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Health Literacy and Decision Making Styles for Complex Antithrombotic Therapy Among Older Multimorbid Adults

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Abstract

Objectives—To evaluate the effect of functional health literacy (FHL) on preferences for decision-making; and among those initially preferring a passive decision-making role, to explore how preferences change if their physician actively encourages their involvement.

Methods—Consecutive older adults with cardiovascular disease receiving complex antithrombotic therapy completed a comprehensive assessment including measures of FHL and preferences for shared decision making.

Results—Half of all participants had inadequate or marginal FHL. Those with inadequate FHL were more likely ($p=0.01$) to prefer passive rather than active decision making styles even after controlling for age, education, and numeracy. However, 40% of patients preferring passive styles had adequate FHL and these patients were significantly more likely to change their preference to more active styles (Odds Ratio = 7.17, $P<.01$) if their physician “was more supportive or encouraged participation.”

Conclusions—Screening FHL can provide insight into patients’ preferences for active participation in decision making. Clinicians’ encouragement of participation can increase engagement by patients with adequate FHL.

Practice Implications—We propose an algorithm for screening FHL and preferences for participating in decisions about complex medication regimens.

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Aging; Drugs; Prevention; Literacy; Doctor-patient relationship

1. INTRODUCTION

A fundamental principle of patient-centered care and informed decision-making is active patient participation in the decision-making process [1-3]. However, patients vary in their desire to participate in shared decision-making [4,5], with a number of patients preferring passive roles and deferring decisions to their physician. While there may be several reasons underlying a preference for less personal control over medical decision-making, two factors explored in this study are reduced capacity due to the patient's limited functional health literacy (FHL) and the lack of physician support for greater patient participation.

Over one-third of all Americans have limited FHL [6]. For these patients, routine tasks such as understanding informational brochures, providing informed consent, and even reading their medication bottles may be difficult. Impairments in functional health literacy (FHL) are higher in patients with low educational attainment, multiple chronic conditions, and older age [7], all of which are variables associated with preferences for a more passive role in medical decision-making [4,5]. The importance of diagnosing and addressing limited FHL is more than an academic exercise. Limited FHL is associated with increased hospitalizations for chronic illness [8], delayed or late diagnosis of cancer [9], and increased mortality in older adults [10]. Limited FHL may also influence outcomes through its effect on patients' capacity and willingness to participate in medical decision making and treatment planning [11]. The difficulty patients with limited FHL have in comprehending written materials and health-related information could be an important barrier to a patient's willingness to discuss preferences for care and difficulties with managing medication regimens. In previous studies, decreased willingness to participate among diabetics with low FHL was associated with oral communication problems for both English and Spanish speakers [12].

Yet, patient participation in decision-making is also strongly influenced by the physicians' communication style. A number of studies show that, when clinicians use partnering and facilitative communication (e.g. soliciting the patient's agenda, asking about their preferences, accommodating requests, avoiding interruptions), patients are more likely to be assertive, ask questions, express their concerns and participate in decision-making [13-16]. Thus, an important clinical question is whether patients who initially report a preference for a more passive role in decision-making will change their preference if their clinician encouraged their involvement and whether FHL would affect this change in preferences.

In this study, we examine the impact of FHL on patients' willingness to discuss and plan treatments that involve multiple or complex antithrombotic treatment (CAT) regimens, a largely underexplored area. While there is sufficient evidence to suggest that patients with limited FHL will have difficulty with written and oral communication regarding complex medication regimens [17], the relation of limited FHL and preferences for participating in decision making regarding complex drug treatments are poorly understood. Research exploring the moderating role of physician facilitation and support of patient involvement in decision making is needed, as decision making preferences may be mutable [18]. An important clinical question is whether patients inclined to be passive decision makers would prefer to become more active if physicians encouraged their involvement. Furthermore, what role does FHL play in this relationship, and can we identify easy-to-use FHL screening questions that can be integrated into routine doctor-patient encounters?

The current study has two objectives. The first objective is to characterize the association of FHL and older, multimorbid patients' preferences for involvement in decision making about complex drug regimens. The second objective is to determine the affect of FHL on patients' willingness to switch from a passive to active decision making style if their clinician supported and encouraged participatory decision making.

2. METHODS

2.1 Study Participants and Procedures

Study participants were recruited from a sample of patients attending a group cardiology practice at the Michael E. DeBakey VA Medical Center. Potential participants received a recruitment letter and were approached prior to their next clinic appointment if they reported discussing treatment regimens for a cardiovascular condition that included the use of aspirin, and an anti-platelet or anti-coagulant medication. Of 118 patients approached for participation, 100 (85%) consented to participate. There were no significant socio-demographic differences between these groups. To avoid volunteer bias common in literacy studies [19,20], participants were informed that the investigators were "looking at how patients understand healthcare information and what they think about when communicating with their doctor." Study participants completed a two-part questionnaire. The first portion consisted of a self-report survey administered just prior to the scheduled clinic appointment with their cardiologist. The second portion consisted primarily of assessments administered by the research coordinator immediately following the patient's scheduled appointment. To lessen the impact of unmasking low literacy, the research assistant was trained to express the following sentiment, "I am not here to embarrass you, frustrate you, or make you feel uncomfortable. I am willing to stop if you want to, but the information you can give me is very special and valued highly by all of us here...(pause)...may I continue?" The study protocol was approved by the Institutional Review Committee at Baylor College of Medicine and all participants gave informed consent.

2.2 Study Variables

The self-reported survey conducted prior to the physician visit included standard socio-demographic and functional status questions and a well-validated, one-item measure of patients' preference for decision making (decision making style) [21]. The decision making style item states, "When it comes to making decisions about my care, I am most comfortable when." Survey respondents choose from one of five response options which were dichotomously scored to reflect *active* versus *passive* styles for decision making. An active decision making style was defined by the responses, "I make the final selection with little input from the doctor", "I make the final decision after considering the doctor's opinion", or "The doctor and I share responsibility for decision treatment." In contrast, a passive decision making style was defined by the responses, "I leave decisions about treatment to my doctor", or "The doctor makes final decisions but considers my opinion." After completing a routine visit with their physician, participants were then asked to complete the second (assessment) portion of the study. This assessment began with the Short Test of Functional Health Literacy in Adults (S-TOFHLA), a 36-item, 7-minute timed test of reading comprehension validated as a reliable and valid measure of functional health-related literacy (FHL) [12]. The S-TOFHLA contains two health care passages and tests literacy using the Cloze procedure in which every fifth to seventh word in a passage is omitted and multiple-choice options are given [12,22]. The standardized convention for categorizing FHL using S-TOFHLA includes *adequate* (scores 23-36), *marginal* (17-22) characterized as having difficulty comprehending more complex materials like educational brochures, and *inadequate* (0-16) characterized by poor understanding of simple materials such as prescriptions, appointments, and nutrition labels [12]. In addition, participants were asked

one-item FHL screen questions (each with five possible response options) originally developed and validated against S-TOFLA by Chew et al [23], and subsequently validated in other studies using both the Rapid Estimate of Adult Literacy in Medicine (REALM) [24,25] and S-TOFLA [26]. These one-item screening measures include: (1) “How confident are you filling out medical forms by yourself?” (extremely, quite a bit, somewhat, a little bit, or not at all); and (2) “How often do you have someone help you read hospital materials?” (never, occasionally, sometimes, often, or always).

Participants also completed a validated 8-item test of respondents’ ability to convert frequencies into percentages, percentages and odds into frequencies, and compute changes in risks (health numeracy test), which was scored along a continuous range (0-8) [27]. Patients were then reminded about their reported preferences for participating in decisions (decision making style) related to their complex antithrombotic treatment regimen. Patients who originally reported a passive decision making style were asked about the mutability of their preference for a passive decision making style: “If my doctor was supportive and encouraged me to participate in my medical decisions, then my preference to participate would change? [yes/no]” (willingness to change decision making style). Participants who originally reported a preference for an active decision making style were not asked about their willingness to change decision making style.

2.3 Statistical Analysis

Participants were initially stratified into active versus passive decision making styles and descriptive statistics were used to identify participant characteristics that significantly differed between these two groups. These characteristics included socio-demographic traits, functional status, S-TOFLA category, and cardiovascular disease status and medication use. Bivariate and multivariate (Model 1) logistic regression examined the independent association of age, education, health numeracy score, and S-TOFLA category with participants’ response to *decision making style* question [active versus passive]. Another multivariate analysis (Model 2) examined the independent association of age, education, and S-TOFLA category with participants’ response to the *willingness to change decision making style* question. Analyses for Model 2 only included participants who originally reported a passive decision making style. Diagnostic statistics (sensitivity, specificity, and likelihood ratios) were calculated for the one-item FHL screening measures to ascertain the validity of identifying patients with inadequate FHL as defined by S-TOFLA categories. The diagnostic validity of responses to these one-item FHL screening measures with S-TOFLA results in the current study was similar to results found in the published literature (data not shown) [23,26]. All statistical analyses were two-sided with a significance threshold of $P < 0.05$.

3. RESULTS

Among patients agreeing to participate in the current study, 54% reported a preference for an active decision making style with their cardiologist regarding their complex antithrombotic therapy. Half of all study participants had inadequate (33%) or marginal (17%) FHL. Participants with inadequate FHL were significantly more likely ($p=0.01$) to report a preference for passive rather than active decision making style. Table 1 describes the distribution of FHL categories by decision making style. Participants preferring passive decision making style (46%) were older, had lower health numeracy scores, and less likely to use an aspirin plus anticoagulant drug combination (see Table 1). There were no significant differences in gender, race, functional status, years of education, number of comorbidities, occupation type, prevalence of particular cardiovascular diseases, or other medication combinations between those reporting active versus passive decision making styles (see Table 1). Among those initially preferring a passive style, more than half (54%)

reported a willingness to change their decision making if their cardiologist encouraged their participation.

Using two multivariate logistic regression models, factors associated with preferences for *decision making style* (Model 1) and *willingness to change decision making style* (Model 2) were examined (see Table 2). In Model 1, age, education, and health numeracy score were not significantly associated with reporting an active decision making style. However, both adequate (odds ratio = 3.29 [1.12 to 9.69]) and marginal (odds ratio = 4.22 [1.06 to 16.9]) categories compared with an inadequate S-TOFLA category were significantly associated with preferring an active decision making style (see Table 2). Only participants with a preference for passive decision making style (46% of the sample) were included in Model 2, which assessed the *willingness to change decision making style* question as the dependent variable. In this model, adequate FHL category compared to inadequate FHL category was significantly associated with willingness to change decision making style (see Table 2). Marginal FHL category compared to inadequate FHL category, age and education were not significantly associated with willingness to change preference.

4.1 DISCUSSION

In this sample of older, multimorbid patients taking complex antithrombotic therapy for cardiovascular illnesses, half had marginal or inadequate functional health literacy (FHL) and nearly half reported a preference for a passive decision making style when discussing their antithrombotic regimens. After controlling for age, education and numeracy scores, adequate or marginal FHL was significantly associated with choosing an active decision making style. However, almost 40% of patients citing a preference for a passive style had adequate FHL. This is an important group to highlight as adequate FHL was independently associated with willingness to switch from passive to active decision making style if physicians supported and encouraged participation in complex antithrombotic regimen discussions.

The prevalence of inadequate and marginal FHL in this study was significantly higher than prior studies evaluating FHL in primary care settings [25-26]. Compared to prior studies evaluating FHL in primary care, subjects in the current study were older and had multiple chronic morbidities. The clinical significance of limited FHL, particularly for older adults with complex medical conditions, is well characterized [7]. Moreover, the importance of active decision making in the management of complex and chronic illnesses is also well documented [11,16,28,29]. The differences in the distribution of FHL categories between participants reporting active versus passive decision making styles in the current study were statistically significant. These differences may provide a rationale for the poorer clinical outcomes of patients with limited FHL described in prior studies [7]. Our findings are similar to other studies done in primary care clinics suggesting that patients with limited FHL ask fewer questions [30], and have difficulty discussing technical or explanatory aspects of medical decisions [12]. Furthermore, physicians' communication and encouragement of their patients' involvement in planning, deciding, implementing, and modifying complex regimens cannot be understated as these factors have been correlated with patient adherence to medications [31]. Among patients prescribed CAT, medication adherence is ultimately a key health services outcome since adherence to these complex regimens is highly correlated to their clinical effectiveness [32]. This study also found novel evidence suggesting that physician encouragement and support of active decision making was likely to encourage patients with adequate (but not those with limited) FHL to change from passive to active decision making style. Previous studies have only evaluated the relation of FHL and perceptions of physician's supportive behavior [11], but not the relative

importance of encouraging or supportive behavior in facilitating active decision making style.

4.2 Conclusion

Limited FHL is highly prevalent among older patients taking complex antithrombotic therapy and these patients seem to prefer a more passive decision making style. Physicians can encourage more active decision making styles, especially among patients with adequate FHL. Further research is needed to identify strategies to encourage willingness to change to an active style among patients with limited FHL. Furthermore, the current study extends a growing body of evidence supporting the use of one to three brief questions to efficiently and pragmatically screen for limited FHL to now include older, multimorbid patients receiving chronic cardiovascular care [23-26].

4.2.1 Limitations

There are limitations to the current study. Most importantly, the sample size and overwhelmingly male, older age, and Veteran based population limit the generalizability of our study results. The sample size also contributes to the wide confidence intervals in the multivariate analyses. However, the current study provides novel and valid insights into a potential cause and remedy for poor patient engagement among an important high risk group. Second, the study design limits the ability to make causal inferences of the associations between predictor variables including FHL and preferences for decision making style. A prospective study may help to further characterize the predictive validity of FHL and participation in decision making about CAT regimens. Third, most measures were obtained by patient self-report; however, FHL was assessed using a well-validated performance measure [12].

4.3 Clinical Implications

Given the evidence that active patient participation in decision making and management of chronic conditions improves health outcomes, physicians should routinely take a supportive and encouraging approach to shared decision making and treatment planning for complex antithrombotic therapy [7,16]. However, in some circumstances, patients may not be responsive to such partnership-building because of inadequate health literacy. Our results provide additional support for the use of FHL screening in treating complex patients. Not only would such an assessment provide insight into potential difficulties the patient may have in understanding information and treatment options, it would also help determine which patients may need additional help in becoming involved in the decision-making and treatment planning.

Screening for FHL can be done using one-item measures that can be included in intake forms and other materials often completed prior to a medical visit or as part of a comprehensive History and Physical exam done on a first visit. FHL screening measures are more likely to elicit a valid and reliable response if they are seen as routine or matter-of-fact. Figure 1 provides a clinical pathway for screening FHL and discussing prescriptions for complex medication regimens based on preferences for decision making style and responses to FHL screening measures. If a patient begins the clinical encounter using an active decision making style, then the physician can simply continue to support a participatory approach (see Figure 1, second box). Conversely, if the patient is acting with a passive decision making style, then the physician can review responses to FHL screening measures (see third box, Figure 1). The clinical utility of these screening tools lies in their ability to confidently identify the subgroup of patients with inadequate or marginal FHL who appear resistant to adopting a more active decision making style. For example, if patients respond

with “a little bit” or “not at all” to the question, “how confident are you filling out medical forms by yourself,” then it is unlikely that they have adequate FHL. This group of patients may benefit more from an approach that reduces the cognitive and literacy barriers to medication management given that their style during doctor-patient encounters is likely to remain passive. However, all other responses to this screening question would suggest a higher likelihood of adequate FHL. Additional behaviors by physicians that nurture patient activation and participation in decision making for complex antithrombotic regimens could facilitate a gradual switch from a passive to active style (See Figure 1), which in turn could contribute to better cardiovascular outcomes.

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Figure 1. Clinical Pathway for Integrating Preferences for Decision Making Style and Screening Measures of Functional Health Literacy in Patients Taking Complex Medication Regimens

*Appropriate settings to screen for FHL include waiting room and patient intake forms, initial History & Physical exams, etc.

Measure 1: "How confident are you filling out medical forms by yourself?" Response

Options are: "not at all", "a little bit", "somewhat", "quite a bit", and "extremely"

Measure 2: "How often do you have someone help you read hospital materials?" Response

Options are: "never", "occasionally", "sometimes", "often", and "always".

Table 1

Baseline Characteristics N = 100

Characteristic	Active Decision Making Style n = 54	Passive Decision Making Style n = 46	P
Age in years , mean (SD)	71.24 ± 5.79	74.52 ± 5.70	<0.01
Health numeracy score , mean (SD)	5.17 ± 2.84	3.91 ± 3.00	0.04
Number of Comorbidities , mean (SD)	5.98 ± 1.67	5.80 ± 2.01	0.64
Male Gender , n (%)	54 (100)	46 (100)	
Race , n (%)			0.50
White	43 (79.63)	34 (73.91)	
Other	11 (20.37)	12 (26.09)	
Education years , mean (range)			0.16
Any college, n (%)	31 (57.41)	20 (43.48)	
High school graduate or less, n (%)	23 (42.59)	26 (56.52)	
Occupation , n (%) *			0.85
“White Collar”	23 (42.59)	17 (36.96)	
“Blue Collar”	30 (55.56)	28 (60.87)	
Lives alone , n (%)	13 (24.07)	17 (36.96)	0.16
Dependent for help with daily activities , n (%)	16 (29.63)	17 (36.96)	0.44
S-TOFHLA , mean (SD)			<0.01
Inadequate (score 1 – 53), n (%)	9 (16.67)	24 (52.17)	
Marginal (score 54 – 66), n (%)	12 (22.22)	5 (10.87)	
Adequate (score 67 – 100), n (%)	33 (61.11)	17 (36.96)	
Cardiovascular disease , n (%)			
Coronary artery disease	45 (83.33)	34 (73.91)	0.25
Atherosclerosis	6 (11.11)	2 (4.35)	0.21
Atrial Fibrillation	13 (24.07)	16 (34.78)	0.24
Cerebral Vascular Accident	1 (1.85)	1 (2.17)	0.91
Myocardial infarction	28 (51.85)	23 (50.00)	0.85
Use of Cardioprotective agents , n (%)			
Low-dose Aspirin	44 (81.48)	37 (80.43)	0.89
Clopidogrel	22 (40.74)	17 (36.96)	0.70
Warfarin	19 (35.19)	9 (19.57)	0.08
Complex antithrombotic therapy , n (%)			
ASAP	17 (31.48)	14 (30.43)	0.91
ACAP	6 (11.11)	2 (4.35)	0.21
ASAC	14 (25.93)	4 (8.70)	0.03
TRIP	6 (11.11)	2 (4.35)	0.21

S-TOFHLA = Short Test of Functional Health Literacy in Adults

ASAP = low-dose aspirin + antiplatelet agent (i.e., clopidogrel or ticlopidine)

ACAP= anticoagulant agent (i.e., warfarin, dicumarol, enoxaparin) + antiplatelet agent

ASAC= low-dose aspirin + anticoagulant agent

TRIP= low-dose aspirin +antiplatelet agent +anticoagulant agent

“Blue Collar” = Skilled manual laborers, other laborers, and homemakers

“White Collar” = Managerial positions, professional positions, technical positions, administrative and clerical positions

*
Two participants did not respond

Table 2

Functional Health Literacy and Preferences for *Decision Making Style* and *Willingness to Change Decision Making Style* Among Multimorbid Patients Receiving Complex Anti-thrombotic Therapy (CAT)

Independent Variables	Model 1 (n=100) ^a	Model 2 (n=46) ^b
-----Odds Ratios (95% Confidence Interval)-----		
Age	0.95 (0.87-1.03)	1.08 (0.94-1.24)
Education		
Any College *	1.44 (0.59-3.54)	1.16 (0.31-4.29)
Numeracy Score	1.09 (0.93-1.28)	
S-TOFHLA		
Adequate †	3.29 (1.12-9.69)	7.17 (1.21-41.1)
Marginal †	4.22 (1.06-16.9)	1.24 (0.15-10.9)

S-TOFHLA = Short Test of Functional Health Literacy in Adults

^a Model 1 = Multivariate logistic regression with *decision making style* as the dependent variable among all study participants.

^b Model 2 = Multivariate logistic regression with *willingness to change decision making style* as the dependent variable among those originally reporting preference for “passive” *decision making style*.

* reference = high school graduate or less

† reference = inadequate