adherence to treatment, which affects the risk of relapse. In this study, nonadherence was relatively challenging in the clinical setting. Patients with IBD miss sufficient knowledge of their prescribed medications to be able to participate in IBD treatment effectively. A generalized understanding of the prescribed drug, especially the name, dosage, and side effects, has improved the results [20].

Education and Knowledge

Three studies reported correlations between education level and disease-related knowledge [19,35,37]. Jones (1993) reported a positive correlation between years spent in full-time education and knowledge scores. The knowledge score correlated with the number of years spent in full-time education (R=0.48, $p < 0.001$) and vice versa with age (R=0.33, $p < 0.02$) but did not correlate with the duration of the disease [19]. Simian et al. (2017) reported no correlation between education level and disease-related knowledge. When low health literacy patients were characterized by education level, income, and employment status, the majority (56%) had an education level of high school or less, the majority (56%) had an income of <$40,000 per year, and only 11% were employed full time [37]. The patients who participated in an IBD program had poor disease-related knowledge, and their knowledge levels were like those in developed countries. However, there was no correlation between the CCKNOW score and patient education level [35].

Comparison with other diseases

Two articles discussed different diseases and their unique challenges [34,40]. Patients with cirrhosis had significantly worse health literacy than patients with cancer or IBD in subscales such as "feeling understood and supported by caregivers," "having sufficient information to manage my health," "assessing health information," "ability to engage with caregivers actively," or "understanding health information well enough to know what to do" ($p < 0.05$ for cirrhosis versus IBD or cancer, respectively) [40]. In another study, selected young Belgian adults suffering from CD for >5 years had similar and sufficient health literacy compared with patients with diabetes mellitus [34]. For example, Kaps et al. (2022) reported that patients with cirrhosis had worse health literacy than did those with cancer or IBD, whereas Carels et al. (2021) reported that young adults with CD had health literacy levels like those of patients with diabetes.

Disease-Related Knowledge

Outcomes of Health Literacy

Health literacy outcomes are shown in previous studies [20,34,37,40,41]. Health literacy is positively correlated with quality of life in patients with CD [34]. Patients with limited health literacy are associated with lower ratings of subjective health and depression in IBD [41]. Another study revealed no correlation between QOL and PIS scores in patients with ulcerative colitis and CD. Greater disease-related knowledge could reduce the need for step-up therapy in IBD patients [36]. The level of disease-related knowledge appeared to be better in patients with CD, although it did not seem to affect QOL [42]. There are no differences in readmission rates between patients with low and adequate health literacy in patients with IBD [37]. Patients with CDs with adequate health literacy are more likely to be in clinical remission (mean Harvey–Bradshaw Index score < 5) (a disease activity measure) than those with limited health literacy. There is no association between health literacy and clinical disease activity (SCCAI) (a disease activity measure) in ulcerative colitis patients. Limited health literacy is associated with more symptoms of active disease in patients with CD. Health literacy is linked to health outcomes and seems to be a modifiable risk factor for poor health outcomes in individuals with IBD [41]. Patients with lower health literacy have demonstrated reduced disease-related knowledge, particularly in areas concerning pregnancy/fertility and surgery/complications. This trend was more pronounced in patients over 50 years old, those with ulcerative colitis, those with disease durations of less than five years, and those without a history of surgery [40].

Health literacy is a significant predictor of both drug risk perception and willingness to transition to a new drug, independent of educational level or race. The impact of limited health literacy on the willingness to initiate a disease-modifying antirheumatic drug was mediated through risk perception [37]. A study has shown that a higher IBD-KNOW score was associated with medical acceleration in step-up therapy for patients with IBD [36].

Impact of Hospitalization

Three studies measured secondary outcomes according to hospital length of stay, readmission, and complications [20,37,43]. The secondary outcome for patients with IBD was significant abdominal surgery; the overall mean postoperative length of stay, a marker of resource consumption, is an essential outcome. The duration of stay was 5.5 (SD 4.5) days for the patients who underwent surgery. The length of stay was not significantly different between those with low and adequate health literacy. Twenty-four patients (28.9%) were readmitted: five with low health literacy and 19 with adequate health literacy [37]. Other studies revealed that gastrointestinal patients' health literacy levels are negatively associated with their health outcomes (hospital length of stay, readmission, and complications) [20,43]. Patients with recent hospitalization or surgery had a higher Crohn's Disease Activity Index (CDAI) and problematic health literacy, whereas those without recent hospitalization or surgery had sufficient health literacy. Low quality of life and the worst pain intensity (WPI) were higher for hospitalized patients. Patients with IBD face difficulties in their usual activities, pain/discomfort, or anxiety and have low median health literacy, low quality of life and a higher CDAI than patients without those issues do [34].

Compliance with knowledge and treatment

Health literacy is a key factor in these articles. Studies emphasize the importance of education and knowledge in managing IBD. Higher health literacy levels are associated with better disease management and treatment adherence. Health literacy improves patient engagement and health behaviors [40,44]. Information was identified as an important aspect of care (73.9%) [36].

Support Systems

Support systems encouraging participation in interest associations. The importance of support systems, such as caregivers and interest associations, suggests that being part of an interest association or having supportive caregivers can significantly enhance patients' knowledge and management of their condition [19,27,45]. Patients who are members of an interest association achieve considerably higher scores than non member patients do in terms of their knowledge of IBD and its treatment, i.e., the Crohn's and Colitis Knowledge (CCKNOW) score [27]. Another study also shows the importance of being part of an interest association. Eighty percent of the patients wanted to know more about their disease. Knowledge scores were higher in patients who were members of an interest association ($p < 0.005$) and in patients with CD rather than ulcerative colitis ($p < 0.005$). The study revealed that most patients would have liked more information [19]. Providing training and support for caregivers can enhance their ability to assist patients in managing their disease, leading to better adherence and health outcomes [41]. Access to an IBD specialist was the most critical aspect of care. Good care, friendly and receptive health care professionals, and long delays in diagnosis were reported. IBD specialists, nurses, family, and friends were very helpful in managing the condition. Physical and emotional symptoms decrease social engagement, and medication is a challenging aspect of living with IBD [45].

Educational interventions with quality and improved knowledge

Patient materials, education portals, and health literacy-based interventions improve health knowledge for patients with IBD [20,31,34,35,37,44,46]. The implementation of comprehensive education programs for patients and caregivers can significantly improve health literacy and treatment adherence. For example, better knowledge of prescribed medications and participation in educational programs can improve treatment adherence and health outcomes [20,31]. The implementation of structured educational programs, as Casellas et al. (2019) suggested, can significantly improve patients' knowledge and adherence to treatment. Improving health literacy with adequate programs may offer health benefits. It may seem intuitive that better health literacy reflects a better quality of life. However, more knowledge about the disease and possible complications may generate more anxiety [34]. As measured by the QUECOMIICAT questionnaire and VAS, patients' IBD knowledge increased significantly 24 hours after they participated in the educational program and remained statistically significant one month later. There were significantly lower scores in the control group than in the patients with IBD, both in terms of total and general knowledge, clinical knowledge, treatment, and lifestyle [31].

All patient materials should be developed with patient input and constantly improved for comprehension and acceptance. Healthcare professionals should ensure that patients with limited health literacy are given understandable and culturally appropriate instructions to reduce misunderstandings and prevent adverse outcomes [37]. An evidence-based, online educational portal can significantly improve and maintain IBD-specific reproductive patient knowledge for more than six months. Patients with IBD and low health literacy may benefit from health literacy-based interventions at clinic visits, hospital stays, and outreach after discharge. Health literacy principles include patient-centered communication with plain language (avoiding jargon), "teaching back" to confirm patient understanding, and offering help in completing forms. Written information provided to patients needs to be formatted for reading accessibility/understandability, including pictures and graphics. All patient materials should be developed with patient input and constantly improved for comprehension and acceptance. Healthcare professionals should ensure that patients with limited health literacy receive understandable and culturally appropriate instructions to reduce misunderstandings and prevent adverse outcomes [37]. Frequent use of official information websites can significantly enhance disease-related patient knowledge. Various sources of patient information are linked to improved knowledge or increased anxiety levels. Face-to-face education and written materials continue to be the primary methods for patient education [21]. Health literacy improved significantly in the intervention group (28.1 before and 31.8 after; $p < 0.01$ for health check-ups; 28.3 before and 31.3 after; $p < 0.01$ for IBD). Health behavioral intentions improved significantly in the intervention group (3.5 before and 4.1 after; $p < 0.01$ for health check-ups; 3.6 before and 4.0 after; $p < 0.01$ for IBD). The control groups had no such effect. High-quality health information increases health literacy and behavioral intentions in healthy individuals and those with specific conditions such as IBD. Providing reliable online health information is necessary, as are future efforts to curate and ensure access to high-quality health content [44].

Self-management-based interventions can improve health outcomes in patients with chronic diseases, and multiple patient characteristics are associated with the development of self-care behaviors [41]. In another study, health literacy and self-care independently mediated the relationship between fear of progression and quality of life. There is a significant chain mediating effect of health literacy and self-care on the relationship between fear of progression and quality of life [39].

Development of tailored communication strategies

The development of tailored communication strategies that consider patients' health literacy levels can improve understanding and adherence [21,41,44]. Transparent, simple language, and providing written materials [41]. The tailored strategies recommended by Park et al. (2024) and Selinger et al. (2017) suggest the continued use of face-to-face teaching by healthcare professionals and written patient information materials as first-line patient education. Referring patients to official websites with patient information from healthcare and support organizations is necessary [21]. As patients with limited health literacy face more uncertainty and fear of decisional regret, providing support that enhances their engagement and empowerment in decision-making is crucial [37].

Ensuring Regular Follow-ups

Ensuring regular follow-ups and reducing intervals between clinic visits can help maintain patient adherence and reduce the risk of relapse, as suggested by Tae et al. (2016). One study reported the knowledge of well-informed patients: 53% of the patients with ulcerative colitis and 75% of the patients with Crohn's disease were considered well informed [42].

Discussion

This integrative review aimed to explore health literacy among patients with IBD. Our results revealed low health literacy in patients with IBD, which is well known. The question is how we can increase adherence to knowledge in patients with IBD. The results also revealed that health literacy is positively correlated with patients' quality of life. Patients with limited health literacy reported worse overall health and more depressive symptoms. Within the need for information, health information-seeking behaviors among patients with IBD, including treatment-related information, mainly medication-related information, are identified as the most critical information need. Other information requirements include basic IBD-related information, daily life and self-management, sexual and reproductive health, and other needs [47]. A protocol for the implementation of an equity-promoting national health literacy program for patients living with IBD is provided, and the aim of the project is to implement the Optimizing Health Literacy and Access (Ophelia) process over three years to find ways to improve the delivery of information for patients with IBD and their caregivers collaboratively [48].

The review emphasized that healthcare professionals and patient associations are key players in patients' access to and use of health information. The importance of support systems, such as supportive healthcare professionals and interest associations, can enhance patients' knowledge and management of their condition. Our result aligns with the fact that the internet is the most frequent source of information, while face-to-face communication with healthcare professionals is preferred [47]. General information should be the focus of patient organizations and medical societies. In Western Europe, specialist nurses in IBD play a vital role in reducing the burden of patient management [47]. Types of health information-seeking behavior among patients with IBD refer especially to active searching and social information seeking, expressed as the predominant common type of health information-seeking behavior for patients with IBD [47]. This study aligns with an earlier study, which reported a greater proportion of patients (92%) who used the internet [49].

By focusing on communicative strategies, healthcare professionals can enhance patients' adherence to knowledge and improve overall health outcomes. The review supported the importance of health communication as a dimension of healthcare professional competence. There is a need to train and improve the competencies of healthcare professionals to counsel and guide patients, with a focus on health literacy and digital health literacy in healthcare to adapt services and the possible handling of patients with low health literacy. The article provides an overview of HL and eHealth literacy in healthcare, shows the opportunities to adapt services, and describes the possible handling of patients with low eHealth literacy [50]. The promotion of health literacy in patients by primary healthcare organizations and professionals has different dimensions, depending on their perspective: the (sociocultural, spiritual) preconditions, circumstances, and needs of communities are diverse, and group-oriented approaches are needed to strengthen health literacy. Additionally, an Maybe unfavourablesocial environment is associated with low levels of health literacy. Health care professionals, who are the first contacts for health problems in the community, can reach people directly in their living environment and empower them to access, understand, and apply health information. In this context, more research is needed to explore the potential of nurse-led approaches in the gastroenterological ward or primary care context. Healthcare professional strategies for clear communication were expressed in one study [51]. The "teach-back" method, which involves providing understandable and culturally appropriate instructions, is effective in reducing misunderstandings and preventing adverse outcomes for patients with IBD. This approach ensures that patients can repeat the information to healthcare professionals, confirming their understanding. It supports patient engagement and empowerment in decision-making [52]. Another study explored the personal attributes, behaviors, and skills of IBD specialists that can make a difference in patient care. The difference between desired and perceived satisfaction with and trust in the treating physician [53].

Other studies refer to the motivational interview approach. Despite being time-consuming, the motivational interview appears considerably at the first visit and in younger patients. Motivational interviewing can help healthcare professionals deal with their patients, moving from "curing" to "care" [54]. Motivational interviewing is a process that allows patients to resolve their ambivalence and move toward healthy change. Healthcare professionals create a supportive environment by using basic principles, showing empathy, and understanding the patient's point of view without judgment. This approach helps patients understand the differences between their behaviors and life goals. When patients notice these differences, they can push for their changes. This method avoids arguments. Additionally, healthcare professionals accept resistance by recognizing mixed feelings and encouraging patients to find solutions. Ultimately, they support self-efficacy, bolstering patients' belief in their ability to change [50]. Higher levels of knowledge are associated with significantly lower healthcare costs [55]. Higher levels of knowledge are associated with significantly lower healthcare costs [56,57]. There are gender differences in coping, and the impacts of economic status and emotion-focused coping vary with the activity of CD. Psychological treatment might improve satisfaction with life and quality of life in CD patients [58].

Our findings show that regular follow-up is crucial for improving health knowledge in patients with IBD. This finding is supported by other studies that emphasize the complex effects on patients' lives, which require a thorough approach to care. This aligns with the literature that highlights the multifaceted impact of IBD on patients' lives, necessitating a comprehensive approach to care. Its relapsing and remitting course significantly affect patients' quality of life. Studies have shown that patients with IBD often experience psychological distress, social isolation, and a diminished ability to engage in daily activities. Regular follow-ups help by providing ongoing support, education, and reassurance. They also improve patients' mental health and social connections [59]. Patients who understand their health better can follow treatment plans and notice early signs of problems. Follow-up appointments allow healthcare professionals to teach patients, answer their questions, and strengthen their self-care habits. This ongoing interaction helps patients understand their condition and take charge of their care [60].

Socioeconomic status is a factor affecting how well patients manage their IBD [61,62]. Patients with lower incomes often face challenges and low health literacy. Regular follow-ups can help by providing consistent care, especially for those in need. Studies explore IBD-related expenditures on insurance and household income [62]. During these visits, healthcare professionals can offer educational interventions tailored to these patients' specific needs and problems [61].

The healthcare system must adapt to the evolving needs of patients with IBD. Policies that promote regular follow-up and integrated care models can enhance patient outcomes and reduce the long-term burden of the disease. For example, multidisciplinary teams involving gastroenterologists, specialist nurses, dietitians, psychologists, and social workers can provide holistic care that addresses the medical, nutritional, psychological, and social aspects of patients with IBD. Such an approach improves health literacy and ensures comprehensive patient support throughout their disease journey. Regular follow-up is pivotal in enhancing health literacy and overall outcomes for patients with IBD. By addressing the psychosocial, educational, and socioeconomic aspects of care, healthcare professionals can improve the quality of life for these patients.

Conclusions

The review suggests that low health literacy affects the behaviors necessary for patients with IBD and the development of self-care skills. Given that self-care strategies are core components for the effective treatment of IBD, low health literacy poses a considerable health concern. When describing aspects of health literacy, a cultural perspective is needed. Specifically, there will be variation in what is pleasurable when making personal choices within a country, between different countries, and between individuals. By guiding patients, healthcare professionals can significantly enhance patients' understanding of their medications and treatment plans. Effective communication strategies and regular follow-up support patients' journey toward better health.

Clinical Implications

Future work should focus on disseminating educational content in regular care. One major challenge could be quality assurance, as anyone could publish apparent educational content without expert review. If healthcare professionals actively use these platforms in the future, a high level of quality educational material could be ensured. Potential ways to reduce retention issues include high-quality content, high levels of monitoring and interaction, or the use of Instagram ads to increase visibility. Further research is needed to understand the influence of health literacy on disease-related knowledge, self-care, and beliefs. Considering the prevalence of low health literacy among patients with IBD, healthcare professionals must adopt communication strategies that could minimize its effect on patients' health outcomes. Future research should explore innovative follow-up strategies and their impact on health literacy and disease management in diverse patient populations.

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Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author.

Declaration of Conflicting Interests

The author(s) declare that there is no conflict of interest to disclose. Both authors have approved the manuscript for submission.

Confirmation

The content of the manuscript has not been published, or submitted for publication elsewhere.

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