POPULATIONS AT RISK

Low Health Literacy Is Associated with HIV Test Acceptance

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BACKGROUND: The Centers for Disease Control and Prevention has proposed increasing the proportion of people who learn their HIV sero-status. The health care setting represents a logical site to accomplish this goal. However, little is known about factors that determine acceptability of HIV testing in health care settings, particularly patients' health literacy.

OBJECTIVE: To evaluate the association between patients' health literacy and acceptance of HIV testing among individuals at an urgent care center (UCC).

METHODS: As part of a prospective study that sought to increase HIV testing at a UCC located in an inner-city hospital serving an indigent population, we surveyed patients who had been offered an HIV test by their providers and had accepted or refused testing. Pretest counseling was provided using a low-literacy brochure given to patients upon registration into the clinic. We measured health literacy level using the Rapid Estimate of Adult Literacy in Medicine (REALM) scale.

RESULTS: Three hundred seventy-two patients were enrolled in the study. In univariate analysis, no statistically significant difference between HIV test acceptors or refusers was found for gender, race/ethnicity, marital status, income, type of health insurance, educational level, or type of test offered. Acceptors were more likely to have a low literacy level (odds ratio [OR], 1.763; 95% confidence interval [CI], 1.084 to 2.866) and be less than 40 years old (OR, 1.639; 95% CI, 1.085 to 2.475). In multivariate analysis, low health literacy was shown to be a predictor of HIV test acceptance controlling for age and education (OR, 2.017; 95% CI, 1.190 to 3.418).

CONCLUSIONS: Low health literacy was shown to be a predictor of HIV test acceptance. Patients presenting to a UCC with poorer health literacy appear more willing to comply with health care providers' recommendations to undergo HIV testing than those with adequate health literacy when an "opt-out" strategy combined with a low-literacy brochure is used.

KEY WORDS: health literacy; HIV testing and counseling.

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Defined as the "degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions,"¹⁻⁴ health literacy has been recognized as a major factor affecting patient-physician communication and health outcomes.⁵ Low health literacy is associated with poor understanding of written or spoken medical advice and may nega-

tively impact the health of the population.^{4,6} Patients with inadequate health literacy have a complex variety of communication difficulties that limit their ability to read and understand educational brochures, appointment slips, informed consent documents, and labels on pill bottles.¹ Not surprisingly, patients who have inadequate health literacy who are also HIV infected are less likely to know and understand essential information about their medical condition,^{6,7} similar to patients with other chronic diseases such as hypertension, diabetes, and asthma.^{3-5,8-10} HIV-infected patients with low health literacy appear to be four times more likely to be non-adherent with their antiretroviral medications than patients with adequate literacy,¹¹ and programs designed to enhance health literacy promote adherence to therapy.¹² Furthermore, better health literacy correlates with improved outcomes among HIV-infected patients.^{6,13,14}

However, the full impact of patients' health literacy on HIV/AIDS has not been widely explored.⁷ The association between educational attainment, health literacy, and risk of HIV infection varies between populations and over time. Earlier studies in sub-Saharan Africa found that those with more education are at increased risk of HIV infection, though this issue remains controversial given more recent reports.¹⁵ Nevertheless, lower educational attainment and health literacy may be potential barriers for HIV testing because patients at risk for HIV may not request or consent to being tested because they may not understand information presented to them.⁷

Certain groups have an especially high prevalence of low literacy. They include people who have completed fewer years of education, persons of certain racial or ethnic groups, the elderly, and persons with lower cognitive ability.⁶ Other factors associated with lower literacy include living in the South or Northeast, female gender, incarceration, and income status classified as poor or near poor. In addition, it is common to find that individuals seeking medical care at public hospitals have a lower literacy level than those receiving care at private hospitals.¹⁶⁻²¹ Unfortunately, these populations pose a greater risk of acquiring diseases such as HIV, yet many of these individuals are not being tested.²²⁻²⁶

The importance of evaluating potential barriers for HIV testing, such as the level of health literacy, becomes clear when we take into account that one third of the 900,000 people infected with HIV do not know that they are HIV positive.²² Despite more than a decade of successful education and prevention, major obstacles remain for the prevention of HIV infection. In response to these obstacles, counseling and testing programs focused on populations at high risk for HIV are key components of the Centers for Disease Control and Prevention (CDC) "HIV Prevention Strategic Plan Through 2005."^{22,23}

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The purpose of this study was to examine the previously unexplored association between the level of health literacy among patients at an inner-city public hospital urgent care center (UCC) and their willingness to be tested for HIV.

METHODS

Study Design and Setting

With approval from the Institutional Review Board of Emory University and the Grady Memorial Hospital Research Oversight Committee, a 6-month cross-sectional study was conducted from March 20 to September 1, 2000. Patients being seen at the UCC of Grady Memorial Hospital in Atlanta, Georgia were routinely recommended an HIV test by their providers consistent with recommendations by the CDC. Upon entrance to the UCC, patients were given a low-literacy (6th grade reading level) brochure that contained information about risk factors for HIV and the availability of HIV testing. After patients saw their providers, they were approached by interviewers to take part in a survey. If they met the eligibility criteria described below, they were enrolled in the arm of the study comparing HIV test acceptors to HIV test refusers. They were also given a \$20 incentive for their time. Interviewers screened all available patients to determine eligibility.

Eligibility Criteria

Any patient who had been offered an HIV test by their provider and accepted, and was between the ages of 18 and 65, was not known to be HIV positive, had not been tested within the previous 6 months, was not too ill to participate, spoke English, and was able to give consent, was considered for the study. The control group was defined as any patient who had been offered an HIV test by their provider and refused, was between the ages of 18 and 65, was not known to be HIV positive, had not been tested within the previous 6 months, was not too ill to participate, spoke English, and was able to give consent.

Interview Process

All patients were interviewed by research assistants who underwent extensive training prior to the onset of patient enrollment. Interviewers used a brief series of screening questions to determine patient enrollment eligibility. Once eligibility was established, patients were then taken to a private room where informed consent was obtained and health literacy was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM). The full survey was then administered. Of the 415 questionnaires administered, 372 (89.6%) of participants completed it, 33 (8%) failed to complete the entire questionnaire, and 10 (2.4%) were later found to be ineligible (7 were found to have been previously interviewed, 1 was found to be < 18, and 2 were found to be > 65) and were excluded from the analysis.

Health literacy was assessed prior to administering the questionnaire. The REALM was used in order to assess health literacy²⁷ because it correlates highly ($r=.88$ to $.97$) with standardized reading tests. Administering the REALM involves having patients read aloud from a 66-item list of medical terms arranged in increasing order of difficulty. The REALM score is a simple count of correctly pronounced words. It requires 1 to 3 minutes to administer and provides 1 of 4 reading grade

range estimates: 1) 3rd grade and below, 2) 4th to 6th grade, 3) 7th to 8th grade, and 4) high school.

Subsequently, questionnaires customized for HIV test acceptors and HIV test refusers were then administered by the interviewer sitting next to the patient while the interviewer read each question out loud and the patient was allowed to read along silently. Interviewers then marked the response indicated by the patient. Interviewers were trained to answer patients' questions without introducing bias to survey responses.

The different knowledge scores were comprised of questions taken from the questionnaire pertaining to HIV test knowledge, HIV transmission knowledge, HIV treatment knowledge, HIV risk perception, and HIV attitudes and beliefs. These scores were calculated by totaling the number of questions each patient answered correctly. The possible number correct varied between 0 and 13 for each particular category.

Statistical Analysis

All analyses were performed using the 8.0 version of SAS software (SAS Institute, Cary, NC). Univariate analyses were expressed in terms of odds ratios (OR) and corresponding 95% confidence intervals (CI). Measures of association for each of the exposure variables and outcome were obtained using ORs and corresponding 95% CIs.

RESULTS

Data were analyzed for 372 of the 415 patients enrolled, with 200 patients accepting HIV testing (acceptors) and 172 refusing to be tested for HIV (refusers) when the test was offered by their provider. Characteristics of patients enrolled in the study are presented in Table 1. Overall, patients were more likely to be African-American because that is the predominant population being served at our institution. The majority of those interviewed were male, had children, were single, had no form of insurance, and made less than \$10,000 a year. Interestingly, the majority (70%) had been previously tested for HIV.

In univariate analysis, acceptors were more likely to be younger than 40 years old when compared to refusers ($\chi^2=5.521$; $P=.019$). In addition, HIV test acceptors were more likely to have a better knowledge about HIV testing ($\chi^2=7.787$; $P=.005$) and to have a lower health literacy level ($\chi^2=5.27$; $P=.022$). Literacy level was determined according to REALM score. Overall, 8% of those interviewed had a literacy score equivalent to a 3rd grade reading level or below, 16% were between 4th and 6th grade, 32% were between 7th and 8th grade, and 44% had a literacy score equivalent to a high school level. No statistically significant difference between HIV test acceptors or refusers was found for gender ($P=.21$), race ($P=.61$), income ($P=.33$), educational level ($P=.93$), type of health insurance, or marital status.

In multivariate analysis, low health literacy was shown to be the best predictor of HIV test acceptance controlling for age and education (OR, 2.017; 95% CI, 1.190 to 3.418). Because education was not significant in either univariate or multivariate analyses, it was found not to alter the odds ratio of the health literacy variable and was thus included in the final model.

When asked why they were not tested for HIV, individuals from our study responded that they had been practicing safe sex and so did not consider themselves to be at risk. In addition, when compared to HIV test acceptors, the majority of

Table 1. Characteristics of Patients Who Accepted HIV Testing (Cases) and Patients Who Refused to Have an HIV Test (Controls)

Variable		Cases (N=200)		Controls (N=172)		Odds Ratio	95% CI
		n	%	n	%		
Age, y	<40	122	61	84	48.8	1.639	1.085 to 2.475*
Gender	Male	112	56	85	49.4	1.303	0.854 to 1.961
Children	Yes	143	71.5	115	66.9	1.244	0.800 to 1.934
Marital status							
	Divorced	38	19	26	15.1	1.317	0.763 to 2.276
	Single	135	67.5	111	64.5	1.141	0.742 to 1.755
	Widowed	4	2.0	7	4.1	0.481	0.138 to 1.672
	Married	23	11.5	28	16.3	0.668	0.369 to 1.210
Insurance							
	Private	26	13	20	11.6	1.136	0.610 to 2.116
	Public	37	18.5	38	22.1	0.801	0.482 to 1.329
	None	137	68.5	114	66.3	1.106	0.716 to 1.709
Race							
	African-American	187	93.5	163	94.8	0.794	0.331 to 1.906
Income							
	< \$10,000	111	55.5	104	60.5	0.816	0.539 to 1.233
Health literacy							
	High	141	70.5	139	80.8	1.763	1.084 to 2.866*
Education							
	≥ High school	134	67	116	67.4	1.020	0.661 to 1.575
Previously tested for HIV							
	Yes	135	67.5	125	72.7	1.281	0.819 to 2.003
HIV test knowledge							
	High	146	73	102	59.3	0.539	0.349 to 0.833*
HIV transmission knowledge							
	High	110	55	108	62.8	1.381	0.911 to 2.093
HIV/AIDS treatment Knowledge							
	High	152	76	125	72.7	0.840	0.527 to 1.339
Risk perception							
	High	133	66.5	125	72.7	1.339	0.858 to 2.092
Attitudes and beliefs							
	Good	132	66	126	73.3	1.411	0.903, 2.206

*Significant.

Income indicates annual income.

Health literacy: low, 6th grade level REALM score; high, > 6th grade level REALM score.

CI, confidence interval; REALM, Rapid Estimate of Adult Literacy in Medicine.

refusers were found to have been tested within the last year ($\chi^2=4.420$; $P=.036$). Another reason was that they knew their steady partner was HIV negative. Interestingly, however, when asked whether HIV was a serious problem for people they knew, an astonishing 73% ($\chi^2=166.39$; $P=.0001$) admitted that it was, yet they did not perceive themselves to be at risk and were not tested.

DISCUSSION

Testing and prevention remain key factors to stopping the spread of HIV, and being tested is an essential first step to identify patients eligible for treatment. Yet major barriers exist to the successful implementation of HIV testing and counseling strategies: 1) patients' recognition of their risk of HIV, 2) access to testing, 3) acceptance of testing, 4) receipt of results, and 5) entry into preventive and treatment services. A major reason for not undergoing HIV testing is that persons at risk may not perceive themselves to be at high risk for acquiring infection, and thus do not seek to be tested.^{24,25} However, to our knowledge, the association between the factors of health literacy and HIV testing has not been previously examined in the context of other barriers to HIV testing. Despite the fact that there are no reports to suggest that populations with low

literacy level are at risk of undertesting for HIV, we were particularly interested in exploring whether patients' health literacy level impacted willingness to undergo HIV testing. Our results indicate that it does not in the setting of provision of a low-literacy educational pamphlet and health care provider recommendation.

Previous studies have found that individuals with low health literacy are less likely than individuals with adequate literacy to know essential information about their health,¹⁻⁶ to have poorer health outcomes, and increased hospitalization rates.^{6,17,18} In addition, higher rates of low health literacy have been demonstrated in public hospital settings, where the patient population may be at higher risk for HIV^{4,7,10,11} compared to Medicare managed care populations.¹⁶ As HIV testing efforts are expanded and HIV testing is incorporated into the medical care setting, providers need to know the impact of health literacy on HIV testing behaviors.¹⁴

The associations of health literacy and HIV have only been studied among individuals who were already HIV positive.^{11,13,14} Among HIV-positive patients taking highly active antiretroviral therapy, low health literacy was associated with poor self-reported adherence to medications and thus worse outcomes.¹¹ The relationship between literacy and control of HIV infection has been reported in three different

cross-sectional studies. In these reports, better health literacy was associated with greater odds of undetectable viral load and greater odds of having CD4 counts greater than 300.^{11,13,14} Studies of health literacy and HIV prevention have found that instructions on condom packages and HIV/AIDS educational materials require a college reading level.²⁸ Thus, low health literacy appears to be associated with problems disseminating HIV prevention messages and poorer treatment outcomes among patients already HIV infected.

Fortunately, the results of this study indicate that low health literacy may not be a barrier to patients accepting HIV testing when recommended by a health care provider. Specifically, low health literacy was found to be a predictor of HIV test acceptance among patients seeking care at an inner-city hospital. Other possible factors such as trust and dependence on health care providers should be considered as possibly influencing HIV testing acceptance, but these were not measured. Future studies evaluating factors affecting HIV test acceptance should include such measures. The distribution of low-literacy brochures as part of the HIV pretest counseling process during our study may have increased the proportion of people with low health literacy that accepted an HIV test. Provision of the brochures when the patient was registered allowed time for review in the waiting area of the clinic before being seen. In addition, the brochures were designed to be straightforward with a clear message, and written at a 6th grade level. Our study supports that the expected barrier of low health literacy can be overcome, and health care providers can utilize opportunities to increase HIV testing in health care settings that serve inner-city populations with expected high rates of HIV infection.

In summary, we found that patients with health literacy at or below a 6th grade level were more likely to accept HIV testing than patients with adequate health literacy. Furthermore, low health literacy was found to be associated with increased HIV testing controlling for age and education. Given the current dynamics of the HIV epidemic in the United States that increasingly affects minority inner-city populations where low health literacy is frequently found, campaigns using low health literacy ads and brochures may increase the number of people seeking HIV testing and counseling services.

Identifying strategies to overcome the above-mentioned barriers for HIV testing with prevention strategies that incorporate aspects such as health literacy, gender, race, and ethnicity may provide an invaluable avenue to improve the rates of HIV testing in the United States. We hope that these strategies will support the recommendations made by the CDC Serostatus Approach to Fighting the HIV Epidemic (SAFE) initiative.²⁴ Further research in chronic diseases such as HIV infection should focus on comparing interventions directed specifically at reducing health-related barriers with other means of improving health outcomes.

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REFERENCES

1. **Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs AMA.** Health literacy: report of the Council on Scientific Affairs. *JAMA*. 1999;281:552-7.
2. **Baker D.** Reading between the lines: deciphering the connection between literacy and health. *J Gen Intern Med*. 1999;14:315-7.
3. **Williams MV, Baker DW, Parker RM, et al.** Relationship of functional health literacy to patients' knowledge of their chronic disease: A study of patients with hypertension and diabetes. *Arch Intern Med*. 1998;158:166-72.
4. **Institute of Medicine.** Health literacy: a prescription to end confusion. In: Nielsen-Bohman L, Panzer AM, Kindig DA, eds. Washington, DC: National Academy Press; 2004.
5. **Williams MV, Davis TC, Parker RM, Weiss BD.** The role of health literacy in patient-physician communication. *Fam Med*. 2002;34:383-9.
6. **Berkman ND, DeWalt DA, Pignone MP, et al.** Literacy and Health Outcomes, Summary, Evidence Report/Technology Assessment No. 87. Prepared by RTI International-University of North Carolina Evidence-based Practice Center. Publication No. 04-E007-1. Rockville, MD: Agency for Healthcare Research and Quality; January 2004.
7. **Kalichman SC, Benotsch E, Suarez T, et al.** Health literacy and health related knowledge among persons living with HIV/AIDS. *Am J Prev Med*. 2000;18:325-31.
8. **Williams MV, Baker DW, Honig EG, et al.** Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest*. 1998;114:1008-15.
9. **Bennett CL, Ferreira MR, Davis TC, et al.** Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *J Clin Oncol*. 1998;16:3101-4.
10. **Schillinger D, Grumbach K, Piette J, et al.** Association of health literacy with diabetes outcomes. *JAMA*. 2002;288:475-82.
11. **Kalichman SC, Ramachandran B, Catz S.** Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *J Gen Intern Med*. 1999;14:267-73.
12. **van Servellen G, Carpio F, Lopez M, et al.** Program to enhance health literacy and treatment adherence in low-income HIV-infected Latino men and women. *AIDS Patient Care STDs*. 2003;17:581-4.
13. **Kalichman SC, Rompa D.** Functional health literacy is associated with health status and health-related knowledge in people living with HIV/AIDS. *J Acquir Immune Defic Syndr Hum Retrovirol*. 2000;25:337-44.
14. **Kalichman SC, Rompa D.** Emotional reactions to health status changes and emotional well-being among HIV-positive persons with limited reading literacy. *J Clin Psychol Med Settings*. 2000;7:203-11.
15. **Glynn JR, Carael M, Buve A, et al.** Does increased general schooling protect against HIV infection? A study in four African cities. *Trop Med Int Health*. 2004;9:4-14.
16. **Williams M, Parker R, Baker D, et al.** Inadequate functional health literacy among patients at two public hospitals. *JAMA*. 1995;274:1677-82.
17. **Gazmararian J, Baker D, Williams M, et al.** Health literacy among Medicare enrollees in a managed care organization. *JAMA*. 1999;281:545-51.
18. **Weiss BD, Hart G, McGee DL, D'Estelle S.** Health status of illiterate adults: relation between literacy and health status among persons with low literacy skills. *J Am Board Fam Pract*. 1992;5:257-64.
19. **Baker DW, Parker RM, Williams MV, Clark WS, Nurss J.** The relationship of patient reading ability to self-reported health and use of health services. *Am J Public Health*. 1997;87:1027-30.
20. **Baker DW, Parker RM, Williams MV, Clark WS.** Health literacy and the risk of hospital admission. *J Gen Intern Med*. 1998;13:791-8.
21. **Ebrahim SH, Anderson JE, Weidle P, Purcell DW.** Race/ethnic disparities in HIV testing and knowledge about treatment for HIV/AIDS: United States, 2001. *AIDS Patient Care STDs*. 2004;18:27-33.
22. **Kellerman SE, Lehman JS, Lansky A, et al.** HIV testing within at-risk populations in the United States and the reasons for seeking or avoiding HIV testing. *J Acquir Immune Defic Syndr*. 2002;31:202-10.
23. **Centers for Disease Control and Prevention.** Revised Guidelines for HIV Counseling, Testing, and Referral. Atlanta, GA, October 17, 2000.
24. **Centers for Disease Control and Prevention.** Advancing HIV prevention: new strategies for a changing epidemic—United States, 2003. *MMWR Morb Mortal Wkly Rep*. 2003;52:329-32.
25. **Nyamathi AM, Stein J, Swanson JM.** Personal, cognitive, behavioral, and demographic predictors of HIV testing and sexually transmitted diseases in homeless women. *J Behav Med*. 2000;23:123-47.
26. **Solomon L, Landrigan J, Flynn C, Benjamin GC.** Barriers to HIV testing and confidentiality: the concerns of HIV-positive and high-risk individuals. *AIDS Public Policy J*. 1999;14:147-56.
27. **Davis TC, Long SW, Jackson RH, et al.** Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Fam Med*. 1993;25:391-5.
28. **Richwald GA, Wansley MA, Coulson AH, et al.** Are condom instructions readable? Results of a readability study. *Public Health Rep*. 1988;103:355-9.