# Health Literacy in People Living with Human Immunodeficiency Virus Infection: A Narrative Review

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Overall literacy talents comprise an individual's capacity to read, write and recognise written information (print literacy), articulate and interpret oral language (oral literacy) and interpret and apply for numbers in everyday activities (numeracy). Health literacy, a subset of overall literacy talents, is relatively correlated with it and has been described as the extent to which people can gain, approach, and understand introductory medical information and services required to take health decisions. Concerning HIV, people with low health literacy have less information on the illness and their medical care needs. Moreover, they show poor drug compliance, potentially leading to treatment failure and lack of achievement of the target viral load reduction. The shortfall of non-conceptual models of health literacy is an issue in the utilization of general proficiency instruments. HIV disease-specific health literacy instruments would be more useful and likely to provide more meaningful results rather than those obtained through the use of general instruments. Further exploration of HIV health literacy is demanded. Prospective studies should involve different geographical areas with different socioeconomic characteristics, societal structures and regional healthcare settings. This narrative review has limitations. The vast majority of the HIV research referenced in this study was conducted among the western and African populations with HIV. The studies generally excluded individuals over 50 years of age, restricting the applicability of the study findings.

**Keywords:** Education; Health Literacy; HIV/AIDS; PLHIV; Sustainable Development Goals; SGD; Wellbeing Proficiency.

Overall literacy talents comprise an individual's capacity to read, write and recognise written information (print literacy), articulate and interpret oral language (oral literacy) and interpret and apply for numbers in everyday activities (numeracy). <sup>1-2</sup> A subset of general academic skills is health literacy, which is generally associated

with it and has been described as the extent to which people can gain, approach and understand introductory health care information and its services required to take health decisions. <sup>3</sup> In contrast to individuals who are relatively well-educated and health literate, those with restricted or deficient health literacy tend to have more adverse



outcomes following medical care, have issues in adhering to clinical directions, experience the ill effects of both adverse physical and psychological circumstances, and have worse future well-being. Restricted well-being proficiency is connected with imperfect well-being results, particularly in the context of chronic diseases like diabetes mellitus, hypertension and human immunodeficiency virus (HIV) disease. 4-10

As a result, low health literacy has been associated with negative health outcomes, including increased hospitalization rates, more frequent hospital visits, and a higher risk of developing illnesses. Conversely, a higher level of health literacy has been linked to improved health outcomes. Given these impacts, it is clear that improving health literacy can have a significant impact on both individual and community well-being, particularly for populations such as people living with HIV (PLHIV). Interventions aimed at increasing health literacy can play an important role in improving overall health outcomes and reducing disparities in healthcare.<sup>11</sup>

Concerning HIV, people with low health literacy have less information on the illness and their medical care needs. Moreover, they show poor drug compliance, potentially leading to treatment failure and lack of achievement of the target viral load reduction.<sup>8,12-15</sup>

The disparity in literacy levels within a society can lead to significant inequalities, as those with lower reading skills are often disadvantaged compared to others, even when controlling for other factors such as age, wealth, education, and ethnicity. This has been demonstrated in studies which have shown that those with lower literacy skills tend to have worse physical and mental health outcomes. These findings highlight the importance of addressing literacy levels to reduce health disparities and promote equal access to resources and opportunities. <sup>16-19</sup>

Nutbeam (2008) highlights the negative impact of low health literacy on individual health outcomes. People with limited health literacy skills are more prone to adverse health consequences. This is because they struggle to understand and use health information, services, and technologies effectively. This may lead to difficulties in navigating the healthcare system, making informed decisions about health, and following treatment

plans. Low health literacy also exacerbates existing health disparities and negatively impacts health outcomes for vulnerable populations. Thus, addressing health literacy is crucial in improving the overall health and well-being of individuals and communities. <sup>20</sup>

Health literacy is influenced by a variety of factors, including education level, socioeconomic status, age, language proficiency, and cultural and social norms. People with lower levels of education may struggle to understand and interpret health information. Those with lower socioeconomic status may have limited access to healthcare, knowledge about health and wellness, and health information. Older populations may have lower health literacy due to a lack of understanding of modern technology and medical advancements. Furthermore, individuals who are not proficient in the language used in health education materials may have difficulty comprehending them, leading to lower health literacy. Cultural and social norms can also impact an individual's understanding of health information. 21-22

In the African country of Mozambique, wherein the adult population living with acquired immunodeficiency syndrome in 2007 was 11.5%, a survey showed that only half of the population was educated. Low health literacy might adversely affect the capacity of individuals to self-manage their disease. To Evidence from research in the United States demonstrates that HIV subjects with limited health literacy had minimal HIV-related information, lower capacity

to deal with his/her medicine and fewer chances of accomplishing imperceptible viral burdens than people with good health literacy. 8,11,18-23 A few investigations have shown an association between a lack of well-being education and non-adherence to antiretroviral therapy (ART), although some other studies have failed to demonstrate a relationship between health literacy and medication adherence. 13,24-25

Despite the emphasis placed on ending epidemics such as AIDS, Tuberculosis (TB), and Malaria, and through Sustainable Development Goal 3.3 (SDG), it remains a challenge without adequate understanding of the burden of health literacy and the factors associated with it. These factors play a crucial role in clinical care, epidemiology, and cost-effectiveness. It is alarming

to note that approximately 25% of the global population is illiterate, highlighting the need for increased literacy efforts. While these estimates provide a rough estimate of the burden, a comprehensive synthesis of evidence is still lacking. To effectively address the challenge of ending these epidemics, a deeper understanding of health literacy and its associated factors is imperative.

In response to the need for a deeper understanding of health literacy and its associated factors, we conducted a literature review in the present study. Through a thorough analysis of available studies and research articles, we aimed to provide a comprehensive narrative on the current understanding of health literacy and its implications in clinical care, epidemiology, and cost-effectiveness. Our review aimed to address the gap in knowledge and to provide a basis for future studies in this area. The conclusion of our study underscores the importance of continued research and exploration in the field of health literacy to effectively address the challenge of ending epidemics such as AIDS, Tuberculosis, Malaria, and Neglected Tropical Diseases.

An essential goal of this review is to describe the characteristics associated with health literacy in people living with HIV that have a significant impact on clinical practices and that need to be considered in determining well-being proficiency and foreseeing health outcomes.

#### Race

Waldrop et al (2010) investigated the association of race to well-being proficiency and medicine compliance among African-American HIV patients (n = 207) participating in an AIDS drug-help program. Health literacy was measured by perusing the understanding subscale of the Test of Functional Health Literacy in Adults (TOFHLA).26The review showed that wellbeing proficiency among African-Americans was lower than their Caucasian partners, particularly since African-Americans adhered to treatment directions less accurately and was below than their Caucasian partners. Hence, racial variations might be a significant indicator of well-being proficiency abilities among black Americans in their selfadministration and prescription compliance.20

Chandra Y et al (2007) investigated the relationship between well-being proficiency,

prescription compliance and race. The investigator utilized the Rapid Estimate of Adult Literacy in Medicine (REALM) to quantify well-being proficiency.27 The tool requires the subjects to pronounce words commonly used in the clinical scenario (for example," prescription ", "medication ", and "pill") and the ability to identify the correctness of the articulation. The investigators found that of the 204 participants, 45.1 % were black Americans, the rest being Caucasians; race was not an important element variable determining well-being proficiency, even though Black-American subjects were less compliant with the prescribed regimen compared to their non-African American counterparts.<sup>14</sup>

Even though most HIV research on racial disparities in well-being proficiency mainly involved Black Americans, earlier studies have been conducted among Latin Americans. Mari-Lynn *et al* (2008) studied 231 patients with HIV and found that Latinate was fourfold as likely to have poor health proficiency as compared with Caucasians. Also, individuals who spoke Spanish in comparison to English-speaking individuals had poorer health proficiency.

### Gender-specific

The relationship between gender and health proficiency is indecisive. C Ann Gakumo et al (2013) studied the levels of health literacy among both genders; results showed that females were more likely to peruse and understand health information than males, while males had better grades in arithmetic abilities.<sup>30</sup> Drenna Valverde et al investigated the health proficiency of 204 subjects and observed that females were bound to have greater well-being proficiency grades than male subjects. Males scored higher than females on arithmetic abilities despite health proficiency grades being not significantly different between the groups. Males also performed better compared to females in comprehension of HIV prescription details. Consequently, males were more likely to appreciate and follow up on clinical directions in contrast to females.31

#### Education

Low education levels were appreciably connected with low health literacy.<sup>32-33</sup> Seth C. Kalichman *et al* (1999) studied wellbeing proficiency in 339 subjects with HIV infection and observed that those with low wellbeing proficiency

had minimal structured education, contrasted with individuals with better-structured education. <sup>13</sup> An investigation of individuals on antiretroviral therapy showed that those with college-level education or higher had better proficiency abilities, increased CD4 cell count and lesser viral burden than the individuals with secondary school education. A good indicator of antiretroviral treatment compliance was health proficiency and level of education. <sup>10,33</sup>

The association between schooling, healthrelated arithmetic skill and well-being proficiency in people with HIV has been established in previous studies.<sup>7,35</sup> One study analysed health proficiency, health-related numeric skills and its interrelation with educational attainment in 184 subjects, more than 50% of whom were Black Americans. 30 Health education was measured by the Test of Functional Health Literacy in Adults (TOFHLA) and wellbeing arithmetic skill by the numeracy scale of TOFHLA.<sup>36-37</sup> It showed a significant association between levels of educational status, levels of well-being proficiency, well-being arithmetic skill and prescription compliance. The trial inferred that schooling was an important component for good outcomes in the Black-American population affected by HIV infection.38

Shenoy A K et al (2023) studied health literacy and medication regimen complexity in patients with human immunodeficiency virus infection in the Indian population. The participants in the study had varying levels of education, with 5.6% having no formal education and 20% have completed college. The median age of participants was 49 years, with an equal distribution of male and female participants. When it came to health literacy (HL) scores, no significant difference was seen based on age. However, a statistically significant increase in HL scores was observed based on the participants' educational status, with those having higher levels of education scoring higher.<sup>39</sup>

#### Ageing

In contrast to the general population, older individuals appear to have low levels of well-being literacy. Over 66% of the American population with advanced age has minimal well-being proficiency. The Short Test of Functional Health Literacy was utilized by Juli A. *et al* (1999) to assess the well-being education of health insurance members from the United States (n

= 3260).4 The result showed that 53.9% of the Española-speaking population and 33.9% of the English-speaking population aged 65 years or higher had marginal well-being proficiency.4 Cognitive handicaps and educational status were connected with well-being proficiency too. Even though the two elements were controlled, well-being proficiency decreased extensively with age.40 The study by Debra A. et al (2010) on well-being proficiency in adolescents (mean age 20.5 years) with HIV showed no significant association between well-being proficiency and HIV prescription compliance (n = 186).37 The study by Mari-Lynn et al.(2008) revealed an association between advancing years and lower well-being proficiency;29 meanwhile a few other studies didn't find such an association. 11,39,32,29

From 2012 through 2017 stable fractions of newer diagnosed HIV-positive patients older than 50 years is around 17% with this 50% of HIV cases in an advanced country like the USA, where HIV prescription is accessible were 50 years or more advanced age group. Since advancing age prompts an increase in comorbid conditions along with HIV, elderly persons are required to remember and follow a large number of clinical instructions.<sup>4</sup> Remembering such information can be challenging, considering the potential presence of cognitive impairment in this population, which might create problems with thinking and planning. 13,41 Therefore, more studies are required to elucidate the effects of well-being education and well-being numeracy, as well as scholarly inability, on the treatment outcomes in this increasing population.

#### Adherence

Poor medication adherence is a serious barrier to successful chronic disease management. Miranda C. *et al* (2015) identified higher levels of health literacy, specifically reading comprehension, as significantly related to neuropsychological variables, sociocultural variables, and behavioural and clinical health outcomes in adults with HIV infection. <sup>42</sup> Multiple studies concluded that health literacy is related to prescription compliance. <sup>44-46,22,31,50-55</sup> Marta Rivero *et al* (2015) found significant interactions between adherence and functional health literacy. <sup>56</sup> The study by Kalichman *et al* (2011) proposed that health literacy prognosticates prescription compliance. <sup>57</sup>

#### DISCUSSION

The aim of this review, following the methodology outlined by Arksey and O'Malley 58, is to evaluate the breadth, depth, and nature of research on the impact of health literacy interventions on health outcomes. The objective is to determine the effectiveness of health literacy interventions in improving health outcomes and reducing health disparities. By increasing individuals' understanding and utilization of health information, health literacy interventions have the potential to improve health outcomes and promote informed health decision-making, leading to better self-management of chronic conditions. They can also enhance access to health services and reduce health disparities among vulnerable populations. Moreover, the efficient delivery of care resulting from health literacy interventions can reduce healthcare costs. The outcome of this study will shed light on the significance of health literacy interventions and their role in promoting better health outcomes.

# Insufficient information in the research literature and scope for future studies

The review was investigated with consideration regarding Characteristics related to health literacy among individuals living with human immunodeficiency virus. Characteristics related to HIV well-being proficiency have significant ramifications for HIV research in a clinical setting. For example, we will want to foster instruments to gauge HIV health literacy, alter the variables related to limited well-being proficiency and anticipate health outcomes.

## Implication on clinical practice

The shortfall of non-conceptual models of health literacy is an issue in the utilization of general proficiency instruments. HIV disease-specific health literacy instruments would be more useful and likely to provide more meaningful results rather than those obtained through the use of general instruments. The lack of such specific instruments, chiefly those that focus on disease-related knowledge, needs to be addressed. HIV well-being education exploration should identify factors related to well-being proficiency and create interventions that can further improve health outcomes, particularly prescription adherence.

#### Limitations

This narrative review has limitations. The vast majority of the HIV research referenced in this study was conducted among the western and African populations with HIV. The studies generally excluded individuals over 50 years of age, restricting the applicability of the study findings. The health literacy assessment instruments which are utilized in the studies were not disease-specific which limits the generalizability of findings. These inadequacies comprise a significant research gap that needs to be taken into consideration in future studies.

#### CONCLUSION

In conclusion, this narrative review highlights the important role that health literacy plays in the management of HIV. However, it is crucial to acknowledge the limitations of the studies reviewed in this article, which were primarily conducted among western and African populations and excluded individuals over 50 years of age. Additionally, the health literacy assessment instruments used in these studies were not specific to the disease, which limits the generalizability of the findings.

In light of these limitations, it is recommended that further research be conducted on HIV health literacy in diverse geographical locations with varying socioeconomic, societal, and healthcare characteristics. Such studies will provide a more comprehensive understanding of the relationship between health literacy and the management of HIV and inform the development of effective interventions to improve health literacy among individuals living with HIV.

In conclusion, this review highlights the need for ongoing efforts to enhance our understanding of the complexities of health literacy and its impact on the management of HIV and to develop innovative strategies to address the disparities that exist.

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