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# Do Brief Screening Questions or Provider Perception Accurately Identify Persons with Low Health Literacy in the HIV Primary Care Setting?

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## Abstract

Rapid and accurate health literacy screening tools could assist interventions to improve care in the HIV clinic setting. Prior studies described brief screening questions for identification of persons with low health literacy, but the performance of these questions in HIV clinics is unknown. We examined the accuracy of provider perception and previously described brief screening questions for identification of low health literacy among 147 persons attending two HIV specialty clinics. Mean age was 41 and 48% were African American. Using the short Test of Functional Health Literacy in Adults (S-TOFHLA) as reference measure, the combined prevalence of marginal and inadequate health literacy (low health literacy) was 16%. Sensitivity and specificity of provider perception for identifying persons with low health literacy were 0.47 and 0.79. The screening question "How confident are you filling out medical forms by yourself?" had an area under the receiver operator characteristic curve (AUROC) of 0.67. Response of "somewhat" to this question had sensitivity 0.30, specificity 0.91, positive likelihood ratio 3.4 (95% confidence interval [CI] 1.8–6.4) and negative likelihood ratio 0.76 (95% CI 0.4–1.4). Educational attainment was a more sensitive but less specific measure of low health literacy (sensitivity 0.90, specificity 0.61 for completed high school or fewer years education), but was overall a more accurate discriminator of health literacy than either provider perception or screening questions (AUROC 0.79;  $p < 0.05$  for comparison of AUROCs). HIV providers often misjudge patients' health literacy. In the absence of rapid and accurate health literacy screening tools, clinics caring for persons with HIV/AIDS should implement clinic-wide interventions to improve health communication.

## Introduction

THE NATIONAL LIBRARY OF MEDICINE defines health literacy as "the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions."<sup>1</sup> Among persons with HIV, prior studies have associated low health literacy with lower HIV-specific knowledge, inconsistent use of antiretroviral therapy, and worse health outcomes.<sup>2–4</sup> Among African Americans with HIV, low health literacy may contribute to attitudes that discourage acceptance of their HIV diagnosis.<sup>5,6</sup>

Literacy limitations carry significant social stigma, and persons with health literacy barriers may not discuss their

difficulties comprehending health information and navigating the healthcare system with providers.<sup>7</sup> Prior studies outside of the HIV care setting indicate that providers are often unaware when patients face health literacy barriers.<sup>8–10</sup> This has led to interest in developing rapid health literacy screening tools for use in the clinical setting, although such screening remains controversial.<sup>11–13</sup> Several instruments exist for measurement of health literacy, but even abbreviated versions such as the Short Test of Functional Health Literacy in Adults (S-TOFHLA) require 7 minutes or more to administer and are not practical during busy clinic encounters.<sup>14</sup>

Various investigators have developed rapid health literacy screening tools that require only a few minutes to complete.<sup>12,13,15</sup> Chew and colleagues<sup>12</sup> described brief health

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literacy screening questions that assess an individual's ability to understand information or perform tasks encountered in the health care setting. When compared to existing health literacy measures, the best of these questions performed moderately well in identifying persons with low health literacy, as measured by areas under the receiver operator characteristic curve (AUROC) ranging from 0.65 to 0.87.<sup>12,16,17</sup> Attempts to improve performance of the screening tool by estimating a summary score from a combination of questions have been unsuccessful.<sup>16,17</sup>

Rapid and accurate screening tools for identification of persons with low health literacy could guide interventions to improve care in the HIV primary care setting. However, the HIV primary care setting differs substantively from other healthcare settings and this may cause health literacy screening questions to perform differently than in other settings. Prior studies of the accuracy of provider perception and brief screening questions for identifying persons with low health literacy generally involved older and largely Caucasian populations in Veterans Administration or academic clinics.<sup>16,17</sup> In comparison, persons in care for HIV are younger and more likely to be members of minority populations.<sup>18</sup> These demographic differences may impact performance of screening questions. In addition, HIV providers and patients must routinely discuss topics carrying significant stigma, such as HIV infection itself and the roles of high-risk sex and substance abuse in HIV transmission.<sup>19</sup> In this setting, persons with HIV may be more comfortable disclosing literacy barriers during encounters with providers and in responses to brief screening questions, leading to increased sensitivity for these measures. Alternatively, stigmas associated with HIV infection and low literacy may be cumulative, leading to greater reluctance to disclose literacy barriers and lower sensitivity for provider perception and brief screening questions in HIV clinics. Thus, it is necessary to validate the performance of previously described brief health literacy screening tools in the HIV primary care setting before considering their application in HIV care.

In this study, we examined the accuracy of provider perception and brief screening questions previously described by Chew et al.<sup>12</sup> for identifying persons with low health literacy in two HIV primary care clinics. We elected to evaluate the screening questions by Chew due to their simplicity, brevity, and prior validation in several studies outside the HIV care setting.<sup>17</sup> The primary goals of this study were: (1) to determine the accuracy of provider perception and brief screening questions for identification of persons with low health literacy in the HIV primary care setting and (2) to use these results to determine whether these questions may be useful in health literacy screening in HIV clinics. The secondary goal of this study was to compare the accuracy of brief screening questions to provider perception and simple patient-reported educational attainment. In the HIV primary care setting, we hypothesized that brief screening questions are a more accurate determinant of low health literacy than provider perception or self-reported education.

## Methods

### *Study design and participants*

This was a cross-sectional study of a convenience sample of persons presenting for appointments at two academically

affiliated HIV specialty clinics located in the central United States between June 2005 and June 2006 (Washington University in St. Louis, Missouri and University of Missouri in Columbia, Missouri). These are high-volume (combined HIV patient volume approximately 1000) dedicated HIV clinics operating within infectious disease specialty clinics and are staffed by a mixture of infectious disease specialists and infectious disease fellows in training. The Institutional Review Boards at Washington University and the University of Missouri approved the study. Patients were eligible if they had been seen at least once previously in the clinic. Exclusion criteria were age less than 21, known diagnosis of dementia or cognitive impairment, visual impairment (corrected vision worse than 20/50 as measured using Snellen eye chart), or persons for whom English was a second language (ESL). We realized that exclusion of ESL persons would limit the generalizability of study findings, however, the prevalence of ESL persons in study clinics was low and we expected that we would not enroll sufficient numbers of ESL persons to justify increasing the complexity of the study.

### *Data collection*

Patients were asked by providers to participate in the study during routinely scheduled clinic visits. During face-to-face interviews in private rooms adjacent to the clinic waiting rooms and after verbally obtaining informed consent, study personnel administered the S-TOFHLA to all participants.<sup>14</sup> The S-TOFHLA uses a modified Cloze procedure, requires approximately 7 min to administer, is reliable ( $\alpha = 0.97$  for reading measures), and has good criterion validity ( $r = 0.81$ ) compared to the Rapid Estimate of Adult Literacy in Medicine (REALM).<sup>14</sup> S-TOFHLA scores may range from 0 to 36, with scores 0–16 defined as “inadequate health literacy” and 17–22 as “marginal health literacy.”<sup>20</sup> We defined low health literacy as a score less than 23, including persons with either marginal or inadequate health literacy. Study personnel also read aloud a set of the 7 best-performing brief screening questions for identification of persons with limited health literacy as previously described by Chew et al.<sup>12</sup> (Table 1). Responses were scored along five level Likert scales (Table 1). Participants also reported demographic information including age, race/ethnicity, gender, and years of education.

Following the visit, study personnel identified the provider the patient had seen during the visit. Although all participating patients had previously been seen in clinic, one of the study sites employed provider teams, and it is possible that in this clinic a given provider may not have met the patient prior to the visit on the day of the study. After providing consent to participate in the study, providers were given the National Library of Medicine definition of health literacy and a description of health-related activities that may be difficult for patients with limited health literacy. Providers then reported their perception of which study participants under their care might have limited health literacy (yes or no).

### *Analysis*

The primary outcomes were the accuracies of provider perception, brief screening questions, and self-reported educational attainment for identification of participants

TABLE 1. BRIEF SCREENING QUESTIONS

How confident are you filling out medical forms by yourself?	1) Extremely	2) Quite a bit	3) Somewhat	4) A little bit	5) Not at all
How confident are you in following the instructions on the label of a medication bottle?	1) Extremely	2) Quite a bit	3) Somewhat	4) A little bit	5) Not at all
How often are appointment slips written in a way that is easy to read and understand?	1) Always	2) Often	3) Sometimes	4) Occasionally	5) never
How often do you have problems learning about your medical condition because of difficulty understanding written information?	1) Always	2) Often	3) Sometimes	4) Occasionally	5) never
How often are medical forms difficult to understand and fill out?	1) Always	2) Often	3) Sometimes	4) Occasionally	5) never
How often do you have difficulty understanding written information your health provider gives you?	1) Always	2) Often	3) Sometimes	4) Occasionally	5) never
How often do you have someone help you read clinic materials?	1) Always	2) Often	3) Sometimes	4) Occasionally	5) never

with low health literacy, using the S-TOFHLA as standard reference for health literacy measurement. Following the analyses of Chew and others, we used the AUROC as a measure of accuracy.<sup>12,16,17</sup> An ideal measure of low health literacy would produce AUROC of 1.0, while an AUROC of 0.5 indicates that a measure provides no information. For each measure we also determined sensitivities, specificities, and likelihood ratios (LR). Likelihood ratios combine information on sensitivity and specificity and provide a useful summary of the performance of screening questions at each response threshold.

We compared the accuracies of provider perception, brief screening questions, and educational attainment for identifying persons with low health literacy through comparison of AUROCs. Statistical analyses, including calculation of AUROCs and comparisons of AUROCs, were performed using MedCalc for Windows, version 10.4.0.0 (MedCalc Software, Mariakerke, Belgium). Comparisons of AUROCs accounted for correlation between measured AUROCs due to origination from the same sample.<sup>21</sup>

In order to evaluate the possibility that screening questions may perform better in combination, we created summary scores for all combinations of the three best-performing questions by summing the Likert responses. We also created summary scores for combination of screening questions and educational attainment (assigning numeric values to educational achievement levels: less than high school=1, completed high school=2, some college=3, completed college=4). We then compared the AUROC for summary scores to those for the best-performing screening question or educational status alone.

Our ability to estimate a sample size necessary to demonstrate that brief screening questions are a more accurate measure of low health literacy than provider perception was limited by difficulty estimating expected accuracies of each measure due to variation in measurement and reporting in prior studies.<sup>8,9,12</sup> We estimated that a sample of 150 would be reasonable to demonstrate that screening questions are more sensitive than provider perception, assuming a sensitivity of 50% for provider perception, sensitivity of 85% for screening questions, and a prevalence of 25% for low health literacy.<sup>3,4,8,9,12</sup> We also estimated that this sample size would provide adequate power to demonstrate that screening

questions are overall more accurate discriminators of low health literacy than provider perception, assuming low-literacy prevalence 25%, AUROC for questions 0.80, and provider perception AUROC 0.60. Estimates for input parameters were conservative; we selected values consistent with available literature that maximized the estimated sample size. Each calculation assumed probability of type I error ( $\alpha$ ) of 0.95 and type II error ( $\beta$ ) of 0.80.

## Results

We recruited 149 persons for the study. Two persons (1.3%) declined to participate, and no persons were excluded due to English as a second language (ESL). More patients were recruited from the Washington University clinic than the University of Missouri clinic (97 versus 50). The majority of participants were under 50 years of age and were men, and nearly half were African American (Table 2). The combined prevalence of limited and marginal health literacy, referred to subsequently as low health literacy, was 16%. Information on race/ethnicity and educational attainment was missing for four respondents and analyses of the accuracy of screening questions, educational attainment, and provider perception included the 143 respondents with complete data. The 143 respondents identified 21 separate care providers as their usual source of HIV care. Five providers were infectious disease fellows in training, and 16 were infectious disease staff physicians.

The overall best-performing brief screening question was "How confident are you in filling out medical forms by yourself?" with AUROC=0.67 (Table 3). A response of "somewhat" to this question had a sensitivity of 0.30 and specificity of 0.91. The associated LR+ was 3.4 (95% confidence interval 1.8–6.4) and LR– was 0.76 (95% confidence interval 0.4–1.4). A response of "somewhat" or less confident to this question would increase the odds of low health literacy 3.4-fold, while a more confident response would reduce the odds of low literacy by 0.76-fold.

The sensitivity and specificity of provider perception for identifying persons with low health literacy were 0.47 and 0.79. A provider's perception that a patient had low health literacy increased the odds of low health literacy 2.3-fold

TABLE 2. CHARACTERISTICS OF 147 RESPONDENTS

	n	Percent
Age		
18–30	25	17
31–40	48	33
41–50	50	34
51–65	24	16
Educational status		
College degree	24	16
Some college	53	36
High school complete	47	32
High school incomplete	19	13
Missing	4	3
Race–ethnicity		
African American	68	46
White, non-Hispanic	72	49
Hispanic	2	1
Other	1	1
Missing	4	3
Gender		
Men	104	71
Women	43	29
Health literacy		
Inadequate/marginal	23	16
Adequate	124	84

(LR+ 2.3, 95% confidence interval 1.5–3.5), while perception of adequate literacy decreased odds of low health literacy 0.66-fold (LR– 0.66, 95% confidence interval 0.4–1.1). Overall no screening question performed better than provider perception with statistical significance ( $p$  value 0.48 for comparison of AUROCs for provider perception and best-performing question).

Self-reported educational attainment was an overall more sensitive identifier of persons with low health literacy than provider perception or brief screening questions, but had lower specificity (sensitivity 0.90, specificity 0.61 for having completed high school or fewer years of education). Educational attainment was an overall more accurate discriminator of low health literacy than either provider perception or any screening question (AUROC = 0.79,  $p$  = 0.02 for comparison of AUROCs for educational status and provider perception; and  $p$  = 0.03 for comparison of AUROCs for educational status and question “How confident are you filling out medical forms by yourself?”).

Combination of responses to the best-performing screening questions as described above did not improve discrimination. Combination of educational status with the best-performing screening question also did not improve performance. The AUROC of combinations of questions or educational attainment for identifying low health literacy was not significantly

TABLE 3. PERFORMANCE OF BRIEF SCREENING QUESTIONS, PROVIDER PERCEPTION, AND EDUCATIONAL ATTAINMENT FOR IDENTIFYING PARTICIPANTS WITH LIMITED HEALTH LITERACY

Measure	AUROC (95%CI)	Sensitivity	Specificity	+LR (95% CI)	–LR (95% CI)
Provider perception	0.63 (0.55–0.71)	0.47	0.79	2.3 (1.5–3.5)	0.66 (0.4–1.1)
Confident with forms <sup>a</sup>					
≤ Extremely	0.67 (0.59–0.75)	1.00	0	1.0	
≤ Quite a bit		0.61	0.71	2.1 (1.5–3.0)	0.55 (0.3–1.0)
≤ Somewhat		0.30	0.91	3.4 (1.8–6.4)	0.76 (0.4–1.4)
≤ A little bit		0.09	0.95	1.8 (0.5–6.8)	0.96 (0.4–2.1)
≤ Not at all		0.09	0.98	3.6 (1.0–13)	0.94 (0.3–2.9)
Help read <sup>b</sup>					
≥ Never	0.64 (0.55–0.71)	1.00	0	1.0	
≥ Occasionally		0.39	0.86	2.9 (1.7–4.8)	0.71 (0.4–1.2)
≥ Sometimes		0.30	0.92	4.2 (2.3–7.8)	0.75 (0.4–1.5)
≥ Often		0.13	0.98	8.1 (2.8–23)	0.88 (0.2–3.5)
≥ Always		0.13	0.99	16.2 (5.6–46)	0.88 (0.1–6.2)
Problems learning <sup>c</sup>					
≥ Never	0.62 (0.54–0.70)	1.00	0	1.0	
≥ Occasionally		0.43	0.79	2.1 (1.3–3.3)	0.72 (0.4–1.2)
≥ Sometimes		0.30	0.90	2.9 (1.6–5.4)	0.78 (0.4–1.4)
≥ Often		0.09	0.98	5.4 (1.4–20)	0.93 (0.2–3.7)
≥ Always		0.04	0.98	2.7 (0.4–18)	0.97 (0.2–3.9)
Educational status					
≤ College degree	0.79 (0.72–0.85)	1.00	0	1.0	
≤ Some college		1.00	0.20	1.2 (0.9–1.8)	0.0
≤ High school complete		0.90	0.61	2.4 (1.9–2.9)	0.15 (0.1–0.6)
≤ High school incomplete		0.33	0.90	3.4 (1.8–6.2)	0.74 (0.4–1.4)

<sup>a</sup>“Confident with Forms”—How confident are you filling out forms by yourself?

<sup>b</sup>“Heal Read”—How often do you have someone help you read clinic materials?

<sup>c</sup>“Problems Learning”—How often do you have problems learning about your medical condition because of difficulty understanding written information?

AUROC, area under the receiver operator characteristic curve; +LR, positive likelihood ratio; –LR, negative likelihood ratio.

greater than the AUROC for the best-performing single question or education alone (results not shown).

## Discussion

We found that HIV providers are often unaware when their patients face health literacy barriers. This suggests that screening may enhance identification of persons with low health literacy in HIV clinics. However, the likelihood ratios associated with the brief screening questions described by Chew indicate that these measures have only moderate accuracy for identifying persons with low health literacy in the HIV primary care setting. Based on comparison of AUROCs, screening questions were not more accurate measures of health literacy than provider perception. Simple self-reporting of educational attainment was an overall more accurate discriminator of low health literacy than either provider perception or brief screening questions. Using a summary score for a combination of screening questions did not improve performance. Overall, we conclude that these screening questions provide insufficient information about patient health literacy to consider them for use in health literacy screening in the HIV care setting.

As in studies outside the HIV care setting, we found that HIV providers were often unaware when their patients had low health literacy.<sup>8–10</sup> Providers incorrectly identified 53% of persons with HIV and low health literacy as having adequate health literacy. This suggests that although providers and patients in HIV clinics may routinely discuss other stigmatized topics such as HIV infection, high-risk sex, and substance use, they do not often discuss literacy barriers to care. Prior studies have found that overestimation of patient literacy may be particularly common for African American patients and suggested that this may contribute to racial disparities in care, but this study was too small to examine the impact of patient race or provider/patient race concordance on provider perception of health literacy.<sup>9</sup>

Based on examination of likelihood ratios and associated confidence intervals reported in Table 3, we conclude that these brief screening questions provide insufficient additional information about patient health literacy for use in health literacy screening in the HIV clinic setting. According to a common rule of thumb, useful tests should have a positive likelihood ratio greater than 10 or a negative likelihood ratio less than 0.1.<sup>22</sup> A prior study suggested screening with the question “How confident are you filling out medical forms by yourself?” and applying a response threshold of “somewhat” to guide interventions.<sup>17</sup> In our study, the likelihood ratios associated with this approach did not fall in a useful range. Assuming a prevalence of low health literacy in HIV clinics of 20% and the likelihood ratios in Table 3, a person responding “somewhat” or less confident to this question would have a post-screening probability of low health literacy of 46% (95% confidence interval 31–62%). For a person with a more confident response, the probability of low health literacy would decrease to 16% (95% confidence interval 9–26%). In our opinion, these ranges do not include values that would allow clinicians to make decisions about modification of care or delivery of specific interventions based on health literacy.

It is difficult to compare our results directly with the results of prior studies of these screening questions. Prior studies used widely ranging methods, including use of varying health

literacy measures for comparison (S-TOFHLA versus REALM) and cutoff points for low health literacy (inadequate versus inadequate or marginal).<sup>12,16,17</sup> Despite these differences, several points are notable. As in prior studies, “How confident are you filling out medical forms by yourself” was the overall best-performing question.<sup>16,17</sup> The performance of this question in our study was on the low end of the range reported by other studies (AUROC = 0.67 for marginal or inadequate health literacy in our study, compared to 0.72 in a prior study).<sup>17</sup> Overall, we found these screening questions to be less sensitive and more specific measures of low health literacy than in prior studies.<sup>16,17</sup> For example, in our study a response of “somewhat” to the question “How confident are you filling out medical forms by yourself?” had sensitivity 0.30 and specificity 0.91, where Wallace et al.<sup>16</sup> reported 0.77 and 0.75 for identification of limited/marginal health literacy compared to the REALM.

The study by Wallace et al.<sup>16</sup> reported that educational attainment had an AUROC of 0.67, lower than that reported for screening questions in the same study. In contrast to Wallace’s finding and our initial hypothesis, our study found the AUROC associated with educational attainment to be greater than that for the best performing screening question. Compared to the respondents in prior studies, our sample was in general younger and more likely to be African American, in keeping with the demographics of the HIV epidemic in the United States.<sup>18</sup> These differences in respondents may have contributed to differences in our results compared to prior studies of these questions. It is also possible that perceived stigma associated with low literacy and stigma associated with HIV are cumulative, and this may make persons with HIV less likely to report literacy-related difficulties on screening questions and lead to lower sensitivity for these questions in HIV clinics than other settings.<sup>23</sup>

What are the implications of this study for clinicians and clinic directors striving to provide high quality care for persons with HIV? Paasche-Orlow and Wolf<sup>11</sup> recently reviewed the available evidence for health literacy screening in general clinical settings. They found that there is currently little evidence for benefit from screening in the form of targeted interventions that would be delivered solely to those found to have low literacy, and that there is potential harm from shame and alienation that might result from screening. They concluded, “At this time, there is insufficient evidence to recommend clinical screening for health literacy.” Stigma may contribute to the association between low health literacy and poor antiretroviral adherence among persons with HIV, and we believe that HIV clinicians should be particularly sensitive to screening interventions that may increase stigma.<sup>23</sup> In light of these facts and our results showing that brief screening questions are at best moderately accurate identifiers of persons with low health literacy in HIV clinics, we agree that routine health literacy screening is not currently worthwhile in the HIV clinical setting.

This study has several limitations. Our sample included mostly men, and the performance of screening questions and provider perception may differ by gender. This study did not include persons for whom English was a second language, and such persons represent a high proportion of patients attending many HIV clinics. We enrolled a convenience sample of persons presenting to clinic for care. Persons who frequently miss clinic visits are likely underrepresented in our

sample, and health literacy and the performance of screening questions may differ in these persons. We demonstrated that simple linear combinations of screening questions did not improve performance, however, this study was not designed to explore more complex approaches to combination of screeners.

Our study included persons previously seen in clinic, but did not require that the patient had seen the provider who estimated their literacy prior to the visit on the day of the study. The two clinics in this study adopt somewhat different approaches to HIV primary care. In one clinic approximately 40% of patients have a provider outside of clinic, and patients are sometimes seen by different fellows in training on the same care team. In the second clinic, less than 10% of patients have a provider outside the HIV clinic and individual fellows and staff provide all care for individual patients. Continuity of care may promote discussion of literacy barriers, and accuracy of provider perception may improve when there is a longstanding provider-patient relationship.

This study lacked power to demonstrate small differences between accuracy of provider perception and brief screening questions. Based on limited available prior data, we originally estimated a sample of 150 to demonstrate that screening questions outperformed provider perception. Our analysis included 143 participants. Performance of provider perception (AUROC 0.63) and the best-performing screening question (AUROC 0.67) were similar in our study, but it is possible that a larger study could demonstrate small but statistically significant differences in performance. Despite this, we note that our study was adequately powered to demonstrate that simple knowledge of educational attainment outperformed the previously described screening questions in identifying persons with low health literacy in the HIV care setting. To be of use, screening questions should provide information about health literacy beyond that provided by simple and readily available demographic data such as education.

In conclusion, we found that HIV providers are often unaware when their patients have low health literacy, but that the brief screening questions by Chew provide insufficient information about the likelihood of low health literacy to consider them for use in screening in the HIV primary care setting. Providers should be aware that they may misjudge patients' health literacy in the HIV clinic. In the absence of rapid and accurate health literacy screening tools, HIV clinicians and clinic directors should consider interventions to improve health communication with all persons attending the clinic. Examples of simple interventions include creation of written clinic materials at a reading level accessible to all patients (we recommend a fifth-grade level), routine use of visual aids, confirmation of patient understanding when discussing care ("teach back"), and avoidance of unnecessary medical jargon.<sup>24,25</sup> These interventions may benefit all patients, particularly those with low health literacy.

#### Author Disclosure Statement

No competing financial interests exist.

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