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Health Literacy: Impact on the Health of HIV-Infected Individuals

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Abstract

Health literacy is known to affect vulnerable communities such as persons living with HIV/AIDS. The purpose of this review was to provide a current summary of research on the impact of health literacy on the health of persons living with HIV/AIDS and to address future areas of need. Contemporary studies focused on expanding the reach of health literacy in HIV/AIDS to retention in HIV care, use of technology for assessing and intervening to improve health literacy, and health literacy across the globe, for example. A number of studies did not find health literacy to explain health behaviors whereas other studies supported such a relationship. Future issues relevant to health literacy in HIV/AIDS include the aging of the HIV population and associated comorbidities, studies to understand the role of health literacy in specific populations affected by HIV/AIDS, and the continued need to refine the definition and measurement of health literacy.

Keywords

Health literacy; HIV; AIDS; Treatment adherence; Technological interventions; Health literacy measures; Aging; Disparities; Global literacy

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Introduction

Health literacy continues to evolve as a concept because it shares commonalities with other fields such as decision-making, patient-provider communication, cognition [1-3], and basic academic skills such as reading and mathematics [4, 5]. Development of a comprehensive definition of health literacy that defines how it is distinct from related domains is a challenge. Despite this challenge, most authors agree that health literacy is a complex phenomenon involving access to and skillful use of health-related information to inform and improve health decision-making, behaviors, and outcomes.

Health literacy is closely related to socioeconomic status and education, thereby increasing risk for low health literacy among those who are most vulnerable. HIV/AIDS disproportionately impacts these high-risk groups (e.g., the poor and members of racial and ethnic minorities) making their low levels of health literacy a factor that complicates their health care [6, 7]. Moreover, due to advances in treatment, HIV-infected individuals now live to ages at which other chronic health problems are more common [8, 9]. While better health and longer life are the goals of HIV treatment, new challenges in achieving adequate health literacy arise as patients age with HIV. Notably, approaches for managing chronic illnesses are often different from those used to manage acute conditions [10] and older adults are at particular risk for low health literacy [6]. As the HIV/AIDS population ages and lives longer with the disease, the issue of low health literacy in this group may be particularly salient. For these reasons, continuing research to understand and improve health literacy among persons living with HIV/AIDS is vital.

Adequate health literacy may be an essential prerequisite to improving the health of HIVinfected individuals. Early studies showed that persons with low health literacy – i.e., those who had limited skill for obtaining and acting in ways to benefit their health – had lower HIV disease related knowledge [11] and were less likely to take and adhere to antiretroviral medications [12, 13]. Whether low health literacy then leads to more advanced disease has not been established and has remained a topic of continued interest [11, 12, 14, 15].

In order to promote continued research on the impact of health literacy on health among persons living with HIV/AIDS, it is important to periodically evaluate the research literature to better understand what is known, what questions remain, and future directions. This review will focus on the current state of knowledge regarding the impact of health literacy on the health outcomes of HIV-infected individuals. Observations and implications for future study in the area will also be explicated.

Methods

An electronic literature search was conducted in PubMed and Web of Science. In order to obtain the most relevant articles, the terms health literacy and HIV were searched for in the title and abstract in PubMed and as a topic search in Web of Science. Articles were included if the reference reported empirical data that addressed the relation of health literacy to any type of health outcome in persons infected with HIV; there were no limits placed on publication language and all study designs were included.

A secondary search was then conducted to expand the scope of health literacy to include general health knowledge. Additional articles were obtained from performing a manual search of the reference lists from all of the results. To focus on the current knowledge in the field, the final review included the studies published between January 2012 and July 2013.

Results

Fifteen articles met the criteria for inclusion in the review. Three pertained to health literacy and HIV prevention, and ten focused on the impact of health literacy on health outcomes in those with HIV. Figure 1 displays the flow chart that generated the articles for the review. Measures typically used to assess health literacy in these articles were the Test of Functional Health Literacy in Adults (TOFHLA) [16, 17], and the Short-TOFHLA (S-TOFHLA) [17]. Other scales, such as those measuring HIV or antiretroviral therapy (ART) knowledge, were used less often. Outcome measures included medication adherence, HIV viral load, and CD4 cell counts. Where applicable, studies that used both subjective and objective measurements of these outcome measures were included. Studies that statistically tested the relation of health literacy or HIV knowledge to health outcomes were considered of particular importance; these studies are denoted with a double bullet and summarized in Table 1. Taken together, recent studies have evaluated the impact of health literacy on health behaviors and outcomes in HIV by investigating the efficacy of interventions to improve health literacy, by examining the role of social support in understanding medical information, and by pioneering the use of technology to improve health literacy. Discrepant findings on the relation of health literacy to health outcomes can likely be attributed to the varying measures of health literacy and definitions of health outcomes. Key findings are presented below.

Observational Studies Relating Health Literacy to Health Behaviors

Health Literacy and Retention in HIV Care

Linkage and retention in HIV care is an essential component of effective disease management [18, 19]. Research on health literacy and retention in care has only recently emerged but suggests that patients' health literacy may be important [20]. A key index of engagement in care is the extent to which patients attend appointments for routine care. Jones et al. [21••] reported that adequate health literacy, defined as a patients' knowledge of their viral load and CD4 count, more than doubled the odds of attending more than 75 % of scheduled appointments for HIV care. Along with a good provider relationship, HIV knowledge was also associated with higher CD4 counts and greater odds of viral suppression [21••].

HIV Knowledge, Treatment-Seeking Intention, and HIV Suppression

In developing a measure for intention to adhere to HIV treatment, Nelsen and colleagues [22••] administered a survey to 287 adults infected with HIV (89.0 % male, mean age=50.8 years) at two HIV clinics in Houston, Texas. The survey measured both intention and HIV knowledge and demonstrated good internal consistency and predictive validity for both constructs. Importantly, greater intention and HIV knowledge were associated with better

HIV viral suppression (HIV-1 viral load <400 RNA copies/mL) [22••]. This study underscores how objective health outcomes are impacted not only by HIV knowledge but also the patient's intention to adhere to treatment.

Health Literacy and Social Support

It has been suggested that social support may be a mechanism to compensate for low health literacy [23]. However, in HIV-infected populations, the evidence currently available does not support this observation. In a study of 474 participants with lower health literacy skills, those who requested assistance in reading, interpreting, and understanding medical information were compared to those who did not ask for help [24•]. Those who requested assistance had lower health literacy and numeracy and less education. This group also reported greater utilization of multiple adherence strategies. Despite this, participants who asked for assistance had significantly poorer medication adherence and significantly less frequent suppression of HIV replication. These findings indicate that even though persons with low health literacy may ask for help navigating medical information, this help may not be sufficient. This counterintuitive finding could be the result of several factors. Low health literacy is inextricably linked to socioeconomic status suggesting that other people that these patients rely on for assistance may also be challenged by limited health literacy. Additionally, patients do not necessarily disclose difficulties in reading or understanding medical information due to such social evaluative factors as shame or embarrassment. Moreover, participants requesting assistance had lower health literacy and therefore may have been at risk for intentional non-adherence; the adherence strategies used by these participants would be ineffective when knowingly choosing to skip a medication dose. As noted earlier, health literacy requires cognitive/decision-making skills. The extent to which the type of assistance measured in this study can impact these skills is not well understood and may be important for future studies.

Health Literacy in HIV/AIDS across the Globe

Data on the relationship of health literacy to HIV/AIDS treatment knowledge and behaviors in the global arena are scarce. Nachega and colleagues [25••] measured health knowledge as part of the AIDS Treatment for Life International Survey (ATLIS) in five global regions including the United States, Brazil, Europe, Asia Pacific, and Africa. Health outcomes were measured using a single item that asked if respondents recalled missing one or more ART tablets in the past 30 days. Aside from reporting differences between countries, the authors found significantly greater ART adherence rates amongst participants who had discussed adherence issues with their health care providers (57 % vs. 50 %), in those who understood that suboptimal adherence can result in medications losing effectiveness (55 % vs. 36 %), and those who understood the meaning of HIV drug resistance (83 % vs. 72 %).

Validated health literacy measures for use in contexts outside of the United States are essential yet virtually nonexistent. Research has been done to adapt measures of general literacy into other languages [26•] along with measures specific to HIV knowledge, such as the HIV Knowledge 27 Scale for use in Mozambique [27•]. Health literacy research among PLWH globally is increasing. Thorough validation of measures that address not only linguistic translations but also meet equivalence standards for a particular cultural context are essential to move this area forward.

Interventions to Improve Health Behaviors and Health Outcomes in Persons Living with HIV/AIDS

Interventions Targeting PLWH with Low Health Literacy

A number of studies show that health literacy is associated with antiretroviral medication adherence [12, 28, 29]. Kalichman et al. [30••] developed an intervention aimed to improve medication adherence and HIV viral load for HIV-infected persons with moderate to low health literacy. This study randomly assigned 446 HIV-infected individuals on antiretroviral therapy to pictograph-guided adherence counseling (intervention components presented as pictograph-guided instructions with minimal wording), standard adherence counseling (educational information with text and illustrations), and a general health improvement counseling control group; all conditions used the Social-Cognitive Theory of behavior change [31, 32]. Participants were grouped as having marginal (TOFHLA score between 85 and 90 % correct) or lower health literacy (TOFHLA score <85 % correct).

A greater proportion of participants with marginal literacy were considered virally suppressed (<50 copies/mL) in the pictograph-guided (40 %) and standard adherence conditions (45 %) than in the general health improvement condition (33 %), while lower literacy participants had better viral suppression in the standard adherence (35%) and general health improvement conditions (40 %) compared to those who received pictographguided counseling (28 %) [30••]. For the medication adherence outcome, marginal health literacy participants had greater adherence in the pictograph-guided and standard adherence conditions compared to the general health improvement counseling; lower health literacy participants had greater adherence in the general health improvement condition than in either of the two adherence counseling groups. Taken together, Kalichman et al. [30••] surmised that those with only modest health literacy deficits may best be served by brief and focused adherence counseling, whereas those with greater literacy deficits benefit from more intensive provider-directed adherence interventions. It should be noted that cognitive impairment has been consistently associated with lower adherence in HIV [13, 33] and can further reduce adherence in those with low health literacy [34]. Cognition may have been a relevant factor in the above study. Since no measure of cognitive functioning was included in this study, it is not possible to determine the extent to which participants' cognitive function may have influenced findings.

Culturally Tailored Interventions

Previous research has reported on the mediating effects of health literacy on the relationship between race and HIV medication adherence in underserved and underrepresented populations of HIV-infected individuals [1, 14, 35]. African Americans comprise one such group. Rikard et al. [36•] detailed the development of a peer-to-peer, culturally-tailored HIV/AIDS health literacy toolkit designed to disseminate HIV/AIDS health information using teach-back methods. Development of the toolkit was initiated from the understanding that health literacy should include factors such as culture. This study details methods for

effective engagement with African American community members and community service organizations to inductively create a tool accepted by and relevant to that community. Although this qualitative study did not report outcomes from implementation of the toolkit, it identified factors affecting prevention and treatment efforts in the African-American community. Studies such as these can guide further research into culturally-tailored interventions in improving health literacy.

The Use of Technology to Improve Health Literacy

The mainstream use of portable devices such as laptops, tablet computers, and smartphones has expanded the tools for interventions aimed at improving health literacy. Ownby et al. [37••] targeted participants' health literacy as a strategy to increase antiretroviral medication adherence using a computer-delivered intervention program based on the Information-Motivation-Behavioral Skills Model (IMB) [38]. Touch screen computers delivered a one hour multimedia presentation supplemented with multiple choice questions to assess patients' learning. The TOFHLA [16] was used to measure health literacy, medication adherence was recorded with the Medication Event Monitoring System (MEMS; Aardex Group Ltd, Sion, Switzerland) and elements of the IMB were measured using the LifeWindows IMB scale [39]. After the intervention, adherence significantly improved among participants with baseline levels of adherence less than 95 % even after adjusting for participants' cognitive functioning and baseline health literacy. Further, results suggested that those with lower baseline levels of adherence showed the greatest increases in adherence after the intervention [37..]. Overall, participants had relatively high baseline levels of medication adherence that may have diminished intervention effects, and the study did not include a control group. However, the study successfully established the feasibility and proof of concept of employing a computer-based intervention to improve health literacy; the intervention was also shown to be cost effective [40•].

Technology has also expanded the way in which health literacy can be measured. The 20item, computer delivered HIV Health Literacy Scale (HIV-HL) was developed to create an automatically administered and scored health literacy measure specifically focused on HIV/ AIDS [41••]; medication adherence using MEMS caps was measured as a secondary outcome. Patients were asked to interpret medication labels and respond to questions about the content of a video vignette portraying a simulated patient-provider interaction. The questionnaire demonstrated good content validity and was correlated with the TOFHLA [16, 17] and HIV-related knowledge [39]. The HIV-HL was effective at identifying participants with low health literacy (AUC=0.77, z=2.57, p=0.01). Additionally, the HIV-HL was significantly correlated with medication adherence [41••]. This study provides evidence for implementing technology to measure health literacy using real-world health encounters.

The use of computer-delivered interventions for HIV prevention is also increasing in countries other than the United States. For example, the Sharing Medical Adherence Responsibilities Together (*SMART*) *Couples* multimedia intervention [42, 43], which utilized social-action theory [44] as the conceptual framework to improve medication adherence, has recently been translated into Xhosa and adapted for a South African

population to deliver a culturally-tailored intervention in the region of the world most affected by HIV [45•].

Lack of Associations between Health Literacy and Health Outcomes

Despite a number of studies reporting a significant relation between health literacy and outcomes, some recent studies have not supported this finding. Nelsen et al. [46•] conducted a study with 244 adult participants (92 % male; mean age=51.8 years) from two HIV clinics in Houston, Texas. A self-reported survey measured HIV knowledge (four questions), awareness of disease biomarkers (one free-response question), and health literacy (one question) [46•]. Using self-reported adherence as an outcome, this study did not find a significant association between HIV knowledge, biomarker awareness, or health literacy and medication adherence. Health literacy was measured using a single question ("How confident are you filling out medical forms by yourself?") with responses on a 5-point Likert rating scale; although previous studies have reported the predictive validity of this single-item measure and more comprehensive health literacy. Aside from the self-reported nature of the survey, failure to find significant differences between adherent and non-adherent participants (all participants were recruited from similar HIV clinics).

Colbert, Sereika, and Erlen [49••] also did not find an association between health literacy and medication adherence. Using a score of 75 % or less on the S-TOFHLA to categorize patients as having inadequate health literacy, the study did not find group differences in medication adherence as measured by self-report and MEMS caps. Potentially, the categorization of patients using a 75 % S-TOFHLA cutoff and the inclusion of a self-reported outcome may have contributed to the lack of association between health literacy and medication adherence reported in this study.

Several recent studies with HIV-infected adolescents have also failed to confirm the relation between health literacy and outcomes. Navarra, Neu, Toussi et al. [50••] used the TOFHLA [16] and the Rapid Estimate of Adult Literacy in Medicine-teen (REALM-teen) [51] to evaluate the relation between health literacy and three-day self-reported medication adherence in 50 HIV-infected adolescents (mean age=19.7 years). Using a multivariate logistic regression model that included health literacy, positive outcome expectancy, reading level, and substance use as predictors, they found that health literacy did not predict self-reported estimates of adherence, with 100 % adherence as the cutoff between being adherent and non-adherent, may have introduced enough measurement error to yield a lack of association between health literacy and medication adherence.

Konkle-Parker et al. [52••] used the IMB model [37••, 53] as the conceptual basis for an intervention to improve treatment adherence and disease status. Although health literacy *per se* was not the basis for the intervention, the goals of increased HIV knowledge, problem solving to overcome adherence barriers and education on the use of adherence tools (e.g., pill boxes) are aligned with key elements of health literacy. Participants' health literacy with

the S-TOFHLA [17] was characteriezed but it was not used in analyses. A total of 72 participants were randomized to the intervention or to usual care; the LifeWindows IMB Skills ART Adherence Questionnaire [38] was administered before and after the intervention to measure the patients' 1) adequacy of information on HIV medication adherence, 2) degree of personal and social motivation to adhere to medication regimens, and 3) ability to implement the behaviors to adhere to the medication regimen. Self-reported adherence on a visual analogue scale and refill rate were used to measure adherence; medical appointments, viral loads, and CD4+ levels were also used as outcomes. Despite the soundness of the study's design, there was a high level of attrition (51 %) along with some participants in the treatment group not receiving the full intervention because of missed visits. The investigators report no significant differences on any outcome variable between the treatment groups and attributed these findings to low power to detect differences.

Conclusions

The impact of health literacy on health outcomes among persons living with HIV/AIDS continues to be a growing area of research. The most recent literature in this area supports the notion that health literacy can affect knowledge of one's disease; however, whether or not this knowledge then directly influences health behaviors among persons living with HIV/AIDS is less clear. While recent studies have shown that antiretroviral medication adherence improves after increasing HIV knowledge [36•, 45•], and that greater health literacy and/or HIV knowledge is associated with better health outcomes [21•, 22•, 25•, 41••], others have not found evidence in support of these associations [46•, 49•, 50••]. However, methodological differences in measures of both health literacy and medication adherence may have contributed to these disparate findings. Self-reported medication adherence and simple screening items for health literacy can have limited validity and are less desirable than other measures when attempting to understand whether interventions to improve health literacy are efficacious. Failure to control for key factors in adherence, such as cognitive status or social support, may also affect study outcomes, especially in studies with the limited power associated with small sample sizes.

The use of technology as both an assessment and an intervention tool was well represented in the recent literature. Computer-delivered health literacy assessments provide opportunity to measure health literacy beyond mere reading and numeracy ability by allowing simulations of real-world health encounters. Such stimuli provide greater ecological validity to measures. Interventions delivered via technology can reduce costs associated with providing face-to-face interventions and can potentially be adapted to mobile platforms as an ecological momentary assessment. Recent evidence suggests that health literacy evaluation and interventions delivered via technology are quite promising for future research.

Few studies were conducted within the time frame of this review that focused on specific populations at risk for low health literacy or those disproportionately affected by HIV/AIDS, although studies reported on the development of measures and interventions in different populations [26•, 27•, 36•]. One study with HIV-infected adolescents reported no relationship between health literacy and medication adherence [50••]. More studies focused

on special populations (e.g., adolescents and young adults, older adults, racial/ethnic minorities) are urgently needed. HIV/AIDS affects a wide range of individuals and factors that may affect their health behaviors and outcomes may be related to their individual characteristics and barriers experienced by them.

Observations and Future Directions

For HIV-infected persons with access to antiretroviral treatments, HIV/AIDS has become a chronic condition requiring a lifetime commitment to managing the disease. Chronic disease care models advocate for patient teams that work in coordination with providers, patients, and families. These teams can teach and provide support for managing the disease, mitigating symptoms, and dealing with the social and emotional consequences of HIV [54]. Chronic disease, particularly in older adults, is rarely isolated but instead is co-morbid with a number of other chronic conditions [55]. This may be especially true for persons living and aging with HIV/AIDS since studies show the appearance of conditions common in older adults in the general population at significantly younger ages among HIV-infected individuals [56, 57]. No studies in this review were located with a focus on health literacy as a predictor or mediator/moderator of health behavior or outcomes for those with chronic conditions in addition to HIV/AIDS. Evidence shows that older adults in the general population and those with multimorbidities are at greater risk for low health literacy and may be more negatively affected by low health literacy [58]. With half of the HIV/AIDS population expected to be 50 years of age and older by 2015, health literacy should be a central component of studies with this population.

Cognitive functioning is integral in the study of aging and multimorbidity. Approximately 50 % of persons living with HIV/AIDS have some level of cognitive impairment and rates of impairment increase with age. Studies show that health literacy shares commonalities with and cannot be completely separated from cognitive functioning [1, 2]. For example, the acquisition of health information is likely affected by attention, working memory, and executive functions, and subsequent carrying out of health behaviors is further influenced by prospective memory [59] and executive functions [32]. Since health literacy is closely aligned with cognitive skill, health literacy studies with persons living with HIV/AIDS would benefit from the inclusion of measures of cognitive ability. Such studies would be informative both in terms of how health literacy is affected in populations at risk for cognitive impairment and in efforts to understand in what ways the concept of health literacy may be defined by cognitive functions.

Consistent measurement of health literacy in groups affected by HIV/AIDS is also needed. In many cases, it may be prudent to measure health literacy specific to HIV/AIDS, particularly when HIV-related health behaviors and health outcomes are of interest. The HIV-HL Scale reviewed here [41••] offers a number of advantages and builds upon growing support for technology-based assessments. General measures of health literacy (e.g., TOHFLA or REALM) may be less sensitive to detect changes in HIV-specific disease outcomes. In contrast, however, general health literacy measures may be preferable (or a valuable addition) for studies incorporating multiple chronic conditions in addition to HIV/ AIDS as discussed above.

Health literacy is a complex construct that shares traits with other important foci of study. It can also impact a number of areas of health behaviors and outcomes. Methods to study these complexities require sophisticated models that can account for latent constructs that better represent the intricacies inherent in the lives of real patients. Persons living with HIV/AIDS would be better served through studies that attempt to approximate these relationships among those most impacted by low health literacy.

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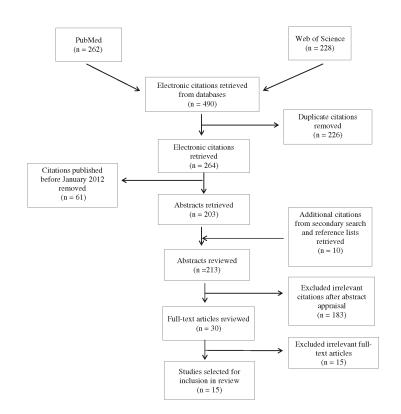


Fig. 1. Systematic literature review flow diagram

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Table 1

Summary of reviewed studies

Reference	Study design	Participants	Health literacy/HIV knowledge measures	Literacy or knowledge categorization	Health outcome measure	Association between health literacy & health outcomes?
[21••] Jones et al., 2012	Cross-sectional survey	210 adults (mean age=47 years)	Knowledge of CD4 count and viral load	Dichotomized: knew both their CD4 count and viral load or did not know both measures	Viral load dichotomized: undetectable (<20 copies/mL) or detectable (>20 copies/mL); CD4 count analyzed as continuous variable	Greater knowledge predicted higher CD4 count and undetectable viral loads
[22••] Nelsen et al., 2012	Instrument validation	287 adults (mean age= 50.8 +9.9 years)	Intention to Adhere to HIV Treatment Scale	Analyzed as continuous variable	Viral load dichotomized: undetectable (<400 copies/mL) or detectable (>400 copies/mL)	Higher intention to adhere to treatment and HIV knowledge increased the odds of viral suppression
[25••] Nachega et al., 2012	Cross-sectional survey	2035 adults	ATLIS	Dichotomous knowledge questions	Self-report 30-day medication adherence: Dichotomous measure, missed >1 tablet	Higher ART adherence rates in those who had discussed adherence with their health care providers and knew about medication effectiveness and HIV drug resistance
[30••] Kalichman et al., 2013	Intervention	446 adults	TOFHLA	Dichotomized: marginal literacy (85-90 %) or lower literacy (<85 %)	Viral load dichotomized: undetectable (<50 copies/mL) or detectable (>50 copies/mL); Unannounced pill count adherence analyzed continuously	Differential improvement in outcomes based on intervention type and health literacy
[37••] Ownby et al., 2012	Intervention	118 adults (mean age= 47.1+8.69 years)	TOFHLA	Analyzed as continuous variable	MEMs percent correct; Analyzed as continuous variable	Increase in information predicted better medication adherence
[41••] Ownby et al., 2013	Instrument validation	122 adults (mean age= 47.1+8.69 years)	ЛН-УІН	Analyzed as continuous variable	MEMs percent taken, correct, & scheduled; Analyzed as continuous variable	Significant, positive correlation between HIV-HL and MEMS measures
[49••] Colbert et al., 2013	Cross-sectional survey	302 adults (mean age= 43.9+7.94)	S-TOFHLA	Dichotomized: inadequate/ marginal (<75) or adequate (>75)	MEMs percent days correct; Dichotomized: adherent (>85 %) or non-adherent (<85 %)	No significant association between health literacy and medication adherence
[50••] Navarra et al., 2013	Cross-sectional survey	50 adolescents (mean age=19.7+ 3.13 years)	TOFHLA	Dichotomized: inadequate (<75) or adequate (>75)	3 day self-report adherence; Dichotomized: <100 % adherent or 100 % adherent; undetectable (<400 copies/mL) or detectable (>400 copies/mL)	No significant association between health literacy and medication adherence nor viral suppression

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