Health Literacy and Satisfaction with Decision-Making in Inflammatory Bowel Disease Patients

Original Article

Ghada Enani

Department Colorectal Surgery, King Abdulaziz University, Jeddah, Saudi Arabia.

ABSTRACT

Background: Health literacy (HL) is a measure of an individual's ability to understand and utilize health information and is associated with health outcomes in patients with Inflammatory Bowel Disease (IBD).

Aim: We aim to measure HL in surgical patients with IBD and investigate its correlation to satisfaction with decision-making.

Patients and Methods: In this prospective observational study, IBD patients younger than 18 years of age treated surgically in King Abdulaziz University Hospital completed a validated eHealth Literacy Scale and Satisfaction with Decision tools. HL scored as sufficient (27–40), problematic (21–26 points), or deficient (8–20 points). Univariate and multiple logistic regression were performed to examine the association between limited eHealth Literacy Scale and level of satisfaction with decision-making.

Results: A total of 44 were included (2.3% of participants have ulcerative colitis, and 97.7% have Crohn's disease). The age distribution reveals that 77.3% of participants are in the 25–54 age range. The distribution of HL scores in our cohort is categorized into inadequate (18.2%), problematic (59.1%), and sufficient (22.7%) levels. The distribution of satisfaction level of decision-making scale scores among participants were categorized as neutral (20.5%) and satisfied (79.5%). The regression coefficients reveal that the HL score has a significant positive association with decision-making satisfaction (Estimate= 0.5955, SE= 0.0535, *t*=11.131, *P*< 0.001).

Conclusion: Most of the selected patients with IBD have low and problematic HL scores. HL score is correlated with satisfaction in decision-making. Future research is needed to understand the role of HL in IBD treatment decisions.

Key Words: Health literacy, Inflammatory Bowel Disease, Satisfaction with decision-making.

INTRODUCTION

Health literacy (HL) is a critical determinant of health outcomes, particularly for patients managing chronic conditions such as Inflammatory Bowel Disease (IBD). In Saudi Arabia, where the prevalence of IBD is rising[1], understanding the HL levels among these patients is essential for improving their health management. HL encompasses the ability to access, understand, and utilize health information effectively, which is vital for self-management of chronic diseases[2]. Low health literacy has been linked to poor health outcomes, including increased disease activity, depression, and lower quality of life among IBD patients[2,3].

Research indicates that individuals with limited HL often struggle with understanding medical instructions, which can lead to non-compliance with treatment regimens and inadequate use of healthcare services[4]. This is particularly concerning in the context of IBD, where effective self-management is crucial for controlling symptoms and preventing complications. For instance, studies have shown that patients with higher HL are more likely to adhere to treatment protocols and engage in preventive health behaviors[5]. Furthermore, HL has been identified as a significant factor influencing healthcare utilization, with those possessing lower literacy levels often experiencing higher rates of hospital visits and admissions[6].

In Saudi Arabia, the cultural and educational context may further complicate HL levels among IBD patients. Factors such as socioeconomic status, education, and access to healthcare resources can significantly impact an individual's ability to comprehend and act on health information[7]. Therefore, assessing HL in this population is not necessary for tailoring educational interventions

and enhancing patient engagement and self-management strategies[3,4].

This study aims to measure HL among IBD patients in Saudi Arabia. Our secondary outcome is to investigate their correlation to satisfaction with the decision scale to assess whether a high HL score can predict behavioral intention when deciding on surgery. By identifying gaps in HL, we can develop targeted interventions that empower patients, improve their health management, and ultimately enhance their quality of life.

PATIENTS AND METHODS:

This study presents a cross-sectional analysis of patients diagnosed with IBD who underwent surgical resection as part of their treatment at King Abdulaziz University Hospital (KAUH). Approval was secured from the KAUH Institutional Review Board. Data pertaining to IBD patients registered in the KAUH database were collected for the period from January 2022 to October 2024. To minimize the potential for recall bias, only patients who had undergone surgery for IBD within the last two years were included. The database encompasses information regarding their disease progression and treatment history. Informed consent was obtained from all participants involved in this research.

The inclusion criteria specified that participants must be diagnosed with Crohn's disease, Ulcerative Colitis, or indeterminate colitis by their gastroenterology provider, and must be older than 18 years of age while receiving medical care at KAUH. Patients with significant cognitive impairments, defined as those lacking the capacity to make their own healthcare decisions, or those who regularly require interpreter services for clinical interactions, were excluded from the study.

A questionnaire containing demographic information age, race, ethnicity, educational attainment, marital status, occupation, recent employment, and availability of finances was given to patients who met the study's inclusion requirements. A validated instrument that demonstrated higher sensitivity among HL questionnaires was the Arabic version of the Health Literacy Scale (eHEALS) (Appendix 1)[8]. Respondents are asked to assess each of the eight items on the eHEALS scale using a five-point Likert scale: strongly disagree, disagree, neither agree, and strongly agree. Higher scores indicate higher self-perceived eHL. Total scores range from 8 to 40[9]. eHEALS scores were broken down into three threshold values: sufficient (27–40), problematic (21–26 points), and deficient (8–20 points)[8,9].

Satisfaction with Decision Instrument is a validated tool to measure patients' satisfaction with healthcare plan and management and predict their certainty with decision-making. It consists of six questions scored on five-point scale ranging from 1 to 5 (Appendix 2)[10].

Primary endpoint was to measure the HL score among patients with IBD who underwent surgical resection at KAUH. The secondary endpoint is to identify if there is a correlation between the level of HL and satisfaction of decision-making for patients with IBD who underwent surgical resection.

Statistical analysis

Descriptive statistics will be used to analyze demographic characteristics of the study population, and summary statistics will be calculated: number (%) for categorical variables and mean (SD) for continuous variables.

The associations between limited eHL (dependent variables) and independent variables will be evaluated by univariate and multiple logistic regression analysis. Independent variables are the parameters the patients' demographic (Appendix 3).

The results are presented as unadjusted (crude) and adjusted odds ratios with 95% confidence interval (CI).

Then univariate and multiple logistic regression will be performed to examine the association between limited eHL and level of satisfaction with decision-making.

All data will be analyzed using IBM SPSS Statistics version 27 (IBM Corp), and a two-tailed P value less than 0.05 was considered significant.

RESULTS:

Demographic

There were 44 people who took part in the study, 2.3% of participants have ulcerative colitis and 97.7% have Crohn's disease. The age distribution reveals that 77.3% of participants are in the 25–54 age range. Of the participants, 79.5% identify as Saudi, and 54.5% are male. Of the cohort, 45.5% have a graduate degree, 47.7% have a postgraduate degree, and 6.8% have only finished elementary school.

The duration of illness was an average of 9.14 years. The average number of surgeries reported by participants is 2.23 (Table 1). Physicians (93.2%), the internet (27.3%), social support groups (18.2%), family or friends (13.6%), and nurse practitioners (6.8%) are among the sources of information regarding IBD.

HL score

The distribution of HL scores in our cohort is categorized into inadequate (18.2%), problematic (59.1%), and sufficient (22.7%) levels. The source of information showed no significant difference in HL scores. Educational

attainment shows that a higher percentage of those with a graduate degree exhibit inadequate HL (62.5%) compared with those with postgraduate education (Table 2). Satisfaction with decision score.

Table 1: Demographic and clinical characteristics of study participants:

Characteristic	N(%) or Mean (SD)
Overall	44
Age (year)	
19-24	5(11.4)
25-54	34(77.3)
55-64	5(11.4)
Sex=Male (%)	24(54.5)
Ethnicity=Saudi (%)	35(79.5)
Marital status=Single (%)	23(52.3)
Educational attainment (%)	
Graduate degree	20(45.5)
Postgraduate education	21(47.7)
Primary school	3(6.8)
Recent employment=Yes (%)	15(34.1)
Duration of illness in years (mean (SD))	9.14(5.18)
Number of surgeries (mean (SD))	2.23(2.74)
Type of Inflammatory bowel disease (%)	
Crohn's disease	43(97.7)
Ulcerative colitis	1(2.3)

Table 2: Distribution of health literacy scores among demographic and clinical characteristics:

	Health literacy score				
	Inadequate, *n*(%)	Problematic, *n*(%)	Sufficient, *n*(%)	Total, *n*(%)	*P*
Total *n*(%)	8(18.2)	26(59.1)	10(22.7)	44	
Age (year)					
19-24	1(12.5)	1(3.8)	3(30.0)	5(11.4)	0.185
25-54	7(87.5)	21(80.8)	6(60.0)	34(77.3)	
55-64	0	4(15.4)	1(10.0)	5(11.4)	
Sex					
Female	3(37.5)	13(50.0)	4(40.0)	20(45.5)	0.763
Male	5(62.5)	13(50.0)	6(60.0)	24(54.5)	
Ethnicity					
Non-Saudi	3(37.5)	5(19.2)	1(10.0)	9(20.5)	0.346
Saudi	5(62.5)	21(80.8)	9(90.0)	35(79.5)	
Educational attainment					
Graduate degree	5(62.5)	10(38.5)	5(50.0)	20(45.5)	0.520
Postgraduate education	2(25.0)	15(57.7)	4(40.0)	21(47.7)	
Primary school	1(12.5)	1(3.8)	1(10.0)	3(6.8)	
Frequency of internet use					
Every or several days per week	7(87.5)	22(84.6)	8(80.0)	37(84.1)	0.905
One day per week or less	1(12.5)	4(15.4)	2(20.0)	7(15.9)	
Duration of illness					
Mean (SD)	8.4(5.7)	9.5(4.7)	8.8(6.4)	9.1(5.2)	0.845
Number of surgeries					
Mean (SD	2.1(1.6)	2.3(3.4)	2.0(0.9)	2.2(2.7)	0.940

	Health literacy score				
	Inadequate, *n*(%)	Problematic, *n*(%)	Sufficient, *n*(%)	Total, *n*(%)	*P*
Yes	5(62.5)	10(38.5)	3(30.0)	18(40.9)	
Inflammatory bowel disease					
Crohn's disease	8(100.0)	26(100.0)	9(90.0)	43(97.7)	0.176
Ulcerative colitis	0	0	1(10.0)	1(2.3)	
Source Info IBD Physician					
No	1(12.5)	1(3.8)	1(10.0)	3(6.8)	0.629
Yes	7(87.5)	25(96.2)	9(90.0)	41(93.2)	
Source Info IBD Internet					
No	5(62.5)	19(73.1)	8(80.0)	32(72.7)	0.708
Yes	3(37.5)	7(26.9)	2(20.0)	12(27.3)	
Source Info IBD Social internal support group					
No	7(87.5)	20(76.9)	9(90.0)	36(81.8)	0.594
Yes	1(12.5)	6(23.1)	1(10.0)	8(18.2)	
Source Info IBD Family/friends					
No	7(87.5)	23(88.5)	8(80.0)	38(86.4)	0.799
Yes	1(12.5)	3(11.5)	2(20.0)	6(13.6)	
Source Info IBD Nurse practitioner					
No	7(87.5)	25(96.2)	9(90.0)	41(93.2)	0.629
Yes	1(12.5)	1(3.8)	1(10.0)	3(6.8)	

The distribution of satisfaction level of decision-making scale scores among participants were categorized as neutral (20.5%) and satisfied (79.5%). Ethnic comparison reveals that a higher percentage of Saudi participants report satisfaction (82.9%) compared with non-Saudis.

Educational attainment highlights that those with a post-graduate education are more likely to be satisfied (54.3%) than those with a graduate degree.

The analysis results indicated no significant associations between demographic or clinical characteristics and medical decision-making satisfaction, as reflected by the *P* values in the table.

Relationship between HL and satisfaction with decision-making

The linear regression model demonstrates a strong fit, with an R^2 of 0.824, indicating that 82.4% of the variance in decision-making satisfaction is explained by the model. The overall model is statistically significant [$F_{(8, 34)}$= 19.8, $P< 0.001$].

The regression coefficients reveal that the HL score has a significant positive association with decision-making satisfaction (Estimate= 0.5955, SE= 0.0535, *t*= 11.131, $P< 0.001$). Age group comparisons indicate that participants aged 25–54 show significantly higher satisfaction compared with those aged 19–24 (Estimate= 2.5416, SE= 0.9773, *t*= 2.601, *P*= 0.014), and those aged 55–64 exhibit even greater satisfaction (Estimate= 4.1915, SE= 1.3157, *t*= 3.186, *P*= 0.003). The analysis results showed no significant differences in decision-making satisfaction based on gender (Estimate= 0.0688, SE= 0.6271, *P*= 0.913), duration of illness (Estimate= 0.0734, SE=0.0610, *P*= 0.237), number of surgeries (Estimate= 0.0263, SE=0.1109, *P*= 0.814), or ethnicity (Estimate= 1.0863, SE= 0.8627, *P*= 0.217). Marital status approached significance, with married participants showing a trend towards lower satisfaction compared with single participants (Estimate= 1.1185, SE= 0.6411, *P*= 0.090) (Table 3).

Table 3: Linear regression analysis of factors associated with satisfaction in decision-making:

			95% confidence interval			
Predictor	Estimate	SE	Lower	Upper	*t*	*P*
Intercept '	5.2326	1.7739	1.6275	8.838	2.950	0.006
HL score	0.5955	0.0535	0.4868	0.704	11.131	<0.001
Age:						

Predictor	Estimate	SE	95% confidence interval		t	P
			Lower	Upper		
24-19-54-25	2.5416	0.9773	0.5554	4.528	2.601	0.014
24-19-64-55	4.1915	1.3157	1.5176	6.865	3.186	0.003
Sex						
Male – Female	−0.0688	0.6271	−1.3432	1.206	−0.110	0.913
Duration of illness	0.0734	0.0610	−0.0506	0.197	1.203	0.237
Number of surgeries	−0.0263	0.1109	−0.2517	0.199	−0.237	0.814
Ethnicity						
Saudi – Non-Saudi	1.0863	0.8627	−0.6668	2.839	1.259	0.217
Marital status:						
Married – Single	−1.1185	0.6411	−2.4214	0.184	−1.745	0.090

[a]: Represents reference level; R^2= 82.4%, [$F_{(8, 34)}$= 19.8, P< 0.001].

DISCUSSION

This study represents the inaugural investigation into the correlation between HL and satisfaction with decision-making among patients diagnosed with IBD. The findings indicate a positive relationship between HL and satisfaction in decision-making processes. Notably, demographic and clinical factors associated with IBD did not appear to affect decision-making satisfaction; rather, it was significantly related to the HL score. Despite the overall high educational attainment within this cohort, a majority exhibited problematic or insufficient HL scores. Those holding postgraduate degrees tended to achieve higher HL scores compared with their graduate counterparts. It is noteworthy that variables such as the number of surgical procedures, the duration of the illness, and the source of information regarding IBD from healthcare providers did not significantly influence HL scores. This underscores the importance of addressing patients' HL in the management of IBD.

Patients diagnosed with IBD frequently experience symptoms and complications that render them to undergo high-risk surgical procedures during their illness[11]. There is a significant gap in understanding the surgical experience of patients with IBD. A study shows that IBD patients who underwent stoma creation often experienced an improved quality of life postsurgery, surpassing their expectations. Their decision-making was heavily influenced by perioperative support and their social networks[12]. Regarding the type of information required, patients with IBD generally have high expectations for the clinical information provided by their healthcare professionals[13]. Another study on the experiences of black and white patients with IBD revealed significant differences in surgical experiences, primarily due to the quality of information received. Negative outcomes were linked to a lack of knowledge about IBD and poor surgeon understanding[14,15]. Thus, it is essential to emphasize the importance of patient education and the effective delivery of information to individuals with IBD when making management decisions.

Patients diagnosed with IBD often access a variety of information regarding their condition from multiple sources, including healthcare providers, support groups, YouTube, and social media platforms. They do not solely depend on their healthcare providers for information, given the wide range of available resources[16]. However, despite this diversity, the quality of the information obtained is inconsistent, which frequently leaves IBD patients feeling dissatisfied with the guidance they receive from both their providers and online sources[17]. A study found that even with access to various information channels, IBD patients often perceive a lack of adequate information about their condition[18]. This study results show no significant correlation between decision-making satisfaction and the sources of information used by patients. Thus, prioritizing high-quality information is more beneficial than merely increasing the number of sources. This highlights the critical need to enhance the communication of clinical information and to provide education to patients, particularly those preparing for surgical interventions.

Individuals with IBD often have limited HL, which is associated with poorer patient-reported outcomes. Those with active disease, recent hospitalizations or surgeries show lower HL and quality of life compared with others[14,19]. This may explain the low HL score in this cohort, where all the participants had surgeries in the past two years. Limited HL is commonly seen in racial and ethnic minorities[14,20,21]. This research found no significant difference in HL scores between Saudi and non-Saudi individuals, though Saudi patients reported greater satisfaction with their decision-making. This may be due to limited medication and

insurance access for non-Saudis. The available data, though limited, indicates that the application of specific decision support tools among populations with low literacy can enhance knowledge[22], increase the ability to indicate a test preference and reduce decisional conflict[23].

This study encountered several limitations. The participant pool was restricted due to the specific inclusion criteria established for the study. Efforts were made to reduce recall bias by selecting patients who underwent surgery within the last two years. Additionally, a significant portion of patients treated at KAUH do not speak Arabic, which constrained the ethnic diversity within this cohort. A comparison among various ethnic groups could enhance our understanding of how to effectively communicate health information to patients. This factor also contributed to the limited number of participants in the study. Future research is essential to investigate HL levels within the Saudi population on a broader scale.

This study is the first to investigate satisfaction levels in decision-making among patients with IBD and their HL. The findings are vital for physicians managing IBD, as understanding HL's impact on surgical experiences may improve their outcomes. Patient satisfaction with medical decisions enhances the overall clinical experience, making it essential to provide clear, tailored information that matches patients' knowledge and HL levels, especially in populations with limited understanding. This approach could lead to new management strategies for IBD patients preparing for surgery.

CONCLUSION

This study found that HL score is correlated to satisfaction with decision-making. It also point the need for further investigation into the link between HL and treatment choices for IBD and the creation of effective decision aids for those with limited HL. These efforts could improve patient outcomes and ensure everyone has the resources to make informed healthcare decisions.

CONFLICT OF INTEREST

There are no conflicts of interest.

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Appendix 1: Arabic Translation of the eHealth Literacy Scale (eHEALS):

أسئلة حول المعلومات الصحية على شبكة الإنترنت

أوافق تماماً	أوافق	لست متأكد	لا أوافق	لا أوافق أبداً	
					لكل عبارة أدناه، أي أجابة تتوافق أحسن مع رأيك أو تجربتك في الوقت الحاضر أشر على الخيار الذي يطابق إجابتك الأحسن في كل سطر.

1. أنا اعرف أي من المعلومات الصحية متواجدة على الإنترنت

2. أنا أعرف أين أجد المعلومات الصحية المفيدة على الإنترنت

3. أنا أعرف كيفية العثور (الوصول) على المعلومات الصحية المفيدة على الانترنت

4. أنا أعرف كيف أستخدم الإنترنت للإجابة على أسئلتي التي تتعلق بالصحة

5. أنا أعرف كيف أستخدم المعلومات الصحية التي اجدها على الإنترنت لمساعدتي

6. لدي المهارات اللازمة لتقييم ما إذا كانت المعلومات الصحية التي أجدها على الإنترنت يمكن الوثوق بها

7. أنا أستطيع التمييز بين المعلومات الصحية ذات الجودة العالية وبين المعلومات الصحية ذات الجودة المنخفضة التي أجدها على الإنترنت

8. أنا اثق بقدرتي في إستخدام المعلومات التي أجدها على الإنترنت لإتخاذ قرارات حول الصحة

Appendix 2: Satisfaction with Clinical Decision Instruments.

You have been considering whether to consult your health care provider about hormone-replacement therapy. Answer the following questions about your decision. Please indicate to what extent each statement is true for you AT THIS TIME.

Use the following scale to answer the questions.

1 = strongly disagree

2 = disagree

3 = neither agree nor disagree

4 = agree

5 = strongly agree

1. I am satisfied that I am adequately informed about the issues important to my decision.

2. The decision I made was the best decision possible for me personally.

3. I am satisfied that my decision was consistent with my personal values.

4. I expect to successfully carry out (or continue to carry out) the decision I made.

5. I am satisfied that this was my decision to make.

6. I am satisfied with my decision.

Appendix 3: Demographic information:

Inflammatory Bowel Disease Type	Crohn's Disease Ulcerative Colitis
Duration of illness	
Type of Surgery	Ileocolic resection Subtotal colectomy Right hemicolectomy Sigmoid resection Proectectomy / APR Small bowel resection Loop ilesotomy Closure of ileostomy Lysis of adhesion Examination under anesthesia Seton placement LIFT / advancement flap
Number of Surgeries performed	
History of Stoma creation	
Age	19-24 25-54 55-64 65+
Gender	
Frequency of internet use	Every or several days per week One day per week or less
Usability of the interent	Useful Unsure Not very useful or not useful at all

Source on information on IBD	Health care: Physician, nurse practioner, stoma nurse Family/friends Social internal support group Internet.
Ethnicity	
Educational attainment	Primary school Secondary school Graduate degree Post graduate education
Marital status	
Occupation	
Recent employment	
Adequacy of finances	