

Exploring Patient Involvement in Treatment Decision-Making for Diabetic Retinopathy: A COM-B Model-Based Cross-Sectional Survey

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Background: Patient involvement in treatment decision-making has increasingly been emphasized in the healthcare system. However, research on patient involvement in treatment decision-making for diabetic retinopathy (DR) remains scarce in China. Guided by the Capability-Opportunity-Motivation-Behavior (COM-B) model, this study aimed to explore the current status and influencing factors of patient involvement in treatment decision-making for DR.

Methods: This cross-sectional study recruited 336 patients with DR by convenience sampling from a tertiary hospital in Shanghai, China. The All Aspects of Health Literacy Scale (AAHLS), Social Support Rating Scale (SSRS), Facilitation of Patient Involvement Scale (FPIS), Decision Self-Efficacy Scale (DSES), and Patient Expectation for Participation in Medical Decision-making Scale (PEPMDS) were used to evaluate health literacy, social support, ophthalmologist facilitation of patient involvement, decision self-efficacy, and need for decision-making involvement, respectively. The Control Preference Scale (CPS) was used to assess patients' actual involvement roles in treatment decision-making. Descriptive statistics, univariate, and unordered multinomial logistic regression analyses were conducted.

Results: Among the 336 patients with DR, 21.1% reported an active role, 30.7% a collaborative role, and 48.2% a passive role. Compared to passive roles, younger age, higher income, lower ophthalmologist facilitation, and higher need for deliberation were associated with a higher likelihood of adopting active roles; higher income, greater critical health literacy, higher ophthalmologist facilitation, and higher need for deliberation increased the likelihood of adopting collaborative roles. Compared to active roles, collaborative roles were significantly associated with older age, higher objective support, and higher ophthalmologist facilitation.

Conclusion: This study demonstrates that passive involvement remains the predominant decision-making role among DR patients in China. Promoting patient involvement in decision-making is therefore imperative and calls for strategies that enhance health literacy, strengthen ophthalmologist facilitation and objective support, and address the need for deliberation. Future research could develop and evaluate integrated interventions informed by these COM-B components.

Keywords: diabetic retinopathy, patient involvement in treatment decision-making, COM-B

Introduction

Diabetic retinopathy (DR), an ocular microvascular complication of diabetes, is a leading cause of visual impairment and blindness among working-age individuals.¹ An estimated 103 million individuals are currently living with DR worldwide, and this number is projected to rise to 160 million by 2045, driven by an aging population and improved survival rates among individuals with diabetes.² Between 1990 and 2015, DR-related blindness increased from 200,000 to 400,000 cases and visual impairment from 1.4 million to 2.6 million, reflecting a steady increase in global prevalence that poses a critical public health challenge.³ Treatment decisions for DR are often complex, as patients face a variety of options, including retinal laser photocoagulation, anti-vascular endothelial growth factor (anti-VEGF) drugs,

corticosteroids, and pars plana vitrectomy.⁴ These treatment options differ in their efficacy, risks, economic burden, and impact on daily life.⁵ Improper decision-making may lead to severe consequences, including significant vision loss, irreversible blindness, and other serious secondary complications.^{5,6} Evaluating these complex, high-stakes trade-offs presents significant challenges to decision-making for patients with DR.

The World Health Organization (WHO) advocates for patient involvement in clinical decision-making to uphold patients' rights to participate in their treatment plans and maximize treatment benefits.⁷ Previous studies have demonstrated that patient participation in treatment decision-making can not only improve treatment adherence and reduce medical visits but also enhance the doctor-patient relationship and improve health outcomes.^{8,9} Therefore, involving DR patients and incorporating their preferences is essential. However, little is known about patient involvement in DR treatment decisions, especially in the context of the Chinese healthcare system. Compared to many Western countries, Chinese medical culture has traditionally been characterized by a physician-centered model, in which physicians are regarded as authorities and patients often adopt a passive role, with compliance considered optimal.¹⁰ Thus, a systematic exploration of the factors influencing patient involvement in DR decision-making in China is warranted to enhance clinical decision quality.

Previous studies suggest that factors such as age, gender, economic status, educational level, health literacy, and social support may influence participation in decision-making.^{11,12} However, several factors remain controversial. Two studies found that older patients tended to play a passive role in treatment decision-making,^{13,14} whereas one study reported no significant age-related effects.¹⁵ One study found that female patients, compared to men, reported a greater preference for a collaborative role and a lesser preference for a passive role in decision-making,¹⁶ while another study demonstrated the opposite conclusion.¹⁷ A study indicated that high social support was associated with increased patient participation in surgical decision-making.¹⁸ In contrast, a qualitative study revealed that family support, a component of social support, sometimes hindered patient involvement and, in some cases, led to family members making decisions on the patient's behalf.¹⁹ These contradictory findings underscore the necessity for a more systematic and theoretically grounded approach to understanding patient involvement.

To fully capture the influencing factors, a comprehensive theoretical framework is essential. The Capability, Opportunity, Motivation – Behavior (COM-B) model offers such a framework.²⁰ Widely recognized for its comprehensive and systematic approach, the COM-B model has been extensively applied to understand a range of patient health behaviors.^{21–23} The model posits that an individual's behavior is a result of their capability, opportunity, and motivation, with capability and opportunity also affecting behavior both directly and indirectly through their impact on motivation.²⁰

Through literature review and group discussions, we identified a set of potential determinants which were then mapped onto the COM-B framework. Capability is defined as an individual's psychological and physical ability to perform a behavior. Health literacy reflects the patient's ability to access, comprehend, and utilize health information.²⁴ This ability allows patients to understand their treatment options, evaluate risks and benefits, and communicate their preferences meaningfully. In this study, capability was conceptualized as health literacy. Opportunity encompasses physical and social factors that facilitate or prompt a behavior. After seeking medical attention, physicians often serve as the primary source of medical information for patients in China.²⁵ Research has shown that physician support is a crucial facilitator for patient involvement in treatment decisions.²⁶ Furthermore, social support from interpersonal networks, including family members and friends, can enhance patients' psychological resilience and mitigate decision-making pressure.²⁷ For this study, we conceptualized ophthalmologist facilitation of patient involvement and social support as opportunity. Motivation refers to the internal brain processes that energize and direct behavior, including both reflective and automatic mechanisms. Patients with higher decision self-efficacy are more likely to seek information, express their preferences, and play a more engaged role in the treatment process.²⁸ Additionally, the need for decision-making involvement reflects patients' intrinsic desire or preference for participation. In this study, we measured motivation through decision self-efficacy and the need for decision-making involvement. [Figure 1](#) illustrates the conceptual framework that guided our study.

Given that constructs such as health literacy, social support, and need for decision-making involvement are complex and multifaceted, we conducted our analysis on their respective sub-dimensions. For example, we analyzed the functional, communicative, and critical sub-dimensions of health literacy. This approach enabled us to more comprehensively understand how different layers of capability, opportunity, and motivation collectively influenced patient decision-making behavior. The

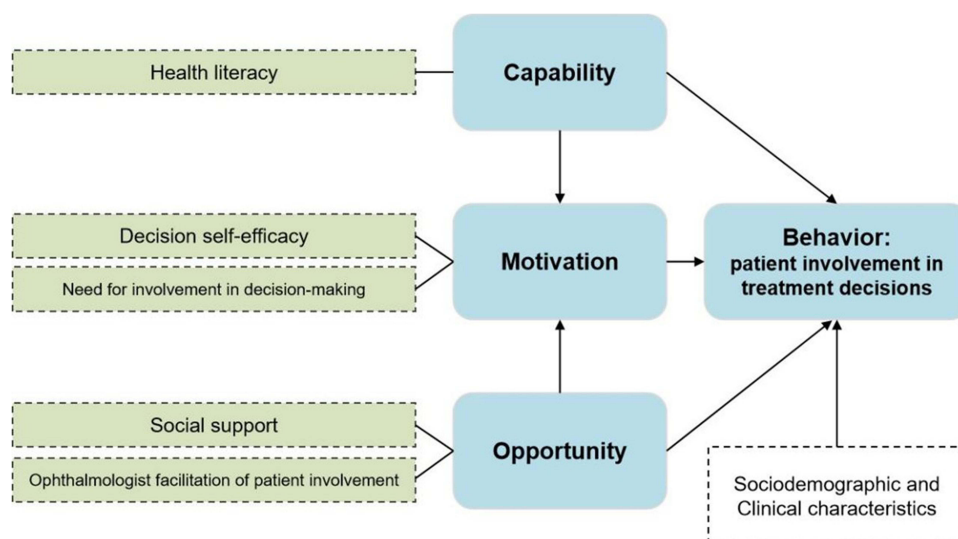


Figure 1 The conceptual framework guiding the study.

aims of this study were to investigate the current status of actual involvement roles in treatment decision-making among patients with DR and to analyze the influencing factors. The research results will provide a valuable reference for developing measures to promote patient involvement in decision-making.

Method

Study Design and Participants

This cross-sectional study was conducted at the ophthalmology center of a large public hospital in Shanghai, China, from August 2024 to January 2025. The institution serves as a regional referral center for a broad geographic area encompassing Shanghai municipality and the surrounding provinces of Jiangsu, Zhejiang, and Anhui. The study participants were recruited using a convenience sampling method. Participants meeting the following criteria were included: (1) age 18 years and above; (2) diagnosed with DR stages III to VI; (3) voluntary participation in the study and signed informed consent. Patients with mental illness, intellectual disability, or verbal communication disorders, as well as severe cardiac, hepatic, or renal dysfunction, respiratory failure, or critical illness, were excluded from the study. According to the Kendall sample size estimation method, which is calculated based on the principle that the sample size should be at least 5 to 10 times the number of variables.²⁹ Through a literature review, this study included a total of 24 predictive influencing variables, comprising 13 sociodemographic and disease characteristics and 11 variables from five scales. Considering a 10% attrition rate, the calculated total sample size of this study ranged from 134 to 267 cases. Ultimately, the study obtained 336 valid samples. This study was reported using the STROBE guidelines.

Ethical Considerations

This study was performed in line with the principles of the Declaration of Helsinki. Ethical approval was granted by the Ethics Review Committee of Shanghai General Hospital (Approval No. 2024–098). All participants provided written informed consent and retained the right to withdraw at any time. All data were collected and analyzed anonymously to guarantee confidentiality.

Measurements

Sociodemographic and Clinical Information

The questionnaire was designed based on a literature review and consultation with ophthalmology experts. It includes the following information: gender, age, marital status, educational level, monthly per capita household income, method of healthcare payment, duration of disease diagnosis, DR stage, and comorbidities.

Control Preference Scale (CPS)

The CPS is used to assess actual roles in treatment decision-making among patients with DR. The scale was originally developed by Degner and later adapted and revised by Nolan.³⁰ Chinese scholar Xu Xiaolin and colleagues translated and revised the scale, and the Cronbach's α coefficient of the Chinese version is 0.899.³¹ The CPS is a unidimensional scale consisting of five options to characterize the types of patient involvement in treatment decision-making. Options 1 and 2 represent the active type, option 3 represents the collaborative type, and options 4 and 5 represent the passive type.

All Aspects of Health Literacy Scale (AAHLS)

The AAHLS is used to assess patients' health literacy levels. The scale was developed by Chinn in 2013,²⁴ and translated and revised by Wu in 2016.³² It consists of 11 items across three dimensions: functional health literacy, communicative health literacy, and critical health literacy. Each item is scored on a 3-point Likert scale (1 = rarely, 2 = sometimes, 3 = often). The total score ranges from 11 to 33, with higher values indicating greater health literacy. In this study, the Cronbach's α coefficient of the scale was 0.834.

Social Support Rating Scale (SSRS)

The SSRS, developed by Xiao, is used to assess patients' social support levels.³³ It includes 10 items across three dimensions: objective support, subjective support, and utilization of social support. The total score ranges from 8 to 44, with higher scores indicating higher social support. In this study, the Cronbach's α coefficient of the scale was 0.800.

Facilitation of Patient Involvement Scale (FPIS)

The FPIS is used to measure the extent to which patients perceive that their healthcare professionals involve them in their healthcare, developed by Martin.³⁴ The Chinese version was translated and revised by Wu in 2015.³² It is a unidimensional scale with nine items. Each item is scored on a 6-point Likert scale ranging from 1 (never) to 6 (always). The scale yields a total score ranging from 9 to 54, with higher values reflecting greater healthcare providers' facilitation of patient involvement in treatment decisions. In this study, the Cronbach's α coefficient of the scale was 0.830.

Decision Self-Efficacy Scale (DSES)

The DSES is used to assess patients' confidence in making treatment decisions for themselves and was developed by O'Conner.³⁵ It is a unidimensional scale comprising eleven items, each rated on a 5-point Likert scale from 0 (not at all confident) to 4 (very confident). The total score is calculated by averaging the sum of 11 items and then multiplying by 25 to convert it to a 0–100 scale. Higher scores reflect greater patient self-efficacy in treatment decision-making. In this study, the Cronbach's α coefficient of the scale was 0.864.

Patient Expectation for Participation in Medical Decision-Making Scale (PEPMDS)

The PEPMDS, developed by Xu, is used to assess patients' need for participation in treatment decisions.³⁶ This scale consists of 12 items in three dimensions: need for information, need for deliberation, and need for decisional control. Items are rated on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree). The total score ranges from 12 to 60, with higher scores indicating greater patient need for involvement in treatment decisions. In this study, the Cronbach's α coefficient of the scale was 0.846.

Data Collection

Before conducting the questionnaire survey, all research team members received standardized training to ensure the consistency and uniformity of terminology and procedures in the survey. During the distribution of the questionnaires, researchers provided participants who met the inclusion criteria with a detailed explanation of the study's purpose, content, and procedures, and obtained their written informed consent. Participants' medical information was collected via the hospital's electronic medical record system. Questionnaires were distributed and collected on-site, with immediate checks to ensure the completeness and accuracy of data collection. For participants who were unable to complete the questionnaire independently due to visual impairment, the researchers administered the questionnaire via dictation based on their verbal responses.

Statistical Analysis

Data were entered independently by two investigators using EpiData 3.1 and exported to SPSS 26.0 for analysis after verification. Descriptive analyses were performed for all included variables. Frequencies and percentages were used for categorical variables, means and standard deviations ($M \pm SD$) were used for normally distributed continuous variables, and medians and interquartile ranges (IQR) were used for non-normally distributed continuous variables. The χ^2 test was used to analyze the differences in the types of patient involvement in treatment decision-making between categorical variables. One-way ANOVA or the non-parametric Kruskal–Wallis H -test was used to analyze continuous variables. Variables with a $P < 0.05$ in univariate analysis were subsequently included in the unordered multinomial logistic regression analysis to determine independent factors associated with the types of patient involvement in treatment decision-making. The Variance Inflation Factor (VIF) was used to analyze whether the variables in the model have multicollinearity. A two-sided test was used, and a P -value < 0.05 was considered statistically significant.

Results

Participant Characteristics

A total of 362 questionnaires were distributed in this study. Following the exclusion of 26 unqualified questionnaires, 336 valid questionnaires were collected, yielding an effective response rate of 92.8%. The mean age of the participants was 53.74 ± 13.01 years. Among the participants, 52.1% were male, and 40.2% had attained a junior high school education or below. The largest proportion of patients was diagnosed with DR Stage IV, accounting for 47.3%. Patients who received retinal photocoagulation accounted for the largest treatment group, at 30.0%. Furthermore, 56.5% of patients presented with ocular comorbidities, and 62.5% had systemic comorbidities. The sociodemographic and clinical characteristics of the patients are shown in Table 1.

Table 1 Comparison of Sociodemographic and Disease Characteristics Among Patients with Diabetic Retinopathy in Different Decision-Making Involvement Roles (N = 336)

Characteristic	Total n (%) / ($M \pm SD$)	Involvement in Decision-Making Roles n (%) / ($M \pm SD$)			χ^2/F	P
		Active (n=71)	Collaborative (n=103)	Passive (n=162)		
Gender					0.026	0.987
Male	175(52.1)	37(21.1)	53(30.3)	85(48.6)		
Female	161(47.9)	34(21.1)	50(31.1)	77(47.8)		
Age (years)	53.74±13.01	44.51±13.09	50.93±11.40	59.57±10.89	46.489	<0.001***
Marital status					2.583	0.275
Unmarried/Divorced/Widowed	48(14.3)	14(29.2)	15(31.3)	19(39.6)		
Married	288(85.7)	57(19.8)	88(30.6)	143(49.7)		
Educational level					90.944	<0.001***
Junior high school or below	135(40.2)	10(7.4)	22(16.3)	103(76.3)		
High school/Technical	94(28.0)	19(20.2)	33(35.1)	42(44.7)		
College or above	107(31.8)	42(39.3)	48(44.9)	17(15.9)		
Monthly per capita household income (CNY)					90.889	<0.001***
≤3000	45(13.4)	2(4.4)	5(11.1)	38(84.4)		
3001~5000	137(40.8)	20(14.6)	26(19.0)	91(66.4)		
5001~10,000	118(35.1)	39(33.1)	50(42.4)	29(24.6)		
>10,000	36(10.7)	10(27.8)	22(61.1)	4(11.1)		
Healthcare payment method					2.448	0.294
Medical insurance	284(84.5)	64(22.5)	84(29.6)	136(47.9)		
Out-of-pocket	52(15.5)	7(13.5)	19(36.5)	26(50.0)		

(Continued)

Table I (Continued).

Characteristic	Total n (%) / (M ± SD)	Involvement in Decision-Making Roles n (%) / (M ± SD)			χ^2/F	P
		Active (n=71)	Collaborative (n=103)	Passive (n=162)		
Living arrangement					5.773	0.217
Living with family	312(92.8)	65(20.8)	92(29.5)	155(49.7)		
Living alone	12(3.6)	2(16.7)	5(41.7)	5(41.7)		
Other	12(3.6)	4(33.3)	6(50.0)	2(16.7)		
Course of disease					12.782	0.120
<3 months	63(18.8)	5(7.9)	20(31.7)	38(60.3)		
3~6 months	87(25.9)	20(23.0)	29(33.3)	38(43.7)		
7~12 months	50(14.9)	11(22.0)	17(34.0)	22(44.0)		
13~24 months	72(21.4)	22(30.6)	20(27.8)	30(41.7)		
>24 months	64(19.0)	13(20.3)	17(26.6)	34(53.1)		
DR stage					11.016	0.088
Stage III	55(16.4)	14(25.5)	23(41.8)	18(32.7)		
Stage IV	159(47.3)	38(23.9)	47(29.6)	74(46.5)		
Stage V	106(31.5)	16(15.1)	28(26.4)	62(58.5)		
Stage VI	16(4.8)	3(18.8)	5(31.3)	8(50.0)		
Ocular comorbidities					1.518	0.468
Yes	190(56.5)	39(20.5)	54(28.4)	97(51.1)		
No	146(43.5)	32(21.9)	49(33.6)	65(44.5)		
Systemic comorbidities					0.626	0.731
Yes	210(62.5)	42(20.0)	67(31.9)	101(48.1)		
No	126(37.5)	29(23.0)	36(28.6)	61(48.4)		
Family history of diabetes					0.439	0.803
Yes	127(37.8)	25(19.7)	38(29.9)	64(50.4)		
No	209(62.2)	46(22.0)	65(31.1)	98(46.9)		
Treatment method					15.494	0.216
RP	101(30.0)	18(17.8)	31(30.7)	52(51.5)		
Anti-VEGF drugs	41(12.2)	10(24.4)	8(19.5)	23(56.1)		
PPV	52(15.5)	13(25.0)	12(23.1)	27(51.9)		
RP+PPV	26(7.7)	6(23.1)	5(19.2)	15(57.7)		
RP+Anti-VEGF drugs	42(12.5)	7(16.7)	17(40.5)	18(42.9)		
Anti-VEGF drugs+PPV	61(18.2)	16(26.2)	23(37.7)	22(36.1)		
RP+Anti-VEGF drugs+PPV	13(3.9)	1(7.7)	7(53.8)	5(38.5)		

Note: ***P<0.001.

Abbreviations: CNY, Chinese Yuan; RP, Retinal Photocoagulation; Anti-VEGF, Anti-Vascular Endothelial Growth Factor; PPV, Pars Plana Vitrectomy; n, denotes count; M, Mean; SD, Standard Deviation; F, One-way ANOVA statistic.

Descriptive Statistics of Patient Involvement in Treatment Decision-Making for Diabetic Retinopathy

Regarding actual patient involvement in treatment decision-making roles, 21.1% of patients reported being active, 30.7% reported being collaborative, and the largest proportion, 48.2%, reported being passive.

Univariate Analysis

The mean scores for the 336 patients with DR were AAHLS (24.84±3.53), SSRS (43.59±5.51), FPIS (40.39±4.78), DSES (72.03±11.44), and PEPMDS (47.89±5.39). Univariate analysis revealed significant differences in actual involvement in decision-making roles among patients with DR across several factors, including: age, educational level, monthly

Table 2 Comparison of COM-B Factors Among Patients with Diabetic Retinopathy in Different Decision-Making Involvement Roles (N = 336)

Variable	Total (M ± SD)	Involvement in Decision-Making Roles (M ± SD)			F	P
		Active	Collaborative	Passive		
Health literacy	24.84±3.53	26.70±3.00	25.97±3.02	23.30±3.40	37.050	<0.001***
Functional health Literacy	9.53±1.58	10.52±1.35	10.00±1.31	8.80±1.48	45.420	<0.001***
Communicative health literacy	6.95±1.18	6.86±0.99	6.94±1.03	6.99±1.34	0.365	0.695
Critical health literacy	8.36±1.59	9.32±1.44	9.03±1.32	7.51±1.35	62.323	<0.001***
Social support	43.59±5.51	44.34±5.85	45.32±5.00	42.15±5.32	11.964	<0.001***
Objective support	13.48±1.54	13.27±1.44	13.97±1.54	13.27±1.51	7.809	<0.001***
Subjective support	21.89±3.43	22.45±3.81	22.84±3.19	21.04±3.21	10.434	<0.001***
The utilization of social support	8.21±1.58	8.62±1.52	8.50±1.53	7.85±1.57	8.846	<0.001***
Ophthalmologist facilitation of patient involvement	40.39±4.78	40.56±3.78	43.62±4.27	38.27±4.30	51.613	<0.001***
Decision self-efficacy	72.03±11.44	79.10±9.54	76.08±8.24	66.36±11.18	50.015	<0.001***
Need for decision-making involvement	47.89±5.39	51.45±4.90	50.42±3.27	44.72±4.85	79.396	<0.001***
Need for information	13.18±1.45	13.61±1.25	13.60±1.13	12.73±1.58	16.385	<0.001***
Need for deliberation	23.49±3.23	25.68±2.74	25.12±2.20	21.51±2.76	90.802	<0.001***
Need for decisional control	11.21±1.59	12.17±1.62	11.70±1.07	10.49±1.52	40.358	<0.001***

Note: *** P<0.001.

Abbreviations: M, Mean; SD, Standard Deviation; F, One-way ANOVA statistic.

per capita household income, health literacy, social support, ophthalmologist facilitation of patient involvement, decision self-efficacy, and need for decision-making involvement (P<0.05). See Table 1 and Table 2.

Multinomial Logistic Regression Analysis

An unordered multinomial logistic regression analysis was conducted to identify the independent factors influencing patient involvement in treatment decision-making for diabetic retinopathy. Prior to conducting the multinomial logistic regression, multicollinearity was assessed among all independent variables. The aggregate variables social support and need for decision-making involvement demonstrated perfect collinearity with their respective sub-dimensional variables, as indicated by a tolerance value of 0.000. The variable health literacy also exhibited significant collinearity, with a VIF of 11.381. Since the simultaneous inclusion of these aggregate variables and their subdimensions would have rendered the model unstable and statistically un-fittable, they were excluded in accordance with established statistical principles. Consequently, only the sub-dimensional variables were retained in the final model. This approach ensured the robustness of the model while enabling evaluation of the impact of specific components within each theoretical construct on decision-making behavior. After refitting, all remaining variables had VIF values below 4, indicating no substantial multicollinearity. The following variables were retained and subsequently entered into the multinomial logistic regression analysis: age, educational level, monthly per capita household income, functional health literacy, critical health literacy, objective support, subjective support, utilization of social support, need for information, need for deliberation, need for decisional control, ophthalmologist facilitation of patient involvement, and decision self-efficacy. The assigned values of the included independent variables are shown in Table 3.

The likelihood ratio test indicated that the final model provided a significantly better fit than a null model ($\chi^2 = 272.002$, $df = 32$, $P < 0.001$). This conclusion was bolstered by the pseudo R² values (Cox & Snell R² = 0.555; Nagelkerke R² = 0.634), which collectively suggest that the model captures a substantial proportion of the outcome’s variability and signals a good overall fit. The results identified age, monthly per capita household income, critical health literacy, ophthalmologist facilitation of patient involvement, objective support, and need for deliberation as significant independent predictors of patient decision-making roles. Compared to passive roles, patients adopting active roles tended to be younger, have higher income, report lower ophthalmologist facilitation, and express higher need for deliberation. Conversely, compared to passive roles, collaborative roles were associated with higher income, greater critical health

Table 3 Assignment of Independent Variables

Independent Variables	Assigning Values to Variables
Age	Raw value input
Educational level	Junior high school or below=1, High school/Technical =2, College or above=3
Monthly per capita household income (CNY)	≤3000=1, 3001~5000=2, 5001~10,000=3, >10,000=4
Functional health Literacy	Raw value input
Critical health literacy	Raw value input
Objective support	Raw value input
Subjective support	Raw value input
The utilization of social support	Raw value input
Ophthalmologist facilitation of patient involvement	Raw value input
Decision self-efficacy	Raw value input
Need for information	Raw value input
Need for deliberation	Raw value input
Need for decisional control	Raw value input

literacy, stronger ophthalmologist facilitation, and elevated need for deliberation. Furthermore, when collaborative roles were compared to active roles, patients adopting the former were significantly older, reported higher objective support, and experienced greater ophthalmologist facilitation. The detailed results are shown in [Table 4](#).

Discussion

To our knowledge, this is the first study to examine actual treatment decision-making involvement among Chinese patients with DR and explore its influencing factors using the COM-B framework. Overall, the passive role was the most common pattern observed. Furthermore, our analysis identified several key factors significantly influencing patient involvement: age, monthly per capita household income, critical health literacy, ophthalmologist facilitation of patient involvement, objective support, and need for deliberation.

Current Status of Patient Involvement in Treatment Decision-Making for Diabetic Retinopathy

The results revealed that 48.2% of patients reported passive roles, 30.7% reported collaborative roles, and 21.1% reported active roles. The proportion of passive role was relatively higher in patients with DR than in those with inflammatory bowel disease (32.12%),³⁷ gynecologic cancer (29.9%),³⁸ or atrial fibrillation (40.3%).²⁶ These differences may be attributed to distinct study populations and research settings. Specifically, DR has one of the lowest levels of public awareness compared with other ophthalmic diseases, which is likely due to the high professional barriers inherent in its diagnosis and treatment.³⁹ This low awareness is evidenced by a Chinese study where only 1.2% of diabetic patients could correctly identify symptoms of DR.⁴⁰ Furthermore, the combination of diverse treatment options, prognostic uncertainty, and the older demographics of the patient cohort may collectively impair patients’ understanding of the disease and therapeutic alternatives, thus predisposing them to passive decision-making.

Capability and Patient Involvement

Previous studies have pointed out that health literacy, encompassing various dimensions, is necessary for patient involvement in decision-making.^{41,42} Successful patient involvement is predicated on patients possessing practical communication skills, the ability to acquire, comprehend, and communicate relevant information about disease and treatment from healthcare professionals, and critical evaluation skills.⁴¹ However, few studies have explored the distinct impacts of these different health literacy dimensions on patients’ actual involvement in decision-making. Our findings indicate that patients with higher critical health literacy are more likely to adopt collaborative decision-making roles. This result is consistent with a study conducted in the Netherlands, which found that critical health literacy was more important for patient participation than its functional and communicative counterparts.⁴³ In contrast, a French study

Table 4 Multinomial Logistic Regression Analysis of Factors Influencing the Actual Involvement in Decision-Making Roles Among Patients with Diabetic Retinopathy (n=336)

Independent Variables	Active vs Passive				Collaborative vs Passive				Active vs Collaborative			
	B	OR	95% CI	P	B	OR	95% CI	P	B	OR	95% CI	P
Age	-0.074	0.929	0.884–0.976	0.003**	-0.024	0.976	0.936–1.019	0.268	-0.050	0.951	0.908–0.997	0.037*
Educational level												
Junior high school or below	-1.312	0.269	0.045–1.602	0.149	0.192	1.211	0.275–5.332	0.800	-1.503	0.222	0.039–1.278	0.092
High school/Technical	-0.739	0.478	0.145–1.576	0.225	0.025	1.025	0.343–3.065	0.965	-0.763	0.466	0.159–1.363	0.163
College or above	Ref											
Per capita monthly household income (CNY)												
≤3000	-3.541	0.029	0.003–0.253	0.001**	-2.931	0.053	0.009–0.303	0.001**	-0.610	0.543	0.068–4.352	0.566
3001~5000	-1.725	0.178	0.041–0.777	0.022*	-2.126	0.119	0.031–0.456	0.002**	0.400	1.492	0.465–4.791	0.501
5001~10,000	-0.275	0.759	0.181–3.179	0.706	-0.833	0.435	0.119–1.590	0.208	0.557	1.746	0.628–4.853	0.286
>10000	Ref											
Functional health Literacy	-0.128	0.880	0.549–1.411	0.595	-0.382	0.683	0.450–1.036	0.073	0.254	1.289	0.809–2.054	0.286
Critical health literacy	0.279	1.322	0.876–1.995	0.184	0.424	1.528	1.065–2.191	0.021*	-0.145	0.865	0.592–1.265	0.455
Objective support	-0.105	0.900	0.674–1.202	0.477	0.187	1.206	0.930–1.563	0.157	-0.292	0.747	0.566–0.985	0.039*
Subjective support	0.032	1.032	0.881–1.209	0.695	0.036	1.037	0.892–1.204	0.639	-0.004	0.996	0.863–1.149	0.953
The utilization of social support	0.188	1.207	0.817–1.785	0.345	-0.033	0.967	0.687–1.361	0.848	0.222	1.248	0.866–1.800	0.235
Ophthalmologist facilitation of patient involvement	-0.220	0.802	0.704–0.915	0.001**	0.159	1.173	1.054–1.305	0.004**	-0.379	0.684	0.602–0.778	<0.001***
Decision self-efficacy	-0.052	0.949	0.886–1.017	0.138	-0.046	0.955	0.900–1.014	0.134	-0.007	0.993	0.930–1.061	0.843
Need for information	-0.174	0.841	0.598–1.181	0.317	-0.007	0.993	0.747–1.318	0.959	-0.166	0.847	0.597–1.200	0.350
Need for deliberation	0.513	1.670	1.346–2.073	<0.001***	0.451	1.570	1.303–1.892	<0.001***	0.062	1.064	0.872–1.299	0.541
Need for decisional control	0.008	1.008	0.690–1.472	0.968	-0.192	0.826	0.590–1.155	0.264	0.199	1.221	0.858–1.737	0.268

Notes: *P<0.05; **P<0.01; ***P<0.001; Ref, reference category.

Abbreviations: B, regression coefficient; OR, odds ratio; 95% CI, 95% confidence interval.

reported a positive correlation for functional and communicative health literacy with patient involvement but no association for critical health literacy.⁴⁴ This discrepancy may be attributable to the relatively homogeneous scores for functional and communicative health literacy in our cohort, which exhibited limited variability. Our research suggests that the ability to simply acquire information and communicate with healthcare professionals is insufficient for meaningful participation in medical decision-making. Therefore, future interventions should focus on enhancing the critical health literacy of patients with DR, empowering them to analyze, evaluate, and question health information to make informed decisions that align with their personal values and preferences.

Opportunity and Patient Involvement

Our study revealed that increased ophthalmologist facilitation is significantly associated with patients adopting a collaborative role over either a passive or an active one. This suggests that when ophthalmologists proactively provide information, encourage questions, and respect patient concerns, they effectively bridge the inherent information and power asymmetry. Such empowerment fosters a climate of equitable dialogue, promoting patient engagement to collaborate rather than simply shifting the decision-making burden onto them. This finding aligns with a qualitative meta-summary which highlighted that clear information delivery, active listening, and trust-building are critical facilitators for patient engagement.⁴⁵ Furthermore, our results showed that greater ophthalmologist facilitation decreased the likelihood of an active role. A potential explanation is that highly facilitative ophthalmologists build a strong foundation of trust, engendering a sense of security and understanding in patients. Consequently, the perceived need for patients to assume a solely autonomous, active role diminishes. This perspective is supported by Kraetschmer's research, which established that an active role is associated with low trust, a passive role with blind trust, and a collaborative role with high but not excessive trust.⁴⁶ Conversely, when patients perceive a lack of support or transparency, their trust may diminish, compelling them to adopt an active, patient-dominated role as a compensatory strategy to regain a sense of control.⁴⁷ Physician support, therefore, bridges the information and power gap, enabling true shared decision-making rather than pushing patients toward extremes.⁴⁸ This is further corroborated by a cross-sectional study which showed that physicians' facilitative communication predicted greater patient participation.⁴⁹ Consequently, future interventions should focus on implementing training programs for ophthalmologists to enhance communication skills, integrate appropriate decision aids into practice, and foster patient empowerment and collaboration.

Visual impairment caused by DR leads to significant consequences, including disrupted family functioning, increased social isolation and dependence, and economic constraints, and inadequate social support is common in patients with DR.⁵⁰ Previous studies have established that social support promotes greater patient participation in decision-making by providing financial, emotional, and informational resources that reduce psychological stress and decision-making conflicts.^{51–53} However, few studies have specifically evaluated the distinct impacts of different dimensions of social support on patient involvement in decision-making. Our study found that higher objective support was significantly associated with the adoption of a collaborative role in treatment decision-making. Objective support, in this context, refers to the tangible, visible, and practical assistance that patients receive from their social network, such as family, relatives and friends. Our study suggests that objective support is a more robust predictor of a patient's decision-making role than are subjective support and the utilization of social support. Objective support provides the concrete resources necessary for shared information exchange, preference clarification, and joint deliberation.⁵⁴ This association is particularly salient in cultural contexts with strong family involvement and collectivist values, where health decisions are often regarded as a shared family responsibility.⁵⁵ In such settings, adequate objective support helps mitigate unilateral physician dominance while also alleviating the burden of solitary patient decision-making, thereby promoting a collaborative approach. Therefore, healthcare professionals should systematically assess the objective support levels of patients with diabetic retinopathy. Interventions should simultaneously focus on encouraging patients to strengthen their ties with social networks, such as family, relatives, and friends, and guide family members to become engaged partners in the patient's treatment journey, thereby bolstering the decision-making support available to them.

Motivation and Patient Involvement

Need for decision-making reflects an individual's intrinsic motivation to control the process and outcome of medical decisions.²⁸ Patients with a strong need for decision-making typically desire in-depth disease information, weighing pros and cons, participating in discussions, and having more personal control over treatment decisions. Charles et al categorized the treatment decision-making process into three components: information exchange, deliberation, and decision-making control.⁵⁶ The three dimensions of the PEPMDs correspond to the treatment decision-making process.⁵⁷ The univariate analysis results in our study indicate that all three dimensions are related to the patient's decision-making role. In the multinomial logistic regression model, only the need for deliberation remained statistically significant. Our research suggests that the need for deliberation is a better predictor of patients taking a collaborative or active role in decision-making than the need for information and decision control. Logically, patients necessarily need access to sufficient medical information if they are to deliberate, and crucially, the process of deliberation often serves as a means for patients to strive for or achieve decision control. Therefore, when the need for deliberation is included in the model, it may have already captured most of the variation explained by the need for information and decision control. This finding suggests that patients, even if well-informed and possessing control, may still choose passive decision-making if they do not have the will to deliberate. Rather than just passively providing information or asking the patient about their willingness to take control of the decision, it is more important to identify whether patients are willing to think deeply, weigh the pros and cons, and discuss with healthcare professionals.

Other Factors Associated with Patient Involvement

Our research indicated that as patients age, those with diabetic retinopathy were more likely to adopt a passive or collaborative role in decision-making. This finding aligns with Salm's study,⁵⁸ while it conflicts with the null results reported by Xie.¹⁵ Several contextual factors might explain this discrepancy. In contrast to Xie's research, which involved undergraduate students and community-dwelling older adults in the United States and focused on general health decision-making scenarios, our work specifically examined patients with sight-threatening diabetic retinopathy. These patients face complex, urgent decisions, such as choosing intravitreal injections or laser surgery that directly affect their vision. For older adults, who may experience age-related cognitive decline or feel overwhelmed by technical medical information, the perceived complexity and high stakes of these decisions likely diminish their capacity to adopt proactive decision-making.⁵⁹ Furthermore, in the cultural context of our study, younger patients, compared with older patients influenced by traditional paternalistic norms in the doctor-patient relationship, tend to place greater emphasis on asserting personal autonomy and maintaining control over medical decisions.⁶⁰ Therefore, the effect of age may not be a simple main effect but is likely moderated by the disease context, the nature of the treatment decisions, and the cultural environment. We found no statistically significant association between gender and decision-making roles, a finding that stands in contrast to studies which concluded that females were more participatory or males were more involved.^{16,17} This divergence suggests that the purported effects of gender may not be a stable, universal phenomenon but are likely contingent upon specific contextual moderators. Overall, there was no consistent evidence to support associations between decision-making roles and gender. Our findings presented that patients with a monthly per capita household income of ≤ 3000 yuan and 3001–5000 yuan were more inclined to take a passive role in actual decision-making for diabetic retinopathy compared to those with higher incomes. Similar to our results, Wang et al reported that patients with a monthly per capita household income of 5000–7999 yuan exhibited a greater tendency for collaborative decision-making than low-income patients.³⁷ This socioeconomic disparity in decision-making involvement is particularly consequential, given that diabetic retinopathy requires lifelong management involving significant ongoing costs. Treatments such as anti-VEGF therapy, while effective, are relatively expensive. In China, access to these therapies is further constrained by medical insurance policies requiring strict clinical indications and imposing limits on the cumulative reimbursable doses. Consequently, patients with lower household incomes often face substantial financial toxicity, which forces them to weigh treatment costs against potential efficacy and experience heightened psychological distress. This economic pressure frequently leads them to adopt a passive stance, accepting the more economical options recommended by physicians.⁶¹ In contrast, patients with higher incomes are less burdened by cost considerations. Their

relative financial security, coupled with potentially greater access to comprehensive health information and support services, reduces the perceived burden of decision-making and fosters greater participation in choosing their treatment options. These observed disparities underscore the critical need for reforms in the national medical insurance payment system. Such reforms should aim to alleviate the financial barriers that currently prevent equitable access to preferred treatments and hinder the full participation of socioeconomically disadvantaged patients in treatment decision-making.

Strengths and Limitations

The study has two primary strengths. First, its theory-driven approach, underpinned by the COM-B model, allowed for a systematic and integrated analysis of the determinants of patient involvement, offering clear targets for future interventions. Second, its comprehensive assessment of key variables within the specific, high-stakes context of diabetic retinopathy enhanced the clinical relevance and applicability of the findings. This study has several limitations. First, the generalizability of our findings is limited by the sample, which was not only relatively small in size but also drawn from a single tertiary hospital in Shanghai. This specific context may not be representative of broader populations, particularly those in community clinics or rural settings where patient demographics and healthcare resources differ considerably. Second, the cross-sectional design cannot establish causal relationships between variables. Longitudinal studies are necessary to untangle these complex temporal dynamics and verify the directionality of these associations. Third, the reliance on self-reported data may introduce social desirability and recall biases, potentially affecting measurement validity. Future studies could incorporate objective measures, such as audio recordings of clinical encounters, to improve accuracy. Finally, our analytical strategy of using sub-dimensions limited our ability to quantify the overall impact of the integrated COM-B constructs. Given these limitations, the findings should be interpreted as exploratory and require validation in larger, more diverse cohorts. Future large-scale studies will also be better equipped to employ advanced statistical modeling techniques to further elucidate these complex relationships.

Conclusions

This study, the first to apply the COM-B model to decision-making involvement among DR patients in China, revealed a predominance of passive involvement among patients. Our findings suggested several potential determinants consistent with the COM-B framework, including capability factors such as critical health literacy, opportunity factors including ophthalmologist facilitation of patient involvement and objective support, and motivation factors like the need for deliberation, in addition to demographic variables such as age and income. These findings underscore the necessity for multifaceted interventions, including tailored patient education programs, clinician communication training, and accessible decision aids, to promote shared decision-making. However, given the constraints of the cross-sectional design and limited sample size, these conclusions should be considered exploratory. Future research should focus on large-scale longitudinal studies to track changes in patient decision-making roles over time, as well as intervention trials assessing the effectiveness of COM-B-based strategies in promoting shared decision-making.

Abbreviations

DR, diabetic retinopathy; COM-B, capability, opportunity, motivation, and behavior; CPS, control preference scale; AAHLS, all aspects of health literacy scale; SSRS, social support rating scale; FPIS, facilitation of patient involvement scale; DSES, decision self-efficacy scale; PEPMDS, patient expectation for participation in medical decision-making scale.

Data Sharing Statement

The datasets used and analyzed during the current study are available from the corresponding author upon reasonable request.

Ethics Approval and Consent to Participate

This study was conducted in accordance with the Declaration of Helsinki and approved by the Ethics Committee of Shanghai General Hospital (Approval No. 2024-098). Written informed consent was obtained from all participants.

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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

The authors report no conflicts of interest in this work.

References

- Cheung N, Mitchell P, Wong TY. Diabetic retinopathy. *Lancet*. 2010;376(9735):124–136. doi:10.1016/s0140-6736(09)62124-3
- Teo ZL, Tham YC, Yu M, et al. Global prevalence of diabetic retinopathy and projection of burden through 2045: systematic review and meta-analysis. *Ophthalmology*. 2021;128(11):1580–1591. doi:10.1016/j.ophtha.2021.04.027
- Flaxman SR, Bourne RRA, Resnikoff S, et al. Global causes of blindness and distance vision impairment 1990–2020: a systematic review and meta-analysis. *Lancet Glob Health*. 2017;5(12):e1221–e1234. doi:10.1016/s2214-109x(17)30393-5
- Raj A, Singla A, Sidana S. Preventive and therapeutic strategies via health care delivery system to minimize sight-threatening diabetic retinopathy: a narrative review. *Curr Diab Rep*. 2025;25(1):36. doi:10.1007/s11892-025-01591-5
- Shughoury A, Bhatwadekar A, Jusufbegovic D, Hajrasouliha A, Ciulla TA. The evolving therapeutic landscape of diabetic retinopathy. *Expert Opin Biol Ther*. 2023;23(10):969–985. doi:10.1080/14712598.2023.2247987
- Salvetat ML, Pellegrini F, Spadea L, et al. The treatment of diabetic retinal edema with intravitreal steroids: how and when. *J Clin Med*. 2024;13(5). doi:10.3390/jcm13051327
- Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2017;4(4):Cd001431. doi:10.1002/14651858.CD001431.pub5
- Becker C, Gross S, Gamp M, et al. Patients' preference for participation in medical decision-making: secondary analysis of the BEDSIDE-OUTSIDE trial. *J Gen Intern Med*. 2023;38(5):1180–1189. doi:10.1007/s11606-022-07775-z
- Ruhnke GW, Tak HJ, Meltzer DO. Association of preferences for participation in decision-making with care satisfaction among hospitalized patients. *JAMA Network Open*. 2020;3(10):e2018766. doi:10.1001/jamanetworkopen.2020.18766
- Li B. The power paradox of patient-centred care in Chinese community health: towards a conceptualisation. *Soc Sci Med*. 2025;371:117883. doi:10.1016/j.socscimed.2025.117883
- Tang C, Wang A, Yan J. Exploring motivations and resistances for implementing shared decision-making in clinical practice: a systematic review based on a structure-process-outcome model. *Health Expect*. 2022;25(4):1254–1268. doi:10.1111/hex.13541
- Truglio-Londrigan M, Slyer JT, Singleton JK, Worrall P. A qualitative systematic review of internal and external influences on shared decision-making in all health care settings. *JB Libr Syst Rev*. 2012;10(58):4633–4646. doi:10.11124/jbisrir-2012-432
- Singh JA, Sloan JA, Atherton PJ, et al. Preferred roles in treatment decision making among patients with cancer: a pooled analysis of studies using the Control Preferences Scale. *Am J Manag Care*. 2010;16(9):688–696.
- Fischer M, Visser A, Voerman B, Garssen B, van Andel G, Bensing J. Treatment decision making in prostate cancer: patients' participation in complex decisions. *Patient Educ Couns*. 2006;63(3):308–313. doi:10.1016/j.pec.2006.07.009
- Xie B, Wang M, Feldman R, Zhou L. Exploring older and younger adults' preferences for health information and participation in decision making using the Health Information Wants Questionnaire (HIWQ). *Health Expect*. 2014;17(6):795–808. doi:10.1111/j.1369-7625.2012.00804.x
- Lechner S, Herzog W, Boehlen F, et al. Control preferences in treatment decisions among older adults - results of a large population-based study. *J Psychosom Res*. 2016;86:28–33. doi:10.1016/j.jpsychores.2016.05.004
- Torrente-Jimenez RS, Feijoo-Cid M, Rivero-Santana AJ, et al. Gender differences in the decision-making process for undergoing total knee replacement. *Patient Educ Couns*. 2022;105(12):3459–3465. doi:10.1016/j.pec.2022.08.014
- Tang H, Dong S, Wang S, et al. Perceived participation in decision-making on primary surgery and associated factors among early breast cancer patients: a cross-sectional study. *Cancer Nurs*. 2023;46(2):111–119. doi:10.1097/ncc.0000000000001071
- Jiang Y, Guo J, Sun P, et al. Perceptions and experiences of older patients and healthcare professionals regarding shared decision-making in pulmonary rehabilitation: a qualitative study. *Clin Rehabil*. 2021;35(11):1627–1639. doi:10.1177/02692155211010279
- Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implement Sci*. 2011;6:42. doi:10.1186/1748-5908-6-42
- Shi Y, Xie XY, Lao AD, Shao L, Wang ZA, Zhang JE. Prevalence of physical inactivity and its determinants among older adults living in nursing homes: a cross-sectional study based on COM-B model. *J Clin Nurs*. 2025;34(1):204–217. doi:10.1111/jocn.17325
- Zhang M, Guo L, Namasseyam G, et al. Factors associated with health behaviours among stroke survivors: a mixed-methods study using COM-B model. *J Clin Nurs*. 2024;33(6):2138–2152. doi:10.1111/jocn.17103

23. Shpendi S, Norman P, Gibson-Miller J, Webster R. Cervical screening attendance in young women and people with a cervix: an application of the COM-B model. *Br J Health Psychol.* 2025;30(3):e70016. doi:10.1111/bjhp.70016
24. Chinn D, McCarthy C. All Aspects of Health Literacy Scale (AAHLS): developing a tool to measure functional, communicative and critical health literacy in primary healthcare settings. *Patient Educ Couns.* 2013;90(2):247–253. doi:10.1016/j.pec.2012.10.019
25. Lu L, Liu J, Yuan YC. Health information seeking behaviors and source preferences between Chinese and U.S. populations. *J Health Commun.* 2020;25(6):490–500. doi:10.1080/10810730.2020.1806414
26. Dong F, Wu Y, Wang Q, Huang Y, Wu Q. Factors influencing patient engagement in decision-making for catheter ablation of atrial fibrillation: a cross-sectional survey. *Eur J Cardiovasc Nurs.* 2025;24(1):150–157. doi:10.1093/eurjcn/zvae141
27. Wang Y, Qiu Y, Ren L, Jiang H, Chen M, Dong C. Social support, family resilience and psychological resilience among maintenance hemodialysis patients: a longitudinal study. *BMC Psychiatry.* 2024;24(1):76. doi:10.1186/s12888-024-05526-4
28. Wu H, Fan Y, Cheng Y, Zhang JE. Predictors of shared decision-making in patients with recurrent and metastatic nasopharyngeal carcinoma: an observational structural equation modeling approach. *Eur J Oncol Nurs.* 2025;76:102869. doi:10.1016/j.ejon.2025.102869
29. Rodríguez Del Águila M, González-Ramírez A. Sample size calculation. *Allergol Immunopathol.* 2014;42(5):485–492. doi:10.1016/j.aller.2013.03.008
30. Nolan MT, Hughes M, Narendra DP, et al. When patients lack capacity: the roles that patients with terminal diagnoses would choose for their physicians and loved ones in making medical decisions. *J Pain Symptom Manage.* 2005;30(4):342–353. doi:10.1016/j.jpainsymman.2005.04.010
31. Xu X. The patients satisfaction with participation in medical decision-making scale: development, reliability, and validity. 2010.
32. Dong F, Wu Y, Wang Q, Huang Y, Wu Q. Factors influencing patient engagement in decision making for catheter ablation of atrial fibrillation: a cross-sectional survey. *Eur J Cardiovasc Nurs.* 2024;24(1):141.
33. Xiao S. Theoretical basis and research application of social support rating scale. *J Clin Psych.* 1994;4(2):98.
34. Martin LR, DiMatteo MR, Lepper HS. Facilitation of patient involvement in care: development and validation of a scale. *Behav Med.* 2001;27(3):111–120. doi:10.1080/08964280109595777
35. Bunn H, O'Connor A. Validation of client decision-making instruments in the context of psychiatry. *Can J Nurs Res.* 1996;28(3):13–27.
36. Xu X, Mao J, Wang J, Zhao H. Developing strategy and item selection of the patients' expectation for participation in medical decision making scale. *China Mod Med.* 2012;19:162–164.
37. Wang Y, Zhang S, Fang W, et al. Factors influencing decision-making preferences among patients with inflammatory bowel disease: a cross-sectional study in China. *Patient Prefer Adherence.* 2025;19:1047–1057. doi:10.2147/ppa.S517510
38. Abe M, Hashimoto H, Soejima A, et al. Shared decision-making in patients with gynecological cancer and healthcare professionals: a cross-sectional observational study in Japan. *J Gynecol Oncol.* 2025;36(3):e47. doi:10.3802/jgo.2025.36.e47
39. Scott AW, Bressler NM, Ffolkes S, Wittenborn JS, Jorkasky J. Public attitudes about eye and vision health. *JAMA Ophthalmol.* 2016;134(10):1111–1118. doi:10.1001/jamaophthalmol.2016.2627
40. Su C, Wang Z, Dong X, Ma X. Experiences of seeking diabetic eye care among patients with diabetes in China: a community-based convergent mixed methods study. *Public Health.* 2024;234:24–32. doi:10.1016/j.puhe.2024.05.021
41. Muscat DM, Shepherd HL, Nutbeam D, Trevena L, McCaffery KJ. Health literacy and shared decision-making: exploring the relationship to enable meaningful patient engagement in healthcare. *J Gen Intern Med.* 2021;36(2):521–524. doi:10.1007/s11606-020-05912-0
42. Bravo P, Edwards A, Barr PJ, Scholl I, Elwyn G, McAllister M. Conceptualising patient empowerment: a mixed methods study. *BMC Health Serv Res.* 2015;15:252. doi:10.1186/s12913-015-0907-z
43. Brabers AE, Rademakers JJ, Groenewegen PP, van Dijk L, de Jong JD. What role does health literacy play in patients' involvement in medical decision-making? *PLoS One.* 2017;12(3):e0173316. doi:10.1371/journal.pone.0173316
44. Ousseine YM, Durand MA, Bouhnik AD, Smith A, Mancini J. Multiple health literacy dimensions are associated with physicians' efforts to achieve shared decision-making. *Patient Educ Couns.* 2019;102(11):1949–1956. doi:10.1016/j.pec.2019.05.015
45. Mertens L, Kasmi T, Bekkering GE, et al. Shared challenges and opportunities: uncovering common ground in patient participation across different healthcare settings and patient groups. A qualitative meta-summary on patient-reported barriers and facilitators to participation in shared decision-making. *Patient Educ Couns.* 2025;130:108475. doi:10.1016/j.pec.2024.108475
46. Kraetschmer N, Sharpe N, Urowitz S, Deber RB. How does trust affect patient preferences for participation in decision-making? *Health Expect.* 2004;7(4):317–326. doi:10.1111/j.1369-7625.2004.00296.x
47. Tefera GM, Ngondwe P, Varol S. Trust matters: a qualitative study on healthcare access and utilization among African immigrants in the United States. *J Community Health.* 2025. doi:10.1007/s10900-025-01481-7
48. Scherer KA, Büdenbender B, Blum AK, et al. Power asymmetry and embarrassment in shared decision-making: predicting participation preference and decisional conflict. *BMC Med Inform Decis Mak.* 2025;25(1):120. doi:10.1186/s12911-025-02938-4
49. Street RL, Liu L, Farber NJ, et al. Keystrokes, mouse clicks, and gazing at the computer: how physician interaction with the EHR affects patient participation. *J Gen Intern Med.* 2018;33(4):423–428. doi:10.1007/s11606-017-4228-2
50. Fenwick E, Rees G, Pesudovs K, et al. Social and emotional impact of diabetic retinopathy: a review. *Clin Exp Ophthalmol.* 2012;40(1):27–38. doi:10.1111/j.1442-9071.2011.02599.x
51. Xiang JM, Gao LL. Decisional conflict, anxiety, and social support among Chinese pregnant women making further prenatal testing decisions. *J Reprod Infant Psychol.* 2025;43(1):34–46. doi:10.1080/02646838.2023.2232380
52. Wu M, Wang W, He H, Bao L, Lv P. Mediating effects of health literacy, self-efficacy, and social support on the relationship between disease knowledge and patient participation behavior among chronic ill patients: a cross-sectional study based on the capability-opportunity-motivation and behavior (COM-B) model. *Patient Prefer Adherence.* 2025;19:1337–1350. doi:10.2147/ppa.S513375
53. Nguyen TQ, Le TD, Fan SY, Ke LS, Pham TVH, Kao CY. Exploring relational autonomy of vietnamese patients' experiences in decision-making regarding hematopoietic stem cell transplantation: a qualitative interview study. *Psychooncology.* 2025;34(6):e70185. doi:10.1002/pon.70185
54. Wang H, Xiu M, Yang F, et al. Perceptions of shared decision-making participation during cardiac rehabilitation in coronary heart disease patients after coronary artery bypass surgery grafting: a qualitative study. *BMC Cardiovasc Disord.* 2025;25(1):529. doi:10.1186/s12872-025-04996-y
55. Lin ML, Huang CT, Chen CH. Reasons for family involvement in elective surgical decision-making in Taiwan: a qualitative study. *J Clin Nurs.* 2017;26(13–14):1969–1977. doi:10.1111/jocn.13600

56. Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment? *BMJ*. 1999;319(7212):780–782. doi:10.1136/bmj.319.7212.780
57. Yan S, Wang D, Huang Q, et al. Examining cancer patient preferences during three stages of decision making and family involvement: a multicenter survey study in China. *BMC Med Inform Decis Mak*. 2025;25(1):9. doi:10.1186/s12911-024-02846-z
58. Salm H, Schuler MK, Hentschel L, et al. Preferences on treatment decision making in sarcoma patients: prevalence and associated factors - results from the PROSa study. *Oncol Res Treat*. 2025;48(4):174–185. doi:10.1159/000543456
59. Drewniak D, Brandi G, Buehler PK, et al. Key factors in decision making for ECLS: a binational factorial survey. *Med Decis Making*. 2022;42(3):313–325. doi:10.1177/0272989x211040815
60. Sio TT, Chang K, Jayakrishnan R, et al. Patient age is related to decision-making, treatment selection, and perceived quality of life in breast cancer survivors. *World J Surg Oncol*. 2014;12:230. doi:10.1186/1477-7819-12-230
61. Ambigapathy R, Chia YC, Ng CJ. Patient involvement in decision-making: a cross-sectional study in a Malaysian primary care clinic. *BMJ Open*. 2016;6(1):e010063. doi:10.1136/bmjopen-2015-010063

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