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## Health Literacy and Antiretroviral Adherence Among HIV-infected Adolescents

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### Abstract

**Objective**—This study investigates HIV positive adolescents' health literacy and whether factors associated with health literacy in HIV-positive adults are associated with health literacy among HIV-positive adolescents.

**Methods**—Adolescents in this study were behaviorally and perinatally HIV-infected youth ( $N = 186$ ) from five U.S. cities. Participants had a mean age of 20.5, and 49.5% were male.

**Results and Conclusions**—Contrary to findings for adult HIV-positive patients, among adolescents health literacy was not significantly associated with: medication adherence adjusting for age and education level; viral load; or self-efficacy to adhere to medication regimens. The only significant association was of health literacy with medical care received.

**Practice Implications**—Practice implications are discussed.

### Keywords

HIV; Adolescent; Health Literacy

## 1. Introduction

Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information to make appropriate health decisions [1]. HIV-infected adults with low health literacy show more adverse health outcomes [2,3], are less likely to have undetectable viral load [4], and are 3.3 times more likely to be non-adherent to their antiretroviral regimen [5] **than HIV-infected adults with high health literacy**. Some studies have contradictory findings: Paasche-Orlow et al. [6] found low literacy was not associated

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with lower odds of adherence or virologic suppression. Most studies have not included adolescents [7]. One adolescent study utilizing the Test of Functional Health Literacy in Adults (TOFHLA; [8]) found the relationship between reading and numerical skills in adults is much stronger than in teens [9].

To our knowledge, health literacy has never been evaluated among HIV-positive adolescents. This study investigates the reliability of the TOFHLA [10], provides descriptive information on health literacy among HIV-positive youth, and investigates whether factors associated with health literacy in HIV-positive adults are associated with health literacy among HIV-positive adolescents.

## 2. Methods

Participants were HIV-infected youth from five U.S. sites, primarily through the Adolescent Trials Network: Fort Lauderdale, FL; Philadelphia, PA; Baltimore, MD; and Los Angeles, CA.; one non-network site was located in Detroit, MI. Inclusion criteria included HIV-positive status, ages 16 to 24, and English-speaking. Youth must have engaged in two of the following: currently prescribed antiretroviral medications, or told by physician s/he should be on antiretroviral medications (whether taking them or not); ever had sexual intercourse; ever tried alcohol/drugs. At least one behavior had to be at problem level: adherence < 90% in the last month, unprotected intercourse within the last 3 months, or screening at problem level for alcohol and/or drug [11]. Ten youth refused screening. Of 375 screened, 205 enrolled, 151 were ineligible, 15 declined enrollment, and 4 were lost to follow-up. Of the 205 enrolled, 19 did not complete baseline data. The sample consisted of 186 participants.

Each site's Institutional Review Board approved the protocol and a certificate of confidentiality was obtained from the National Institutes of Health. Waiver of parental consent was permitted for youth < 18. Computer assisted personal interviewing was utilized. Compensation was \$30.

Assessment included questions on race/ethnicity; gender; income; medical care visits, emergency room visits, and inpatient hospitalizations over the previous 3 months. Other standard scales are as follows.

The Test of Functional Health Literacy in Adults (TOFHLA; modified) has four scores: Reading Comprehension; Numeracy-Short Form; Numeracy-Long Form; and the combined score of Reading Comprehension and Numeracy-Short Form (S-TOFHLA), as in Baker et al. [12]. Scores indicate inadequate, marginal, or adequate health literacy. In the current study, 4 more items from the full Numeracy section of the original TOFHLA were included in the S-TOFHLA, to test its relevancy in an HIV adolescent population.

Youth completed the Diabetic Self-Care Practice Instrument [13], adapted for HIV+ adolescents, assessing illness management ( $\alpha = .99$ ), and Module 1 of the Pediatric Adherence Questionnaire [14], for current HIV medications and number of missed doses over the last three days. (If they failed to identify medications, the interviewer provided prompts from information obtained by chart review).

The Alcohol, Smoking and Substance Involvement Screening Test (ASSIST; [15]) assesses drug and alcohol use for the past three months.

The Brief Symptom Inventory measures mental status [16]. Higher index scores indicate higher psychological distress.

Self-Efficacy for Health Promotion and Risk Reduction [17] assesses confidence taking medications and keeping health care appointments ( $\alpha = .84$ ).

Laboratory evaluations included CD4+ measures, and plasma HIV-1 RNA (viral load). Due to highly skewed data, log transformation of viral load was utilized.

Cronbach's alpha assesses measure reliability (alpha levels of .7 or higher considered acceptable). The Fisher-Freeman-Halton exact test assessed association of health literacy with categorical measures of adherence [18]; Wilcoxon rank sums test assessed association of health literacy with viral load [19]. Regression modeling tested health literacy as a predictor of adherence, adjusting for age and education level. For continuous dependent variables this involved linear regression modeling (SAS Proc GLM), and for binary and multinomial dependent variables logistic regression modeling (SAS Proc Logistic). SAS, Version 8 was used with  $p$ -values of 0.05 or less defining statistical significance [20].

### 3. Results

Demographic characteristics are in Table 1. Health literacy descriptive statistics are in Table 2: 11.8% of subjects were found to have inadequate, 2.7% had marginal, and 85.5% had adequate functional health literacy. The Reading Comprehension, numeracy subscore (long form), and combination of the reading comprehension plus numeracy (short form) have acceptable reliability (alpha > .7); the numeracy subscore (short form) did not (alpha = .56). Subsequent analyses utilize the former.

Analyses of adherence were based on categorizing adherence into three levels (see Table 3): adherent ( $\geq 90\%$ ), less than adherent ( $> 0\%$  to  $< 90\%$ ), and totally non-adherent (0%). Results based on combining adherence for the last month with the past three months did not differ appreciably from those based on 3-day adherence, so the latter are presented.

The univariate association of health literacy with adherence was examined (Table 3). Given the small numbers of subjects with inadequate and marginal literacy, these categories were combined. Among participants with adequate functional health literacy, 35.7% were categorized as adherent, 23.8% as less than adherent, and 40.5% as totally non-adherent. Among participants with marginal/inadequate health literacy, 23.5% were categorized as adherent, 41.2% as less than adherent, and 35.3% as totally non-adherent. Medication adherence measure was not associated with health literacy ( $p > 0.3$ ). Health literacy was not associated with adherence of HIV medications over the past 3 days ( $p = 0.98$ ; Table 4). Viral load was not associated with health literacy ( $p > 0.1$ ).

The association of health literacy with the BSI Global Severity Index was of borderline significance in the adjusted model ( $p = 0.0531$ ); increased reading comprehension was associated with increased GSI, but with only modest fit ( $r^2 = 0.182$ ). Health literacy was positively associated with substance use ( $p = 0.0181$ ;  $r^2 = 0.081$ ). However, adjusting for age and education, these two variables were not associated with adherence, or viral load, and were not included in subsequent models ( $p > 0.05$ ).

Health literacy was significantly associated with medical care received ( $p = 0.0002$ ). The odds ratios indicate likelihood of receiving medical care increased with increasing health literacy; a unit increase in Reading Comprehension was associated with a 9% increase in likelihood of receiving medical care three or more times compared to none (95% confidence interval [CI] 1.04 – 1.15) and a 6% increase in likelihood of receiving medical care once or twice compared to none (95% CI 1.02 – 1.09).

Health literacy was not found to be associated with CD4 count, self-efficacy to adhere to medication regimen or to keep medical appointments, emergency room visits, overnight hospital stays, or race/ethnicity ( $p > 0.1$ ).

## 4. Discussion and Conclusion

### 4.1. Discussion

As noted in the results, the TOFLA is reliable among adolescents, except for the numeracy short form. The majority of HIV-positive adolescents in care have adequate health literacy. Contrary to findings in the adult literature for HIV-positive patients, health literacy was not associated with HIV medication adherence, viral load, or self-efficacy to adhere to HIV medication regimens among adolescents. The only significant associations were with medical care received (and substance use involvement, although this was a poor fit)--consistent with Paasche-Orlow et al.'s [6] finding that health literacy was not associated with adherence or viral load.

These unexpected findings were not due to participants' having a "ceiling" of good adherence; only 34% were adherent, a lower rate than found in previous studies of HIV-positive adolescents (e.g., [21,22]). This may be partially explained by the fact that these adolescents were all fairly comparable in terms of health literacy: almost 86% had adequate health literacy. They were enrolled at state-of-the-art HIV care clinics able to manage co-morbidities, biomedical complications, or psychosocial issues. Varied adherence levels among this sample appear to be attributable to factors other than health literacy. It should be noted that measures of adherence used in this study were subjective, and that is a study limitation.

### 4.2. Conclusion

Previous research has indicated a wide variety of factors are associated with non-adherence to antiretroviral regimens [23]. Schwarz et al. [24] reported that adolescent perception of poor health was associated with prescriptions of HAART, suggesting that the personal decision to accept antiretroviral therapy is related to the belief that one's health is deteriorating. The current sample of adolescents was fairly healthy. It is possible that the adolescents in this sample may not have sufficient motivation for strong antiretroviral adherence--despite having good health literacy skills--because they experience few, if any, illness symptoms.

### 4.3. Practice implications

Health literacy was significantly associated with medical care received: receipt of medical care increased with increasing health literacy. Frequent medical care visits, and opportunities to interact with providers, may increase adolescent health literacy.

We confirm all patient/personal identifiers have been removed/disguised so the patient/person (s) are not identifiable.

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**Table 1**

Demographic characteristics of the study population (n = 186)

Characteristic	
Age:	
<i>M (SD)</i>	20.5 (2.3)
Median	20.0
Range	16 – 24
Education: <i>n (%)</i>	
Less than high school graduate	93 (50.0)
High school graduate/GED	61 (32.8)
Attended school beyond high school	32 (17.2)
Race/ethnicity: <i>n (%)</i>	
African American/Black only	145 (78.0)
European American only	6 (3.2)
Hispanic only	21 (11.3)
Mixed race/ethnicity	14 (7.5)
Gender: <i>n (%)</i>	
Male	92 (49.5)
Female	88 (47.3)
Transgender/transsexual	6 (3.2)
Sexual orientation: <i>n (%)</i>	
Heterosexual/straight	103 (56.6)
Gay/lesbian	22 (12.1)
Bisexual	53 (29.1)
Other	4 (2.2)
Missing	4
Monthly income:	
<i>M (SD)</i>	\$644.30 (\$626.50)
Median	\$506.00
Range	\$5.00 – \$4,000
Perinatally HIV-infected: <i>n (%)</i>	
Yes	31 (16.7)
No	155 (83.3)
Log <sub>10</sub> viral load (copies/ml):	
<i>M (SD)</i>	3.71 (1.18)
Median	3.92
Range	1.40 – 5.88
Geometric mean	5075
CD4+ count (cells/μl):	
<i>M (SD)</i>	465.0 (275.1)
Median	446.5
Range	0 – 1196
Hospital emergency room visits during the past three months:	

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<b>Characteristic</b>	
Number of participants visiting ER	54
<i>M (SD)</i>	1.3 (0.7)
Median	1
Range	1 – 4
Overnight or longer hospital stay during the past three months:	
Number of participants with overnight stay	17
<i>M (SD)</i>	1.1 (0.3)
Median	1
Range	1 – 2

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**Table 2**

Distribution of Health Literacy Scaled Measures at baseline and Cronbach's alpha determined for the scales

Health literacy scaled variable	Overall distribution	Cronbach's Alpha	
		Raw variables	Standardized variables
Reading Comprehension Raw Score:		0.94	0.96
<i>M (SD)</i>	29.4 (10.6)		
Median	34.0		
Minimum	0		
Maximum	36		
Functional health literacy: n (%)			
Inadequate functional health literacy	22 (11.8)		
Marginal functional health literacy	5 (2.7)		
Adequate functional health literacy	159 (85.5)		
Numeracy subscore (long form):		0.78	0.79
<i>M (SD)</i>	6.5 (1.8)		
Median	7.0		
Minimum	0		
Maximum	8		
Numeracy subscore (short form):		0.56	0.67
<i>M (SD)</i>	24.0 (6.0)		
Median	28.0		
Minimum	0		
Maximum	28		
Reading Comprehension Raw Score + numeracy (short form):		0.93	0.93
<i>M (SD)</i>	82.8 (24.3)		
Median	92.0		
Minimum	0		
Maximum	100		
Functional health literacy: <i>N (%)</i>			
Inadequate functional health literacy	24 (12.9)		
Marginal functional health literacy	3 (1.6)		
Adequate functional health literacy	159 (85.5)		

**Table 3**

Distribution of select characteristics according to level of Health Literacy (Reading Comprehension Raw Score)

Characteristic	Health Literacy			<i>p</i> <sup>a</sup>
	Overall	Adequate functional health literacy	Inadequate/marginal functional health literacy	
Average percentage adherence of all medications taken over past 3 days: <i>n</i> (%)				
≥ 90%	34 (33.7)	30 (35.7)	4 (23.5)	0.37
> 0 to < 90%	27 (26.7)	20 (23.8)	7 (41.2)	
0%	40 (39.6)	34 (40.5)	6 (35.3)	
Log <sub>10</sub> viral load:				
<i>N</i>	185	158	27	0.70
<i>M</i> ( <i>SD</i> )	3.71 (1.18)	3.69 (1.19)	3.82 (1.08)	
Median	3.92	3.93	3.73	
Range	1.40 – 5.88	1.40 – 5.88	1.70 – 5.67	
Geometric mean	5075	4855	6572	

<sup>a</sup>For adherence measure the Fisher-Freeman-Halton exact test p-value is included in the table; for viral load, the p-value for the nonparametric Wilcoxon rank sums test is provided.

**Table 4**

Investigation of associations of Health Literacy [HL] (unit change in Reading Comprehension Raw Score) with subject characteristics, adjusting for age and education level<sup>a</sup>

Dependent variable	<i>n</i>	Health literacy coefficient ( <i>SE</i> )	Odds ratio (95% CI)	<i>p</i>
Average percentage adherence of all meds taken over the past 3 days:				
≥ 90% adherence	34	0.0007 (0.023)	1.00 (0.96 – 1.05)	
> 0% and < 90%	27	–0.004 (0.023)	1.00 (0.95 – 1.04)	
0%	40		1.00	0.98
Log <sub>10</sub> viral load	185	–0.007 (0.008)	NA	0.13
CD4: cells/mm <sup>3</sup>	182	2.78 (1.95)	NA	0.15
BSI GSI (T-score)	185	0.186 (0.095)	NA	0.0531
Total substance involvement	185	0.433 (0.182)	NA	0.0181
Self-efficacy to adhere to HIV medication regimens:				
Mean ≥ 4	150	–0.012 (0.019)	0.99 (0.95 – 1.03)	
Mean < 4	36		1.00	0.55
Self-efficacy to keep medical appointments:				
Mean ≥ 4	172	0.005 (0.028)	1.01 (0.95 – 1.06)	
Mean < 4	14		1.00	0.85
Emergency room visit:				
≥ 1	54	–0.016 (0.015)	0.98 (0.96 – 1.01)	
None	132		1.00	0.28
Overnight hospital stay:				
≥ 1	17	–0.031 (0.021)	0.97 (0.93 – 1.01)	
None	169		1.00	0.14
Race/ethnicity:				
African American	155	–0.014 (0.037)	0.99 (0.92 – 1.06)	
Hispanic	21	–0.014 (0.042)	0.99 (0.92 – 1.07)	
Other	10		1.00	0.93
Medical care received:				
Three or more times	63	0.089 (0.025)	1.09 (1.04 – 1.15)	
Once or twice	87	0.055 (0.017)	1.06 (1.02 – 1.09)	
None	36		1.00	0.0002

Age coded in years and highest completed level of education coded as less than high school graduate, high school graduate or attended school beyond high school.