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Effect of Health Literacy on Decision-Making Preferences among Medically Underserved Patients

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Abstract

Introduction—Participation in the decision-making process and health literacy may both affect health outcomes; data on how these factors are related among diverse groups are limited. This study examined the relationship between health literacy and decision-making preferences in a medically underserved population.

Methods—We analyzed a sample of 576 primary care patients. Multivariable logistic regression was used to examine the independent association of health literacy (measured by the Rapid Estimate of Adult Literacy in Medicine-Revised) and patients' decision-making preferences (physician-directed or patient-involved), controlling for age, race/ethnicity, and gender. We tested whether having a regular doctor modified this association.

Results—Adequate health literacy (OR=1.7; p=0.009) was significantly associated with preferring patient-involved decision-making, controlling for age, race/ethnicity, and gender. Having a regular doctor did not modify this relationship. Males were significantly less likely to prefer patient-involved decision-making (OR=0.65; p=0.024).

Discussion—Findings suggest health literacy affects decision-making preferences in medically underserved patients. More research is needed on how factors, such as patient knowledge or confidence, may influence decision-making preferences, particularly for those with limited health literacy.

Keywords

shared decision making; health literacy; medically underserved patients

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CONFLICTS OF INTEREST

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INTRODUCTION

In the United States, there has been a recent shift in decision-making models toward shared decision-making [1, 2]. With growing emphasis on patient-centered care, shared decision-making can better align medical decisions with the patient's preferences for care [3–5]. Shared decision-making might be particularly important to improve outcomes among patients with limited health literacy, which is about 36% of U.S. adults [6]. Research shows that individuals with limited health literacy are more likely to be hospitalized and make medication errors and less likely to obtain preventive care and know how to manage their health problems [7–9].

However, research on the relationship between health literacy and decision-making preferences is limited [10–13]. Most prior studies have been framed around disease-specific contexts [10, 12–18], have largely examined white, highly educated, or female populations [11–13, 16–20], or have not specifically assessed decision-making preferences [17–20]. Examination of decision-making preferences among medically underserved groups is particularly warranted as research suggests that shared decision-making interventions may provide greater benefits for disadvantaged groups [21].

Our study examined the relationship between health literacy and decision-making preferences in a medically underserved population. We hypothesized that patients with limited health literacy would be more likely to prefer a physician-directed decision-making role than patients with adequate health literacy. We also explored whether having a regular doctor would modify this association.

METHODS

Setting

This study was conducted in the Primary Care Clinic in the Center for Outpatient Health (COH) at Barnes-Jewish Hospital, a large urban hospital. The COH primarily serves a medically underserved population drawn from St. Louis, Missouri and the surrounding region and is the primary training site for a large internal medicine residency program.

Data collection

Between July 2013 and April 2014, patients in the waiting rooms of the COH were approached by trained data collectors and asked to complete a self-administered written questionnaire and an assessment of health literacy that was verbally administered by a data collector. To be eligible for the study, participants had to be at least 18 years old, be a patient at the COH, and speak English. The primary reason for incomplete surveys was inadequate time between the start of the survey and when the clinic was ready to begin the patient evaluation. There were no significant differences in gender between individuals with complete surveys and those with incomplete surveys; a higher proportion of those not completing the survey were African Americans (75%) compared with those who completed the survey (63%; $p=0.003$). Survey respondents were similar to the underlying COH primary care clinic patient population with respect to gender, age, race, and location of residence. All participants completed a verbal consent process and signed a written consent form before

completing the survey. This study was approved by the Human Research Protection Office at Washington University School of Medicine.

Measures

The outcome variable was patient decision-making preferences, measured by asking: “Which statement best describes how you would like decisions about medical treatments to be made?”. Response options were on a 5-point scale, adapted from the Control Preferences Scale [22]: I prefer to leave the decision to my doctor (1), I prefer that my doctor makes the decision, but seriously considers my opinion (2), I prefer that my doctor and I share responsibility for deciding (3), I prefer to make my own decision after seriously considering my doctor’s opinion (4), and I prefer to make my own decision regardless of my doctor’s opinion (5) [16]. For analysis, responses were categorized as physician-directed (1–2) or patient-involved (3–5) decision-making preference [13, 23], with the latter including any level of patient involvement from shared to patient-directed decision-making.

The primary predictor was patient health literacy, measured by the Rapid Estimate of Adult Literacy in Medicine-Revised (REALM-R), a validated word recognition measure where individuals are asked to read eight common medical words aloud [24]. Patients who pronounced 7–8 words correctly were categorized as having adequate health literacy, and those with 0–6 correct responses as limited health literacy. Additional covariates included age (measured continuously), whether they had a regular doctor or health professional (yes/no), race/ethnicity, and gender. Race/ethnicity was categorized as non-Hispanic White (reference group), non-Hispanic Black, and Other. Gender was categorized as male or female (reference group).

Analysis

An analytic sample of 576 patients who had completed measures of health literacy and decision-making preferences was used for this analysis (Figure 1). Patients were categorized into patient-involved or physician-directed decision-making preferences, and bivariate analysis was used to examine patient characteristics that significantly differed between these two groups. Multivariable logistic regression analysis was used to examine the independent association of health literacy and decision-making preferences, controlling for sociodemographic characteristics. To investigate whether having a regular doctor moderated this relationship, we tested the interaction of health literacy and having a regular doctor on decision-making preferences in a multivariable model. All statistical analyses were conducted using SPSS for Windows, Version 20 (IBM Corp., Armonk, NY). Statistical significance was assessed as $p < 0.05$.

RESULTS

Demographic characteristics are shown in Table 1. The mean age of patients was 51 years (range: 20–93); 66% were female, and 60% identified as non-Hispanic Black. The majority of patients (54%) had no more than a high school diploma/GED; 47% had a yearly household income less than \$10,000. About half (45%) had limited health literacy; 58%

preferred patient-involved decision-making. Most patients (67%) reported having a regular doctor.

In bivariate analysis (Table 2), health literacy was significantly associated with decision-making preferences ($p < 0.001$), with patient-involved decision-making more preferred among those with adequate health literacy (65%) compared to those with limited health literacy (50%). Decision-making preferences were also significantly associated with gender, race/ethnicity, and education level ($p < 0.05$).

In an unadjusted model, adequate health literacy was significantly associated with preferring patient-involved decision-making (OR=1.88; $p < 0.001$; 95% CI=1.35–2.63). This association was also significant in an adjusted model controlling for age, gender, and race/ethnicity (OR=1.66; $p = 0.009$; 95% CI=1.14–2.42). Gender was significantly associated with decision-making preferences in this model, with males less likely to prefer patient-involved decision-making (OR=0.65; $p = 0.024$; 95% CI=0.45–0.94). When we added having a regular doctor to the multivariable model, this variable was not a significant predictor of decision-making preferences ($p = 0.958$), and the interaction between having a regular doctor and health literacy on decision-making preferences was not significant ($p = 0.560$).

DISCUSSION

To our knowledge, this study is novel in its examination of health literacy and decision-making preferences specifically among medically underserved patients. In our study, patients with adequate health literacy were almost two times more likely than those with limited health literacy to prefer patient-involved decision-making. This finding is consistent with previous work [10, 12] and highlights the impact of health literacy on the decision-making process. Patients with limited health literacy may have difficulty understanding medical information and lack the self-efficacy to be actively involved in their care [12, 18]. Due to the stigma of low health literacy, some patients may also experience feelings of shame, thereby not admitting their difficulties or seeking assistance when needed [25, 26]. Future research should examine the influence of factors such as patient knowledge, self-efficacy, and perceptions of stigma on decision-making preferences among those with limited health literacy.

Furthermore, patients with limited health literacy may be unaware of their options to participate in decision-making, instead assuming physicians know the best course of action. Particularly in cases where no clear solution exists, however, the engagement of patients and consideration of their values is important [27]. Physicians should clearly provide contextual information and available options, as improved communication can facilitate patients' informed decision-making preferences. While some patients may ultimately prefer to leave decisions to their physicians, they may want to be engaged in the process [27]. This suggests that a broader definition of shared decision-making should be considered and that physicians should recognize patients' expressed preferences regarding their decision-making role.

Additionally, gender was a significant predictor of decision-making preferences in our study, consistent with other research indicating that females prefer a patient-involved decision-

making role [28–30]. We did not find other sociodemographic characteristics, such as race/ethnicity and age, to be associated with decision-making preferences, which differs from prior studies [15, 18, 28–32]. There may be other factors impacting decision-making preferences among this medically underserved population, further highlighting the importance of examining diverse patient populations.

Our hypothesis that having a regular doctor would modify the relationship between health literacy and decision-making preferences was not supported. Contrary to our findings, some prior research shows that having a well-established relationship with a health care provider may facilitate patient-involved decision-making for patients [33–35]. One explanation for our differing results is our variable of having a regular doctor did not take into account relational factors important for decision-making, such as trust and continuity. Due to the resident clinic structure of our setting, patients may be assigned a new regular provider every three years and do not necessarily see the same physician for every visit. More research is needed on how patient-provider relationships might affect decision-making preferences among patients with varying health literacy levels and who are seen in different health care contexts.

These findings should be interpreted given study limitations. The outcome was measured by a single question, and general decision-making preferences were assessed rather decision-making preferences for a specific decision. Additionally, while health literacy was measured using a validated instrument, existing measures do not capture all domains of health literacy [36]. Secondly, convenience sampling was used to recruit patients, limiting the generalizability of results. As patients in this study were a difficult-to-reach, underserved population in a busy primary care clinic, the response and survey completion rates were low; as such, the survey participants may not be representative of the whole patient population. To generalize these findings, more work is needed with other medically underserved populations. Finally, this study assessed patients at a single point, but health literacy and decision-making preferences may change over time. Furthermore, individuals preferring a patient-involved role may engage in behaviors to improve their health literacy; examining the causal direction of this association is an area for future research.

Conclusion

This study addresses an important research gap in its examination of health literacy and decision-making preferences among medically underserved patients. Multiple factors may contribute to patients' decision-making preferences, notably health literacy. Results suggest that interventions to promote shared decision-making may be particularly important for patients with limited health literacy. Since health literacy is a dynamic between the individual's capabilities and the demands of a health care system [37, 38], interventions are likely needed both to assist patients with limited health literacy to participate in decision-making, as well as to support physicians in engaging with patients [13, 27]. Future research should examine other factors associated with decision-making preferences to identify additional points of intervention.

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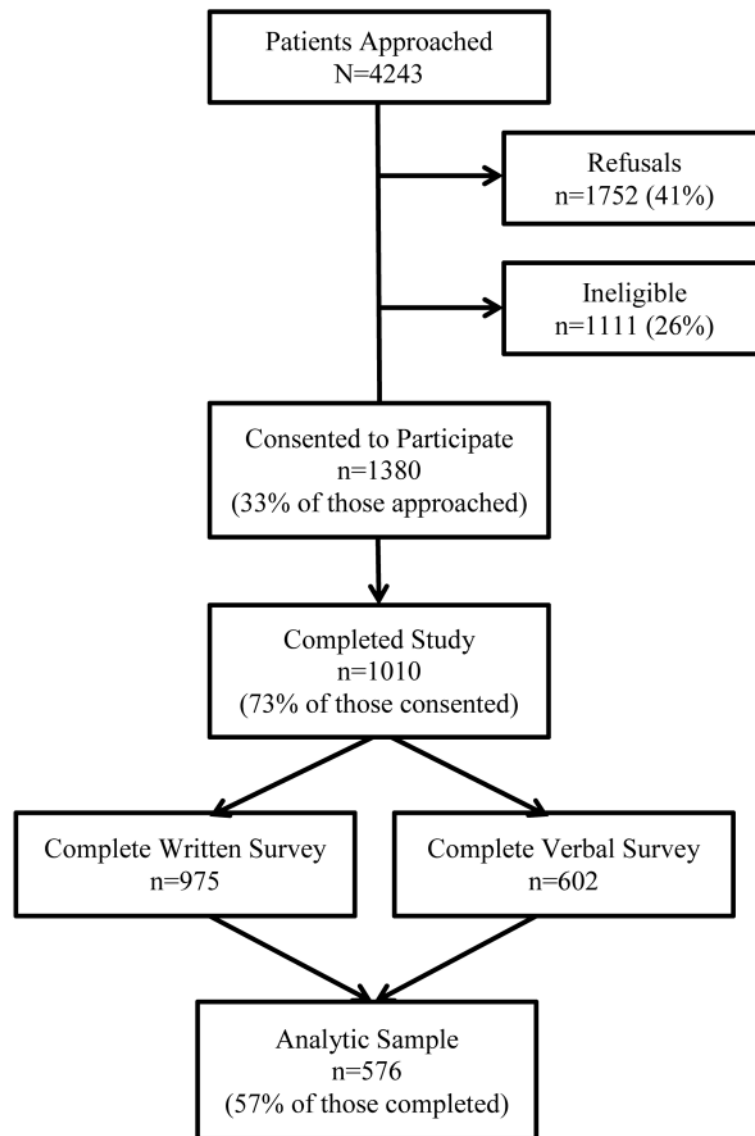


Figure 1.
Recruitment flow diagram

Table 1

Patient characteristics

Characteristic	<i>n</i>	%
Gender (n=565)		
Female	373	66.0
Male	192	34.0
Race/Ethnicity (n=565)		
Non-Hispanic White	189	33.5
Non-Hispanic Black	339	60.0
Other	37	6.5
Education Level (n=550)		
Less than high school degree	90	16.4
High school diploma/GED	207	37.6
Some college/Associate degree	168	30.5
College degree or higher	85	15.5
Employment Status (n=551)		
Employed	96	17.4
Unemployed	113	20.5
Retired	57	10.3
Disabled	225	46.3
Other	30	5.4
Household Income (n=515)		
<\$9,999	240	46.6
\$10,000-\$29,999	186	36.1
\$30,000-\$49,000	56	10.9
\$50,000+	33	6.4
Marital Status (n=568)		
Married/Living as married	137	24.1
Widowed	40	7.0
Divorced/Separated	195	34.3
Never married	196	34.5
Decision-Making Preference (n=576)		
Leave decision to doctor	109	18.9
Doctor makes decision, but seriously considers patient's opinion	133	23.1
Doctor and patient share responsibility	218	37.8
Make own decision after seriously considering doctor's opinion	97	16.8
Make own decision regardless of doctor's opinion	19	3.3
Health Literacy (n=576)		
Limited	262	45.5
Adequate	314	54.5
Have Regular Doctor (n=550)		
No	184	33.5

Characteristic	<i>n</i>	%
Yes	366	66.5
Perceived Health Status (n=561)		
Good/Excellent	216	38.5
Fair	255	45.6
Poor	90	16.0
	<i>n</i>	<i>mean (SD)</i>
Age	552	50.7 (11.676)

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Bivariate associations between decision-making preferences and patient characteristics

Table 2

	Physician-Directed Decision-making		Patient-Involved Decision-making		<i>t</i> or χ^2 ; <i>p</i> -value
	<i>n</i>	%	<i>n</i>	%	
Health Literacy (n=576)					13.81; p=<0.001
Limited	132	50.4	130	49.6	
Adequate	110	35.0	204	65.0	
Gender (n=565)					7.45; p=0.006
Female	140	37.5	233	62.5	
Male	95	49.5	97	50.5	
Race/Ethnicity (n=565)					6.52; p=0.038
Non-Hispanic White	72	38.1	117	61.9	
Non-Hispanic Black	155	45.7	184	54.3	
Other	10	27.0	27	73.0	
Education Level (n=550)					18.52; p=<0.001
Less than high school degree	52	57.8	38	42.2	
High school diploma/GED	96	46.4	111	53.6	
Some college/Associate degree	54	32.1	114	67.9	
College degree or higher	31	36.5	54	63.5	
Employment Status (n=551)					3.54; p=0.472
Employed	42	43.8	54	56.3	
Unemployed	51	45.1	62	54.9	
Retired	23	40.4	34	59.6	
Disabled	107	42.0	148	58.0	
Other	8	26.7	22	73.3	
Household Income (n=515)					6.52; p=0.089
<\$9,999	105	43.8	135	56.3	
\$10,000-\$29,999	67	36.0	119	64.0	
\$30,000-\$49,000	30	53.6	26	46.4	
\$50,000+	12	36.4	21	63.6	
Marital Status (n=568)					0.92; p=0.821

	Physician-Directed Decision-making		Patient-Involved Decision-making		<i>t</i> or χ^2 ; <i>p</i> -value
	<i>n</i>	%	<i>n</i>	%	
Married/Living as married	59	43.1	78	56.9	
Widowed	16	40.0	24	60.0	
Divorced/Separated	77	39.5	118	60.5	
Never married	86	43.9	110	56.1	
Have Regular Doctor (n=550)					0.36; p=0.548
No	73	39.7	111	60.3	
Yes	155	42.3	211	57.7	
Perceived Health Status (n=561)					2.47; p=0.292
Good-Excellent	86	39.8	130	60.2	
Fair	115	45.1	140	54.9	
Poor	33	36.7	57	63.3	
Age (Mean, SD) (n=552)	50.68	12.19	50.75	11.32	-0.07; p=0.942