

Factors Associated with Health Literacy among People Living with HIV: A Narrative Review

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Abstract

Health literacy is an important topic in people living with human immune deficiency virus (HIV). This review examined factors associated with health literacy among people living with HIV. We searched the literature available from PubMed and Scopus-Elsevier. Compound terms “health literacy” and “HIV health literacy” were employed to retrieve the relevant literature. The terms were typed in the following fields: article title, abstract and key words through the Boolean operator “AND”. We limited our searches to articles published in the period between 1993 and 2017 and in the English language. Factors associated with health literacy were critically reviewed and categorized. A total of 40 articles met inclusion criteria and were included in this literature review. They were clinical trials (n = 28), cross-sectional (n = 10) and pilot (n = 2) studies. The majority of the studies (68.42%) were conducted in the United States (US), while the rest were conducted in Africa. Whether gender plays a role in health literacy among people living with HIV was inconclusive. Factors associated with HIV health literacy among people living with HIV included education, age, and race. These factors could be used to predict the level of health literacy among people living with HIV. Further research conducted in other geographical regions is needed, given limited generalizability of these published articles’ results.

Keywords : health literacy, associated factors, HIV/AIDS, education, age, race

Health literacy is the ability to read, write, understand, process and act according to medical information, as well as to use numbers in daily life (numeracy).^{1,2} Tique et al.³ defined general health literacy as “the degree to which individuals have the capacity to act, understand basic health information and use health care services for appropriate health decisions”. In comparison to people who have stronger health literacy, those with limited or inadequate health literacy overuse health care services, have problems in following medical instructions, suffer from both physical and mental conditions and fail to exceed the average life expectancy.⁴⁻¹⁰ Limited health literacy is related to suboptimal health outcomes, especially in chronic conditions such as diabetes, hypertension and HIV infection.

With regards to HIV, individuals with limited health literacy have less knowledge of the disease and limited perceptions of their health conditions and treatment needs. Furthermore, they exhibit low rates of medication adherence, inadequate management of their antiretroviral therapy (ART) and a general inability to achieve undetectable viral loads.^{9, 11-15} In Mozambique, where the prevalence of adults living with HIV in 2007 was 11.5%, census data reported that only 55% of the population were literate.³ Such a low literacy rate may have a negative impact on the ability of patients to self-manage their HIV infection. Evidence from the US studies shows that HIV patients with low health literacy had less HIV-related knowledge, less capacity to manage their medication and lower chances of achieving undetectable viral loads than those with high health literacy.^{9,13,16-19} Some studies illustrate a link between a shortage of health literacy and non-adherence to ART while other studies found no relationship between the two factors.^{12,20-23}

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Most of the previous studies on health literacy among people living with HIV were conducted in the US and Africa.^{3,20} Nonetheless, the findings may not be generalizable to other geographical regions with differences in socioeconomic characteristics, cultural aspects and local healthcare policies. A primary objective of this review was to provide a critical analysis of factors associated with health literacy among people living with HIV.

Methods

This article was a narrative literature review of publications, such as articles, case reports and books on health literacy and people living with HIV/AIDS. We searched for literature from PubMed and Scopus-Elsevier. Compound terms “health literacy” and “HIV health literacy” were used to retrieve the relevant literature. The terms were typed in the following fields: article title, abstract and keywords through the Boolean operator “AND”. We limited our searches to the time period between 1993 and 2017 and to articles written in the English language. Factors associated with health literacy were critically reviewed and categorized. Gaps in research and implications on clinical practice are discussed at the end of this article.

Results and Discussion

Of the 74 identified articles, 40 met our criteria. Most of the articles belonged to the subject areas of the “Medicine,” “Nursing,” and “Social Science” fields. Articles included in the literature review were 28 clinical trials, 10 cross-sectional, and 2 pilot studies, and mainly involved non-representative and/or convenience samples. Of these studies, 68.42% were conducted in the United States and the rest in Africa.

Education

Low health education levels were significantly associated with limited health literacy.^{29,30} Kalichman and Rompa³¹ (1999) examined health literacy in 339 patients living with HIV and found that those with limited health literacy had a lower level of formal education, compared to those with higher health literacy. A study of individuals with HIV on ART demonstrated that HIV patients, who graduated from college, had higher reading-literacy skills, higher CD4 count and lower viral load than those who graduated from a high school. A strong predictor of antiretroviral medication adherence was health literacy and the number of years of academic study.^{7,29}

The relationship between education, health numeracy and health literacy in individuals with HIV was found in an earlier study.^{9,31} One study examined health literacy, health numeracy and their association with an education level among 184 patients, of which 54% were African-American.³² Health literacy was assessed by the Test of Functional Health Literacy in Adults (TOFHLA) and health numeracy by the numeracy scale of TOFHLA. The study found a significant relationship between levels of education, levels of health

literacy, health numeracy and medication adherence. The study concluded that education was an important factor for patients with HIV in African-American communities.

Gender

An association between gender and health literacy is inconclusive. Gakumo et al.³² compared levels of health literacy between men and women. Findings showed that women had a better performance of reading and comprehension of health information than men, while men had significantly higher scores than women in numeracy skills. Waldrop-Valverd et al. studied the health literacy of 204 participants with HIV and found that female participants were more likely to have higher health literacy levels than male participants.³³ They also examined the links of health literacy, health numeracy and HIV-medication management among participants in the Southeastern US. Reading comprehension was used to measure health literacy and the applied problems subscale of the Woodcock Johnson-III Tests of Achievement was used to measure health numeracy. Results show that men scored higher than women on the numeracy skills, while health literacy levels were not different between men and women. Men also performed better than women in understanding HIV medication information. Accordingly, men were more likely to comprehend and act on medical instructions than women.

Aging

Compared to the general population, the elderly seem to have lower levels of health literacy.¹ Over two-thirds of the US people aged 60 years or above have limited health literacy.³² The Short Test of Functional Health Literacy was used by Gazmararian et al.⁴ to test the health literacy of Medicare participants from all over the US (n = 3260). Their findings revealed that 53.9% of Spanish-language speakers and 33.9% of English-language speakers aged 65 or above had limited health literacy.^{2,33} Intellectual disabilities and education levels were related to health literacy as well. Even though the two factors were controlled, health literacy still dwindled considerably with age.⁴ Murphy et al.³⁴ conducted one of the first studies on health literacy in teenagers with HIV and found no relationship between health literacy and antiretroviral adherence in this population (n = 186; mean age 20.5 years). Drainoni et al.³⁵ (2008) reported that a relationship between increasing age and lower health literacy had been found, while some other studies did not find such a correlation.^{13, 28, 30, 35}

By 2015, approximately half of HIV patients in developed countries where antiretroviral medication is accessible were 50 years and older. Since increasing age leads to an augment of comorbidities in adults with HIV,³⁶ aging patients will need to abide by a significant number of medical recommendations. Coping with more information can result in difficulties, especially for thousands of adults with HIV who are undergoing neurological operations which may cause trouble with reasoning and planning.^{12,36} Therefore, it is important that more details be provided describing how health literacy and health

numeracy, as well as intellectual disability, tend to affect health conditions in a rising population.

Race

Osborn et al.¹⁴ studied associations of health literacy, medication adherence and race. The researchers used the Rapid Estimate of Adult Literacy in Medicine to measure health literacy.³⁶ All participants engaged in the examination were required to read a list of medical terms aloud (e.g., “prescription”, “medication”, “pill”) and scoring was based on correctness of pronunciation. The researchers found that, among the participants (n = 204; 45% African American), race was not a significant factor with respect to level of health literacy, although African-American patients were reportedly more non-adherent to their HIV medications than their Caucasian counterparts.¹⁴

Waldrop-Valverde et al.¹⁸ studied the relationship of race to health literacy and medication adherence among African-American HIV patients (n = 207) at an infectious-disease clinic and an AIDS drug-assistance program. Health literacy was evaluated by reading the comprehension subscale of the TOFHLA.³⁷ The study showed that health literacy among African-Americans was less than their non-African American counterparts, especially since African-Americans followed medication instructions less correctly and their HIV-medication management was lower than their non-African American counterparts. Thus, racial disparities may be an important predictor of health literacy skills among African-Americans in their self-management and medication adherence.

Even though the majority of HIV studies that referred to racial differences in health literacy have focused on African-Americans, early studies had also mentioned disparities in the Latino population. Drainoni et. al.³⁵ examined a high-risk sample of individuals with HIV (n = 231) and demonstrated that Latinos were four times as likely to have low health literacy as Caucasians. Also, those whose native language is Spanish, as compared to native speakers of English, had lower health literacy. Health literacy with respect to specific racial groups has been addressed in the literature, as well.³⁸

Gaps in research

The study was reviewed with attention to factors associated with health literacy among people living with HIV. Factors associated with HIV health literacy have important implications for HIV research in a clinical setting. Even though recent data have been studied for factors associated with general health literacy, the data pertaining to factors associated to HIV literacy was limited. Sufficient knowledge of the factors associated with HIV health literacy can be applied to clinical use. For instance, we will be able to develop instruments to measure HIV health literacy, modify the factors associated with limited health literacy and predict health outcomes.

Implication on clinical practice

The factors associated with health literacy among HIV patients have important implications for clinical practice. Even though recent studies have examined the interrelationship of health literacy, factors associated with health literacy and health outcomes, much work will be needed in order to approach a complete grasp of the nature of HIV. In particular, HIV health literacy test development, intervention methods and studies of factors associated with health literacy studies are going to be essential.

The absence of non-abstract examples in terms of health and medicine is still a problem in the use of general literacy instruments.^{39,40} HIV-targeted health literacy instruments would be much more suitable to health outcomes and would work more effectively than general instruments. While it is not encouraging that certain instruments, mainly those that emphasize HIV literacy, are scarce, it is fortunate that there are two HIV health literacy instruments which can be used as surrogates. HIV health literacy research should focus on factors associated with health literacy and developing interventions that can improve health outcomes, not only in medication adherence, but also in decision-based laboratory evaluations.

Limitations

This narrative review of the literature has its limitations. First, most of the HIV research mentioned in this review were conducted among westerners and African HIV patients, while only a few studies involved Asian HIV patients. Second, the majority of the mentioned HIV health literacy studies did not include a significant number of participants over 50 years old, limiting the ability to draw age-group comparisons. This deficiency constitutes an important gap that needs to be addressed, as the aging population living with HIV continues to grow.

Conclusion

Health literacy has an important role to play in the successful use of health information, accessing health care services, one's self-care of chronic conditions and maintaining health and well-being. The factors associated with health literacy among HIV patients have important implications for clinical practices that can be applied to measuring health literacy and predicting health outcomes. This study demonstrated that education, gender, age and race among living HIV patients were associated with levels of health literacy and should be considered for HIV care in clinical practice. Further research on HIV health literacy is needed, conducted in different geographical areas with differences in socioeconomic characteristics, cultures and local health policies.

References

1. Institute of Medicine Committee on Health L. In: Nielsen-Bohlman L, Panzer AM, Kindig DA, editors. Health literacy: A prescription to end confusion. Washington (DC): National Academies Press (US); 2004.
2. Rothman RL, Montori VM, Cherrington A, et al. Perspective: the role of numeracy in health care. *J Health Commun.* 2008;13(6):583-95.
3. Tique JA, Howard LM, Gaveta S, et al. Measuring health literacy among adults with HIV infection in Mozambique: Development and validation of the HIV literacy test. *AIDS Behav.* 2017;21(3):822-32.
4. Gazmararian JA, Baker DW, Williams MV, Parker RM, Scott TL, Green DC, et al. Health literacy among Medicare enrollees in a managed care organization. *JAMA.* 1999;281(6):545-51.
5. Sudore RL, Mehta KM, Simonsick EM, et al. Limited literacy in older people and disparities in health and healthcare access. *J Am Geriatr Soc.* 2006;54(5):770-6.
6. Davis TC, Wolf MS, Bass PF, 3rd, Middlebrooks M, Kennen E, Baker DW, et al. Low literacy impairs comprehension of prescription drug warning labels. *J Gen Intern Med.* 2006;21(8):847-51.
7. Georges CA, Bolton LB, Bennett C. Functional health literacy: an issue in African American and other ethnic and racial communities. *J Natl Black Nurses Assoc.* 2004;15(1):1-4.
8. Wolf MS, Davis TC, Tilson HH, Bass PF, 3rd, Parker RM. Misunderstanding of prescription drug warning labels among patients with low literacy. *Am J Health Syst Pharm.* 2006;63(11):1048-55.
9. Wolf MS, Davis TC, Arozullah A, et al. Relation between literacy and HIV treatment knowledge among patients on HAART regimens. *AIDS care.* 2005;17(7):863-73.
10. Baker DW, Wolf MS, Feinglass J, et al. Health literacy and mortality among elderly persons. *J Gen Intern Med.* 2007;167(14):1503-9.
11. Kalichman SC, Benotsch E, Suarez T, et al. Health literacy and health-related knowledge among persons living with HIV/AIDS. *Am J Prev Med.* 2000;18(4):325-31.
12. Kalichman SC, Ramachandran B, Catz S. Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *J Gen Intern Med.* 1999;14(5):267-73.
13. Kalichman SC, Cherry J, Cain D. Nurse-delivered antiretroviral treatment adherence intervention for people with low literacy skills and living with HIV/AIDS. *J Assoc Nurses AIDS Care.* 2005;16(5):3-15.
14. Osborn CY, Paasche-Orlow MK, Davis TC, et al. Health literacy: an overlooked factor in understanding HIV health disparities. *Am J Prev Med.* 2007;33(5):374-8.
15. Wolf MS, Davis TC, Osborn CY, et al. Literacy, self-efficacy, and HIV medication adherence. *Patient Educ Couns.* 2007;65(2):253-60.
16. Keikelame MJ, Swartz L. Lost opportunities to improve health literacy: observations in a chronic illness clinic providing care for patients with epilepsy in Cape Town South Africa. *Epilepsy Behav.* 2013;26(1):36-41.
17. Waldrop-Valverde D, Jones DL, Gould F, et al. Neurocognition, health-related reading literacy, and numeracy in medication management for HIV infection. *AIDS Patient Care STDS.* 2010;24(8):477-84.
18. Waldrop-Valverde D, Osborn CY, Rodriguez A, et al. Numeracy skills explain racial differences in HIV medication management. *AIDS Behav.* 2010;14(4):799-806.
19. Kalichman SC, Amaral CM, Stearns H, et al. Adherence to antiretroviral therapy assessed by unannounced pill counts conducted by telephone. *J Gen Intern Med.* 2007;22(7):1003-6.
20. Osborn CY, Davis TC, Bailey SC, et al. Health literacy in the context of HIV treatment: introducing the Brief Estimate of Health Knowledge and Action (BEHKA)-HIV version. *AIDS Behav.* 2010;14(1):181-8.
21. Miller LG, Liu H, Hays RD, et al. Knowledge of antiretroviral regimen dosing and adherence: a longitudinal study. *Clin Infect Dis.* 2003;36(4):514-8.
22. Colbert AM, Sereika SM, Erlen JA. Functional health literacy, medication-taking self-efficacy and adherence to antiretroviral therapy. *J Adv Nurs.* 2013;69(2):295-304.
23. Liu H, Miller LG, Hays RD, et al. A comprehensive evaluation of survey questions for adherence to antiretroviral medications and exploratory analyses for identifying optimal sets of survey questions. *AIDS Patient Care STDS.* 2006;20(11):760-72.
24. Howard LM, Tique JA, Gaveta S, et al. Health literacy predicts pediatric dosing accuracy for liquid zidovudine. *AIDS.* 2014;28(7):1041-8.
25. Dowse R, Lecoko L, Ehlers MS. Applicability of the REALM health literacy test to an English second-language South African population. *Pharm World Sci.* 2010;32(4):464-71.
26. Lori JR, Dahlem CH, Ackah JV. Examining antenatal health literacy in Ghana. *J Nurs Scholarsh.* 2014;46(6):432-40.
27. Ciampa PJ, Vaz LM, Blevins M, et al. The association among literacy, numeracy, HIV knowledge and health-seeking behavior: a population-based survey of women in rural Mozambique. *PLoS One.* 2012;7(6):e39391.
28. McTavish S, Moore S, Harper S, et al. National female literacy, individual socioeconomic status, and maternal health care use in sub-Saharan Africa. *Soc Sci Med.* 2010;71(11):1958-63.
29. Kalichman SC, Pope H, White D, et al. Association between health literacy and HIV treatment adherence: further evidence from objectively measured medication adherence. *J Int Assoc Physicians AIDS Care (Chic).* 2008;7(6):317-23.
30. Nokes KM, Coleman CL, Cashen M, et al. Health literacy and health outcomes in HIV seropositive persons. *Res Nurs Health.* 2007;30(6):620-7.
31. Kalichman SC, Rompa D. Functional health literacy is associated with health status and health-related knowledge in people living with HIV-AIDS. *J Acquir Immune Defic Syndr.* 2000;25(4):337-44.
32. Gakumo C, Vance D, Moneyham L, et al. Health numeracy and health literacy within the context of management of patients with human immunodeficiency virus. *Nursing: Research and Reviews.* 2013;3:23-31
33. Waldrop-Valverde D, Jones DL, Jayaweera D, et al. Gender differences in medication management capacity in HIV infection: the role of health literacy and numeracy. *AIDS Behav.* 2009;13(1):46-52.
34. Murphy DA, Lam P, Naar-King S, et al. Health literacy and antiretroviral adherence among HIV-infected adolescents. *Patient Educ Couns.* 2010;79(1):25-9.

35. Drainoni ML, Rajabiun S, Rumptz M, et al. Health literacy of HIV-positive individuals enrolled in an outreach intervention: results of a cross-site analysis. *J Health Commun.* 2008;13(3):287-302.
36. Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Fam Med.* 1993;25(6):391-5.
37. Cressman MN, Liljequist L. The effect of grade norms in college students: using the Woodcock-Johnson III Tests of Achievement. *J Learn Disabil.* 2014;47(3):271-8.
38. Van Servellen G, Brown JS, Lombardi E, et al. Health literacy in low-income Latino men and women receiving antiretroviral therapy in community-based treatment centers. *AIDS Patient Care STDS.* 2003;17(6):283-98.
39. Fagerlin A, Zikmund-Fisher BJ, Ubel PA, et al. Measuring numeracy without a math test: development of the Subjective Numeracy Scale. *Med Decis Making.* 2007;27(5):672-80.
40. Lipkus IM, Samsa G, Rimer BK. General performance on a numeracy scale among highly educated samples. *Med Decis Making.* 2001;21(1):37-44.