

Factors Influencing Decision-Making Preferences Among Patients with Inflammatory Bowel Disease: A Cross-Sectional Study in China

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Purpose: This study aimed to evaluate the current status and the discrepancies between anticipated and actual involvement in decision-making roles among patients with inflammatory bowel disease, as well as to explore the factors that influenced actual decision-making participation.

Patients and Methods: From December 2023 to June 2024, a convenience sampling method was employed to recruit patients with inflammatory bowel disease from the Department of Gastroenterology at a tertiary hospital in Anhui, China. A general information questionnaire, the Control Preference Scale, the All Aspects of Health Literacy Scale, and the Decision Dilemma Scale were utilized for investigation and analysis.

Results: A total of 274 patients with inflammatory bowel disease were recruited. The distribution of patients' expected participation in decision-making preferences was as follows: 68 cases (24.82%) actively, 143 cases (52.19%) shared, and 63 cases (22.99%) passively. Actual participation in decision-making roles was as follows: 39 cases (14.23%) actively, 147 cases (53.65%) shared, and 88 cases (32.12%) passively. Expected participation in decision-making preferences and actual participation in decision-making roles were moderately consistent, with a compliance rate of 69.34% and a kappa value of 0.498 ($p < 0.001$). The overall health literacy score was (24.34 ± 5.47), and the decision-making dilemma score was (25.22 ± 15.20). Factors affecting actual participation in decision-making roles included marital status, education level, Average monthly household income, current work status, type of disease diagnosis, current treatment modalities, and health literacy.

Conclusion: Patients with inflammatory bowel disease have high expectations and a genuine willingness to participate in decision-making, along with overall health literacy. However, decision-making dilemmas persist, and a discrepancy exists between expectations and actual decision-making roles. Healthcare professionals should prioritize assessing patients' individual circumstances and decision-making needs while actively engaging them in the decision-making process. Patient engagement and satisfaction can be enhanced by providing targeted and personalized strategies.

Keywords: decision-making preferences, inflammatory bowel disease, health literacy, decision-making dilemmas, shared decision-making

Introduction

Inflammatory bowel disease (IBD) is a group of chronic, immune-mediated intestinal disorders of unknown etiology, characterized by nonspecific inflammation. The extensive and heterogeneous nature of intestinal lesions often complicates diagnosis. IBD primarily affects individuals aged 18–49 years,¹ with Ulcerative Colitis (UC) and Crohn's Disease (CD) representing its two main subtypes.² Disease heterogeneity and risk-benefit-balanced therapeutic options enhance the potential for personalized IBD management. The selection of the “optimal” treatment is increasingly influenced by patient preference, with distinct decision-making needs emerging across disease stages and individual clinical profiles. Improper decision-making can lead to progressive and cumulative systemic inflammation, which may adversely affect

intestinal function and result in irreversible intestinal damage and an increased risk of multiple complications.³ Therefore, it is crucial to consider the decision-making preferences of patients with IBD in the complex process of therapeutic care.⁴ Decision-Making Preferences refer to the belief that in the absence of an ideal solution for a disease, patients' sensitivity to preferences and uncertainty equip them to be the best evaluators of alternative treatments, to weigh the pros and cons, and to assert their right to participate in decision-making to achieve a desired outcome.⁵

Song et al demonstrated that patients with IBD actively seek health information from multiple sources during therapeutic interventions. This extensive information-seeking behavior leads to diverse decision-making needs related to the selection of biologic agents, surgical options, and corticosteroid use.⁶ Given the inherently preference-sensitive nature of IBD management, neglecting patient values and preferences can result in dissatisfaction, poor treatment adherence, and ultimately compromised clinical outcomes. This challenge is particularly pronounced in China, where reserved cultural expressions and a traditional "paternalistic" approach often inhibit patients from voicing their decision-making needs. Shared decision-making (SDM) can address these needs by actively involving patients in their diagnosis and treatment, while healthcare professionals can engage in SDM to better understand patients' values and treatment preferences. Therefore, incorporating patients into the decision-making process and discussing their preferences after thoroughly exploring treatment options can mitigate decision-making risks and enhance patient compliance. However, Numerous factors influence the preferences of patients with IBD regarding their participation in decision-making.⁷ The Ottawa Decision Support Framework (ODSF), a tool designed to assist decision-makers in making the right choices in the face of challenging healthcare decisions by incorporating their values, can be utilized to guide researchers in assessing patients' decision-making needs.⁸ Specifically, it comprises three components: decision needs, decision support, and decision outcomes. Decision needs can be categorized into decision uncertainty (presence of decision dilemmas) and insufficient knowledge related to decision-making (health literacy), among others. Decision support includes tailored solutions to address decision needs (exploring decision roles), which can enhance decision-making outcomes by providing appropriate decision support tools/methods tailored to the needs.⁹ Therefore, based on the decision needs and decision support aspects of the ODSF theoretical framework, this study investigates the current status of IBD patients' expected participation in decision-making preferences and their actual participation in decision-making roles. It analyzes the influencing factors to identify patients' preferences and actual level of participation in medical decision-making at various stages of the medical decision-making process. The aim was to match targeted and personalized decision-making solutions with their preferences, reducing decision-making conflicts and enhancing the quality of medical decision-making to improve patients' health outcomes.

Materials and Methods

Survey Subjects

From December 2023 to June 2024, a convenience sampling method was employed to recruit patients with IBD from the Department of Gastroenterology at a tertiary hospital in Anhui, China. Inclusion criteria: ① Meeting the diagnostic criteria for IBD set by the Inflammatory Bowel Disease Collaborative Group of the Chinese Medical Association Gastroenterology Branch; ② Age ≥ 18 years; ③ Normal communication and comprehension abilities, able to complete the questionnaire independently or with assistance; ④ Agreeing to participate in the study and willing to sign an informed consent form. Exclusion criteria: ① Presence of psychiatric diseases or disorders of consciousness; ② Other serious, life-threatening diseases or complications. This was a cross-sectional survey study, and the sample size was calculated using the formula $n = \mu^2 \alpha / 2\sigma^2 / \delta^2$.¹⁰ With α set at 0.05, $\mu/\sigma = 1.96$. The pre-survey measured the consistency between the anticipated and actual decision-making role preferences of patients with IBD at 42% and set the permissible error at 0.5., $\delta = 0.5$. Considering a 20% inefficiency rate, the estimated minimum sample size was 197.

Questionnaire

General Information questionnaire

The Patient General Information Questionnaire was developed jointly by the research team following a literature review and in-depth discussions. The questionnaire encompassed demographic and disease-related data pertaining to the patients. The primary elements comprised gender, age, education level, per capita monthly household income, type of

health insurance, place of residence, type of residence, disease diagnosis, duration of illness, current treatment, and disease activity.

Control Preference Scale (CPS)

The scale was originally developed by American scholars Degner et al in 1997 to assess patients' preferred decision-making roles in healthcare decision-making expectations,¹¹ and was later modified by Nolan et al to measure patients' attitudes toward decision-making and actual participation.¹² The scale comprises five entries and three decision-making roles (active, shared, and passive) and is widely used to accurately evaluate patients' expected participation in decision-making preferences and actual involvement in decision-making roles. Scholar Xu adapted it to Chinese in 2010,¹³ achieving a retest reliability of 0.82–0.87.

All Aspects of Health Literacy Scale (AAHLS)

The scale was compiled by British scholars Chinn et al.¹⁴ Wu et al adapted it to the Chinese version,¹⁵ with 11 items and 3 dimensions (ability to use written health information, ability to communicate with health care providers, and ability to evaluate and apply health information), which is scored on a 3-level Likert scale, with a score of 1 (seldom) to 3 (often), and the higher the score, the higher the level of health literacy for the individual. A score ranging from 11 to 22 is classified as low health literacy, whereas a score greater than 22 is considered high health literacy.¹⁶ Cronbach's α coefficient of the scale in this study was 0.875.

Decision Dilemma Scale

The scale was compiled by O'Connor scholars;¹⁷ Li adapted it to the Chinese version,¹⁸ with 16 items and 3 dimensions (information and values, decision support, decision effectiveness, and decision uncertainty). This is scored on a 5-level Likert scale, ranging from 0 (yes) to 4 (no). The final scores were converted to a percentage scale, where 25/16 yielded a mandatory (converted) score from 0 to 100. Scores exceeding 25 indicated a decision dilemma, while those above 37.5 suggested a delayed decision-making situation. The Cronbach's α coefficient for this study was 0.898.

Data Collection and Quality Control Methods

The data collection period was set at one day before the patients' discharge or on the day of discharge itself. The research nurse introduced the purpose of the survey, the importance of the questionnaire, and the filling instructions to eligible patients using a standardized guide to obtain informed consent. Questionnaires were distributed on-site in an anonymous format, with a suggested completion time of 15 minutes to ensure the validity of the responses. All questionnaires were collected and checked on-site, with any deficiencies promptly addressed through questioning and supplementation of the patient.

Ethical Considerations

This study adhered to the Declaration of Helsinki and was approved by the Ethics Committee of the First Affiliated Hospital of Anhui Medical University (PJ2024-02-27). All participants provided informed consent.

Statistical Methods

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) for Windows, version 24.0 (IBM Corporation, Armonk, New York, United States) software. Count data were presented as frequency counts and constituent ratios, while measurement data were expressed as mean \pm standard deviation ($\bar{x} \pm s$). The McNemar-Bowker test and Cohen's kappa statistic were employed to assess the differences and consistency between patients' expected participation in decision-making preferences and their actual participation in decision-making roles. The χ^2 test was conducted for univariate analysis. Variables that exhibited statistically significant differences in the analysis were selected as independent variables, with actual participation in decision-making roles serving as the dependent variable in an unordered multivariate logistic regression analysis. A difference was deemed statistically significant when $P < 0.05$.

Results

Current Status of Decision-Making Preferences in Patients with IBD

In this study, a total of 280 questionnaires were distributed, and 274 valid questionnaires were retrieved, yielding a valid recovery rate of 97.86%. The patients' expected participation in decision-making preferences was active decision-making in 68 cases (24.82%), shared decision-making in 143 cases (52.19%), and passive decision-making in 63 cases (22.99%). However, in actual participation in decision-making roles, 39 cases (14.23%) were active decision-making, 147 (53.65%) were shared decision-making, and 88 (32.12%) were passive decision-making. The detailed information is shown in Table 1. The McNemar-Bowker test was used to assess the difference between the desired and actual participation in decision-making preferences of IBD patients. The difference between the two groups was statistically significant ($\chi^2=25.241$, $p<0.001$), and then Cohen's kappa statistics were used to analyze the consistency between the two groups. Expected participation in decision-making preference was moderately consistent with actual participation in decision-making roles, with 69.34% compliance and a kappa value of 0.498 ($p < 0.001$).

Univariate Analysis of Actual Participation in Decision-Making Roles Among Patients with IBD

The overall health literacy score of 274 patients with IBD was (24.34 ± 5.47), and the decision dilemma score was (25.22 ± 15.20). The actual participation in decision-making role type of patients with IBD was statistically significant in different genders, ages, marital status, education level, average monthly household income, Current address, type of residence, current work status, health insurance payment method, type of disease, current treatment, health literacy, and decision-making dilemmas ($p < 0.05$). Differences were not statistically significant ($P > 0.05$) in duration of illness and disease activity; see Tables 2 and 3.

Logistic Regression Analysis of Actual Participation in Decision-Making Roles Among Patients with IBD

The actual participation in decision-making roles of patients with IBD is treated as the dependent variable and the statistically significant single-factor factors of gender, age, literacy, health literacy, and decision-making dilemma as the independent variables, a multivariate logistic regression analysis was carried out, and the assigned values of the independent variables are shown in Table 4. The results showed that marital status, education level, Average monthly household income, current work, Type of disease, current treatment, and health literacy were the factors influencing the patients' actual participation in decision-making roles. Compared with passive decision-making roles, the higher the

Table 1 Current Status of Expected Participation in Decision-Making Preferences and Actual Participation in Decision-Making Roles Among Patients with IBD

	Actual PARTICIPATION in Decision-Making Roles (N%)			Total
	Active Decision-Making Roles	Shared Decision-Making Roles	Passive Decision-Making Roles	
Expectation of participation in decision-making preferences				
Active decision-making roles	27/9.9	29/10.6	12/4.4	68/24.8
Shared decision-making roles	8/2.9	111/40.51	24/8.76	143/52.2
Passive decision-making roles	4/1.5	7/2.6	52/19.0	63/23.0
Total	39/14.2	147/53.7	88/32.1	274/100.0
McNemar-Bowker	$\chi^2=25.241$	$p<0.001$		
Cohen's kappa	0.498	$p<0.001$		

Notes: Statistical significance was indicated by $p < 0.01$.

Table 2 Univariate Analysis of Actual Participation in Decision-Making Roles by Patients with IBD (Demographic Data)

	Category	Total	Actual Participation in Decision-Making Roles (N%)			χ^2	P
			Active Decision -making roles	Shared Decision -Making Roles	Passive Decision -Making Roles		
Gender	Male	202	29 (14.4)	11 (58.9)	54 (26.7)	10.913	0.004*
	Female	72	10 (13.9)	28 (38.9)	34 (47.2)		
Age (years)	18–30	95	13 (13.7)	69 (72.6)	13 (13.7)	31.278	<0.001*
	31–50	117	20 (17.1)	55 (47.0)	42 (35.9)		
	>50	62	6 (9.7)	23 (37.1)	33 (53.2)		
Marital status	Unmarried	95	15 (15.8)	62 (65.3)	18 (18.9)	14.014	0.007*
	Married	177	24 (13.6)	83 (46.9)	70 (39.5)		
	Divorced or widowed	2	0 (0.0)	2 (100)	0 (0.0)		
Current address	City	155	26 (16.8)	94 (60.6)	35 (22.6)	14.979	0.001*
	Countryside	119	13 (10.9)	53 (44.5)	53 (44.5)		
Type of residence	Living with family	229	37 (16.2)	111 (48.5)	81 (35.4)	15.395	0.004*
	Living alone	45	2 (4.4)	36 (80.0)	7 (15.6)		
Education Level	Primary and below	33	1 (3.0)	7 (21.2)	25 (75.8)	54.986	<0.001*
	Junior high school	61	9 (14.8)	22 (36.1)	30 (49.2)		
	High school or junior college	41	7 (17.1)	24 (58.5)	10 (24.4)		
	College and above	139	22 (15.8)	94 (67.6)	23 (16.5)		
Average monthly household income (CNY) ^a	<3000	70	10 (14.3)	20 (28.6)	40 (57.1)	38.911	<0.001*
	3000–4999	115	17 (14.8)	66 (57.4)	32 (27.8)		
	5000–7999	65	7 (10.8)	50 (76.9)	8 (12.3)		
	≥8000	24	5 (20.8)	11 (45.8)	8 (33.3)		
Current work	Student	29	5 (17.2)	21 (72.4)	3 (10.3)	2.901	0.004*
	Employees	107	19 (17.8)	66 (61.7)	22 (20.6)		
	Other	81	5 (6.2)	39 (48.1)	37 (45.7)		
	Retired	57	10 (17.5)	21 (36.8)	26 (45.6)		
Medical insurance	New type of rural cooperative medical care	92	11 (12.0)	38 (41.3)	43 (46.7)	24.727	<0.001*
	Employee medical insurance	119	17 (14.3)	81 (68.1)	21 (17.6)		
	Urban Residents' Medical Insurance	63	11 (17.5)	28 (44.4)	24 (38.1)		

Notes: ^aA currency exchange rate of CNY 1=us\$0.14 is applicable; *Represents the statistically significant values.

Table 3 Univariate Analysis of Actual Participation in Decision-Making Roles by Patients with IBD (Disease Related Data and Others)

	Category	Total	Actual Participation in Decision-Making Roles (N%)			χ^2	P
			Active Decision -Making Roles	Shared Decision -Making Roles	Passive Decision -Making Roles		
Type of disease	CD	220	27 (12.3)	126 (57.3)	67 (30.5)	6.707	0.035*
	UC	54	12 (22.2)	21 (38.9)	21 (38.9)		
Time of illness	Initial diagnosis	37	3 (8.1)	21 (56.8)	13 (35.1)	1.815	0.936
	Within 1 month-1 year of diagnosis	66	10 (15.2)	37 (56.1)	19 (28.8)		
	Within 1–3 years of diagnosis	88	14 (15.9)	46 (52.3)	28 (31.8)		
	Diagnosed ≥ 3 years	83	12 (14.5)	43 (51.8)	28 (33.7)		

(Continued)

Table 3 (Continued).

	Category	Total	Actual Participation in Decision-Making Roles (N%)			χ^2	P
			Active Decision-Making Roles	Shared Decision-Making Roles	Passive Decision-Making Roles		
Disease Activity	Remission period	94	15 (16.0)	53 (56.4)	26 (27.7)	9.558	0.145
	Mild activity period	98	10 (10.2)	60 (61.2)	28 (28.6)		
	Moderate activity period	56	8 (14.3)	24 (42.9)	24 (42.9)		
	Heavy activity period	26	6 (23.1)	10 (38.5)	10 (38.5)		
Current treatment	Biological agents	173	24 (13.9)	101 (58.4)	48 (27.7)	15.782	0.003*
	Expectant treatment	57	3 (5.3)	27 (47.4)	27 (47.4)		
	Biological agents and Expectant treatment	44	12 (27.3)	19 (43.2)	13 (29.5)		
Health literacy	Low health literacy	86	8 (9.3)	24 (27.9%)	54 (62.8)	54.343	<0.001*
	High health literacy	188	31 (16.5)	123 (65.4%)	34 (18.1)		
Decision-making dilemma	No decision-making dilemma	151	24 (15.9)	93 (61.6)	34 (22.5)	16.247	0.003*
	There are decision-making dilemmas	74	7 (9.5)	36 (48.6)	31 (41.9)		
	Delay in decision-making	49	8 (16.3)	18 (36.7)	23 (46.9)		

Notes: *Represents the statistically significant values.

Abbreviation: CD, Crohn's Disease; UC, Ulcerative Colitis.

Table 4 Assignment of Independent Variables in Logistic Regression for Factors Influencing Decision-Making Role Preferences Among Patients with IBD

Category	Assign Values to Independent Variables
Gender	1=Female, 2=Male
Age(years)	1=18-30, 2=31-50, 3≤50
Marital status	1=Married, 2=Unmarried, 3=Divorced or widowed
Current address	1=City, 2=Countryside
Type of residence	1=Living with family, 2=Living alone
Education level	1=Primary and below, 2=Junior high school, 3=High school or junior college, 4=College and above
Average monthly household income	1= <3000, 2= 3000–4999, 3= 5000–7999, 4= ≥8000
Current work	1=Student, 2=Employee (institutions and self-employed), 3=Other (self-employed, farmers), 4=Retired (unemployed, suspended, retired)
Medical Insurance	1=New type of rural cooperative medical insurance, 2=Employee medical insurance, 3=Urban Residents' Medical Insurance
Type of disease	1 = CD, 2 = UC
Current treatment	1=biological agents, 2=Expectant treatment, 3=biological agents + Expectant treatment
Health literacy	1 = low literacy (11–22 points), 2 = high literacy (23–33 points)
Decision-making dilemma	1 = no decision dilemma (≤25), 2 = decision dilemma (≤37.5), 3 = decision delay (>37.5)
Types of practical participation in decision-making	1 = active decision-making role, 2 = shared decision-making role, 3 = passive decision-making role

Abbreviation: CD, Crohn's Disease; UC, Ulcerative Colitis.

education level, the more active decision-making roles, the higher the household income, the higher the health literacy, and the more shared decision-making roles, and the results are shown in Table 5. Compared with shared decision-making roles, married patients were more likely to be in active decision-making roles than unmarried patients, and the more complex the occupation (self-employed, farmer), the type of disease (Crohn's disease), and the more complex the treatment modality, the more shared decision-making roles were preferred, The results are shown in Table 6.

Table 5 Multiple Logistic Regression Analysis of Factors Influencing the Actual Participation in Decision Making Roles of Patients with IBD (n=274)

Actual Participation in Decision-making Roles	Category	Regression Coefficient	Standard Error	Wald χ^2 value	P	OR Value	95% CI	
							Lower Limit	Limit
Active Decision-making roles	Education level (primary and below)	-3.640	1.566	5.404	0.020	0.026	0.001	0.565
	Disease diagnosis (CD)	-2.428	0.730	11.069	0.001	0.088	0.021	0.369
	Current treatment (biological agents)	-1.396	0.679	4.226	0.040	0.247	0.065	0.937
Shared Decision-making roles	Current treatment (Expectant treatment)	-2.899	1.057	7.515	0.006	0.055	0.007	0.438
	Education level (primary and below)	-1.844	0.824	5.011	0.025	0.158	0.031	0.795
	Average monthly household income (5000–7999)	1.982	0.740	7.175	0.007	7.258	1.702	30.952
	Health literacy (low literacy)	-1.410	0.447	9.954	0.002	0.244	0.102	0.586

Notes: The reference category is: passive decision-making roles; bold fonts represents statistically significant values.

Abbreviation: CD, Crohn's Disease; OR, Odd Ratio.

Table 6 Multiple Logistic Regression Analysis of Factors Influencing the Actual Participation in Decision Making Roles of Patients with IBD (n=274)

Actual participation in decision-making roles	Category	Regression coefficient	Standard error	Wald χ^2 value	P	OR value	95% CI	
							Lower Limit	Limit
Active Decision-making roles	Marital status (married)	17.357	0.866	401.564	0.020	0.000	34,517,708.087	6,320,734.841
	Current work (individual, farmer)	-1.635	0.813	4.046	0.044	0.195	0.040	0.959
	Disease diagnosis (CD)	-1.603	0.647	6.140	0.013	0.201	0.057	0.715
	Current treatment (biological agents)	-1.142	0.544	4.408	0.036	0.319	0.110	0.927
	Current treatment (Expectant treatment)	-2.674	0.980	7.444	0.006	0.069	0.010	0.471

Notes: The reference category is: Shared decision-making roles; bold fonts represents statistically significant values.

Abbreviation: CD, Crohn's Disease; OR, Odd Ratio.

Discussion

Most Patients with IBD Expect to Be Involved in Healthcare Decision-Making and Put It Into Practice

Shared decision-making (SDM) is a collaborative approach where clinicians and patients share the best available evidence when facing a decision. Patients are expected to fully express their preferences and values, and both parties should ultimately make a decision that is in the patient's best interest.¹⁹ The results of this study indicated that 211 patients (77.01%) desired to actively participate in medical decision-making or share the entire decision-making process with healthcare workers. Furthermore, 186 patients (67.88%) were able to maintain consistency with their expected roles in actual decision-making. This is in line with the fact that most individuals in the IBD group are young to middle-aged, adept at gathering information widely through the Internet or other means, and willing to learn about SDM-related knowledge.⁷ This knowledge enhances communication convenience with healthcare workers during decision-making and encourages patients to consider their wishes and choices more thoroughly. Meanwhile, the percentage of patients with IBD choosing shared decision-making roles during participation in decision-making (53.65%) was higher than that of adolescent cancer patients with concurrent systemic complex symptoms (34%),²⁰ schizophrenic patients (35%),²¹ and elderly patients with chronic kidney disease (43%).²² This may be due to the fact that patients with IBD have

opportunities to make decisions regarding multiple treatment options and medication use, which leads to improved communication with healthcare providers and decision-making abilities. Therefore, in future clinical practice, healthcare professionals should enhance their assessment of patient's values and preferences within the shared decision-making model.

Medium Level of Consistency in the Type of Participatory Decision-Making Roles Expected and Actualized by Patients with IBD

The results of this study indicated that the actual participation of a segment of patients with IBD falls short of their anticipated involvement, and the overall congruence between their preferences and actual decision-making roles is moderate. This aligns with previous research,²³ which attributes this to the unequal power dynamics between healthcare providers and patients during the decision-making process. Healthcare providers often reinforce the perception of patients' vulnerability and incapacity in their illness, disregarding their seemingly unreasonable demands, which leads to unmet decision-making needs for patients. This level of congruence is lower than the 70% concordance found in a systematic review of expectancy preferences and perceived involvement in cancer treatment decision-making.²⁴ This implies that despite the continuous emergence of new IBD therapies, there is a deficiency in personalized risk prediction for patients by gastroenterologists. Additionally, there is a lack of educational strategies that guide patients' decision-making with easily understood, evidence-based data.²⁵ Therefore, future research should focus on exploring culturally adaptive SDM strategies and designing decision support tools that align with the expectations and communication habits of Chinese patients with IBD. It is essential to assess the extent to which patients accept the power imbalance in the doctor-patient relationship, establish formal and effective communication feedback platforms and mechanisms, clarify the roles and responsibilities of both doctors and patients, enhance patients' sense of personal control and confidence, strengthen trust between doctors and patients, and reduce the distance between them.

Actual Decision-Making Role Preferences of Patients with IBD are Influenced by Many Factors

Several studies have shown that The higher the cultural level of patients with IBD, the greater their acceptance and awareness of the disease.^{26,27} The results of this study indicated that patients with IBD who have higher education levels are more inclined to take on active roles in decision-making, and this group of people was able to obtain disease information through a wide range of channels, and their higher self-management ability prompted them to deal with decision-making in a better way, and they were able to identify their own decision-making needs; married patients were more inclined to active decision-making roles in agreement with the study of Hu et al and married patients had more experience of dealing with emergencies and are more willing to take decision-making control into their own hands compared to unmarried patients,²⁸ while couple support can enhance patients' sense of control and confidence in their disease, which to a certain extent can improve their initiative to participate in medical decision-making. Therefore, in the future, medical professionals should concentrate on refining the communication channels between healthcare providers and patients, ensuring that decision-making information is both comprehensive and relevant. In particular, for those with low-literacy, the provision of easily understandable educational materials and personalized consulting services can assist them in better comprehending their health conditions and treatment plans. They should facilitate shared decision-making for patients and their partners, create decision-making support tools designed for joint use by couples, evaluate the pros and cons of various treatment options, and encourage mutual participation in medical decision-making by both parties.

The results of this study show that patients with an average monthly household income at the middle and high-income levels are more inclined to share decision-making roles, and patients at the low-income level are inclined to passive decision-making roles. A web-based survey on the financial burden of a large sample of patients with from China showed that 98% of the patients were worried about their income, and that low-income patients would have fewer visits to the clinic or follow up visits,²⁹ which means that they have fewer opportunities to participate in the decision-making process, and also worry that Active participation in decision-making or sharing decision-making with health care will cost extra money, not as passive acceptance of decision-making is more economical and convenient; the results of this study also

showed that other occupations (individuals, farmers), disease type (CD), and treatment modality were more complex and tended to share decision-making roles, which is consistent with previous studies.^{24,30} These may be related to the free and flexible working properties; CD has more options for treatment modalities, medication types, dietary management, etc. than UC, which requires more patient participation in the decision-making process; and with increasing disease duration, experience, patient knowledge, self-management skills, and comfort, shared decision-making can help patients to choose the most appropriate decision-making option for themselves in a complex treatment modality. This also suggests that in subsequent clinical practice, low-income patients should have access to economically viable decision support programs. Additionally, special financial assistance programs could be considered to alleviate their financial burdens and ensure that every patient receives adequate treatment information and personalized medical decision support that caters to their unique circumstances. Furthermore, targeted health education materials should be tailored for patients from diverse occupational backgrounds, ensuring that the delivery of information aligns with their specific occupational characteristics and preferred methods of information acquisition.

Health literacy refers to the competencies and skills necessary for patients to participate in the process of diagnosis and treatment of their illnesses and is even more central to improving patients' participation in healthcare decision-making,³¹ and the health literacy of patients with IBD is even more important in influencing their health outcomes.³² The results of this study also show that patients with high health literacy are more willing to participate in shared decision-making roles, which is consistent with the study of Lin et al.³³ Patients with weak health literacy usually lack the necessary health knowledge and information, have a weak sense of participation in clinical decision-making, have difficulty in communicating effectively with healthcare providers, have limited perceptions of their decision-making roles, and habitually accept the decision-making opinions of professionals, which makes them confused and helpless in the face of clinical decision-making, difficult to form clear expectations, unable to fully express their expectations and needs, and even more difficult to make informed decisions. This also suggests that healthcare professionals should pay more attention to patients with weak health literacy skills and improve their health literacy skills by providing health knowledge and information, supporting self-management, and promoting doctor-patient communication so that they can better participate in clinical decision-making.

Finally, the results of this study showed that patients with IBD had decision-making dilemmas, but the effect on the type of actual participation in decision-making was not significant, which may be related to the following reasons: ① Patients with IBD span a broad age range, and adolescents in transition grapple with the dual challenges of personal and parental decision-making. In young adulthood, they must consider issues related to childbearing and employment pressures. As they enter middle and old age, concerns shift to the upbringing of children and the burden of their symptoms. Patients at various life stages have distinct perceptions, understandings, and responses to their condition, which leads to differences in their attitudes and behaviors when making decisions. Some patients may experience internal conflict yet still lean towards deferring to their doctors for guidance. For instance, young Patients with IBD contemplating childbearing decisions may be particularly susceptible to external influences due to the sensitive nature of the topic, the experiential aspect, and the information disparity between doctors and patients, potentially resulting in uncritical compliance; ② Patients may also lack sufficient information to make effective decisions, especially grave patients with IBD when facing complex medical information and treatment plans. They may feel confused and helpless. This lack of information may lead to hesitation and anxiety in the decision-making process, further affecting their enthusiasm and effectiveness in participating in decision-making, thus preventing decision conflicts from being transformed into actual participation behaviors; ③ In China, the doctor-led decision-making model is widespread, and the uneven distribution of medical resources may also put patients in a passive position during the decision-making process. This may cause patients with IBD, even if they have internal conflicts, fail to participate actively due to concerns about adding extra burden to doctors or fear of resources being occupied. ④ In the face of complex treatment choices and multiple In the face of complex treatment choices and multiple decision-making situations, patients may feel tired or confused, and this "decision fatigue" may cause them to give up participation and hand over decision-making responsibilities to professionals; however, based on the Ottawa Decision Support Framework, it can be seen that decision conflict is a key factor in assessing the need for decision-making, and alleviating decision conflict can help patients to reduce negative emotions, such as anxiety and depression, as well as decision regrets and decision delays. Emotions, and reduce the occurrence of adverse consequences such as decision regret,

decision delay, reduced quality of life, and increased doctor-patient conflict.³⁴ In future research, it is still necessary to emphasize the important role of decision-making conflict in the decision-making process. Establish a psychological counseling mechanism to provide professional psychological support to patients who feel decision-making conflicts and help them better cope with decision-making stress.

Conclusions

Patients with IBD generally exhibit high health literacy and demonstrate a willingness to engage in SDM. However, discrepancies persist between their decision-making role expectations and actual participation levels, accompanied by notable preference conflicts. These patterns may be related to numerous factors, such as educational background, socio-economic status, disease phenotype, and characteristics of the therapeutic regimen. This also suggests that not only should patients' willingness to participate be taken into account in decision-making or in realizing joint decision-making between doctors and patients, but it is also necessary to take into account the actual situation and decision-making ability of patients, emphasize the important role of health literacy in decision-making, address the key issues leading to decision-making conflicts, and provide feedback on the concerns and needs of patients promptly to increase the degree of patients' participation in decision-making.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising, or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

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