Preliminary Study: Reliability of HIV Health Literacy Test (HIV-HLT) among People Living with HIV

Sitthiphon Bunman, MSc1; Thana Khawcharoenporn, MD, MSc2; Anan Malarat, PhD3; Pasitpon Vatcharavongvan, MD, PhD1

Abstract

OBJECTIVES: The aim of this study is to test the validity and reliability of HIV-HLT among people living with HIV.

MATERIALS AND METHODS: All 42 participants who visited the HIV clinic, Thammasat University Hospital on October 2019 were enrolled. Participants were patients aged 18 - 64 years old, diagnosed with HIV infection. We developed a 20-item scale in 2019. The principal two components analysis was used to assess the construct validity and reliability of the 20-item scale. The HIV health literacy test is to assess the health literacy needed to participate in HIV care.

RESULTS: A total of 42 participants were included in this study. The mean age was 44.95 ± 12.31 years old, 54.8 % were female and 42.8% of the participants graduated with a bachelor’s degree. Of all participants, 42.9% had been diagnosed with HIV for ≥5 years. 92.9% had a CD4 count of more than 200 cells/cm3 and 81% had viral load below 20 copies/ml. The corrected item-total correlation of 20 items were higher than 2 with Cronbach’s alpha of 0.89.

CONCLUSION: HIV-HLT is a reliable instrument. A further study is required to confirm whether items are appropriately listed under each domain.

Keywords: health literacy test, HIV, HIV health literacy, HIV-HLT

Health literacy is an individual’s ability to understand and act on medical or health information and services in order to make appropriate health decisions. A growing body of evidence has shown that, compared to their counterparts, individuals with limited health literacy are less likely to use health care services appropriately, face difficulty following medical information, have a shorter life expectancy, and have worse physical and mental health. Specific to HIV, individuals with limited health literacy skills are more likely to possess inappropriate knowledge of their disease and its treatment, and have poor rates of medication adherence.

The Institute of Medicine (IoM) recognizes that existing measures of health literacy are only approximations of reading skills framed within a broad healthcare context and development of a specific tool to better estimate patients’ understanding and capacity to understand health information and the true definition of health literacy is needed. Health literacy experts agree with the IoM and develop several instruments to assess health literacy both in general and in specific to diseases or health conditions, including HIV.

We initially developed HIV-HLT from the literature review. This preliminary study aims to test its reliability and validity among people living with HIV.

Materials and Methods

Participants were recruited from the HIV clinic of Thammasat University Hospital in October 2019. This study was approved by the human research ethics committee of Thammasat University No.1, Faculty of medicine, (Protocol Approval No. MTU-EC-CF-0-099/62). The participants needed to meet all the inclusion and exclusion criteria listed below.
Inclusion criteria:
1. Both males and females
2. Age between 18 – 64 years old
3. Be diagnosed with HIV infection.
4. Being able to read, write and understand the Thai language.

Exclusion criteria: Participants had one or more of the following conditions, as noted in the medical record:
1. Cognitive impairment at any degree
2. Psychosis disorder
3. Memory impairment
4. Severely impaired vision not correctable with eyeglasses or blindness
5. Hearing problems uncorrectable with a hearing aid or deafness

Variables

Demographics data

Self-reported socio-demographic data included patient age, sexual orientation, marital status, family living, levels of educational attainment, occupations, income per month (baht), and medical scheme. Duration of HIV infection, CD4 count (cells/mm$^3$) and viral load (copies/ml) were obtained through medical charts.

HIV health literacy

HIV health literacy was assessed with a HIV-HLT in Thai. The HIV health literacy questionnaire had two domains: HIV knowledge (10 items) and medication adherence (10 items). All interviews were conducted in a private room in the HIV clinic on the clinic appointment day before being seen by a physician.

Statistical analysis

Descriptive statistics were used to describe the percentage and frequencies. Principal components (PC) analysis was used to assess the construct validity of the 20-item scale. Corrected Item-Total Correlation is an index that ranges between 0 and 1. Corrected Item-Total Correlation of ≥ 2 was considered acceptable. Cronbach’s alpha was used to examine the reliability of derived HIV knowledge and medication adherence. The value of Cronbach’s alpha is an index that ranges between 0 and 1. A Cronbach’s alpha of 0.70 or higher indicates that items within the same scale measure the same underlying construct. All analyses were performed using SPSS version 22.0.

Results

A total of 42 consecutive HIV infected patients were recruited to participate in the study. The participants (n = 42) had the mean age of 44.95 years (SD = 12.31 years), 40.5% were male, 54.8 % were female and 4.7% were transgender women, respectively. For the duration of HIV infection, 42.9% of the participants were diagnosed with HIV for more than 5 years. The majority of the participants had a CD4 count of >200 cells/cm$^3$ and viral load of < 20 copies/ml (Table 1).

Table 1: Demographic data of participants (n=42)

| Demographic data | n (%) |
|------------------|-------|
| Gender Identity  |       |
| - Male           | 17 (40.5) |
| - Female         | 23 (54.8) |
| - Transgender woman, (male-to-female (MTF)) | 2 (4.7) |
| Age (years), mean ± SD | 44.95 ± 12.31 |
| - Range          | 21 - 64 |
| Sexual Orientation |       |
| - Male           | 27 (64.3) |
| - Female         | 14 (33.3) |
| - Bisexual       | 1 (2.4) |
| Marital status   |       |
| - Single         | 19 (45.2) |
| - Couple         | 19 (45.2) |
| - Divorce        | 4 (9.6) |
| Family living    |       |
| - Living alone   | 9 (21) |
| - Living with couple | 15 (35.7) |
| - Living with parent | 12 (28.6) |
| - Living with relative | 6 (14.3) |
| Educations       |       |
| - Uneducated     | 8 (19) |
| - Primary school | 2 (4.8) |
| - Junior high school | 6 (14.3) |
| - Senior high school | 1 (2.4) |
| - Bachelor’s degree | 18 (42.8) |
| - Higher than bachelor’s degree | 7 (16.7) |
| Occupations      |       |
| - Unemployed     | 5 (11.9) |
| - Student        | 2 (4.8) |
| - Civil Services | 13 (31) |
| - State enterprise employee | 4 (9.5) |
| - Officer        | 3 (7.1) |
| - Private business | 11 (26.2) |
| - Employment     | 3 (7.1) |
| - Agriculturist  | 1 (2.4) |
| Income per month (Baht) |       |
| - Below 5,000    | 4 (9.5) |
| - 5,000-10,000   | 7 (16.7) |
| - 10,001-15,000  | 4 (9.5) |
| - 15,001-20,000  | 12 (28.6) |
| - 20,001-25,000  | - |
| - Higher than 25,000 | 15 (35.7) |
| Medical scheme   |       |
| - Civil servant medical benefit scheme | 17 (40.5) |
| - Social security scheme | 10 (23.80) |
| - Private insurance | 1 (2.4) |
| - Universal coverage scheme | 6 (14.3) |
| - Self-pay       | 8 (19) |
| Duration of HIV infection |       |
| - Below 6 months | 5 (11.9) |
| - 6 months - 1 year | 3 (7.1) |
| - More than 1 year - 5 years | 16 (38.1) |
| - More than 5 years | 18 (42.9) |
| CD4 count (cells/cm$^3$) |       |
| - Below 200      | 3 (7.1) |
| - 200 - 499      | 18 (42.9) |
| - 500 - 1,500    | 21 (50) |
| Viral load (copies/ml) |       |
| - Below 20       | 34 (81) |
| - More than 20   | 8 (19) |
Preliminary Study: Reliability of HIV Health Literacy Test (HIV-HLT) among People Living with HIV

The corrected item-total correlation of the 20 items was higher than 2, which was considered acceptable. The 20 items were further analyzed using PC analysis to assess validity, and Cronbach’s alpha was used to evaluate internal consistency. The scale had a Cronbach’s alpha of 0.89, which indicated that items within the same scale measured the same underlying construct (Table 2). More than 80% of participants responded correctly to 16 out of 20 items (Table 3).

| Questionnaires                                                                 | Corrected Item-Total Correlation | Cronbach’s alpha |
|--------------------------------------------------------------------------------|---------------------------------|------------------|
| 1. What is CD4?                                                                | 0.431                           |                  |
| 2. Is the goal of treatment to make the CD4 count go up or down?                | 0.499                           |                  |
| 3. What is viral load?                                                          | 0.547                           |                  |
| 4. Is the goal of treatment to make the viral load go up or down?               | 0.507                           |                  |
| 5. If I take my medicine every day, it will decrease opportunistic infection.   | 0.362                           |                  |
| 6. If I take my medicine every day, it will decrease viral resistant drugs.     | 0.386                           |                  |
| 7. If I take my medicine every day, it will decrease HIV transmission.          | 0.619                           |                  |
| 8. If I take my medicine every day, it will decrease HIV transmission to partner. However, I must use a condom every time. | 0.554                           |                  |
| 9. Antiretroviral drugs can prevent HIV transmission from mother to child.      | 0.354                           |                  |
| 10. When I have questions about my medicines, I consult doctors or pharmacists | 0.784                           |                  |
| 11. I don’t take my medicines when I am too tired.                              | 0.654                           |                  |
| 12. I don’t take my medicines when I feel sad.                                  | 0.525                           | 0.89             |
| 13. I don’t take my medicines when I feel good.                                 | 0.575                           |                  |
| 14. I don’t take my medicines because it causes weakness                        | 0.640                           |                  |
| 15. I don’t take my medicines because it causes allergy                         | 0.763                           |                  |
| 16. I don’t take my medicines because it causes nausea and vomiting             | 0.763                           |                  |
| 17. Doctor don’t know. I have been stopped to take my medicines when I am too tired. | 0.763                           |                  |
| 18. I don’t take my medicines when I am drinking alcohol.                       | 0.856                           |                  |
| 19. I don’t take my medicines when I am taking supplements or vitamins.         | 0.520                           |                  |
| 20. Nowadays, I don’t need to take antiretroviral drugs every day.              | 0.580                           |                  |

Table 3: Association between HIV Literacy items and correct responses among 42 adults on treatment for HIV infection (n = 42)

| Questionnaires                                                                 | N (%)                      |
|--------------------------------------------------------------------------------|----------------------------|
| 1. What is CD4?                                                                | 32 (76.2)                  |
| 2. Is the goal of treatment to make the CD4 count go up or down?                | 33 (78.6)                  |
| 3. What is viral load?                                                          | 34 (81)                    |
| 4. Is the goal of treatment to make the viral load go up or down?               | 29 (69)                    |
| 5. If I take my medicine every day, it will decrease opportunistic infection.   | 39 (92.9)                  |
| 6. If I take my medicine every day, it will decrease viral resistant drugs.     | 37 (88.1)                  |
| 7. If I take my medicine every day, it will decrease HIV transmission.          | 42 (100)                   |
| 8. If I take my medicine every day, it will decrease HIV transmission to partner. However, I must use a condom every time. | 38 (90.5)                  |
| 9. Antiretroviral drugs can prevent HIV transmission from mother to child.      | 25 (59.5)                  |
| 10. When I have questions about my medicines, I consult doctors or pharmacists | 39 (92.9)                  |
| 11. I don’t take my medicines when I am too tired.                              | 40 (95.2)                  |
| 12. I don’t take my medicines when I feel sad.                                  | 41 (97.6)                  |
| 13. I don’t take my medicines when I feel good.                                 | 42 (100)                   |
| 14. I don’t take my medicines because it causes weakness                        | 39 (92.9)                  |
| 15. I don’t take my medicines because it causes allergy                         | 39 (92.9)                  |
| 16. I don’t take my medicines because it causes nausea and vomiting             | 41 (97.6)                  |
| 17. Doctor don’t know. I have been stopped to take my medicines when I am too tired. | 42 (100)                   |
| 18. I don’t take my medicines when I am drinking alcohol.                       | 40 (95.2)                  |
| 19. I don’t take my medicines when I am taking supplements or vitamins.         | 40 (95.2)                  |
| 20. Nowadays, I don’t need to take antiretroviral drugs every day.              | 41 (97.6)                  |
Discussion

This study preliminarily tested the reliability and validity of HIV-HLT. Findings show that HIV-HLT was both valid and reliable for measuring health literacy among Thai patients living with HIV. This HIV-HLT is a novel instrument for HIV health literacy assessment. The study highlights several potential challenges related to patients’ ability to understand HIV information.

On previous studies of the development of HIV health literacy instruments, we found only two other similar studies conducted in sub-Saharan Africa measuring HIV literacy’s role in HIV related behaviors, knowledge, and outcomes. One recent study reported an association between limited literacy with lower HIV knowledge, and virologic suppression of HIV.11-13 Both studies applied suboptimal HIV health literacy measures since these were not specific to the HIV disease or health context of the studies.14

Participants had difficulty interpreting commonly used drugs, understanding the number of pills to take daily and correct time, and understanding discussed disease-related HIV concepts such as viral load, CD4 (T-lymphocyte) cell count, etc.11 The 20-items version of the HIV health literacy tool was also proven valid and reliable to measure HIV health literacy skills.

Identifying limited HIV health literacy is the first step in the development of strategies to access health information in HIV patients. For example, in the US, an intervention to improve communication of HIV-related information using pictograph-guided adherence counseling to HIV patients was developed for those with limited health literacy.15 This improved ART adherence and undetectable HIV viral loads, compared to HIV patients submitted to general health counseling. Improving health education materials, treatment instructions and simplifying commonly used prescription cards together with applying basic communication strategies such as the “teach-back/feedback model” are a few examples of interventions that can be used for those living with HIV.16-20

Conclusion

The HIV-HLT was designed to maintain items that assess HIV knowledge, medication adherence that can easily be used in the clinical setting to identify patients with limited health literacy skills. HIV-HLT is valid and reliable for Thai people living with HIV. The scale can be used for future research focusing on understanding the role of HIV health literacy as a mediator of HIV-associated behavior and health outcomes.

The limitations of the study

The reliability of HIV-HLT was only preliminarily studied due to the limited number of participants. Further investigation of the reliability of HIV-HLT among large participants is required.

Acknowledgements

This study was supported by a grant from Faculty of Medicine, Thammasat University, Pathum Thani Province, Thailand fund and facility support services from Thammasat Hospital University to S. Bunman is also acknowledged.

References

1. Institute of Medicine Committee on Health L. In: Nielsen-Bohman L, Panzer AM, Kindig DA, editors. Health Literacy: A Prescription to End Confusion. Washington (DC): National Academies Press (US) Copyright 2004 by the National Academy of Sciences. All rights reserved; 2004.

2. Gazmararian JA, Baker DW, Williams MV, et al. Health literacy among Medicare enrollees in a managed care organization. JAMA 1999;281:545-51.

3. 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;54:770-6.

4. Davis TC, Wolf MS, Bass PF, et al. Low literacy impairs comprehension of prescription drug warning labels. J Gen Intern Med 2006;21:847-51.

5. Wolf MS, Davis TC, Arozullah A, et al. Relation between literacy and HIV treatment knowledge among patients on HAART regimens. AIDS Care 2005;17:863-73.

6. Wolf MS, Davis TC, Tilson HH, et al. Misunderstanding prescription drug warning labels among patients with low literacy. Am J Health Syst Pharm 2006;63:1048-55.

7. Baker DW, Wolf MS, Feinglass J, et al. Health literacy and mortality among elderly persons. J Gen Intern Med 2007;167:1503-9.

8. Osborn CY, Paasche-Orlow MK, Davis TC, et al. Health literacy: an overlooked factor in understanding HIV health disparities. Am J Prev Med 2007;33:374-8.

9. 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;18:325-31.

10. Weiss BD, Mays MZ, Martz W, et al. Quick assessment of literacy in primary care: the newest vital sign. Ann Fam Med 2005;3:514-22.

11. 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;14:181-8.

12. 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:e39391.

13. Hegazi A, Bailey RL, Ahadzie B, et al. Literacy, education and adherence to antiretroviral therapy in The Gambia. AIDS Care 2010;22:1340-5.

14. Owlbry RL, Waldrop-Valverde D, Hardigan P, et al. Development and validation of a brief computer-administered HIV-Related Health Literacy Scale (HIV-HL). AIDS Care 2013;17:710-8.

15. Osborn CY, Paasche-Orlow MK, Davis TC, et al. Health literacy: an overlooked factor in understanding HIV health disparities. Am J Prev Med 2007;33:374-8.

16. 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;18:325-31.

17. Weiss BD, Mays MZ, Martz W, et al. Quick assessment of literacy in primary care: the newest vital sign. Ann Fam Med 2005;3:514-22.
15. Weidle PJ, Wamai N, Solberg P, et al. Adherence to antiretroviral therapy in a home-based AIDS care programme in rural Uganda. *Lancet* 2006;368:1587-94.

16. 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;16:3-15.

17. Mayeaux EJ Jr, Murphy PW, Arnold C, et al. Improving patient education for patients with low literacy skills. *Am Fam Physician* 1996;53:205-11.

18. Kripalani S, Weiss BD. Teaching about health literacy and clear communication. *J Gen Intern Med* 2006;21:888-90.

19. Vermund SH, Van Lith LM, Holtgrave D. Strategic roles for health communication in combination HIV prevention and care programs. *J Acquir Immune Defic Syndr* 2014;66 Suppl 3:S237-40.

20. Tomori C, Risher K, Limaye RJ, et al. A role for health communication in the continuum of HIV care, treatment, and prevention. *J Acquir Immune Defic Syndr* 2014;66 Suppl 3:S306-10.