

Health numeracy and health literacy within the context of management of patients with human immunodeficiency virus

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Abstract: Health literacy, although an important topic in human immunodeficiency virus (HIV), often eclipses health numeracy, which may be equally important for those living with this disease. Health numeracy is the knowledge and application of numerical concepts in health decisions. In our synthesis of the literature, the emerging concept of health numeracy in relation to HIV disease management is reviewed within the context of health literacy. Specifically, we examine health literacy and numeracy by gender, race, education, and age group. From this synthesis, we identify practical implications of health numeracy related to HIV.

Keywords: health literacy, health numeracy, human immunodeficiency virus, acquired immune deficiency syndrome, medication adherence

Introduction

Patients with any recent diagnosis or chronic medical condition must process a great deal of new information. They need to learn about the origins of the disease, its cause, and the potential treatment options, if any. Also, patients need to understand how the disease affects them, requiring them to quickly learn new terms and concepts about normal human physiology as well as disease pathologies. In addition, patients must correctly interpret the health information provided. The responsibilities of navigating a complex health care system can be particularly difficult for low-literate individuals. Unfortunately, being diagnosed with any disease, particularly a disease that is stigmatizing or life-threatening, such as human immunodeficiency virus (HIV), can produce anxiety and depression. Such negative affect can interfere with learning and processing new information.¹ The general consensus is that it is important for patients to possess and utilize medical information to make better informed treatment decisions;² however, it is unclear whether patients actually process and apply this information in the way it is intended. For this reason, understanding health literacy and health numeracy is especially relevant for clinical populations.

Health literacy is the capacity of an individual to understand and utilize health information and services in making informed health decisions.³ In 2003, nearly 80 million US adults (36%) had limited health literacy.³ Health literacy includes an array of skills, including the ability to interpret documents accurately, read and write, and communicate effectively in order to function adequately in the health care system.⁴ Although much attention over the past decade has been paid to health literacy and its effect on health outcomes, there is a current trend of research focused on health numeracy as a separate construct rather than as a component of health literacy.⁵

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The concept of health numeracy has recently been addressed in the literature on HIV-related health outcomes,^{6,7} as well as other areas of health, such as anticoagulation control,⁸ diabetes,⁹ and self-management of asthma.¹⁰ However, it is important to distinguish between basic numeracy and health numeracy. Whereas numeracy is the understanding and use of numbers in daily life,¹¹ health numeracy extends this concept to health-related phenomena. More specifically, it has been defined as “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions”.⁵

The purpose of this paper was to examine and synthesize the concept of health numeracy within the context of HIV disease management. In order to do so, we provide a brief review of health literacy as a backdrop to the emerging concept of health numeracy in HIV. Following this, we provide a specific focus on health numeracy in HIV, while examining specific clinical populations, including education level, gender, age, and race. As depicted in Figure 1, individuals with less education, older adults, males, and minorities have been associated with disparities in health literacy. We begin to tease apart similarities and differences in these groups within the literature on both health literacy and health numeracy. From this, we suggest implications for nursing practice and research.

Health literacy versus health numeracy

Health literacy and health numeracy are related concepts that are both important in making informed choices for healthy

lifestyles, yet require a different set of skills.⁹ Based on the National Center for Education Statistics, a greater percentage of US adults have limited numeracy skills (22%) when compared with other types of literacy skills (14% limited in prose literacy and 12% limited in document literacy).¹² Although some patients have adequate health literacy, a great majority are found to have inadequate health numeracy.^{11,13} In other words, although some individuals have a basic understanding of health information and services, many still lack numerical understanding at the level required for making health decisions. Thus, the importance of health numeracy in relation to health-related decisions and outcomes cannot be overstated.

The association between health literacy and health numeracy with regard to health services and outcomes has recently been reviewed by Berkman et al.⁴ Based on their review of the studies examining both health literacy and health numeracy ($n = 4$), health numeracy was more highly correlated than health literacy with patient outcomes. For example, one study¹⁴ examined health literacy, general numeracy, and diabetes-related health numeracy in a sample of adults with type 2 diabetes ($n = 383$). Their findings indicated that low levels of diabetes-related health numeracy, not health literacy, were associated with poor glycemic control. Health numeracy may reflect the actual application of health-related information because people may be able to use quantitative data more easily to achieve better health outcomes. These findings highlight the need for a stronger focus on the concept of health numeracy for HIV disease management and outcomes.

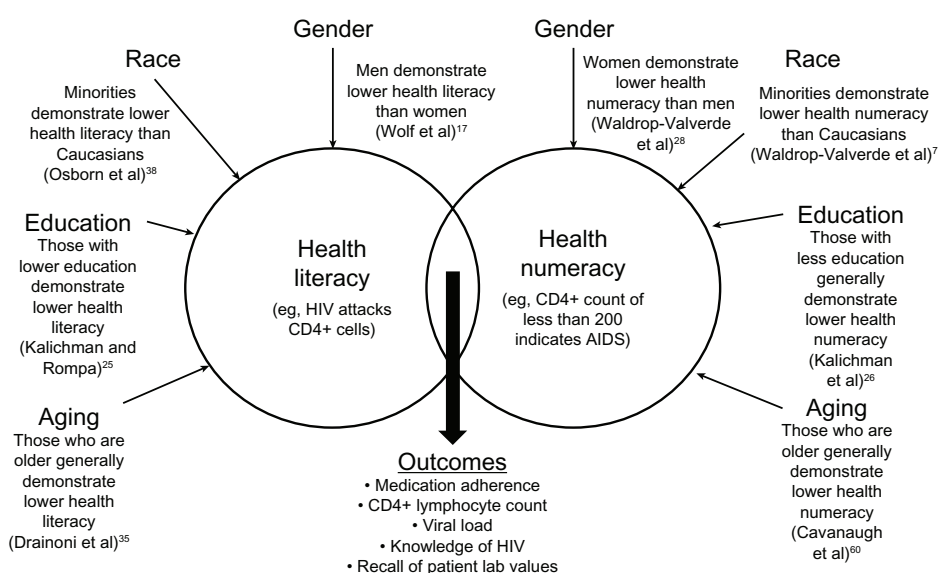


Figure 1 Overlap of health literacy and health numeracy that may relate to HIV.

Health literacy, health numeracy, and HIV

Health literacy is especially important for individuals living with HIV because those with inadequate health literacy skills are less knowledgeable about their HIV disease and treatment and are also less likely to adhere to treatment.^{15–17} For example, in a study examining the relationship between health literacy and health-related knowledge of individuals with HIV ($n = 228$), those with lower levels of health literacy were less likely to have undetectable viral loads and less likely to actually know their CD4+ lymphocyte counts and viral loads.¹⁵ Similarly, in another study of 204 individuals with HIV,¹⁸ patients with limited health literacy were less likely to report correctly their CD4+ lymphocyte counts and viral loads, and less likely to identify their antiretroviral medications correctly.

Health numeracy is relevant for individuals with HIV because much of their health information is quantitative. Successful management of HIV requires a great deal of quantitative information, such as counting pills and medication timing, as well as monitoring and interpreting one's CD4+ lymphocyte count and viral load, eg, a CD4+ lymphocyte count below 200 is indicative of acquired immune deficiency syndrome (AIDS). Furthermore, as individuals with HIV live longer, they are more likely to develop other chronic medical conditions such as hypertension, hyperlipidemia, and diabetes.^{19,20} These conditions also require proficiency in numeracy skills to promote healthy decision-making and wellness. For example, although it is important for patients to be literate about their lipid levels to decrease their risk of heart disease, eg, ("My LDL [low-density lipoprotein] is my bad cholesterol which can cause clogging in my arteries"), it is equally important to know what numerical values can decrease this risk (eg, "My goal for my next doctor's visit is to get my LDL below 100"). Tables 1 and 2 provide numeric information associated with HIV and related comorbidities.

The relationship between limited health literacy and increasingly disparate health outcomes is well noted in the literature among individuals with limited educational backgrounds, as well as among minority populations and older adults.²¹ However, health numeracy is not as prevalent in the scientific literature. In the following sections, health literacy and health numeracy by education level, gender, age group, and race are briefly examined within the context of HIV. It should be noted that although the literature in health numeracy is limited, the expected direction of relationships (eg, minorities demonstrate worse health numeracy than Caucasians) is similar to studies in health literacy.

Educational differences

Poor health literacy has been associated with lower education levels in numerous studies.^{22–24} Kalichman and Rompa²⁵ examined health literacy in individuals with HIV and found that those with limited health literacy were more likely to have less years of formal education than those with higher health literacy ($n = 338$). On the other hand, a higher level of education may not necessarily translate into higher health literacy levels. In a study of individuals with HIV on antiretroviral therapy,¹⁸ ($n = 204$) more than 60% of the sample reported having some college education; however, 30% had less than a high school reading level (ie, health literacy level) when administered a health-related reading test. Interestingly, health literacy has been shown to be a stronger predictor of antiretroviral medication adherence than years of education.²³

An early study²⁶ found a significant positive correlation between health literacy and health numeracy in individuals with HIV ($n = 184$; 54% African-American). Health literacy was measured by a shortened version of the Test of Functional Health Literacy in Adults (TOFHLA).²⁷ Health numeracy was measured by the numeracy scale of the TOFHLA. Although health literacy was examined in association with patients' adherence to combination antiretroviral therapies, health numeracy was only measured to validate the TOFHLA internally. Among the overall findings, the relationship between health literacy and medication adherence was not significant for participants with fewer than 12 years of education, but significant for participants with 12 or more years of education. Thus, within the more highly educated subsample, those with lower health literacy scores were less likely to be adherent to their medications when compared to those with higher health literacy scores.

Gender differences

The literature supports the existence of gender differences in both health literacy and health numeracy. For example, the National Center for Education Statistics found that although women had slightly higher scores than men in reading/comprehension of health information, men had significantly higher scores than women in numeracy skills.¹² A study of health literacy among 204 individuals with HIV¹⁷ found that males were significantly more likely to have limited health literacy than females.

Waldrop-Valverde et al²⁸ examined the relationship of health literacy, health numeracy, and HIV medication management by gender in a sample of patients recruited from

Table 1 Numeric health information associated with human immunodeficiency virus

Quantitative information	Quantitative values	Interpretation	Example
ART regimen	<ul style="list-style-type: none"> • Number of pills • Dosage of pills • Frequency of pills • Time of day 	95% adherence rate is expected for optimal viral suppression ⁶¹	Patient with 1 dose a day who missed only 3 doses during the past month may think they are adherent, but are 90% adherent
Clinic visits	<ul style="list-style-type: none"> • Date of visit • Time of visit • Frequency of visits 	Missed clinic visits are associated with virologic failure and disease progression ⁶⁶	Patient nonadherent to clinic visits or unable to access care may miss laboratory tests or instructions for medication regimen
CD4	<ul style="list-style-type: none"> • 500–1500 mm³ • <350 mm³ • <200 mm³ 	<ul style="list-style-type: none"> • 500–1500 mm³ (normal range) • <350 mm³ (begin ART regimen) • <200 mm³ progression to AIDS⁶² 	Patient may misinterpret goal of treatment (eg, “I take my meds to make my CD4 go down”)
VL	<ul style="list-style-type: none"> • <50 copies/mL • ≥50 copies/mL 	<ul style="list-style-type: none"> • <50 copies/mL (HIV undetectable) • ≥50 copies/mL (HIV detectable) 	Patient may misinterpret goal of treatment (eg, “I take my meds to make my VL go up”)

Abbreviations: ART, antiretroviral therapy; CD4, CD4+ lymphocyte count; VL, viral load.

affiliated HIV care clinics in the Southeast US (n = 155; 87% African-American). Health literacy was measured by the reading comprehension subscale of the TOFHLA. Health numeracy was measured by the applied problems subscale of the Woodcock Johnson-III Tests of Achievement, ie, the mathematical problem is read aloud by the examiner and the participant decides the appropriate mathematical calculation.²⁹ Although no significant differences were noted between men and women in the health literacy measure, women scored significantly lower than men on the numeracy measure. Women also scored significantly lower in understanding HIV medication instructions, although this relation-

ship was negated by numeracy. Thus, gender differences in numeracy have important implications for health disparities because men may be more likely to understand and adhere to quantitative medical information than women.

Age differences

Health literacy is poorer among older adults as compared with the general population.^{21,30} Regardless of educational background, more than two-thirds of US adults aged 60 years or older have low or marginal literacy skills.³¹ Using the Short Test of Functional Health Literacy in Adults,³² Gazmararian et al³³ examined health literacy among Medicare enrollees

Table 2 Numeric health information associated with HIV-related comorbidities

Quantitative information	Quantitative values	Interpretation	Example
BP	<ul style="list-style-type: none"> • <120/80 mmHg 	<ul style="list-style-type: none"> • <120/80 mmHg (normal) 	Patient may think a systolic BP in the 140s is normal
Comorbidity Hypertension	<ul style="list-style-type: none"> • 120/80–139/89 mmHg • 140/90–159/99 mmHg • ≥160/100 mmHg • ≥180/110 mmHg 	<ul style="list-style-type: none"> • 120/80–139/89 mmHg (prehypertension) • 140/90–159/99 mmHg (hypertension, stage 1) • ≥160/100 mmHg (hypertension – stage 2) • ≥180/110 mmHg (hypertensive crisis)⁶³ 	
BG	<ul style="list-style-type: none"> • Fasting BG ≥ 126 mg/dL 	<ul style="list-style-type: none"> • Diagnosis of diabetes: 	Patient may not know normal blood glucose values
Comorbidity Diabetes	<ul style="list-style-type: none"> • 2-hr oral glucose tolerance test ≥ 200 mg/dL • Random BG ≥ 200 mg/dL • Fasting BG 100–125 mg/dL 	<ul style="list-style-type: none"> • Fasting BG ≥ 126 mg/dL • 2-hr oral glucose tolerance test ≥ 200 mg/dL • Random BG ≥ 200 mg/dL • Diagnosis of prediabetes: • Fasting BG 100–125 mg/dL⁶⁴ 	
LDL	<ul style="list-style-type: none"> • LDL 70–130 mg/dL 	<ul style="list-style-type: none"> • LDL, <100 mg/dL is optimal 	Patients may confuse HDL with LDL (eg, “I want to keep my LDL high and my HDL low.”)
HDL	<ul style="list-style-type: none"> • HDL > 40–60 mg/dL 	<ul style="list-style-type: none"> • HDL, ≥60 mg/dL is optimal 	
Total cholesterol	<ul style="list-style-type: none"> • Total cholesterol < 200 mg/dL 	<ul style="list-style-type: none"> • Total cholesterol, <200 mg/dL is optimal 	
Triglycerides	<ul style="list-style-type: none"> • Triglycerides 10–150 mg/dL 	<ul style="list-style-type: none"> • Triglycerides, <150 mg/dL is optimal⁶⁵ 	
Comorbidity Hyperlipidemia			

Abbreviations: BP, blood pressure; BG, blood glucose; LDL, low-density lipoprotein; HDL, high-density lipoprotein.

across the US ($n = 3260$). These researchers found that 33.9% of English-speaking and 53.9% of Spanish-speaking adults aged 65 years or older had inadequate or marginal health literacy. Level of education and cognitive impairment were also associated with lower health literacy. Even after controlling for these two factors, health literacy declined significantly with age.³³ Unfortunately, health numeracy was not measured, but given what is known about the close relationship between health literacy and health numeracy, older adults in general may also possess poorer health numeracy skills which could impact their health outcomes. Murphy et al³⁴ conducted one of the first studies on health literacy in adolescents with HIV, and found no relationship between health literacy and antiretroviral adherence in this population ($n = 186$; mean age 20.5 years). In adults with HIV, Drainoni et al³⁵ reported a relationship between older age and poorer health literacy while other studies^{17,23,25} found no association.

In developed countries where patients have access to antiretroviral medication, nearly half of those with HIV will be 50 years and older by 2015.³⁶ Little is known about health literacy and health numeracy in this burgeoning clinical population. Given that comorbidities increase with advanced age in adults with HIV,²⁰ older patients will be juggling a great deal of medical information to help inform health care decision-making (see Table 2). Juggling such information may be particularly difficult for many older adults with HIV who are vulnerable to neurological insults resulting in poor memory and trouble with reasoning and planning.³⁷ Thus, more information is needed on how health literacy and health numeracy, along with cognitive problems, will impact health outcomes in this growing population.

Racial differences

Osborn et al³⁸ examined the mediating effect of health literacy on the relationship between race and HIV medication adherence. Health literacy was measured by the Rapid Estimate of Adult Literacy in Medicine.³⁹ The task involves asking the participant to read aloud a list of medical words (eg, “pill”, “prescription”, “medication”) and scoring for correct pronunciation. In their sample ($n = 204$; 45% African-American), they found that African-American patients were significantly more likely to be nonadherent with their HIV medications than their Caucasian counterparts. However, when health literacy was included in the model, the effect of race was not significant.³⁸

Building on the previous study, Waldrop-Valverde et al⁷ examined numeracy as a potential mediator between race and medication management among patients recruited from an infectious disease clinic and an AIDS drug assistance

program ($n = 207$; 84% African-American). Health literacy was measured by the reading comprehension subscale of the TOFHLA and numeracy was measured by the Applied Problems subscale of the Woodcock Johnson-III.²⁹ Using a simulated medication regimen approach in which participants were questioned about a series of mock HIV medication instruction labels, African-Americans were less likely than non-African-Americans to follow medication instructions correctly. Interestingly, although no differences in health literacy scores were noted between races, African-Americans scored significantly lower in numeracy scores than their non-African American counterparts. Moreover, the relationship between race and HIV medication management was negated by numeracy.⁷ Thus, health numeracy skills may be an important predictor in explaining racial disparities that exist for African-Americans in HIV medication adherence and management.

Although the majority of HIV studies that examine racial disparities in health literacy and health numeracy focus on African-Americans, recent studies address disparities in the Latino population. In their study of a high-risk sample of individuals with HIV ($n = 231$), Drainoni et al³⁵ found that Latinos were four times as likely to have limited health literacy as Caucasians, and those whose native language was Spanish were twice as likely as native-English speakers to have lower health literacy. Health literacy interventions targeting this specific population have also been noted in the literature.⁴⁰

Implications for nursing practice

Nurses are on the forefront in efforts to address both health literacy and health numeracy concerns and patient outcomes in health care. What may seem simple and straightforward among health care professionals may be difficult for patients to understand, regardless of their level of education. With the concept of health numeracy emerging from the health literacy movement, there are numerous opportunities for nurse leaders to provide the infrastructure for improved patient understanding within the context of HIV disease management.

Nursing curricula and continuing education

Whether dealing with a new disease process, discharge teaching, or managing a chronic condition, nurses often provide one-on-one health education to patients.⁴¹ To prepare those diagnosed with HIV for self-management of a complex medication regime properly, nurses must be educated to: conduct a patient risk assessment for low health literacy

and health numeracy; identify the knowledge level of each patient; and prepare patient education materials at the appropriate reading and numeracy levels.⁴²

In response to health literacy reports by the Joint Commission⁴³ and Healthy People 2020^{2,44} nursing schools have begun to explore curricula revision to include a health literacy component. Nielsen-Bohlman et al³ noted the necessity of revising nursing education curricula to include content preparing health care professionals to identify patients with low health literacy skills (numeracy and reading comprehension). To prepare patients effectively for a complex self-management care plan involving functional numeracy skills, nurses must be prepared by undergraduate and graduate level curricula to communicate effectively with patients.⁴²

Experienced nurses may also need continuing education to understand fully and recognize the risks associated with limited health literacy and health numeracy. In a study of an academic health center, Jukkala et al⁴⁵ examined health care providers' and college students' knowledge of the impact of health literacy on patients and the health care system ($n = 230$). Participants in the study included nursing, dentistry, and medical professionals, as well as college students. Among health care professionals, nurses had the highest percentage of knowledge deficits in health literacy (17.1%). Furthermore, only 8.5% of nurses in the sample ($n = 7$) had knowledge of the growing percentage of adults with difficulty understanding health care information and instructions.

Patient communication and participatory decision-making

In general, patients want to know more about their disease,⁴⁶ but those with limited health literacy and numeracy may be unlikely to ask questions about things they do not understand. Furthermore, health care providers in the HIV care setting may not easily perceive that their patients face health literacy and numeracy barriers to care.⁴⁷ For this reason, it is ethically imperative that verbal and written health communication to all patients be relayed in a way that is clear and easy to understand. Recently, national efforts have been made to provide nurses and other health care professionals with the tools they need to address issues of limited health literacy and numeracy in their patient populations.^{48,49} Although further testing is needed to determine the effectiveness of these programs, this is an important step in engaging the patient as an active participant in the plan of care. Participatory decision-making involves a collaborative relationship between the patient and the nurse, characterized by actively communicating to improve the patient's understanding and involvement in

decision-making for better health outcomes.⁵⁰ For individuals with HIV, such a relationship is invaluable to understanding laboratory values and a complex treatment plan.

Implications for nursing research

The complex concept of health numeracy has important implications for nursing research. Although recent strides have been made in examining the relationship between health numeracy and health outcomes, much work is needed to advance the field in HIV. In particular, instrument development and interventional studies are needed.

General numeracy instruments lack any real concrete example within a context of health and medicine.^{51–53} Health numeracy instruments that are HIV disease-specific would resonate with patients and be more applicable to health outcomes than general numeracy instruments. Unfortunately, there are no instruments that specifically focus on health numeracy related to HIV; however, there are two health literacy instruments that come close.

Osborn et al⁵⁴ developed a health literacy instrument within the context of HIV disease treatment, ie, the Brief Estimate of Health Knowledge and Action – HIV Version (BEHKA-HIV). This eight-item instrument was designed to assess knowledge of CD4 lymphocyte count, viral load, and current HIV medications, as well as medication adherence. Its subscales have reported reliability coefficients of 0.73 and 0.79.⁵⁴ What is interesting about the BEHKA-HIV is that there are two items that are somewhat related to HIV health numeracy (ie, “Is the goal of treatment to make the CD4 count go up or down?” and “Is the goal of treatment to make the viral load go up or down?”). Although no real numbers or ranges of optimal or suboptimal values are asked, these two items reflect a cursory understanding of the importance of health numeracy related to HIV. Obviously, it would be helpful to know if a CD4 count of 199 is good or bad or whether a viral load that increases to one million is harmful. Future development of instruments should take such items into account, as well as other numeracy items related to medication schedules, and clinic appointments (see Table 1).

More recently, Ownby et al⁵⁵ developed the HIV-Related Health Literacy (HIV-HL) scale. This computer-administered, 20-item instrument assesses skills in taking medications properly and has several items related to HIV infection and treatment. Although the instrument has a stronger focus on health literacy, there are numeracy-type items included. For example, participants must understand basic numerical items (“Take two pills two times a day”) as well as more

complex numerical items (“If you take two pills two times a day, how long will this prescription last?”). The reported reliability coefficient of the revised 19-item HIV-HL was 0.69.⁵⁵ Although the development of this instrument advances the field primarily through evaluating listening comprehension, it requires further testing in a clinical setting.

There have been numerous intervention studies focused on improving health literacy to promote health outcomes among those living with HIV.^{35,40,56} The majority of studies on health numeracy have so far been descriptive. HIV studies in particular have thus far primarily examined relationships between health numeracy and medication adherence.^{7,28,57} Future intervention studies in HIV should incorporate graphics and visual displays of the numerical values being presented to facilitate comprehension in patients with HIV.^{55,58}

Health numeracy research should focus on developing interventions that improve understanding of quantitative health information to improve health outcomes not only in medication adherence, but also in understanding laboratory values. A participatory design method with low health-numerate individuals can be used to determine how patients understand numerical information as well as patient preferences on how they like to receive this information. An intervention can then be developed based on these preferences and tested for feasibility and effectiveness on health outcomes. Such health numeracy interventions should also be tailored to specific clinical populations and socially disadvantaged groups most affected, such as African-Americans and/or older adults with HIV, especially those with cognitive deficits.

Limitations

Our synthesis of the literature has its limitations. Although we discuss a brief review of the literature on health literacy, the main purpose of our manuscript is to discuss the emerging concept of health numeracy. Thus, our synthesis is not a complete review of the research in health literacy. Furthermore, Figure 1, which depicts an overview of demographic considerations in health literacy and numeracy, reflects a limited number of studies and should be viewed as a starting point for future research. For example, there is a dearth of health numeracy research in the aging population, because the majority of HIV studies do not include a significant number of individuals over the age of 50 years from which to draw age group comparisons. This is an important gap to address, as the population aging with HIV continues to grow.³⁶

Conclusion

As part of President Obama’s National HIV/AIDS Strategy,⁵⁹ which focuses in large part on reducing HIV-related health disparities and inequities and increasing access to care, health literacy and health numeracy are clearly important topics. There has been a recent trend towards health numeracy studies that focus on chronic diseases such as diabetes.^{14,60} However, more research is needed to disentangle the separate effects of health literacy and health numeracy in HIV (Figure 1). The focus on health numeracy and its effects on HIV disease progression are important not only for patients with HIV but also for caregivers, educators, clinicians, and researchers within this growing field.

Disclosure

The authors report no real or perceived vested interests that relate to this article (including relationships with pharmaceutical companies, biomedical device manufacturers, grantors, or other entities whose products or services are related to topics covered in this manuscript) that could be construed as a conflict of interest.

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