Review Article

Health Literacy Among Individuals Living with HIV

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Abstract

Health literacy is essential, especially among people living with HIV. Health outcomes of good health literacy are increased CD4, decreased VL, and include OIs. The factors associated with health literacy among people living with HIV are essential for clinical outcomes, such as gender, age, and race. Three instruments to assess health literacy among people living with HIV/AIDS have been developed. The brief estimate of health knowledge and action HIV version (BEHKA-HIV) is the most popular health literacy assessment. However, the BEHKA-HIV assessment is currently available in English only.

Keywords : health literacy, HIV health literacy, HIV

Health literacy refers to the knowledge, understanding, and social skills that determine individual motivations and abilities to reach an understanding and to use medical information to achieve good health, including developing knowledge and competence in health care changes in attitudes and motivations to create healthy behaviors for oneself.[1,2] Health literacy first appeared in the literature of a seminar on health education in 1974.[3] The World Health Organization launched a campaign for member states to develop and promote people's health literacy in 1998. As a result, health literacy has been accepted and pushed into public policy in many countries. In Thailand, the term health literacy was first used in academic papers in 1998 by the Public Health Research Institute. However, the data on HIV health literacy in Thailand has been limited. The review's objective was to describe HIV health literacy, factors associated with health literacy, and factors related to an improved health outcome.

Health literacy among people living with HIV/AIDS

HIV is a human immunodeficiency virus. HIV is an RNA virus in *Retroviridae* and its subfamily *Lentiviridae*. HIV was discovered and reported Dr. Luc Montagnier, a French scientist, and Dr. Robert Gallo, an American scientist. When HIV enters the physical body, it destroys T lymphocyte CD4 (CD4), B cells, dendritic cells, macrophage, etc.[4] When CD4 is lower than 200 cells/mm^3, the patient is likely to have an opportunistic infection (OIs) and acquired immunodeficiency syndrome (AIDS), the final stage of an HIV infection. AIDS was reported as a new disease in 1981 and increasing among young homosexual men who succumbed to unusual opportunistic infections and rare malignancies.[5] In 2017 the number of people infected with HIV globally was 36.7 million people, or 0.8 percent of the world's population. This includes about 17 million children under 15 years of age, of whom around 1.5 million live in Sub-Saharan Africa.[6] Out of the total number of people infected with HIV, only about 17 million people, or 46.32%, have received ART (antiretroviral therapy). In Thailand, the first HIV infection was reported in 1984.[7] In 2016, there were approximately 423,800 people or 1.1% of Thailand's population,

which although low, is higher than the global prevalence.[8] HIV was originally most common among men having sex with men (MSM), followed by men having sex with women (MSW).

Currently, there is no cure for HIV infection. However, its effects can be reduced with antiretroviral (ARV) drugs, and it is imperative that people take ARVs regularly and on time throughout their lives. Therefore, specific health knowledge of HIV is essential for people living with the disease, including knowing how to access local health services and knowing the right treatment to use, having a good understanding of the disease, including interacting appropriately within their community, consulting with medical personnel when in doubt, as well as understanding the benefits of taking ART and being aware of the side effects of taking them.[9] If people with HIV have good health literacy, it will have a direct and positive affect on their health. For example, good health literacy will help the infected person to continue taking ART regularly, which, in turn will decrease the number of HIV viruses in their body, give them higher CD4 levels, reduce the likelihood of OIs, reduce health care costs, reduce transmissions to sexual partners, and improve the quality of life of those infected with HIV.[10,11]

The level of health literacy is linked to health behaviors. Health behavior modification illnesses and complications are caused by the disease itself, but those with a high level of health literacy can help themselves change their health behaviors to make them healthier. For people living with HIV, it was found that those with a good level of health literacy had not just a positive effect on their health, including self-care but also more frequent health behavior modification access to health care services and regular antiretroviral therapy. As a result, the viral load was lowered, and the CD4 count was increased, thereby reducing the incidence of OIs, reducing the spread of the virus to sexual partners, and the number of new infections.[12] It also increased the quality of life for people living with HIV. On the other hand, people with HIV who have a low level of health literacy have negative health consequences, such as neglecting their health. Inaccessibility of antiviral drugs, failure to consistently take ART resulting in higher viral loads, lower CD4 counts, a greater likelihood of OIs, and potentially progressing to the AIDS stage. Therefore, health literacy for HIV-infected people is crucial for their care.[12]

The classification of health literacy levels

At present, there is no clear definition of how many levels health literacy should be divided into. However, following Nutbeam's concept, health literacy levels can be divided into three levels as follows:[1]

Level 1: Fundamental health literacy is the ability to read, write and to provide oneself with access to essential primary health content. The necessary reading and writing skills related to health include: reading consent forms, reading drug labels, writing and understanding the forms of health information from physicians, nurses, and pharmacists, including following instructions such as taking medication, making appointments to see a doctor and acting in accordance with the doctor's orders.

Level 2: Interactional health literacy is the ability to use communication knowledge to enable participation in health care. Social skills that allow patients to participate in their health care including relaying and questioning information from doctors to increase the ability to take care of themselves.

Level 3: Critical health knowledge is the competency in assessing existing health information; to be able to make decisions and choose to act to promote health and maintain good health continually.

Factors associated HIV health literacy

Gender

Waldrop-Valverde et al.[13] conducted a health literacy study in people with HIV/AIDS. Of the 155 participants, 87% were African-American. It found that the level of health literacy among females was significantly lower than that of males. The level of health literacy related to computational processes was lower among females than males[14, 15] African-American males are savvier in terms of health than African-American females and their computational processes.

Age

A study of health literacy among the general population found that age affects health literacy, especially among those younger than 12 years and over 60 years of age.[16] In the study by Drainoni et al.,[17] health literacy was lower than those aged between 12-60. A study by Cavanaugh et al., found that those aged 60 and over had lower levels of health literacy in computational health. The numbers are lower than those between 12-60.[18] This may result from age-related brain degeneration in those over 60, resulting in a decline in health literacy, while those under 12 years of age are not yet old enough to think analytically. As a consequence, these factors mean that it makes health literacy lower in these groups than other age groups.

Race

Osborn et al.,[19,20] investigated the relationship between health literacy and medication adherence in people with HIV/AIDS. Using the REAM assessment, ethnic minority populations had lower health literacy and medication adherence levels than Caucasian residents. Waldrop-Valverde et al.[14] also found that minority populations have lower levels of health literacy in calculating numbers than Caucasians, but no conclusive evidence has been reached.

Instruments to assess health literacy among people living with HIV/AIDS.

Although instruments to assess health literacy among people living with HIV/AIDS have been developed, there have

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been few studies done in this area. Furthermore, no standardized tools have been used to assess them. The currently popular health literacy assessment among HIV/AIDS patients is as follows:

Brief Estimate of Health Knowledge and Action HIV Version (BEHKA-HIV)

This assessment developed by Osborn et al.[21] was first assessed in 2001 and published in 2008. It consists of eight questions divided into general HIV knowledge and antiretroviral therapy questions. The assessment could be used among adults aged between 18 to 64 years. The scores are divided into three levels: 0–3 is a low level of health literacy, 4-5 is an average level of health literacy, and more than 5 is a high level of health literacy. The BEHKA-HIV is a psychometric tool for evaluating HIV treatment, health knowledge, and predicting non-adherence to HIV medications. However, the BEHKA-HIV assessment is currently available in English and has not been translated into other languages.[21]

HIV Literacy Test (HIV-LT)

The HIV-LT assessment scale, a health literacy scale developed by José et al., was first assessed in 2012 and published in 2016. There are 16 questions in total, divided into 3 parts: in the first part, the patient indicates that they can tell the date of the doctor's appointment and the date of the laboratory examination. The second part is about CD4, and the third part is about the antiretroviral drugs that the infected person takes. The HIV-LT assessment scale can be used in adults aged between 18 to 64 years. Cronbach's alpha confidence value is 0.87. Currently, the HIV-LT assessment scale is available in Portuguese only. There are also translations and assessments available, but they are still under development and are not available now.[22]

HIV-Related Health Literacy Scale HIV-HL

The HIV-HL assessment is a health literacy assessment developed by Raymond L Ownby,[23] a US psychiatrist, and colleagues. The study, published in 2013, consists of 20 questions. Three domains can be assessed in adults aged between 18 to 64 years. Cronbach's alpha confidence is 0.69 (acceptable $\geq$ 0.8) on the current HIV-HL assessment scale. Available in English only, the HIV-HL assessment has not been used in clinical practice or other studies due to low reliability. There is an English version only. The HIV-HL Assessment is still being developed with question and answer formats. Patients can answer questions online before they visit the doctor or, if inconvenient, can write on the answer sheet.[23]

Relationship of level of health literacy and health outcomes among people living with HIV/AIDS.

Health literacy is directly related to health outcomes. especially those infected with HIV/AIDS, both directly and indirectly, as follows:

CD4 level

Good health literacy rates are linked to patients with a high level of CD4 who, therefore, are better able to take care of themselves than those with HIV who have lower health literacy, i.e., taking antiretroviral drugs and consulting doctors by appointment regularly. In particular, people with HIV who started taking antiretroviral drugs early after their infection status was known had increased CD4 counts close to normal levels, had the fastest decreasing opportunistic infection complications, and reduced lengths of hospital stay, including reduced expenses incurred from medical treatment. The level of health literacy with lower CD4 counts had one reported among Black and Hispanic adults only, but it was not reported in the non-Hispanic White adults. However, findings from this study have a small sample and methodological limitations.[24]

VL level

Lows et al., 2015 studied health literacy in HIV treatment. This study was semi-structured interviews with 32 people living with HIV from two U.S. cities. The study shows that most reported to have good adherence to ARV, high CD4 cell count, and low viral load. However, the relationship between health literacy and VL level was limited because most people follow medication according to their doctors' instructions without understanding their disease or biological marker.[25]

Conclusion

Health literacy was important for people living with HIV to understand health information, access health care services, maintain health and self-care chronic conditions. The level of health literacy is associated with increased CD4 counts, decreased VL counts, decreased opportunistic infection, and other complications. Moreover, gender, age, and race are associated with health literacy and should be considered for HIV care in clinical practice.

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