

**FUNCTIONAL HEALTH LITERACY AMONG PEOPLE LIVING WITH HIV/AIDS:
RESEARCH FINDINGS AND DIRECTIONS FOR FUTURE RESEARCH IN SUB-
SAHARAN AFRICA**

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ABSTRACT: *The aim of this review is to provide a synoptic view of functional health literacy among people living with HIV/AIDS (PLWHA) across the globe, so as to suggest directions for future research in sub-Saharan Africa. Thirteen published empirical studies from hard copy and on-line journals on the subject matter are reviewed. However, all the studies were conducted in other regions other than sub-Saharan Africa, which points up to the fact that research on the subject matter is seriously desired in the region. Based on the studies' findings, directions for future research are outlined. These include that: 1) further research is needed to examine the role of treatment programmes in mediating relationships between individual predisposing factors and health literacy and the linkages between health literacy, and subsequent health status in at-risk populations, and 2) further research needs to be conducted in order to learn more about the relationships between HIV infection and rural living and the needs of people who live in such situations. With this knowledge, appropriate healthcare services can be developed and implemented to enhance the well-being and quality of life for individuals, families, and communities in this age of HIV/AIDS pandemic.*

KEYWORDS: Functional literacy, people living with HIV/AIDS (PLWHA), future research

INTRODUCTION

Health literacy is the ability to read, understand and act on written material commonly encountered in health care settings (Scott, Gazmararian, Williams, & Baker, 2002). Functional health literacy is the ability to apply reading and numeracy skills in a health care setting (Center for Health Care Strategies, 2002). Parker, Baker, Williams, and Nurss (1995) described functional health literacy as having two components, i.e., reading comprehension and numeracy. Reading comprehension refers to the ability to read and understand written word passages of health-related information. Numeracy refers to the ability to read and understand numbers. With low levels of functional health literacy, an individual cannot understand consent forms, medicine labels and inserts, and other written health care information. An inability to understand impairs an individual's ability to act upon necessary procedures and directions, such as medication and appointment schedules; it also affects a

nurse practitioner's approach to providing written and oral information (French & Larrabee, 1999).

Adults with chronic medical problems face tremendous learning demands. Their ability to learn the self-management demands of chronic illness partially determines whether or not they will experience illness stability or years of struggling with the exacerbations and disability of illness. In a sample of adults (mean age 54 years) diagnosed with diabetes for an average duration of 6 years, Slocum, Ryan, Gallina, Ferguson, and Ernst (1999) found that higher literacy scores were associated with lower HbA1c levels on initial visit to the diabetes clinic. Gordon, Hampson, Capell, and Madhok (2002) examined the impact of illiteracy on disease severity and function in a sample of 123 patients (median age 56 years) with rheumatoid arthritis. Although sex, age, disease duration, and numbers of joint replacements were not influenced by illiteracy, illiterate patients had more anxiety and had three times more hospital visits when compared to the patients with higher literacy scores. Other investigators have examined the relationship between health literacy and a 2-day recall of HIV and AIDS treatment adherence and found that education and health literacy were significant and independent predictors of treatment adherence (Artinian, Lange, Templin, Stallwood, Hermann, 2003; Kalichman, Ramachandran, & Catz, 1999).

Use of preventive services also is influenced by health literacy. Scott, Gazmararian, Williams, and Baker (2002) found that inadequate health literacy is independently associated with lower use of preventive services such as receiving influenza and pneumococcal vaccinations, mammograms, and Papanicolaou smears. Other investigators found health literacy to be associated with advanced prostate cancer at diagnosis, (Kim, Bennett, Chan, Chmiel, Falcone, Knight, et al., 1999) possibly due to inadequate use of prevention cancer screening services such as receiving prostate-specific antigen tests.

Knowing that a certain level of inadequate health literacy exists makes the ability to recognize illiteracy an important one. According to the Joint Commission on Accreditation of Healthcare Organizations' (JCAHO) standards on patient and family health education (Joint Commission for Accreditation of Health Care Organizations, 2002), it is incumbent upon health professionals to identify learning and educational needs, use appropriate educational resources, and to assess the patient's and family's ability to comprehend, use and apply information taught. Assessment of literacy level is an essential part of this process. However, amid the demands of disease management, understanding complex clinical presentations, knowing multiple differential diagnoses, interpreting laboratory and diagnostic tests, literacy assessment may pale in comparison. Moreover, it may be easy to lose sight of patients' unique concerns, especially as related to literacy, when care is often carried out in health care settings increasingly fraught with time demands and cost concerns.

Keeping the benefits of literacy assessment in mind may motivate nurse practitioners and clinical nurse specialists to find ways to address the issue of delivering care suitable to a patient's literacy level. Delivering care tailored to patients' literacy levels is key element to enabling patients to engage in the process of care and to accessing all the resources that may be available to them. Literacy assessment is an important component of effective advanced practice nurse-patient communication, enabling a nurse practitioner or clinical nurse specialist to elicit a better medical history, explain a treatment plan in understandable terms, assist the patient to integrate treatment recommendations into their usual daily routine, be sensitive to other psychosocial issues the patient may be dealing with, and convey empathy. All of these factors may lead to increased patient satisfaction with care, an important health

care outcome and indicator of quality of care that is valued by patients, payers, and health care administrators.

Considering the fact that poor health literacy is a barrier to medical care and people with lower health literacy experience greater illness severity than people with higher health literacy (Kalichman & Rompa, 2000), health literacy may therefore be an important factor in the health of and treatment of people living with HIV/AIDS (PLWHA) in sub-Saharan Africa. In 2006, 63% of all persons infected with HIV lived in sub-Saharan Africa. An estimated 2.8 million adults and children became infected with HIV in 2006, more than in all other regions of the world combined. The epidemic differs between countries and within countries, with some experiencing either stabilisation or reduction in new infection and HIV/AIDS prevalence. Even within the region, significant variations exist in HIV prevalence rates, such as Angola, which has a 3.7% prevalence rate compared to neighbouring South Africa, Nigeria, Botswana, Lesotho, Namibia and Swaziland, with prevalence rates close to or over 20% (United Nations Programme on HIV/AIDS [UNAIDS], 2006). Noteworthy HIV prevalence declines are reported in Uganda, Kenya, and Zimbabwe, as well as in urban Rwanda, Malawi and Ethiopia. Specifically, overall adult infection rates decreased in Kenya from a peak of 10% in the late 1990s to 7% in 2003, and HIV rates among pregnant women in Zimbabwe declined from 26% in 2003 to 21% in 2004 but levels remain unacceptably high (World Health Organization, 2006). The HIV/AIDS in the regions demands that PLWHA possess an appreciable literacy level to enable them follow management regimens.

Functional health literacy is associated with illness-related knowledge, understanding, and treatment perceptions for several chronic illnesses which include HIV/AIDS. People living with HIV/AIDS who have lower health literacy could show poorer treatment adherence and more adverse health outcomes. This paper reviews functional health literacy research among PLWHA and suggests directions for future research in sub-Saharan Africa.

RESEARCH FINDINGS

Studies conducted worldwide have shown varying results regarding functional literacy among PLWHA. For example, Kalichman, Catz and Ramachandran (1999) investigated the association between education literacy to HIV treatment adherence and barriers to care among African Americans living with HIV/AIDS. A community-recruited sample of 85 African-American men and 53 women receiving HIV treatment completed measures of health literacy, health status, treatment adherence, emotional well-being, and barriers to care. Nearly one-third (29%) of the participants had < 12 years of education or were functionally illiterate, and those with low-education literacy were less likely to be adherent to HIV medications within the previous two days. Lower-education literacy also was related to reasons for missing medications and barriers to accessing medical care. Individuals of low-education literacy also were more emotionally distressed, lacked social support, and were less optimistic than those with higher education.

In a UK community, Kalichman, Ramachandran, and Catz (1999) conducted a study to test the significance of health literacy relative to other predictors of adherence to treatment for HIV and AIDS. Community sample of HIV-seropositive men (n = 138) and women (n = 44) currently taking a triple-drug combination of antiretroviral therapies for HIV infection; 60% were ethnic minorities, and 73% had been diagnosed with AIDS. An adapted form of the Test

of Health Literacy in Adults (TOFHLA), a comprehensive health and treatment interview that included 2-day recall of treatment adherence and reasons for nonadherence, and measures of substance abuse, social support, emotional distress, and attitudes toward primary care providers. Multiple logistic regressions showed that education and health literacy were significant and independent predictors of 2-day treatment adherence after controlling for age, ethnicity, income, HIV symptoms, substance abuse, social support, emotional distress, and attitudes toward primary care providers. Persons of low literacy were more likely to miss treatment doses because of confusion, depression, and desire to cleanse their body than were participants with higher health literacy.

Kalichman and Rompa (2000) conducted a study in order to determine the association of functional health literacy with health status and health-related knowledge in PLWHA in United Kingdom. A community-recruited sample of 339 HIV-infected men and women completed surveys and interviews that assessed functional health literacy, health status, AIDS-related disease and treatment knowledge, and health care perceptions and experiences. Medical records were available for chart abstraction of health status for a sub-sample of participants. Results of the study showed that 1 of 4 people living with HIV-AIDS demonstrated difficulty comprehending simple medical instructions and therefore lower health literacy. HIV-infected people with lower health literacy had lower CD4 cell counts, higher viral loads, were less likely to be taking antiretroviral medications, reported a greater number of hospitalizations, and reported poorer health than those with higher health literacy. In addition, after adjusting for years of formal education, lower health literacy was associated with poorer knowledge of one's HIV-related health status, poorer AIDS-related disease and treatment knowledge, and more negative health care perceptions and experiences.

In another study Kalichman, Benotsch, Suarez, Catz, Miller, and Rompa (2000) examined health literacy in relation to knowledge and understanding of HIV/AIDS among people living with HIV/AIDS in Eastern Europe. PLWHA who were recruited from AIDS service organizations and HIV clinics completed the Test of Functional Health Literacy for Adults (TOFHLA) reading comprehension scale and measures of health status, knowledge and understanding of health status, perceptions of primary care givers, and perceptions of anti-HIV treatments. The results of the study showed that 18% of the sample scored below the cutoff for marginal functional health literacy on the TOFHLA. Controlling for years of education, persons of lower health literacy were significantly less likely to have an undetectable HIV viral load, somewhat less likely to know their CD4 cell count and viral load, and lower health-literacy persons who knew their CD4 count and viral load were less likely to understand their meaning. Lower health literacy was also related to misperceptions that anti-HIV treatments reduce risks for sexually transmitting HIV and beliefs that anti-HIV treatments can relax safer-sex practices.

In a small city in UK, Kalichman, Benotsch, Weinhardt, Austin, and Luke (2002) investigated Internet access among people living with HIV/AIDS and its relation to health. The cross-sectional survey, using the questionnaire, was adopted in the study. Results of a survey of men (n = 175) and women (n = 84) living with HIV/AIDS recruited from infectious disease clinics and community-based AIDS services showed that 51% (n = 116) of participants reported ever using the Internet, of which 59% (n = 68) had used the Internet to access health-related information. As expected, Internet users were significantly more likely to be better educated and of higher incomes. Internet users, including those who used the Internet for general purposes and those who reported health-related use, also demonstrated

significantly greater knowledge of HIV disease and greater confidence in their ability to adhere to medications. Persons who used the Internet for general purposes were more likely to have an undetectable viral load compared to persons who had not used the Internet.

Van Servellen, Brown, Lombardi, and Herrera (2003) conducted a study to describe deficits in health literacy in a sample of 90 low-income HIV-infected Latino men and women reported to have problems with treatment adherence. Additionally, correlates of health literacy were examined to identify the relative impact of these factors in predicting lower levels of health literacy in this at-risk population. Results of the study indicated that years of education was associated with understanding HIV terms and accurately reading and understanding instructions on prescription bottles. In a multivariate context, individual predisposing and system enabling factors accounted for 22% of the variance in patients' understanding HIV terms. Individual predisposing and individual enabling factors accounted for 17% of the variance in reading and understanding instructions on prescription bottles.

Wolf, Davis, Cross, Marin, Green, and Bennett (2004) examined the relationship between patient understanding of HIV and its treatment and health literacy. Structured interviews were conducted with 157 HIV-infected individuals receiving care at a community-based clinic in Shreveport, Louisiana, USA. In all, 48% of patients were reading below a 9th grade level. One-third of patients could not name their HIV medications and this was significantly related to low literacy ($p < 0.01$). Two-thirds of those reading below the 9th grade level did not know how to take their medications correctly ($p < 0.05$), and 75% did not know the meaning of a CD4 count or viral load ($p < 0.001$). Patients with low literacy skills were more likely to state that their physician was their sole source of HIV information ($p < 0.005$).

Kalichman, Cherry, and Cain (2005) undertook the development and pilot testing of a brief HIV treatment adherence improvement counseling intervention for people with lower health literacy who were taking antiretroviral medications. Guided by a theory of health behavior change, health education principles for lower literacy populations, and formative research, the authors designed a two-session plus one booster session nurse-delivered HIV treatment adherence intervention. Results from a pilot test with 30 HIV-positive men and women with lower health literacy showed that the intervention increased HIV/AIDS knowledge, intentions to improve adherence, and self-efficacy for adhering to medications. Participants exposed to the intervention also showed improvement in medication adherence, with reductions in numbers of missed pills and reductions in numbers of doses taken off-schedule.

Wolf, Gazmararian, and Baker (2005) evaluated the association between health literacy, self-reported physical and mental health functioning, and health-related activity limitations among new Medicare managed care enrollees. A cross-sectional survey of 2923 enrollees was conducted in Cleveland, Ohio; Houston, Tex; Tampa, Fla; and Fort Lauderdale-Miami, Fla. Health literacy was measured using the short form of the Test of Functional Health Literacy in Adults. Results showed that after adjusting for the prevalence of chronic conditions, health risk behaviors, and socio-demographic characteristics, individuals with inadequate health literacy had worse physical function (67.7 vs. 78.0, $p < 0.001$) and mental health (76.2 vs. 84.0, $p < 0.001$) than individuals with adequate health literacy. Individuals with inadequate health literacy were more likely to report difficulties with instrumental activities of daily living (odds ratio [OR], 2.25; 95% confidence interval [CI], 1.74-2.92) and activities of daily living (OR, 2.83; 95% CI, 1.62-4.96), limitations in activity because of physical health (OR, 1.79; 95% CI, 1.39-2.32), fewer accomplishments because of physical health (OR, 1.90; 95%

CI, 1.48-2.45), and pain that interferes with normal work activities (OR, 2.01; 95% CI, 1.46-2.77).

Wolf, Davis, Arozullah, Penn, Arnold, Sugar, et al. (2005) examined the relationship between patient literacy and understanding of HIV treatment among HIV/AIDS. Literacy, knowledge of CD4 count and viral load, and correct identification of HIV medications in regimen were evaluated in 204 patients receiving care in Shreveport, Louisiana and Chicago, Illinois. One-third of patients had limited literacy skills. These patients were less able to describe CD4 count ($p < 0.001$), viral load ($p < 0.001$) and to correctly identify medications in their regimen ($p < 0.001$). In the multivariate analysis, limited literacy was an independent predictor of poor understanding of CD4 count (OR 2.9, 95% CI: 1.3-6.3) and viral load (OR 4.1, 95% CI: 1.9-8.8). For correct medication identification, a significant interaction was found between number of HIV medications and literacy level. Among patients taking only 1-2 HIV medications, 100% of higher literate patients were able to identify their medications, compared to none of the lower literate patients prescribed three or more HIV medications.

A study (Hicks, Barragan, Franco-Paredes, Williams, & del Rio, 2006) evaluated the association between health literacy and human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) knowledge among patients seen at an inner-city, public hospital urgent care center (UCC). Adopting a prospective survey of patients offered an HIV test by their providers during a UCC visit; patients' health literacy level was measured using the Rapid Estimate of Adult Literacy in Medicine (REALM) scale and assessed their HIV/AIDS knowledge using a 22-item questionnaire. A total of 372 patients were enrolled in the study. Among participants in this relatively young sample (55% were under the age of 40), 92 (25%) had a REALM score at or below a sixth-grade level, and 122 (33%) did not have a high school diploma. Patients' mean HIV/AIDS knowledge scores differed significantly between patients with inadequate health literacy and those with marginal or adequate health literacy. In multivariate analyses, patients' REALM scores were positively associated with patients' HIV/AIDS knowledge even after adjusting for income, education, and risk perception.

Nokes, Coleman, Cashen, Dole, Sefcik, Hamilton, et al. (2007) in a study examined the influence of personal characteristics and health literacy on body change distress, depressive symptoms, and HIV symptom intensity in a convenience sample of 489 HIV-seropositive adults throughout the United States. Health literacy was measured with the Rapid Estimate of Adult Literacy in Medicine (REALM) instrument. Those 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.

Wolf, Davis, Osborn, Skirpkaukas, Bennett, and Makoul (2007) examined the relationship between patient literacy level and self-reported HIV medication adherence, while estimating the mediating roles of treatment knowledge and self-efficacy on this relationship. Structured patient interviews with a literacy assessment, supplemented by medical chart review, were conducted among 204 consecutive patients receiving care at infectious disease clinics in Shreveport, Louisiana and Chicago, Illinois. Literacy was measured using the Rapid Estimate of Adult Literacy in Medicine (REALM), while the Patient Medication Adherence Questionnaire (PMAQ) was used to assess medication self-efficacy and adherence to antiretroviral regimens in the past 4 days. Results of the study showed that approximately one-third of patients (30.4%) were less than 100% adherent to their regimen and 31.4% had

marginal to low literacy skills. In multivariate analyses, low literate patients were 3.3 times more likely to be non-adherent to their antiretroviral regimen ($p < 0.001$). Patients' self-efficacy, but not knowledge, mediated the impact of low literacy on medication adherence (AOR 7.4, 95% CI 2.7-12.5). While low literacy was a significant risk factor for improper adherence to HIV medication regimens in the study, self-efficacy mediated this relationship.

Osborn, Paasche-Orlow, Davis and Wolf (2007) conducted a study to examine the mediating effect of limited health literacy on the relationship between race and HIV-medication adherence among African Americans. A total of 204 patients infected with HIV were recruited from two clinics in 2001. Structured in-person interviews were conducted to obtain information on patient demographics, medication adherence, and health literacy. Multivariate regression models were run in 2006 to examine the associations among race, literacy, and HIV-medication adherence after adjusting for relevant covariates. In an adjusted analysis that excluded literacy, African Americans were 2.40 times more likely to be non-adherent to their HIV-medication regimen than whites (95% confidence interval [CI] = 1.14-5.08). When literacy was included in the final model, the effect estimates of race diminished 25% to non-significance. Literacy remained a significant independent predictor of non-adherence (adjusted odds ratio [AOR] = 2.12, 95% CI = 1.93-2.32).

Directions for Future Research in sub-Saharan Africa

Based on the findings of the studies, the following directions for future research in sub-Saharan Africa are suggested:

1. Further research is needed to examine the role of treatment programs in mediating relationships between individual predisposing factors and health literacy and the linkages between health literacy, health promotion behaviours, and subsequent health status in at-risk populations.
2. Further research needs to be conducted in order to learn more about the relationships between HIV infection and rural living and the needs of people who live in such situations. With this knowledge, appropriate healthcare services can be developed and implemented to enhance the wellbeing and quality of life for individuals, families, and communities.
3. Furthermore, future research would benefit from studies with larger sample sizes that conduct an 'intention-to-treat' analysis (analysis of participants based on the groups to which they were originally allocated) to better understand outcomes of participants that withdraw from exercise interventions.
4. The association of cognitive abilities and literacy has important implications for health literacy models and for interventions to reduce the impact of low health literacy on health outcomes. Therefore research to determine the association between cognitive abilities and literacy are pertinent.
5. Moreover, identifying patients' numeracy strengths and weaknesses will enable the development of focused numeracy interventions and may contribute to moving individuals further along the continuum of health literacy proficiency. Therefore research identifying patients' numeracy strengths and weaknesses is desirable in this part of the world.

6. Additional research into the dynamics of these relationships is imperative as we continue to see increases in the number of patients with HIV/AIDS.
7. Determinants of literacy include: education, early childhood development, and aging, living and working conditions, personal capacity/genetics, gender and culture (Rootman & Ronson, 2005).
8. In a study (Baker, Gazmararian, Sudano, and Patterson, 2000) functional health literacy was markedly lower among older age groups. Future studies should prospectively examine whether functional literacy declines with age and whether this is explained by declines in cognitive function.
9. Finally, limitations in study design used in the studies reviewed, interventions tested, and outcomes assessed make drawing conclusions about effectiveness difficult. Further research is required to understand better the types of interventions that are most effective and efficient for overcoming literacy-related barriers to good health.

CONCLUSION

This review of functional health literacy among people living with HIV/AIDS (PLWHA) revealed that there has been extensive research on and vast body of knowledge on the subject matter. The findings revealed a true picture of how functional health literacy affected treatment adherence among PLWHA across the globe. Such findings, though perhaps alarming, simply point to the fact that if PLWHA are to lead a normal life; their level of health literacy needs to be improved. Future research, especially in sub-Saharan Africa, may need to suggest interventions to improve the health literacy of PLWHA.

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