

HIV/AIDS Literacy Impact Towards the Self-Care Performance of People Live with HIV/AIDS in Indonesia

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Abstract: The lack of health literacy has become a problem for HIV infected people. They were dependent on medical service and the low level of health status and the emergence of infection opportunities. They require an increase in health literacy to enable them to perform self-care. The study aims to describe the ability of health literacy of HIV/AIDS among people living with HIV/AIDS (PLWHA), and the health literacy impact on the PLWHA ability to perform self-care. The research used a qualitative approach. The subjects were PLWHAs, and Peer Support Groups, which were appointed by a snowball. The data collected by interview, observation, and focus group discussion. This study found that PLWHAs treat their problem with health literacy is based on medication and spiritual-religious values as well. Their health literacy also covers the corps handling and burial of infected patients. Secondly, PLWHAs have increased their ability and skill to perform self-care and self-care group. Self-care and self-care group can produce direct benefits in terms of health conditions, social, and economic situation.

Keywords: Health Literacy, Self-care, HIV/AIDS, People with HIV/AIDS

1. Background

People who live with HIV/AIDS (PLWHA) often need medical service when they experience disturbing symptoms [1]. The symptoms will effect negatively on the lives of PLWHA if they are not treated as soon as possible, both physically and psychologically [2]. Yet the primary issue in the health service for PLWHA is the lack of competent medical providers for HIV. In the rural area, PLWHAs are not only lack of qualified medical professionals but also transportation issue to reach the health center, HIV-related stigma, confidentiality issue, discrimination, and the lack of fund to access health services [3].

The HIV/AIDS treatment cannot merely rely on the total intervention from the government due to limited funds, but it also must involve the patients themselves. To treat HIV/AIDS, Indonesia always experiences a lack of funds

budget. In the Spending Projection of the year 2019, Indonesia needs \$184,706 to perform the maximum intervention on HIV/AIDS treatment. Meanwhile, the government budget only provides \$75,586, which means there is a lack of funds that reaches \$109,120. The lack of funds enables the government to perform only a partial and limited intervention. The impact of hard-to-access of health service, in general, has caused the PLWHA experience interrupted-medication or the failure to follow up the medication, which eventually resulted in the increased of the mortality rate. In 2015 the PLWHA who experienced interrupted-medication reached 21.87%, and the mortality rate was 1.07. While in 2018, the mortality rate increased to 1.08 [4]. Therefore, the patients must empower themselves to manage some of their symptoms and the HIV/AIDS impact through a self-care treatment. The self-care is an attempt to handle the disease's symptoms and is one of the many experiences faced by the PLWHA.

There is the fact that it will require a high cost to only depends on the health facility in treating life-time patients with HIV/AIDS infection. Apart from the free service facility in the public health clinic, the treatment before the ART can be costly, especially for the poor and unemployed people. Baker and friends found that the patients in general hospitals with limited health literacy have a higher inpatient level than those with adequate literacy. Baker concluded that the increase of inpatient duration correlates with a more top source of them with limited health literacy [5].

Another study in the clinical population showed a decrease in health expense rate and the usage of health facilities after the patients had the opportunity of intervention to improve their self-care practice [6]. The self-care can also increase the usage of prevention behavior, obedience in using the medication, and reduce the need for medical service [7].

The ability of PLWHA to manage and overcome the HIV/AIDS impact is known as the self-care skill. Self-care is a significant aspect of chronic disease management for the PLWHA [6]. HIV infection has become a long-term chronic disease that requires sustainable monitoring and health care management. Most treatment for HIV infection is in the form of outpatient and in-house therapies. As a consequence, the PLWHA must be able to perform self-care to handle the physical symptom and psychological pressure from the disease. It requires the ability to understand and master the treatment of self-care, which will increase HIV disease management significantly [8]. The self-care consists of all PLWHA activities and effort to improve their health quality, management of its symptoms, prevention of opportunistic infection, and health recovery [8]. The PLWHA must adopt a healthy lifestyle and keep themselves in good health [1]. HIV-infected people need adequate health literacy to improve their health situation. A study reveals that people with low health literacy will have the limited skill to take necessary action, which has benefits for their health [9] and cannot obey the antiretroviral medication properly [10].

On the contrary, patients with higher health literacy tend to become more obedience to HIV medical treatment [11]. Another research showed that the compliance towards the antiretroviral medication increased after the PLWHA improved their knowledge on HIV [12-13], and that a better health literacy on HIV would produce a higher health level [14-15]. The equality of health literacy can increase HIV/AIDS patients' skills to perform various self-care such as diet, physical exercise, complementary therapy, changing lifestyle, and stress-reduce technique [2]. The purpose of this study is to describe HIV/AIDS health literacy towards PLWHA, and impact of health literacy on PLWHA ability in self-care.

2. Literature Review

2.1. Self-Care

Involving patients to effective self-management is one of the ways to decrease chronic illness. Self-management is

equated with self-care, which covers someone's essential tasks to get a good life, notwithstanding he/she is in a chronic condition. This task covers gaining self-confidence to deal with medical management, role management, and emotional management [16].

Patients have utilized various self-care management strategies to deal with their HIV/AIDS symptoms [2]. Self-care management strategy encompasses dietary habits, change, self-comfort, drugs, complementary treatment, spiritual treatment, daily thought and activity, sports, and ask for assistance [1].

Self-care is a process in which patients implement their acquaintance and ability to manage an illness, to know their condition, and to have collaboration with the self-care [17]. Levin [18] define self-care as a process in which a layperson can function effectively for themselves to promote health, prevention, illness detection, and primary health literacy in the health treatment system. Moreover, self-care covers the ability of self-care, therapeutic self-care demand, and self-care regulations. Self-care activity is initiated and done by individuals for themselves, to keep their life, health, and welfare.

Self-care is a multidimensional concept which refers to knowledge, attitude, and behavior. Likewise, they are developed, maintained, and done by patients to manage their health problems or to upgrade their health status. The acquaintance about HIV/AIDS self-care comprises HIV/AIDS patient's information to conduct their self-care practice. The scope of self-care practice in HIV/AIDS covers two levels; general self-care for health maintenance, for example, nutrition, exercise, stress reduction [19], and specific self-care managing HIV treatment and care, for example, symptom management, medication adherence, involved in medicine [20].

Self-care can increase the involvement of people autonomously in managing their health and providing equal opportunities for health service users, quality of care, and financial protection for users. Self-care can improve the efficiency of health service delivery by including users as lay health workers. Therefore it increases community access to health services [7].

2.2. Health Literacy and Self-Care

The knowledge about HIV/AIDS self-care comprises HIV/AIDS patient's information to conduct their self-care practice. The information about self-care can be accessed through an infected person, their friends, family, mass media, internet, health service providers, community, and society [8; 1]. Knowledge about HIV/AIDS self-care is a patient's ability to acquire an accurate understanding and to implement information about which significant effect on their health and welfare. This knowledge and expertise are called "health literacy." Health literacy is defined as a level of individual capacity to gain, interpret, understand necessary information, and health service, which is required to make an appropriate decision. It is divided into three levels, functional, communication, and critical [21].

Health literacy plays a vital role in self-management for managing chronic diseases. Individuals must be able to understand and assess health information to can manage chronic conditions for daily care over a long time, which includes complex medical regimens, planning and making lifestyle adjustments, making decisions, and understanding how to access health care if necessary [22]

Health literacy contains cognitive and social skills which determine individual motivation and ability to gain access to health services, understand and utilize information, and maintain good health [23]. Health literacy has a variety of skills, and it can provide social and cognitive knowledge, skills, and perceptions that are needed for the proper management of the disease for patients [24]. Health literacy skill is an essential factor for improving patients' self-care with chronic diseases. These skills can enhance self-esteem and patients' ability to communicate effectively with health care providers as well as increasing patients' ability to participate and work with the health system [25].

People with low health literacy skills have worse health status. Moreover, a low level of health literacy causes drug abuse or misconceptions about health information. Low literacy rates lead to preventable use of health services, including emergency care [26]. People with little reading skills often have difficulty seeking medical help, resulting in a state of a health crisis. This fact reveals that education is a crucial thing in all self-care practices [27]. Limited health literacy will harm health, including knowledge about health and health-care, hospitalization, general health measures, and some chronic diseases. Limited literacy also causes patients difficulties when interacting with the health care system and also on the coping strategies which they use to avoid their problems [28].

The relationship between health literacy and self-management ability is often ignored, whereas self-management capabilities consist of a general repertoire of cognitive and behavioral skills to manage external resources. Consequently, physical and social well-being can be maintained or restored [29], self-management abilities are associated with increased welfare [30]. Therefore, health care is very important for patients because individuals need the concern to maintain quality of life [31]. Care for HIV is managed mainly at home, and outside the patient's setting. In a nutshell, self-care becomes a vital aspect in the management of HIV and AID [32].

3. Method

The research utilized a descriptive qualitative approach. The subjects were selected by snowballing sampling and focusing on PLWHA who had received health literacy and had self-care abilities. The data collection is done by in-depth interviews to gain understanding and experience of PLWHA; the researcher employed unstructured questions.

Moreover, the observation was conducted to identify

PLWHAs' self-care. Furthermore, FGD was also established by the researcher to add more data. After the data were collected, the researcher conducted data reduction by selecting data that is relevant to the purpose of the study. The chosen data are classified and explained. In the data display, research findings are discussed. Finally, a conclusion was formulated.

4. Finding and Discussion

4.1. Health Literacy About HIV/AIDS

PLWHA health literacy is a process of providing knowledge and changing the understanding of the disease, recognizing the symptoms of infection probability, recognizing the level of immunity, ART, and ART, coping stress, how to access health care, healthy living and health maintenance and treatment. These findings are under some opinions from [17-20]. Unfortunately, they did not find health literacy from a religious perspective.

Health literacy for the treatment of PLWHA is not only limited to knowledge and skills that derive from medical education, but also religion. This knowledge includes praying for health and how to take care of the burial of the body under religious rules. In eastern culture, knowledge about health and sick cannot be separated from religious values. Consequently, health literacy involves prayer as a process of healing and empowerment for patients with PLWHA. Praying is a way of communicating with God to help PLWHA gain peace of life and have a willingness to take his/her illness. Moreover, their primary purpose is to get a miracle to recover from HIV / AIDS and awarded paradise when he dies.

The results of this study also revealed health literacy to PLWHA about corpse care, ritual procedures, and ceremonial burial. Corpse care's literacy of PLWHA bodies is necessary because many people refuse to treat, bury the bodies of PLWHA, and they do not want to do rituals and ceremonial deaths based on religion. Consequently, the bodies of PLWHA are abandoned because people are lack health literacy, afraid of being infected, and have a strong stigma about HIV/AIDS disease. On the other hand, PLWHA's family may not depend on health providers and religious leaders If PLWHA dies. It is because they need to pay for it, the number of health service providers is limited, and only a few of them have an excellent skill to take care of the bodies of PLWHA.

Chou et al. [8] stated that the sources of health literacy are infected people, their friends, family, mass media, the internet, health service providers, community, and society. However, the results of this study prove that there is a role of religious leaders in health literacy, which includes prayer literacy, ritual processional literacy, and ceremonial care and burial. If the spiritual and formal process of treating and burying a corpse is not based on religious rules, it can create a psychological burden on the family and strengthen the stigma and discrimination of PLWHA.

4.2. The Impact of Health Literacy on the Change of PLWHA Self-Care

The effects of health literacy are that PLWHA should master self-care skills and knowledge. The self-care ability is the ability of PLWHA patients to understand HIV / AIDS correctly. Additionally, it is knowing about ART and keeping up the rehabilitation, finding out how to detect and prevent infection probability, leaving bad habits and having a healthy life, consuming nutritional foods, being able to manage stress, coping, and access health services. This finding is undoubtedly the same as the previous researchers such as the management of symptoms related to HIV/AIDS [8]; changes in diet, self-comfort, medicine, spiritual care, and exercise [2, 32], managing illnesses and understanding their condition [17, 18], prevention and detection of disease, and care [18] safeguarding life, health and well-being, symptom management, medication adherence, involvement with care [20].

Self-care also involves religious aspects, such as teaching them to pray as part of the patient's healing techniques. The spiritual approach also teaches healthy living through lessons written in the holy book about the prohibition of God, such as the prohibition of consuming alcohol drug abuse, and prostitution practices. Furthermore, it also unveils God's advice to be loyal to the husband/wife and consume halal food and beverages.

The concept of self-care in this finding not only refers to individuals as well as Geboers, de Winter, Spoorenberg, Wynia, & Reijneveld's results but also groups [21]. They are to deal with and cope with the group's problems. It is because it is impossible to depend on health officers, other people, or other groups due to the stigma and discrimination. After receiving literacy, a peer support group (PSG) can independently treat the bodies of PLWHA. Moreover, they take the body from the hospital, bathe, infest, bury, and perform rituals and ceremonies. All of them are based on religious values. Accordingly, literacy not only makes PLWHA be able to do "self-care" but also group independence for self-care called "self-care group." By mastering high-level health literacy, PLWHA can become an expert patient. Likewise, they can become expert patient-trainers (EPT) who train other PLWHAs, health officers, and community groups.

The effect of health literacy is how to improve the acquaintance and skills of patients to take care of themselves without being dependent on others or health officer. There are three benefits of health literacy's impact on self-care. Firstly, the health status of PLWHA who reaches a high CD4 level and has no chance of infection. Secondly, social benefits, it is because PLWHA knows from essential to expert level; consequently, they can do health literacy to others, including health workers as expert patient-trainers (EPT). Third, the economic benefits, it is because PLWHA will not pay much for treatment, and they can live productively healthy by earning money.

5. Conclusion

This study aims at describing the impact of health literacy on the ability of PLWHA to conduct self-care. In many health literacy kinds of literature and the findings of health literacy practices, it is limited to approaches based on science. In this study's findings, health literacy was also carried out not only on a scientific method but also based on religious values. This health literacy content delivers acquaintance about the power of prayer as a cure for an illness, about God's advice and prohibitions relating to health.

Additionally, it also concerns the cares; burial of PLWHA, including the knowledge of processions and rituals according to culture and religion. The effect of health literacy does not only increase the ability of PLWHA to perform self-care but also being able to take care of their groups. PLWHA obtains three benefits from having a health literacy ability, namely health benefits, social benefits, and economic benefits.

References

- [1] Marie-Modeste, R. R., & Majeke, S. J. (2014). Sources and types of information on self-care symptom management strategies for HIV and AIDS. *Curationis*, 37 (1), 127. <https://doi.org/10.4102/curationis.v37i1.127>.
- [2] Fang-Yu Chou, R. N., & Holzemer, W. L. (2004). Linking HIV/AIDS clients' self-care with outcomes. *Journal of the Association of Nurses in AIDS Care*, 15 (4), 58–67. <https://doi.org/10.1177/1055329003255592>.
- [3] Pellowski, J. A. (2013). Barriers to care for rural people living with HIV: A review of domestic research and health care models. *Journal of the Association of Nurses in AIDS Care*, 24 (5), 422–437. <https://doi.org/10.1016/j.jana.2012.08.007>.
- [4] Kemenkes RI. (2018). *Laporan_HIV_AIDS_TW_4_Tahun_2017__1_.pdf*.
- [5] Baker, D. W., Gazmararian, J. A., Williams, M. V., Scott, T., Parker, R. M., Green, D., ... Peel, J. (2002). Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health*, 92 (8), 1278–1283. <https://doi.org/10.2105/AJPH.92.8.1278>.
- [6] Vickery, D. M., Golaszewski, T. J., Wright, E. C., & Kalmer, H. (1988). The effect of self-care interventions on the use of medical service within a medicare population. *Medical Care*, 26 (6), 580–588. <https://doi.org/10.1097/00005650-198806000-00006>.
- [7] Panagioti, M., Richardson, G., Small, N., Murray, E., Rogers, A., Kennedy, A., ... Bower, P. (2014). Self-management support interventions to reduce health care utilization without compromising outcomes: A systematic review and meta-analysis. *BMC Health Services Research*, 14 (1). <https://doi.org/10.1186/1472-6963-14-356>.
- [8] Chou, F. Y., Holzemer, W. L., Portillo, C. J., & Slaughter, R. (2004). Self-care strategies and sources of information for HIV/AIDS symptom management. *Nursing Research*, 53 (5), 332–339. <https://doi.org/10.1097/00006199-200409000-00008>.

- [9] Kalichman, S. C., Benotsch, E., Suarez, T., Catz, S., Miller, J., & Rompa, D. (2000). Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine*, 18 (4), 325–331. [https://doi.org/10.1016/S0749-3797\(00\)00121-5](https://doi.org/10.1016/S0749-3797(00)00121-5).
- [10] Kalichman, S. C., Pope, H., White, D., Cherry, C., Amaral, C. M., Swetzes, C., ... Kalichman, M. O. (2011). Association between health literacy and HIV treatment adherence: Further evidence from objectively measured medication adherence. *Journal of the International Association of Physicians in AIDS Care*, 7 (6), 317–323. <https://doi.org/10.1177/1545109708328130>.
- [11] Graham, J., Bennett, I. M., Holmes, W. C., & Gross, R. (2007). Medication beliefs as mediators of the health literacy - antiretroviral adherence relationship in HIV-infected individuals. *AIDS and Behavior*, 11 (3), 385–392. <https://doi.org/10.1007/s10461-006-9164-9>.
- [12] Remien, R. H., Mellins, C. A., Robbins, R. N., Kelsey, R., Rowe, J., Warne, P., ... Stein, D. J. (2013). Masivukeni: Development of a multimedia-based antiretroviral therapy adherence intervention for counselors and patients in South Africa. *AIDS and Behavior*, 17 (6), 1979–1991. <https://doi.org/10.1007/s10461-013-0438-8>.
- [13] Rikard, R. V., Thompson, M. S., Head, R., McNeil, C., & White, C. (2012). Problem posing and cultural tailoring: Developing an HIV/AIDS health literacy toolkit with the African American community. *Health Promotion Practice*, 13 (5), 626–636. <https://doi.org/10.1177/1524839911416649>.
- [14] Jones, D., Cook, R., Rodriguez, A., & Waldrop-Valverde, D. (2013). Personal HIV knowledge, appointment adherence, and HIV outcomes. *AIDS and Behavior*, 17 (1), 242–249. <https://doi.org/10.1007/s10461-012-0367-y>.
- [15] Nelsen, A., Trautner, B. W., Petersen, N. J., Gupta, S., Rodriguez-Barradas, M., Giordano, T. P., & Naik, A. D. (2012). Development and validation of a measure for intention to adhere to HIV treatment. *AIDS Patient Care and STDs*, 26 (6), 329–334. <https://doi.org/10.1089/apc.2011.0318>.
- [16] McGowan, P. (2005). New Perspectives: International Conference on Patient Self-Management Centre on Aging Self-management. Self-Management: A Background Paper, 1–10. Retrieved from [http://bcm.bluelemonmedia.com/uploads/Support for Health Professionals/Self-Management support a background paper 2005.pdf](http://bcm.bluelemonmedia.com/uploads/Support%20for%20Health%20Professionals/Self-Management%20support%20a%20background%20paper%202005.pdf).
- [17] Ishikawa, H., Takeuchi, T., & Yano, E. (2008). Measuring functional, communicative, and critical health literacy among diabetic patients. *Diabetes Care*, 31 (5), 874–879. <https://doi.org/10.2337/dc07-1932>.
- [18] Levin, L. S. (1983). Self-care in health. *Ann. Rev. Public Health* (15), 181–201.
- [19] Sowell, R. L., Guillory, L. J., Seals, B., & Cohen, L. (1997). Self-Care Activities of Women Infected with Human Immunodeficiency Virus. *Holist Nurs Pract.*, 11 (2), 18–26. <https://doi.org/10.1097/00004650-199701000-00005>.
- [20] Holzemer, W. R., Corless, I. B., Nokes, K. M., Turner, J. G., Brown, M. A., Powell-Cope, G. M., ... Portillo, C. J. (1999). Predictors of self-reported adherence in persons living with HIV disease. *AIDS Patient Care and STDs*, 13 (3), 185–197. <https://doi.org/10.1089/apc.1999.13.185>.
- [21] Geboers, B., de Winter, A. F., Spoorenberg, S. L. W., Wynia, K., & Reijneveld, S. A. (2016). The association between health literacy and self-management abilities in adults aged 75 and older, and its moderators. *Quality of Life Research*, 25 (11), 2869–2877. <https://doi.org/10.1007/s11136-016-1298-2>.
- [22] Lloyd, L. L. J., Ammary, N. J., Epstein, L. G., Johnson, R., & Rhee, K. (2006). A Transdisciplinary approach to improve health literacy and reduce disparities. *Health Promotion Practice*, 7 (3), 331–335. <https://doi.org/10.1177/1524839906289378>.
- [23] Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science and Medicine*, 67 (12), 2072–2078. <https://doi.org/10.1016/j.socscimed.2008.09.050>.
- [24] Lai, A. Y., Ishikawa, H., Kiuchi, T., Mooppil, N., & Griva, K. (2013). Communicative and critical health literacy and self-management behaviors in end-stage renal disease patients with diabetes on hemodialysis. *Patient Education and Counseling*, 91 (2), 221–227. <https://doi.org/10.1016/j.pec.2012.12.018>.
- [25] Davis, T. C., Williams, M. V., Marin, E., Parker, R. M., & Glass, J. (2002). Health literacy and cancer communication. *CA: A Cancer Journal for Clinicians*, 52 (3), 134–149. <https://doi.org/10.3322/canjclin.52.3.134>.
- [26] Castro, C. M., Wilson, C., Wang, F., & Schillinger, D. (2007). Babel babble: Physicians' use of unclarified medical jargon with patients. *American Journal of Health Behavior*, 31 (SUPPL. 1), 22–25. <https://doi.org/10.5993/ajhb.31.s1.11>.
- [27] Geteri, L. M., & Angogo, E. M. (2013). Self-care among caregivers of people living with HIV and AIDS in Kakola location, Nyando District, Kisumu County, Kenya. *Sahara J*, 10 (2), 65–71. <https://doi.org/10.1080/17290376.2013.807065>.
- [28] Wolf, M. S., Davis, T. C., Tilson, H. H., Bass, P. F., & Parker, R. M. (2006). Misunderstanding of prescription drug warning labels among patients with low literacy. *American Journal of Health-System Pharmacy*, 63 (11), 1048–1055. <https://doi.org/10.2146/ajhp050469>.
- [29] Steverink, N., Lindenberg, S., & Slaets, J. P. J. (2005). How to understand and improve older people's self-management of well-being. *European Journal of Ageing*, 2 (4), 235–244. <https://doi.org/10.1007/s10433-005-0012-y>.
- [30] Cramm, J. M., Hartgerink, J. M., de Vreede, P. L., Bakker, T. J., Steyerberg, E. W., Mackenbach, J. P., & Nieboer, A. P. (2012). The relationship between older adults' self-management abilities, well-being, and depression. *European Journal of Ageing*, 9 (4), 353–360. <https://doi.org/10.1007/s10433-012-0237-5>.
- [31] Williams, A. B., Wang, H., Burgess, J., Li, X., & Danvers, K. (2013). Cultural adaptation of an evidence-based nursing intervention to improve medication adherence among people living with HIV/AIDS (PLWHA) in China. *International Journal of Nursing Studies*, 50 (4), 487–494. <https://doi.org/10.1016/j.ijnurstu.2012.08.018>.
- [32] Marie-Modeste, R. R., & Majeke, S. J. (2010). Self-care symptom-management strategies amongst women living with HIV /AI DS in an urban area in KwaZulu-Natal. *Health SA Gesondheid*, 15 (1), 1–8. <https://doi.org/10.4102/hsag.v15i1.509>.