



# Health Literacy and Health Outcomes in Persons Living with HIV Disease: A Systematic Review

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## Abstract

Low health literacy is associated with challenges for those living with HIV including medication non-adherence and poorer health outcomes. The aim of this study was to systematically review the literature on health literacy and health outcomes in persons living with HIV. The extended guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement, as well as A Measurement Tool to Assess Systematic Reviews (AMSTAR) checklist were utilized to guide the approach to the review. A variety of electronic databases including PubMed, CINAHL, PsychInfo, and Cochrane Library were searched. Additional literature available on U.S. government websites was also included in the search. Search terms were used in a variety of combinations and included HIV, health literacy, adherence, and health outcomes. Forty-eight studies were identified that addressed health literacy and health outcomes in HIV. Although several studies in this review did not provide robust results of statistical significance linking health literacy with health outcomes, all of the studies addressed the key significance of health literacy within the scope of living with HIV disease. The relationship between health literacy and the identified health outcomes requires further research and explication.

**Keywords** HIV · Health literacy · Health outcome · Adherence

## Introduction

The importance of health literacy as a key component in encounters with health care providers in managing chronic illness is critical and understudied. Low health literacy is associated with poor medication adherence for patients in HIV care and is thus linked with poorer health outcomes [1]. In 2018, a report was developed by the National Academies of Science, Engineering and Medicine based on a roundtable aimed at addressing health literacy and the quadruple aim of: improving the health of communities, providing better care, providing affordable care, and improving the experience of

the health care team [2]. The National Institutes of Health (NIH) and the Agency for Healthcare Research and Quality (AHRQ) [3] report suggests that limited or low health literacy is negatively associated with preventive care, chronic conditions such as diabetes and HIV, and medication adherence. Medication errors and lack of adherence, as well as development of HIV viral resistance are other areas where health literacy is of major concern [4, 5]. The burden of low health literacy disproportionately affects those of ethnic and racial and under-represented groups—those who are also more likely to be living with and managing their HIV care [6]. In 2018, the American Academy of Nursing issued a policy brief on health literacy that addresses three major domains to reduce health literacy disparities and to increase empowerment of patients: *practice* (communications between provider and patient to increase health literacy including using tools such as the Health Literacy Universal Precaution Toolkit); *systems of care* (addressing health care systems and their provision of information for their patients to better navigate, understand, and use health information); and *partnerships* (increasing collaboration with other organizations, including other health specialties) [7].

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Clear and plain communication is bi-directional in that the strength of the patient–provider interaction is critical to prevent challenges to patients making informed decisions about care and to effectively manage their health conditions [8]. Health literacy has emerged as a major area of interest and essential to research in a variety of chronic illness. Since HIV affects those with limited health literacy in resource-rich as well as resource-limited settings, the study of the nature and quality of health literacy in persons living with HIV is important to study.

## Methods

### Search Strategy

The extended guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement, as well as A Measurement Tool to Assess Systematic Reviews (AMSTAR) checklist were used to guide the approach to the review. In consultation with a health sciences librarian, we utilized a variety of electronic databases including PubMed, CINAHL, EBSCO, PsychInfo, and Cochrane Library for our search. Additional literature available on US government websites was also included in the search. Search terms were used in a variety of combinations and included HIV, health literacy, adherence, and health outcomes. We also searched for the following exact phrases: health literacy, medication adherence, HIV health outcomes. We also reviewed and hand-searched the reference lists of relevant articles.

### Screening

Two reviewers on two teams (total of four reviewers) developed the protocol to ensure rigorous review and concordant understanding of the inclusion/exclusion criteria. Reviewers then independently reviewed the titles and abstracts of article yielded from the consultation with our health sciences librarian. Articles were then divided between the two teams for full text review. If both reviewers agreed that a study did not meet inclusion criteria, the reason was noted in the study data collection instrument via Research Electronic Data Capture (REDCap). If there was disagreement, the study was reviewed with both teams (total of 4 reviewers) for determination of inclusion/exclusion.

### Eligibility

The literature search took place between November 1, 2017 and February 1, 2018. Articles were included in the review if they were published between 1996 and February 1, 2018. The starting year of 1996 was selected so studies that were

published after the introduction of highly active antiretroviral therapy (HAART) would be reviewed, as well as studies that addressed health literacy, adherence, and health outcomes in persons living with HIV.

## Results

### Study Selection

Figure 1 provides a PRISMA diagram of the study selection procedure regarding health literacy and HIV. The authors used multiple electronic databases for the search with the assistance of a health sciences librarian. After narrowing the results to peer-reviewed publications published between 1996 and 2018, the results yielded a total of 239 potential studies. Cochrane Database of Systematic Reviews yielded relevant articles specific to health literacy and HIV outcomes for this systematic review; the sole article was related to online health literacy for consumers. One-hundred and forty-five irrelevant articles resulting from the keyword search were removed leaving 94 studies with 68 excluded after full text review. All authors screened titles and abstracts from each of two databases (PsychInfo and EBSCO or PubMed and CINAHL). The four researchers worked in teams of two, and after independently reviewing manuscripts, pairs conferred, subsequently reaching consensus with 100% agreement on inclusion/exclusion of studies. Of the total of 94 studies, the final yield of 48 studies were retained for the systematic review.

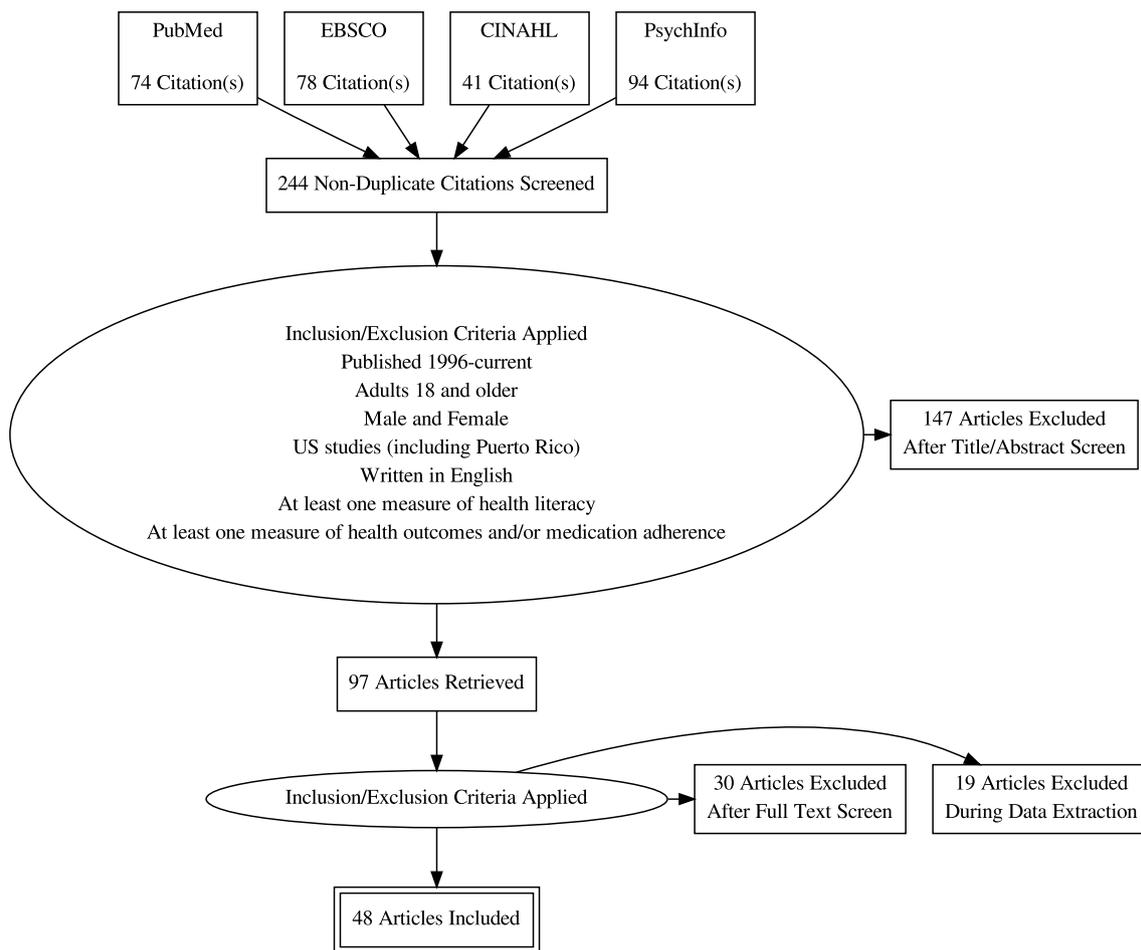
### Diagram of the Literature Search

#### Data Extraction

The authors of this study created a data extraction form that was specifically developed via REDCap for this study and based on the *Cochrane Handbook for Systematic Review of Interventions*. The authors thoroughly reviewed each study and extracted the following data: study design, sample characteristics, sample size, location of the study (U.S. regions or Puerto Rico), intervention characteristics, health literacy measure, adherence, and outcome measures including viral load, CD4 count, HIV knowledge, medication knowledge, depression, and substance use disorders.

#### Data Synthesis

The high level of heterogeneity among the included studies made meta-analysis of the outcomes of the HIV and health literacy not feasible. The studies varied in measures of health literacy, adherence, health outcomes, and participant



**Fig. 1** PRISMA diagram

characteristics related to health literacy in HIV. Studies were conducted in the U.S. or Puerto Rico. Across the studies, the samples included men, women, and transgender individuals. Racial and ethnic backgrounds included white, black/African-American, Latino/a and other. Specific sample characteristics included individuals with literacy deficits and those with higher health literacy, Spanish-speaking participants, and individuals with challenges related to medication adherence. Study designs were quantitative-intervention, quantitative-cross sectional, and qualitative designs, as well as intervention studies and secondary data analyses.

## Adherence

Our findings from this systematic review noted that the relationship between medication adherence and health literacy in persons living with HIV was explored using a variety of approaches. Several studies suggested that health literacy was directly associated with medication adherence [9–15]. Osborn et al. [16] noted that limited health literacy mediated the relationship between race and HIV medication

adherence. Using literacy measures, Rivero-Mendez et al. [17] found an interaction effect between medication adherence and literacy. Persons with adequate, marginal, and inadequate literacy reported high levels of adherence to ART. Similarly, Waldrop-Valverde and colleagues [18, 19] reported that an executive skillset (verbal memory, planning, and motor speed) was positively correlated with medication management. The study by Kalichman et al. [14] suggested that literacy predicted medication adherence.

Other studies found a relationship between health literacy and medication adherence using additional criteria. The study by Waldrop-Valverde et al. [20] found that participants who used illicit drugs with low literacy and cognitive impairment were at high risk for non-adherence, even after adjusting for recent cocaine use. Being female [21] was associated with non-adherence as well as having a low monthly income and unstable HIV [22] and food insufficiency and hunger [23]. Poorer treatment adherence was also associated with requesting additional information during unannounced, telephone-based pill counts [23]. Beliefs about HIV also contributed to medication adherence. Participants who

endorsed denialism beliefs were significantly less adherent to their medications [24] as were those who believe that debate exists among scientists about whether HIV causes AIDS [23].

Communication by providers with clients regarding the importance of adherence was associated with greater medication adherence [25]. After controlling for health literacy, patients who requested additional medical information from their health care provider engaged in strategies to improve adherence [26] and in maintenance of a healthy diet and exercise patterns [26]. Interventions aimed at improving medication-taking competence increased adherence [27–29]. Holtzman [30] identified barriers to and facilitators of retention to care and suggested that there were four distinct aspects linked with adherence—medication characteristics, pharmacy services, health literacy, and health beliefs. However, some studies demonstrated no relationship or inconclusive results between health literacy and medication adherence [31–34].

## Health Outcomes

### Viral Load

To determine whether a relationship existed between poor health literacy, decreased CD4 count, and elevated viral load, articles yielded from the keyword search were reviewed. Overall, findings were mixed. In the majority of studies examining health literacy and viral load, the hypothesized relationship between poor health literacy and increased HIV viral load was found to be significantly correlated. In a study by Kalichman et al. [35], persons with higher health literacy as measured by the TOFHLA were significantly more likely to report an undetectable viral load. Similar findings were noted in studies by Miranda [9] and Pelkowski [36]. However, in a study by Paasche-Orlow et al. [1] in which HIV medication adherence, viral load, and CD4 count were measured along with health literacy in a population of persons with HIV and a history of alcohol use disorder, the findings were contradictory. Paasche-Orlow et al. [1] reported that participants with lower health literacy had increased viral suppression over those with higher health literacy. This was hypothesized to be related to the enhanced resilience in persons with a history of alcohol abuse. Conversely, Pellowski [36] found that increased health literacy and decreased alcohol use were related to optimal viral load outcomes.

### CD4 Count

Many studies in which a correlation between CD4 count and health literacy were explored indicated that those with lower levels of health literacy had lower CD4 counts, although overall, the findings were mixed. A study by Mayben et al.

[37] found that persons with lower health literacy had lower mean CD4 counts. Kalichman et al. [35] found that individuals with higher health literacy were nearly two times more likely to know their CD4 counts and understand what CD4 values mean than those with lower health literacy. However, in another study by Kalichman et al. [35], participants with lower health literacy also had lower CD4 counts. Additionally, Walker et al. [38] found that lower levels of health literacy were linked to lower CD4 cell count for Hispanic and Black participants, but not for non-Hispanic White participants. Interestingly, several studies observed a correlation between health literacy and comprehension of HIV disease which was demonstrated by participants' abilities to accurately report their CD4 count and differentiate between CD4 count and viral load.

## HIV Knowledge

The relationship between health literacy and health knowledge was consistently reported. In a study conducted by Kalichman et al. [28], a medication adherence counseling intervention increased knowledge on the AIDS Knowledge Test from 57 to 67% at a 3-month follow-up. Likewise, the van Servellen et al. *Es Por La Vida* intervention improved HIV knowledge and misconceptions regarding HIV terms from baseline to 6-month follow-up [39]. When using a knowledge test to determine knowledge related to HIV disease and management, findings were also consistent. Kalichman and Rompa [40] reported that participants with lower health literacy had more incorrect answers on the HIV Disease and Treatment Knowledge Test. Graham et al. [12] found that REALM scores were lower for those with mistaken beliefs, e.g., presence or absence of side effects signifies lack of efficacy, absence of side effects means medications are not working, or having side effects should lead to decreasing dosing. Similarly, Tsuyuki and Surratt [22] reported that higher scores on a 3-item summative health literacy scale were related to higher HIV illness and treatment knowledge. Interestingly, Wigfall et al. [41] suggested that participants with high health literacy were more likely to have read health care provider instructions, although comprehension was not measured.

## Medication Knowledge

Our search did not yield any studies that measured the relationship between health literacy and medication knowledge directly. Instead, education literacy was used as a measure of literacy. In the study by Kalichman et al. [42] participants with lower education literacy (health literacy not specified) were more likely to miss medications because of confusion or sleeping through a dose. Additionally, participants with lower education literacy were more likely to have problems

with accessing medications because of fear, lack of trust, or substance use. Participants with lower education literacy also tended to miss medications. Although not a direct measure of medication knowledge, the study by Kalichman et al. [26] suggested that participants with the poorest ratings on health literacy requested more assistance with reading, interpreting, and understanding medication information. Rivero-Mendez et al. [17] found that participants with marginal health literacy had higher mean scores on adherence than did those with inadequate literacy levels, and health literacy is highly correlated with level of education.

### Depression

The relationship between health literacy and depression was not clearly found in our review of papers, however, several studies suggested a potential relationship between literacy and depression. Participants with lower education literacy were more likely to miss medications because they were depressed [42, 43], were more likely to be depressed [42], and perceived less social support [42, 43]. Kalichman and Grebler [44] found that poorer adherence to medications was related to greater social and health stressors and to higher rates of depression.

### Substance Use Disorder

The relationship between health literacy and substance use disorder was not found in our sample. Instead, medication adherence was found to be related to substance use disorder. The study by Waldrop-Valverde et al. [20] indicated that cocaine use within the last week was associated with greater reports of medication non-adherence. Similarly, Kalichman and Grebler [43] found that lower medication adherence was related to illicit drug use.

### Other

Studies included additional outcomes that were interesting to note. The additional outcomes were clustered into broad categories. The findings within these studies included both overlapping and disparate concepts.

### Behavior

Two studies focused on risky behaviors. The study by Surratt et al. [45] addressed anti-retroviral medication diversion. Interestingly, findings indicated that higher treatment knowledge and higher health literacy increased the odds of anti-retroviral medication diversion. The study by Blackstock et al. [46] focused on high risk sexual or substance-use related behaviors. The researchers noted that participants who engaged in risky behaviors were likely to report poorer

overall health but had higher electronic health literacy (eHealth Literacy). One study focused on positive behaviors. Pellowski and Kalichman [36] found that for participants engaged in healthy diet and exercise behaviors, a healthy diet and regular exercise were linked with antiretroviral adherence more than traditionally established predictors of medication adherence.

### Resources and Capacity

Several studies examined individual resources and capacity. In a systematic review of community health worker interventions, Han et al. [47] found that key psychosocial determinants such as health literacy, self-efficacy, self-advocacy, and hope influenced HIV outcomes. Nokes et al. [48] found that greater adherence self-efficacy was a robust predictor of higher health literacy and that environmental factors did not mediate the relationship between functional health literacy and medication adherence. Lack of resources and capacity were included in our review of studies. Kalichman and Grebler [44] found that two-thirds of the participants in their study had less than 85% adherence and that inadequate food and hunger predicted non-adherence, thus supporting the importance of nutrition in HIV adherence. Waldrop-Valverde and Osborn [49] found that low numeracy skills were linked with poorer self-management of medications with African-American women at higher risk of having low numeracy skills. HIV-associated neurocognitive disorders (HAND) were associated with difficulty in conducting health-related tasks [50]. Results also suggested that these patients are at risk of decreased health literacy and poorer medication adherence and those participants who had decreased health-related decision making had poorer test performance scores related to memory and health literacy. Similar results were found in a study of individuals with HAND by Morgan et al. [51]. Among individuals with HAND, lower scores on the *Newest Vital Sign* health literacy scale were associated with greater severity of neurocognitive dysfunction and self-reported dependence in activities of daily living. The researchers found that HAND hinders both fundamental and critical health literacy capacities.

### Patient–Provider Relationship

The patient–provider relationship was also discussed in our sample. In a qualitative study by Laws et al. [25] the researchers found that most people trust their healthcare providers and simply follow instructions “without needing further explanation” (p. 642), even though they may not know the importance or consequences of the instructions. Similarly, Kalichman and Rompa [40] found that lower health literacy was associated with poorer health and perceptions of inadequate medical care by HIV positive participants.

Dawson-Rose et al. [52] found that an ongoing and trusting patient–provider relationship is a major contributor to health literacy. Positive and trusting relationships between patient and provider were linked with higher health literacy. Holtzman et al. [30] identified 18 barriers/facilitators to retention in care and ART adherence: 11 common to both behaviors (stigma, mental illness, substance abuse, social support, reminder strategies, housing, insurance, symptoms, competing life activities, co-location of services, provider factors), three distinct to retention (transportation, clinic experiences, appointment scheduling), and four distinct to adherence (medication characteristics, pharmacy services, health literacy, health beliefs). Identified barriers/facilitators were all mapped to Anderson’s Behavioral Model (ABM) domains. The researchers concluded that use of ABM as a framework for classifying factors influencing HIV-specific health behaviors is valid.

### Information

Various aspects of management, knowledge, and interpretation of information were examined by several studies. Walker et al. [53] found that Black participants demonstrated fewer health literacy appraisal skills and that lower levels of health literacy were linked to poorer CD4 cell count (an index of immune functioning) for Hispanic and Black individuals and not for non-Hispanic White individuals. Doyle et al. [54] found that lower health literacy was linked with poorer medical decision-making. In a study by Bynam et al. [55], the influence of health literacy on women living with HIV and their cervical cancer screening knowledge and behaviors was examined with 38% of the women reporting low health literacy. The findings suggested that there was no difference in cervical cancer or human papillomavirus knowledge among those with low versus high health literacy and behaviors. In a qualitative study by Gakumo et al. [56] examining HIV knowledge and understanding, four key themes were identified: (a) HIV lab numbers are important to understand health status; (b) the numbers are often confusing; (c) mutual communication between provider and patient is essential to understand the numbers; (d) when communicating numbers, providers should use less detail. Although not statistically significant, Drainoni et al. [57] found that participants with lower health literacy were less likely to discuss lab results and treatments with their providers and were also more likely to be out of care for 6 months or more.

### Instrumentation

Our systematic review yielded a variety of instruments that measured health literacy. It is interesting to note that the most frequently utilized instruments for measurement were

the *Test of Functional Health Literacy in Adults* (TOFHLA) ( $n = 25$  studies) and the *Rapid Estimate of Adult Literacy in Medicine* (REALM) ( $n = 9$ ). This was an interesting finding since HIV-specific measures exist including the *HIV Health Literacy Scale*, which has been found to be a reliable and valid measure of HIV health literacy [11]. Some studies ( $n = 3$ ) measured health literacy by a single question and several studies ( $n = 11$ ) used a variety of other measures of health literacy. One study used the *Newest Vital Sign* health literacy scale, a newer health literacy scale, to assess HIV health literacy in persons with HAND. As noted by Perazzo, Reyes, and Webel [57], researchers should use “rigorously developed, disease-specific health literacy instruments such as the *HIV Health Literacy Scale* in addition to reliable measures of general health literacy skills to accurately identify health literacy deficits” (p. 820). Thus, it was an unanticipated finding that so few studies utilized an HIV-specific instrument (Table 1).

### Discussion

The purpose of this systematic review was to identify, appraise, and synthesize current published literature on health literacy and health outcomes for persons living with HIV. This review is one of few studies examining the impact of health literacy related to health outcomes and to our knowledge is the first to critically appraise published literature related to health literacy and outcomes in HIV. Although multiple studies in this review did not provide robust results of statistical significance linking health literacy with health outcomes—and some results were equivocal or contradictory—perhaps indicating that confounding or selection biases existed across the studies yielded in this systematic review. All of the studies addressed the key significance of health literacy within the scope of living with a chronic illness such as HIV disease, however further research should explore both confounding and selection biases. The relationship between health literacy and the identified health outcomes requires further research and explication. Of the 48 studies yielded from the systematic review, 37 were of a quantitative cross-sectional design, seven were quantitative intervention studies, and four were qualitative. It is critical that further studies be designed to include interventions aimed at addressing and improving health literacy.

As discussed earlier, there are recommendations that HIV-specific health literacy instruments such as the *HIV Health Literacy Scale* [11], in addition to reliable measures of general health literacy aimed at identification of health literacy successes and deficits be implemented. Our sample included a variety of health literacy instruments, many of which were not specific to HIV disease. A newly developed measure of health literacy, the *Newest Vital Sign*

**Table 1** Synthesis table of reviewed articles

Author(s)/design/ sample characteristics	Health Literacy measure	Outcomes measured	Results
Blackstock et al. [46] Quantitative cross sectional n = 63. Median age 49 (44–54), Sex not reported. 56.7% non-Hispanic Black, 38.3% Hispanic, 5% multiracial/other	Electronic Health Literacy Scale	Infection Co-morbidity Lymphocyte count Depression	Compared with lower eHealth literacy (eHL), women with higher eHL were more likely to report current HIV transmission risk behavior, even after controlling for age, income, and self- perceived health status
Colbert et al. [31] Quantitative cross sectional Secondary analysis n = 302. Mean age 43.9 (SD 7.94), 75% male. 58.6% African American	TOFHLA	Lymphocyte count Viral load	Higher medication-taking self-efficacy (SE) was associated with higher medication adherence. Functional health literacy was not significantly related to either medication adherence or self- efficacy beliefs. Medication-taking self-efficacy did not mediate the relationship between func- tional health literacy and medication adherence. Increased medication SE associated with > adher- ence
Dawson-Rose et al. [52] Qualitative n = 135. Mean age 48 (SD 9.18), 50.37% female. 45.11% African American, 25.56% Hispanic/ Latino, 17.29% non-Hispanic white, 15.04% other	Probing questions	Relationship of HIV health literacy with its com- ponents to interactions with providers and other professional care team members	An ongoing and trusting patient–provider relation- ship is a major contributor to health literacy (HL). Positive and trusting relationships between patient and provider were linked with HL
Doyle et al. [54] Quantitative cross sectional n = 135. Overall demographics not reported	REALM	Outcome assessment Hospitalization Substance related disorders Anxiety Depression	HIV Associated Neurocognitive Disorders (HAND) was an independent predictor of performance on measures of health related decision making. HAND+ had significantly lower scores relative to comparison groups. In HIV + sample, poorer health-related decision making was associated with worse performance on tests of memory, risk, and health literacy. HAND had lower scores on most measures. Decreased health related decision making correlated with poorer test performance related to memory and HL

Table 1 (continued)

Author(s)/design/sample characteristics	Health Literacy measure	Outcomes measured	Results
Drainoni et al. [57] Quantitative cross sectional n = 231. Mean age not reported. 76% male, 22% female, 5% transgender. 46% Black/African American, 30% white, 11% Latino/a, 13% other	TOFLHA	Outcome assessment Hospitalizations Quality of life Substance related disorders	Scores in marginal or inadequate range for health literacy were more likely to be African American or Latino/a, heterosexual, speak Spanish as primary language, and have less than a high school education. Literacy was associated with $\geq 95\%$ adherence (64% for $\geq 9$ th grade level vs. 40% for $< 9$ th grade level). Participants with $< 95\%$ adherence had a lower threshold of acceptable adherence than those with $\geq 95\%$ adherence [80% adherence (interquartile range 70–90%) versus 90% adherence (interquartile range 80–90%)]. The effect was independent of literacy. No other beliefs assessed were associated with adherence. Although the beliefs assessed do not mediate the relation between literacy and adherence, low adherence norms were a potentially modifiable belief associated with adherence
Echenique et al. [21] Quantitative cross sectional n = 34. Mean age 22 (SD 3.27). All female. 70.6% African American, 11.8% Haitian, 8.8% Hispanic, 2.9% white, 5.9% other	Other	Identify knowledge, attitudes, and behaviors associated with conception	Behaviorally HIV + and Perinatally HIV + women were similar in conception-related health literacy (HL). Despite having adequate reproductive knowledge, most of the women in this sample were not using contraception
Gakumo et al. [56] Qualitative n = 20. Mean age 54.9 (SD 6.3). 50% male. Race/ethnicity not reported	Semi-structured interview	Lymphocyte count Viral load	Four key themes identified: (a) HIV lab numbers are important to understand health status; (b) the numbers are often confusing; (c) mutual communication between provider and patient is essential to understand the numbers; (d) when communicating numbers, providers should use less detail
Graham et al. [12] Quantitative cross sectional n = 87. Median age 44 (37–48). 76% male. 88% Black, 12% white	REALM	Lymphocyte count Viral load Substance related disorders Anxiety Depression	Literacy was associated with higher adherence. Participants with $< 95\%$ adherence had a lower threshold of acceptable adherence than those with greater adherence. This effect was independent of literacy. No other beliefs assessed were associated with literacy

Table 1 (continued)

Author(s)/design/sample characteristics	Health Literacy measure	Outcomes measured	Results
Holtzman et al. [30] Qualitative n = 51. Median age 45 (25–65), 53% male, 80% Black 12% white, 6% Hispanic, 2% other	Semi-structured interview guide	Medication adherence	Eighteen barriers/facilitators to retention in care and antiretroviral therapy (ART) adherence were identified: 11 common to both behaviors (stigma, mental illness, substance abuse, social support, reminder strategies, housing, insurance, symptoms, competing life activities, colocation of services, provider factors), 3 distinct to retention (transportation, clinic experiences, appointment scheduling), and 4 distinct to adherence (medication characteristics, pharmacy services, health literacy, health beliefs). Identified barriers/facilitators mapped to all Anderson's Behavioral Model (ABM) domains. Data support the use of ABM as a framework for classifying factors influencing HIV-specific health behaviors
Kalichman et al. [35] Quantitative Interventional n = 30. Mean age 44.8 (SD 7.3), 17 men, 10 women, 3 transgender. 28% African American	TOFHLA	Lymphocyte count Viral load Medication knowledge	Participants in intervention group receiving a brief HIV treatment adherence intervention significantly increased their level of AIDS related knowledge based on the AIDS knowledge test. Medication adherence improved at 3-month follow-up after intervention
Kalichman et al. [35] Quantitative cross sectional n = 294. Mean age 40.2 (SD 7.2). Overall sex, race/ethnicity not reported	TOFHLA	Lymphocyte count Viral load	Health literacy groups did not differ in CD4 counts. Significant association found between health literacy and viral load - higher health literacy participants were significantly more likely to report having an undetectable viral load than lower health literacy participants. Individuals of higher health literacy nearly 2X more likely to know their CD4 counts and their viral load and 2X more likely to understand what it means (CD4). This effect was 3X more likely for viral load
Kalichman et al. [44] Quantitative cross sectional n = 343. Overall demographics not reported	TOFHLA	Lymphocyte count Viral load Medication knowledge	1/5 participants stated that there is no proof that HIV causes AIDS and that HIV treatments do more harm than good. AIDS denialism beliefs were more often endorsed by people who more frequently used the internet after controlling for confounding factors. Believing that there is a debate among scientists about whether HIV causes AIDS was related to refusing HIV treatments and poorer health outcomes

**Table 1** (continued)

Author(s)/design/ sample characteristics	Health Literacy measure	Outcomes measured	Results
Kalichman et al. [14] Quantitative cross sectional n = 145. Mean age 44.9 (SD = 6.3). 67% Male, 30% Female, 0.01% Transgender. 93% African American, 6% white, 1% other	TOFHLA	Medication adherence Substance related disorders Depression	Participants with lower health literacy demonstrated poorer adherence compared to higher literacy. Literacy predicted adherence over and above all factors
Kalichman et al. [23] Quantitative cross sectional n = 188. Overall demographics not reported	TOFHLA	Outcome assessment Lymphocyte count Viral load Substance related disorders Depression	Entire sample classified as having low health literacy. 2/3 of the sample had adherence below 85% of pills taken. Food insufficiency and hunger predicted ART non-adherence more than depression, internalized stigma, substance use, and HIV-related social stressors
Kalichman et al. [26] Quantitative interventional n = 446. Overall demographics not reported	TOFHLA	Infection Co-morbidity Lymphocyte count Viral load Substance related disorders	Participants with marginal health literacy in the pictograph-guided and standard-counseling conditions demonstrated greater adherence and undetectable HIV viral loads compared to general health counseling. Participants with lower health literacy skills in the general health improvement counseling condition demonstrated greater adherence compared to the two adherence counseling conditions
Kalichman et al. [26] Quantitative cross sectional n = 474. Overall demographics not reported	TOFHLA	Infection Co-morbidity Lymphocyte count Viral load Substance related disorders Depression	After controlling for health literacy scores, requesting informational assistance was associated with strategies used to improve adherence; individuals who asked for assistance were significantly more likely to use multiple adherence strategies. Despite requesting informational assistance and using more adherence strategies, participants who requested informational assistance evidenced poorer treatment adherence and poorer suppression of HIV replication. Requesting assistance was more common among those with the poorest health literacy and therefore greatest challenges to adherence
Kalichman et al. [15] Quantitative cross sectional n = 138. Overall demographics not reported	TOFHLA	Depression Medication knowledge	Poorer medication adherence noted in the lower health literacy group. The lower literacy group was more likely to miss medications due to confusion about what to take. Lower education literacy correlated with depression

Table 1 (continued)

Author(s)/design/sample characteristics	Health Literacy measure	Outcomes measured	Results
Kalichman et al. [15] Quantitative cross sectional n = 318. Overall demographics not reported	TOFHLA	Lymphocyte count Viral load	Nonadherent participants reported significantly lower CD4 counts and were less likely to have an undetectable viral load. Those with lower reading literacy were nearly 4X more likely to be nonadherent
Kalichman et al. [35, 40] Quantitative cross sectional n = 339. Mean age 40.2(7.2). Male 67%. “Mostly minority”	TOFHLA	Lymphocyte count Viral load Hospitalizations	Significant association between health literacy level and viral load (high literacy = lower viral load). Lower health literacy participants had significantly lower CD4 cell counts. Persons with higher health literacy were significantly more likely to be receiving antiretrovirals. Persons with lower health literacy were significantly more likely to have been hospitalized 3 or more times for HIV related conditions compared with persons of higher health literacy
Laws et al. [25] Qualitative n = 32. Age range 22–63. 68.8% male. Race/ethnicity not reported	Semi Structured Interviews	Medication knowledge Medication adherence	Most participants were found to have poor functional understanding of HIV disease, ART and disease markers. Participants understood ART adherence was important based on provider instructions but did not understand why. This could explain the inconsistent results of studies of the relationship between health literacy and ART adherence
Lyons et al. [32] Quantitative cross sectional n = 124. Median age 48.5 (40.5–55). 71% male. 65.3% Black, 33.9% white, 4% Hispanic, 0.8% other	Simulated scenarios	Lymphocyte count Viral load	Regardless of education level, patients’ understanding of adherence percentage is poor. Alternative formats, e.g., calendar plot, are more meaningful and preferred methods to communicate HIV medication adherence information
Mayben et al. [37] Quantitative cross sectional n = 119. “85% between 18 and 49” years old. 74% Male, 36% Female. “more than 1/2 Black” 28% Hispanic	TOFHLA	Lymphocyte count	Persons with inadequate health literacy had a somewhat lower mean CD4 count at time of diagnosis than persons with adequate health literacy. This finding was not statistically significant

**Table 1** (continued)

Author(s)/design/sample characteristics	Health Literacy measure	Outcomes measured	Results
Miranda [9] Quantitative cross sectional n = 129. Mean age 48 (SD 8.2). 69% male. 71% Latino	TOFHLA	Viral load	Higher levels of health literacy (reading comprehension) were significantly related to neuropsychological variables, sociocultural variables, medication adherence, and HIV viral load. Spanish language was linked with lower health literacy. Health literacy can be negatively impacted by poor neuropsychological functioning, low levels of education, Spanish language dominance, and low levels of US acculturation. Health literacy variables were the best predictors of self-reported medication adherence and HIV viral load
Morgan et al. [51] Quantitative cross sectional n = 80. Overall demographics not reported	REALM ENS NVS BLHS	Infection Lymphocyte count Viral load Substance related disorders	Among individuals with HAND, lower scores on the NVS were associated with greater severity of neurocognitive dysfunction and self-reported dependence in ADLs. HAND hinders both fundamental and critical health literacy capacities
Nelsen et al. [33] Quantitative cross sectional n = 244. Mean age 51.8 (SD 9.5). 92% male. 57% non-Hispanic black, non-Hispanic white 37%, Hispanic 16%	Single question	Medication adherence	No association found between health literacy and medication adherence
Nokes et al. [24] Quantitative cross sectional n = 1414. Mean age 46.6 (SD 8.9). 71.1% male, 26.3% female, 2% transgender. 39.5% African American/Black, 24.3 Hispanic/Latino, 26.1 white/Anglo, 20% Native American	HIV Adherence Self Efficacy Scale	Outcome assessment Co-morbidity Lymphocyte count Viral load Depression	Treatment self-efficacy as measured by the HIV Adherence Self-Efficacy Scale was a robust predictor of ART adherence behavior, serving a partial mediating role between environmental influences and cognitive or personal factors. Environmental factors did not mediate the relationship between adherence self-efficacy and ART treatment adherence
Nokes et al. [48] Quantitative cross sectional n = 489. Mean age. 42.6 (SD 8.77). Sex demographics not reported. 50% African American, 20%, Latino 20% white/Anglo non-Hispanic, 2% Native American, 1% Asian/Pacific Islander, 0.1% other	REALM	Outcome assessment Infection Depression	Participants with higher health literacy scores reported more body change distress, depressive symptoms, and HIV symptom intensity. Being Latino and having higher health literacy scores were associated with poorer health outcomes

Table 1 (continued)

Author(s)/design/sample characteristics	Health Literacy measure	Outcomes measured	Results
Quantitative cross sectional n = 204. Mean age 40.1 (SD 9.2). 79.9% male. 45.1% African American	REALM	Infection Co-morbidity Substance related disorders Anxiety Depression Medication knowledge	Brief Estimate of Health Knowledge and Action – HIV version (BEHKA-HIV) had high internal consistency, and construct validity. Lower scores on the BEHKA-HIV were independently associated with poorer rates of HIV medication adherence, as were the lowest scores on the REALM. BEHKA-HIV is a psychometrically sound tool for assessing health knowledge and action regarding HIV treatment, and predicting non-adherence to HIV medications
Osborn et al. [16] Quantitative cross sectional n = 204. Mean age 40.1 (9.2). 79.9% male. 45.1% African American	REALM	Co-morbidity Substance related disorders Anxiety Depression	Limited health literacy mediated the relationship between race and HIV- medication adherence. In an adjusted analysis that excluded literacy, African Americans were more likely to be nonadherent to their HIV-medication regimen than whites. When literacy was included in the final model, the effect estimates of race diminished. Literacy remained a significant independent predictor of nonadherence
Owby et al. [11] Instrument Development n = 120. Mean age 47.1 (SD 8.69). Sex and race/ethnicity demographics not reported	TOFHLA HIV-HL	Depression Medication Adherence	The computer administered HIV specific health literacy instrument developed was related to other measures of general health literacy (TOFHLA) and to measures of HIV related knowledge. The instrument could predict whether someone had low health literacy and cores on the measure were correlated with participants' medication adherence
Paasche-Orlow [13] Quantitative Interventional n = 235. Mean age 42 (SD 9); 79.2% male. 45% African American, 38% white, 17% other	REALM	Viral Load	The odds of ART adherence and HIV-RNA suppression were higher in those with lower literacy
Pelkowski et al. [27] Quantitative Interventional n = 188. Demographics not reported	TOFHLA	Outcome assessment Infection Co-morbidity Lymphocyte count Viral load Substance related disorders	Higher levels of health literacy and lower levels of alcohol use were the strongest predictors of achieving HIV viral load optimal outcomes. Alcohol use may have specific effects among a low literacy population

**Table 1** (continued)

Author(s)/design/sample characteristics	Health Literacy measure	Outcomes measured	Results
Pellowski et al. [27] Quantitative cross sectional n = 437. Mean age 46 (SD 7.9). "Largely male". Race/ethnicity demographics not reported	TOFHLA	Outcome assessment Infection Lymphocyte count Viral load Substance related disorders Depression	All participants had low health literacy. Diet and exercise composite predicted antiretroviral adherence more than several established predictors of medication adherence. Higher usage of supplements predicted lower adherence. Findings supported an integrated approach to adherence. Intervening on diet alone or diet and medication adherence together may result in increased medication adherence  No significant correlation between health literacy and gender, insurance status, physical condition, psychological condition, level of social support, symptom intensity. Health literacy highly correlated with years of education and age (younger patients tended to have higher health literacy). Adherence and literacy showed significant interaction effects- persons with adequate, marginal and inadequate literacy reported high levels of adherence to ART
Rivero-Mendez et al. [17] Quantitative cross sectional n = 200. Age range 21–78. Sex, race/ethnicity demographics not reported	TOFHLA	Lymphocyte count Viral load	Male gender, severe depression, severe anxiety, substance dependence, recent homelessness, and high HIV-related stigma were each associated with increased odds of diverting prescribed ARV medications. Odds of diversion were lower among participants reporting higher HIV-related treatment knowledge and higher health literacy, and among those achieving 95% ARV adherence
Surratt et al. [45] Quantitative cross sectional n = 503. Mean age 45.9 (SD 7.9). 66.1% male. Race/ethnicity demographics not reported	Not specified	Substance related disorders Anxiety Depression Medication knowledge	The best fitting model to predict ARV diversion identifies having a low monthly income and unstable HIV care as salient enabling factors that promote ARV diversion. Higher scores on the health literacy scale correlated with lower odds of ARV diversion. Health care need factors did not protect against ARV diversion. ARV diversion provides a link between social vulnerability and sub-optimal ARV adherence, with ARV diversion and domains from the Behavioral Model explaining 25% of the variance in ARV adherence
Tsuyuki et al. [22] Quantitative cross sectional n = 503. Mean age 46.2 (SD 7.8). 60% male. 68% Black/African American, 18% Hispanic/Latino, 14% non-Hispanic white	HIV Treatment Knowledge Scale	Infection Co-morbidity Lymphocyte count Substance related disorders Depression Medication knowledge	

Table 1 (continued)

Author(s)/design/sample characteristics	Health Literacy measure	Outcomes measured	Results
Van Servellen et al. [29] Quantitative interventional n = 85. Mean age Intervention group 41.8 (SD 8.3), Comparison group 39.5 (SD 9.3). Male Intervention group 92.9% Comparison group 88.4%. Race/ethnicity not reported	REALM	Lymphocyte count Viral load Medication knowledge	HIV knowledge/literacy increased more for intervention group than comparison group. Comparison group showed a significant increase in nonadherence compared to the pilot group. No statistically significant difference between the 2 groups on missed ART doses over the past 4 days. Comparison group had lower viral loads
Van Servellen et al. [39] Quantitative interventional n = 85. Mean age Intervention group 42.9 (SD 8.47), Comparison group 39.55 (SD 9.32). Intervention group 87.8% male. Comparison group 92.5% female. Race/ethnicity not reported	REALM	Lymphocyte count Viral load Medication knowledge	Intervention group had significantly greater knowledge of HIV/AIDS and recognition and understanding of HIV terms at 6-week follow-up. No significant differences on adherence measures/behaviors
Waldorp-Valverde et al. [49] Quantitative cross sectional n = 207. Overall demographics not reported	TOFHLA	Medication adherence	Poor management of simulated HIV medication regimen among African Americans and women was mediated by lower numeracy. African American women may be at particular risk. Interventions to improve HIV medication self-management through addressing numeracy skills may help to narrow the gap in health disparities among African Americans with HIV/AIDS
Waldorp-Valverde et al. [18] Quantitative cross sectional n = 155. Age not stated. Male 58%, Female 42%. African American 87%, "non-Black" 28%	TOFHLA	Medication knowledge	Women and men performed similarly on the TOFHLA. Women had lower scores than men on the numeracy and medication management tools
Waldorp-Valverde et al. [20] Quantitative cross sectional n = 57. Mean age 42.77. 78.95% men. 89.47% Black. 7% Hispanic, 3.5% white	TOFHLA	Lymphocyte count Viral load Substance related disorders	Performance on measures of literacy and cognitive functioning were below average, with severe deficits noted in psychomotor functioning. After adjusting for recent cocaine use, those classified as low literate/low cognition were over 9X more likely to be non-adherent than the referent high literate/high cognition group. Low literacy and cognitive impairment placed HIV-positive drug users at high risk for non-adherence, even after adjusting for recent cocaine use

**Table 1** (continued)

Author(s)/design/sample characteristics	Health Literacy measure	Outcomes measured	Results
Waldorp-Valverde et al. [34] Quantitative cross sectional n = 210. Mean age 47.8 (SD 7.4). 52.86% female, 46.19% male, 0.95% transgender. 82.86% Black/African American, 10.48% Hispanic 4.29% white, 1.43% other	TOHFLA	Viral load	Participants who attended more than 75% of phlebotomy visits were more likely to be virally suppressed. Health literacy was not associated with adherence to medical or phlebotomy visits. Cognitive impairment (CI) was not directly related to medical or phlebotomy visit adherence; however, those with CI and greater use of social support were less likely to miss medical visits
Waldorp-Valverde et al. [19] Quantitative cross sectional n = 191. Mean age 44.81 (SD 8.43). 57% male, 43% female. 83% African American, 11% Hispanic, 4% white, 2% other	TOFHFLA	Medication management	TOFHFLA scores for reading comprehension along with numeracy were associated with an executive skill set. The executive skillset was positively correlated with ability to manage medications
Walker et al. [38] Quantitative cross sectional n = 81. Mean age 45 (SD 10). 36.67% female. 56% non-Hispanic white, 22% Hispanic, 22% Black	TOFHFLA	Lymphocyte count Viral load Substance related disorders Anxiety Depression Medication knowledge	Hispanic and Black individuals demonstrated less HIV knowledge than non-Hispanic white (NHW) individuals. Black participants demonstrated fewer health literacy appraisal skills. Lower levels of health literacy were linked to poorer CD4 cell count (an index of immune functioning) for Hispanic and Black individuals and not for NHW individuals. Findings suggest race group differences for health literacy on current CD4 cell count play an important role in clinical health outcomes in HIV
Wigfall et al. [41] Quantitative cross sectional n = 145. Mean age 45.5 (SD 10.4). 100% female. 87% non-Hispanic black, 8% other	Single question	Outcome assessment	Participants with higher health literacy were significantly more likely to have read the information received about abnormal Pap tests and to have understood the cancer information they read. Provider communication is lowest among participants with low health literacy and lower SES
Wigfall et al. [41] Quantitative cross sectional n = 106. Mean age 46.3 (SD 10.9). 100% female. 92% non-Hispanic black, 8% other	Single question	Outcome assessment	84% of participants adhered to Pap test guidelines for women living with HIV/AIDS (WLHA). One-third had low health literacy. Exam assessment with cervical cancer knowledge and understanding of Pap outcomes
Woods et al. [50] Quantitative cross sectional n = 46. Overall demographics not reported	TOFHFLA	Co-morbidity Lymphocyte count Viral load Substance related disorders Anxiety Depression	Individuals with HAND have difficulty accurately completing routine online healthcare tasks. HAND effects were not better explained by other factors. Individuals with HAND are at risk for low health literacy and difficulties with medication adherence

**Table 1** (continued)

Author(s)/design/sample characteristics	Health Literacy measure	Outcomes measured	Results
Quantitative interventional n = 204, 47.1 (SD 7.4). 52.9% women, 46.2% men, 82.9% African American, 10.5% Hispanic, 4.3% white	Not specified	Outcome assessment Depression	High prevalence of depressive symptoms in participants. Negative mood/somatic symptoms were associated with greater odds of missing a visit in any of the observed 4-month time periods than positive mood factor

*TOFHLA* test of functional health literacy in adults, *REALM* rapid estimate of adult literacy in medicine, *ENS* Expanded Numeracy Scale, *NVS* newest vital sign; *BHLS* brief health literacy screen, *HIV-HL* HIV Health Literacy Scale

health literacy scale should be further explored for utility in measurement of HIV-specific literacy. With such a variety of instrumentation, conclusions and recommendations must be adopted with caution. Measurement error with multiple instruments across studies and most studies not utilizing an HIV specific instrument, the interpretation and generalizability of the results is complex. The range of approaches to the study of health literacy and health outcomes makes it difficult to determine the overarching outcomes related to these two critical areas of the health continuum in HIV disease. Quantitative studies with approaches to design that were both cross-sectional and interventional were prevalent as were some qualitative approaches to the study of health literacy and health outcomes. The heterogeneity of the study designs and the variability in findings makes the efficacy of health literacy levels more complex in the analysis of outcomes. Methodological limitations of the studies made it difficult to achieve significance in the findings of several studies. Small sample size and lack of randomization or control of demographic variables limited the generalizability of the study outcomes. Both external validity (generalizability) and internal validity (validity of the results and inferences of the studies are limited due to confounding and selection biases. Few studies addressed potential confounding variables or study selection bias.

One of the most compelling areas for further investigation is related to computer-delivered adherence interventions as a cost-effective strategy to improve adherence in persons receiving HIV care. In the study by Ownby et al. [11], the researchers developed a computer-delivered intervention which aimed to improve patients' level of health literacy and to improve their HIV medication adherence. Their findings suggested that the intervention increased patients' adherence, however, it was unclear whether the benefits resulting from the increase in adherence justified the costs of the computer-delivered intervention. Further investigation of computer-delivered adherence interventions, associated costs, and the linkage with health outcomes is a critical area for further research—particularly since few studies have addressed computer-based approaches since Ownby et al. [11] published their earlier work.

Another area that requires further investigation is the relationship between health literacy and health outcomes including physiological markers such as viral load and CD4 count, HIV knowledge, medication knowledge, depression, and substance use. Physiological markers such as CD4 count, viral load, and other key markers of HIV progression have variable outcomes in studies related to HIV-related health literacy. Robust intervention studies that address these health outcomes across the spectrum of an individual's HIV experience are needed.

In our study, we limited the systematic review to studies conducted in the U.S. and Puerto Rico and those studies

published in the English language. Few studies utilized intervention approaches and there were few longitudinal studies of efficacy of interventions. Based on the inclusion/exclusion criteria, the variability in design of studies, which yielded heterogeneity in findings, we were limited in our systematic review. Future study should address the need for larger sample sizes, control of confounding variables, and interventional approaches to address the relationships among health literacy, health outcomes, and mediating variables. In our systematic review, only one study explicitly addressed control of confounding variables, thus this is a critical area to address in future research [31]. In addition, addressing health literacy and health outcomes in global areas where HIV is highly prevalent is a critical area for further research.

There is an urgent need to address limitations in the measurement of health literacy in HIV disease and examining the complex relationship with health outcomes. It has been noted in the Institute of Medicine (IOM) report that causal relationships between limited health literacy and health outcomes have yet to be fully understood although cumulative findings lend some support to a causal connection [3]. This is consistent with our findings in this systematic review of health literacy and health outcomes in HIV. Finally, Perazzo et al. [58] note that further research that is aimed at determining the influence of health literacy as a process variable that influences health management and health outcomes is crucial. Culturally appropriate approaches to the study of health literacy and health outcomes are key areas for further research. Limitations in health literacy and its relationship with health outcomes across the complex spectrum of HIV as a chronic illness are important to examine as those living with HIV live longer lives, often with co-morbid illnesses.

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## Compliance with Ethical Standards

**Conflict of interest** None of the authors have any conflicts of interest to report.

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### Asterisk included in systematic review

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